Parents’ Experiences with Learning to Manage Medications in Pediatric Rehabilitation

by

Alexandra Maryrose Stanhope

A thesis submitted in conformity with the requirements for the degree of Master of Science (Health Services Research) Institute of Health Policy, Management and Evaluation University of Toronto

© Copyright by Alexandra Maryrose Stanhope 2017
Parents’ Experiences with Learning to Manage Medications in Pediatric Rehabilitation

Alexandra Maryrose Stanhope
Microsoft of Science (Health Services Research)
Institute of Health Policy, Management and Evaluation
University of Toronto
2017

Abstract

**Introduction:** There is a significant amount of risk associated with the transition from hospital to home due to the fact that care can become fragmented and discontinuous. Children with chronic complex conditions are particularly susceptible to this risk because of their multiple health care needs, including complicated medication regimens.

**Methods:** Qualitative interviews were used to capture a description of parents’ experiences with learning to manage their child’s medications prior to discharge from a pediatric rehabilitation hospital.

**Results:** Two key thematic categories emerged from the interviews: 1) learning to manage the technical aspects of medications and 2) learning to integrate medication management into everyday life.

**Conclusions:** More research is needed to identify effective models of care where hospitals partner with the community to improve the integration of medication management into home life.
# Table of Contents

Abstract................................................................................................................................................... ii

Table of Contents.................................................................................................................................... iii

List of Tables............................................................................................................................................... v

List of Figures.............................................................................................................................................. v

Chapter 1: Introduction............................................................................................................................. 1

1.1 Medication in the context of Children with Special Health Care Needs........ 1

1.2 Medication Safety at Discharge......................................................................................................... 2

1.3 Living with Complex Care Needs in the Community................................................................. 4

1.4 Medication Errors in the Community.............................................................................................. 5

1.5 Medication Management Challenges............................................................................................. 5

1.6 Causes of Medication Errors in the Community........................................................................... 9

1.7 Health Literacy and Medication Management.............................................................................. 11

1.8 Teaching Families Self-Management Strategies........................................................................... 13

1.9 Family Centered Care..................................................................................................................... 15

1.10 Rationale for Research.................................................................................................................. 19

Chapter 2: Research Methods.................................................................................................................. 22

2.1 Setting.............................................................................................................................................. 22

2.2 Research Questions......................................................................................................................... 22

2.3 Study Design.................................................................................................................................... 23

2.4 Sampling.......................................................................................................................................... 24

2.5 Data Collection................................................................................................................................. 25

2.6 Data Analysis.................................................................................................................................... 28
2.7 Quality and Rigor………………………………………………………………….31
2.8 Ethical Considerations…………………………………………………………….31
Chapter 3: Results I – Description of Sample……………………………………33
Chapter 4: Results II – Learning to Manage Technical Aspects of Medications………35
  4.1 Complex Administration………………………………………………………35
  4.2 Palatability of Medications…………………………………………………….37
  4.3 Volumes of Medications………………………………………………………38
  4.4 Delivery of information…………………………………………………………40
Chapter 5: Results III – Learning to Integrate Medications Management into Everyday
  Life………………………………………………………………………………………………44
  5.1 Family Involvement……………………………………………………………..44
  5.2 Time Management……………………………………………………………..46
  5.3 Discharge Planning……………………………………………………………..49
Chapter 6: Discussion…………………………………………………………………….53
  6.1 Major Themes and Comparison to Literature………………………………..53
  6.2 Limitations…………………………………………………………………………59
  6.3 Recommendations for Future Research and Implications for Practice………62
References……………………………………………………………………………………..64
Appendix 1: Information Letter…………………………………………………………65
Appendix 2: Background Questionnaire……………………………………………….74
Appendix 3: Interview Guide……………………………………………………………75
List of Tables

Table 1: Demographic Characteristics of Caregivers................................................35
Table 2: Demographic Characteristics of the Children..............................................36

List of Figures

Figure 1: Summary of Themes
CHAPTER 1 – INTRODUCTION

The following chapter will outline challenges that parents face in learning to manage the medications of children with special health care needs, as described in the current literature. The philosophy of Family Centered Care (FCC) and its application to this particular topic will also be discussed. Finally, rationale for the study at hand will be presented.

1.1 Medications in the context of Children with Special Health Care Needs

Approximately 1 in 8 children have special health care needs (van Dyke, Kogan, McPherson, Weissman, & Newacheck, 2004). A child with special health care needs requires “health services of a type or amount beyond that required by children generally”, as a result of having or being at risk for a chronic physical, developmental, behavioural or emotional condition (van Dyke et al., 2004). Such needs may include an inpatient stay in a pediatric rehabilitation hospital at some point in the child's life. Pediatric rehabilitation hospitals across Canada provide a variety of services to children with disabilities and acquired injuries from birth up until the age of 21 (King & Chiarello, 2014). Some of the medical conditions seen in pediatric rehabilitation hospitals include Cerebral Palsy, Spina Bifida, Epilepsy, Acquired Brain Injury, Spinal Cord Injury, Orthopedic Injuries, Autism, Muscular Dystrophy, Amputations, Arthritis, and other developmental disabilities.

Children who require inpatient stays in pediatric rehabilitation hospitals often have highly complex medication regimens (Grady & Gough, 2014). Within the pediatric rehabilitation population, children are most frequently on medications to manage pain and gastrointestinal diseases, control muscle spasms, promote bone health, maintain
respiratory function, and prevent seizures. Due to the numerous medications that these children take, they are at an increased risk for medication errors, both in the hospital as well as at home (Neuspiel & Taylor, 2013). A medication error is defined as “an error in [medication] ordering, transcribing, dispensing, administering, or monitoring” (Kaushal et al., 2007), where a patient experiences an unintended injury or complication that is not a result of their disease, but is instead caused by health care management (Baker et al., 2004). An Adverse Drug Event (ADE) is “an injury from a medicine, or lack of medicine” (Institute for Safe Medication Practices (ISMP) Canada, 2005). ADEs are caused by mismanagement of medications rather than the medication itself. Some of the most common conditions related to ADEs in the pediatric rehabilitation population include increased pain, increased seizures, difficulties breathing, increased risk of fractures, excessive sedation, as well as gastrointestinal issues such as increased acid reflux, aspiration of food, and irregular bowel movements. The unintended injuries and complications that result from ADEs can lead to additional hospital stays for the patient, profound disability, and even death (Baker et al., 2004; Swanlund, Scherck, Metcalfe, & Jesek-Hale, 2008). Moreover, failing to adhere to the prescribed medication regimen can reduce the efficacy of medications (Swanlund et al., 2008).

1.2 Medication Safety at Discharge

There is a significant amount of risk associated with the transition from hospital to home due to the fact that care can become fragmented and discontinuous (Shoeb, Merel, Jackson, & Anawalt, 2012). Children with chronic complex conditions are particularly susceptible to this risk because of their multiple health care needs, including complicated medication regimens (Jurgens, Spaeder, & Pavuluri, 2014). Such medical
complexities can make the transition to home challenging as well as increase the chance that the child will be readmitted to inpatient care within 30 days (Cohen et al., 2011; Feudtner et al., 2009). Based on the analysis that Jurgens and colleagues conducted in 2014, it is estimated that 19% of children with complex conditions will be readmitted to an acute care facility within 30 days of discharge from a sub-acute care facility, such as a rehabilitation hospital. One of the most significant risk factors that contributes to the likelihood of readmission to acute care is the number of medications the child is taking at home (Jurgens et al., 2014). Specifically, each additional medication the child is prescribed at discharge increases the odds of the child being readmitted by 11% (Jurgens et al., 2014).

Moreover, when a child transitions from inpatient care to the community, the responsibility of medication management is transferred from the inpatient care team to the family (Shoeb et al., 2012). Often, these responsibilities are assumed by the child’s family caregiver (Benavides, Huynh, Morgan, & Birars, 2011; Neuspiel & Taylor, 2013) who can be a parent, legal guardian, or another family member (Institute for Safe Medication Practices - Canada, 2014). Medication management responsibilities can include carrying out medication instructions (such as storage and administration), monitoring the effects of the medication, as well as identifying adverse events and determining when to seek medical attention for ADEs (Budnitz & Layde, 2007). Given the large number of medications that children with disabilities and acquired injuries are prescribed, performing all of the medication related activities can be challenging (Grady & Gough, 2014; Ryan & Sawin, 2009). The risk of caregivers making errors in medication management is especially high following discharge from a hospital where
new medications may have been added to the child’s previous home regimen (Knight, Thompson, Mathie, & Dickinson, 2013). Adding medications to a child’s regimen increases the likelihood of mismanagement because family caregivers may not yet be familiar with the possible side effects associated with that drug.

There is limited research on what enables parents to manage medications effectively, what barriers they face in medication management, or how health care providers can improve the transition from inpatient care to the community. However, we do know that parents are often overwhelmed with the amount of information they receive before leaving the hospital. Given the heightened stress that surrounds this transition in a child’s care, it can be increasingly difficult for caregivers to remember the instructions they were given (Solan et al., 2015). Therefore, careful consideration must be given to how information is delivered to caregivers in order to maximize its impact.

1.3 Living with Complex Care Needs in the Community

Over time, the number of children with complex health care needs has increased due to advancements in the diagnosis of pediatric conditions as well as improved treatments for disabilities and acquired injuries (Rothman, Yin, Mulvaney, Homer & Lannon, 2009). As a result of increasing survival rates for children with disabilities and acquired injuries, more and more children with complex medication regimens are living in the community (Walsh et al., 2013). The majority of efforts to prevent medication errors and ADEs occur at the time of prescribing, often in the inpatient setting, while the majority of medication administration that takes place in a child’s life happens in the community, where a parent or other family caregiver is often responsible for administering the medication (Budnitz & Layde, 2007). Despite this reality, the literature
on outpatient care has failed to catch up to the literature on inpatient pediatric care (Walsh et al., 2013). As a result, there is limited knowledge of how families manage medications at home (Walsh et al., 2013). Therefore, there is increasing need for error prevention in outpatient settings, such as the community, where responsibility is shifted to patients, parents, and other family caregivers (Budnitz & Layde, 2007).

1.4 Medication Errors in the Community

Approximately 16% of all children who receive ambulatory care experience adverse drug events (ADEs) (Kaushal et al., 2007). In the United States, there are over half a million medication errors that occur in the community every year and this number has the potential to grow with the increasing number of children with medical complexity living in the community (Rothman et al., 2009). Given the high incidence of ADEs, it is evident that current discharge medication education practices are not meeting the needs of patients and their families. This shortcoming is relevant as ADEs not only cause unnecessary harm to children, but also pose a financial burden to our healthcare system as they frequently lead to unplanned hospital readmissions (Accreditation Canada, the Institute for Healthcare Improvement, the Canadian Patient Safety Institute, & the Institute for Safe Medication Practices, 2012).

1.5 Medication Management Challenges

There are several challenges that are unique to managing the medications of children, some of which are unique to the community environment. Previous research has shown that approximately 70% of preventable ADEs that occur in children receiving ambulatory care in the community are caused by parent drug administration errors (Kaushal et al., 2007). Precise dosage and medication management of children's
medications is important because children are more susceptible to adverse effects of overdosing due to their limited ability to physiologically process excess medications (Benavidas, Huynh, Morgan, & Briars 2011; Levine et al., 2001). In the pediatric population, accurately measuring the dosage of medications is the most frequently described challenge related to medication management within the literature (Benavides et al., 2011; Yin et al., 2010).

There are a number of reasons that correct dosing of pediatric medications can be challenging. First of all, medications are not always dispensed from the pharmacy in the dosage that the child requires (Benavides et al., 2011; Levine et al., 2001). As a result, parents must cut pills and mix solutions in order to give the child the correct dosage for their age and weight (Benavides et al., 2011; Levine et al., 2001; Walsh, Kaushal, & Chassare, 2005). Having to manipulate products to meet the child’s dosing requirements provides an opportunity for an error to occur.

Second, a significant proportion of pediatric medications come in liquid form. Across the literature, it is evident that parents find it challenging to measure accurate doses of liquid medication. In fact, anywhere from 40% to 60% of parents are known to have made an error while administering liquid medications (Frush, Luo, Hutchinson & Higgins, 2004; Goldman & Scolnik, 2004; Li, Lacher, & Crain, 2000). Given that the substantial proportion of parents who make errors in the dosing of liquid medications, there is a significant amount of risk associated with this process. Therefore, ensuring parents are confident in their ability to accurately administer medications is essential to preventing ADEs once the child has gone home.
In addition to parental measurement skills, another notable factor that contributes to inaccurate dosing of medication in the community is the use of inconsistent administration devices, such as household tablespoons and teaspoons (Benavides et al., 2011; Levine et al., 2001; Yin et al., 2014). When Yin and colleagues (2014) observed parents measuring liquid medications in 2 emergency departments, they found that almost 17% of parents chose to use a household tablespoon or teaspoon rather than a standard measurement tool. Moreover, parents with lower levels of literacy are more likely to use non-standardized dosing instruments in comparison to those with higher literacy levels (Rothman et al., 2009; Bailey et al., 2009). Using these household items is dangerous because teaspoons and tablespoons can vary greatly in volume, from as little as 2.5mL up to 7.8mL (Benavides et al., 2011). Therefore, the potential to overdose and or underdose is much higher compared to when standard measurement tools, such as syringes, are used to administer liquid medications (Yin et al., 2014).

Medication adherence in the pediatric population can also be more challenging depending on how palatable the medication is to the child (Benavides et al., 2011). Palatability of the medication is a particular challenge in pediatrics because, as previously mentioned, a large proportion of medications are liquid and pills are often crushed for administration. Both of these preparation methods make the unpleasant taste of the medication more noticeable to a child. Getting a child to take the medications often requires creative solutions such as mixing medications with juices and foods to mask the unpleasant taste (Benavides et al., 2011). However, even with the addition of pleasant tasting vehicles for the medication, children can often still taste
the medication, which can make it unpleasant to take and thereby impact adherence (Benevides et al., 2011).

In the community, the use of over-the-counter (OTC) medications can create further challenges for caregivers (Rothman et al., 2009). OTCs can be challenging because caregivers must first choose the appropriate medication for their child. To do so safely, caregivers must be able to assess the ingredients of the OTC medication to ensure that they are safe to use in conjunction with the other medications that the child is taking (Rothman et al., 2009). If not correctly assessed, they may choose a medication that contains medicinal ingredients that are present in the child’s other medications, contributing to a risk of overdose, (Rothman et al., 2009), or which result in a drug interaction with their existing medications.

In addition, OTC medications for children require caregivers to interpret weight and age based dosing charts to determine how much medication they should give their child (Rothman et al., 2009). Such dosing charts are often heavy with textual information, which can cause confusion for caregivers. In 2007, Kumar, Sanders, and Loker demonstrated the magnitude of this problem when they evaluated 180 parents’ abilities to interpret an infant’s medication dosing table for acetaminophen. They found that approximately half of the parents failed to interpret the dosing chart correctly (Kumar et al., 2007). This is alarming given the implications that incorrect dosing of a medication can have on a child’s health. Further more, multiple studies have found that accurately interpreting text-heavy dosing charts can be particularly difficult for caregivers with lower levels of literacy (Kumar et al., 2007; Rothman et al., 2009; Yin et al., 2007). Given the challenges that parents encounter when using OTC medications,
it is of the utmost importance that healthcare providers equip them with the skills to interpret dosing tables accurately.

Finally, limited availability of certain medication packaging strategies can also create additional challenges for parents of children with complex medication regimens. In the adult literature, blister packs that are pre-filled by the patient’s pharmacy and dosettes are often used to help patients adhere to their medication regimen (Canadian Patient Safety Institute, 2015). However, because a large proportion of the medications that children use are liquids, pre-filled blister packs and dosettes cannot always be used to organize all of their medications. Therefore, it is then left up to the parent to manually measure and keep track of the medications that are not incorporated into the blister pack or dosettes.

All of the above challenges may ultimately lead to ADEs, which may require hospitalization of the child in order to resolve (Jerant, von Friederiches-Fitzwater, & Moore, 2004; Swanlund et al., 2008). Therefore, it is important for family caregivers to know how to effectively manage their child’s medications in order to prevent medication errors and the ADEs that may follow as a result (Yin et al., 2014). Overall, the effective management of medications leads to the improvement of health outcomes as well as an overall increase in quality of life for children with disabilities and acquired injuries (Ryan & Sawin, 2009).

1.6 Causes of Medication Errors in the Community

In most cases, medication errors in the community are a result of a deficiency in the caregiver’s knowledge and/or skills rather than intentional negligence (World Health Organization - WHO, 2003). Often, family caregivers are blamed for not knowing how
to manage their child’s medications safely (World Health Organization – WHO, 2003). However, it is important to consider that there are a number of things that can influence a parent’s ability to effectively manage their child’s medication – including how well the health system prepared them in the first place (WHO, 2003).

One of the most frequent causes of adverse events that occur shortly after discharge is poor communication of discharge instructions by health professionals (Moore, Wisnivesky, Williams, & McGinn, 2003; Tarn, Patterniti, Williams, Cipri, & Wenger, 2009). There are a number of factors that can contribute to ineffective communication of discharge instructions. First, the type of information provided during the instruction should be tailored to the information needs of the family (World Health Organization, 1998). If it is not relevant to the caregivers, they are less likely to pay attention/remember it. Second, the amount of information provided to a family is also important. Providing the family with too much information at one time will likely overwhelm them. At the same time, providing not enough information can also be detrimental to caregiver’s understanding of discharge instructions (Tarn et al., 2009). The way in which the information is communicated is also important. Using plain, understandable language that is at the appropriate parents’ grade level and without medical jargon makes it easier for families to understand discharge instructions (Tarn et al., 2009). Moreover, having caregivers repeat instructions back to the provider is another way to ensure that all of the information that is given was understood by the recipient (Tarn et al., 2009). In addition to poorly delivered discharge education, failing to plan for life in the community and lack of coordination of care can also contribute to an increase in adverse events post-discharge (Shoeb et al., 2012).
1.7 Health Literacy and Medication Management

The Public Health Agency of Canada (PHAC) defines health literacy as “the ability to access, comprehend, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course.” (PHAC, 2014). According to the Centers for Disease Control and Prevention (CDC) in the United States, health literacy also includes the ability to “make appropriate health decisions” based on the health information provided (CDC, 2015). The health literacy skills of patients and their families is a major factor that determines their ability to understand medical information, engage in discussions about their health, and follow through with recommendations that they are given (WHO, 1998; Rothman et al., 2009). When a patient or family caregiver has limited health literacy and numeracy skills they are more likely to have poor health knowledge, which can lead to poor health behaviours, and as a result, worse clinical outcomes overall (Rothman et al., 2009).

There are a number of skills that a patient or family member must possess in order to be considered health literate. Arguably, one of the most important skills is the ability to understand the language in which health information is being provided (WHO, 1998). Understanding the language that the information is provided in encompasses both the cultural language, for example, English, French, or Spanish, as well as the technical language or jargon that is used by health professionals (WHO, 1998). When Leyva and colleagues (2005) evaluated Spanish speaking parents’ abilities to understand dosing instructions for Ferrous Sulfate, they found that only 22% of parents were able to correctly administer the required dose and frequency (Leyva, Sharif, & Ozuah, 2005). Of the parents in the study, those who perceived themselves as comfortable with speaking
English demonstrated correct dosing 50% of the time, whereas those who were not comfortable speaking English only demonstrated correct dosing 21% of the time (Leyva et al., 2005). Comfort with speaking English also was also correlated with ability to administer the Ferrous Sulfate the correct number of times per day. Those who perceived themselves as comfortable with speaking English demonstrated the correct administration frequency 93% of the time, whereas those who were not comfortable speaking English only gave the medication at the correct frequency 51% of the time (Leyva et al., 2005). Overall, in this setting, comfort with speaking English is an independent predictor of accurate medication administration – where non-English speaking parents are more likely to make errors in medication administration (Leyva et al., 2005; Neuspiel & Taylor, 2013).

Level of education has also shown to be an independent predictor of parents’ abilities to carry out medical instructions, such as medication administration (Neuspiel & Taylor, 2013). However, given the complexity of health information, even the most highly educated patients and families can find it confusing and thereby struggle with health literacy (du Pre, 2010). In Canada, it is estimated that 60% of adults are not health literate (PHAC, 2014). Given that 60% of adults in Canada are not health literate, it is not surprising that the literature is starting to show that low levels of health literacy in the adult population has a detrimental impact on the health of children (Rothman et al., 2009). Rothman and colleagues (2009) identified that caregivers with limited capacity, when it comes to health literacy, have a tougher time with understanding their child’s medical instructions, performing health care tasks for their child, and navigating the health system as a whole.
The level of health literacy that is required in order to understand and accurately execute medication instructions is substantial (Rothman et al., 2009). In the United States, it is estimated that 1 in 5 people are unable to read a prescription bottle and 1 in 2 cannot understand a medical brochure (du Pre, 2010). There are a number of implications of health literacy levels for the management of medications. Patients and caregivers with limited health literacy skills struggle with the implementation of medication instructions more so than their health literate peers (Rothman et al., 2009). They also experience significantly more difficulties with monitoring the effects of their medication as well as knowing when to seek medication attention for any adverse effects they may be experiencing (Rothman et al., 2009).

Additional research to evaluate the impact that parental health literacy has on pediatric patient safety and chronic disease management is needed (Rothman et al., 2009). In addition to the health literacy skills that patients possess on their own, it is also important to consider what the health system does to accommodate the diverse literacy needs within the Canadian population. Further understanding the health literacy needs of parents in Canada is important because it is a modifiable factor with the help of health professionals (Rothman et al., 2009). Not only is it important to help patients and their families develop their health literacy skills, but it is also essential that health information is accessible, reliable, and relevant to patients and their families (WHO, 1998).

1.8 Teaching Families Self-Management Strategies

Some studies have demonstrated that family caregivers frequently do not feel prepared to take on care responsibilities, such as medication management, when they
transition from hospital to the community (Leske & Pelczynski, 1999; Paterson, Kieloch, & Gmiterek, 2001). In 2012, the Canadian Pharmacists Association (CPhA), the Canadian Society of Hospital Pharmacists (CSHP), and ISMP Canada collaborated to formally define medication management. Together, these organizations defined medication management as “patient-centered care to optimize safe, effective, and appropriate drug therapy” (CPhA, CSHP, ISMP Canada, 2012). Furthermore, such care should be “provided in collaboration with patients and their health care teams” (CPhA, CSHP, ISMP Canada, 2012).

Typically, discharge planning activities, such as medication education, are done in a top down fashion where the health care providers educate families on what they think the family needs to know in order to safely provide care at home (Durocher, Kinsella, Ells, & Hunt, 2015). The most common topics included in medication education are technical, including the names of the medications, preparation of the medications, dosage, routes of administration, administration schedule, expected benefits of the medications, and how to monitor for adverse effects (American Society of Health-System Pharmacists (ASHP), 1997). In the health promotion literature, it is well known that the acquisition of knowledge on its own does not lead to a change in behaviour (Institute of Medicine, 2002, Lorig & Holman, 2003). Simply providing parents with more information about their child’s medications has shown to be an ineffective strategy to improve their medication management skills (Weiss et al., 2008). Parents and other family caregivers usually require support from their health care providers to acquire the skills that are necessary to manage their child’s medications and other health needs (Ryan & Sawin, 2009).
In contrast to traditional medication education, family medication management training goes beyond providing family caregivers with information about medications (Grady & Gough, 2014). Family and self-management training differs from education in that it includes activities that promote learning of the skills required to manage a child’s medications, rather than just the provision of knowledge. These skills can include problem solving, decision making, resource utilization, developing relationships with providers, and creating action plans that are tailored to the needs of the family (Ryan & Sawin, 2009). The skills that family caregivers learn through self-management programs can be applied to the management of healthcare needs beyond medications (Ryan & Sawin, 2009). Learning such behaviours through collaboration between families and health professionals is referred to as social facilitation and it is an integral component of the individual and family self-management process (Ryan & Sawin, 2009). The participants in the study conducted by Swanlund and colleagues (2008) identified that social facilitation was one of the strongest influences on their ability to adhere to their medication regimen. Medication education programs that are based on individual and family self-management principles have the potential to bridge the gap between medication education as a means of knowledge provision and comprehensive medication management training.

1.9 Family-Centered Care

In pediatric rehabilitation, Family-Centered Care (FCC) has been identified as fundamental to the delivery of health services for quite some time and it is now considered to be a model of best practice within the field (Dickens, Matthews, & Thompson, 2011; King & Chiarello, 2014). FCC refers to the way in which health
professionals interact with families, how they provide their services, and the extent to which they involve the family in the child’s care (King & Chiarello, 2014). The philosophy of FCC is based on a number of principles. First, it is important that health care providers form a collaborative relationship with the family where parents are ever present and, if desired, parents participate in the care of their child (Butler, Copnell, & Willets, 2014). In the context of family-centered medication education, parents are sometimes given the opportunity to administer the child’s medications while in hospital, if the clinical scenario permits. Their participation in this process not only allows parents to practice administration techniques before they go home, but it can also be comforting to the child to have their parent providing their care. In the FCC model, there is also an emphasis on the strengths of children and their families, rather than focusing on their deficits (King & Chiarello, 2014).

Within FCC, health professionals provide open and honest information to assist children and their families in making choices that are in alignment with their goals, priorities, and needs (Butler, Copnell, & Willets, 2014; King & Chiarello, 2014). Specifically, health care providers who embrace FCC practices take the cultural, socio-economic, and developmental needs of the child and their family into consideration when delivering care (King & Chiarello, 2014). For example, family-centered medication education would include efforts to make medications more affordable based on their socio-economic status and insurance coverage, in addition to teaching them how to administer the medications safely in their natural home setting. Other information may include the pros and cons of selecting one medication over another so that parents can make decisions for their children based on their own priorities, such as quality of life.
Providing parents with this information can help them make informed decisions so they can develop a medication management plan that will meet the needs of their family (Neuspiel & Taylor, 2013).

While family participation is essential for FCC, the execution of a family-centered model of care is largely the responsibility of health care providers. Moreover, health professionals must also collaborate with each other, in addition to children and their families, in order to provide care that is truly family-centered (Butler, Copnell, & Willets, 2014; King & Ciarello, 2014). In a hospital setting, inter-professional collaboration can be complex given that nurses, pharmacists, and physicians can all be part of the medication education process; however, hospital care providers benefit from co-location and regular contact. In contrast, community-based health professionals may have fewer opportunities for direct collaboration. Since multidisciplinary collaboration is vital to providing FCC, there must be a support system in place to guide open communication, collaborative goal setting, and teamwork (Coyne et al., 2001; King & Chiarello, 2014). It is also important to be cognizant of the balance between family empowerment and participation in care and providing adequate support. Achieving this balance will provide families with a sense of control but not impose additional stress and unwanted responsibility (King & Chiarello, 2014).

During major events in health care, such as the transition from hospital to home, patient and family-centered care is especially important (Hesselink et al., 2015). In 2015, Hesselink and colleagues, as well as Durocher and colleagues identified several facilitators of and barriers to providing patient centered discharge planning. Teaching parents to manage their children’s medications is a substantial part of discharge
planning. Providing patients and their families information about their discharge, such as their medications, at multiple points throughout their hospitalization and checking if patients understood this information, using methods such as teach back, were considered to be vital aspects of patient centered discharge planning (Hesselink et al., 2015). Furthermore, keeping community care providers such as family physicians informed about the patient’s hospital care and plan for discharge long before they go home helps to ensure continuity of care for the patient and thereby enhances patient centeredness (Hesselink et al., 2015). Providing discharge planning that is family-centered can improve medication adherence as well as overall family satisfaction and readiness to take on care at home (Solan et al., 2015).

Despite the recent emphasis on providing family-centered discharge planning, many families still leave the hospital feeling unprepared to manage post discharge care (Hesselink et al., 2015). This is most likely due to the fact that there are many barriers to providing health care that is family-centered, especially at the time of discharge (Hesselink et al., 2015). One of the most prominent barriers is lack of time for providers to discuss patient preferences and tailor discharge planning accordingly (Durocher et al., 2015; Hesselink et al., 2015). Health professionals in Canadian institutions often have to balance competing demands due to a lack of resources, which leaves little time to dedicate to working with individuals and their families to develop family-centered discharge plans (Durocher et al., 2015). Moreover, providing discharge planning that is safe is often prioritized over providing discharge planning that is family-centered (Durocher et al., 2015). Since safety is of the utmost importance, FCC often falls by the wayside because there is not enough time for health professionals to address both.
As discharge planning may not be addressed in a family-centered context, caregivers of pediatric patients often leave the hospital feeling unprepared and anxious about providing care at home (Hesselink et al., 2015). Addressing these barriers and conflicting health system pressures that prevent health professionals from providing family-centered discharge planning has the potential to improve parents’ ability to provide care (such as medication management), as well as reduce anxiety and avoidable readmissions (Hesselink et al., 2015). Interventions such as Patient Oriented Discharge Summaries (PODS) and post discharge phone calls have been implemented in pediatric rehabilitation to provide a framework for health professionals to provide family-centered discharge care. However, health professionals that were interviewed to develop the following research identified that they do not receive any additional training on how to implement these tools in a family-centered way. Therefore, within the institution that this research will take place in, it is up to the discretion of each individual health professional to provide discharge teaching using strategies that they perceive to be family-centered. To that end, the most effective ways in which health professionals should apply the principles of FCC to using these interventions remains elusive within the literature as well as within Canadian health care institutions.

1.10 Rationale for Research

Over time, the health system’s expectation of family caregivers to take on the responsibility of managing their child’s chronic condition has increased (Ryan & Sawin, 2009). However, health professionals’ understanding of how to teach family caregivers the knowledge and the skills required to manage a child’s care has not grown at such a rapid rate (Ryan & Sawin, 2009). This lack of knowledge can create a significant gap in
communication between health professionals and families when it comes to teaching parents how to manage their child’s medications and other health care needs (Kaushal et al., 2007). When gaps in communication between caregivers and health professionals exist, there is a lower level of adherence to the medication plan among parents (Kaushal et al., 2007; Newcomb, McGrath, Covington, Lazarus, & Janson, 2010). As a result, the overall quality and safety of care can be compromised (Newcomb et al., 2010).

In addition, transitioning from the hospital to home is a vulnerable and stressful event for both children and their caregivers (Solan et al., 2015). Organizations such as Accreditation Canada, the Institute for Healthcare Improvement, the Canadian Patient Safety Institute, and the Institute for Safe Medication Practices (2012) support the need to improve the teaching practices used at the time of hospital discharge, especially for medication management. Currently, there is a significant gap in the literature when it comes to understanding how FCC can be maximized to improve the handover of medication management from the hospital to the caregiver of children. Weiss and colleagues suggest that the delivery of medication education should be examined in order to determine the optimal processes that meet the learning needs of family caregivers (Weiss et al., 2008). Patterson et al. (2001) echo this sentiment as they identify the necessity for further inquiry into the needs and preference of family caregivers during discharge teaching.

In regards to medication education, it is critical that patients and their families are actively involved in the design of the process because their experiential knowledge will provide insight to potential safety issues that may arise as a consequence of ineffective
medication management strategies (Accreditation Canada, 2013; HQO, 2013). To our knowledge, no literature exists that examines the process of medication education from the perspective of patients and their families. Therefore, this research will focus on understanding caregivers’ experiences with learning to manage medications in order to learn more about how best to prepare caregivers before they leave the hospital. Specifically, we hope to understand and identify the medication education processes that facilitate, or conversely, inhibit the effective management of medication regimens for children with complex needs in the community. Ultimately, this research will focus on collecting this information from family caregivers in order to bridge this gap in knowledge and provide a foundation for local quality improvement initiatives.
CHAPTER 2: RESEARCH METHODS

This chapter contains a description of the methods that will be applied to gather and analyze the data required to answer the research questions.

2.1 Setting:

The research reported in this thesis was conducted in collaboration with a pediatric rehabilitation hospital with academic affiliation in a large Canadian city. The hospital serves children with conditions such as Cerebral Palsy, Spina Bifida, Muscular Dystrophy, Epilepsy, Autism, and other congenital abnormalities as well as acquired injuries including Acquired Brain Injuries and Spinal Cord Injuries. The hospital is a regional rehabilitation hospital, treating patients from all over the province. Nurses and pharmacists from the rehabilitation hospital were informally interviewed to gain a general understanding of what medication management discharge teaching looks like at this hospital and how FCC is integrated into this process – see description on page 19.

2.2 Research Questions:

The primary research question that this study aims to answer is:

1. What are family caregivers' experiences with medication education during their child’s inpatient rehabilitation?

The secondary research questions that this study aims to answer include:

2. What medication education strategies do family caregivers perceive to be helpful?

3. What medication education strategies do family caregivers perceive to be unhelpful?

4. Are there any gaps or improvements that can be made within current medication education practices from the perspective of family caregivers?
2.3 Study design:

For this study, qualitative methods were determined to be the most effective way to capture an authentic description of parents’ experiences with learning to manage their child’s medications. Qualitative studies, in general, can assist health care providers in understanding self-management beliefs of patients and their caregivers due to the detailed descriptions of the experience that they produce (Kaushal et al., 2007; Swanlund et al., 2008). As was previously mentioned, patient and family perceptions of health care frequently do not align with those of health care providers (Paterson, Kieloch, & Gimterek, 2001; Tarn et al., 2009). By applying qualitative methods rather than surveys, patients are not limited to expressing their opinions about medication education topics in categories defined by health care providers. Instead, participants are given the flexibility to discuss the areas of medication education that they perceive to be important and the various management strategies that are effective for them.

For this study, a grounded theory approach was adopted as the methodology. According to Creswell (2007), grounded theory can be described as a research methodology in which the investigator produces a general explanation – or “theory” - of a process, action, or interaction based on the perceptions of people who have experienced the process. Through grounded theory, theories and explanations of behaviour are constructed based on observing the process of interest and applying inductive reasoning to analyze what is observed (Jacobsen, 2001). The general description of the process is “grounded” in the data that describes the actions, interactions, and social processes of the experience (Charmaz, 2002; Creswell, 2007; Strauss & Corbin, 1990). To that end, we are interested in the process of medication
education and management from the perspective of family caregivers and their views of the interactions they have with clinicians during the medication education process (Newcomb, McGrath, Covington, Lazarus, & Janson, 2010; Swanlund et al., 2008). Ultimately, this research aims to produce a description of how parents learn to manage their child’s medications upon discharge from inpatient rehabilitation care.

2.4 Sampling

For this study, convenience and purposive sampling methods were applied (Jacobsen, 2011). These sampling methods were chosen to ensure that participants are selected based on their ability to provide in-depth accounts of their experiences with medication education in a way that is of relevance to our research questions (Sandelowski, 2000). Purposive sampling consisted of recruitment of family caregivers from the Brain Injury Rehabilitation Team (BIRT) and the Specialized Orthopedic and Developmental Rehabilitation (SODR) units at the hospital. In total, there are three units at the hospital. The third unit at the hospital is a complex continuing care unit, which patients are rarely discharged home from. When patients are discharged, they usually receive substantial support with tasks such as managing medications in the community from organizations such as Community Care Access Centers. Therefore, the BIRT and SODR units were selected because the families discharged from these units are representative of the majority of patients that are seen in rehabilitation hospitals. Convenience sampling involved inviting all eligible caregivers within these units to participate, and interviewing those who provided consent to participate.

Inclusion Criteria for selection of participants in this study were as follows:

1. The client in the family was an inpatient on BIRT or SODR
2. The client must be currently taking more than 3 medications – including prescription medications, over the counter medications, vitamins, and supplements.

3. The family caregiver must be responsible for managing the child’s medications at least 50% of the time.

4. The family caregiver must be able to recall having received medication education while at the hospital between January 2016 and April 2016.

5. The caregiver must be able to speak and understand English, without the assistance of a translator.

Family caregivers were recruited until it was determined that no further information could be gained by interviewing more participants, otherwise known as the saturation point (Charmaz, 2002). For a homogenous sample, like the one described in this study, it was estimated that saturation could be achieved by interviewing anywhere from 8-10 individuals (Guest, Bunce, & Johnson, 2006; Sandelowski, 1995). When Lebensburger and colleagues (2015) interviewed first-time parents of children with sickle cell anemia about the health education they received at a sickle cell clinic, they were able to reach saturation by interviewing 8 parents.

2.5 Data Collection

Participant Recruitment

From January 2016 to April 2016, an information letter was sent to all families that were discharged from the brain injury and orthopedic units and met the inclusion criteria for the study (Appendix 1). The letter explained the study and notified families that somebody from the research team would be contacting them within 1 week to discuss taking part in the study. If families did not wish to be contacted about the study,
they were instructed to leave a telephone message on a phantom mailbox indicating their wishes. A phantom mailbox is a voice mailbox that is not connected to a live phone line. The phantom mailbox was used so that families could let the researchers know they were not interested in the study without having to speak with the researchers directly.

Families who did not leave a message on the phantom mailbox received up to 3 follow up phone calls. During the follow up calls, the researcher answered any questions the family had about the study, confirmed their eligibility, and if applicable, scheduled an interview at a time that was convenient for them. If contact could not be established within those 3 phone calls, then active recruitment of that family would end.

**Collection of Demographic Data**

Each participant completed a background questionnaire before starting the interview. The background questionnaire collected demographic information about each family; including the caregiver’s role, their level of education, the language they speak at home, as well as the child’s diagnosis and the child’s age (Appendix 2). All demographic data was then entered into a spreadsheet using Microsoft Excel version 2010, separate from any participant identifiers.

**Interviews**

The majority of the data for this study was collected through semi-structured, one-on-one interviews with family caregivers. The one-on-one interviews were used to collect the data required to develop a description of caregivers’ experiences with medication education (Creswell, 2007; Milne & Oberle, 2005; Sandelowski, 2000). Family caregivers were given 3 options for participating in the interview:
1. The caregiver could elect to be interviewed face-to-face at the hospital.

2. The caregiver could elect to be interviewed in their home, if they lived within the vicinity of the hospital. The lead researcher would travel to the family’s home to complete the face-to-face interview.

3. The caregiver could elect to be interviewed over the telephone.

Face-to-face interviews are preferred to obtain data that is of the highest quality (Seidman, 2006). However, due to the fact that a lot of the families who received care at the hospital live a significant distance away, it was necessary to provide alternative options for completing the interview.

All of the interviews were completed between February 2016 and April 2016. The interviews took place approximately 2 weeks to 1 month after the family was discharged. Each interview lasted approximately 20 - 30 minutes.

Each interview was structured using the interview guide – refer to Appendix 3. The interview guide was developed in consultation with several different professionals at the rehabilitation hospital as well as the researcher’s thesis committee. The health professionals that contributed to the interview guide included pharmacists, the patient safety manager, and a clinician investigator who is also a registered nurse and family therapist, as well as a member of the researcher’s thesis committee. When using the interview guide, it was essential to be flexible in the way questions were posed to ensure that participants were able to tell their own stories in their own way (Milne & Oberle, 2005). Allowing participants to tell their stories in their own way promotes authenticity by giving participants the freedom to speak and feel like their voices are being heard (Milne & Oberle, 2005).
Each interview began with a brief introduction, followed by the parent describing their child’s day-to-day medication routine. This description allowed the researcher to gain insight to the complexity of the medication regimen that the family deals with as well as position herself to ask relevant probing questions throughout the interview. After the parent provided an overview of the child’s medication routine, the researcher asked questions about the medication education that parents received while they were an inpatient, as well as other hospitals that they were at prior to coming to the rehabilitation hospital. Finally, the interview concluded by asking the parent if they had any additional comments or suggestions that they would like to make about their experiences with medication discharge instructions and home medication administration. In order to ensure that we collected an in-depth account of participants’ experiences with medication education, probing questions were used throughout the interviews to clarify what the participants said and to gain a further understanding of their experience (Milne & Oberle, 2005).

After each interview, the researcher set aside time to write a memo about the interaction. The memo took the form of a free-flowing piece of writing and it was used to document the researcher’s initial impressions of the interview including emerging ideas about concepts and relationships between concepts (Charmaz, 2002).

2.6 Data Analysis

In person interviews were recorded using a digital audio recorder and then transferred to the hospital’s internal server as a password protected MP3 file. Data was transferred from the audio recorder to the server immediately following the interview to safeguard the file. Once the audio recording was transferred to the hospital’s server it
was deleted from the digital audio recorder. When the digital audio recorder was not in use it was stored in a locked cabinet in a locked room at the hospital.

Phone interviews were recorded using the Premier Global conference calling system. Once the lead researcher and the participant were both connected to the teleconference, the interviewer began recording the interview. Once the interview was complete, the researcher was sent an email with a link to the audio recording. This system has sufficient security to ensure that the file was not lost or sent to someone who is not meant to receive it. The audio recording was then saved to the hospital’s server as a password protected MP3 file and deleted from the email system. After the file was saved to the hospital’s server it was also deleted from the conference calling system.

Following the interviews, the data was transcribed verbatim into a document using Microsoft Word version 2010. The transcript was then uploaded to NVivo qualitative data analysis software, Version 10, by QSR International, to facilitate the coding and organization of data. A code book was also used to record the definitions of each code (Creswell, 2007; Lebensburger et al., 2015).

The coding process occurred simultaneously with data collection so that both processes are mutually shaped by one another (Charmaz, 2002). True to the methods traditionally used in grounded theory studies, a number of sensitizing concepts that originate from prior knowledge of the Individual and Family Self-Management theory and FCC models were used to guide the coding process (Charmaz, 2002; King & Ciarello, 2014; Ryan & Sawin, 2009).
This initial coding process where codes are based on pre-existing concepts is referred to as deductive coding (Miles, Huberman, & Saldana, 2014). Once codes have been established, those that appear frequently will be applied to subsequent interviews and used to organize the data (Charmaz, 2002). Following deductive coding, inductive coding took place. Inductive coding allows for the application of codes that have emerged throughout data collection process (Miles et al., 2014). Throughout the data collection and analysis process, the researcher frequently shared her thoughts about emerging themes with the thesis committee to obtain multiple perspectives on how to view the data as it was being coded.

When the data was being coded and organized into categories, it was important to take steps to ensure that the context of each individual interview is not lost during this process. To ensure this, descriptive codes were applied to help create a picture of any contextual information about the medication education process (Miles et al., 2014). Moreover, the researcher also reviewed the memos that were written after each interview to expand on the codes (Charmaz, 2002). Reviewing memos that are written during data collection aided in the analysis by helping the researcher stay true to the illustrative story of the medication education process, as told by the participants, and it allowed her to reflect on any biases that may have been present at the time of the interview (Charmaz, 2002).

In total, each interview underwent two cycles of coding, as recommended by Miles and colleagues (2014). The purpose of the first cycle of coding was to summarize the various segments through both deductive and inductive coding of descriptions, processes, and actions related to medication education (Miles et al., 2014). The second
cycle of coding was used to expand on the initial summaries and identify categories, themes, relationships, explanations, and theoretical constructs (Miles et al., 2014). Codes that were consistent across multiple interviews were identified as categories (Charmaz, 2002). Subsequently, the categories were integrated using statements of relationship to form the description of the medication education process (Charmaz; 2002; Strauss & Corbin, 1990).

2.7 Quality and Rigor

Two of the eight transcripts were independently reviewed by a medical student with training in qualitative research. The two transcripts were selected because they covered a wide variety of the themes that were identified by the primary researcher. Independent review was done to ensure that family caregivers’ perceptions are accurately represented in the codes that are selected by the researcher (Milne & Oberle, 2005; Sandelowski, 2000). Differences in coding were discussed between the two reviewers and negotiated until a consensus was reached.

2.8 Ethical Considerations

Prior to the commencement of recruitment and data collection, this study received research ethics approval from the pediatric rehabilitation hospital and the University of Toronto. Ethics approval for this thesis research project was obtained from the hospital and from the University of Toronto in January 2016. Throughout the duration of this study, standard practices were followed in regards to consent, participation, and data storage.

The method for obtaining consent from participants varied depending on how the interview was conducted.
For participants who completed their interview over the phone, the researcher reviewed the information form with the participants and made sure that they understood all of their rights to privacy, confidentiality, and that they could withdraw from the study at anytime, without consequence. Additionally, the researcher asked the participants if they had any questions before formally obtaining consent. Once all questions were answered, the researcher then confirmed that the participant was in agreement with everything outlined in the consent form and that they would like to proceed with the interview. The participant’s consent was audio recorded and indicated as such on a paper consent form that the researcher signed and kept a copy of.

When a participant was interviewed in person, the researcher reviewed the consent form and answered the participant’s questions in the same format as was used with participants doing their interview over the phone. When a participant was doing their interview in person, written consent was given prior to starting the interview. As part of the consent process, permission to record the interview was obtained from each participant.

Each participant was assigned a study ID. In addition, identifying information, such as names, were removed from the interview transcripts and replaced with [child#].
CHAPTER 3: RESULTS I – DESCRIPTION OF SAMPLE

Consistent with the study conducted by Lebensburger and colleagues (2015) as well as other literature on grounded theory methods, we were able to achieve saturation by interviewing 8 family caregivers. Saturation was determined when the researcher was able to identify common themes across multiple interviews and it was felt that no further knowledge would be gained by interviewing more participants (Sandelowski, 2000). In total, 2 interviews (25%) were conducted in person and 6 (75%) interviews were conducted over the phone.

Table 1 outlines the descriptive data that was collected as part of the background questionnaire that each parent answered prior to the interview. Of the 8 caregivers that were interviewed, 7 identified themselves as the child’s mother and 1 identified as the child’s father. The level of education that parents had achieved ranged from ‘some college’ to an ‘advanced degree’. The majority of parents, 7 out of 8, reported that the primary language they speak at home is English. The demographic questionnaire did not elicit the geographic residence of the caregivers (e.g., urban or rural).

Table 1. – Demographic Characteristics of Caregivers

<table>
<thead>
<tr>
<th>Parent Characteristics</th>
<th>Responses</th>
<th>Response Rate n=8 n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self- Identified Caregiver Role</strong></td>
<td>Mother</td>
<td>7 (88%)</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>1 (12%)</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td>Some College</td>
<td>1 (12%)</td>
</tr>
<tr>
<td></td>
<td>College Diploma</td>
<td>3 (38%)</td>
</tr>
<tr>
<td></td>
<td>Undergraduate Degree</td>
<td>2 (25%)</td>
</tr>
<tr>
<td></td>
<td>Advanced Degree (e.g. Masters, Ph.D, MD)</td>
<td>2 (25%)</td>
</tr>
<tr>
<td><strong>Language Spoken at Home</strong></td>
<td>English</td>
<td>7 (88%)</td>
</tr>
<tr>
<td></td>
<td>South-Asian</td>
<td>1 (12%)</td>
</tr>
</tbody>
</table>
The age of the children that were discussed in this study ranged from 1-year-old to 17-years-old. Half of the children were under the age of 12. The other half were over the age of 12 but still required their caregiver to be responsible for managing their medications.

The types of medical conditions that children experienced also varied widely. The most common conditions were Epilepsy (n = 2), Traumatic Brain Injury (n=2), and Stroke (n = 2). Table 2 further demonstrates the distribution of age and the medical conditions of the children that will be discussed in this study.

Table 2. – Demographic Characteristics of the Children

<table>
<thead>
<tr>
<th>Child Characteristic</th>
<th>Responses</th>
<th>Response Rate n=8</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>0-4 years</td>
<td>3 (38%)</td>
</tr>
<tr>
<td></td>
<td>5-9 years</td>
<td>0 (0%)</td>
</tr>
<tr>
<td></td>
<td>10-13 years</td>
<td>1 (12%)</td>
</tr>
<tr>
<td></td>
<td>14-17 years</td>
<td>4 (50%)</td>
</tr>
<tr>
<td><strong>Child’s Condition</strong></td>
<td>Epilepsy</td>
<td>2 (25%)</td>
</tr>
<tr>
<td></td>
<td>Stroke</td>
<td>2 (25%)</td>
</tr>
<tr>
<td></td>
<td>Cerebral Palsy</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td></td>
<td>Traumatic Brain Injury</td>
<td>2 (25%)</td>
</tr>
<tr>
<td></td>
<td>Orthopedic condition</td>
<td>1 (12.5%)</td>
</tr>
</tbody>
</table>
CHAPTER 4: RESULTS II – LEARNING TO MANAGE TECHNICAL ASPECTS OF MEDICATIONS

Throughout the participants’ recollections of learning to manage their child’s medications, two broad categories emerged. The first being learning to manage technical aspects of medication regimens. For the purpose of this analysis, technical aspects of medication management include processes that are directly related to the preparation, administration, and monitoring of medication. Overall, technical aspects of medication management that parents recalled being discussed during education sessions included medication names, purpose of the medication, how to prepare it, how much to give, how often to give it, and what side effects to monitor for. This description was consistent across all interviews.

4.1 Complex administration

The first technical issue with medication management that parents encountered was implementing complex administration techniques. Within the sample, six of the children were on medication regimens that included at least one medication that was complex to administer. Examples of complex administration methods that were describe by interviewees included injections, administration via gastronomy tube (g-tube), mixing suspensions, crushing pills to create liquids, and tapering schedules. Specifically, two of the parents described the precision that these methods require to be challenging for them.

“it was a liquid dose and at home I have the powder so it was very challenging to make that into a liquid and continue giving him the dose – it’s very technical, you have to measure with weight and this and that” – Participant 003

and
“now that we’ve switched to the Tinzaparin we are back to the vial draw. So just making sure you know that we’re sterilizing the vile, and making sure that we’re getting the exact amount, we’re not under dosing or over dosing her.” – Participant 002

One of the other parents also identified that having to split pills to create the child’s exact dose in combination with having to mix it into a solution with water was challenging.

“…there’s a challenge for us in terms of like, you know, like we are giving him a certain dose… the infant dose is not available so we need to cut the medications to complete the dose… Then we need to crush it and mix it with water and give it to him. So it is kind of like some like mixing process involved in here so it takes a little bit longer time usually to give him the medication” – Participant 007

Throughout the medication education process, health care providers demonstrated these techniques to parents and allowed them to practice some of these skills in the hospital. During demonstrations, the health care provider would show the parent step by step and then get the parent to demonstrate the technique back to them. This is often referred to as the “teach back” method.

Parents were then given further opportunities to practice these skills while in hospital. For example, when two of the interviewees were learning to give their child’s injection, the nurse offered to bring up oranges from the cafeteria so that they could practice. Parents also reported being given opportunities to practice crushing pills as well as administration via g-tube. For procedures such as injections and g-tube administrations, parents must demonstrate their ability to complete these tasks before the child can be discharged as per hospital policy. Several of the parents reported that the practicing and demonstration of their skills to satisfy this requirement helped to build their confidence in their ability to perform these complex tasks safely at home.
“so we did it and it was great, they stood right there and talked me through each step so I felt confident in how we were doing it” – Participant 002

and

“I know that they were trying to look for a pill crusher but the nurse I had that one day was like “oh you don’t need a pill crusher, you put your pills in the syringe and you kind of pump the syringe up and it’s crushing it while it’s hitting the surfaces” and that was neat because I have all that at home and I don’t have a pill crusher so we always used a knife or you know the back of a spoon and we were always worried about how sanitized area that our home was when we did things like that. So the pill crushing method from one nurse was great… So going home with that method was great because I could show my husband and we don’t have to worry about how clean the spoon is or the surface is” – Participant 003

4.2 Palatability of Medications

Two of the parents with younger children (age 1 and 10) also found administration challenging at times due to the taste of some of the medications that their children take. While this challenge is usually most prevalent in children who take liquid medications, even one child who was able to swallow pills struggled with the taste of her medications:

“[S]he would sometimes spend, and I’m not even kidding, 20 minutes trying to work up the courage to swallow these pills because she had to take 6 of them and they tasted horrible.” – Participant 002

In this scenario, the pharmacist suggested crushing the pills and putting them in a gel capsule to take away the bitter taste. Not only did this solution help with the taste, but it also decreased the number of pills the child had to take each day; which the child resisted. While this administration method was more complex, the trade off was worth it for the parent so that her daughter didn’t have to struggle through taking a foul-tasting medication every day. This is a good example of a health professional helping a parent tailor a medication regimen to their child’s preferences in order to improve quality of life.
A second interviewee also mentioned that nurses worked with her to develop ways to modify the taste of the medications using juices, yogurts, etc. in order to make taking the medication more appealing to the child. In both scenarios, the health professionals were working in partnership with caregivers to find viable solutions to their problems, which is in alignment with FCC.

### 4.3 Volume of Medications

Another technical challenge that parents discussed during the interviews was the volume of medications that their children take. The volume of medication was challenging for parents because they often received “push back” from their children because taking that amount of medication was unpleasant. This challenge was most common among parents of children that were age 4-10 years. Four parents mentioned that it was important to them that their child is on as few medications as possible. Participant 004 reported that her confidence in her ability to manage her child’s medications increased as the number and quantity of medication her child had to take decreased. In general, parents were not only concerned about large medication volumes from a logistical perspective but they were also concerned about the long term impact of the medications on their child’s health.

Two of the parents discussed how they dealt with the large amounts of medications that their children take to make it manageable for their families. As previously mentioned, one of the pharmacists came up with the solution to decrease volume for the child of participant 002 through crushing the pills and putting them in gel capsules – which was quite successful for the mother.
“…it works really well for her. It decreases the number of tablets she has to swallow um and kind of takes some of the anxiety, because she has quite a few things she has to take each day” – Participant 002

Another mother would have her son take 1 of his medications every 10 minutes so that he did not have to take all of his pills at once. This process ended up turning medication time into a bit of a “game” for the child which made taking his medications more “fun”.

In families where the child receiving the medication was of appropriate age and developmental status, parents found that it was easier to get their child to take the medications if the child was involved in the process in some way. For one parent, she found that it was easier to overcome bouts of resistance from her daughter when the child had an understanding of why she had to take each medication and what the medication was doing in her body.

“…when you’re sitting down to breakfast and you’ve just woken up and you have 8 pills to swallow I get a little push back. I still get push back on you know “do I have to take my calcium today?”, “Yes you do”, “Why?”, so sometimes I’ve found it is helpful to know what each medication is for because she’s a kid, she doesn’t want to take it, she’d rather not so having reasons and understanding what is happening in her body and being able to explain that to her I can’t imagine not knowing what it’s for… so I mean she will even watch the clock sometimes and say to me “you have to give me my Baclofen in 20 minutes” or “don’t forget to give it to me” because she knows the value of it, she’s been educated as well… but the more the child knows I think the easier it is” – Participant 002

This parent attributed her daughter’s knowledge about her medications to the time that the nurses spent explaining the purpose of each medication to her when they were administering it at the rehabilitation hospital. Educating the child about the purpose of their medications assists parents in dealing with resistance to taking medications when they are at home because they can then reinforce these hospital conversations. While younger children may not have the capacity to understand the rationale for the
medications they are taking, involving them in the administration process in other ways can still be beneficial. Another mother in the study spoke of how the nurses at the rehabilitation hospital “educated” her child about his medications during administration even though he was only 4 years old:

“…the nurses always made the medication a great experience for [child3], bringing it over to him, talking to him about medication, not just to me. You know “[child3] it’s your med time, eat your breakfast, have your meds, I got your Frankenstein vitamins” and showing it to him. He’s looking at the image.” – Participant 003

4.4. Delivery of Information

Technical information about medications was provided to parents verbally as well as in the form of information sheets. Depending on prior knowledge and how much change was made to the child’s medication regimen during hospital stay, parents sometimes felt that they did not require information sheets; verbal explanations were sufficient. Those who received information sheets were appreciative of the resource. Even Participant 001 who did not feel she needed the information sheets herself identified that she could see them being of use to families who are new to managing medications. All of the interviewees also reported that the information that was given to them was in plain, understandable language.

However, despite the fact that the delivery of technical information given to parents was fairly consistent across interviewees, one parent did report receiving conflicting information regarding the process for administering her daughter’s injection:

“I think the only thing that I would say in terms of giving an injection there was varying information regarding post injection do you hold the site or do you not hold the site and some people were adamant “yes you absolutely hold the site so as to prevent bruising” and other people were “no no no if you hold the site you’re
This information was inconsistent between nurses at the rehabilitation hospital as well as the tertiary care hospital the child had been at prior. The same parent also mentioned that while they were at the rehabilitation hospital, a nurse gave inaccurate information to her child in regards to her medication. The nurse told the child that there was a good chance that she will be able to come off of her injectable blood thinner once she becomes more mobile. However, this was not the case for this particular child given that she was taking the blood thinner in order to prevent further strokes – therefore she would not be able to come off of it even when she became more mobile. The parent acknowledged that she felt the nurse was well meaning, but it was still frustrating to her as a parent because she now had to correct the misconception to her daughter.

Despite parents being provided with all of this information, and reporting that they are satisfied with the amount of information given to them by their health care providers, parents often sought out their own additional information sources. In total, six out of the eight participants in this study reported consulting alternate sources of information to learn about their child’s medications. The most prevalent source of information that parents accessed was websites they found through search engines such as Google. Specifically, parents were most often looking for information on side effects of the medications their child is taking. For Participant 001, her family members who worked in the medical field were also an important source of information.

“I have family members in the medical field so they knew all this stuff so I never really had to, I never needed as much help as I guess I would if I didn’t, if I wasn’t already, if I hadn’t already been through or know people in that situation I guess.” – Participant 001
In addition to looking things up on the internet, another parent mentioned she also considered information that her son had seen on a medical talk show. On the show, a celebrity with multiple sclerosis who had experienced pain that was not well controlled by medication discussed an alternative treatment that he had found success with. That treatment was Cannabidiol (CBD) which is not yet well studied in children. Since her son had a similar experience of prolonged pain that was not well controlled on medications, she began to explore the recommended treatment to see if it would be right for her son.

Despite reporting that they received enough information about their child’s medications from their health care providers, many parents who were interviewed in this study discussed doing their own additional research. The reason that parents sought other sources of information is unclear at this time. However, in the case of the mother who was looking into alternative treatments for her son’s pain, she did not feel that she was given enough information about the pros and cons of pursuing that option and she was left on her own to find reputable information.

“I'm looking for a professional guidance...The pharmacist here I didn’t find helpful. She didn't even really want to discuss it. She didn’t want to go there so, you know, it left me, I don’t know if she figured she was shutting me down and get me off the path but as a parent, no, we’re gonna look...your gonna do what we have to for our children... as a professional, I find that everybody knows about the neurological part, impact, right? And you you’ve done the studies, I know what I’ve read and I understand a lot, but I’m also his parent...and I know my kid...but yeah it would have been helpful if somebody, if I’m asking questions about medication that somebody would actually talk to me about it, educate me, “this is what I know”. I mean outcomes, pros, cons, anything...” – Participant 006

Throughout the medication education process, she felt as though she was “shut down” by the pharmacist whenever she would bring up the topic of CBD. While this parent’s experience differs from the others in satisfaction with the information provided about
medications, her motives are quite similar in that they all want to understand the medications their children are on and make sure that they align with the family’s treatment and quality of life goals as best as possible. The parent who was looking into CBD was trying to find a remedy for her son so that he did not have to live in pain any longer than he already has.
CHAPTER 5: RESULTS III – LEARNING TO INTEGRATE MEDICATION MANAGEMENT INTO EVERYDAY LIFE

5.1 Family Involvement

Although the interviews in this study focused on the experiences of the caregivers who are primarily responsible for managing each child’s medications, the role that other family members play in medication management was brought up by a number of participants. Other family members who were mentioned as involved in the medication management include the other parent, siblings, and grandparents. Each individual plays their own role in medication management that is unique to each family’s circumstances. For example, in participant 008’s family, her older daughter and her husband help with administration of her son’s medication whenever she is unable to be there.

“every person in my family, so my husband and my older daughter, all know the timing so if I’m not here it’s a matter of we communicate about it so that they make sure that they give it to him.” – Participant 008

In participant 003’s family, her daughter plays more of a supportive role where she gets involved with the daily routine of medication administration.

“It’s a part of our everyday routine… sister also helps and says it’s time for meds and he runs into the kitchen he lines up for his meds… telling him you know “[child3] come over and mommy has to give you your stuff.”” – Participant 003

Parents also mentioned that some of the medication management strategies they have established at home are based on the fact that there are multiple family members involved in the management process.

“I just put it on the calendar in terms of when we would decrease and to what we would decrease. Not only for my organization but also just in case for whatever
reason I wasn’t around and my husband had to administer the medication he would know where we were in the wean schedule.” – Participant 004

It was also important for parents to have a system in place when occasional caregivers had to take responsibility for the administration of the child’s medications. For example, participant 001 keeps all of the medications in one spot and labels them with the time of day they need to be administered so that it easier for occasional caregivers, such as her child’s grandparents, to know when to give her daughter her medications.

Moreover, it was also important for parents to involve the child in medication management in a number of ways. In addition to educating child about the purpose of their medications, parents also liked to involve the child in the administration process as much as possible. For participant 003, involving her child in the medication administration process in a fun way made the whole experience better for the child.

“So I always got [child3] involved with his experience throughout the whole journey and he loves counting the pills, putting it inside the syringe and then you know we sing through the pumping “let’s pump the syringe”, and he’s excited and has a better experience taking his pill that way.” – Participant 003

For older children, such as the children of participants 006 and 008, listening to their children’s preferences and suggestions about their medication regimen was important. In child 008’s case, he preferred to give his injection himself and let his mother look after the rest of his medications. In response to this request, the health care providers at the rehabilitation hospital worked with him to train him to administer the injection. Child 006’s parent showed a sensitivity to her child’s preferences when he came to her wanting to investigate using CBD as an alternative to treat his pain.
Overall, communication amongst all family members involved in medication management, including the children themselves, was described as essential in order to ensure the process was done smoothly and safely and that the medication regimens fit the needs of all its members.

5.2 Time Management

Time management was one of the most frequent challenges that parents encountered when they went home and were responsible for integrating their child’s medication schedule into their daily life. One of the reasons that time management was challenging for parents is some medications require precise dosing intervals that do not always align with other daily routines and activities. Participant 007 reported struggling with managing his son’s dosing intervals in conjunction with his sleeping schedule. One of his son’s medications needs to be given 12 hours apart, with the first dose being around 10:00am. This father described the evening dose to be challenging as the child often wanted to go to sleep before it is time for his evening dose at 10:00pm. In order to give him the dose on time, participant 007 had to keep his son awake. Participant 003 anticipates similar challenges with her son when he starts school in the fall given that his medications also have to be given at precise intervals in combination with meal times.

Precise dosing intervals can also impact the ability of the family to live a normalized life; for example, when the family wants to go on day trips away from the home or to social events. Several participants described scenarios where they were out as a family and they had to rush home to give a medication because they had not brought any with them. The three parents that had this experience described it as
having to “learn the hard way” to plan in advance and bring medications with them just in case they were later than expected coming home.

“If we go on an outing and we forgot his medication, like it’s a huge deal right? Cause he’s got nerve pain so I mean he, if he doesn’t have it he’s he’s kind of screwed (laughter). He really is, I mean cause he’s he’s pale, he can’t...he’s not enjoying himself, and then he’s just looking for a place to lie down.” – Participant 006

Occasionally, parents recalled being told about what to do in the event they missed a dose. However, this was not a topic that parents recalled being discussed at length during their conversations with health professionals about their child’s medications. Planning medications for day trips was described as something new that parents had to learn to do themselves post discharge. Planning for time away from the home is a new skill to some parents for a number of reasons. First, some of the children that are treated for injuries at the rehabilitation hospital are not on any medications prior to their admission, such as participant 008’s child. Since it is something they have never had to manage before, planning in advance for outings is new to these parents. In other cases, parents of children with existing conditions, sometimes limit their trips out of the home due to the child’s medical condition before they come to the rehabilitation hospital – for example participant 003:

“So we’ve learned the hard way to take meds with us which is something we’ve never done before because we never did go anywhere, we were always, before surgery [child3] had a lot of seizures so we were always were home between certain times where we knew he needed a rest.” – Participant 003

In addition to challenges with integrating the medication schedule into daily life, parents also reported remembering when to give their child their medications to be challenging at first. Even though parents are given the opportunity to practice medication administration in the hospital, the time management portion is still largely
done by the nursing staff. In the hospital, nurses come by when it is time for the child to take his or her medications. This sort of reminder is not present at home.

“well initially until I got used to having, because while we were at the hospital of course the staff there would give her her meds and then she would come home for a LOA [Leave of Absence] and it would be, the importance of being in routine again I would spend the whole week not giving it to her and making sure oh yeah 2pm we either if we’re out have I prepped to have the medication with me um so I have little alarms set until I got into the routine so I wouldn’t forget” – Participant 002

However, several parents identified that they utilize alarm reminders on their cell phones to keep track of when they need to give medication doses – similar to the effect of a nurse coming by the hospital room at set times to administer medications. Participant 008 also recalled text messaging her child to remind him to take his mid day medication dose when he went back to school. These were coping strategies that parents implemented on their own during their LOAs and then continued to use after they were discharged from the hospital. This was one of the reasons that parents found weekend LOAs to be helpful in preparing them to manage their child’s medications post discharge. However, it is important to acknowledge that LOAs aren’t always entirely representative of what the family’s actual experience will be like when they go home.

First, when families go on LOAs, hospital staff give them all their medications in an organized fashion. In addition, when families go home on weekends, other life factors such as going to school and parents juggling care with going to work and other daily activities of the family are often not present. So while LOAs are useful in preparing parents to manage their child’s medication, there are other areas of the management process that may benefit from further thought and planning prior to discharge.
Parents also use a number of organization techniques that help with adhering to the medication schedule. The most commonly used technique was dosettes. Several parents would prefill their child’s dosette for the week ahead. Doing so enabled the parents to better manage their child’s medications in conjunction with other every day demands and activities. To a similar effect, parents of children who were on liquid medications would keep them all in the same spot since using a dosette is not an option when using liquid medications. Parents also reported that using such strategies also helped when occasional caregivers had to administer medications.

5.3 Discharge Planning

In addition to teaching parents to administer medications in preparation for discharge, there are number of other activities that the parents in this study identified as essential to making the transition to home easier. While interviewees were not directly questioned about the planning that was done to make sure they were set up to manage their child’s medications in the community, half of the parents mentioned support in this area as something that was an important factor in their ability to manage their child’s medications within the first few days of being home as well as beyond.

At this pediatric rehabilitation hospital, the majority of the children are discharged on Fridays. In general, this is beneficial for families because it gives them the weekend to adjust to having their child home again before they are thrown into the activities of every day life. However, having a Friday discharge can be challenging for parents if they need to order medications from their pharmacy. This is particularly true for families of children who are on medications that are not routinely stocked in retail pharmacies or require unique compounds to be made. Fortunately, the pharmacists at the hospital are
cognizant of this limitation and help families plan accordingly – as was described by participant 002.

“In order to make sure that we were at ease they gave us like a day and a half supply just in case the pharmacy didn’t have everything like they were trying to um because my one concern, particularly with the blood thinner is you can’t go home and not have that available to you…there was delay in getting it in the local pharmacy so I appreciated that it was it wasn’t just a “ok you’re leaving, you’ve got a day, you’re good to go” it was “Hmmm ok let’s make sure that you’re seriously covered and let’s imagine our worst case scenario and make sure you’re covered for that”…because that could have been nerve wracking otherwise” – Participant 002

In order to help families feel comfortable, the pharmacists often ensured that families had enough medications and administration supplies, such as syringes, to last until they had time to get to their pharmacy or until their pharmacy could get the medication in stock. If they did not, the pharmacist from the rehabilitation hospital supplied them with enough of these items to get them through a couple of days at home. Not only did this help to ensure therapeutic continuity but it also gave families one less thing to worry about during the stressful transition period, as was described by participant 002.

Before parents left the hospital, pharmacists also ensured that families were connected with a provider in the community that would be able to handle their unique medication needs. As was described by participant 008, prior to leaving the hospital it was identified that her son’s pediatrician did not have enough experience with the narcotics that he was on to safely carry out the tapering schedule and ongoing management. In response, the pharmacist that was working with the family referred them to the pain clinic at another local hospital to ensure there was someone within their circle of care that had the expertise to guide the family through managing the child’s complex medication regimen in the community. As a result of the pharmacist
taking on the coordination for this for the family, participant 008 “felt that [she] was going
from one nurturing environment to the other”. For this parent, having the support of the
team from the pain clinic at the other hospital was essential to her successfully
managing medications at home as doing so was a completely new experience for her.
Even though participant 008 had the support from the team at the pain clinic, she stated
that it still would have been nice to hear from the team at the rehabilitation hospital after
they had been discharged because they had spent so much time there:

“nobody from [rehabilitation hospital] ever reached out, a week into being home,
“how are things? How are you managing?” you know “how’s [child8] doing?”. Not
a nurse, not a doctor, not a social worker it was like we left and that was it. And
and that for me is is, you know, is disappointing because it’s we spent a long time
there right? A long long time there and it’s just there’s no nothing. So that for me
is is, you know, I would say the one thing that I think, you know, could be done,
you know, better.” – Participant 008

Participant 007 echoed participant 008’s sentiment in that he would also have liked
follow up with from somebody at the rehabilitation hospital in regards to his child’s
medications once they had gone home.

“maybe a phone call one month maybe two months later, how the parents are
doing in terms of giving the meds that will help feel as though that people care
about us, that people think about us...maybe they have any questions or
anything maybe they can discuss with the nurse or the doctors there” –
Participant 007

For this father, not only was the follow up important to him so that any technical issues
could be addressed, but he also mentioned he would have appreciated it on a personal
level as well – similar to participant 008.

While parents felt they were well supported immediately in their transition to the
community, there were some aspects of the transition that occurred later on that were
overlooked when discharge planning took place. In participant 002’s story, throughout
their journey her child had been seen by 3 different teams of physicians at 3 different hospitals. Once she went home, she realized that she had no idea which set of doctors to contact for further prescriptions. Luckily the mother realized this before she anxiously needed a refill; however, it is still concerning to her that she cannot recall being told who to contact for further refills or for questions about events such as side effects. Also, none of the parents mentioned any preparation being done to integrate medications into the child’s routine at school. Participant 008’s spoke of how she has navigated this process on her own with her child’s school, but she did not mention any assistance from the rehabilitation hospital staff. As was mentioned earlier, participant 004 also had concerns about integrating her child’s medication routine into his school day when he started in the Fall of 2016. It is possible that these topics were not discussed with parents as school was still months down the road for both of these children, but it is important to note that it was still a concern for them.
CHAPTER 6: DISCUSSION

The following chapter summarizes the key findings from this study and examines them in relation to current literature. Limitations to this study, as well as recommendations for further research and implications for practice are also discussed.

6.1 Major themes and comparison to current literature

Throughout the parents’ descriptions of their experiences with learning to manage medications, two key thematic categories emerged: 1) learning to manage the technical aspects of medications and 2) learning to integrate medication management into everyday life. Within each category, several specific themes illustrate the challenges parents encountered and the processes that were applied to overcome them to achieve successful medication management in the community. Figure 1 summarizes the common themes within each category.

Figure 1: Summary of Themes

Learning to integrate medication management into everyday life
- Family Involvement
- Time Management
- Discharge Planning

Learning to manage technical aspects of medications
- Complex administration
- Palatability of medications
- Volumes of medications
- Delivery of information

Technical aspects of medication management, such as administration techniques and adherence, can be complex (Grady & Gough, 2014). Technical issues such as
complex administration processes and unpalatable medications were acknowledged by parents in this study as well as throughout the literature (Benevides et al., 2011, Grady & Gough, 2014; Levine, 2001). Given the prevalence of these challenges, hospital based medication education focuses on preparing patients and their caregivers for these tasks before they leave the hospital as it is essential to ensuring the safety of the child (ASHP, 1997). A focus on educating caregivers about the technical aspects of medication management was a salient theme throughout this study as well as the literature - where the majority of interventions aimed at improving medication education evaluate their effectiveness based on individuals being able to recall or correctly demonstrate administration information such as name of medication, how much to give, and how often (Frush et al., 2004; Goldman & Scolnik, 2004; Li et al., 2000; Yin et al., 2014). Through parents’ descriptions, it was evident that the health professionals at the rehabilitation hospital prepared them quite well to administer their child’s medications through various techniques, such as the teach back method, demonstrations, and having parents practice. These hands-on, visual, methods have been shown to be effective teaching methods throughout patient education literature (Tarn et al., 2009). In this study, parents affirmed the effectiveness of these teaching methods as they reported that they helped them feel confident in their ability to administer their child’s medications safely before they went home from the hospital.

However, it was evident that integrating medication management into daily life, including family context, the home environment, and routine presented a challenge for many of the caregivers in this study; especially to those who had just undergone significant change in the child’s medication regimens. Integrating medication
management into every day life can be challenging because parents have to find a way to balance this task in conjunction with other daily activities of the family – such as outings, attending school, and meal times. Moreover, parents must also establish the roles that other family members, such as siblings and occasional caregivers, will play in the management of their child’s medication. These aspects of medication management were not typically addressed by health professionals in this study or in the medication education literature. The absence of the broader context in which medication management occurs in the community is further evident in the definition of medication management put forth by the CPhA, CSHP, and ISMP Canada. Their definition of medication management emphasizes safety, effectiveness, and appropriateness but does not mention broader medication management factors, such as time management and integration of medications into every day life, which have been identified as challenges for parents in this study. While the definition is inclusive of providing medication education that is “patient centered”, the true context that children exist within, and are part of their family, is not acknowledged (King & Chiarello, 2014). Given that the definition of medication management and the current literature fail to acknowledge this important facet of medication management, the full complexity of managing children’s medications in the community has not yet been fully understood, nor has how to best prepare parents to do so.

Despite the lack of formal education provided to assist parents with integrating medication management into daily life, interviewees exhibited incredible resourcefulness in developing strategies to cope with these challenges on their own.
For example, many parents utilized technology, developed support networks with their families and community care providers, and engaged in effective problem solving to facilitate successful management of their child’s medications. Moreover, it is important to note that the practices of health professionals that were in alignment with FCC and self management principles were what parents found most helpful in learning to manage the technical aspects of their child’s medications. Such practices mentioned by parents in their interviews included getting to practice medication administration in hospital, practicing management at home during LOAs, and tailoring medication regimens to family preferences. These findings highlight that medication education programs are beginning to adopt the tenets of FCC; however, there is still further application that can occur in order to enhance patient care.

One of the ways FCC can be further applied to improve medication education is by involving the child in the education process even though their parent is the one who is ultimately responsible for overall management. Involving the child in the medication education process, when appropriate, was identified by parents in this study as a key element of effective medication management. The pediatric rehabilitation literature on FCC also supports engaging children in education as it can have positive outcomes for both the child and their parent (King & Ciarello, 2014). Involving children in the education process from an early age is essential, especially if one day they will be responsible for taking over the medication management for their chronic condition. However, it is important to consider another major tenet of FCC when involving the child in the education process. Not only for the sake of the child, but also for the sake of the parent, it is critical to balance family empowerment and participation in care with
providing adequate support (King, King, Rosenbaum, & Goffin, 1999). Therefore, while involving the child in the medication education process can be beneficial, it is also important to ensure they do not become overwhelmed in the process. Achieving this balance will provide families with a sense of control but not impose additional stress and unwanted responsibility (King & Chiarello, 2014).

Moreover, based on what we have learned from the parents in this study, learning to manage medications in the hospital is just the beginning of the process. Parents are continually learning through day to day experiences about what works for them and how to adapt what does not work so that it is more manageable. In order to do this safely, parents have identified that it is essential for them to have a point of contact in the community that can address medication questions, facilitate continual learning, and provide on-going support. Similar to the patients interviewed by Hesselink and colleagues (2015), parents in this study appreciated being proactively linked with community care providers that have expertise in managing complex medication regimens in children so they do not experience a gap in support during their transition from hospital to home. Given that the family is the only common thread between the hospital and community care providers, it is important for additional connections to be made to ensure a smooth transition (Hesselink et al., 2015). While this may not be considered as a traditional aspect of medication education, it is still essential to the discharge planning process as failing to plan for life in the community and lack of coordination of care can contribute to an increase in adverse events post-discharge (Shoeb et al., 2012).
Overall, this study has shown that while safe medication administration is a priority for families, so is the ability to enjoy normal family life in the context of disability. Within the current literature, there appears to be a disconnect between current medication education practices that place emphasis on parents mastering the technical aspects of medication management and the broader family-centered care and family management literature that emphasizes the importance of doing so within the context of the family and their day-to-day life. While health professionals in this study did teach parents about the technical aspects of medication management using family-centered techniques, the integration of these processes into the context of the family’s everyday life was not as prominent (Ryan & Sawin, 2009). There are several possible explanations as to why this occurred. It is possible that the health professionals providing discharge teaching overlooked the importance of helping parents cope with integrating medication management into every day life. This may be especially true for some of the patients in this study who had pre-existing medical conditions and were already taking medications at home. Second, health professionals may have addressed integrating medication management into daily life but the learning may have gotten lost in the complexity of discharge. The third possibility is this disconnect is not necessarily a result of lack of awareness or effort on the part of health professionals at all. Rather, it is a reflection of the need to prioritize patient safety and deliver medication education within the resource constraints of the institution in which they provide care (Durocher et al., 2015).

This research contributes to bridging a gap in the literature in that it highlights ways in which health professionals can help parents prepare for managing their child’s
medications at home beyond preparing them to give their child the right dose of the right medication at the right time. The priorities and insights highlighted by families in this study should be taken into consideration in the alignment of medication education programs with family identified needs in the context of day-to-day family life. Other personnel, besides hospital staff may also offer important advice and services. In particular, community pharmacists' have the ability to help with various medication management tasks, such as selection and dosing of OTC medications, and the compounding, and coordination of refills. In this study, parents often took on these tasks themselves instead of utilizing the expertise of their community pharmacists. It is unclear whether this underutilization of community pharmacy services stemmed from lack of patient awareness, or lack of availability of more specialized services like compounding in some settings. This study, as well as other literature have identified that hospitals should take ownership of connecting patients with community care providers, such as pharmacists, prior to discharge to facilitate effective handover of care (Hesselink et al., 2015). This connection is not only important from a safety perspective, but it also reduces the likelihood that patients and their families will feel abandoned by the hospital, similar to how parent 8 felt about elements of her son’s post discharge care (Solan et al., 2015).

6.2 Limitations

It is important to note that the results of this study are based on the study of processes in rehabilitation care, and therefore are not necessarily transferable to acute care. While two parents did mention getting to practice medication administration at tertiary care facilities before coming to the rehabilitation hospital, this opportunity was
influenced by their children's stable medical condition and this factor may not be applicable for all cases in acute care. Therefore, further investigation into what family-centered medication management education would look like in acute care pediatrics is needed.

The diverse age range of children in this study can also be considered a limitation, as different age groups, for example, school-aged children, experience different challenges when it comes to medication management. Also, our sample did not recruit any caregivers with children age 5-9 due to the small overall sample size. Further research with a larger sample size that can be age-stratified may be beneficial to acquire a deeper understanding of the unique barriers encountered by each age group in integrating medication management into everyday life.

Since this research focused on medication education that was done in the hospital, we did not collect information regarding the setting in which each family lived. For example, we did not distinguish those who live in rural areas from those who live in urban areas. The area in which a family lives could influence their ability to manage medications since urban areas generally have greater availability of advanced pharmacy services, such as compounding. In addition, we also did not ask families about their relationship with their community pharmacy in the interviews. When making recommendation for future practice, it will be important to understand how these factors impact a family's ability to manage medications in the community.

When analyzing qualitative data, it is often preferred that 2 people review the transcripts and coding to identify when saturation is reached. In this study, the primary research was solely responsible for this task. This is considered to be a limitation
because it is possible that the primary researcher who did the interviews may have a different opinion on when saturation was reached than an independent assessor who was not involved in the interview.

Furthermore, due to limitations of our resources, we were unable to include individuals with limited English in the study. As a result, the majority of parents in this study spoke English as their primary language, with only 1 parent reporting that they spoke a language other than English at home. As demonstrated in literature, those with limited English in English dominant environments generally have a harder time with understanding medication information and administering correct doses (Leyva et al., 2005; Neuspiel & Taylor, 2013). While it was not possible to interview individuals who do not speak English, these individuals would have been able to illustrate unique challenges that they encounter while learning to manage medication that were not present in the current sample. In addition to being fluent in English, the parents in this study were also generally well educated, with only 1 participant having not completed post secondary training. As was previously mentioned, while being well educated does not necessarily imply that a person is health literate, the two characteristics have been shown to be related (Neuspiel & Taylor, 2013). To that end, given the sample characteristics, we did not get to fully explore the learning needs of those who struggle with health or English literacy.

Moreover, limitations also exist in terms of what parents were able to recall about their experiences with learning to manage medication during their interviews. Since the interviews took place a few weeks after the family had been home from the hospital, it is possible that they may have forgotten about some elements of their experiences given
the amount of time that had passed – otherwise known as recall bias. The fact that they were under significant stress at the time of teaching may have also made it hard to remember certain details of the interaction. It is important to acknowledge that just because parents did not mention something, does not mean it was not done for them or they were not taught about it. However, it is also important to consider that what parents were able to recall weeks later represents the most memorable, and thus, possibly, the most effective, elements of medication education that they experienced.

6.3 Recommendations for future research and implications for practice

In conclusion, there are several lines of inquiry that should be explored in future research to understand how the Canadian health system can improve handovers of medication management to caregivers of children with special health care needs in a way that is both safe and family-centered. Firstly, further research on the strategies caregivers with low health literacy and limited English proficiency use to learn to manage medications, and other health care needs, is essential to designing interventions that will meet the needs of Canada’s diverse population. It will also be important to gain understanding of how this process would operate in acute pediatric care, given the higher acuity of patients and shorter lengths of stay in comparison to rehabilitation. Further, learning more about how parents of children with complex medical needs balance all areas of home life and family care would be useful to inform the design of comprehensive discharge planning programs.

On a broader scale, deeper inquiry into how family-centered care can be realistically implemented prior to discharge, not only in relation to medications but other care areas as well, would be relevant. For example, this holistic inquiry can be started
during the LOAs to give families an opportunity to identify challenges with integrating medication management into every day life. It will also be important to implement policies that help make family-centred medication education and discharge planning more integrated and seamless between hospital and community care providers.

Currently, hospitals bear the majority of responsibility for preparing patients and their families for safe transitions to home. However, patients and their families are not always able to recognize all of their post hospital needs before being discharged (Knier, Stichler, Ferber, & Catterall, 2015). It is therefore unrealistic to expect hospital based health professionals to anticipate and address all of a family's discharge needs prior to going home. While tools such as PODS and post discharge phone calls have been implemented to help address as many of a family’s needs as possible, a lack of time and competing priorities still prevent health professionals in hospitals from fully delivering family-centered discharge care. Moreover, health care providers who work in hospital settings may not fully appreciate the challenges and realities that families face once the child is discharged into the community. This gap presents an opportunity to further develop community partnerships to facilitate improvements in care co-ordination across hospital to community care transitions. Community care providers could play a greater role in discharge planning and post-hospital follow-up to ensure families have the support that they need to integrate medication management into everyday family life. To that end, more research is needed to identify collaborative models of care that have potential to improve the hospital to home transition, including medication management from a FCC perspective. These models then need to be tested in a range
of populations and evaluated to determine their overall effectiveness and family centeredness.
References


February 4\textsuperscript{th}, 2016

Dear Family,

My name is Caron Gan. I am part of a research team at Holland Bloorview. I am supervising a student researcher from the University of Toronto named Ally Stanhope. Together, we are doing a study on parents’ experiences with learning to manage their child’s medications. We would like to ask you to take part in this study. This study is being funded by the Health System Performance Research Network. Before agreeing to take part in this study, it is important that you understand how you will be involved.

\textbf{What is the study about?}
Some parents tell us that they do not learn enough about their child’s medications before leaving the hospital. There are a number of things that can affect what and how parents learn about their child’s medications in the hospital. We would like to know what our staff can do to make this learning process easier for parents.

In this study, we will talk to 8 to 10 parents so we can learn more about this. We want to invite you to be one of the parents.

\textbf{How will I be involved in this study?}
We want to invite you to Holland Bloorview for an interview with a research assistant. We will choose a time that is convenient for you.

During the interview we will ask you about your experience with learning about your child’s medications while an inpatient at Holland Bloorview. We will also ask you about your experiences with your child’s medications after you left Holland Bloorview. Here are some examples of the questions we will ask you:

1. Can you describe the medication instructions you received at Holland Bloorview?
2. Can you describe to me your experience with managing your child’s medications since you have been home from Holland Bloorview?
3. In your opinion, what does the ideal medication education program look like?

The interview will take 30 minutes to one hour. If you are unable to come to Holland Bloorview we may be able to arrange for you to complete an interview in your home or on the telephone.
Will anyone know what I say?
We will use an audio recorder to record what you say during the interview. We need to use the audio recorder to review what you say during the interview in more detail. Only researchers on the project will listen to what you said during the interview. We will be typing what you say word-for-word but we will remove any information that may identify you or your child. We will destroy the recording at the end of the project.

All the information we collect about you and your family will be kept private. We will not make public anything that might identify you or your family, unless legally required to do so. For example, if you tell us that you do not give your child their medication at all and this hurts your child we will have to report it to the hospital.

We plan to write up our study so that others can read about it in journals. We also plan to make a poster to share what we have learned with other researchers. In these write ups, we will not use your name or any information that identify you. We may use quotes from your interview in the write ups about this study. If we do use one of your quotes, we will not use your name or any details that could identify you or your child. We must keep the research data we collect for 7 years as required by Holland Bloorview.

Do I have to do this?
You do not need to do this study. It’s okay if you do not want to take part. If you decide to take part, you can change your mind at any time. If you change your mind, please contact the student researcher, Ally Stanhope, to withdraw from the study. If you decide to stop taking part in the study we can remove all of your information if you would like. Whatever you decide will not affect the services you and your child get from Holland Bloorview.

What are the risks and benefits?
We do not think that anything bad will happen to you if you take part in this study. You and your child may not directly benefit from this research. However, we think that the things we learn from you will help improve the way we teach other parents about their child’s medications.

While talking to us about your experience, you may begin to feel upset. If you do, we can stop the interview. If you would like, we can also connect you with the social worker you saw at Holland Bloorview.

You will not waive your legal rights in the event of research-related harm if you decide to take part in this study.

What if I have questions?
If you have any questions please contact Ally Stanhope at 416-425-6220 extension 6445 or Caron Gan at 416-425-6220 extension 3514. Please ask our student researcher, Ally Stanhope, to explain anything you don’t understand before signing the consent form. If you leave a message, she will return your call within 48 hours.

You will receive a $10 gift card to say thank you for taking part in this study. If you are coming to Holland Bloorview outside of your regular appointments we will also pay for your parking. If you
need daycare for your children during the interview, they can come to the Ronald McDonald playroom at Holland Bloorview if needed.

We will send you a letter at the end of the study to share what we learned.

If you have any questions about your rights as a research participant, please contact the Holland Bloorview Research Ethics Board at 416-425-6220 ext. 3507.

Thank you for thinking about helping us with this project.

Sincerely,

Caron Gan, RN, MScN, RMFT  Ally Stanhope, BPH, MSc (Candidate)
Principal Investigator,  Student Researcher,
Clinical Team Investigator  University of Toronto
Phone: 416-425-6220 ext. 3514  Phone: 416-425-6220 ext. 6445

G. Ross Baker, PhD  Dr. Ayelet Kuper, MD, DPhil, FRCPC
Co-Investigator,  Co-Investigator,
University of Toronto  University of Toronto
416-978-7804  416-480-61000 ext. 5495

Version date: November 2015

Page 3 of 4
CONSENT FORM
HOLLAND BLOORVIEW KIDS REHABILITATION HOSPITAL

Re: Parents’ Experiences with Learning to Manage Medications

Please complete this form below and return it to the researcher. You will receive a signed copy of this form.

________________________________________________________________________ explained this study to me. I read the attached Information Letter dated November 2015 and understand what this study is about.

I understand that I may drop out of the study at any time.

I agree to participate in this study.

______________________________  _____________________  __________
Parent’s Name (please print)     Signature                  Date

I have explained this study to the above participant/parent and have answered all their questions.

______________________________  _____________________  __________
Name of Person Obtaining Consent  Signature                  Date

Version date: November 2015

Page 4 of 4
Appendix 2: Background Questionnaire

Study Title: Parents’ Experiences with Learning to Manage Medications

Please complete the following questionnaire and return it to Ally Stanhope. This questionnaire is designed to provide us information about the participants in the study in general terms. Answers that you give will remain private and confidential. You do not have to answer any questions you do not want to.

1. Self-identification of caregiver role
   a) Mother
   b) Father
   c) Family member
   Explain __________________
   d) Legal guardian
   e) Other __________________

2. Highest level of education completed (caregiver)
   a) No high school
   b) High school diploma
   c) College diploma
   d) Undergraduate Degree
   e) Advanced University Degree (Masters, PhD, MD, etc.)

3. Most used language at home: _________________

4. Child’s Age ___

5. Child’s Diagnosis/Reason for admission
   ______________________________________________________________________________________
   ______________________________________________________________________________________
   ______________________________________________________________________________________
   ______________________________________________________________________________________
Appendix 3: Interview Guide: Parents’ Experience with Learning to Manage Medications

1. Can you please tell me about your child’s daily medication routine?
   1.2. How many medications does your child currently take? – Including over the counter medications, inhalers, vitamins and supplements, injections, topical creams, and drops
   1.3. Any injections/G-tube, NG-tube?

2. How would you describe your child’s medication routine at home?
   2.2. Ease of management?
   2.3. Challenges you face?

3. As a caregiver, what influences your ability to manage your child’s medications?
   3.2. Things that help?
   3.3. Things that make it hard?

4. Before coming to Holland Bloorview, did you receive medication education at another hospital (e.g. Sick Kids)?
   4.2. IF YES, can you briefly tell me about it?
   4.3. What about it was useful/not useful?

The next set of questions will be about the medication education that you received while your child was an inpatient at Holland Bloorview.

5. Given that there are many things for caregivers to learn about their child’s care before discharge, how does medication education compare in importance?

6. Can you describe the medication education you received at Holland Bloorview?
   6.2. Content?
   6.3. Timing of information being given?
   6.4. Which health professionals taught it to you? Were there multiple team members involved? If so, what did you think about this?
   6.5. How it was taught/demonstrated – verbal? With resources? Using plain/understandable language? Use of demonstration materials?
   6.6. Were you given a chance to practice the medication administration and demonstrate your knowledge to the health professionals?
   6.7. Was the information provided useful?
   6.8. If not, what else would you have wanted to know?
   6.9. Were you given opportunities to ask the health professional questions about your child’s medications?

7. What do you think about this way of learning about your child’s medications?
7.2. What parts were helpful or effective?
7.3. What parts were not helpful or not effective?

8. Did you do any leave of absences (LOA’s) where you went home from the hospital on weekends?

8.2. If yes, how did managing your child’s medications go during that time at home?
8.3. Was this scenario comparable to your experience with medications at home after being discharged from Holland Bloorview? What was different? What was similar?
8.4. Did you experience any medication challenges during your LOA? If so, were they addressed before you were discharged?
8.5. Were LOA’s useful to help prepare you for managing your child’s medications after discharge?

9. When you left Holland Bloorview did you feel confident in your ability to manage your child’s medications at home?

9.2. Can you describe this feeling? What does being prepared mean to you?
9.3. How did you know you were/weren’t prepared?
9.4. Where there certain things that happened or situations that made you feel this way?

10. Can you describe to me your experience with managing your child’s medications since you have been home from Holland Bloorview?

10.2. What strategies do you use?
10.3. Where did you learn these strategies/get this information?
10.4. How did the teaching done in the hospital influence your experience with managing your child’s medications at home?

11. As a caregiver, can you tell me about the challenges you face when managing your child’s medications?

12. Now that you are home, is there anything that could have been done differently to prepare you to manage your child’s medications?

12.2. Content that was taught?
12.3. The way the content was taught?
12.4. The health professionals involved in the teaching of medication education?
12.5. When it was taught to you?
12.6. Materials that were given to you?
13. Since discharge, has your child experienced and negative health effects from their medications?

   13.2. If yes, how did you deal with this?
   13.3. Who did you call/reach out to?
   13.4. Is there anything the hospital staff could have done to help avoid this situation?

14. As a family caregiver, what would you consider to be successful medication management?

15. In your opinion, what does the ideal medication education program look like?

   15.2. What topics should be covered?
   15.3. How should it be delivered?
   15.4. When should it be delivered?
   15.5. What kinds of resources should be provided?
   15.6. Health professionals involved in the medication education process?

16. Are there any additional comments you would like to make?