

**CARE COORDINATION FOR CHILDREN WITH MEDICAL COMPLEXITY:
A MIXED-METHODS EVALUATION**

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ABSTRACT

In the US and the world, the number of children living with chronic and complex medical conditions is growing. Many also have unmet health needs. While these children are frequent users of high-cost health services, their care is often received in home- and community-based settings, with families assuming responsibility for care management and direct care. Care coordination is part of the recommended standard of care to improve patient outcomes and ensure patient-/family-focused, comprehensive care across service settings for children who have special health care needs.

Living with a child with medical complexity can place psychological, social, and financial strains on a family. It is hypothesized that families at risk of poor outcomes stand to benefit from care coordination, and that care coordination could lead to cost-savings for the health system. Despite growth in the research on care coordination and some evidence of its benefits on health outcomes and costs, substantial variation in definition, implementation, and evaluation remains. This issue has public health significance because care coordination may be an effective strategy to reduce high-cost health services use, prevent unnecessary care, improve the patient/family experience, and ultimately improve patient outcomes.

The goals of this dissertation were to review the literature on key aspects of care coordination for children with special health care needs and their associations with

empowerment, assess the implementation of a pilot care coordination program, and use interviews and surveys to explore families' experiences of care coordination.

As per agency policy, the pilot care coordination program provided tiered support based on medical and psychosocial acuity. Higher-acuity families received more staff contacts and longer contact time. Trends show the majority of families reduced acuity from enrollment to the end of the study period.

Higher-acuity families and families enrolled for a longer period rated the family-centeredness of the care coordination they received higher than those at lower acuity and those in the program for less time. Higher-acuity families self-reported a reduction in emergency department use and hospitalization since enrolling. While there were no significant results on empowerment, families described numerous benefits of care coordination, including: efficiency, legitimacy, support, and stress reduction.

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1.0 CHAPTER ONE: INTRODUCTION

1.1 RESEARCH QUESTIONS

This dissertation has three broad aims. The first aim is to review and summarize key implementation and outcome literature on care coordination for children with medical complexity, particularly examining what aspects of care coordination are associated with family empowerment. Secondly, the study provides an implementation assessment of a model pediatric care coordination program for medically complex children located at the Children's Institute in Pittsburgh, Pennsylvania. The final aim is to explore family experiences of care coordination at the Children's Institute and the program's associations with family empowerment. To these ends, the overall research questions are:

1. What are the key elements of a high-quality care coordination program for children who are medically complex?
2. How is family empowerment associated with these key elements of care coordination?
3. How is care coordination being implemented at the Children's Institute?
4. Is parent satisfaction with care coordination related to family-centered care, family acuity level, or length of time in the care coordination program?
5. What value do families of medically complex children find in care coordination?
6. How are care coordination and family characteristics related to family empowerment?

1.2 DISSERTATION ORGANIZATION

This dissertation is structured as three manuscripts that are organized into six chapters, including an overall introduction, a chapter on methods, and a final discussion uniting the manuscripts. **Manuscript One** presents a literature review of key aspects of care coordination for medically complex children and how those aspects may be associated with family empowerment. The Methods chapter describes the approaches used to determine the study samples, and to collect and analyze data. **Manuscript Two** analyzes data from 274 participants of one pediatric care coordination program to provide an implementation evaluation, description of participants, and key aspects of implementation. **Manuscript Three** presents the results of a mixed methods study of 22 families in the care coordination program that is discussed in Manuscript Two. In-depth interviews and the Family Empowerment Scale were used to assess certain family-level variables. The six chapters are followed by appendices and references used in all manuscripts.

1.3 BACKGROUND

The background section focuses on the literature describing the significance of health care services for children and youth with special health care needs, the unique challenges they and their families face, and the role of care coordination as a solution to some of those challenges.

1.3.1 Children and Youth with Special Health Care Needs

The United States Maternal and Child Health Bureau defines “children and youth with special health care needs” (CYSHCN) as those who are “at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.” (McPherson, Arango, Fox, 1998; Stille & Antonelli, 2004, page 700). In the research literature, categorical definitions, based upon diagnoses or conditions, tend to focus on the significant risk for morbidity or mortality of these children. Service- or cost-based definitions focus on their increased use of costly health care resources. Functional status definitions are based on a child’s inability to complete developmentally- or age-appropriate tasks (Wise, Huffman, & Brat, 2007). According to the most recent (2009/2010) National Survey of Children with Special Health Care Needs, over 11 million American children have special health care needs. Of these, 27% report that their conditions usually or always affect their daily activities in a significant way, 24% have an unmet need for a specific health care service, 23% need help getting needed referrals, and 35% do not have family-centered care (Cohen et al., 2011). The aggregate term ‘children and youth with special health care needs’ masks the extensive range of conditions, abilities, and experiences of these children and their families, and includes children at increased *risk*, not only those currently living with a condition (Bramlett, Read, Bethell, & Blumberg, 2009; Davis & Brosco, 2007). Research on this population is complicated by the variability in use of the term CYSHCN, and a disconnect between terms, definitions, and corresponding datasets (Wise, Huffman & Brat, 2007).

Regardless of challenges with terminology, the population of CYSHCN is large and growing, as more children are living longer with chronic conditions. Many of these children

receive the majority of their care in the home and community, with family members providing both significant direct care and care management. Outside the home, CYSHCN often rely on numerous treatment, rehabilitative, social, and educational supports, which require skilled coordination to prevent unnecessary or fragmented services (Antonelli, McAllister, & Popp, 2009).

1.3.2 Children with Medical Complexity

Children with medical complexity (CMC) are a subpopulation of CYSHCN that is defined as having “medical fragility and intensive care needs that are not easily met by existing health care models” and therefore require additional “time, expertise, and resources...to reach optimal health outcomes” (Cohen et al., 2011, page 529). This population is important to health services research because the growing number of CMC has increased the demand for expensive long-term care that involves multiple service providers and settings, and requires linkages among medical, social service, and educational settings (Navarra et al., 2016). The health care use of only the top 1% of pediatric health care consumers results in about one-third of health care spending on children overall, and most pediatric hospital admissions or readmissions (Kuo & Houtrow, 2016). Due to the extensive and often high cost of health care use by CMC, it is critical to identify effective strategies to achieve high-value care for this population.

In an attempt to operationalize the term “children with medical complexity”, Cohen et al. (2011) developed a four-domain model: needs, chronic conditions, functional limitations, and health care use. The significance of each of these domains will vary over the child’s developmental progression and the course of a chronic illness. The model describes CMC as children who have a combination of:

1. One or more chronic clinical conditions that result in high morbidity or mortality rates and the course of which is long-term or lifelong.
2. Many family-identified health care and service needs, which have significant impact on the family.
3. Significant limitations in bodily function or structure that interfere with activity and participation in community life.
4. High levels of health care use.

Chronic conditions are those that have an extended duration, do not resolve spontaneously, and are often never cured completely (Stanton et al 2007; Compas, Jaser, Dunn, & Rodriguez, 2012). Chronic childhood illness has also been conceptualized as a physical, emotional, or mental condition that prevents a child from participating in the typical activities for their developmental age or that requires frequent consultation or treatment from a health professional, regular use of any medication, or use of special equipment (VanCleave, Gortmaker, & Perrin, 2010). Regardless of the exact terminology applied, CMC are those whose medical acuity results in significant impacts on their daily lives.

1.3.3 The Need for Care Coordination for Children with Medical Complexity

The enhanced life expectancy of CMC combined with a shift to home- and community-based care has led to greater consideration by the health care community of the daily caregiving challenges and quality of life impacts for families of CMC. It is not uncommon for families to engage with public services (e.g. Supplemental Nutritional Assistance Program), developmental supports (e.g. Early Intervention), mental health providers, physical health providers, rehabilitation services, the education or special education system, and social supports (e.g. peer groups for both parents and children) (Wood et al., 2009).

Care coordination (CC) is one strategy proposed as a result of greater recognition of the burden of care and the need to support families of CMC (Kuo & Houtrow, 2016). However, it is not always clear what is meant by the term ‘care coordination’ and the term is used inconsistently in research literature. In an effort to create a shared definition of CC, the Agency for Healthcare Research and Quality’s (AHRQ) Evidence-Based Practice Centers conducted a technical review in 2007 using literature and internet searches and expert consultation. Based on common elements from over 40 definitions, AHRQ defined CC as “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services.” (McDonald, et. al, 2007; page v).

Since the Patient Protection and Affordable Care Act (ACA), and a move toward integrated care, CC has received significant attention as a promising strategy to increase quality and efficiency in health care services, and patient outcomes, for individuals who are frequent users of health care. The ACA has pushed for providers to be accountable for patient outcomes rather than just providing tasks associated with treatment (Looman et al., 2013). Even before the ACA, the Institute of Medicine and the American Academy of Pediatrics had noted that uncoordinated care results in poor quality, fragmented services, and unsatisfying experiences for children and their families. A lack of coordination has also been associated with poor health outcomes, medical errors, unnecessary services, and high use of expensive and procedures (Johansson & Harkey, 2014; Musich & Paralkar, 2007).

As noted, there is no standardized definition or application of care coordination, perhaps due to the absence of a strong theoretical base (Wise, Huffman & Brat, 2007). The American Academy of Pediatrics’ (AAP) definition of CC is often used in the research literature on CMC,

which describes: “a process that links children and youth with special health care needs and their families with appropriate services and resources in a coordinated effort to achieve good health” (2005). In 2014, the AAP emphasized these elements of CC: patient- and family-centeredness; a team approach; being proactive, planned, and comprehensive; working across multiple medical and non-medical settings; and enhancing families’ capabilities by promoting self-care skills and independence (American Academy of Pediatrics, 2014a; Van Cleave et al., 2015).

The AAP identifies CC as a core component of a medical home, which is the recommended standard of care for children with chronic or disabling conditions to ensure positive patient outcomes and promote efficiency and continuity in care (American Academy of Pediatrics, 2014b; Stille & Antonelli, 2004; Zlateva et al., 2015). A medical home model is a primary care approach that is preventive, family-centered, comprehensive, continuous, accessible, team-based, compassionate, coordinated, focused on quality and safety, and culturally effective (Antonelli et al., 2009; Homer, et al 2008; Medical Home Initiatives for Children with Special Needs Advisory Committee, 2004). The medical home framework has been used to push the pediatric health care system to become more coordinated and patient- and family-centered (Zlateva et al., 2015). Within a medical home, CC has been linked to positive practices such as enhanced continuity of care; appropriate referrals and information sharing among health care providers, and between medical and community-based services; and greater use of electronic or centralized record keeping (Wise, Huffman & Brat, 2007).

The national consensus framework for systems of care for CYSHCN says the components of a unified framework of care are: family-professional partnerships, medical home, insurance and financing, early and continuous screening and referral, services that are easy to use, transition to adulthood, and cultural competence (Kuo & Houtrow, 2016). The US Maternal

and Child Health Bureau (MCH) has also outlined objectives for the care of CMC in its Title V programs that align with the principles of a medical home and emphasize the critical role of the family in pediatric care. The MCH Bureau advocates for: shared decision-making between families and providers, coordinated care within a medical home, community-based services that are easily accessible, adequate insurance, and transition support for youth entering adult services (Homer, Klatka, Romm, Kuhlthau, Bloom, Newacheck, Van Cleave, Perrin, 2008).

These and other descriptions of CC in key literature are summarized in Table 1.

1.3.4 Barriers to Implementing Care Coordination

Despite the benefits, there are barriers and disincentives to implementing CC in pediatric settings. Pediatricians report the primary obstacles are: insufficient time, lack of necessary staff, communication challenges, and limited reimbursement mechanisms (Antonelli & Antonelli, 2004). Another barrier is inadequate pediatrician training to successfully refer families to non-medical, community-based services and supports (Stille & Antonelli, 2004). A recent study of pediatricians indicated that only 22% had received formal training in community child health during residency, and 20% in medical school, while 44% indicated they received no training. Three quarters of pediatricians answering the survey reported that they had located resources for individual children, most often via the internet, and that their skills in locating these resources were moderate or high. Overall, however, this study shows there is a disconnect between pediatricians and community health services (Minkovitz, Grason, Solomon, Kuo, & O'Connor, 2013).

Most (71%) of pediatricians surveyed by AAP reported that their practices provided some type of CC. Some practices hire a staff social worker while others refer patients to an external

CC service (Antonelli et al., 2009). In focus groups exploring care for CMC, medical residents and recent graduates revealed several perceived barriers, including: insufficient care coordination, complex technology management, and patients' pervasive psychosocial needs, in addition to the lack of effective provider training. Participants offered solutions to these challenges, such as: greater integration of primary care providers with other types of providers, attention to psychosocial needs through shared-decision making, and integration of longitudinal patient relationships into provider training (Bogetz, Bogetz, Rassbach, Gabhart, & Blankenburg, 2015). In similar research, pediatric providers reported the lack of training on how to manage complex chronic care patients led to providers feeling overwhelmed and discontinuity in care. They also reported that multiple providers being involved led to a lack of provider 'ownership' of the patient and reduced provider autonomy (Bogetz et al., 2014).

Other research has documented the challenges providers face within reimbursement structures that often do not cover CC activities (Antonelli & Antonelli, 2004; Schor, Billingsley, Golden, McMillan, Meloy, & Pendarvis, 2003). While costs are a barrier, one study found the costs of providing CC in pediatric practices was significant but not prohibitive. In this case, costs were offset by having trained non-medical staff lead CC efforts. These researchers recommended that CC practices be standardized and performed by the most cost-effective staff that is appropriately trained.

Of course, the cost of implementing CC varies by the frequency and intensity of activities and the acuity levels of patients. Less technical CC activities can be provided by staff with less experience and training than a physician who demands higher reimbursement rates. Families with very complex needs may need more intensive supports that require a higher level of trained staff, however. This study recommended creating mechanisms to finance pediatric office-based

CC, and make CC that bridges the medical office and community supports a regular part of primary care for CYSHCN (Antonelli & Antonelli, 2004).

Finally, there are macro system level challenges to implementing CC. At the organizational level, differences in terminology, provider training and philosophy, funding sources, eligibility requirements, and regulations impede cross-agency and cross-systems communication and collaboration. There are also legal and regulatory differences at local, state, and federal levels that create barriers to seamless provision of services (Perrin et al., 2007). These barriers exist across medical settings, and especially across medical, educational, and social services settings.

1.3.5 Outcomes of Care Coordination

According to a 2007 technical review of care coordination for CYSHCN, there is limited empirical evidence regarding outcomes of CC, especially for CYSHCN. Most literature focuses on describing CC activities for CYSHCH or making recommendations of what CC should be (Wise, Huffman & Brat, 2007). Despite this, care coordination is seen as an integral component of a family-centered medical home for CMC. A medical home has been associated with families receiving greater access to community based services, increased contact with providers, reduced hospitalizations and emergency department visits, and lower medical costs (Homer, et al, 2008). A medical home has also been found to lead to higher professional satisfaction for many providers (McAllister, Cooley, Cleave, Boudreau, & Kuhlthau, 2013).

Care coordination itself has been shown to be critical to family functioning for CMC (Drummond, Looman, & Phillips, 2012), family-provider relationships (Turchi et al., 2009), improve continuity of care and family satisfaction, and has been linked to improved child

outcomes and cost savings (Stille & Antonelli, 2004). A care coordinator within a medical home provides a single point of contact for families, which promotes continuity of care (Stille & Antonelli, 2004). Continuity of care has been associated with improved outcomes and reduced costs for patients with chronic diseases (Musich & Paralkar, 2007). Families who reported receiving coordinated care also reported greater satisfaction with care and greater sense of partnership with providers, and had decreased odds of problems with referrals and lower likelihood of leaving paid employment to care for medically complex children (Hughes, 2014). Farmer et al. found a pilot rural CC program for CYSHCN resulted in increased access to mental health services; decreased primary care and specialty care visits; reduced need for social services, financial, and material supports; decreased strain on the family; and fewer school absences (Farmer, 2005).

Families of CMC experience a high degree of stress when they have unmet needs or feel their care is fragmented, however, this stress can be mitigated by coordinated and comprehensive care (Wood et al., 2009). Other research indicates that families of CYSHCN identify CC as their top care priority (Bachman, Comeau, & Jankovsky, 2015), although one study found that only 60% of families of CYSHCN reported receiving adequate CC (Turchi et al., 2009). Notably, even when CC is available, families report disparities their experience of quality, satisfaction, and outcomes. One study found parents reported there could be substantial improvement in the communication among doctors and other providers (Strickland et al., 2004). Parent perception of the adequacy of CC is also associated with the timeliness of care being received (Miller, 2014). Other research indicates that the benefits of CC and family-centered care vary by race and ethnicity, primary language, child's condition and severity, and socioeconomic status (Hughes, 2014). Table 2 provides an overview of key studies of care coordination.

1.3.6 Evaluating Care Coordination

While CC has been described as one essential step to improve health care quality for CMC, implementation of CC has varied widely and the outcomes of existing evaluations are difficult to compare. There are few robust outcome studies of CC due to the variations in implementation and the lack of a consensus on how to evaluate it (Van Cleave et al., 2015). Much of the evaluative work on CC has come from analyzing data from the National Survey of Children with Special Health Care Needs, which includes a much broader population than CMC. Most prospective studies have looked at parent and family experiences of children with a specific type of complex medical condition or functional limitation. Some studies only examine CC during in-patient care. Very few studies have examined the role of significant psychosocial stressors (e.g. untreated parent mental health, housing instability), in addition to medical complexity, in a family's experience of CC.

Using data from the National Survey of Children with Special Health Care Needs (NSCSHCN), researchers found that 68% of families reported receiving some care coordination. Of this group, 41% reported they felt the CC they received had been inadequate. This analysis found that the 59% who felt their CC was adequate were more likely to report receiving family-centered care, partnership with their health care professionals, and satisfaction with services. This group also had fewer specialty care referral problems, fewer missed days of school, fewer ED visits, and lower out-of-pocket costs (Turchi et al., 2009). However, these authors noted more research is needed to understand which aspects of CC are most beneficial for families and if these effects are present among the various subgroups of children included in this broad dataset. The 2001 NSCSHCN showed only 37% of parents said their communication with

providers was very good or excellent (Drummond et al., 2012), indicating a positive trend over time.

The challenge of determining appropriate outcomes that are attributable to CC further complicates evaluation efforts. The value of CC is often in the costly medical care or poor patient outcomes that it prevents. Uncoordinated care can lead to unnecessary health care procedures, costs, family stress, poor quality care, and negative health outcomes (Miller, 2014; Peter et al., 2011; Ratliffe, Harrington & Haley, 2002). Most outcome evaluations of CC have attempted to assess the impact on reduction in emergency department use or hospitalizations; cost savings to payers, providers and families; increased family satisfaction with care; reduced stress on families; or increased provider satisfaction. Refer to Table 2 for a summary of findings from CC evaluations.

A retrospective analysis of the adoption of CC activities in pediatric practices indicated that proactive CC activities are beneficial because: they stabilize families, increase families' perceptions of efficiency, make staff workflow more predictable, increase staff satisfaction, and build relationships across staff (Van Cleave et al., 2015). Other research has found that CC improves family outcomes such as: ease of obtaining referrals, lower out-of-pocket expenses, reduced time spent coordinating care, reduced impact on parental employment, fewer school absences, fewer ED visits, and high family satisfaction (American Academy of Pediatrics, 2014a; Turchi et al., 2009). "Effective" CC results in improved communication among families and providers, increased family satisfaction, and fewer barriers to care (van Dyck, Kogan, McPherson, Weissman & Newacheck, 2004). CC has also been found to be associated with children receiving mental and specialty health care services at higher rates (Miller, 2014).

Like any intervention, the benefits of CC are related to the quality of implementation, which is influenced by the experience, skills, and knowledge of the care coordinator. Some indicators of high-quality implementation of CC include: if the family receives needed assistance in a timely manner, at all points of care; if CC enables the family to develop CC skills themselves; and if CC is culturally and linguistically competent. Support for these functions can be found in family-centered curricula for CC staff, transition-focused resources for youth, and the growing endorsement by organizations that patients and families are entitled to effective CC (Antonelli et al., 2009).

To address the challenges of evaluation, AHRQ created the Care Coordination Measures Atlas in an attempt to review the theoretical frameworks behind CC, create a common definition of CC, and identify measures to evaluate common domains in CC. The AHRQ review concludes that there is a growing evidence base that CC contributes to high value, patient-centered care, but the health care services field is still struggling to measure the extent of CC implementation and link CC mechanisms to desired outcomes. Existing systematic reviews of CC have used variable measures, very few of which are focused on implementation or process, or describe intermediate outcomes of CC. AHRQ created the Atlas to help evaluators choose the best available measures to assess CC (McDonald et al., 2014).

In 2008, a panel of experts created the Medical Home Care Coordination Measurement Tool© based on the University of Massachusetts Medical School Care Coordination Tool (Stille, Jerant, Bell, Meltzer & Elmore, 2005). The new tool attempts to describe and measure the type and value of pediatric CC activities delivered in the medical home, including activities that are typically not reimbursable or systematically tracked (Antonelli, Stille & Antonelli, 2008). The tool is publicly available and is meant to address quality improvement and be adapted by its

users (Rosenberg, n.d.). In a study piloting the use of the tool, six pediatric practices implementing different CC models were asked to track CC activities using the tool over an eight-month period. CC activities that were tracked were defined as an activity taking longer than five minutes, was conducted by the participating medical practice's personnel, and that contributed to the development and/or implementation of the child's/family's plan of care, but was otherwise not reimbursable by third party payers. The tool recorded information such as patient complexity, the type of CC activity, what staff completed the activity, time spent, and outcomes prevented, which was a subjective estimate based on the staff completing the form (Antonelli, Stille & Antonelli, 2008).

The results indicated that while all pediatric patients used CC, those with greater medical need required longer CC encounters with staff, and particularly those with psychosocial risk factors in their families required more staff time for CC activities. This study included both CYSHCN and those without. CYSHCN comprised 30% of the study sample and used 35% of all CC encounters, totaling 44% of total time spent on CC activities across all practices. Activities for lower-need patients without psychosocial risk factors were typically for clinical and referral management, whereas activities involving patients with psychosocial needs tended to focus on mental health, social services, and legal needs. Patients with psychosocial needs comprised 24% of the sample but used 41% of CC time, with the highest average time spent per CC activity. Seventy-five percent of all of CC encounters fell within the 5- to 19-minute range. Ten percent of the encounters required 20-29 minutes. A total of 1.8% of encounters required 50 minutes to perform, ranging from 50 to 120 minutes in this study.

Overall, most CC activities focused on coordinating services among different medical, community and social services providers. Approximately 25% of CC encounters addressed

multiple needs. The majority of CC activities involved problems not considered medically typical, pointing to the issue of medical personnel not being adequately trained or prepared to provide CC to families with complex needs. Across practices, the majority of CC activities involved telephone contact (45-80%) between the provider and the parent or family (21-65%) (Antonelli et al., 2008).

Outcomes were assessed by the person completing the tool and were defined as the result of the CC activity for the family, based on the staff's judgment of what type of more intensive use of health services had been prevented due to the CC activity. Results indicate 32% of CC activities prevented the use of a more intensive health service, i.e. beyond the primary care setting. More activities conducted by nurses (62%) prevented additional service use than activities conducted by physicians (33%). The top outcomes prevented, in aggregate, were visits to the pediatric office (58%), emergency department use (26%), and a visit to a subspecialist (10%).

Finally, the study estimated the direct cost of care coordination by the type of staff conducting the CC activity. Not surprisingly, the largest cost factor of implementing CC was the amount of CC activities conducted by a physician. In addition to physicians and several types of nurses, researchers estimated CC costs involving social workers, clerical staff, and parent advocates. Across practices and staff types, the cost per CC activity by registered nurses or physicians ranged from \$4.39-\$12.86. Nurses appear to have the highest cost-effectiveness based on this study due to the number of higher service use costs they prevented. These cost savings data are significant findings for health systems, payers and families, who stand to spend less time seeking health care and missing work or school with the support of CC (Antonelli et al., 2008).

Looman, et al. (2013) examined the “match” between the patient/family and CC provided by advanced practices nurses to determine the efficiency and effectiveness of this type of care coordinator. They describe the characteristics of low-intensity and high-intensity CC on five domains: description, population, roles and responsibilities of the care coordinator, aims of care, and competencies. This analysis leads the researchers to develop a “Zone of Value” in which the intensity of care coordination and the population’s needs are aligned. Basic nursing practice in lower doses is sufficient for patients with low complexity needs. However, patients with higher complexity needs require advanced nursing practice and higher doses of nursing. The researchers conclude that having an advanced practice nurse as a care coordinator has potential to decrease fragmentation in care and improve efficiency especially for children with complex health care needs (Looman et al., 2013).

In summary, CMC and their families often rely on numerous medical, social, and educational services, which require significant coordination to prevent unnecessary or fragmented services and to appropriately support the child and family (Antonelli et al., 2009). While CMC are best served through coordinated partnerships among various providers and settings, these partnerships take considerable time and skill to identify, build, and nurture (Cohen et al., 2012). In practice, care coordination has been implemented in a variety of ways, at varying doses and levels of quality, across numerous settings. From the literature, it can be hypothesized that high quality CC will be associated with enhanced child clinical outcomes and family and child functional outcomes, greater patient/family and professional satisfaction, and reduced costs due to an increase in efficiency and effectiveness of health services delivery and a prevention of high-cost reactive or emergency treatments (Antonelli et al., 2009), yet the hard evidence tying CC to some of these outcomes is limited. Studies attempting to evaluate certain aspects of CC

implementation or outcomes are numerous, but the variability in activities provided as “care coordination” makes drawing conclusions challenging. There is still a need for a robust evaluation that can illustrate the potential cost-savings of CC for children with medical complexity, and determine how to compensate providers for CC activities that provide value to families of CMC but are not reimbursable.

1.3.7 The Research Setting

This dissertation research took place at the Children’s Institute (CI), an independent nonprofit organization located in Pittsburgh, Pennsylvania, which is dedicated to improving the quality of life for children with special needs and their families through a continuum of specialized services. These services include a hospital, a private day school for children and youth ages five to 21, numerous outpatient therapies, community outreach, and programs for adoption, foster care, and family visitation. CI offers specialty rehabilitation programs in behavioral health, brain injury, functional feeding, pain management, Prader-Willi syndrome, spinal cord injury, and ventilator management (www.amazingkids.org).

Based on a community needs assessment that identified over 15,000 children with complex medical conditions within CI’s service area, CI obtained private foundation funding to pilot a care coordination program for children with medical complexity. CI contacted the University of Pittsburgh’s Graduate School of Public Health to evaluate the pilot.

The researcher worked closely with several CI staff to learn about the CC program, understand the data being collected, and design the evaluation. These staff included the director of the care coordination program and her staff, the medical director, the director of the Institutional Review Board (IRB) at CI, a teacher/educational advocate who also served as the

project's co-investigator, and representatives from the information services divisions. Over a period of about nine months, the researcher observed numerous CC case review meetings and met with CC staff to understand the process of delivering CC and the nature of the client population. The researcher also met regularly with the co-investigator and the director of the IRB to plan the evaluation based on the best available data.

The scope of the evaluation and the outcomes that could be assessed were limited by several data challenges, which emerged as the project progressed. First, the design of the data system in which CC staff enter client data made it challenging to extract a complete dataset on the entire CC patient population. The data system, while user-friendly for the staff entering data, made the extraction and review of aggregate data difficult. Second, patient administrative information and key CC implementation information were contained in separate databases. There was no simple way to link data across these systems. Even internally, different types of staff are permitted access to different datasets, as necessary for job duties, making it challenging for any one person to have a good grasp of the potential for data analysis across all databases. Third, the CC client data system also contained protected health information, to which the researcher was not permitted access. The CI IRB felt that because CC participants had not consented for their information to be used for research purposes, no protected health information could be shared with the researcher, even if de-identified. It was also determined by the researcher and CC staff to be extremely unlikely that many CC participants would sign and return an additional hard-copy consent form for research, although the Children's Institute was beginning to develop a research registry across all its programs to solve this issue for future research. The limitations of the dataset are discussed in a later section.

To work around these challenges, key variables needed for the evaluation that were permissible to be shared had to be identified, a process that took representatives from CC staff, information services, the researcher, and co-investigator to complete. These variables were extracted from various databases by the information systems staff, then linked by an honest broker and provided to the PI. While care coordination staff were very accommodating and supportive in planning and implementing the evaluation, the overall process highlights some of the challenges of data collection and management when patient data are desired for research purposes.

**2.0 CHAPTER TWO: MANUSCRIPT ONE: ELEMENTS OF CARE
COORDINATION THAT ARE ASSOCIATED WITH EMPOWERMENT FOR
FAMILIES OF CHILDREN WITH MEDICAL COMPLEXITY**

2.1 ABSTRACT

Care coordination, although part of the recommended standard of care for children who are medically complex, is often loosely defined and variably implemented across settings. A goal of care coordination is to increase family empowerment, which is operationalized as the capacity of family caregivers to control of factors that influence quality of life. Although linked to family wellbeing, empowerment is an under-researched outcome of care coordination for families with medically complex children. This paper reviews the literature on: aspects of the family experience of caring for a medically complex child, the key elements of care coordination, and definitions of family empowerment, then identifies care coordination activities that are associated with an increase in empowerment among families caring for medically complex children.

2.2 INTRODUCTION

In the United States and the world, the population of children with special health care needs is large and growing as more chronically ill children are living longer. Many of these children receive the majority of their care in the home and community, with family members assuming the roles of direct care provider and care manager (Kuo & Houtrow, 2016). Children with medical complexity (CMC) are a subpopulation of children and youth with special health care needs, who require intensive medical, educational, and social supports. Medical complexity is described as “medical fragility and intensive care needs that are not easily met by existing health care models” and therefore require additional “time, expertise, and resources...to reach optimal health outcomes” (Cohen et al., 2011, page 529).

Cohen et al. state there has been no broadly-applied definition of CMC or clear research agenda, therefore it is difficult to evaluate the outcomes of programs to support this population. These authors propose health care professionals need to: 1) ensure a family-centered system of care that supplies families with information, connects them to resources, and empowers families; 2) provide needed knowledge and support across all levels of care for chronic conditions; 3) ensure families have needed social, material and technological supports to participate in community life; and 4) provide care coordination that promotes high quality and efficient care, characterized by clear provider roles across all care settings (Cohen et al., 2011).

In recent years, care coordination (CC) has received significant attention as a promising strategy to increase quality and efficiency in health care services for individuals with complex needs who are frequent users of health care (Kuo & Houtrow, 2016). Even before health care reform supported CC, the Institute of Medicine and the American Academy of Pediatrics have pushed for coordinated care for CMC, noting that uncoordinated care results in poor quality,

fragmented services, and unsatisfying experiences for children and their families. Increasing family capacity to care for children and manage care is one goal of care coordination for CMC (American Academy of Pediatrics, 2005).

Because the definition and implementation of care coordination has varied widely in practice and in the research literature, CC may be best understood in terms of its activities. The essential elements or activities of pediatric CC are presented below and summarized in Table 1. Then, a review of the literature on family empowerment is presented in an attempt to identify what activities of CC are associated with empowerment.

2.2.1 Care Coordination Activities

In the literature, CC is often described by its primary activities. These activities are broader than case management, which is a more general approach that addresses the health needs of patients and cost control for high service users (Antonelli et al., 2009). CC goes beyond typical case management because it focuses on the integration of services beyond medical needs, and CC is driven by improving patient care, not cost reduction (Stille & Antonelli, 2004). CC is needed to provide CYSHCN and their families support within a medical home model and must be considered an integral part of the pediatric office. Antonelli also asserts that CC must be measurable, auditable, and amenable to continuous quality improvement (2008).

In adult care settings, CC often means the management of chronic conditions, but pediatric CC must assess and consider children's and families' supports within and beyond a strict medical view. Just as CC activities must adapt over time with the developmental stages of the child and appropriate service systems (Antonelli et al., 2009; Wise, Huffman & Brat, 2007), it must also evolve with the family's needs throughout the chronic illness experience or

“lifecycle”. CC typically first responds to acute needs and current struggles of the family, then becomes more proactive over time as the focus shifts to preventing future acute events and minimizing disruptions in families’ lives. “Proactive” is defined here as controlling a situation by preventing or causing something to occur rather than responding to an event, for example pre-visit assessments via phone, gathering family priorities and goals, and written care plans or health summaries (Van Cleave et al., 2015).

Table 1. Key Elements of Pediatric Care Coordination

Description of Care Coordination Key Elements	Relationship to Family Empowerment	Citation
<p>AHRQ defines care coordination as “The deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services.”</p>	<p>Family are active participants in identifying needs, goals, and a plan to address them.</p> <p>Family can use plan of care to guide interactions with providers.</p>	<p>McDonald, et al. (2007), page v</p>
<p>The AAP’s 1999 statement by its Committee on Children with Disabilities described CC as occurring when a “specified care plan is implemented by a variety of service providers and programs in an organized fashion.”</p> <p>The goals of care coordination are:</p> <ul style="list-style-type: none"> • Gain access to and integrate services and resources • Link service systems with the family • Avoid duplication and unnecessary costs • Advocate for improved individual outcomes. <p>Primary care coordination activities are: integrating services and resources across domains of care and between the medical and non-medical realms, linking services to the patient/family; increasing efficiency in service use; reducing health care costs; and advocating for patient/family centered care.</p>	<p>Access to information and resources increases family capacity to be involved in care planning and decision-making.</p> <p>Family can use plan of care to advocate for their needs and preferences.</p> <p>Families and care coordinators can take a holistic view of child because the plan of care spans service settings.</p> <p>Care coordination facilitates access between families and services/resources.</p> <p>Care coordination advocates for families.</p>	<p>Wise, Huffman, & Brat (2007)</p>
<p>Care coordination is “A process that links children and youth with special health care needs and their families with appropriate services and resources in a coordinated effort to achieve good health.”</p> <p>Pediatric care coordination should transcend settings, service systems, and life stages to include services such as: early intervention, early care and education, school and afterschool settings, nutrition, physical health care, mental and behavioral health needs, and community based social supports.</p> <p>The AAP emphasizes these elements of CC: patient- and family-centeredness; a team approach; being proactive, planned and comprehensive; working across multiple medical and non-medical settings; and enhancing families’ capabilities by promoting self-care skills and independence.</p>	<p>Access to information and resources increases family capacity to be involved in care planning and decision-making.</p> <p>Families and care coordinators can take a holistic view of child because the plan of care spans service settings.</p> <p>Care coordinators coach and support families to build capacity, autonomy, and skills.</p>	<p>American Academy of Pediatrics (2005)</p> <p>American Academy of Pediatrics (2014)</p> <p>American Academy of Pediatrics (2014); Van Cleave, Gortmaker, & Perrin (2015)</p>

Table 1 Continued

<p>Pediatric CC is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. CC addresses the interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.</p> <p>The National Quality Forum describes CC as ensuring patients' needs and preferences for health services and information are met. To this end, they support a framework whereby CC covers five domains: the medical home; a proactive plan of care that includes ongoing reassessment; communication among all members of the care team and patient, which emphasizes shared decision-making with families; electronic record keeping; and coordinated hand-offs among providers at times of transition</p> <p>A seminal review of the functions of Care Coordination identified the following as key activities, depending on a family's level of need:</p> <ol style="list-style-type: none"> 1. Establish relationships with families through introductory visits that set expectations for the care coordination relationship 2. Communicate among professionals and families 3. Conduct a child and family assessment 4. Develop a plan of care with the family that states mutual goals 5. Coordinate and track referrals and test results 6. Provide resources for medical, financial, educational and social needs of child and family, and coach for the transfer of skills to families to care for their children 7. Integrate multiple sources of health care information and share this information among all care partners and the family 8. Manage and facilitate all transitions in care or among services 9. Use health information technology to deliver, monitor and improve care coordination 10. Coordinate family centered team meetings 	<p>Care coordination activities are driven by family needs and preferences.</p> <p>Family and providers are a team.</p> <p>Care coordinators can coach family capacity- and skill-building.</p> <p>Care coordinators can advocate for family when needed.</p> <p>Family uses plan of care to guide interactions with providers and promote shared decision-making.</p> <p>Family has open access to child's health records and other information for decision-making.</p>	<p>Antonelli, McAllister, & Popp (2009)</p>
<p>The National Quality Forum Framework for Care Coordination emphasizes the development, monitoring, and ongoing revision of a plan of care; open communication between the patient/family and all members of the health care team, with an emphasis on shared decision-making with families; use of electronic medical records and information sharing; and coordination during transitions among health care settings</p>	<p>Families can use the plan of care to guide interactions with providers.</p> <p>Families participate in shared-decision making and transition-planning.</p> <p>Families have open access to child's medical records and other information.</p>	<p>National Quality Forum (2009)</p>

Table 1 Continued

<p>The Massachusetts Child Health Quality Coalition Care Coordination Task Force determined the key elements of high-performing pediatric care coordination are needs assessment and ongoing engagement in care coordination, care planning, communication, facilitating care transitions, connecting children/families with community resources, and managing the transition to adult care</p>	<p>Families are a team with providers.</p> <p>Families have access to information and the shared plan of care to guide care planning, transitions, and shared decision-making.</p>	<p>Antonelli (2013)</p>
<p>A care coordination activity is anything that contributes to the creation or implementation of a plan of care and links families to services that optimize outcomes in the patient-centered plan of care.</p>	<p>Families can use the plan of care to guide interactions with providers and self-advocate.</p>	<p>Antonelli, Stille, & Antonelli (2008)</p>
<p>The Boston Children’s Hospital’s Pediatric Care Coordination Curriculum outlines the fundamental structures of a medical home, team-based, care coordination framework:</p> <p><u>Fundamental structures:</u></p> <ol style="list-style-type: none"> 1. Access to medical home, health care, and other resources 2. Community connections <p><u>Fundamental processes:</u></p> <ol style="list-style-type: none"> 1. Proactive care planning <p>Improving and sustaining quality</p>	<p>Access to information and resources increases family capacity to be involved in care planning and decision-making.</p>	<p>Antonelli, Browning, Hackett-Hunter, McAllister, & Risko (2014), Module 1.10</p>
<p>The Care Coordination Measures Atlas outlines a CC measurement framework with coordination activities in the following domains:</p> <ul style="list-style-type: none"> • Establish accountability or negotiate responsibly • Communicate <ul style="list-style-type: none"> ○ Interpersonal ○ Information transfer • Facilitate transitions • Assess needs and goals • Create a proactive plan of care • Monitor, follow up, and respond to change • Support self-management goals • Link to community resources • Align resources with patient and population needs 	<p>Families and providers are a team with clearly identified roles and responsibilities.</p> <p>Families can use the plan of care to guide interactions with providers, including care planning, transitions, shared decision-making, and self-advocacy.</p>	<p>MacDonald, et. al (2014)</p>
<p>A generally acknowledged element of CC is communication among various health care providers, the family, the school system, and community-based supports and services, of historical information on illness and services, as well as current care and future needs.</p>	<p>Families and care coordinators can take a holistic view because the plan of care spans service settings and can be a planning tool across settings.</p>	<p>Strickland, et. al (2004)</p>
<p>The key features of CC for CMC and their families are:</p> <ul style="list-style-type: none"> • Linkage to community-based services 	<p>Access to information and resources increases family capacity to be involved in care planning and decision-</p>	<p>Henry (2015)</p>

Table 1 Continued

<ul style="list-style-type: none"> • A qualified care coordinator • Intake screening • Comprehensive assessment • A plan of care • Planning and goal setting for patient and family needs • Providing services (which includes preparation activities, advocacy, and financial support) • Information-sharing among all providers • Patient/family – care coordinator relationships • Enhancing patient/family capacity to be care caregiver and care coordinator • Monitoring and ongoing reassessment 	<p>making.</p> <p>Family uses plan of care to guide interactions with providers.</p> <p>Care coordinators can advocate for family when needed.</p> <p>Family has open access to child’s health records and other information, for decision-making.</p>	
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Numerous aspects of care coordination as described above lend themselves to the development of family capacity and empowerment. Foremost, families must be active partners in care, including identifying needs and preferences, developing a plan to address them, and making decisions about care. For example, CC is often described as a team process that is driven by patient- and family-identified needs for services and supports (American Academy of Pediatrics, 2014). The AAP recommends that the family, rather than the medical provider, be the ultimate care coordinator, although this may not be a realistic expectation in some families with numerous psychosocial challenges. Regardless, a partnership between families and providers is essential (Wise, Huffman & Brat, 2007). The philosophy of family-centered care and long-term partnership between families and providers is behind the medical home model that strives to promote holistic care of children and their families and assists families to manage acute and chronic conditions (Drummond et al., 2012).

Additionally, from a definition of high-performing pediatric care coordination, Antonelli, emphasizes the potential of CC to enhance the caregiving capacities of families through at least two activities: patient/family coaching and the plan of care (Antonelli et al., 2009). He states “The effectiveness of a care coordination system can be measured by the experiences of the families that receive these services. Therefore, families must play a proactive role in informing the design of the infrastructure and policies that will support the development of care coordination as an integral part of the health care system.” (Antonelli et al., 2009, page viii). CC promotes self-care and independence for patients and families by increasing access to knowledge needed for self-management, and supporting families to build the necessary skills to navigate the complex health care and other support systems in which they exist. Care coordinators can advise

or model behaviors to obtain needed resources. Of course, many families are already excellent caregivers and care coordinators for their children. For them, CC can support and further develop their competencies (Antonelli et al., 2009).

2.2.2 Definition of Empowerment

Empowerment has two facets: a sense of confidence in one's internal resources, and opportunities to exert influence and autonomy in one's own life (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015). Tengland has published an extensive summary of the literature on empowerment and a definition that was created through conceptual analysis to deconstruct and clarify empowerment and other terms that are often used with varying definitions or interchangeably. He concludes there are two functional uses of the term empowerment in the context of providing human services: empowerment as a goal and empowerment as a process or approach. As a goal, empowerment refers to an individual (e.g. a client or patient) having control over the determinants of his/her own quality of life. There are six determinants over which individuals have at least some degree of control: health, home, work, close relationships, leisure time, and values (Tengland, 2008).

As a goal (i.e. something to be gained), empowerment refers to a trait of a client before, during, or after the relationship with a professional, and the trait can vary over time (Tengland, 2008; Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015). The trait of empowerment is associated with one's internal resources and sense of ownership over one's life, and is built through the process of empowerment. That process is conceptualized as acquiring a sense of mastery over one's life by building confidence and self-esteem, developing coping mechanisms and skills, and taking control of decision-making. An individual can increase his/her own

empowerment, or it can be built through a relationship with a professional (Tengland, 2008). Professionals working with an individual may reinforce the trait of empowerment, or they may create the conditions in the service context that foster parent empowerment (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015). The process of increasing empowerment occurs when clients have access to the knowledge, skills, and resources they need to gain positive control over their lives (Singh, Curtis, Ellis, Nicholson, Villani, & Wechsler, 1995).

When empowerment is a process within the client-professional relationship, it refers to creating a dynamic of shared power and meaningful client involvement, through which the client takes control of determinants in his/her life, and sets the goals and the means to use the relationship. Empowering relationships are characterized by a balance of power, client leadership in determining the problems on which the working relationship is focused, and client identification of appropriate responses or solutions to those problems. The professional takes a “step back” to facilitate the client’s autonomy in determining how to assess and approach the challenges in the client’s life. The professional often may have more influence at the start of the relationship, but this influence wanes gradually as the client’s autonomy increases. Over time, the meaningful involvement of the client grows and the role of the professional is minimized as the client increases his/her responsibility in the change process (Tengland, 2008). Therefore, empowerment through client-professional relationships occurs in degrees and is based on the nature of the relationship in addition to each partner’s personal traits. Not all client-professional relationships are empowering; some can have the opposite effect.

Tengland’s literature review suggests there are three general goals of empowerment that operate at different levels, namely: 1). Increase in control at the individual level; 2). Increase in the individual’s ability to control his/her life; and 3). Increase in ability to change the world

(Rodwell, 1996). These levels mirror the those measured by the Family Empowerment Scale (FES) (Koren, DeChillo, & Friesen, 1992). On the FES, the family subscale focuses on the parent's sense of how they cope with and manage the child's condition in everyday life; seek help when needed; and acquire the knowledge, skills and abilities the parent may need to care for the child. The service situations subscale focuses on the parent's sense of his/her knowledge, understanding and rights related to the child's needed services and supports; the parent's sense of his/her collaboration with professionals; and parent participation in decision-making and securing needed services for the child. The service system subscale focuses on the parent's sense of his/her knowledge and rights within the system and his/her sense of how he/she can influence and contribute to improving the system (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015).

2.2.3 Family Empowerment and Care Coordination

This paper focuses on one lesser-examined area in the literature: family empowerment as an outcome of participating in pediatric care coordination. In the context of families of CMC, this could be conceptualized as the trait of having, or the process of gaining, control over aspects of the family's quality of life (Resendez, Quist, & Matshazi, 2000; Tengland, 2008). Families of children with medical complexity and who may also face significant psychosocial risks stand to benefit greatly from participating in a well-implemented and effective CC program that promotes and supports empowerment.

Family empowerment is believed to be critical to family wellbeing (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015). Empowerment is an essential characteristic of families who can access and effectively utilize services to achieve desired outcomes for

themselves and their children (Singh et al., 1997). In a recent qualitative study, parents reported that empowerment was essential to help them cope with their new care responsibilities during the child's transition from hospital to home care, indicating the importance of looking at parents' care coordination needs during transition (Zanello et al., 2015). Despite these positive findings, few studies have looked specifically at what aspects of care coordination for CMC have been found to affect families' feelings of empowerment as caregivers and care managers for their children.

The research literature indicates some likely outcomes of family empowerment would include increased access to health, educational, and social services in a timely way; improved continuity of health care; reductions in parental stress; and greater knowledge, skills and feelings of self-efficacy in managing their children's conditions (Kuo & Houtrow, 2016; Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015). Additionally, family empowerment has been associated with child outcomes including improved behavior, and positive psychosocial, physical, verbal and social development. Research also suggests empowerment is associated with higher parental engagement in the child's care, satisfaction with care decisions, continuity of care, and parental rating of service accessibility and level of support (Vuorenmaa, Perälä, Halme, Kaunonen, & Åstedt-Kurki, 2016).

Parents and extended family of CMC often take on considerable responsibility for coordinating care and providing skilled care in the home setting (Kuo & Houtrow, 2016), therefore an exploration of parent experiences is essential to understand the need for and significance of CC. An ethnographic study with 68 parents of CMC explored the concept of "intense parenting," meaning the additional efforts parents of CMC commit to the care of their children. Parents described the time demands of being a caregiver to their children with complex

needs, which trump all other aspects of life including their own needs or family socialization. They also described needing to be ready at all times to provide constant care or to respond to an acute event. Parents felt their role was a hybrid of parent, health care provider, and case manager (Vuorenmaa et al., 2016; Woodgate, Edwards, Ripat, Borton, & Rempel, 2015).

The research is clear that parents of children with disabilities experience higher levels of parenting stress than those of children without disabilities (Boyd, 2002) and parents who also face psychosocial challenges are likely to have even higher stress levels (Dumas, Wolf, Fisman, & Culligan, 1991; Sloper, 1999). Some evidence suggests that parents who are poor or have fewer resources need additional support in problem solving, due to greater cognitive burden imposed on them by poverty, which can impede cognitive performance (Mani, Mullainathan, Shafir & Zhao, 2013). Additionally, problems affecting family wellbeing are often exacerbated when children have developmental challenges (Farber & Maharaj, 2005). Care coordination may be particularly helpful then for families of CMC who also have psychosocial risk factors. However, there are large variations in family coping because parents' individual responses to stressors are affected by the resources and supports available to them (Sloper, 1999). Parenting stress can negatively impact family functioning, parent and child outcomes, and may even reduce or eliminate the positive impacts of intervention (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009). Problems tend to cluster in families, so it is critical that services take into account family members' wellbeing and support them (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015).

2.3 METHODS

Literature was retrieved from the PubMed databases with no date restrictions by searching title and abstract using “care coordination” AND “empowerment” as keywords. Search details: "care coordination"[All Fields] AND ("power (psychology)"[MeSH Terms] OR ("power"[All Fields] AND "(psychology)"[All Fields]) OR "power (psychology)"[All Fields] OR "empowerment"[All Fields]). This resulted in 25 articles. Then the search was revised to include "care coordination" AND “parents OR families” AND “empowerment”. Search terms: "care coordination"[All Fields] AND ("parents"[MeSH Terms] OR "parents"[All Fields]) OR ("family"[MeSH Terms] OR "family"[All Fields] OR "families"[All Fields]) AND ("power (psychology)"[MeSH Terms] OR ("power"[All Fields] AND "(psychology)"[All Fields]) OR "power (psychology)"[All Fields] OR "empowerment"[All Fields]). The search was extended by reviewing and including all relevant citations from retrieved articles and by building on literature and practitioner documents that had been compiled previously by the care coordination program director at the Children’s Institute. Only studies published in English were included.

2.4 RESULTS

In summary, empowerment is being able to exert control over the determinants of one’s quality of life. Changes in some of the abilities (e.g. autonomy) or characteristics described above equate to corresponding changes in empowerment because they necessarily mean an increase in control over these determinants. Increases in other abilities (e.g. knowledge, self-efficacy) often relate to an increase in empowerment, but not always, because they alone are not sufficient to increase

control in one's life. At least one of these abilities is necessary for an increase in empowerment, however, in combination with an increase in self-confidence or autonomy (Tengland, 2008). This description can be combined with Tengland's conclusions about the balance of power in the client-professional relationship to land on a final definition of empowerment:

“We achieve empowerment (in a combined sense) when a person (or group) A acts towards (in relation to) another person (or group) B in order to support B (by creating the opportunity and environment, and giving ‘expertise’ support) in gaining better control over (some of) the determinants (those relevant for the situation or profession) of her (quality of) life through (necessarily) an increase in B's knowledge (self-knowledge, consciousness raising, skills development, competence), or health (e.g. autonomy, self-confidence, self-efficacy, or self-esteem) or freedom (positive or negative), and this acting of A towards B involves minimizing A's own ‘power’ (or influence) over B with regard to goal/problem formulation, decision-making and acting, and B seizes (at least) some control over this situation or process (goal/problem formulation, decision-making, and acting).” (page 93).

Links between empowerment and related concepts

In his literature review, Tengland also defines various concepts that are related to empowerment and sometimes used interchangeably, including: autonomy; knowledge and skill acquisition; self-esteem, self-confidence and self-efficacy; ability; and freedom. How each of these concepts relates to empowerment is briefly summarized here.

Change in autonomy, which is the ability to reflect critically on the choices one has and choose a preference, is positively associated with a change in empowerment. Here, autonomy as self-determination is necessary to empowerment and is also a likely a *result* of empowerment as a process. However, one might have autonomy without the ability to act on desired preferences, and therefore not be empowered. Some degree of autonomy is assumed in the definition of empowerment because self-determination (autonomy) is needed to be able to assess and exert control of factors of one's quality of life (empowerment).

Knowledge and skill acquisition is directly related to empowerment, but knowledge itself is not sufficient to lead to an increase in empowerment because knowledge does not necessarily come with an increased ability to control a determinant in life. There are two kinds of knowledge that can contribute to increased empowerment: consciousness raising and skill development. Consciousness raising is a prerequisite for having control over a situation but not all skill acquisition will lead to an increase in ability to control one's life. Therefore, some kinds of knowledge acquisition are sufficient for an increase in empowerment but not all kinds of knowledge or skills are empowering.

Ability in a general sense is necessary to control one's life. Competence, thought of as having developed an ability through specialized knowledge and training, can be empowering when the competency helps an individual control his/her life. As with knowledge, some types of competence *can* lead to an increase in empowerment, but there are competencies that are not relevant to the definition of empowerment, so are therefore not empowering (Tengland, 2008).

Self-esteem is one's attitude toward one's self and overall view of oneself as an individual. Self-confidence is the belief about one's general capacity to handle life's situations or tasks. Self-efficacy, in contrast, is one's belief about his/her capacity to cope with specific situations or tasks in life (Bandura, 1982). An increase in self-esteem itself is not sufficient for an increase in empowerment because it does not always mean an increase in control. But, paired with knowledge and skills about how to change one's life, self-esteem may lead to empowerment. General self-confidence and specific self-efficacy are often related, but do not have to be. Self-efficacy in one area of life does not equate to self-efficacy in others. High self-confidence would likely mean one had greater feelings of being able to control one's life, i.e. empowerment (Tengland, 2001). However, increases in some types of self-efficacy may not

directly relate to being able to control a situation in one's life, and therefore would not be empowerment (Tengland, 2008). These narrower concepts are either forms of increased control or contribute to increased control. Freedom is also related to empowerment in that it can be an opportunity to have more control over the external factors that influence one's life, but one must also have a perceived sense of increased control to experience empowerment (Tengland, 2007).

Empowerment is defined here as broader than being able to control one's own health, although health is recognized as an important resource and determinant of one's quality of life (the focus of empowerment). In the context of health professions, increasing control over one's health is an important goal, and would be a step towards empowerment (Tengland, 2008).

Chronic Conditions and the Illness Lifecycle

Most chronic conditions have common periods within the experience of the illness "lifecycle". These periods often include initial fear and uncertainty pre-diagnosis; the acute phase of receiving a diagnosis and beginning treatment; a potentially long or cyclical period of maintenance that may include treatment, recovery, and relapse; and periods of transition in condition or care, such as the transition to community-based care or the transition from pediatric to adult services. Each of these phases within the illness experience brings different challenges and stressors for children and their families, with corresponding roles that a care coordinator can play to support families in that phase (Compas et al., 2012; *Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An ethnographic approach*, 2012).

For CMC, optimal health care goals would include maximizing the child's health, development, and functional abilities, and also maximizing family functioning through

coordinated and family-centered care, while being proactive to prevent or reduce acute and critical health events (Kuo & Houtrow, 2016). During the early stages when a diagnosis has not been identified, care coordinators can be helpful by providing information and resources to reduce parent uncertainty and stress. After a diagnosis is received, care coordinators can coach parents to take an active role in their children's care and care decision-making, and establish a family-provider partnership approach to care. When a child transitions to home or community-based care, the care coordinator can create a support network by connecting the family with financial and material resources, home-care, and services and supports. In the maintenance phase, care coordinators continue to provide families with information and resources, and nurture the network of relationships with care providers and supportive services. Finally, care coordinators help families plan for transitions and long-term care (*Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An ethnographic approach*, 2012).

The number of professionals and service systems involved in the lives of medically complex children, and the orientation of our health care system to providing acute or episodic care, has increased the need for care coordination as a strategy to improve quality of care and patient outcomes for those with chronic conditions (Van Houdt, Heyrman, Vanhaecht, Sermeus, & De Lepeleire, 2013). Additionally, medical care providers, to varying degrees, are now giving more consideration to families' preferences regarding treatment options (De Civita et al., 2005). The complexity of service needs for this population and their frequent transitions among care settings and providers, including in-home, leads to poor care coordination and increased hospital use, especially for those with two or more chronic conditions (Navarra et al., 2016).

Additionally, care is harder to obtain in certain locations. For example, some types of specialty care or forms of therapy, mental health services, and individualized education plans (IEPs) can present greater access barriers for families, and outpatient care presents different challenges than inpatient. Compared to the acute phase, the maintenance phase of a chronic illness may present additional challenges. In this phase, the payer has enormous control over a family's access to services and equipment. Although the family may have settled into a routine with the child's condition, they may face increased challenges in obtaining needed care and support. The health system may not be equally well-matched to families' needs at all phases of the chronic illness lifecycle (*Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An ethnographic approach*, 2012).

Home-based Care and Family Support

There has been a dramatic shift in care responsibilities for families as the number of CMC living at home increases (Woodgate et al., 2015). Caring for a child with medical complexity has significant impacts on all aspects of family life. Evidence suggests that chronic conditions can cause more physical and psychological stress than shorter-term acute illnesses (Marin, Chen, Munch, & Miller, 2009) because of the prolonged elevation of the body's stress response hormones (Juster & McEwen, 2010).

Families of CMC report feeling they are expected to navigate the health care system without adequate support from professionals, and about half report they have at least one unmet need (Kuo & Houtrow, 2016). Parents of CMC often experience unmet needs proportionate to the severity and complexity of their child's illness (Farmer, Marien, Clark, Sherman, & Selva, 2004). Frequently unmet needs for CMC include preventive care, oral health care, access to

specialty care, mental health services, transition supports, care coordination, and respite for parents (Kuo et al., 2015). An analysis of the 2007 National Survey for Children's Health, showed that parents of CYSHCN with multiple chronic conditions, mental health needs, and parents of Black or Latino children (compared to white children) reported having greater need for care coordination and more unmet care needs (Toomey, Chien, Elliott, Ratner, & Schuster, 2013). However, data show that high levels of unmet needs in the CMC population occurs across all races/ethnicities, income levels, and insurance types (Kuo et al., 2015). Parents with higher perceived competence, knowledge, and self-efficacy were more satisfied with services and felt more empowered (Resendez et al., 2000).

Parents report spending over 11 hours per week providing direct care to their CMC, and a median of two hours each week coordinating care (Kuo & Houtrow, 2016). Contacts with numerous agencies or providers and a lack of coordination results in parent confusion and more demands placed on them and their time. Parents who did not have a designated care coordinator had more unmet needs, particularly parents who reported the most challenges and fewest resources (Sloper, 1999). Families of CMC need effective and timely medical care, and professional assistance to coordinate services and improve communication among providers. This type of support decreases duplicative services, unnecessary travel and appointments, saves parents time, and reduces their financial and psychosocial burdens (Kuo & Houtrow, 2016).

Family-System Interaction

Families default to different styles when interacting with the medical system, and at different points in the illness lifecycle. They may shift styles over the course of a chronic illness as their autonomy and empowerment increase. A recent ethnographic study with families of

CMC was used to develop a model of these styles, describing them as: Vulnerable, Compliant, Advocate, and Activist. Along this continuum, families progress from feeling incapacitated or overwhelmed by the diagnosis or the health care system in the vulnerable stage. The compliant stage is characterized by the family's reliance on health care professionals, with limited assertiveness. The advocate phase is a progression from compliance to the family using decision-making and partnership with providers to become engaged in the child's care. Finally, the activist stage is when this assertiveness moves beyond the immediate family to becoming a support to others or an advocate for systems reform. When families feel they can influence their children's care through assertiveness, partnership with providers, and decision-making, they feel empowered. This research also indicated that families who are more actively engaged tend to receive a greater number of resources, suggesting that the level of parent assertiveness and participation affects the services chronically ill children receive. An ideal system would not rely on individual advocacy to obtain needed services (*Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An ethnographic approach*, 2012).

Key Care Coordination Studies

As discussed earlier, in literature and practice the term care coordination has been used to refer to a range of different services or supports. To clarify the term and strive for a uniform application of it, several landmark reviews have identified key aspects of pediatric care coordination.

For example, The Standards for Systems of Care for Children and Youth with Special Health Care Needs summarizes existing frameworks of best practice and standards for care

coordination and states that all CYSHCN should have access to family-centered care coordination; have a care coordinator who serves as a member of the medical home team, assists the family in managing transitions, and provides resources appropriate to the child's and family's needs; and develops a plan of care among the primary providers and family (VanLandeghem, Sloyer, Gabor, & Helms, 2014). The national consensus framework for systems of care for CYSHCN says the components of a unified framework of care are: family-professional partnerships, medical home, insurance and financing, early and continuous screening and referral, services that are easy to use, transition to adulthood, and cultural competence (Kuo & Houtrow, 2016). The National Quality Forum Framework for Care Coordination emphasizes the development, monitoring, and ongoing revision of a plan of care; open communication between the patient/family and all members of the health care team, with an emphasis on shared decision-making with families; use of electronic medical records and information sharing; and coordination during transitions among health care settings (National Quality Forum, 2010). Similarly, the Massachusetts Child Health Quality Coalition Care Coordination Task Force determined the key elements of high-performing pediatric care coordination are needs assessment and ongoing engagement in care coordination, care planning, communication, facilitating care transitions, connecting children/families with community resources, and managing the transition to adult care (Antonelli, 2013).

Based on a review of seminal definitions, which are summarized earlier, Antonelli proposes the following primary elements of care coordination. Table 2 then links these elements to key studies of care coordination.

- Establish **relationships** with families through introductory visits that set expectations for the care coordination relationship
- **Communicate** among professionals and families
- Conduct a child and family **assessment**

- Develop a **plan of care** with the family that states mutual goals
- **Coordinate** and track referrals and test results
- Provide **resources** for medical, financial, educational and social needs of child and family, and **coach** for the transfer of skills to families to care for their children
- **Integrate** multiple sources of health care information and **share this information** among all care partners and the family
- Manage and facilitate all **transitions** in care or among services
- Use health **information technology** to deliver, monitor and improve care coordination
- Coordinate **family centered** team meetings (Antonelli et al., 2009)

Table 2. Key Studies of Care Coordination

Study	Design	# Participants	Elements of CC	Outcomes Assessed	Results
Adams, Cohen, Mahant, Friedman, MacCulloch & Nicholas (2013)	Cross-sectional; Qualitative: interviews and focus groups	15 health care providers and 15 parents of CMC	Plan of care; relationships; communication; information integration and exchange	Parents' experiences in creating and using the plan of care; perceived key components and gaps of plan Health care providers' understanding and use of care plans; perceived impact of plans	Care plans are useful tools for both parents and providers to centralize and focus a child's care; Key aspects of the care plan are its <i>characteristics</i> (content, flexibility, shared values), <i>activating factors</i> , and <i>perceived outcomes</i>
Antonelli, Stille & Antonelli (2008)	Piloting a CC implementation measurement tool	6 pediatric practices serving CYSHCN	Implementation: time, required staffing, nature of activity, client outcomes	Staff outcomes: time spent on CC activities, nature of activities; client outcomes of encounter; client outcomes prevented; cost of non-reimbursable staff time	CYSHCN and families with psychosocial problems utilize more staff time; the principal cost driver is physician cost; there could be significant cost savings associated with CC for CYSHCN
Chernoff, Ireys, DeVet & Kim (2002)	Randomized prospective clinical trial	136 children with specific chronic conditions	Family-centered care; contacts; enhanced services (child life specialists)	Child adjustment and mental health challenges	There are modest positive effects of a family support intervention in promoting adjustment for children with specific chronic conditions. The intervention had a significant main effect on post-intervention adjustment, controlling for baseline scores ($p=.01$)
Criscione, Walsh &	Randomized control trial	115 youth with develop-	Referral; service integration,	Hospital admissions,	The CC group had shorter lengths of hospital stays, and

Table 2 Continued

Kastner (1995)		mental disabilities	assessment and plan of care; transition	length of stay, charges	lower hospital charges (over \$200,000 of potentially unnecessary hospital charges)
Dempsey, Keen, Pennel, O'Reilly, & Neilands (2009)	Longitudinal two-group design; Mixed methods: survey and interview	33 parents of a child with an intellectual or develop. disability	Family centered care; relationships	Parent stress, parenting competence, and family-centered support	Components of family-centered practice (<i>parent comfort</i> and <i>autonomy</i>) are significantly associated with parent stress, but there was no significant association between parenting competence and family-centered practice
Drummond, Looman, & Phillips (2012)	Retrospective descriptive (2007 National Survey of Children's Health)	Sample of 18,352 CYSHCN in the NSCH	Coordination among providers and between family and providers; Family centered care; Information integration and exchange	Parent coping; Parent satisfaction; Process of health care	Parents of CYSHCN in a health care home were more likely to be coping well; parents who received adequate CC were more satisfied with provider communication; family-centered care is associated with better parent coping
Farmer, Clark, Sherman, Marien, & Selva (2005)	One group pre-/post- survey; chart review	51 parents of CYSHCN in rural areas	Coordination among providers and between family and providers; information integration and exchange; emotional support to parents	Child health service utilization: number and ratings of services; parent satisfaction with services; family functioning and impact of chronic illness on family; parent strain; child functioning; missed days of work and school; program acceptability	There was a statistically significant increase in parent satisfaction with CC and access to mental health services; decreases in family needs, caregiver strain, missed days of work and school, and utilization of ambulatory services. Families of children with complex conditions reported decrease in needs post-intervention
Fields, Coble, Pollack, & Kaufman (1991)	Prospective cohort	28 technology dependent children in 8 hospitals	Service integration across settings; plan of care; transitions	Parent satisfaction, technology dependence, death, care use, care cost	Families prefer home-based care to inpatient care; child outcomes are comparable; community based care and case management is a reasonable alternative to a hospital-based model
Friedman, Howard, Shaw, Cohen, Shahidi, & Ferrante (2016)	Qualitative: online discussion forum	25 care coordinators	Relationships; Information technology; Resources; Coordination among providers and between family and providers	Barriers and facilitators to implementing pediatric care coordination from care coordinators' perspectives	Relationship building is key to effective CC
Holm, Patterson, & Gurney,	Cross-sectional, Qualitative: focus groups	45 parents of 26 children with cancer	Family centered approach; Shared decision making	Parent advocacy: Advocacy subthemes during	Parents emphasized their roles as advocates during the diagnosis and treatment phases by

Table 2 Continued

(2003)				diagnosis: <i>seeking</i> and <i>persisting</i> ; Advocacy subthemes during treatment: <i>informing</i> , <i>deciding</i> , <i>limiting</i> , and <i>affirming</i>	informing themselves, making medical care decisions, limiting the actions of medical professionals, and affirming and supporting medical professionals
Hummelinck & Pollack (2005)	Cross-sectional; Qualitative: interviews	27 parents of chronically ill children	Communication among professionals and families	Parents information needs and preferences over course of chronic illness	Parents of chronically ill children have complex and varied information needs that are not always understood by professionals
Jackson, Baird, Davis- Reynolds, Smith, Blackburn, & Allsebrook (2008)	Longitudinal; Qualitative: focus groups and interview	10 parents (9 mothers) of children with health care needs	Information exchange; Shared decision making; Relationships	Parent preference of delivery of information; Parent perceived level of support; Relationship between family and professional; Management of events	Verbal, one-on-one delivery of information between a parent and a professional is most effective, in conjunction with written general and child- specific materials; Parents value having direct contact information for professionals; Good communication channels impact relationships between families and professional
Liptak, Burns, Davidson, & McAnarney(1998)	Retrospective descriptive	10,715 children with ICD-defined chronic illness	Case-management and wraparound services across settings	Parent satisfaction, parent missed work, care use, care costs	Over 11 years, mean length of hospital stay decreased, hospital inpatient charges decreased, and a \$78 million savings occurred for inpatient care; almost half of services were not reimbursed in a fee for service model; an investment of funds by a regional insurance company was associated with reduced costs, admissions and lengths of stays that resulted in overall savings for the company
Palfrey, Sofis, Davidson, Liu, Freeman & Ganz (2004)	Prospective cohort	150 children with chronic conditions	Pediatric nurse practitioners, modification of usual pediatric care, plan of care, referrals, communication, service integration across settings	Parent satisfaction, parent work days missed, care use, care costs	Coordinated care made numerous aspects of service delivery easier for families; there was a statistically significant difference in parents' missed work and in child hospitalizations; approximate cost of the program per child per year was \$400
(Pless et al., 1994)	Randomized prospective clinical trial	332 children receiving care in specialty clinics	Care management, family centered care, referrals, communication across settings	Psychosocial functioning	Statistically significant differences on anxiety, depression, and in scholastic competence, behavior, and self- worth

Table 2 Continued

					The intervention prevented or reduced maladjustment; nurses have the skills to implement the program; only a modest investment by pediatric practices is needed
Rahi, Manaras, Tuomainen, & Lweando Hundt (2004)	Two group pre-post; mixed methods: survey and interviews	143 families of children with visual impairment	Family centeredness; Information exchange; Relationships	Family centeredness; Parent satisfaction	Parents' needs during diagnosis are for information, emotional support from professionals, and for informal and formal social networks and support groups; A "key worker" model is one effective strategy of coordinating care for this population
Resendez, Quist, & Matshazi (2000)	Longitudinal; Secondary data analysis	2314 parents or caregivers of children who had received mental health services		Parent empowerment; Parent satisfaction; Child mental health outcomes at intake and discharge	Child mental health is significantly correlated with parent satisfaction, all four FES subscales, child age, gender, and parent education level Caregiver empowerment is related to child's mental health; child mental health scores at intake are related to caregiver knowledge, competency, self-efficacy at intake; Caregiver competency at intake was related to child mental health at discharge; Caregiver empowerment is positively correlated to satisfaction with services; Child's age is associated with caregiver empowerment, caregiver satisfaction, and child mental health
Stille, Fischer, La Pelle, Dworetzky, Mazor, & Cooley (2013)	Qualitative (focus groups)	19 Parents of CYSHCN and 23 clinicians	Shared decision-making; Coordination among providers and between family and providers; Plan of care	Parent-clinician partnership, information sharing and shared decision making	Parents and clinicians supported information sharing and working partnerships; a plan of care is an important parent engagement tool; parents need more information to participate in shared-decision making; clinicians feel time pressure to provide coordinated and family-centered care
Turchi, Berhane, Pomponio, Antonelli, & Minkovitz (2009)	Retrospective descriptive (2005-2006 National Survey of Children with Special Health Care Needs)		Family centered care; Communication; Relationships	Parental satisfaction; Perceived adequacy of CC received; Perceived family-centeredness of care; Perceived partnerships with	Statistically significant results for increased odds of receiving family-centered care, partnerships with professionals, and satisfaction; decreased odds of referral problems, ED use, and missed school

Table 2 Continued

				professionals; Child and family outcomes	
Van Cleave, Boudreau, McAllister, Cooley, Maxwell, & Kuhlthau (2015)	Mixed-method convergent parallel design using interviews, practice self- assessment, and medical record review	48 clinicians, parents, and care coordinator s& chart review of 60 - - -	Coordination among providers and between family and providers; Plan of care Relationships, Monitoring referrals and completion	Items on Care Coordination Measurement Tool©; CC activities and processes from family and clinician perspectives	In high-performing medical homes, CC activities become systematically proactive and comprehensive
Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki (2015)	Cross-sectional; Stratified random sample, survey	955 parents of children aged 0-9	Shared decision making	Parental empowerment Parent attending appointment Parent involvement in decision making Parent perceived influence on last appointment Parent perceived influence on provision of family services	Parental empowerment on the family subscale was high The study showed that sufficient perceived influence and joint decision making on family service appointments were positively associated with parents' sense of how they are able to manage in their everyday life and to exercise influence on the series used by their child Mothers' perceived influence on their children's last appointment and access to information about family services were significant predictors of maternal empowerment Because parents' resources and families' wellbeing are strongly related, professionals can significantly contribute to reinforcing children's and families' wellbeing Access to adequate information and resources is positively associated with related to empowerment

2.5 CONCLUSIONS

The key aspects of CC that emerged from the literature and how they are associated with family empowerment are described in detail below.

Provider-Family Relationships

Qualitative research with care coordinators revealed that relationship-building between the care coordinator and families, or care coordinator and other providers, was considered essential to effective CC (Friedman et al., 2016). Other research has determined that efficiency and effectiveness in CC is dependent on several characteristics of the parent-professional relationship, specifically the “match” between the parent and provider and the intensity of the CC services the family receives (Looman et al., 2013). In an empowerment framework, professionals can use their partnerships with families to help families see the association between their actions and subsequent outcomes that improve their health or life situations (Koelen & Lindström, 2005). More specific research on this issue is needed to explore the role professionals play in parent participation in the child’s treatment and overall feelings of empowerment. Resendez et al. (2000) conclude it may be that the relationship between the professional and the family is the mediator between empowerment and child outcomes. A positive and reciprocal relationship with professionals would increase the parent’s sense of involvement and support received, and would improve empowerment by encouraging the parent to actively participate in the child’s treatment and care. This would increase satisfaction with care received, feelings of empowerment, and child outcomes. The Vanderbilt Family Empowerment Project Model (Heflinger, Bickman, Northrup, & Sonnichsen, 1997) predicts that this relationship and parental involvement will lead to positive parent and child outcomes (Resendez et al., 2000).

Family-centered theory says the manner in which support is provided can either enhance or impede the intended outcomes of the support (Dempsey et al., 2009). That is, *how* professionals assist families matters as much as *what* type of assistance is provided, and that

professionals can be a source of emotional support to parents. The factors of effective “help-giving” are relationship building, communication, honesty and clarity, understanding of families’ concerns, and responsiveness to family values and goals. Care coordinators’ actions such as spending time with families, listening, showing openness, and discussion build parent-professional relationships (Sloper, 1999).

Parents reported the greatest value of having a key worker was having someone to turn to whenever they needed help (Sloper, 1999). Dempsey et al. looked at the associations between parent-centered support, parent stress and competence in population of parents with children with disabilities and found there is are significant associations between parent stress and comfort, and parent stress and autonomy. Surprisingly, higher stress was related to higher self-reported autonomy, which the authors hypothesize may be due to an imbalance of power and support between the parent and professional, instead of shared responsibility that is known to reduce parent stress (Dempsey et al., 2009).

Family-Centered Care Practices

Family-centered care has been defined as a philosophy of care where families are supported in their decision-making roles in an equal partnership with professionals (Pickering & Busse, 2010). Family-centered care is fundamental in a coordinated and effective health care system for CMC. In this framework, the child’s primary support system is the family (Kuo & Houtrow, 2016). The framework for family-centered health care was first developed by the Picker Commonwealth program. This work went beyond patient satisfaction that was used at the time, to look at a patient’s experience of health care. The Picker Institute identified and validated eight dimensions of family-centered care: emotional support and alleviation of fear and anxiety;

coordination and integration of care; involvement of family and friends; respect for patients' values, preferences, and expressed, needs; access to care; information and education; physical comfort; and continuity and transition (Byczkowski et al., 2016; "Picker Institute. The eight Picker principle of patient-centered care.," n.d.). Care coordinators use family-centered practices such as building positive relationship with families, encouraging family participation and shared-decision making, coaching for family skill and knowledge acquisition, and sharing information and resources to strengthen family support networks (Dempsey & Dunst, 2004).

Family systems theory posits a whole-family approach that is focused on strengthening family functioning, commitment to family participation in decision making and family choice, and balanced parent-professional relationships. While more providers are moving towards a family-centered approach, the evidence linking it to family outcomes is relatively limited, and has primarily focused on reduced parent stress and increased parent competence. Dempsey et al. (2009) provide a good summary of this literature. There is surprisingly little research on the relationship between specific practices of CC providers and parent stress or competence. Most studies focus on parent stress and have found no associations or only a moderate relationship between stress and competence. Despite the centrality of parenting competence as an outcome in family-centered practice, there is limited evidence of a connection between family-centered practice and competence, or between these concepts and improved child outcomes (Dempsey et al., 2009). Drummond et al. found maternal stress was lower when mothers felt they received family centered care measured through adequate time, provider respect for their child, quality of care, and their family culture was valued. Mothers were also more likely to seek out assistance from providers when they felt they had a family-centered relationship with them, suggesting that

family centered care and care coordination are associated with family satisfaction and effective coping strategies by families (Drummond et al., 2012).

Holmstrom and Roing (2010) discuss the relationship of the complementary concepts of patient-centeredness and patient empowerment through the lens of the relationships between patients and healthcare providers. A focus on patient centered care may place additional demands on health care professionals. Patient centeredness is defined by several characteristics. One, the professional pays attention to the biological, psychological, and social aspects of patients' health. Two, the professional understands that illness has a personal meaning for each patient and views the patient as a person. Three, the patient and professional share power and responsibility, and to that end, the professional is respectful of the patient's need for information and shared decision-making. Four, there is a therapeutic alliance between the professional and patient in which common goals are developed and a relationship is built. Five, there is a recognition that the professional is also a person, and that the professional's personal qualities may influence his/her practice of healthcare (Holmström & Röing, 2010). Patient centeredness is a goal of an encounter between a patient and a professional and a valuable part of the process of patient empowerment. However, patients may also become empowered without professional assistance. Empowerment is broader than patient-centered practices.

Dempsey argues satisfaction with support, parent self-reported personal control, and parent self-efficacy are hypothesized mediators between family-centered practices and parent outcomes like competence (Dempsey et al., 2009). Care coordinators may apply family-centered practices to explore the patient's illness experience and the effects of the illness on the family. They strive to understand the patient as whole person, within the context of the family unit. Then, they attempt to find common ground regarding approaches to prevention, health

promotion, maintenance, and treatment and use this to improve the patient/family – provider relationship. Holmstrom and Roing (2010) identify activities that lead to patient-centered care and family empowerment, many of which overlap with key activities of care coordination:

- Sharing power between patient and provider
- Sharing responsibility
- Personal involvement and partnership (mutual respect and trust) between patient and provider
- Professional has respect for patient/s beliefs, characteristics, etc.
- Motivation by patient
- Professional surrenders need for control/can be observer
- Professional elicits and acknowledges patient beliefs, priorities and fears
- Professional reinforces psychosocial skills in patients, providers' resources, skills and opportunities for patient to develop a sense of control
- Professional encourages patient to reflect on experiences and successes
- Professional provides patients with info regarding diagnosis, treatment, prognosis
- Professional provides education, resources, decision aids, tools to be self-reflective, etc.

The trend toward patient- and family-centeredness and away from health care providers as experts is relatively recent but one that is embraced in CC. Increasingly, patients are being viewed as experts in their own health, as partners with providers, and their rights and responsibilities within health care are being recognized. Firsthand knowledge is viewed as necessary for treatment to be successful. Patient-centeredness improves the professional's understanding of the patient and allows him or her to see the patient's illness experiences through the patient's eyes (Holmström & Röing, 2010). In a pediatric setting, patient involvement may be limited due to the child's age or developmental ability so parent- or family-centeredness becomes the focus, but strives to include the child directly to the extent possible.

Shared Decision-Making

In the literature, shared-decision making is often a component of patient-/family-centered care and one outcome of following a plan of care. Shared-decision making during the health care experience should be personalized and tailored to families' needs and preferences (Zanello et al., 2015). Joint treatment decision-making among families - and children when possible - and professionals is one way families have become empowered (Resendez et al., 2000). Mothers of CMC reported feeling less empowered in situations where decisions were made by professionals alone. Specifically, the mothers' perceived influence on their children's last appointment and access to information about family services were significant predictors of maternal empowerment (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015). Other research has shown that sense of control and active problem-solving skills are related to lower parental stress (Sloper, 1999).

Family involvement is important to empowerment because it is a way that parents experience control in a situation where otherwise they may feel helpless. Advocacy is a primary way parents are involved in their children's care. Parents (of children with cancer) emphasized the importance of their advocate role during the diagnosis and treatment phases by informing themselves about their children's conditions, being involved in making medical care decisions, and affirming and supporting medical professionals. In parent focus groups, Holm et al. found six themes of parental advocacy: seeking and persisting (in the diagnosis phase), and informing, deciding, limiting, and affirming (in the treatment phase). As advocates, the parent role is to make critical decisions, convey the child's feelings and experiences to professionals, be an important member of child's medical team, and be a source of continuity by monitoring all

aspects of the child's situation and the little changes that professionals may not notice (Holm, Patterson, & Gurney, 2003).

Resources and family wellbeing are strongly related. Research shows that access to adequate information about family services is positively associated with all dimensions of maternal and paternal empowerment, so simply having knowledge about existing resources may increase parent capacity to manage family life. When families have knowledge, they are more equipped to access help directly, suggesting that CC can facilitate initial knowledge acquisition that may lead to empowerment through direct parent access later. Therefore, professionals can support family empowerment by promoting joint decision-making, parent advocacy, providing information, and facilitating greater family influence over service participation. Emphasizing the parent's primary role as family decision-maker and the one responsible for the child's care, reinforces the parent's significance. That includes facilitating access to information, creating a space for parents to share opinions, providing time to process and discuss information, and supporting the family role in decision-making in the presence of other providers (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015).

Parent-provider shared decision-making is an emerging force in pediatrics, but most interventions to promote it have not been rigorously studied. There is limited evidence that these techniques improve parent knowledge and decrease decisional conflict. Of note, most shared-decision making interventions have targeted parents rather than pediatric patients directly (Wyatt et al., 2015), again suggesting that the parent is a mediator between CC and patient outcomes.

Assessment and the Plan of Care

For CMC, care plans can be the foundation of the partnership between families and providers, and among providers, because the shared plan facilitates the implementation of key functions of the medical home model such as comprehensive care coordination, communication between families and providers, and family-centered care (Wirth & Kuznetsov, 2016). The development of a plan of care usually involves an initial assessment of the child's and family's strengths and health, educational, and psychosocial needs; building essential partnerships with providers involved in the plan; creating the plan of care; and implementing the plan (McAllister, 2014). Then the plan should be developed collaboratively by families and providers and maintained and implemented by the provider responsible for overall care coordination (Kuo & Houtrow, 2016). The process of creating the shared plan of care is as important as what it contains because, when done well, the process is an act of an effective family-professional partnership.

Ideally, the care plan is a dynamic document that is updated regularly and available electronically in real time to all parties who need to access the family's information (Kuo & Houtrow, 2016; Wirth & Kuznetsov, 2016). McAllister's principles for the successful use of shared plan of care include:

- Children and families are actively engaged in care.
- Communication among all care team members, and with families, is clear, regular, and timely.
- Care team members have a full understanding of child and family needs, strengths, history, and preferences, and use this understanding to guide assessments.
- Readily accessible information guides shared decision-making.
- Care team members follow a plan of care that includes shared goals and negotiated actions, and all team members understand their roles and responsibilities.
- Progress is monitored against the plans' goals, which are adjusted regularly to ensure the plan is implemented effectively.

- Care team members anticipate and prepare for all transitions.
- The plan of care is a shared document that is acknowledged and used consistently by every provider.
- Care is coordination across all involved organizations and systems (McAllister, 2014, page 3).

Wirth and Kuznetsov describe ten steps to creating an effective shared plan of care, which largely overlap the principals of successful use of a shared plan of care development by McAllister, with the addition of the following: identify who will benefit from having a care plan, and discuss with families and colleagues the value of developing and using a shared plan of care (Wirth & Kuznetsov, 2016).

A *shared* plan of care is different from a traditional care plan that is typically developed by a clinician *for* a patient. The American Academy of Pediatrics describes a shared plan of care as being created and implemented with input from all members of the care team, including health, education and social service providers, and most importantly the family and patient themselves (Medical Home Resident Education Initiative Work Group of the AAP, 2015). The shared plan of care should lead to improved quality of care, care coordination, continuity of care, efficient and timely care, safety, caregiver health and wellbeing, and patient- and family-centered care (Adams et al., 2013). Research shows that a shared plan of care can lead to improved family-provider relationships, support the provision of family-centered care, and provide information that enhances the planning of delivery of social and health care services that meet the medical needs of CMC and their families (Wirth & Kuznetsov, 2016).

Information and Resources

Parents of CMC need vast amounts of information on condition, prognoses, services, financial and material supports, and practical help with day-to-day living. Access barriers to

needed services and information are sources of stress for parents while information seeking is a coping mechanism (Jackson et al., 2008). Material, social and personal resources have all been shown to be strongly related to parental wellbeing (Sloper, 1999). Yet, generally, families are only aware of services with which they have already been in direct contact. This limited exposure or viewpoint constrains the comprehensive care children can receive. Families often need someone like a care coordinator to bring to their attention other available services and resources and help them gain access. Ethnographic research describes this role as expanding families' horizons of knowledge to encompass existing supports (*Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An ethnographic approach*, 2012).

No doubt, parents of chronically ill children have variable information and resource needs based on their unique situations. However, on the whole, research shows that parents seek a considerable amount of information on their children's conditions, management plans, and prognoses. Health care professionals do not always understand or appreciate a family's need for information, therefore these findings highlight the importance of good communication between families and their health care providers (Hummelinck & Pollock, 2006). Focus groups of parents of children with unmet health care needs identified the importance of being consulted about the care of their children, the interaction between the health care provider and the child, and being treated as an individual by the health care provider. Parents seek normality, certainty, and partnership with health care providers. Parents will do extensive independent seeking of information when their information needs are not met by professionals. Information sharing meets psychosocial and practical needs of families. Parents value an open-door policy with health care providers and are receptive to information received one-on-one (Jackson et al., 2008).

As parents gain lived experience, parents' information needs change with their confidence in dealing with their child's condition, and administering his/her treatment on a day-to-day basis. Hummelinck states these factors are indirectly linked to the length of time since diagnosis and the stage of the child's illness. As experience and confidence increases, parents tend to require less information from external supports (Hummelinck & Pollock, 2006).

Family empowerment may be built or increased through access to knowledge, skills, and resources that assist families to improve perceived control of their lives (Singh, Curtis, Ellis, Nicholson, Villani, & Wechsler, 1995). Knowledge has been found to be significantly correlated with family involvement and family involvement is associated with family empowerment (Curtis & Singh, 1996).

As noted earlier, chronic conditions may cause more physical and psychological stress on families than shorter-term acute illnesses (Juster & McEwen, 2010; Marin et al., 2009). Each phase of a chronic condition - diagnosis, treatment, recovery, relapse, and survival - brings different challenges and stressors for children and their families (Compas et al., 2012). The timing of care coordination received during the illness experience may also be significant for family empowerment. For example, during the highly uncertain phase of initial diagnosis, considerable support and information are often needed. At this time good communication between medical professionals and the family is critical; and families feel a need to develop a "therapeutic alliance" between professionals and families (Holm, Patterson, & Gurney, 2003). They need information, resources, emotional support from professionals, and information about connecting with informal support networks like parent groups (Rahi, Manaras, Tuomainen, & Hundt, 2004). At this early stage, families may need assistance to define their role (Holm, Patterson, & Gurney, 2003). When children are hospitalized, parents described feeling that being

with their child was an unconditional aspect of being a parent. While they had a strong desire for participation in the child's care at this phase, parents had significant need for good communication with health care providers and emotional support (Lam, Chang, & Morrissey, 2006).

After the initial period of intensive support, a family may have less need for information and resources as they enter the maintenance phase of the chronic illness. Need may intensify at a later point as the child's situation changes or the family encounters new situations or challenges. Some families do not have access to CC at the time of initial diagnosis because CC is often first offered when the child transitions from inpatient to home- or community-based care. This transition point is also a time of significant information and resource needs for parents, as now the family must re-adjust to care in a different setting, and is likely to be assuming greater responsibility for the child's direct care and care management.

Regardless of the illness lifecycle stage, parents' need for information and resources are recognized in the family-centered care approach used by CC (Holm, Patterson, & Gurney, 2003).

Information Integration and Sharing

A Finnish research team reviewed the literature on CC activities such as increasing access to information, provider-family collaboration, the nature of the parent-professional relationship, the balance of power between the provider and family, and a shared plan of care. They found that fragmented and duplicative social services hinder health care professionals' abilities to provide families with sufficient information about available services and how to access them. Service coordination is essential across systems and services to: ensure families have accurate and timely information, improve early identification and response to problems as

they arise, support families' knowledge of services, and facilitate empowerment. This speaks to the need for a dedicated and experienced care coordinator beyond a medical professional who can only perform these functions in a limited way (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015). Utilizing health information technology, such as electronic health records, is one way to promote accurate and timely information sharing. These records are especially helpful if they are easily accessible and understandable for families.

Transitions and Continuity of Care

Continuity of care (CoC) is often the goal of transition planning and management for CMC. Ethnographic work with families of chronically ill children shows that a family's needs and resources are often misaligned, particularly during transitions such as hospital discharge or aging out of pediatric services (*Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An ethnographic approach*, 2012). Zanello conducted qualitative research with parents to describe three types of CoC – informational, management, and relational - and relates each to family empowerment. Informational CoC refers to using information from past experiences to make current care appropriate for a patient. Management CoC is using a consistent and coherent approach to managing a chronic health condition in a way that is responsive to a patient's changing needs. Finally, relational CoC is the ongoing therapeutic relationship between patients and providers that should bridge current care and future care needs. In this study, empowerment was a process aimed at increasing parents' ability to care for their children, beginning at the time of the child's hospital stay, when professional caregivers provided information and training to parents. This process continues through discharge into home-based care, when professionals teach parents how

to manage their child's condition at home. However, only about half of parents felt this process continued after discharge. Parents described differing needs for the types of continuity of care, and reported variable amounts of support received during transitions (Zanello et al., 2015).

These studies highlight that the existing system of care provides limited breadth of services for children with complex needs. Services are fragmented and there are limited efforts to integrate them (*Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An ethnographic approach*, 2012).

Communication

Communication among all involved parties is a major theme that runs throughout every other key aspect of CC. Markers of high quality family-provider relationships are frequent, open, and trusted communication (Hummelinck & Pollock, 2006). Communication is also critical to developing an accurate and useful plan of care and for knowledge- and resource-sharing between providers and families during the CC relationship. A care coordinator's primary tasks include facilitating communication among parties, which necessitates strong communication skills and good record keeping to manage and integrate numerous sources of information, coordinate referrals and test results, and maintain a holistic picture of a family's needs and assets (Stille et al., 2013). As noted, to ensure continuity of care, open communication is essential between families and providers and among providers, particularly during times of transition.

In summary, each key aspect of CC offers strategies and approaches for care coordinators to build family empowerment. Some of these strategies are direct, such as increasing families' knowledge of resources or working together to create a shared plan of care. Others are indirect,

such as facilitating information-sharing among providers or modeling the advocate role for families. While the specific strategies a care coordinator uses will depend on each family's needs, assets, and situation, all care coordinators are likely to follow the patient-/family-centered care approach described and attempt to implement these key aspects of CC to some degree in their relationships with families.

2.6 DISCUSSION

It is challenging to draw comparisons among existing studies of CC and conclusions about effectiveness are influenced by the variability in what exactly is being implemented under the term care coordination, the nature of the client population, the quality and intensity of implementation, and how key outcomes are measured. Empirical evidence linking specific CC activities to child outcomes is very limited but research suggests that CC can be implemented in a cost-effective way in pediatric settings and lead to reductions in outcomes such as hospitalizations and length of stay, emergency department use, unnecessary health care use, and missed days of work and school. These outcomes may be especially significant for families with psychosocial challenges in addition to a child with medical complexity.

The evidence is stronger between CC activities and intermediate outcomes such as reduction in parent stress, and increase in parent comfort, autonomy, and knowledge – all of which can be necessary components of empowerment. There are also indicators that CC improves the patient and family experience of health care, including family satisfaction, receipt of timely services, and reduced duplication. The review of the literature suggests that the most important aspects of CC are the patient- and family-centered approach that is driven by a holistic

picture of family needs, assets, and service use across settings; partnership-building with families and among providers; proactive planning; and open communication and information-sharing across service settings.

In pediatric populations with special health care needs it can be especially challenging to assess patient experiences directly due to age or developmental stage. In pediatric care coordination much of the “work” of care coordinators is done with families, as the primary decision-makers and managers of care. Therefore, it may be more realistic to expect to see impacts of CC at the level of the parent or family, rather than on child health outcomes.

Qualitative research exploring the meaning of CC and how families use it can be illuminating for those attempting to design and implement, or evaluate, pediatric CC for CMC. Qualitative research can be especially valuable to understand 1). How a care coordination program is implemented, and 2). The family experience of raising a child with medical complexity, the family experience in health services, and the perceived value of CC. For the family, much of the value, such as logistical and emotional support, may be difficult to measure quantitatively. Families also receive variable amounts of support and intervention from CC. Some of this is due to family need and preference, the skill of the care coordinator, or the “fit” between the family and care coordinator. A systematic description of the nature and intensity of a CC program compared to family experiences would be especially helpful.

2.7 LIMITATIONS AND FUTURE RESEARCH

This literature review was intended to be a broad scan of numerous issues related to care coordination, children with medical complexity, and family empowerment, to provide sufficient

background upon which to evaluate the pilot care coordination program at the Children's Institute. Therefore, methodological limitations include the use of only one database and limited search terms. A systematic literature review using additional databases and clearly defined search and inclusion criteria would be an ideal next step to thoroughly explore family empowerment in relation to care coordination for children with medical complexity.

3.0 CHAPTER THREE: MANUSCRIPT TWO: IMPLEMENTATION EVALUATION OF CARE COORDINATION AT THE CHILDREN'S INSTITUTE

3.1 ABSTRACT

This paper presents the results of an implementation evaluation examining the implementation of a pilot pediatric care coordination program for children with medical complexity at the Children's Institute in Pittsburgh, Pennsylvania. Established care coordination policies and procedures and other documents from the Children's Institute are used to describe key elements of the model as it was intended. Then, administrative data are used to describe the program participants by age, gender, and acuity, and the actual implementation of the model on key indicators, including: acuity rating trends over time, staff-family contacts, purpose of contact, method of contact, type of staff, and staff time. Finally, the results of a survey measuring family-centered care and satisfaction are presented. Overall, the care coordination population is young, male, and high-risk. During the analysis period, over half of participants reduced their acuity, suggesting they were stabilized over time. As expected, higher acuity families had more contact with care coordinators and spent more time engaged in those contacts. Most care coordination contacts were conducted by telephone and focused on outreach and engagement, with health coaches logging the greatest number of hours in contact with families. Compared to lower acuity families, higher acuity families spent more time in contact with a care coordinator or social

worker. Participants rated the care coordination services they received as highly family-centered, with a mean score of 33 out of a possible 36. Nearly all (94%) survey respondents were mostly or very satisfied. Collectively, these data indicate that the care coordination program at the Children’s Institute is being implemented following the principles of patient- and family-centered care, and following the established policies guiding contact with families by acuity level. This study is useful for practitioners designing or implementing a pediatric care coordination program with this population because there are few studies in the literature that describe or measure implementation or attempt to link implementation to outcomes.

3.2 INTRODUCTION

Care Coordination at the Children's Institute

The Children’s Institute (CI) care coordination program for children with medical complexity is guided by the Agency for Healthcare Research and Quality framework of CC as the “deliberate organization of patient care activities between two or more participants involved in a patient’s care to facilitate the appropriate delivery of health care services.” CC considers medical, social, developmental, behavioral, education and financial needs to improve overall health and wellness (<http://www.ahrq.gov/>). The CC program is described as a family-centered coordination service for children and families from 23 counties in Western Pennsylvania who are referred by medical providers who are affiliated with the Children’s Institute, nonaffiliated providers, or families. Children do not need to receive services at CI to participate in CC and services are free to participants. CC provides family-centered

care through a respectful family-professional partnership acknowledging the strengths, cultures, traditions, and expertise that all partners bring to the relationship.

There are several desired outcomes of CC. The first is to improve health outcomes for patients and families. This includes increasing quality and efficiency of healthcare, managing care transitions, and increasing compliance for needed treatments. The second outcome is to improve the quality of life for participants. Indicators of importance here are family satisfaction with services, reduced stress on the family, and addressing their psychosocial and material needs. Finally, CC aims to reduce overall healthcare costs by promoting lower cost services over expensive ones such as emergency department utilization, reducing missed appointments, and reducing the family's missed days of work and school. These outcomes are the desired results of the CC implementing these stated objectives of the CC program: 1). Implement a non-medical home model¹ for family-centered care; 2). Improve health and quality outcomes for medically complex children, and 3). Empower and strengthen families as advocates for their children. Family centered care assures the health and wellbeing of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services.

CC focuses on children with medical complexity, and was defined in a previous section. If the support needs of children are conceived as a pyramid-shaped hierarchy, care coordination would appear at the top, as a method to address the needs of the most complex patients who have multiple ongoing medical and social challenges but who are few in number.

¹ The Children's Institute does not operate as a Primary Care Provider, therefore it is not considered a medical home

The Care Coordination program at the Children’s Institute (CI) is designed for children and youth from birth to age 22 with medical complexity, which is defined as those having one of the following: “A severe primary condition in one body system that is more likely to cause significant long lasting health impairment, significant chronic condition in two or more body systems, progressive or life-limiting chronic conditions, or conditions requiring dependence on technology” (Sarneso, A., Randolph, J., & Fallica, 2015).

The pilot CC program at CI began enrolling families on July 1, 2014 but stopped taking new referrals on July 15th, 2016, when the eligibility requirements for the program changed. After July 15, 2016 the CC program only enrolled children in child welfare and infants with neonatal abstinence syndrome. This change was due to the end of private foundation funding that supported CC with the original eligibility requirements and the need to identify other, sustainable funding sources. The families enrolled in CC at the time of the change, who did not meet the new eligibility requirements, were notified of the change and transitioned out of CC by December, 2016.

During the pilot phase, over 600 families had been referred to CC and 364 were served over the two-year program period. About 73% of the referrals to the CC program came from inpatient or outpatient sources associated with the specialty hospital in which CC is situated; however, referrals came from any medical provider (15%) in the participating 23 counties, and families (12%) also referred themselves directly. The majority of enrolled families have Medicaid or medical assistance (UPMC For You 35%; Gateway 19%) (*Demographics of the Care Coordination Program*, 2016).

Of the 364 children served, 64% were male and 36% female. The age breakdown of children is shown in Table 3 and a summary of the most common primary diagnoses of participation children is presented in Table 4.

Table 3. Ages of Care Coordination Participants

Age of Participants (n=364)	
Age Range (years)	Number (%)
< 5	109 (30)
5 – 9	108 (30)
10 – 15	101 (28)
16 +	46 (12)

Table 4. Primary Diagnosis by Prevalence

Primary Diagnosis (n=364)	
Diagnosis	Number (%)
Autism Spectrum Disorder	76 (21)
Genetic Disorder	58 (16)
Acquired Brain Injury	52 (14)
Functional Feeding	38 (10)
Other	29 (9)
Cerebral Palsy	23 (7)
Pain	21 (6)
Developmental Delays	20 (6)
Neurological	16 (4)
Epilepsy/Seizure	13 (3)
Obesity	9 (2)
Spinal Cord Injury	9 (2)

Of the 23 counties included in the CC catchment area, the team received referrals from 19. Based on discharge data from 317 families, about 62% of participants resided in Allegheny County. The next most common counties of residence were Westmoreland (18%), Butler (3%), and Washington (3%) (*Demographics of the Care Coordination Program, 2016*).

The Care Coordination Team

The CC staff includes a physician consultant, 2-3 care coordinators, 3-4 health coaches, one social worker, the director of the program, an education advocate, and an administrative assistant, all working in partnership with enrolled families and their specific medical and supportive service providers. Each CC team member plays a role in ensuring families receive needed supports and services in a timely manner. These qualifications and roles are described in CI policy documents, and are summarized below.

Care Coordinator

The care coordinator is an experienced Registered Nurse. Her main duties are to complete and update comprehensive medical and psychosocial assessment of families, develop and maintain the family-centered plan of care with goals and expectations, maintain ongoing partnership with each family's care providers, and facilitate communication between home health providers and families. The care coordinator also supports the family and its providers to implement clinical interventions and monitors changing needs to update and modify the plan of care accordingly. The care coordinator takes primary responsibility for:

- Supporting each patient's self-management goals to promote the patient/family to the highest level of wellness possible.
- Facilitating productive communication between patients' families and health care providers.
- Developing and implementing systems of care that facilitate close monitoring of high-risk members to prevent and/or provide timely interventions which may minimize acute condition exacerbations.
- Coordinating and continually evaluating laboratory results, diagnostic tests, utilization patterns and other metrics to monitor quality and efficiency results for assigned population.
- Managing partnerships with primary care providers to enhance evidence-based clinical guideline adherence promoting best practice by initiating/adjusting therapies as directed by the practitioner and providing appropriate following up and monitoring.
- Fostering strong professional relationships with members of each patient's medical neighborhood to facilitate the coordination of care and ensure quality

services/products are received in the most cost effective manner. Identify and linking patient to appropriate community resources.

- Maintaining required documentation for all care coordination activities, collecting required data, and utilizing this data to adjust the treatment plan when indicated.

Health Coach

The health coach is a bachelor's level professional who focuses on providing individual patient and family monitoring by conducting ongoing reviews of each family's medical, social, educational, legal and general needs; promoting healthy lifestyle changes and identifying potential barriers; serving as the patient and family advocate; assisting with the development of goals to decrease caregiver stress; and promoting independence, empowerment, and positive self-care in families. The health coach also tracks patient and family data in the care coordination database, highlighting areas of concern to the care coordinator. The health coach is responsible for maintaining a knowledge of community-based health, rehabilitation, and early intervention resources.

Social Worker

The social worker is a master's level licensed social worker whose role is to assess and monitor each family's psychosocial needs, provide social service support to families with indicated needs, and encourage families to be active decision-makers in the services they receive. The social worker reviews each family's stressors and barriers, establishes connections between the family and a wide range of community-based social resources, and coordinates care with community based social service providers to ensure effective service delivery.

The social worker is only involved with families who have psychosocial support needs, which is an estimated 60% of participants. The most common issues addressed by the social worker were: financial stressors, such as a need for utility assistance, durable medical equipment,

and home modifications; and psychosocial resource needs, such as food and housing, transportation and employment (Sarneso, Randolph, & Fallica, 2015).

Tier System

In care coordination, a classification system can be used to identify a family's level of need (McDonald et al., 2014). At CI, a 'Tier Risk Assessment' policy is used to determine the medical and psychosocial acuity of patients and families and defines the level of intervention (i.e. the frequency of contact) a family receives. Using this document as a guide, risks are assessed regularly and tier levels are adjusted according to a family's changing needs and capabilities. This re-assessment and "tiering" is typically done via group discussion during case review meetings with input from each family's care coordinator, health coach, and the CC program supervisor. If applicable, the social worker, education advocate, or medical director may also become involved, and occasionally, outside providers working with the family. Examples of psychosocial risk factors include: parental conflict, limited social supports, transportation barriers, education barriers, housing instability, financial stressors, significant family or patient mental health or medical needs, limited insurance coverage, involvement with child protective services, and substance use in the home. Examples of medical risk factors include: barriers in maintaining medical and therapy services, current or recent inpatient admission, increased medical acuity or poor prognosis, barriers to obtaining medical devices or medications, identified non-adherence with medical plan of care, safety risks, barriers with activities of daily living, and Braden score of less than 13² (Sarneso, Randolph, & Fallica, 2015). The family's tier classification indicates the minimum acceptable frequency of contact between CC staff and the family.

² The Braden Scale is used to determine a patient's risk for developing pressure ulcers and is based on six indicators: sensory perception, moisture, activity, mobility, nutrition, and friction or shear (www.bradenscale.com)

Table 5. Frequency of Contact

Tier Level	Inclusion Criteria	Minimum Frequency of Contact	Frequency of Case Review Meetings
4	3 or more psychosocial OR medical risk factors	Weekly/every other week	Monthly
3	2 psychosocial OR medical risk factors	Monthly	Quarterly
2	1 psychosocial OR medical risk factors	Quarterly	Quarterly
1	0 psychosocial OR medical risk factors	Maintenance	Bi-yearly

The Care Coordination Process

CI's CC process focuses on the following steps: intake referral, assessment, goal setting, care planning, continuous monitoring, and family coaching, which are depicted in their diagram below.

Referral and Outreach

Referrals for eligible children can come from medical providers, service providers, or directly from families for children birth through age 18. After a family is referred, a member of the CC team conducts outreach to the family within 5 business days. This initial contact is where a family receives an overview of the CC program. If the family enrolls, they then provides consent for services, information sharing and data collection. Written procedures are in place for various scenarios: a family is unreachable, the family agrees to services, or the family declines.

Assessment

After the initial outreach, an enrolled family goes through the assessment process where the history, strengths, and needs of the child and family are shared with the CC staff and used to develop a plan for alleviating problems and improving the quality of life for the child and family. Each child in CC will have a comprehensive review conducted during the assessment. This includes past and current medical, psychological, social, and educational functioning, needs and strengths. The team also focuses on the needs of the parent or guardian and family.

CC conducts these assessment interviews in a family-centered and strengths based manner. The child is included when appropriate, and participation is required for children over age 18 who are physically and mentally able. The goal is to elicit parent and child input about what they perceive as strengths, challenges, concerns and wishes for the future. These are directly translated into the plan of care as goals to address the identified problems, challenges and gaps in current services. A key function of CC is facilitating communication among doctor's offices, therapists, school staff, and other service providers.

The assessment interview is completed with a parent or guardian within five days of referral, if possible. Every effort is made to include the child in the interview, when appropriate. For children 18 and older, who are physically and mentally able, it is mandatory to include the child in the interview. CC staff reviews available health records on the child to inform the assessment. The staff requests consent from parents to communicate verbally and in writing with all professional service providers interacting with the family. The assessment is documented in the electronic medical record.

Plan of Care

The CC staff then drafts a Plan of Care (POC). The care coordinator and health coach review the POC and assessment information and assign the family an initial tier level. The draft POC is shared with the family and their ideas are incorporated before the POC is finalized. The POC is shared with the primary care physician's office and contact is established with the other relevant service providers. Finally, the team establishes a method of regular communication among all members of the treating team and the family. Acceptable methods include phone, email, team meetings and written communications. The level of contact between the CC team and the family is guided by the family's tier level.

CC provides ongoing evaluations of the patient's and family's status and adjusts the POC and specific goals accordingly. A family's initial tier rating can be modified when there is a change in patient status warranting it, or during a Case Review meeting when CC staff discuss the case.

Ongoing Monitoring and Re-Assessment

Case reviews are conducted regularly, on a schedule determined by the tier level. Each week the CC team meets to review cases of a certain tier (e.g. tier 4 on Tuesday, tier 3 on Wednesday). All team members attend meetings (Director of Care Coordination, Care Coordinator, Health Coach, Social Worker, and Consulting Physician as applicable). In the meetings, each case is reviewed, updates are provided, any significant changes in need or status are noted, and the team brainstorms how to overcome challenges. The case review ends with the family's tier rating, which, as stated earlier, may either change based on changing status or remain the same. Many families' ratings change often throughout their involvement with CC.

The team social worker is brought in for a social service consult when indicated by psychosocial risk factors in the family situation, either during the initial assessment or later. The social worker will contact the family within 5 days of receiving the referral and reassess the psychosocial risk factors and develop a response plan.

Discharge, Closure, and Follow Up

A family is discharged from CC when one of these criteria are met: Patient has reached age 22; patient/family remains at a tier 1 level for six months; patient/family demonstrates the ability to manage care independently; patient/family declines further involvement; or patient/family disengaged intervention following the completion of the assessment and plan of

care. If a child is transitioning into adult service, specific resources are provided for that transition.

The discharge process is initiated when the care coordinator schedules a discharge review meeting with the family. A discharge summary is completed within one week of that meeting. It is mailed, along with a discharge letter, to the patient/family, their primary care doctors, and other entities serving the family.

At six and twelve weeks post-discharge, the health coach outreaches to the patient/family. The health coach will verify the family has received the discharge summary and inquire about the status of medical recommendations and other resources supporting the family. This information is stored in the family's electronic record at CI.

Cases are also closed when there has been no response from a family for three weeks or when a family chooses to end their involvement in CC. The team will mail a closure letter to the family, which contains instructions for how to re-enroll if they choose.

3.2.1 Exemplary Pediatric Care Coordination Programs

The following exemplary models of care coordination were used as guides when CI created their care coordination program.

Boston Children's Hospital, Boston, Massachusetts

Boston Children's Hospital provides pediatric care coordination and has published a care coordination curriculum and measurement tool. BCH describes care coordination as a patient and family-centered, assessment drive, activity that aims to meet the needs of children and youth while building the family's caregiving capacity. CC focuses on medical, social, developmental, behavioral, educational and financial needs of patients and their families. In the BCH system, the

key care coordination activities identified by BCH include: creating care plans, care tracking, and timely, structured information sharing among all members of the care team, including the patient and family.

A team of experts developed the pediatric care coordination curriculum to support family-centered medical home implementation in medical homes. Their goal was to create a single curriculum that could be adapted to fit local contexts and many pediatric care settings. The tool contains four modules: Building Parent/Family-Centered Care Coordination Through Ongoing Delivery System Design, Care Coordination as a Continuous Partnership, Integrating Care Coordination into Our Everyday Work, and Health-Related Social Service Needs: Strategies to assess and address in the family-center medical home (Antonelli, RC, Browning, DM, Hackett-Hunter, P, McAllister, J, Risko, 2014). The curriculum can be downloaded freely from BHC's website ("Care Coordination Curriculum," 2013).

The Medical Home Care Coordination Measurement Tool© and accompanying Training Manual were developed with support from a US Maternal and Child Health Bureau grant in 2009. The purpose of the tool was to track otherwise non-reimbursable time spent on care coordination activities, by staff type and patient level of acuity. The tool catalogs each CC encounter by documenting patient information including acuity level, the focus of the encounter, CC needs, type of activity (e.g. telephone discussion, chart review), patient outcomes prevented, time spent in the encounter, CC staff completing the encounter. The training manual provides instructions on how to complete the tool. The tool and its application in a study of care coordination costs in six pediatric practices are described in the literature (Antonelli et al., 2008).

Lucile Packard Foundation for Children's Health and Lucille Packard Children's Hospital

The Lucile Packard Foundation is affiliated with the Lucille Packard Children's Hospital and child health programs at Stanford University. There are several ways the foundation and hospital system are connected to care coordination for medically complex children. The hospital offers care coordination liaisons to families in an effort to support patients and their loved ones through a continuum of care, with the goals of reducing and resolving barriers to care and increasing accessibility to needed care. CC liaisons work with social workers, case managers, and housing and transportation coordinators to provide this safety net by offering patients and their families resources and referrals. Information on the program's website describes the liaisons as addressing psychosocial needs such as food, transportation, and housing; enrolling families on public assistance and explaining access to paid Family Medical Leave; solving challenges with insurance; and discharge planning. The program operates under a family-centered care model, which they describe as understanding and respecting each family's unique needs and preferences, partnering with the family as important members of the care team, and providing individualized care.

The foundation's mission is to raise awareness of children's health issues and increase the quality and accessibility of children's health care through leadership and direct investment. In 2009, the foundation undertook a special focus on improving the health care system for children and youth with special health care needs. To start, they convened families, care providers, national thought leaders on CYSHCN, and advocacy groups. Discussion among these groups led to an action agenda for the foundation, which is focused on care coordination, family-centered care, family self-management, financing of care for children with high utilization, and access to pediatric specialty care. In pursuit of these goals, the foundation pilots innovative program and

funding models, facilitates collaboration to improve care coordination, provides trainings for families on how to engage in decision-making and self-management, builds a shared policy agenda among stakeholders, and participates in state and federal policy making for CYSHCN. The foundation also publishes numerous reports and research briefs on issues facing CYSHCN and their families (“Lucile Packard Foundation for Children’s Health Publications,” 2017).

The University Hospitals Rainbow Care Connection at Children’s Hospital

The UH Rainbow Care Connection in Cleveland, Ohio is a model pediatric accountable care organization, funded through a Health Care Innovation grant from the Center for Medicare and Medicaid Innovation for its Physician Extension Team. The Rainbow Care Connection created a physician network that manages the health of over 200,000 Medicaid-enrolled children in northeast Ohio. The goal is to create meaningful relationships across patients, pediatric primary care providers, hospitals, and managed care organizations to drive innovation and achieve better care, better health, and lower costs. The program works to increase PCP adherence to evidence-based national quality measures; improve the care and health of children with complex chronic conditions through an innovative care coordination program; improve access to and coordination of behavioral health services; and decrease unnecessary use of emergency departments and hospitalizations. For patients and families, the program strives to improve quality of outpatient care, increase access to physicians and pediatric behavioral health services, decrease hospitalizations and emergency care use, and improve the functionality and health of children living with complex chronic conditions (“Rainbow Care Connection,” 2017).

The focus on comprehensive care for children with chronic disabilities strives to provide families with a personalized care plan that is shared among PCPs and other providers on the

Physician Extension Team, including a multidisciplinary team of experts. In inpatient and outpatient settings, the team attempts to personalize health care; ease the stress on families and caregivers; address major health, educational and psychosocial needs of families; and maximize the quality of life for patients and their families. The program includes pediatricians, nurse practitioners, nurse coordinators, dietitians, social workers, and family care advocates. The advocates are an innovative feature of the program because they can work with families in their homes, attend medical appointments with and provide support across the continuum of situations families face daily (“Children with Complex Chronic Conditions,” 2017). University Hospitals also has a specialized care coordination program for managing complex pregnancies that provides innovative care for pregnancies that show fetal malformation, prematurity, and maternal conditions that develop before or during pregnancy (“Care Coordination for Complex Pregnancies,” 2017).

3.3 METHODS

Administrative Data Sample

Inclusion criteria for the administrative records review were enrollment in care coordination during the data collection period: July 1, 2014 – April 30, 2016. This period was chosen to maximize the number of families included in the sample from the time the CC program was fully operational until the data was required for analysis. A list of all patients with a CC identification number during this period (n=320) was obtained for administrative data analyses. Data were excluded if a client had been assigned an ID number at enrollment but there was no further data due to inability to contact the client again. If a client was unreachable, he or she would have been

discharged from care coordination. Of the 320, 46 patients had no data except an assigned patient ID, because they had been referred but were never enrolled in the program. These patients were removed, leaving the final sample at 274.

Family Centered Care Survey Sample

During the spring of 2016, a committee of CC staff and CI advisors adapted the Family Centered Care Self-Assessment Tool developed by Family Voices (*Family-Centered Care Self-Assessment Tool*, 2008) to create a brief survey tool (Appendix A) to assess family centered care in CC. A random sample of families, stratified by tier, completed the survey by telephone with a Master's level social work student intern at CI. There were no exclusion criteria except ability to conduct the survey in English. The final sample of families who completed the survey was 63. A detailed table of interview participants is presented in a later section.

Evaluation Goals:

- Describe the key elements of care coordination at the Children's Institute.
- Describe the population that participated in CC.
- Describe the nature and length of contact between CC staff and families generally, and how contact differs by level of acuity.
- Describe population-level changes in acuity during participation in CC.
- Compare contact received to the ideal, based on each family's acuity and established benchmarks.
- Compare parent reported ratings of family-centered care and overall satisfaction to the amount of time in CC and family acuity.

3.4 ANALYSIS

Frequency analyses and cross-tabulations were used to describe the administrative data and all samples. Chi-square tests of independence (Fisher's exact test) and t-tests were used to determine statistical significance between groups on items of the Family-Centered Care Survey.

3.5 RISKS AND BENEFITS

This study presented only minimal risk. All secondary data analyses involved de-identified datasets that did not contain sensitive or protected health information. Both the Children's Institute's Institutional Review Board and the University of Pittsburgh's Human Research Protection office approved these studies.

3.6 RESULTS

Sample Description

Frequency analyses were used to describe the population of children who participated in the CC program by gender, age, and tier. Data on each child's primary diagnosis and enrollment and discharge dates were not permitted to be shared by CI. Data were shared on 274 children enrolled during the period requested. Of these, 181 (66%) were male and 93 (34%) were female. Of the males, about 77% were initially given a high risk tier, that is tier three or four, with 46 (25%) in tier three and 93 (51%) in tier four, initially. Of the females, 71% started in a high risk tier, with 23 (25%) in tier three and 43 in tier four (46%). The distribution of ages at enrollment is summarized in Table 6.

Table 6. Age at Enrollment (n=274)

Age (years)	N	%
< 1	10	3.4
1	5	1.7
2	12	4
3	13	4.4
4	23	7.7
5	28	9.4
6	19	6.4
7	25	8.4
8	13	4.4
9	12	4
10	18	6.1
11	19	6.4
12	10	3.4
13	4	1.3
14	13	4.4
15	11	3.7
16	18	6.1
17	12	4
18	14	4.7
19	10	3.4
20	4	1.3
21	2	0.7
22	2	0.7

Changes in Tier Classification

As described earlier, at enrollment, each family was assigned a tier to represent the family's acuity or risk level, with one being the lowest level of acuity. A family's tier classification could be reassessed and changed based the child's current medical acuity or unmet service needs, family situation, and current psychosocial challenges, or protective elements in the

family. Tier reassessments were made during regular case review meetings or between these meetings if deemed appropriate by the CC staff. Higher tier families’ cases were reviewed more often (monthly or every other month) than lower tiers (quarterly or bi-yearly). Tier ratings changed frequently for some families. Therefore, every family in the program has a unique tier “pattern” over their time in CC.

The data provided by CI show initial tier, highest tier reached, lowest tier reached, and final tier. During the time-period for which data were analyzed, some families were discharged while some remained active; the data do not provide an indicator of status. The “final tier” may be the family’s tier at time of discharge from CC, when it is likely a family “tiered down” to a stable point, or the final tier may be the last recorded tier of an actively enrolled family at the end of the data analysis period. Therefore, last tier is not a reliable indicator of stabilization over time.

In the total sample, 50% of families received an initial tier of four, the highest level of acuity. Another 25% were initially tiered as a three. At the end of the data analysis period, in the total sample, 16% were classified as tier four and 17% as tier three, showing an overall trend of tier reduction across the sample. Table 7 shows the cross-tabulations of first and last tier classifications.

Table 7. First Tier and Last Tier Cross-Tabulation

		Last Tier				Total (% of total sample)
		1	2	3	4	
First Tier	1	15	3	0	0	18 (7%)
	2	26	19	6	0	51 (19%)
	3	23	28	15	3	69 (25%)
	4	20	49	27	40	136 (50%)
Total		84	99	48	43	274
(% of total sample)		(31%)	(36%)	(17%)	(16%)	

Overall, 173 families (63%) in the sample reduced their tier assessment from initial to final tier. Eighty-nine families (32%) had the same tier level at enrollment and final data point. Only 12 families (4%) increased tier level. Of those families who reduced tier, 55% were initially tiered as a four, indicating that those with higher initial tiers were likely to reduce tier over the enrollment period. Of families whose initial and final tiers were the same, 45% were tier four, suggesting that higher acuity families may not have changed tier as often as lower acuity families.

Cross-tabulations were run to describe lowest and highest obtained tier classifications, as shown in Table 8. For 13% of the sample, tier four was the lowest tier ever reached, and tier three the lowest tier reached for another 15%. However, 35% of the sample reached tier one at some point during the data analysis period. About 61% of the sample was classified as tier four at some point, and another 20% at tier three, meaning about 81% of the total families participating in CC had been considered high risk at some point.

Table 8. Lowest Tier and Highest Tier Cross-Tabulation

		Highest Tier				Total (% of total sample)
		1	2	3	4	
Lowest Tier	1	12	27	29	28	96 (35%)
	2	0	13	20	69	102 (37%)
	3	0	0	7	33	40 (15%)
	4	0	0	0	36	36 (13%)
Total		12	40	56	166	274
	(% of total sample)	(4%)	(15%)	(20%)	(61%)	

Care Coordination Encounters

Using tier at enrollment, Table 9. shows the total and average number of encounters between families and any care coordination staff, and the average total encounter time in hours, by tier. Not surprisingly, given their high levels of acuity, tier four families had the highest total

and average number of encounters with CC. A trend of fewer total and average encounters is seen as the tier level declines. Tier four families had an average total encounter time of 21 hours and a much wider range of encounter times than that seen in lower tier levels. These trends support the tier classification system used by CC which dictated the minimum number of contacts a family should receive according to the tier classification. It is logical that higher tier families would require not only more encounters but longer time during an encounter due to higher numbers of or higher complexity challenges.

Table 9. Care Coordination-Family Encounters by Tier

Tier at Enrollment (number of families)	Total Number of Encounters	Average Number of Encounters	Average Total Encounter Time in Hours (range)
4 (136)	8069	59.33	21 (0.75 – 116)
3 (69)	3232	46.84	16 (2 – 81)
2 (51)	1627	31.9	10 (0.25 – 41)
1 (18)	303	16.83	5 (0.25 – 14)

About half of the sample had 50 or fewer encounters with CC, while 33 families, or 12%, had over 90 encounters with CC staff. As with many health care services, this trend suggests there is a small group of very high users of services who consume a high proportion of program resources. Data were provided on all encounters between families and CC staff during the period of data analysis, and labeled by primary purpose of the contact. While nearly 60,000 encounters were listed, a single encounter between a family and a CC staff may have been labeled with one or more primary purposes. There were 13,321 unique encounters. Over one third of all logged encounters were labeled as continuing outreach or engagement.

Table 10. Primary Purpose of Encounter

Primary Purpose	N (of 59,662)	% of Total Encounters
Continuing outreach/engagement	20,072	34%
Coordination of agency services	14,790	25%
Progress monitoring	6,606	11%
Coordination of medical services	5,994	10%
Case documentation	3,672	6%
Coordination of school services	2,788	5%
Follow up referrals	2,223	4%
Order prescriptions, supplies, services, etc.	868	<2%
Make appointments	823	<2%
Research of resources	578	<1%
Coordination of payer services	451	<1%
Other	423	<1%
Record review	334	<1%

Staffing

There are three primary types of CC staff that interact regularly with families: care coordinator, health coach, and social worker. Table 11 describes, by tier, the total and average contact hours between families and CC staff. In each tier, the health coach spends the most time in contact with families. The social worker has a wide range of total contact hours with tier four families, which is congruent with the high levels of psychosocial needs in families in that tier. Notably, the social worker only consulted with about 60% of families, typically those at higher risk. As with earlier data, there is a trend where higher tier families receive more contact hours overall, which holds for all staff types. Table 12 shows the breakdown of each tier's contact time by type of staff. Notable here is that tier four families actually have a greater proportion of their total contact time with the social worker than the care coordinator. As tier level decreases, families spend a larger proportion of their contact time with the health coach, whereas, higher tier families spend more time with the care coordinator or social worker.

Table 11. Contacts Between Families and Care Coordination Staff

Contacts Between Families and Care Coordination Staff						
	Care Coordinator		Health Coach		Social Worker	
Tier at Enrollment (Number of Families)	Total Hours of Contact by Tier (Per family range)	Average Hours of Contact by Family	Total Hours of Contact by Tier (Per family range)	Average Hours of Contact by Family	Total Hours of Contact by Tier (Per family range)	Average Hours of Contact by Family
4 (136)	2124 (0-121)	15.62	3437 (1-186)	25.27	2384 (0-130)	17.53
3 (69)	778 (0-102)	11.28	1567 (1-77)	22.71	887 (0-69)	12.86
2 (51)	311 (0-40)	6.10	889 (0-79)	17.43	418 (0-44)	8.20
1 (18)	43 (0-7)	2.39	204 (1-36)	11.33	56 (0-19)	3.11

Table 12. Percent of Total Tier Contact, by Staff

Percent of Total Tier Contact by Staff				
Tier at Enrollment (number of families)	Total hours of contact with any staff	Percent of total contact hours spent with Care Coordinator	Percent of total contacts hours spent with Health Coach	Percent of total contacts hours spent with Social Worker
4 (136)	7945	27%	43%	30%
3 (69)	3232	24%	48%	27%
2 (51)	1338	23%	66%	31%
1 (18)	303	14%	67%	18%

Method of Encounter

Most (58%) care coordination encounters are conducted by telephone, with nearly half of those (47%) conducted by the health coach. Electronic or written communication was the second most used method of encounter. However, most face-to-face encounters were completed the care coordinator, likely during the initial assessment and development of the plan of care. Care coordinators were least likely to use electronic or written communications as a method, however this type of contact was used by health coaches, likely in outreach and monitoring activities. Social workers also used this type of communication frequently, such as to provide families with information on available resources for psychosocial supports.

Table 13. Method of Care Coordination Encounter

Method of Care Coordination Encounter		
	Total Number of Encounters Logged (n=13,391)	Number of Encounters Logged (percent), by Staff Type
Telephone	7730 (58%)	Care Coordinator: 2290 (29%) Health Coach: 3666 (47%) Social Worker: 1855 (24%)
Electronic or written communication	3139 (23%)	Care Coordinator: 522 (17%) Health Coach: 1347 (43%) Social Worker: 1270 (40%)
Face-to-face	2522 (19%)	Care Coordinator: 1092 (43%) Health Coach: 816 (32%) Social Worker: 614 (24%)

Family Centered Care Survey

Of the 63 families who completed the Family Centered Care telephone survey, 16% were in tier four at the time of the survey, 40% were in tier three, 22% were in tier two, and 22% were in tier one. Children’s ages ranged from two to 21 years at the time of the survey and 50% of the children were aged nine or younger. Table 14 describes the primary diagnoses of the children in participating families.

Table 14. Diagnosis Type

Diagnosis	Number	Percent
Autism Spectrum Disorder	12	19.0
Acute Brain Injury	9	14.3
Genetic disorder	7	11.1
Cerebral Palsy	6	9.5
Developmental delay	5	7.9
Functional Feeding Disorder	4	6.3
Acute Pain Management	4	6.3
Seizure Disorder	4	6.3
Spinal Cord Injury	3	4.8
Obesity	2	3.2
Neurological Disorder	1	1.6
Gunshot wound	1	1.6
Neonatal Abstinence Syndrome	1	1.6
Lymphoma	1	1.6

Table 14 Continued

Spina Bifida	1	1.6
Myositis	1	1.6
Severe Dermatomyositis	1	1.6
Total	63	100.0

The Family Center Care survey scores, minus the last question about overall satisfaction with CC received, were totaled to give each participant an overall score based on 9 questions using a four-point scale of 36 total possible points. The mean and median scores were 31 and 33 respectively, with a range of 14-36. Of the 63, 24 participants (38%) scored CC with a 36/36. These findings indicate that a high number of respondents in this sample felt the services they received in CC were family-centered.

Looking deeper, there were no significant differences on individual survey items or overall FCC score by tier at time of survey or by tier grouping (low= tier 1 or 2; high= tier 3 or 4). Approximately 50% of respondents scored CC at 32 or below. Using an FCC score of 32 as a cut point for low vs high scores, there were no significant differences between high and low risk groups and low or high FCC scores. Table 15 shows the cross tabulations of high and low FCC scores by tier grouping. These results do show, however, that a greater proportion of responders in the high-risk group rated CC highly on family centered care, compared to the low risk responders.

Table 15: Tier Grouping and Total Score Grouping Cross Tabulation

		Total Score Grouping		Total
		low (0-32)	high (33-40)	
Tier Grouping	low risk	19	9	28
	high risk	11	24	35
Total		30	33	63

Question six of the survey asked parents to rate their overall satisfaction with CC. Of the 63 respondents, 41 (65%) said they were “very satisfied”. Another 18 parents were “mostly satisfied”. The sample was broken into three groups by time in CC: less than two months, two to six months, and six months or longer. It is difficult to draw meaningful conclusions about the association between length of time in CC and parent satisfaction because of the 63 parents in the sample, 48 (76%) had been in CC for six months or longer and only one had been in the program less than two months. Of the 14 parents who had been in CC between two and six months, approximately the same proportion responded with “mostly satisfied” and “very satisfied” as in the six months or longer group. One parent in the two-to-six month group reported being “not at all satisfied”. The only respondent in the less than two months group reported being “not very satisfied.” This may indicate that satisfaction increases with time in CC, or these may be unique situations where two families had poor experiences in CC.

3.7 DISCUSSION

Overall, the children included in the analysis were high-risk, male, and young (50% age eight or younger). Over half of the sample reduced tier level during the data analysis period while only 4% increased tier. The trend toward the client population’s overall reduction in tier level while in CC is positive and what the program would hope to see. The trend may also speak to the impact of CC in stabilizing families by addressing their acute medical and/or psychosocial needs, however without a way to match tier level to exact start and end dates for each client it is not possible to assess this trend systematically.

Data on the frequency and time of encounters with CC is congruent with the tier classification system used by CC, which dictates the minimum frequency of contacts with families by acuity level. As expected, higher risk families received both more encounters by CC staff and spent more time with staff in these encounters. Although the data do not allow us to compare the purpose of encounter by type of staff performing the counter, we know that most encounters overall were focused on continuing outreach and engagement. As this responsibility falls under the health coaches' purview, it is logical that we see the most family-CC contacts conducted by health coaches, and by telephone. Similarly, the data indicate that care coordinators most frequently engaged in face-to-face encounters, which reflects their responsibility of conducting initial assessments with families and developing the care plans. Although not captured in this data, in case review meetings and parent interviews, these activities were often described as face-to-face activities, while outreach was described as a telephone activity.

Across all tiers, families had the most contact with health coaches, followed by the social worker, then the care coordinator. This proportion held true for all tiers, however as the tier level decreased, the proportion of overall encounter time spent with health coaches increased. This trend indicates that care coordinators handled encounters with higher risk families and the more complex or technical functions of delivering CC, while health coaches were often the day-to-day contact point with families, especially those at lower risk. It is less straightforward to infer meaning from the social worker's encounter data because she was not involved with every family enrolled in CC. Only about 60% of participants had indicated psychosocial risks. However, it is logical that higher risk families in tiers three and four would be more likely to have social work encounter data. In some families' cases they may have spent considerable time with the social worker, but the data do not include a specific indicator of each family's

psychosocial need. This staffing pattern also suggests a commitment to using the most cost-effective staff (i.e. the health coach) for non-technical CC encounters and leaving higher-skilled staff to create the initial family assessment and care plan, and to address a smaller number of more complex needs over the duration of CC.

The Family-Centered Care survey data indicate that the CC received by respondents was family-centered to a good degree, and nearly 94% of survey respondents were mostly or very satisfied with the CC received. There is an indication that those in the higher acuity group rated their experience in CC as more family-centered than those in the lower acuity group. This difference may be due to the greater number of contacts and/or longer length of contacts the higher risk group had with CC staff, meaning families had more opportunity to experience family-centered care. Lower acuity families would have received, in general, less time with CC staff and perhaps less personalized attention, which may have led to lower ratings of family-centered care. Higher risk families would have also likely had more contacts with the care coordinator and social worker than lower risk families who had more contact with the health coach, which may suggest these staff provided family-centered care to a greater degree than the health coach.

3.8 LIMITATIONS AND RECOMMENDATIONS

Due to the limitations of the study design and available administrative data it was not possible to answer some of the *a priori* evaluation questions or explore the data in greater detail. For example, the purpose of each CC encounter could not be matched to staff type completing the encounter to give a more descriptive picture of the types of activities completed by whom. This

would have allowed an assessment of the “fit” between the type of staff needed to conduct some CC activities and possibly identified ways to increase value by ensuring the most cost-effective staff performed each activity.

Second, there was no specific indicator describing psychosocial risks by which to identify and classify families. This type of variable would have enabled an examination of these families apart from those with only medical risk factors, or families with both, or to examine encounter data and tier classification changes by psychosocial acuity. It is likely that families with many or complex psychosocial challenges require longer or a different type of CC support than those with only medical challenges, and that the presence of psychosocial risks complicates CC staff’s abilities to address medical needs.

Additionally, each child’s primary diagnosis was not available for analysis. That data would have allowed for an exploration of how the nature of a child’s medical condition may be associated with CC contact or tier levels. Families enrolled in CC at varying points in their illness experience: some families were new to having a medically complex child while others had enrolled in CC after years of managing on their own. There are likely associations between families’ lived experiences, levels of need for CC overall, and type of care coordination support needed, which may relate to families’ ratings of care received and overall satisfaction. Having a variable that captures the nature of the child’s illness and status in the illness lifestyle would shed light on families’ changing needs and use of CC throughout the illness experience.

Finally, each family’s enrollment and discharge dates were not available. These data points would have been useful to describe the mean number of days and range of length of time in the program to assess how long it takes a family to stabilize and “tier down” to discharge, or to show a definitive picture of tier changes over the entire period of participation in CC. Without

individual contact data it is also not possible to determine if contact frequency followed tier assignment changes.

Regarding design, without a comparison group, there is no way to determine if families' acuity levels would have trended lower over time without the intervention of CC. A rigorous evaluation would need a comparison group, such as families who were referred to the CC program but declined to participate.

4.0 CHAPTER FOUR: MANUSCRIPT THREE: THE FAMILY EXPERIENCE OF CARE COORDINATION

4.1 ABSTRACT

An entire family system is impacted by having a child with complex medical needs. The nature of the child's needs and stage of the illness, as well as the family context, affect how families experience stress, coping, normalization, and empowerment. Building on each family's unique needs, assets, and goals, care coordination attempts to increase family empowerment, which is conceptualized as the capacity to influence factors that affect the family's quality of life. This study focuses on family empowerment as an outcome of participating in care coordination.

Families of children with medical complexity who have high medical and psychosocial acuity stand to benefit greatly from participating in a well-implemented and effective care coordination program. The research literature indicates likely outcomes of care coordination would include increased access to needed health, educational, and social services in a timely way; improved continuity of health care; reduced use of emergency services and hospitals; and greater knowledge, skills and feelings of self-efficacy of families around managing their children's conditions. This study explores family experiences in care coordination, assesses family empowerment, and examines differences on key themes and outcomes by the length of

time in the program and the family's level of risk, which was defined by medical and psychosocial acuity.

Families of 23 medically complex children completed interviews and a questionnaire comprised of the Family Empowerment Scale and a six-item outcome survey. Interviews revealed that while they are overall very positive and appreciative of the program, families enter the care coordination program at markedly different stages in their children's illness experiences, and with a wide range of needs, assets, and expectations. Experiences in the program also varied in amount and type of support received. Four main themes emerged from the interviews. Families reported experiencing increased efficiency in access to needed services due to care coordination. Some also felt care coordination also added a sense of legitimacy to their requests in the eyes of medical and other service providers. Nearly all families in the program reported feeling increased support and reduced stress due care coordination. Survey results showed that high-acuity families were significantly more likely to report reductions in hospital admissions and emergency department use since enrolling in care coordination. However, there were no statistically significant differences found between groups on indicators of family empowerment or other key outcomes. These findings indicate that care coordination has several positive benefits for parents and families, but these benefits are not experienced to the same degree by all participants, and the impact of care coordination on family empowerment may be influence by other factors in a family's life.

4.2 BACKGROUND

The Family³ Experience

The family experience can be explored qualitatively at all steps of the CC-family relationship: assessment, planning, monitoring, transitions, and critical periods (Antonelli et al., 2009). Care Coordination has been called an essential component in the transformation of health care delivery to be family-centered and participatory (Turchi et al., 2009) To really understand how care coordination is implemented within a family-centered care framework, it is critical to understand the family experience. Families of CMC invest incredible amounts of time and energy in providing care and coordinating needed services for their children, and live day to day with the realities of navigating the health care and social service arenas. As one care coordination expert noted, “the ultimate measure of effectiveness of a system of health care is how patients and families themselves experience it” (Antonelli et al., 2009, page 17). The following sections provide an overview of salient issues in the lives of families of CMC and their experiences accessing medical and social services.

In 2003, the American Academy of Pediatrics issued a “Report of the Task Force on the Family”, in recognition that in pediatrics the family is integral to the patient. It summarizes the influences of the family context on child health and wellbeing, including family income, age of parents, social and cultural beliefs, family composition, parenting style, and other factors. They assert, “Families are the most central and enduring influence in children’s lives. Parents are also central in pediatric care. The health and well-being of children are inextricably linked to their

³ The term ‘family’ is used here generally to refer to the primary caregiving unit for a child, however that unit defines itself. This includes single parents, parent and paramour, grandparents, foster parents, and other arrangements.

parents' physical, emotional and social health, social circumstances, and child-rearing practices" (page 1541). The task force makes two conclusions: one, children's outcomes in all domains of life are heavily influenced by the families' functioning; and two, there is a role for pediatricians to improve child outcomes by supporting families and promoting optimal family functioning (Schor, Billingsley, Golden, McMillan, Meloy, & Pendarvis, 2003).

The AAP describes "successful" families as those whose environments enable members to meet all of their developmental needs. The characteristics of these families include: communication, encouragement of individuals, commitment to family, social connectedness, ability to adapt, clear roles, and time together, among others (Schor, Billingsley, Golden, McMillan, Meloy, & Pendarvis, 2003). A central goal of CC is to build family capacity to fulfill the family's needs while navigating the world of health and social services necessary for its child. CC attempts to reduce acute events and their associated stressors. To do this, care coordinators use a family-focused, strengths-based approach to foster family empowerment. With high-quality CC, it is hypothesized families will feel they have increased knowledge and feelings of self-efficacy to navigate service systems and manage the entire family's needs. Care coordination and family empowerment can lead to improved access to care, satisfaction with care, and continuity of care, which in turn lead to improved outcomes for children and their families.

In the context of children with medical complexity, several theories are useful for understanding how a chronic health condition shapes the lived experience of the family. Systems Theory describes how a child's condition impacts the other members of the family individually, the family as a unit, and the family's relationships to others. Systems theory states that all components (i.e. family members) are connected by their individual relationships. Each child has

a unique relationship one-to-one with each parent, each sibling with each other sibling, and so on. The system forms and evolves over a lifetime, just as its individual members evolve independently. As each component joins the system (e.g. as a new child is born), the system changes and adapts. What impacts an individual also impacts all members of the system. Systems Theory also posits that every system is unique; therefore, even two families with similar characteristics will experience change in different ways (Verhaeghe, S., Defloor, T., and Grypdonck, 2005).

The Family Systems Illness Model

The FSIM is more specific to CMC. FSIM is a framework for understanding the natural longitudinal changes that occur over the course of a chronic condition and the ways a family must adapt accordingly. Each adaptation is a critical transition time for the family. Rolland uses FSIM to describe how “the unfolding of a chronic disorder is viewed in a developmental context, involving the intertwining of three evolutionary threads: the illness, individual and family life cycles” (page 243). Families of CMC face numerous stressors related to their children’s conditions beyond the medical issues themselves, such as the social meaning attributed to the condition, its severity, and the life stage of the family during which the child’s condition occurs (Farber & Maharaj, 2005).

Rolland describes chronic conditions as having distinct phases and corresponding needs: onset, course, outcome, incapacitation, and the level of uncertainty. A family responds by adapting their roles and behaviors. For example, whether a condition has an acute (traumatic brain injury) or gradual onset (Huntington’s Disease) impacts how rapidly a family must respond to and make sense of the change. The course of a disease can be progressive, constant or

relapsing/episodic. Outcome refers to the morbidity and mortality associated with the condition. Incapacitation characterizes the loss of functionality due to a condition, and includes the extent and nature of the resulting limitation, its timing in the life cycle, and other features. Predictability refers to the amount of uncertainty a family lives with day to day due to what is known about the nature of the illness. Chronic diseases are also characterized by phases: crisis, chronic, and terminal. During each of these phases, the family is faced with unique medical and psychosocial demands, new roles, and changing relationships among the family and with their health care providers (Rolland, 1999). The challenges arising in each phase interact with the strengths and vulnerabilities of the family and its members at that time (Nolan, Orlando, & Liptak, 2007).

FSIM conceptualizes how a family gains mastery of a challenging medical situation by first acquiring understanding of the chronic condition, which includes the expected pattern of needs and responses over its duration. The family then begins to conceptualize themselves as a functioning unit. Finally, the family develops an understanding of the dynamic relationships among the demands of the chronic condition, the developmental needs of the family unit, and each member's needs (Rolland, 1999).

In a qualitative study, parents of CMC expressed a need for different types of support at different times in their illness experience. The time of initial diagnosis of the child was also felt to be critical for families to comprehend and plan how to meet the family's needs. The timeliness of receiving a diagnosis, provider sensitivity, and the support given to families by providers during the time of diagnosis were essential for families to make sense of it and impacted the family's ongoing relationships with the provider. This indicates the importance of health care providers delivering this information sensitively and providing the family with needed support to process the information (Whiting, 2014b). Rolland also describes the onset period as critical for

“framing” the illness for families. This is a time of crisis when families rely closely on health care providers as sources of information and guidance (Rolland, 1999).

In situations of acute and unexpected change such as traumatic brain injury, research has documented the family coping process in phases as well. In the initial phase when the child is injured the family reacts with shock and responds by attending to the immediate medical crisis. The next phase can be characterized by relief at surviving but the family may have inappropriate expectations for recovery. Then family members may experience confusion, anxiety, depression, guilt, or other myriad feelings. Lastly, there may be a phase of mourning that is characterized by the family re-conceptualizing their roles and accommodating their “new normal”. Not all families will experience all phases or in the order presented (Verhaeghe, Defloor, & Grypdonck, 2005). The research literature provides strong evidence that social and community supports have positive influences on a family’s adaptive coping and healthy functioning and development over time, throughout their experiences of their child’s condition (Farber & Maharaj, 2005).

Promoting positive family coping and adaptation is critical. In the past, CMC may have spent long periods of time hospitalized, but technological and medical advances have made it common for families to care for children in the home, including providing some types of medical care and maintenance of life-supporting equipment. With home-based care, there is no separation of the “illness” from the daily lives of the rest of the family or the unique caregiving demands that families of CMC face (Dellve, Samuelsson, Tallborn, Fath, & Hallberg, 2006; Drummond et al., 2012). The process of family adaptation to a child’s illness is complex, dynamic, and influenced by factors both internal and external to the family. The child’s condition will affect the individual’s development and all family members in various ways, depending on characteristics such as age at onset of illness, stage of the family life cycle, and other situations

affecting the individual and family at that time (Rolland, 1999). Some families are able to find strength and meaning in the experience and adapt resiliently, while others become vulnerable to dysfunction.

In a summary of the literature of family experiences of stress and coping, Verhaeghe et al. conclude a family's response is related to family characteristics including past experience, age, gender of caregiver, and caregiver response to the child's condition. For example, when a caregiver has experienced medical or psychiatric care directly, the caregiver reports greater stress and anxiety. Families that are younger, have more children, have financial hardship, or have limited social support also experience greater stress and anxiety than families without those situations (2005). Facilitators of successful family adaptation include social support, strong intra-family relationships, knowledge, and acceptance of the child's illness and the family's situation, while strained marriage and other inter-family relationships, emotional burden, and difficulty meeting daily care tasks are recognized as barriers (Dellve et al., 2006).

Whiting's qualitative work with 33 families of CMC found parents made sense of their situations through the lens of their past experiences of disability, their past and current experiences of parenting (both being parented and parenting their own children), and relationships in general. Whiting's work reinforces that the differences in family response are the result of a combination of inputs such as family members' personalities, life experiences, the cohesion of the family as a unit, its support network, and access to professional supports (Whiting, 2014b). Illness and disability can drive a family apart, however they can also bring a family closer together by building cohesion and communication among members. The family response is likely influenced by the "fit" between the demands of the condition, the family's strengths and challenges, and timing in the lifecycle of the family (Rolland, 1999).

Stress and Coping

There is a substantial body of literature focused on various aspects of stress and coping in families of CYSHCN. Some of these stressors directly relate to their child's condition, such as needing to acquire new knowledge and skills. The literature asserts parents providing home-based care often feel stress and uncertainty about their ability to provide such care (Flynn, Carter, Bray, & Donne, 2013). Having a child with complex medical needs may also compound or exacerbate the stressors that any family feels, such as work-life balance, financial burdens, and difficulty managing sibling relationships. The preponderance of literature on families of CMC focus on a few categories of stressors such as limited time, lack of respite, financial burden, social isolation, challenges to the family dynamics, the struggle with role definition (their own role, as well as role in relation to health care providers). A very brief summary of these issues follows.

Stress is a response to an individual's environment and a *stressor* is a stimulus that the individual perceives him or herself unable to respond to appropriately (Monat, & Lazarus, 1985). In this framework, the individual's perception of the stressor is more important than the intrinsic nature and severity of the stress. The response to a stressor is governed by two factors: the individual's assessment of the situation and the possible results, plus the individual's assessment of his or her ability to respond (Verhaeghe, Defloor, & Grypdonck, 2005). This again speaks to the importance of the family's ability to respond to the stressor and adapt positively.

In their report the AAP's Task Force used the Family Stress Model to conceptualize family functioning when caring for CMC. Any type of stressor, explicitly health related or not, has the potential to negatively impact interactions between parent and child and disrupt overall family functioning, in the short or long term. Stressors occurring earlier in a child's life and those

that affect a family for prolonged time periods have the most potential to negatively impact children's outcomes (Schor, Billingsley, Golden, McMillan, Meloy, & Pendarvis, 2003).

The cognitive, behavioral and emotional responses to a stressor is called *coping*. Coping is a dynamic process that varies according to the perceived stressor and the individual's ability to respond. Coping can be problem-oriented, which is focused on the stressor itself (e.g. asking for needed information), or emotion-oriented, which is focused on reducing emotional reactions to the stressor (e.g. ignoring). Coping may be adaptive or maladaptive (or functioning/nonfunctioning) and the response varies by age and gender. For example, women tend to seek social groups for coping while men cope individually. There is limited information on the prevalence of maladaptive responses among family members of CMC, as a group. However, responses to some specific conditions have been studied. For example, traumatic brain injury often impacts young men who may have their own families in their early stages of development. Family impacts associated with TBI include depression, emotional distress, burden, and psychosocial dysfunction (Verhaeghe, Defloor, & Grypdonck, 2005).

Coping is an iterative process of making meaning, shifting perspective, and reflecting on one's situation. Parents' needs fall into categories: the need for normality and certainty, the need for information, and the need for partnership (Fisher, 2001). Families tend to develop effective coping strategies naturally over time, but their development is fostered by professional supports such as having a liaison, by being provided with concrete information and resources, access to peer support groups, and by long-term follow up such as with a social work liaison. Professional support reduces families' experiences of stress and encourages them to cope effectively. The nature of the condition also affects coping. Some studies show parental stress has a stronger statistical link to cohesion, income, family and social support than to the severity of the child's

illness and aspects of child functioning (Dellve et al., 2006). Others have found a relationship between injury severity and psychological strain. Emotional, intellectual, and behavioral consequences of an injury were found to be more closely correlated to family stress than were physical side effects. Children's behavior and parent distress have also been found to be mutually-influencing (Verhaeghe, Defloor, & Grypdonck, 2005).

A review of technology dependent children in home-care situations found parents identified the following needs: to have information about the child's condition and daily care; to feel respected by and in partnership with health care providers; and a need for care coordination, which included networking among all services present in the life of the family, such as medical, community-based, school, insurance, etc. (Jachimiec, & Obrecht, 2015). Nearly 93% of families of children with a disability incur some type of added financial difficulty due to their children's conditions, such as for items such as transportation or special feeding equipment (Harrison, & Woolley, 2004; Whiting, 2014a). Other research has indicated families struggle with missed work for direct care, medical appointments, and due to child care challenges, as well as a lack of flexibility and understanding by employers. Many families choose to reduce or eliminate one parent's job to accommodate caregiving (Whiting, 2013).

Parents of CMC also report impacts on their own health, such as mental health problems, back pain, fatigue, and marital relationship challenges. In one study, while 23% of parents reported their child's needs had brought them closer together, 9% reported their marriage ended, 13% reported significant problems, and 31% reported some problems in their marriage as a result of it (Mencap, 2003, 2006). Additionally, a body of work shows parents feel the effects of lost social opportunity and social isolation due to the demands of child care (Marchant, 2007; Townsley, 2004).

Qualitative research with 33 families of children with disabilities, technology dependence, and life-limiting or life-threatening conditions indicated three primary categories of impacts on family life: lack of time, the struggle to negotiate multiple roles, and the concept of “the disabled family”. Time referred to the substantial time needed to provide care to their child directly, schedule and attend numerous medical and other appointments, and time needed to prepare for in-home professional caregiving (e.g. cleaning the house for in-home nurses). These demands on parents’ time resulted in less time for their own needs, their partners, other children, and socialization outside the home (Whiting, 2014b). The concept of “multiple roles”, was described by parents as the additional demands required of them to meet all the needs of their children with complex conditions. They described being a parent, a nurse, a physical therapist, a bookkeeper, a chauffeur, and other demands on their time, knowledge, and skills. Parents described a sense of conflict between the roles of parenting and providing medical and technical care for their child (Whiting, 2014a). Although not endorsed by all participants, the “disabled family” term used by some families described the effects on numerous aspects of life due to the special needs of their children. They felt their social opportunities, relationships with extended family members, employment opportunities, and general family life were impacted (Whiting, 2014a).

Empowerment

Empowerment is often thought of as an internal sense of power over one’s life. It has been described as a state as well as a psychological and social process by which individuals gain mastery over their lives (Koren et al., 1992; Zimmerman, & Rappaport, 1988) by developing certain attitudes, knowledge, and behaviors. In addition to individual elements, empowerment

has contextual and transactional elements whereby feelings of empowerment are created (Akey, Marquis, & Ross, 2000). Empowerment is not a constant state, but one that varies as an individual acts on his or her own behalf to “achieve a greater measure of control over” in life (Staples, 1990, page 30), such as when parents navigate the social service systems in which they obtain care for their children. Other researchers have linked empowerment with welfare (Benson & Kersh, 2011), self-efficacy (Wakimizu, Fujioka, Yoneyama, Iejima, & Miyamoto, 2011), reduced stress (Nachshen, & Minnes, 2005), fewer symptoms of depression (Martínez, Pérez, Ramírez, Canino, & Rand, 2009), and improved family dynamics and functioning (Scheel & Rieckmann, 1998).

Family empowerment is distinct but related to the concepts of parental self-efficacy and competence. Although sometimes used interchangeably, parental self-efficacy is thought to be a distinct trait from parental competence. Efficacy has to do with the beliefs a parent holds about his or her own capability to execute specific actions related to parenting, whereas parental competence is an assessment made about the parent’s ability by another individual. Parental competence includes skills, behaviors, and the strategies put in place by parents that result in positive child outcomes (de Montigny & Lacharite, 2005; Jones & Prinz, 2005). While there are several validated instruments to measure each of these concepts, none has been validated in the context of parents rearing children who are medically complex and who likely have different and additional needs than those presented to parents of children without medical complexity. This point is especially relevant given the body literature showing parents of CMC often feel their parenting roles are impacted substantially due to their caregiving responsibilities in addition to their parenting responsibilities (Major, 2003; Whiting, 2014a).

In the context of raising a child with medical complexity, the expression of empowerment is typically thought of as how the family manages daily situations, including what the family feels and believes (attitude), what they know and can potentially do (knowledge), and what the family actually does (behavior) (Koren et al., 1992). For empowerment to occur, Kieffer, has described four necessary conditions: a personal attitude that promotes active social involvement, a capacity to critically assess the environment and context in which action would occur, an ability to develop action strategies and acquire or use necessary resources, and an ability to act with others to establish and achieve collective goals (Kieffer, 1981).

Empowerment has become something of a universal aspiration among social service professionals working with children with disabilities and their families, and it is increasingly seen as a goal and an outcome of supportive services. This power is associated with or resulting from services that are strengths-based and emphasize self-reliance, recognizing that services can be provided in ways that either promote or impede family self-efficacy. In the context of service provision, an operationalized definition of empowerment in the social service context might be how parents assess their own feelings of competence to manage their children with disabilities, how they can impact the service systems with which they interact, and the power that individuals have to make decisions and influence their lives or the lives of their families (Koren et al., 1992). Others have operationalized the concept with emphasis on the provider-family relationship, to mean the process by which practitioners foster the growth of clients' abilities, yet encourage independent functioning and self-reliance as an end goal. In this process of engaging with service providers, parental advocacy becomes empowering and reinforcing as needed services are sought and obtained (Cunningham, Henggeler, Brondino, & Pickrel, 1999). In their literature review, Singh et al. conclude "the concept of empowerment has come to imply a process whereby

individuals gain control over their own lives by influencing their interpersonal and social environments” and in the context of social services this means families access all of the tools such as knowledge, skills and resources to improve the quality of their lives (Singh, Curtis, Ellis, Nicholson, Villani, & Wechsler, 1995, page 85).

Developing parents’ knowledge, skills and self-efficacy has been identified as central features of family-centered care. Parent empowerment, measured by increased perception of knowledge and self-efficacy in navigating the health care system, can be achieved through increased parent participation in the health care process and specific empowerment enhancing interventions, however the effect was influenced by parent gender and type of illness (Dellve et al., 2006). A first step is health care providers must take in promoting family empowerment is acknowledging the value and worth of families as full participants, experts on the needs and strengths of their child and family, and decision makers. Then, providers should include families in the planning and delivery of all aspects of care. The actions like these, which make service delivery more family-focused lead to family empowerment (Singh, Curtis, Ellis, Nicholson, Villani, & Wechsler, 1995). Rolland describes empowerment as when a family “can see their predicament in a balanced way as a family issue shared by all members” and instead of thinking of “my problem”, begin framing it as “their challenge” (1999, page 258).

The family’s active roles as drivers and participants in CC coordination is critical (Holm, Patterson, & Gurney, 2003). Families participate in CC through building relationships with medical providers and other professionals, managing medical information, information sharing, and making care decisions. Periods of transition in a child’s care, such as from pediatric to adult services, are times when the family role becomes especially critical to maintain continuity. During times of transition, the family plans, makes decisions, and advocates for their child, and

may provide the best continuity of all care information as providers change (Stille & Antonelli, 2004). Families themselves endorse the concept. In a qualitative exploration of family perceptions on aspects of continuity of care, parents in this study used “empowerment” to describe a progressive process through which they increased their ability to care for their children, during the various phases of their interaction with the health care system. For example, while the child was hospitalized, parents’ experience of empowerment began when health care staff provided information and training for their child’s care. At this stage, both information and training were seen as critical for parents to care for their child directly and training became increasingly important as the family neared discharge and began the transition to home. Parents described empowerment after the discharge as implementing the skills they were taught (Zanello et al., 2015). Family-level empowerment has also been linked to improved family relations (Cunningham, Henggeler, Brondino, & Pickrel, 1999).

Relationships with medical providers

By considering individual traits and environmental factors, the behavioral model of health services use is a way to conceptualize access to health care services and outcomes of the health care process. The model depicts the “predisposing” factors as child’s age and mother’s education. “Enabling” factors are those such as poverty level and insurance status, which are individual characteristics that predict a family’s engagement with “the process of health care”. This process is defined as the interactions between health care providers and patients during health care delivery and is measured through the presence of a health care home, family centered care, and care coordination. The presence of these supports in turn influence the outcome of “parental coping” (Drummond et al., 2012).

Strong relationships with health care providers can mitigate the stress a family feels. Yet while parents look to pediatricians as a trusted source of information and guidance on raising their children, there is mixed evidence on how well pediatricians are prepared to support holistic family needs. Since the later 1970s, several iterations of AAP task forces looking at the future of pediatric training have acknowledged a growing need for pediatricians to manage a broad range of challenges facing families, including children's mental health, and cognitive and social development, as well as connecting families to community based resources that address the social determinants of health (Schor, Billingsley, Golden, McMillan, Meloy, & Pendarvis, 2003).

While families indicate information-sharing and communication with health care providers is critical to their experiences, the AAP notes there is some evidence of poor communication in pediatric practices. Only 15-20% of parents report their pediatrician assesses the psychosocial issues of the family. Parents report they need greater guidance around child rearing and children's behavioral development (Schor, Billingsley, Golden, McMillan, Meloy, & Pendarvis, 2003). This would certainly be the case for families of CMC. Nurses, social workers, others trained in care coordination offer one strategy to bridge the gap of pediatrician training and the informational and relationship-based supports families need. Having these staff provide CC activities is also more cost effective (Antonelli et al., 2008).

Family and Provider Roles

Role Theory conceptualizes a *role* as a set of behaviors that are associated with a certain position and *role negotiation* as the process by which roles develop (Major, 2003). Roles are relevant in several ways. Searching for new roles and/or negotiating changing roles is an adaptive coping mechanism (Verhaeghe et al., 2005). Qualitative research has shown parents of

CMC struggle to understand their dual roles as parent and caregiver (Whiting, 2014a). Families of CMC run the risk of their relationships and becoming completely identified with illness or disability. Families are able to adapt positively when they can “create a narrative about illness or disability that is empowering, sustains hope, and affirms their relationship” (Rolland, 1999, page 264).

Roles are fluid and change as the family system and environment changes. In the family context, other family members, or what is known as the role set, also influence and are influenced by the role negotiation of an individual member. The role set works together to define the focal role (e.g. that of the parent) in a way that is mutually satisfying. Major describes successful negotiation of the many roles as “balanced coping”, which is characterized by the medical and emotional needs of the ill child being met, the caregivers’ mental and physical health needs being met, and caregivers can also meet the needs of their other roles (2003).

Flynn et al. reviewed articles on parental coping with children with tracheostomy and found parents use routines and strategies to maintain “normal” home environments yet felt the constant responsibility to provide medical care resulted in conflict about their role as parent vs. nurse (Flynn et al., 2013). This study confirmed many themes found in studies of families caring for children with other complex medical issues, including feelings of limited time and social isolation, the need for support, the negotiation of the parent-provider relationship (as parents’ expertise about providing medical care and about their child’s condition increased, it changed the conventional parent-provider relationship).

Health professionals may find role theory useful as they work with families through effective relationships to build their capacity as caregivers and care coordinators for their children. Parents/caregivers enter the relationship as experts on their family and the care

coordinators enter the relationship as experts on the resources available to help families. Information sharing between these different parties will enhance the likelihood that an effective plan of care is created and pursued for each family (Major, 2003). Parents rate their satisfaction with CC higher when they feel they have experienced good relationships with providers (Turchi et al., 2009).

Care coordinators can use role theory as a guide while they support families to develop effective coping strategies and build their capacity as caregivers. Major outlines six steps whereby role theory can accomplish this. First, CC can help families understand their role as caregivers for their child's unique condition. This may include medical needs, illness course and characteristics, anticipating effects on work and other family members, etc. Second, CC staff can help families define the role set by identifying and clarifying roles of all family members and caregivers, important extended family, and professional personnel in the life of the child. Third, CC staff can support families to assess the resources, facilitators and barriers they will need to meet their caregiving demands. These resources can cover physical, social, emotional, educational and medical supports, and all of the environments (home, work, community, hospital) in which the family operates. Next, CC staff help families to identify functional roles for all family members in all domains of life. This reduces role ambiguity, role overload, and role conflict. CC staff can assist families toward synergy within the family system so they are effectively coping with stressors. This is known as *role integration*, in systems theory. Lastly, roles need to be re-negotiated as circumstances change over time, as children age, become more independent, and have different care needs. CC staff can work with families to anticipate and respond to these changing needs (Major, 2003).

Research shows family involvement in care and relationships with health care staff are associated with family satisfaction of care received (Van Houdt, Sermeus, Vanhaecht, & De Lepeleire, 2014). Work with parents of hospitalized CMC found parents want to be involved in their child's care, in partnership with health care providers but their actual involvement is influenced by the attitudes and behaviors of the health care providers in relationship to parent involvement in the child's care (Power & Franck, 2008). Other research has confirmed families' involvement levels are related to their satisfaction with CC services (Strickland et al., 2004). Further research describes the role negotiation process among families and health care providers. Ineffective communication, misalignment of expectations about family involvement in care, and power dynamics can negatively impact the family-professional working relationship (Corlett, & Twycross, 2006). Successful role negotiation was characterized by effective interactions among families and staff, such as establishing rapport and sharing care tasks (Corlett, & Twycross, 2006), and the medical provider's recognition of the family's needs *while providing care* for their child (Avis & Reardon, 2008).

Carter et al. found that CC participants wanted different types of care coordinators and different types of support from their care coordinator depending on the stage of the family's experience with the child's illness. For example, when a family was in an earlier stage of coping with the child's illness, they wanted a professional coordinator (vs. a non-professional). Other families wanted an advocate for their children. More experienced families felt they could provide better care coordination themselves. However, most families indicated they wanted someone who was a key point of contact for the family, especially during critical times such as following the initial diagnosis, transition periods, and after acute events. Finally, not all families want a care coordinator (Carter, Cummings, & Cooper, 2007).

In summary, in the pediatric community, care coordination is promoted as a strategy to increase efficiency and quality of service delivery and make healthcare more patient- and family-centered. One goal of care coordination is to build family empowerment, the capacity to influence factors affecting the family's quality of life. Theory and literature suggest that a family's need for care coordination and the usefulness of specific care coordination strategies will vary over time with family characteristics, as the family negotiates the child's course of illness, and as the family gains experience and builds capacity. Empowerment is likely to be enhanced both from lived experience and through deliberate intervention by care coordinators. As the population of children living with medical complexity grows and the need for efficiency and cost-savings for frequent users of expensive health services becomes increasingly urgent, it will be critical to understand in what ways and at what time care coordination can intervene to benefit the most challenging pediatric patient populations, their families, and the health and social service systems that support them.

4.3 METHODS

Eligibility and Recruitment

Participants were recruited through the care coordination program at the Children's Institute. Care coordination staff were provided with the eligibility requirements for the study, which included: 1). Enrollment in care coordination at the Children's Institute for either two months or less, or six months or longer, and 2). Capable of conducting an interview and completing a questionnaire in English. Those who did not meet inclusion criteria or were not willing to talk with the researcher were excluded. The restrictions on enrollment time allowed the researcher to

group interview participants into two groups: “old”, i.e. enrolled in CC for six months or longer, and “new”, i.e. enrolled in CC for two months or less.

Over a period of four months, CC staff made an initial introduction of the study to potential participants then provided the researcher with the names of parents who agreed to be contacted about the study. The researcher then contacted interested participants by phone and/or email, depending on the parent’s preferred method of contact. The researcher obtained consent, enrolled participants, and conducted interviews without the assistance of care coordination staff. While CC staff knew which families had agreed to be contacted by the researcher, the identities of families who participated in interviews was kept confidential. Of the parents referred to the researcher, 70% completed an interview. Participants were given a \$20 gift card as a thank you for their time.

Participants

Twenty-two parents of 23 children who are considered to be medically complex and were currently enrolled or very recently discharged in the care coordination program chose to participate in the study. Six parents of six children were in the “new” group, and 16 parents of 17 children were in the “old” group. Children varied by diagnosis and condition, tier level, time in the program, and the specific care coordination staff they worked with. Characteristics of participants are described in Table 16.

Table 16: Characteristics of Participants

	Tier (at time of interview)	Child Gender	Child Age (years)	Diagnoses/Conditions (as described by parent)	Parent Interviewed
1 (new)	3	M	2	Transverse myelitis after viral infection; quadriplegic	Mother
2 (old)	3	F	11	Autism; non-verbal; blind	Mother
3 (new)	3	M	11	Epilepsy; chronic pain; unclear neurological problems	Mother
4 (old)	1	M	Unk.	Autism; “other disabilities related to autism”; mild Pica	Mother
5 (old)	4	M	13	Autism	Mother
	1	F	11	Autism	
6 (old)	1	M	3	Autism; feeding tube due to severe food aversion	Mother
7 (old)	2	F	8	Cerebral palsy; microcephaly; GERD; epilepsy; “full care”, i.e. non-verbal, non-ambulatory, g-tube	Mother
8 (new)	4	M	5	ADHD; suspected autism (significant speech delays, OT needs)	Mother
9 (old)	4	M	21	Quadriplegic (spinal cord injury from gunshot wound)	Father
10 (old)	3	M	6	Autism (significant feeding and speech challenges)	Mother
11 (new)	3	F	8	Rett Syndrome	Custodial Grandmother
12 (old)	2	F	12	Left-sided hemiparesis (uses wheelchair; left-side paralysis); parent believes condition caused by reaction to meningococcal vaccine and adverse reaction to treatments	Mother
13 (old)	2	M	18	Severe encephalitis after viral infection; quadriplegic; nonverbal; ventilator; trach	Mother
14 (old)	2	M	4	Unclear diagnoses; had acute respiratory incident as infant (possible reaction to mold in home) and subsequent chronic respiratory challenges; unexplained regression (verbal, feeding); significant sensory issues; developmental delays	Mother
15 (old)	1	F	6	Stroke at 2 years old; resulted in speech and other challenges	Mother
16 (new)	3	F	6	Situs inversus; Charcot-Marie-Tooth disease (peripheral neuropathy with muscle atrophy and nerve damage)	Mother
17 (old)	dis-charged	M	10	Suffered an acute trauma by another student at school; significant regression of physical, emotional and social skills	Mother
18 (old)	2	F	3	Down syndrome; 4 holes in heart; co-articulation of the aorta; epilepsy; Regressive Autism; thyroid issues; strabismus	Mother
19 (old)	3	F	15	Eosinophilic esophagitis (digestive disorder); Significant mental illness and history of family trauma	Mother
20 (new)	1	F	3	Feeding tube/enrolled in functional feeding program	Mother
21 (old)	1	M	5	Unclear diagnosis for long time (recently diagnosed with genetic disorder periventricular leukomalacia; delayed development; hypertonia	Mother
22 (old)	1	M	4	Unclear diagnosis; multiple developmental delays; feeding tube; nonverbal	Mother

Data Collection

Each parent participated in one semi-structured interview with the researcher and most also completed a 32-item questionnaire; however, five parents did not complete the questionnaire due to time limitations. Interviews averaged 45 minutes and ranged from 30 to 90 minutes. Parents were given the option of in-person or telephone interviews, scheduled at the time and location of their convenience (see Appendix C for interview protocol). Parents were given the option of in-person or telephone interviews, scheduled at their convenience. Sixteen of 22 (73%) parents chose telephone interviews and provided verbal consent to participate, following approved waiver to document consent procedures. Parents who chose in-person interviews provided written consent. All interviews were audio recorded and transcribed verbatim.

Measures

The questionnaire consisted of two of three subscales of the Family Empowerment Scale (FES) plus six outcome questions of interest (see Appendix B). The FES was created by Koren et al. (1992) to measure empowerment in parents of children with serious emotional disorders. The FES has 34 total items in three subscales: family, service system, and community/political. Only the first two subscales are used in this study because they seemed to measure the types of empowerment most likely to be influenced by participation in care coordination. Detailed information on the psychometric properties of the FES is available elsewhere (Higgins, 2005; Koren et al., 1992).

The Family (12 item) and Service System (12 item) subscales of the original FES were used to measure the level of empowerment of the family within the service system and community context, and the expression of empowerment, which includes attitudes, knowledge and behaviors (Koren, 1992). Empowerment, as measured by the family empowerment scale,

operates at several levels. The *family* level focuses on a parent's perception of how he/she copes with and manages the child's condition in everyday life; how he/she is able to seek help when needed; and how he/she acquires the knowledge, skills and abilities the parent may need to care for the child. The *service situations* level focuses on the parent's sense of his/her knowledge, understanding and rights related to the child's needed services and supports; the parent's sense of his/her collaboration with professionals; and parent participation in decision-making and securing needed services for the child. The *service system* level focuses on the parent's sense of his/her knowledge and rights within the system and his/her sense of how he/she can influence and contribute to improving the system (Vuorenmaa, M., Halme, N., Perala, M., Kaunonen, M., & Astedt-Kurki, 2015).

The original FES has been used in numerous studies and adapted to different populations, languages, and cultures (Singh, et al., 1995). The tool can be used in its entirety or one of the three subscales can be used (Vuorenmaa et al., 2014). In the original and modified versions, the FES has been found to have sound psychometric properties (Singh, et al, 1995). The tool was developed using established scale construction techniques, and the process included pilot item testing and focus groups with 94 parents of children with emotional disabilities. The scale development process and the demographics of that group are described in Koren et al. (1992). The psychometric properties of the FES have been found to be robust in modified versions as well (Dempsey, I. & Dunst, 2004; Nachshen, JS & Minnes, 2005).

In addition to completing the family and service system subscales of the FES, participants were asked to rate their overall level of satisfaction with the care coordination they have received on a five point Likert scale ranging from 'Not at all Satisfied' to 'Very Satisfied'. Finally, participants provided yes/no responses to six outcome questions with the following instruction:

Think about before you were participating in care coordination compared to now. Since you've been in care coordination...

- Has your child missed fewer medical appointments?
- Have you made fewer trips to the emergency room with your child?
- Has your child spent less time admitted to the hospital?
- Has your child missed fewer days of school?
- Have you missed fewer days of work?
- Do you feel you have more support?
- Do you feel less stressed?

4.4 ANALYSIS

The researcher began the study with several *a priori* hypotheses based on the research literature on families of children with medical complexity and concepts of empowerment. These hypotheses included:

- Participation in CC will be associated with increased parental knowledge, skills, and self-efficacy around meeting their children's needs.
- Higher-risk families will find more value in and gain more from CC.
- Families will find that the overall value of CC and what activities are most valuable to them varies by stage of illness and family developmental stage.
- Higher-risk families who are more engaged with CC will find more benefit in CC.
- Families who are actively participating in CC will report better outcomes on key indicators.

Interview Data

Interviews were transcribed verbatim. Transcripts were analyzed using both a deductive content analysis (Elo & Kyngäs, 2008) to determine if and to what extent the interview data supported or contradicted the *a priori* hypotheses proposed, and an inductive analysis approach (Patton, 2015) to identify key themes that emerged from the data. After several initial readings of the transcripts, data were coded line by line using an iterative open coding (Strauss & Corbin,

1990) process of reducing, comparing, and categorizing data, while linking initial codes to the predetermined themes and marking and defining emergent themes. Changes to the developing codebook were marked to review how concepts and relationships among themes developed over multiple readings.

After all transcripts were coded once, an axial coding (Strauss & Corbin, 1990) process was used to revise, interpret, and combine like codes into broader themes, identify sub-codes, and create the final codebook (Appendix D). All transcripts were reviewed and coded again using the final codebook. All data transcription and coding was completed by the PI, using Dedoose version 7.5.9. Key themes and representative quotes are summarized in Table 17. There was no assessment of inter-rater reliability.

Family Empowerment Scale and Outcome Survey Data

Of the 22 parents interviewed, 17 also completed the Family Empowerment Scale and a six item outcome questionnaire asked at the end of the interview. Five parents requested to skip the survey due to time constraints. Each of the 17 participants received a score on two FES subscales, an overall FES score, and had dichotomous (yes/no) outcome data from the 6-item questionnaire. Each item on the Family Empowerment Scale was summed to arrive at two total subscale scores for each participant, which were then summed for a total score comprised of the Service System subscale score the Family subscale score. A composite item mean score in each subscale was also calculated (Koren et al., 1992).

Independent samples t-tests were used to analyze differences on subscale and total FES scores and parent satisfaction ratings among groups (new versus old) and high (tiers 3 and 4) versus low risk (tiers 1, 2, or discharged). Chi-square test of independence were used to analyze

associations between group or tier and dichotomous responses on the following variables: missed medical appointments, emergency department use, hospital admissions, missed school (child), missed work (parent), reduced stress, and increased support.

4.5 RISKS AND BENEFITS

This study presented only minimal risk. The major risk to interview participants was breach of confidentiality and steps were taken to minimize this risk. Only the researcher knew the identities of interviewees. All names and identifiers were removed from the dataset and replaced with ID codes. Only the researcher had access to interview data, which was stored in password protected electronic files. The primary benefit to participating in the study was the opportunity for parents to share their perspectives on participating in care coordination and what it means to raise a child who is medically complex. This information may contribute to a better understanding of parent experiences and preferences for care coordination. Both the Children's Institute's Institutional Review Board and the University of Pittsburgh's Human Research Protection office approved these studies.

4.6 RESULTS

Family Empowerment Scale and Outcome Survey

The Family Empowerment Scale total score mean was 92.2 (range 68 – 105), of a possible 110. The Service System Subscale total mean was 52.0 (range 38 – 59) of a possible 60, with the

composite of 12 items $M=4.32$, $SD=0.82$. The Family Subscale total mean was 48.6 (range 37–56) of a possible 60, with the composite of 12 items $M=4.05$, $SD=0.87$.

The FES scores are high compared to those reported in similar studies. For example, Dixon et al. report a family subscale composite $M=3.42$, $SD=0.59$ and a service system composite $M=3.35$, $SD=0.79$, for family caregivers of those with mental illness (Dixon et al., 2001). In families of children with disabilities, Farber, et al. report baseline total FES scores of $M=48.52$, $SD=6.5$, that increased to $M=71.68$, $SD=8.1$ at follow-up (Farber & Maharaj, 2005). Koroloff, et al. report FES scores of low-income parents utilizing children's mental health services. This study reported Family Subscale total $M=45.6$, $SD=7.1$ and Service System Subscale total $M=49.6$, $SD=5.8$ for the intervention group and slightly higher scores in the comparison group (Koroloff, Elliott, Koren, & Friesen, 1996). Other researches have reported FES results by factors such as: advocacy, knowledge, competency, self-efficacy, and initiative, making it difficult to compare results (Hayslip, Smith, Montoro-Rodriguez, Streider, & Merchant, 2015; Higgins, 2005; Resendez et al., 2000).

It was hypothesized that the length of time in the care coordination program would be associated with higher empowerment. However, there were no significant differences on either FES subscale scores or total scores between the new and old groups of participants. Secondly, the researcher hypothesized that differences in families' acuity level (tier) would be associated with empowerment. However, there were no significant differences on either FES subscale scores or total scores among the four tier levels or low (discharged, 1 and 2) vs. high (3, 4) tier grouping.

Due to small sample size, Fisher's exact tests were used to examine the relationship between groups or tiers and dichotomous variables including: missed medical appointments,

emergency department (ED) use, hospital admissions, missed school, missed work, parent support, and parent stress. The relationship between tier and ED use was significant, $p=.02$. High acuity families (tiers 3 and 4) reported less ED use since enrolling in CC, compared to prior. Likewise, the relationship between tier and hospital admission was significant, $p<.01$. High acuity families reported fewer hospital admissions since enrolling in CC, compared to prior. There were no significant differences on these outcomes between the old and new groups.

The variable of parent satisfaction with care coordination was also analyzed for 21 parents who completed this item, by group and tier, using independent samples t-tests. While there were no differences in satisfaction by tier level, those in the new group reported higher satisfaction ($M=5.50$, $SD=1.761$) than those in the old group ($M=4.81$, $SD=.403$), $t(20)=1.516$, $p=.011$

Parent Interviews

The final interview sample included 22 families of 23 children. Of the children, 57% were male and the average age was 8.4 years. Seven children were in tier one, five were in tier two, seven were in tier three, three were tier four, and one was discharged at the time of interview. The sample was heavily biased toward families in CC longer than six months. Compared to the total population of CC participants, this sample was more evenly split by sex and slightly older.

In addition to the themes explored by the interview script, several themes emerged from the interview data that were either unanticipated or revealed themselves to be primary outcomes of participation in CC, in the minds of parents. Table 17 summarizes the main themes from the parent interviews and provides 1-2 representative quotes for each theme. Although parents

shared a wealth of valuable information about their experiences, only four main themes have been chosen to present in detail this paper because they represent the benefits most discussed by parents that were directly related to participation in CC.

Table 17. Main Themes and Representative Quotes

Main Themes	Saliency of Themes	Representative Quotes
Access to Needed Services, Programs, and Materials		
Efficiency	Code used 52 times: -46% in “old” group -54% in “new” group -60% in low risk group -40% in high risk group	<p>“We have so many doctors’ appointments and problems with insurance. Like getting her Simply Thick covered. My daughter is not allowed thin liquids and I fought for well over a year to get the thickener she needs for her liquids to be covered by insurance. It was costing us over \$200 a month and she needs it to live! I had so many insurance battles on my own. I was getting nowhere. But when care coordination called it was a completely different story. I mentioned how frustrating it was that it was taking up such a huge portion of our monthly budget. Within days she not only had it covered by insurance but it’s now delivered to my house every month. She can make all those phone calls for me that would be fine!”</p> <p style="text-align: right;">- Mom of a child in tier 2, old group</p>
Legitimacy	Code used 27 times: -37% in “old” group -63% in “new” group -80% in low risk group -20% in high risk group	<p>“A lot of times at IEP meetings I am like ‘She does this.’ And they are like ‘We don’t see it at school.’ And you feel like, I mean, I know they probably don’t think I’m making it up, but it’s nice to have someone sit there and say, ‘Yes, these are the things that have been reported to me.’ They are able to advocate for me. [The Education Advocate] is a psychologist so her sitting there saying ‘These are the things [the child] is dealing with.’ means more than me sitting there saying ‘Well she gets really frustrated when she’s doing her homework and she’ll have a meltdown.’”</p> <p style="text-align: right;">- Mom of a child in tier 1, old group</p>
Advocacy	Code used 31 times: -74% in “old” group -26% in “new” group -87% in low risk group -13% in high risk group	<p>“[The education advocate with care coordination] would come to his IEP meetings and any important parent-teacher stuff. It was helpful for me to have that back up there. And it seemed like they listen a little more when you have someone there who they think can you know enforce certain things. I needed that back up there and she also taught me a lot about what the laws are and what my rights as a parent are. And that the ADA covers a lot of things, like if they aren’t following his IEP then they are in the wrong so put it in the IEP.”</p> <p style="text-align: right;">- Mom of a child in tier 1, old group</p> <p>“I think I’m getting to where my opinion counts as much as professionals’. At the beginning we just listened to everybody and we’re starting to learn his needs and how we can hopefully be his voice.”</p> <p style="text-align: right;">- Mom of a child in tier 2, old group</p>
Parent Time	Code used 96 times: -39% in “old” group -61% in “new” group -38% in low risk group -62% in high	<p>“All the time I’d be wasting, like I was before CC, trying to make appointments and fight with insurance and everything like that, it’s time that I wasn’t able to spend taking care of my children. It does make a big difference [having care coordination].”</p> <p style="text-align: right;">-Mom of a child in tier 2, old group</p>

Table 17 Continued

	risk group	
Point of Contact	Code used 85 times: -51% in “old” group -49% in “new” group -60% in low risk group -40% in high risk group	“CC is so much more efficient. I have a phone number I can call and ask questions. I’m not waiting for answered prayers, literally. Somebody’s gonna have a clue about what I should do. I have had resources in the past but those tend to come and go, like teachers, or the wraparound agency we were with had a resource person you could call.... CC is now my first call. They are really good and their resource bank is growing all the time. They are my first call so that saves me an immense amount of time. And time is a factor with these kids.” – Mom of a child in tier 4, old group
Resources	Code used 92 times: -36% in “old” group -64% in “new” group -37.5% in low risk group -62.5% in high risk group	“There’s a lot out there, but it’s how to find it.... When you have somebody who specialized in the area, you could say, it’s 10 times easier. Especially when you start out. I still don’t know what I’m doing, but I’m faking it a lot better these days! It’s just nice to know there’s another resource to go to. Instead of trying to call 20 places, you can call one. That definitely makes your time more efficient.” – Mom of a child in tier 4, new group
Coordination among systems and providers due to CC	‘Team’ code used 60 times: -38% in “old” group -62% in “new” group -58% in low risk group -42% in high risk group ‘CC structure’ code used 24 times: -42% in “old” group -58% in “new” group -82% in low risk group -18% in high risk group	“[Care coordination] works like a network should work. Many people are talking to each other and everybody’s on the same page. Maybe they’re an expert on this page, but they’ll turn the other page for me, to get that thing moving too. They really are coordinated in their care. It’s not like they just do their piece. CC doesn’t just do one thing only. They really work together to coordinate for the family. Whatever the family’s needs are. They really think about it and maybe they’ll do some research and call back.” – Mom of a child in tier 4, old group
Family Support		
Emotional Support	Code used 35 times: -60% in “old” group -40% in “new” group -81% in low risk group -19% in high risk group	“I think there’s a benefit just to knowing someone is there. That someone else knows what all is going on and knows all the moving parts. Because it can be overwhelming, and I feel like I give [the care coordinator] more things to do when I am feeling overwhelmed. This is a really lonely island to be on. It can be very isolating and scary. So to know that there’s someone with that technical background that you could ask and who is your single source, it’s really helpful.” – Mom of a child in tier 3, new group “Sometimes it’s very frustrating. It definitely helps tremendously to have somebody kind of like a guide, that you can also talk to, but you can also express your frustration to, like I don’t know what to do. What do other people do?”

Table 17 Continued

		- Mom of a child in tier 4, new group
Logistical Support	Code used 106 times: -50 (47%) in “old” group -56 (53%) in “new” group -58% in low risk group -42% in high risk group	“Without care coordination, it’s like the parent is on their own. And the system won’t kick in until the parent or the child has failed miserably. They don’t see you until somebody’s hurting themselves or others, somebody lands in the hospital, or something really bad happens. Care coordination is like a safety net to help keep the treadmill running at a faster speed so the parent doesn’t fail.” - Mom of a child in tier 4, old group
Parent Stress	Code used 42 times: -52% in “old” group -48% in “new” group -63% in low risk group -37% in high risk group	“It’s a ton of pressure on me [caring for son]. I get tons of phone calls every day, about all different things. I rarely have time for myself. I don’t leave the house. And this has been for quite some time.” - Dad of a child in tier 4, old group
Developing Capacity		
Lived Experience	Code used 55 times: -55% in “old” group -45% in “new” group -54% in low risk group -46% in high risk group	“Nobody knows this road as well as parents who have lived it.” - Mom of a child in tier 3, new group
Learning System	Code used 54 times: -22% in “old” group -78% in “new” group -38.5% in low risk group -61.5% in high risk group	“Before we were in CC...I would have had no idea that things were available, like where to go for our medical supplies, and how to start or continue that process, or that there was transportation available, or how to sign up for medical assistance. I mean who in your daily life would ever be exposed to these things?” - Mom of a child in tier 3, new group
Parent Perseverance	Code used 31 times: -35% in “old” group -65% in “new” group -26.5% in low risk group -73.5% in high risk group	“You just have to, you know. I would say, and I’m sure any parent would say, you do whatever it is you have to do. And you get used to it.” - Mom of a child in tier 1, old group “That is why I persist. If [care providers] are willing to learn, I’ll work with you. I go in, if you get it right, okay, we’re growing together. And I try to keep the positive attitude. Anger does no good for me. That will eat me from the inside out. So I try to look for the positive.” - Mom of a child in tier 3, new group

Efficiency

One primary theme that emerged from the interview data was efficiency. Of 22 families interviewed, 14 (64%) indicated they felt their participation in CC had resulted in increased efficiency with regard to their children receiving needed supports or services. Specifically, the children received services more quickly and/or with less hassle or family time and energy involved to obtain them, than families experienced without CC. Of these 14 parents, 10 had been in CC for more than six months at the time of the interview. Six of the 14 families were “high risk,” that is, classified in tiers 3 or 4, while eight were low risk (tiers 2, 1 or discharged).

The three most frequently discussed outcomes of increased efficiency were: 1). The family obtaining an appointment with a particular doctor or specialist more quickly, especially for an initial appointment with that provider; 2). The family obtaining needed supplies, paperwork, or referrals more quickly; and 3). Families’ time saved in the search for a needed resource due to care coordination’s intervention, expertise, or care coordination being the “one-stop shop” of information.

While families experienced these benefits to varying degrees, all three types of efficiency were greatly appreciated by families who experienced them because the intervention of CC relieved some responsibility and saved them valuable time. Many families provided examples of how participating in care coordination led to a child getting a needed appointment or medical supply faster, either because the intervention of the care coordinator brought greater urgency or authority to the request, or because the care coordinator was more knowledgeable than the family about how to navigate the system to obtain what was needed. The following quote illustrates this phenomenon.

“The most amazing example was a particular neurologist I had called five times and got nowhere. [The care coordinator] called and within 20 minutes of me calling her and her saying that she’d call the neurologist’s office right now, I got a call back from the office apologizing to me for not getting back to me. If your child has seizures – and she has multiple types of seizures – you kind of want an answer!” - Mom of a child in tier 2, old group

Numerous families talked at length about the myriad demands on their time for activities like making calls, waiting for return calls, completing and submitting paperwork for providers or insurers, and researching programs or answers to their questions. For them, much of the value of participating in CC was due to CC managing tasks that then freed up parents’ time for other demands. Specifically, families described CC as saving them time because one could begin a search for a needed resource by contacting CC, who could then provide a starting point, a vetted list of resources, or otherwise guide or narrow the parent’s search. This support from CC helped families to learn how to approach searches and increased parents’ knowledge of available resources and credible sources of information. For many families they felt more capable conducting searches on their own as their knowledge grew. Examples of this included CC providing a parent with an initial list of dentists who were equipped to work with children with special needs, and a list of sensory-friendly summer programs.

“Having a kid with special needs, I’m not just going to find a dentist who takes my insurance, I need to find a dentist who can handle that. Cause it’s gonna be rough. It’s gonna be hard. And I don’t want somebody ignorantly forcing themselves on him without respecting the fact that it’s an issue, he’s not just a ‘bad kid’.” – Mom of a child in tier 2, old group

“She has five therapies a week at the Children’s Institute, she has DART three days a week, and she has you know, almost a dozen – more than – specialists, but we don’t see them all

regularly. They are through the Institute and Children's. It's a full time job [managing it all] and it was even more so before care coordination because I was literally sitting on the phone some days just trying to get something covered by insurance or get an appointment made. And now if I run into anything I just call [the care coordinator] and she gets it done." – Mom of a child in tier 2, old group

Additionally, some families noted that CC was especially helpful in this way at the point when a child had initially been diagnosed or the family was just beginning its journey navigating these systems. At that time, because it was all unfamiliar territory, families felt they had a lot to learn about what resources and supports were available, what programs their children might qualify for, and how to obtain and pay for these services.

"There's a lot out there, but it's how to find it.... When you have somebody who specialized in the area, you could say, it's 10 times easier. Especially when you start out. I still don't know what I'm doing, but I'm faking it a lot better these days! It's just nice to know there's another resource to go to. Instead of trying to call 20 places, you can call one. That definitely makes your time more efficient." – Mom of a child in tier 4, new group

However, some were unsure or did not feel CC was in a position to increase efficiency in access, especially if the needed service was located outside of the Children's Institute, for example, as one parent stated:

"I feel [frustrated] a lot in dealing with Children's Hospital. I feel like their neurology department has some serious, serious issues. And I don't know if CC can affect the speed with which people can get back to me or to get an appointment. I can't really tell if they have any influence on that. I'm not sure if CC can influence that aspect of the neurology department or not." – Mom of a child in tier 3, new group

In other instances, family expectations of what CC could do did not match the reality.

“I called [CC] whenever I was looking for an ENT. And they sought some out and I had already looked into them all, so they were like ‘You’ve done everything that we could do. So what could we have possibly done differently?’ I think that given [the care coordinator’s] position that you might be able to get an appointment faster – that you have more of an inside resource as opposed to the parent.” – Mom of a child in tier 2, old group

Notably, there was variability in the types and amount of support families received from CC. Some of this variability appears to be due to what type of CC staff the family was interacting with and the specific knowledge and/or role of that staff. Some was likely to due to family preference. However, there was also variability in how families perceived individual CC staff with regard to breadth of knowledge and thoroughness of response. One parent who had been assigned to an initial care coordinator later switched to another because she wasn’t satisfied with the first. From the parent’s perspective there was huge variability in the knowledge between these two staff, especially in how to get medical supplies covered by insurance, which was a primary concern for the family. Furthermore, some families described not receiving a specific type of support such as a resource list from CC that others mentioned they had received. It is unclear to what extent these differences are due do interacting with different CC staff, how the parent approached the request to CC, or another reason.

Legitimacy

Another notable theme that emerged from the interview data was legitimacy. Six families (27%) described CC as adding a sense of legitimacy to their needs in the eyes of medical providers, school staff, or other professionals who were gatekeepers of services. Of these six,

four families had been in CC for over six months and two families were considered high risk (tiers 4 or 3). Families shared examples where the intervention of a CC staff on behalf of the family led to the family's concerns being taken more seriously and acted upon more quickly than when the same concern was presented by the family alone. Legitimacy was co-reported with efficiency, but these six families specifically noted they felt CC added significance to their requests, not just that they received quicker action.

“There’s a lot of times you can call a person, and me and you can be asking for the same thing. And it depends who picks up the phone on the other end. My voice might put you into some kind of way. [The care coordinator] will call back and say the exact same thing and get the approval.” – Dad of a child in tier 4, old group

“It’s a big game. I manage medical benefits for an insurance company and it’s a sad game. I work in the industry but I’m not a part of the authorization process for things. So [the care coordinator] and people at the home health agency are intimately aware of what you need to do to win that game. And if I were doing it on my own there’s no way I could.” – Mom of a child in tier 3, new group

Sometimes families attributed the legitimacy effect to the claim being made by a professional rather than “just a parent”, and in other instances it was because CC brought a team with additional resources to the family's situation.

“[Care coordination] is definitely helpful. A lot of times doctors just kind of look at you like ‘Oh you’re just the mom, what do you know?’ I can make the same phone calls to a particular doctor’s office 5-6 times and get nowhere. [The care coordinator] can call once and get it done.” – Mom of a child in tier 2, old group

“And I know a lot of times when it’s an agency or a business reaching out instead of just one person, people stop dragging their feet or giving the run-around. [Care coordination] was very helpful with that. I did see progress as a result of them reaching out. When the school realized that I’d gotten other people involved in our situation... it kind of lit the fire under them to do the right thing.” – Mom of a discharged child

This legitimacy phenomenon was mentioned by multiple families in the context of Individual Education Plan (IEP) meetings with school personnel. In these cases, either the care coordinator, the Children’s Institute’s Education Advocate, or both, served to increase legitimacy.

“A lot of times at IEP meetings I am like, ‘Well, she does this.’ and they [school personnel] are like ‘Well, we don’t see it at school.’ And you feel like...I know they probably don’t think I’m making it up, but it’s nice to have someone sit there and say ‘Yes, these are the things that have been reported to me.’ They [care coordinators] are able to advocate for me.” – Mom of a child in tier 1, old group

“You need advocates for the school. You’d think the school would get it. Some do, some don’t. Right now I have the best Special Ed Director. I have the dream team. But let me tell you, you go through nightmares with the school and your kids.” – Mom of a child in tier 4, old group

These examples of professionals achieving desired results, when families could not, might make some families feel un-empowered when they feel their voices are not heard directly. During the interviews, no parent mentioned feeling resentful of CC staff for this phenomenon, in fact most sounded appreciative that CC could intervene for them. However, several families expressed a general sense of frustration or resentment that their lived experiences 24/7 with their

children were not afforded as much weight as voices of professionals who may have limited time and experience with their children.

Several families described their extensive struggles to obtain a resource such as durable medical equipment or increased hours for in-home nursing assistance, when both legitimacy and efficiency were mentioned. Often these claims were denied or delayed because the item in question was not considered to be medically necessary, but the family felt it was necessary to maintain or improve the child's quality of life. When CC got involved, families felt their claims were approved more easily.

"They've been trying [to get the home health aides]. They talked with the pediatrician's office and the insurance company too. They've been vouching for me; it's made it easier." – Mom of a child in tier 2, old group

"Care coordination helped us a few times when we were denied supplies. They told us, 'Let me go get a letter from the doctor and get it to you and get it turned in and take that burden off.' They've done that a few times. Wrote it up, got it signed, and we submit it. That kind of stuff comes up a lot. Now we somewhat know what to do. It doesn't mean [the insurance company] won't deny it but, now we know we can ask." – Mom of a child in tier 2, old group

As noted in the quote above, care coordination's involvement also helps families understand their role and rights. Care coordinators not only advocate directly for the child and family, but can model advocacy strategies, and coach families in effective advocacy.

"[The education advocate with care coordination] would come to his IEP meetings and any important parent-teacher stuff. It was helpful for me to have that back up there. And it seemed like they listen a little more when you have someone there who they think can enforce certain things. I needed that backup there, and [the education advocate] also taught me a lot

about what the laws are and what my rights as a parent are. And that the ADA covers a lot of things, like if they aren't following his IEP then they are in the wrong, so put it in the IEP." –

Mom of a child in tier 1, old group

"They [care coordinators] try to see what programs are available and can put in referrals, and be able to advocate for her, and make sure she's getting the services she needs. Like when I first started her at the school I said I wanted them to test her and they didn't want to. Care coordination told me you are legally entitled if you tell them you want them to test her they have to do it. They can't say 'Let's just start her and see how she does.' So care coordination gave me the knowledge to go in there and advocate for my daughter. And they advocate for her directly, in meetings and stuff, so that she can get more support in her IEP. I have had several meetings with the school because I wasn't happy and [care coordinators] are able to come support me or they will call in if they can't be there in person." – Mom of a child in tier 1, old group

Additionally, CC appears to give validation to the concerns and questions facing families when medical or other providers may not. Because care coordinators look at the child and family holistically, they are in a position to see across individual medical specialties or provider roles to have a more comprehensive picture of the child's and family's needs. This vantage point may lead to a child getting access to supports and services to which individual doctors had not thought to refer to the family. Care coordinators also spend considerable time listening to the family's story and developing a plan of care that is based on needs and priorities identified by the family.

"As special needs parents we are just always thinking 'Is it just me? Am I making this up?' But to have somebody say 'It's not you.' is the best thing in the world. You have people

telling you all the time 'It's in your head. You're making it up.'... You're always wondering 'Is she progressing? Is this normal? What is this, what is that?' The doctors hate me because I call them every other day like, 'What does this mean?' And some doctors think you're loony, because they don't see your kid more than every 6 months." – Mom of a child in tier 3, new group

"All the different behaviors and my talking to the pediatricians and therapists and stuff, it was adding up to be something to me, but each individual [provider] was seeing their own thing. So I contacted [the care coordinator] and said 'I need help. This is what I'm seeing. Could it possibly be...? I am concerned.' She was able to contact [a doctor at the Children's Institute] and get us into the Merck program and talk to the people at the Down Syndrome clinic. [The care coordinator] does a lot of the behind the scenes or the background work to make stuff happen." – Mom of a child in tier 2, old group

While many families felt CC had helped them in these situations, others did not. Several felt that their position as “just parents” and CC’s intermediary position had limited power to contradict a medical provider’s or an insurer’s decision, as highlighted in the following quote.

"And I'm only mom so I can't say 'Do this test.' And my insurance company also agrees, 'Look if this doctor says to do it, you should do it.' But my doctor is saying she can't decline a referral for a test when it's something outside of her expertise. So she approves everything but other doctors won't approve what she's asking for. It's like a different network and it's frustrating. There is not much CC can do whenever I don't know what I need." – Mom of a child in tier 2, old group

Family Support

Nineteen of 22 families interviewed (86%) described feeling increased support since enrolling in CC. Of these, 14 families had been in CC for over six months. Eight families were high risk (tier 4 or 3). Care coordinators provided several types of support, including emotional support, such as by listening to the family's concerns; and logistical support, such as being available to trouble-shoot and work to increase families' access to resources. Families noted that logistical support also made them feel emotionally supported. Most appreciated both aspects of CC's support but not all families reported both aspects, or utilized them to the same extent. For example, some stated they were not comfortable or they did not think it was appropriate to rely on CC staff for more intensive emotional support. Others filled this need through family or friends.

“When I realized that CC was like a team of people, somebody for me to talk to, as well as a nurse, and some sort of health coach. I just thought ‘Oh, that is exactly what I’m looking for.’” – Mom of a child in tier 3, new group

“I think there’s a benefit just to knowing someone is there. That someone else knows what all is going on and knows all the moving parts. Because it can be overwhelming, and I feel like I give [the care coordinator] more things to do when I am feeling overwhelmed. This is a really lonely island to be on. It can be very isolating and scary. So to know that there’s someone with that technical background that you could ask and who is your single source, it’s really helpful.” – Mom of a tier 3 child, new group

“For me, [care coordination] definitely helps to validate my feelings about things. And that does help. Like I said, it’s almost like talking to a therapist in a way. I can get things off my

chest. If nothing else, I can let them know how I'm feeling about things.” – Mom of a child in tier 3, new group

Sometimes just knowing of the presence or availability of a CC member was an emotional support to a family.

“It's like once you leave that doctor's office, [care coordination is there to ask] how can we help you? How can we make it easier for you? Because, unlike the doctors, when you go home this issue is still going to exist.” – Mom of child in tier 2, old group.

“I guess [the most beneficial thing about care coordination is] just a lot of support for me. I'm pretty resourceful. I've been dealing with this since she was born, and different things. Just the support is the biggest thing for me. And I think for [child] too. When she sees Elyse she remembers her and knows there are other people out there who care about her.” – Mom of a child in tier 3, old group

“[The education advocate] came to all the [IEP] appointments and she really gave me peace of mind. That was actually probably the most helpful thing. Just feeling like I had somebody who was on my side and hearing my concerns and was really knowledgeable about what we needed and the policy stuff.” – Mom of a child in tier 1, old group

As with the previous themes, logistical support is helpful because it relieves some of the caregiving burden on families, and is usually accomplished by CC drawing on their expertise to set up a needed service or facilitate access to resources.

“I feel like I can do research on the internet, but they almost have like “ins” with For instance, L. was also in therapy with Western Psych, and [the care coordinator] was in contact with them and now we have a service coordinator with them just for some family problems. My

husband and I are separated and I had noticed some behaviors as a result of what was going on at home. So [the care coordinator] set that all up for me.” – Mom of a child in tier 1, new group

Some families used both aspects of support, depending on the current need.

“[The care coordinator] is a great person. She is a rare person, she’s just like that. You might go through a lifetime and never meet anyone like her. As far as the things I’ve been through and the obstacles I’ve had to overcome, I don’t think I’d have been able to get as far as I have without her. If I have problems with anything, my supplies, medical equipment, anything, I can call her. If I’m just having a bad day, I call her and we’ll talk and laugh and stuff like that. She’s been the greatest, honest. And she always says, ‘[Parent name], I’m not doing anything extra. I’m just doing the job I’m supposed to do.’” – Dad of a child in tier 4, old group

Numerous families talked about appreciating that care coordinators took the time to be available and to *listen* to the parent. Care coordinators were perceived as being genuinely concerned for parents’ and children’s wellbeing and interested in helping, and a number of families identified this as feeling different from their interactions with other professionals in similar roles, and from medical providers. Additionally, families described efforts by care coordinators that they felt were “above and beyond” their job responsibilities.

“I think I’d called [care coordination] with a question or something. And I guess it was just noticeable that I was just overwhelmed with everything. [The care coordinator] is quite compassionate and thoughtful, and I felt that she just let me talk when I’m sure that she has many other things to do in her day. I thought that was quite nice, and it’s sometimes quite rare. I probably won’t ever forget it. I just needed someone to care for a second when everything was just so screwed up.” – Mom of a child in tier 1, old group

“They would come find me [at the Children’s Institute] when my son was doing his therapy sessions and sometimes I would just go down to the cafeteria to have a cup of tea or something, and they would look for me to make sure that I was okay. I feel like I’m starting to get a little emotional because I hadn’t thought of that in a while, but it was really, really a hard time. It was one of the hardest times in my life and it was the hardest time in my son’s life. But they were so helpful and instrumental in helping us through that. They were always so considerate and kind. They would reach out and ask how we are doing. And they LISTENED. I was going through a time when I couldn’t get a lot of people to listen. But they would listen. Even though they were just doing their jobs, I don’t know if they realized the full impact that they made on us.” – Mom of a discharged child

“This feels more like a family atmosphere. Like they are all about the parents and the families and it’s very supportive. The other people are like, ‘Yeah, we’ll get to it when we get to it.’ And you have to figure it out on your own because they aren’t going to do anything. Here I don’t have to worry about that.” – Mom of a child in tier 3, new group

Some families described this support as especially helpful during times of discharge from inpatient care to a home or other setting, or at the time of receiving a diagnosis or struggling to find the child’s diagnosis. Families relayed they felt they were being sent home with no support when their child was discharged, after being completely managed during the child’s inpatient stay.

“It is hard, when you’re inpatient and there’s always somebody there holding your hand, no matter where he was. The nurse would say ‘Let me call the doctor or the PT on that.’ And you go home and it’s like you stepped off the cliff. It’s like ‘Who do I call?’ I was thrilled there was

somebody to call 'Like hey, if you don't know where to turn, call us. We'll walk you through it.'"

– Mom of a child in tier 2, old group

A parent of a child who had an acute illness that left him a quadriplegic described leaving the hospital and having to learn every aspect of his care as well as the medical, therapeutic, and education systems in which the family must now operate.

"[We had] no experience at all with anything – at all. I always said I didn't want to go into medicine but... yeah. Everything. I know almost too much now. First of all, you have to learn the care yourself. It's a lot of care. You have to learn how to suction somebody for trach and vent. He's g-tube fed, so learning all that. Just even the simple things, like how to give medicine through the g-tube, stretching him, etc. We had to learn from the PT how to transfer him, all the equipment to get, to utilize... yeah we had to learn everything." – Mom of a child in tier 2, old group

Chronic childhood conditions have common periods within the experience of the illness "lifecycle". These include the acute initial phase of diagnosis, which is followed by a potentially long period of treatment, recovery, relapse, and survival. Each of these phases within the illness experience brings different challenges and stressors for children and their families (Compas et al., 2012). Several families also noted the amount and nature of the support received from CC varied over time in their working relationship with CC, as families' needs changed and as parents became more experienced and comfortable managing their children's conditions. Although families entered CC at differing stages of their children's illness lifecycle, with differing levels of lived experience, many parents noted that the diagnosis stage or an initial acute stage was a time they relied heavily on CC.

“I wouldn’t say that they were just more helpful in the beginning; they were helpful whenever it was necessary. And it was very helpful in the beginning of our relationship... that’s when everything was still fresh. So it was more at the beginning because that’s when it was necessary. And over time, I wouldn’t say that things slowed down or fell off, but they had helped to get the ball in motion. And because it was in motion, things started to fall into place slowly but surely. But it was more necessary in the beginning.” – Mom of a discharged child

“For the most part now we are at like the maintenance level, almost at recovery. So they kind of just check in with me now. But believe me when this first happened, I didn’t know where to turn. I was calling everybody, just frantic.” – Mom of child in tier 2, old group

In most cases, the progression from an acute or initial stage of the child’s illness to a maintenance or stabilized stage represented a period of relative calm for families and a time when parents had accumulated enough lived experience and knowledge that they felt more confident and autonomous in both providing direct care and managing services for their children. The downside to reaching this stage, however, was often that a family’s hours for in-home supports were reduced, resulting in more demands on parents’ time as they assumed primary caregiving responsibilities. Numerous families expressed the need for more in-home help to provide direct care, give the parent respite, or enable the parent to be employed or pursue education outside of the home.

“He’s not critical anymore. When he came home [from the hospital], he was on a ventilator, he had a trach, the whole nine. We don’t have none of that anymore, so he’s made a lot of progress in a year. And the more progress he’s made, the less hours [of in-home help] we can get.” – Dad of a child in tier 4, old group

Several families commented on the benefit of CC staff staying with them over time, compared to other providers or services coordinators who came and went as children transitioned among services. Continuity was important and helpful for families to bond with CC staff.

“We’ve been through all different therapies and time has passed but [the care coordinator] is still there. That’s what is nice about care coordination. They stay with you while others are just there for a little bit of time. It’s a stronger bond, I guess.” – Mom of a child in tier 3, old group

However, even with the support of CC, many families noted there is still room to remove duplication and improve coordination across providers, insurers, and services systems. Nearly all families shared at least one story of a prior bad experience within the health care system, or talked of duplications and inefficiencies in the process of obtaining needed services and supports. Families felt more could be done to make the process of accessing care easier on families.

“There’s all these different agencies out there and all these different doctors and they all do the same thing sometimes. I wish there was a way to streamline the process a little better but until all the agencies start working together a little better...” – Mom of a child in tier 4, new group

“There’re times when I don’t have nurses for days. I’m here, lack of sleep, I’ve been doing this for so long, why do I have to keep giving this same information over and over [to agencies to ask for what I need]?” – Dad of child in tier 4, old group

“You call your medical and they would say, ‘No, autism is mental health.’ And you would call mental health and they would say, ‘No, that’s medical.’ And they would play you back and forth.” – Mom of child in tier 4, old group

“[Care coordination] is referring me to the same groups as the [other service coordinators the family has] and nobody makes appointments. [Care coordination] said they would make appointments but they give you a referral. Everybody will be happy to give you a phone number but you have to make the call. You have to do all the leg work. It seems that everybody likes knowing the resources and giving you the phone numbers but nobody is there for the real work.” – Grandmother of child in tier 3, new group

Despite this parent’s experience in the quote above, in other cases, CC did directly make appointments on the parent’s behalf, when the parent requested it. This particular parent reported a very different experience and level of satisfaction with the type and amount of support received in CC, compared to other families. It should be noted, however, that this parent indicated that her demanding work schedule prevented her from being in regular contact with or taking full advantage of what CC had to offer. It seemed that she had never had the opportunity to explore what CC could offer her, yet she struggled greatly with many of the challenges with which other families had received support from CC.

Family Stress

During the interviews, families talked frequently about constant stress due to the nature of their children’s conditions or uncertainty about their conditions, providing direct care to their children, and managing the care and supports their children need. For many, the endless responsibility of manage services, numerous appointments, their children’s changing needs, various care providers, and insurance claims was a significant burden on their time and emotional resources and often took a toll on other members of the family and the family’s quality of life.

“It’s tough. As anyone with a special needs child will tell you, it’s tough. It’s really stressful.” – Mom of a child in tier 3, old group

“I try not to worry, but there is this part of me that lives in fear. Because they don’t know much about epilepsy at all, even the neurologists. You read about sudden death in epilepsy and it’s just a very scary, scary thing. I live in fear, especially when he’s going through a growth spurt. When he starts eating a lot, just like inside me, I start feeling like, ‘Oh God it could happen soon.’ Because when he’s growing...he could have a break-through from the medicine. Knowing that it could happen at any time. Even in the pool he has to be watched. Bike riding. He can’t just be. He’s 11 and he’s independent but people need to understand that there’s always a chance.” – Mom of a child in tier 3, new group

“We take it one day at a time. Sometimes one minute at a time. Basically, I make work my relaxation, even though it’s stressful too. That’s when I get away... It’s just a different type of stress. Being a caregiver is one type of stress. At work it’s different.”- Grandmother of a child in tier 3, new group

As with the theme of support, 19 families (86%) noted they felt reduced stress since enrolling in CC. Fourteen of these had been in CC over six months, and eight families were considered high risk (tier 4 or 3). Families spoke about care coordination taking responsibility for certain tasks, as well as appreciating just knowing someone was there for them and feeling that they had a place to call and a person to talk to when they had challenges, questions, or concerns.

“I think just knowing that the program is there as a back-up, removes a lot of anxiety in itself.” – Mom of a child in tier 2, old group

“The fact that [the care coordinator] is calling around and trying to find someone [for in-home help], that takes the pressure off of me. I don’t have to worry about that as much, which is nice. Cause I’m not trying to sit around and call and get stressed out about stuff.” – Mom of a child in tier 2, old group

“Knowing that it’s not solely up to me to figure it out helps so much. Like, the pressure would be there, but it would be less than what it is now. I know that if I cannot figure it out, I can go to them and they will.” – Mom of a child in tier 2, old group

“It would be very bad [without care coordination]. I mean I was losing my mind trying to do all of it and trying to figure out what doctor to see. And when she has appointments, when she doesn’t have appointments. Where are we going? So it’s very nice that I have someone to say ‘Ok, we’re going to do this and do that, and we’ll take care of this, and we’ve got your back.’ Me trying to do it all by myself and the stress level is....” – Mom of a child in tier 1, new group

The availability and responsiveness of care coordinators, as well as the parent-coordinator relationship seemed to distinguish the care coordinators from other service providers in parents’ minds.

“Out of all the things that we go through, whatever I go through, I can always fall back on [care coordinator]. She’s been there since day one. The things that she’s done and the things that she’s helped me through, I don’t see how the Institute can go without [the care coordination program]. And I’m certain she doesn’t just do this for me, I am sure she does this for everybody.” – Dad of child in tier 4, old group

“I was stuck in a snowstorm, on a hill, I was visiting one of my friend’s houses, and I ran out of [son’s] formula, and I called CC, and I’m like, ‘I’m stuck here and I’m on this hill and I can’t come home for like a week. This is crazy.’ It was a private drive and they weren’t

shoveling. And [the care coordinator] met me at the bottom of this hill with a can of formula. That's how much they have helped me. I was like 'I don't know what to do.' And she was like 'No honestly, I can get the formula and I will bring it to you.' That's why I love them, you have no idea." – Mom of a child in tier 1, old group

Despite the benefits of CC, families noted that the program cannot remove all of their stress in the day-to-day reality of caring for and raising a medically complex child, which is often very isolating for parents.

"There is still a lot of stress! [Care coordination] has been nice, but when something hits, it's like you're under attack." – Mom of a child in tier 4, old group

"I'm very, very much alone in my world with this child. You know you have friends, and yeah, it's sad and upsetting and they are compassionate, but they really don't know what it's like to go through some of these issues because they're just not dealing with it." – Mom of child in tier 3, new group

"Nobody knows this road as well as parents who have lived it." – Mom of a child in tier 3, new group

4.7 DISCUSSION

As one care coordination expert noted, "The ultimate measure of effectiveness of a system of health care is how patients and families themselves experience it." (Antonelli et al., 2009, page 17). Qualitative research is critical to understanding which aspects of CC are most beneficial for which families and why. No amount of literature review or survey data could have illuminated the complexities of the family experience of raising a medically complex child like the in-depth

interviews or clarified the value of care coordination from the family perspective. There are some important findings about the impact of CC on families of CMC. Families find CC to be a tremendous source of emotional and logistical support, which is a stress reliever. Generally, families also perceive greater efficiency in receiving needed information, resources, and services due to CC. Significantly, high-risk families also perceived a decrease in hospitalization and emergency services uses since enrolling in the program.

After speaking with families, it also became clearer why some *a priori* hypotheses could not be answered and why there were no significant results on some outcomes measured by the survey. First, families joined CC at varying times: some enrolled shortly after an initial diagnosis, as their children transitioned from inpatient to home-based care, while other families had been living with and managing their children's conditions for many years without formal support. Some children in the program had been considered medically complex since birth, while others did not become so until an acute and unexpected event later in life. These factors provided tremendous variability in the families' illness experiences, which seems to be more strongly associated with empowerment than time in the care coordination program.

The association between the length of time enrolled in care coordination and family empowerment seems to be heavily influenced by, or perhaps less important than, the length of time a family has lived with and managed a child's condition, a concept that is supported by the family systems illness model (Farber & Maharaj, 2005). The interviews indicated that, in general, lived experience may have more impact on families' perceived control of factors that influence their quality of life than does the presence of a care coordinator. Despite this, even families with years of lived experience typically still found benefit in CC. Much of the perceived benefit of CC seems to be affected by predisposing factors, that is, family characteristics like

parent age and education level, and enabling factors, such as the amount of supports a family has. The presence of psychosocial stressors facing a family also appears to be related to the family's perceived value of CC, whereby families with greater stressors find greater value. CC may be a facilitator or an accelerant to the development of empowerment by fostering the development of effective coping strategies. CC can provide families with pathways to new knowledge of systems and resources, model self-advocacy and navigation of service systems, remove some access barriers, and bolster families' feelings of emotional support. The initial benefit of access to new knowledge and resources may explain why families new to the program indicated higher satisfaction levels than those in the program over six months. After an initial gain through CC, families may begin to handle tasks autonomously and feel diminishing returns from CC, which may be linked to reduced satisfaction.

It was also difficult to tease out differences in the impacts of CC by family risk level for several reasons. One, tier classifications change with a family's varying needs and resources. Families are "tiered up" or "tiered down" as they cycle through acute periods of need and more stable periods, and as they build up resources to manage their situations autonomously. Therefore, the tier assigned to a family at the time of the interview may not be representative the tier in which the family spent the most time while enrolled in CC, nor an accurate measure of the best overall tier rating for a family. Particularly, families in the "old" group may have been tiered down several times since joining CC, as one goal of the program was to provide supports that enable families to manage their risks and most families reduce tiers as they transition toward discharge from CC. In that context, a lower tier might indicate more fully developed family empowerment as the parent has built his/her capacity to affect change in the family's life over time.

Additionally, families enter CC at different stages of family development and some families are struggling with significant psychosocial risks that may impact their lives even more than their children's medical complexity. While some families were classified as high risk primarily due to their children's medical acuity, others were classified in tiers three or four primarily due to these psychosocial risk factors, in addition to their children's conditions. For example, in some interviews, parents described a history of domestic violence, parental substance use, untreated parental mental illness, and parental suicide, which impacted the child and family unit. Many families described struggling with major financial challenges due to high medical costs and the inability of one parent to work in order to care for the child. Single parents and those with more than one child with special needs faced compounded challenges. Anecdotally, CC staff indicated they felt that psychosocial risks kept their clients tiered as threes or fours after their children's medical needs had been stabilized through CC.

It was more difficult to gain access to higher tier than lower tier parents for interviews, so the nature of psychosocial risks in these families' experiences was not explored as fully as intended. Fewer high risk parents were referred for interviews and most of the parents who were referred but could not be contacted were in tier three or four. This likely speaks to the phenomenon that individuals with a greater number of concerns or burdens are less likely to respond to research due to numerous demands on their time and resources and perhaps more limited capacity, a concept that is supported in the literature on parents of children with special needs (Vuorenmaa, Halme, Perala, Kaunonen, & Astedt-Kurki, 2015).

The finding that CC lends a sense of legitimacy to families' requests for services and supports has several implications. Firstly, it was reported as a benefit for families to have CC intervene on their behalf in this way because it results in families receiving a needed service or

support more quickly or with less burden on the parent to obtain it. Every parent who mentioned this phenomenon in the interviews described it positively. However, in terms of building family empowerment, there is also a downside. It can feel frustrating or demoralizing for a parent when his/her requests are not taken seriously, despite having tremendous expertise about his/her own child's situation and needs. When a professional raises the same request on behalf of the parent and achieves the desired results, it directly goes against the family-centered care values of the family being an equal partner in care planning or decision-making. It also indicates that professionals do not afford families the same respect as other professionals. When families recognize this phenomenon it could be un-empowering. At a systems level, this may indicate a greater need for family-centered care and training to be implemented with medical providers outside of CC, especially specialists and school personnel, who were often identified in these examples during interviews. In direct work with parents, CC may be able to build family empowerment in the face of this phenomenon by coaching effective self-advocacy with professionals and discussing with families the importance of their equal role as decision-makers and care planners.

Notably, a few items on the Family Empowerment Scale indicated families have different expectations regarding their roles as decision-makers. Many families indicated they felt professionals should provide expert guidance and perhaps ultimately be the decision makers. Although not statistically significant, the FES results indicate that fewer parents feel it is "mostly true" or "very true" that parent opinion is just as important as professionals' opinions in deciding what services the child receives (question 12), or that professionals should ask the parent what services he or she wants for the child (question 22). This may indicate that while families do

want to be actively involved in care planning and decision-making, there is a point at which they defer to the medical provider as the expert and final decision maker.

The survey results also indicate that most families report reductions in emergency department use and hospital admissions since enrolling in care coordination. This statistically significant finding was true for families at higher risk and would indicate the potential for cost-savings to the health care system by reducing expensive services use. However, when completing this survey, some families remarked that it was difficult to associate these reductions with CC because over time the child's condition had stabilized and/or the family's capacity to manage the child's condition had increased. These data were self-reported and may be biased by parent recall. It is impossible to know to what extent these decreases in expensive health services use are due to some effect of CC or to what extent they are due to other contemporaneous factors.

Finally, there were several hypotheses posited at the start of the study that cannot be answered by the interview data alone and the associated administrative data were not available to address these questions. For example, there was no objective measure of engagement between a family and CC staff, making it impossible to assess how often a family was involved with CC or if the amount of contact impacted outcomes. According to the tier system, higher tier families received more frequent contacts from CC staff, but there is no way to systematically measure the amount of time each family spent interacting with CC. The amount of contact that was reported by families varied widely but typically coincided with periods of high need. For example, the initial diagnosis period and/or enrollment in CC, times of transition in care, and times of acute health issues were most often reported as the times families relied most heavily on CC and were therefore in most contact. While it is reasonable to assume that higher risk families might face

more of these times, the actual contact between a family and CC seems to vary by factors such as the specifics of the family's situation, the family's relationship with CC staff, the presence of other supports, and the family's preference for seeking support.

5.0 CHAPTER FIVE: DISCUSSION

There is significant agreement on key elements and approaches that should be implemented in a high-quality pediatric care coordination program for children with special health care needs. However, it is also clear that there is a good deal of variability in implementation, which limits the ability to draw conclusions about the effectiveness of care coordination in practice. Generally, care coordination has been linked to positive intermediate outcomes that should lead to improved patient outcomes, greater efficiency, and cost savings. It seems the strongest evidence of impact is on outcomes such as improving patient and family satisfaction and family inclusion in care planning and decision-making.

As indicated in the assessment of the program at the Children's Institute, care coordination should provide a type and level of support that is appropriately matched to each family's medical and psychosocial acuity, preferences, and needs at each stage of the chronic illness lifecycle. Living with a child with a chronic illness affects all aspects of a family. The family adaptive response to a stressor is determined by numerous factors and the "fit" between the child's condition and family's ability to respond. This fit must be adjusted as circumstances change. Specific activities of care coordination and the amount of support will vary in response to family circumstances. Not all families will desire or seek the same type or level of support from care coordination. Other families will face significant barriers to seeking support, often due to psychosocial risk factors. The "fit" between a family and their care coordinator is also

important. When well-aligned, there is evidence that care coordination can result in positive family outcomes and reduced use of expensive health services like the emergency department or hospital.

The philosophy and key elements that drive a well-implemented care coordination program for medically complex children are aligned with actions that could promote family empowerment, as well as related concepts such as self-efficacy, capacity, and coping skills. *How* professionals engage in relations with families is as important as what they do, when developing family empowerment. The care coordinator-family relationship and care coordination activities are likely mediators of empowerment and child outcomes. However, measuring empowerment as an outcome of care coordination is challenging because families' predisposing and enabling factors, and their stage in the chronic illness lifecycle, are likely to influence family empowerment as much or more than participation in care coordination. To tease out the effect of care coordination, a randomized prospective study that can control for variables related to family characteristics and lived experience would be ideal. Also, assessing participating families with the FES before enrollment in CC would provide a baseline measure of empowerment against which to compare the results of a follow up FES after some time in CC.

Despite these limitations, it is evident that care coordination plays a role in facilitating empowerment for families of medically complex children. Care coordination prepares and assists families to manage daily challenges, supports families to grow confident in their abilities, and enables families to be active decision-makers. From the initial meeting, care coordination acknowledges and values the family as an equal partner. Their family-centered approach begins with family-identified needs, strengths, preferences, and goals, which form the shared plan of care. That plan is the guiding document for the care coordinator-family relationship and a tool

used by families to guide their interactions with other providers. Care coordinators encourage families to reflect on and make sense of their situations over time. They help families identify appropriate responses to stressors by facilitating access to information, resources, and services that families may not otherwise have. These are important precursors to active decision-making and care planning, which impact a family's quality of life. Care coordinators can model for or coach families to establish their role as participants and self-advocates, and fit the level of support they provide to each family's needs and circumstance. However, when not strengths-based or family-centered, family-provider relationships can be un-empowering, and not all care coordination activities result in family empowerment. As identified in family interviews, the issue of care coordination adding legitimacy to a family's requests for services is one example where care coordination may disempower families.

While professionals can foster the development family empowerment and create the service conditions in which families may increase their empowerment, there is a complex relationship between empowerment and family experience. Families tend to develop effective coping strategies over time, but professional support can facilitate and expedite the process. Care coordination, in conjunction with family strengths, time, lived experience, and other sources of support all work to increase family empowerment. However, it may be more appropriate to assess care coordination on outcomes that it is more likely to effect, such as patient and family satisfaction, family-centered practices, and increases in knowledge and self-efficacy.

For health services, the shift to patient- and family-centered care is positive and should be implemented beyond the pediatric primary care setting. For families, there is a clear benefit to having a professional coordinator who is appropriately skilled and funded to work across

medical, social service and education settings, guided by a holistic view of a child and family. The challenge is identifying a funding model that can include currently non-reimbursable, but critical, activities of care coordination. Given the suggestive evidence now, with more rigorous evaluation, it seems likely that care coordination for medically complex children will be shown to result in significant cost savings through preventable hospitalizations, emergency department use, and increased efficiency.

5.1 METHODOLOGICAL LIMITATIONS

Literature Review

The literature search strategy was limited by only using articles available in PubMed. A more systematic search strategy could have been utilized by working with MESH terms to define inclusion criteria by specific condition or diagnosis types and care settings rather than searching for terms related to ‘children with medical complexity’. Many studies focus on only one type of condition type or care setting. Furthermore, additional studies may have been included if the search strategy included terms based on key activities or elements of care coordination rather than searching by the term ‘care coordination’.

Administrative Data Analyses

The analyses and conclusions from administrative data were limited by the nature of the data available to the researcher. To better explore the quality of implementation of care coordination at the Children’s Institute, a full data set including individual dates of care coordination encounters, and each patient’s start and end dates in the program would be needed.

Ideally, an evaluation would include all data points available at every care coordination encounter, although this includes protected health information to which the researcher was not allowed access. Further complicating analyses was the structure of the database in which care coordination encounter data are housed. The system is designed for ease of data input and chart review, but not for population-level data analysis. There is no straightforward way to extract one complete dataset containing all that data points collected by patient or encounter. Data extraction and matching by patient ID number was done manually, across data systems, by an honest broker, which was considerably time-consuming and prone to human error.

Interviews

The convenience sample was recruited via care coordination staff, so it is possible that those who were identified to participate and those who completed an interview were parents with stronger relationships to care coordination staff. Ideally, the sample would have been stratified by time in CC; acuity level, to represent all tiers in the care coordination population; and time since child's initial diagnosis, to represent different stages in the illness lifecycle. It was more challenging to get the highest acuity families to participate in interviews, likely due to the greater number of psychosocial and medical risks present in their lives. Additionally, if it had been possible to link interview data to administrative and health records by patient name or ID number, the researcher could have drawn a more complete picture of family characteristics and experience in care coordination, such as by comparing parent reported amount of contact with actual contact with care coordination staff.

5.2 FUTURE RESEARCH

To facilitate research at a population level, researchers need better standardization in definition of CMC and CYSHC in administrative and clinical datasets. Promising CC programs should also be replicated and evaluated for their outcomes across settings and populations.

Ideally, this type of evaluation would be undertaken with full access to all care coordination data and administrative and medical records for families participating in CC, over the duration of the pilot. A comparison group, either of a similar population with no access to CC, or through use of historical medical records would allow for stronger conclusions about the effects of the pilot care coordination program. The interview study would be stronger if families were systematically sampled to represent all tiers, range of diagnoses and conditions, time the child had been considered medically complex, and psychosocial risk factors. If the interview data could have matched to the family's administrative and medical records it would give a more complete and objective picture of the family experience in CC and allow for a comparison between the actual CC services received and family-reported perception of CC. Secondly, using the FES as a pre/post measure would provide a way to assess change in empowerment during time in CC. Ideally, the evaluation would have been planned prior to the initiation of the CC pilot and been implanted simultaneously.

Future research should further explore the experiences of families with intensive psychosocial risk factors, and explore the complex associations between the care coordination's role, specific activities of CC, family characteristics, and how CC influences high-risk families' outcomes. Anecdotal evidence suggests it is the psychosocial risk factors that keep families tiered at higher levels. A systematic analysis of families' medical acuity, psychosocial acuity, and tier ratings over time, compared to specific CC activities received would begin to illuminate

this issue. Additionally, many parents in the interview study described prior poor experiences with services for their children. Future research could further explore the role of CC in improving parent satisfaction with services by examining these poor experiences in detail and what specifically parents felt could be improved, then comparing these recommendations to current and potential CC activities to determine what aspects of parent satisfaction CC might be able to influence and how. Finally, future research on empowerment could explore parent involvement by the developmental stage of child, by the illness stage (diagnosis, treatment, remission), by family demographics in relation to involvement in child's care, and the perspective of professionals on parent involvement. A prospective study of families who join CC at the time their children's conditions begin could be used to examine the development of family empowerment as the family progresses through the stages of a child's chronic illness and examine in more detail the effects of CC and the effects of lived experience.

5.3 CONCLUSIONS

The research literature has made strides to define and measure care coordination for children with complex medical conditions, however, there is still a need for more rigorous evaluation to show clear effects of care coordination on patient outcomes and health care costs. In our fragmented health care system, much of the burden falls on families to coordinate care across settings. Even with care coordination, families often make tremendous sacrifices to provide and manage their children's care. Families would benefit from a better integrated medical, social service, and educational system where family-centered care practices are standard. While families of medically complex children often become savvy consumers of health services, they

cannot do it all. Families still benefit from care coordination to facilitate access to resources, plan for and manage transitions, and protect families' rights. Particularly for the most vulnerable families, care coordination is a significant emotional and logistical support. Because many activities are not currently reimbursable, it will take serious commitment by insurers and providers to offer care coordination at a level of intensity and quality that can benefit families of medically complex children.

APPENDIX A: THE CHILDREN’S INSTITUTE CARE COORDINATION FAMILY-CENTERED CARE FAMILY SURVEY

Family-Centered Care Family Survey (Adapted from Family Centered Care Self-Assessment Tool developed by Family Voices)			
1. Do you and your Care Coordination team decide together what the desired outcomes are? (e.g. improved health status, better school attendance, less pain, or better involvement with social activities?)			
Always	Most of the time	Some of the time	Never
2. Does your Care Coordination team ask about: Your family’s wellbeing (adults and other children) and their needs for supports? Your support network, and the role of faith/religion or other cultural supports? Your family’s concerns and any stresses or successes you may experience as a caregiver? Depression, domestic violence, substance abuse, housing or lack of food in your family?			
Always	Most of the time	Some of the time	Never
3. Does your Care Coordination team offer your family: Information about health and wellness appropriate to your child/youth’s developmental stage? (This includes information about child development, mental health, healthy weight and nutrition, physical activity, sexual development, safety/injury prevention and oral health.)			
Always	Most of the time	Some of the time	Never
4. Does your Care Coordination team: help you identify your strengths, skills, and knowledge related to your child’s health care? Ask you what is working well?			
Always	Most of the time	Some of the time	Never
5. Does your Care Coordination team help your family connect with needed services?			
Always	Most of the time	Some of the time	Never
6. What is your overall level of satisfaction with the care coordination you receive?			
Very satisfied	Mostly satisfied	Not very satisfied	Not at all satisfied
7. Are there any other comments or concerns you’d like to share? (open-ended)			
<u>Scale for questions 1-5:</u> 4= always 3=most of the time 2=some of the time 1=never		<u>Scale for question 6:</u> 4= very satisfied 3=mostly satisfied 2=not very satisfied 1=not at all satisfied	

APPENDIX B: FAMILY EMPOWERMENT SCALE⁴

	Not True at All	Occasionally True	Somewhat True	True	Very True
1. I feel that I have a right to approve of all services my child receives.	1	2	3	4	5
2. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
3. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
4. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
5. I make sure that professionals understand my opinions about my child's needs.	1	2	3	4	5
6. I know what to do when problems arise with my child.	1	2	3	4	5

⁴ Adapted from Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37, 305-321.

7. I feel my family life is under control	1	2	3	4	5
8. I am able to make good decisions about what services my child needs.	1	2	3	4	5
9. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5
10. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
11. I am able to get information to help me better understand my child.	1	2	3	4	5
12. My opinion is just as important as professionals' opinions in deciding what services my child needs.	1	2	3	4	5
13. I tell professionals what I think about services being provided to my child.	1	2	3	4	5
14. I believe I can solve problems with my child when they happen.	1	2	3	4	5
15. I know what services my child needs.	1	2	3	4	5
16. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5

17. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
18. When necessary, I take the initiative in looking for services for my child and family.	1	2	3	4	5
19. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
20. I have a good understanding of the service system that my child is involved in.	1	2	3	4	5
21. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
22. Professionals should ask me what services I want for my child.	1	2	3	4	5
23. I have a good understanding of my child's disorders.	1	2	3	4	5
24. I feel I am a good parent.	1	2	3	4	5
25. What is your overall level of satisfaction with the care coordination you receive?	Not at all satisfied	Not very satisfied	Neutral	Mostly satisfied	Very satisfied

APPENDIX C: FAMILY INTERVIEW PROTOCOL

- What made you decide to participate in Care Coordination?
- When you enrolled in Care Coordination...
 - How long had your child been considered medically complex?
 - How comfortable were you with managing your child's daily needs?
 - How comfortable were you with managing your child's health care and supportive services?
- Since starting in Care Coordination, what, if any, effect has participating in CC had on your ---- around managing your child's care?
 - Your knowledge
 - Your skills
 - How capable you feel?
 - Probes: about your child's condition, about providing care for child, how to navigating services, knowledge of resources, self-care
- Tell me about the interactions that you typically have with CC staff
 - Prompt: who you interact with most, for what sort of things
 - Probe: are they generally able to help you with what you need?
 - Probe: how does your relationship with CC staff compare to your relationship with medical care providers
 - Prompt: such as respecting family expertise, being partners in decision making, etc.
- Tell me about a time when CC was really helpful for your family.
 - Why was this time particularly challenging for your family?
 - What specifically did CC staff do that was helpful?
- Tell me about a time when you did not feel CC was helpful.
 - Why was this time particularly challenging for your family?
 - What specifically would have been more helpful?
- If you didn't have CC now, how would you get the services you need?
- If you didn't have CC now, do you think your family's lives would be different, and why or why not?

Think about before you were participating in Care Coordination compared to now. Since you've been in Care Coordination...		
Has your child missed fewer medical appointments?	Yes	No
Have you made fewer trips to the emergency room	Yes	No

with your child?		
Has your child spent less time admitted to the hospital?	Yes	No
Has your child missed fewer days of school?	Yes	No
Have you missed fewer days of work?	Yes	No
Do you feel you have more support?	Yes	No
Do you feel less stressed?	Yes	No

APPENDIX D: PARENT INTERVIEW CODE HIERARCHY

Main Themes	Key codes included in theme and brief definitions
Efficiency	<p><u>Care coordination staff increased efficiency directly:</u></p> <ul style="list-style-type: none"> • Insurance – Challenges related to insurance coverage or reimbursement. • Duplication - Inefficiency or duplication in services, referrals, billing, etc. <ul style="list-style-type: none"> ○ Number of doctors – Number of medical providers (of all types) caring for child ○ Prior bad experience – A previous negative experience with services that impacts the family's current approach to care • Education – An education-related issue facing the child/family, such as IEP, access to school or educational rights <p><u>Care coordination supported parent capacity, resulting in increased efficiency:</u></p> <ul style="list-style-type: none"> • Equipment and supplies - Specialized equipment or supplies the child needs • Home care – Challenges with obtaining or keeping in-home care and assistance • Paperwork – Amount of paperwork associated with child’s care needs • Parent time – Time spent by parent on direct care or care management • Resources – Knowledge of and access to resources to support child/family • Learning system – Parent gaining knowledge and experience to navigate medical and other systems serving child • Lived experience – Parent’s lived experience with direct care or care management • Resources • Advocacy – Efforts by CC staff related to the child's needs or rights with medical or other providers
Legitimacy	<ul style="list-style-type: none"> • Education • Insurance • Prior bad experience • Progress - Parent description of child's progress in achieving wellness or skill development, or

family's progress in obtaining needed services

Support directly related to CC program:

- Above and beyond – Parent description of CC staff effort that was beyond the job description or obligation
- CC structure – Commentary on the structure of CC program
- CC-family as a team - Parent description of being a team with CC staff, e.g. open communication, sharing decision-making, etc.
- Contact – Amount or nature of CC-family contact
- Team among CC - Parent's perception of teamwork among CC staff
- Team with family - Parent perception of CC-family dynamic and partnership

Other sources of support:

- Extended family - Support or help provided by extended family
- Parent to parent support – Formal or informal support among parents of children with special health care needs
- Home care – Care provided by someone other than the parent in the family's home

Times when support is most needed:

Support

- Appointments - Related to scheduling or keeping necessary appointments for child
- Discharge – Activities or needs at time of child's discharge from inpatient services into home or outpatient care
- Education and IEPs
- Home care – Obtaining/keeping home care or sufficient home care hours
- Initial appointment – Specific challenge of obtaining an initial appointment with a needed doctor or specialist
- Equipment and supplies

Types of support needed and/or provided:

- Emotional support – Parent feeling listened to and supported, particularly for parent's own needs
- Knowledge of child's condition – Parent needing more information on child's diagnosis, condition, or prognosis
- Learning system
- Overwhelmed - Parent's description of own state of being

Parent as source of support:

- Parent advocacy for child - Advocacy done by parent on behalf of child
- Parent initiative and persistence – Examples of parent initiative (e.g. learning about child's

condition), parent persistence in face of adversity to obtain needed services or support

Sources of stress for parents:

- Appointments – Obtaining and managing child’s appointments
- Direct care - Parent providing direct care to child
- Discharge
- Financial – Family financial situation
 - Gave up job – Parent gave up paid employment to care for child
- Education and IEPs
- Insurance
- Learning system
- Life stressor
 - Family discord – Stress in home, e.g. divorce
 - Effect on siblings – Negative repercussions for siblings related to ill child
- Number of doctors
- Parent time
- Prior bad experience
- Unclear diagnosis – Child’s diagnosis is unknown or unclear

Stress

Parent emotions related to stress:

- Overwhelmed – Parent’s description of own state of being
- Parent fear – Fear or uncertainty for child, due to child’s condition or challenges with obtaining needed services, supports, or equipment
- Parent mental health – Parent self-described mental health challenges, e.g. depression
- Isolation – Parent feeling of being isolated due to child’s condition or care demands
- Lived experience
- Respite – Parent need for respite from child’s care
- Trust – Parent feelings of trust/mistrust of someone providing care for child or making decisions about child’s care

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