UNDERSTANDING INFORMATION NEEDS AND DESIGNING

TOOLS FOR CARE COORDINATION OF CHILDREN

AND YOUTH WITH SPECIAL HEALTH

CARE NEEDS (CYSHCN)

by

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ABSTRACT

Inadequate care coordination has been identified as a significant problem in patient care, resulting in diminished satisfaction, increased cost, and reduced quality of care. Comprising an estimated 15.6% (approximately 11 million) of the pediatric population, children and youth with special health care needs (CYSHCN) are "those who have or 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". Caring for CYSHCN is often highly complex, time-, effort-, and resource-intensive, due to complex healthcare conditions, comorbidities, and age of patients. Current electronic health record (EHR) and personal health record (PHR) systems do not adequately support the needs of care coordination. The reasons for this include lack of appropriate tools to support complex care coordination tasks, poor usability, and gaps in information essential for providing team-based patient care. The issues are further amplified while coordinating care for CYSHCN because their health records tend to be voluminous, involve a large care team, and are distributed over multiple systems typically with little to no interoperability. To develop tools that promote effective and efficient care coordination, designers must first understand what information is needed, who needs it, when they need it, and how it can be made available. Our first study focused on identifying and describing information needs and associated goals related to coordinating care for CYSHCN. We found that a critical information goal for care coordination is *care*

networking, which includes building a patient's care team; knowing team member identities, roles, and contact information; and sharing pertinent information with the team to coordinate care. In our second study, we designed and developed two versions of a patient-, family-, and clinician-facing tool to support *care networking*. We then conducted a formative evaluation and compared the usability, usefulness, and efficiency of the two versions. To enable such tools to help with management of information critical to care coordination, information for *care networking* needs to be obtained from all information sources involved in the patient's care. In our third study, we identified and assessed prevalent and emerging national data standards to support electronic exchange and extraction of patient care team related data.

The findings and innovations from this research are envisioned to help guide the design and development of next generation clinician- and patient-/family-facing applications to support care coordination of complex pediatric patients.

To Aai, Baba, Vismaya, Anoushka, and Sandeep.

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CHAPTER 1

INTRODUCTION

1.1 Objectives and Research Questions

The overall goal of this research is to understand the information needs of families and healthcare providers and investigate informatics solutions to promote effective and efficient care coordination of children and youth with special health care needs (CYSHCN). Comprising an estimated 15.6% (approximately 11 million) of the pediatric population, CYSHCN are "those who have or 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".[1,2] The importance of care coordination as an integral part of medical care for CYSHCN is well recognized.[3] Caring for CYSHCN is often highly complex, time-, effort-, and resource-intensive, involves numerous care providers in diverse roles, and can be fragmented across geographical and organizational boundaries.[2]

Current electronic health record (EHR) and personal health record (PHR) systems do not adequately support the needs of care coordination.[4-7] The reasons for this include lack of appropriate tools to support complex care coordination tasks, shortcomings in user interface design, and gaps in information essential for providing patient care. Lack of appropriate software functionality and poor usability has also been linked to patient safety

and quality of care concerns.[8-10] The issues are further amplified while coordinating care for CYSHCN because their health records tend to be voluminous, involve a large care team, and are distributed over multiple systems typically with little to no interoperability.

In the following three studies presented in three distinct chapters, the following research questions were explored:

- What are the information needs and associated information goals of physicians, care coordinators, and families related to coordinating care for CYSHCN (Chapter 3)?

- Does a user interface design based on a user-centered, iterative design approach guided by theory provide useful, usable, and efficient visualization and management of care teams of CYSHCN (Chapter 4)?

- How well do health information exchange (HIE) standards support the data requirements of tools focused on providing information about patient care teams of CYSHCN (Chapter 5)?

1.2 Rationale for Analysis

The Institute of Medicine (IOM) identified care coordination as one of the key strategies for improving quality along six dimensions of making care safe, effective, patient centered, timely, efficient, and equitable.[11] Studies have shown that well-coordinated care improves patient outcomes across clinical settings and patient health conditions.[12] Yet, inadequate care coordination has been identified as a significant problem in health care, resulting in duplicative testing, delays in diagnosis and/or treatment, diminished patient and physician satisfaction, increased cost of care, and reduced quality of care.[2,13,14]

Complex healthcare conditions, comorbidities, fragility, changes in health status, dependence of children on care-givers, and the developmental and formative nature of childhood makes coordinating care for CYSHCN highly involved.[2] Care coordination for CYSHCN typically includes a large number of people in diverse roles, such as family (immediate and extended), medical (e.g., primary care, specialists) and nonmedical (e.g., school, community). As a result, health care data for CYSHCN are typically captured and managed in several disparate systems. Thus, efficiently finding the information needed to provide the best care can be challenging. To develop tools that promote effective and efficient care coordination, designers must first understand what information is needed, who needs it, when they need it, and how it can be made available.

Previous research on health care information needs has either focused on clinicians' needs for relevant scientific evidence or needs for patient information to support care of specific diseases and/or in specific settings.[15-25] In addition, most previous studies have focused on one or two types of participants [21-25] and specific care process activities such as care planning.[26,27] However, much less is known about the information needs and the underlying goals of care coordination for CYSHCN. Goals guide human behavior and perceived needs, actions, and evaluation of outcomes of those actions.[28] In order to uncover the complexity of care coordination for CYSHCN, it is imperative to understand the needs of the key and complementary perspectives of providers, parents, and care coordinators involved in their care. As part of this research, we conducted critical incident interviews with physicians, care coordinators and parents of CYSHCN to elicit their information needs and associated goals related to the process of care coordination. Chapter 3 describes this study in detail.

In the study described in Chapter 3, a critical information goal for care coordination was *care networking*, which includes the need to build a patient's care team or network, determine team member identities and roles, and share pertinent information to enable activities/actions as a team. Study participants reported significant challenges in keeping track of the numerous entities involved in a patient's care, their roles, goals, and preferred contact information; and finding new care team members to match patient and family needs. Currently available EHR- and PHR-based tools do not adequately support management of patient care teams.[7,29] In addition, the usability of EHR systems falls severely short in supporting the needs of complex patients.[30-32] To compensate for the lack of appropriate EHR- and PHR-based functionality, workarounds that use a patchwork of solutions, including spreadsheets, hand-written sticky notes, and refrigerator magnets are employed. These multiple "shadow" systems are not integrated with one another, thus adding risk and inefficiencies to the process of health care delivery. With lack of proper tools to support care coordination, parents of CYSHCN bear the burden of maintaining and sharing information about their child's condition, repeating their "story" and coordinating care between clinical and nonclinical members as well as ancillary services that provide care to their CYSHCN. Our studies described in Chapters 4 and 5 attempt to fill these gaps. We recruited physicians, care coordinators, and parents of CYSHCN to design and conduct a formative evaluation of a tool for clinicians and families to support *care networking*. Chapter 4 describes 1) a user-centered, theory-based, iterative design of *CareNexus*, a tool that supports visualization and management of patient care teams; and 2) a formative evaluation of *CareNexus* comparing the usability, usefulness, and efficiency of two different versions (graphical and tabular) of the tool.

In order to enable tools such as *CareNexus,* information needs to be retrieved from multiple data sources from the various settings involved in the patients' care. Growing participation in HIE has created opportunities for integrating data across information systems to create comprehensive views of patient care teams.[33-35] In Chapter 5, we describe our work focused on mapping and analyzing a set of data standards to enable extraction of patient care team and related data from standards-based HIE to support tools like *CareNexus*. For this purpose, we have investigated the Health Level Seven (HL7) Consolidated Clinical Document Architecture (C-CDA) standard,[36] which is required for EHR certification in the EHR Meaningful Use program defined by the Office of the National Coordinator (ONC) for Health Information Technology;[37] and the HL7 Fast Healthcare Interoperability Resources (FHIR) standard,[38] an emerging data standard that is receiving rapid adoption.

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CHAPTER 2

BACKGROUND

2.1 Care Coordination

The term "care coordination" can have different meanings depending upon the context and purpose of use. A recent technical review identified more than 40 definitions of the term.[1] In spite of the variability of definitions, the review identified five common elements of care coordination: 1) Multiple participants with varied roles are typically involved in care coordination. These include clinical and nonclinical care providers, families, and ancillary services; 2) The participants in care coordination depend on each other to carry out activities involved in the patient's care; 3) To effectively carry out their activities, each participant needs appropriate knowledge of the care team members, their roles, and available resources; 4) In order to coordinate care, care team members rely on exchange of information; 5) Integration of care activities are performed to facilitate appropriate delivery of patient care.

Inadequate care coordination can lead to duplicative testing, delays in diagnosis or treatment, diminished patient and physician satisfaction, increased cost of care and reduced quality of care.[2,3] Pham et al. found that patients with severe chronic conditions may visit up to 16 physicians in a year; this includes up to 12 specialists working at 4 to 9 different practices.[4] Providers involved in patient care often need to access information such as

medical history, laboratory results, referral notes, consultation notes, care summaries, and discharge summaries to provide efficient, effective, continuous, and comprehensive care. However, exchange of information across team and organizational boundaries is often inadequate, not timely, missing, and inconvenient. To enable tools that promote effective care coordination, designers must understand who needs the information, when they need it, what information is needed, and how to make it available.

2.2 Children and Youth with Special Health Care Needs (CYSHCN)

The definition of CYSHCN recommended by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), and accepted by the American Academy of Pediatrics (AAP) is as follows: "Children with special health care needs are those who have or 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".[5,6] CYSHCN are children who have complex medical conditions such as autism spectrum disorder, childhood absence epilepsy, intellectual disability/mental retardation, attention deficit hyperactivity disorder (ADHD), asthma, and depression. CYSHCN comprise an estimated 15.6% (approximately 11 million) of the pediatric population and their healthcare costs are three times higher than for other children.[7,8] Caring for CYSHCN is highly complex and often involves multiple health care and non-health care professionals working independently and using disparate information systems.

A technical review of care coordination strategies for CYSHCN performed for the

Agency of Healthcare Research and Quality (AHRQ) notes that there are various strategies to implement the definition of CYSHCN given above.[6] One of the recommended strategies uses "categorical definitions based upon diagnoses or clinical conditions perceived to convey a significant risk for morbidity or mortality." The Medical Home Portal follows a similar strategy to define and operationalize CYSHCN and will be the basis of identifying CYSHCN for this research.[9]

2.3 Care Coordination for CYSHCN

The AAP and the Committee on Children with Disabilities define care coordination for CYSHCN as "a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of the children and provide them with optimal health care".[10] Care coordination includes assessing, planning, implementing, and evaluating options and services, to meet the individual needs of CYSHCN and their families.[9] Care coordination for CYSHCN may involve a variety of participants and settings, can be highly complex, and often lacks a single point of entry or governance.[10,11] The clinical care team caring for CYSHCN often includes the primary care provider, the care coordinator, and any number of specialists (e.g., behavioral and mental health specialists, subspecialists caring for certain physiological conditions), therapists (e.g., physical, occupational, speech), and home nursing. The ancillary services for CYSHCN may include durable medical equipment (DME) providers, social workers, government agencies, and cultural and charitable support services. For school-age CYSHCN, care is also provided at schools and allied settings. Community resources such as support groups and family advocacy groups are often part of the care network for

CYSHCN. There may be multiple payers and organizations involved in taking care of the financial aspects of caring for CYSHCN. Finally, the parents and other family members of CYSHCN often lead the coordination for the complex care team.

The medical home model has been increasingly adopted as a care coordination strategy for CYSHCN.[6] Patient-centered medical homes (PCMH) seek to deliver patient-centered, comprehensive, team-based, coordinated, accessible, safe, and high-quality care.[12] In a medical home, a primary care physician and her/his team works with patients and families to ensure that their medical and nonmedical needs are met. It is an approach to comprehensive health care that encourages and facilitates partnership among clinicians, patients, and families. Boudreau et al. found that care coordination was associated with decrease in unmet specialty care needs with additional reduction among the cohort receiving care within a medical home versus those without a medical home.[13]

2.4 Information Needs to Support Care Coordination of CYSHCN

Clinicians' needs for medical knowledge on the diagnosis and treatment of specific conditions and patients' needs for clinical information from their healthcare record are well studied.[14-20] Prior studies on the information needs of parents of children with chronic conditions have focused on needs related to understanding the health conditions, management and treatment of those conditions, and coping with the diagnosis.[21-27] Some of these studies have largely focused on specific health conditions (e.g., cancer, asthma), while others have restricted the scope to certain age groups (e.g., infants, 11-17 years). Douglas et al. found that parents of infants with intellectual disabilities experienced challenges accessing quality information regarding: 1) the infant's condition, 2) the infant's

specific needs, and 3) available services.[21] Parents of children with asthma sought information about: 1) asthma basics, 2) treatment modalities, 3) coping with asthma, and 4) medical expectations.[24] Maree et al. reported four themes related to the information needs of parents of children with cancer: 1) the shock of the diagnosis, 2) the child's condition, 3) living with treatment, and 4) communication of information.[22] Parents of long-term childhood cancer survivors reported information needs about late effects of the disease.[23] Lipstein et al. found that parents struggled to find information regarding treatment side-effects and efficacy when making decision about their child's treatment.[25] A more recent study has explored the internet-based information-seeking behavior of parents of children with rare conditions and found that parent-to-parent support systems enabled by the internet are prominent sources of information for parents.[26] An integrative review of experiences of and interactions between parents and providers of technology-dependent children elicited information needs focused on caring for patients in the home setting.[27] Care coordination between the entire network of providers emerged as a theme in this study and financial and communication breakdown between systems were listed as barriers to care coordination.

While all of the studies above stressed the need for understanding the information needs of parents of children with chronic conditions, we found no studies that offered a comprehensive understanding of parental information needs related to care coordination of CYSHCN. In addition, the majority of previous studies focused on only one type of participant - the parent.[21-26] However, the process of care coordination for CYSHCN spans professionals and non-professionals in diverse roles and care settings. The roles played by various participants have a bearing on the types of information needs they may have.

The literature reports studies on care coordination interventions such as case management and multidisciplinary teams.[1,6] Other studies have focused on care process activities involved in care coordination such as care planning that tends to be predictable and well-defined.[28-30] However, the information needs related to coordinating care for the unpredictable world of CYSHCN is underexplored. Moreover, the methods used to understand the information needs in these studies primarily include surveys/questionnaires and focus groups. While these methods are useful, the complexity of caring for CYSHCN warrants qualitative research techniques that allow better memory activation and in-depth elicitation of knowledge.

2.5 EHRs, PHRs, and HIT for Care Coordination of CYSHCN

Special needs in children often result in use of extra medical and mental health services, limitation in activities, and use of specialized therapies.[31] Health records of CYSHCN tend to be more voluminous and complex than other children without special needs.[32] Complex health care conditions, comorbidity, frequent changes in health status due to progression of disease, and multiple providers of health care may result in data fragmented across multiple information systems.

Electronic health records (EHR) do not adequately support care coordination between clinicians and settings across institutional boundaries. The issues include lack of appropriate and widespread data exchange standards, shortcomings in technical design, and solutions requiring time-consuming workflows. Rudin and Bates concluded that "the current marketplace has failed to provide adequate solutions" for care coordination.[33] They proposed a framework of four types of care coordination activities to guide the

development of care coordination tools: 1) the need to identify collaborators, 2) contact collaborators, 3) collaborate, and 4) monitor, where collaborators include clinicians, care givers, and health care organizations. O'Malley et al. investigated the ability of commercial electronic medical records (EMR) to support providers coordinate care for their patients.[34] Six themes that emerged from this study include: 1) EMRs facilitated intra-office communication well; 2) EMRs did not adequately support coordination between providers and settings; 3) information overflow from EMRs was a challenge for providers; 4) EMRs did not support care planning well; 5) care coordination processes need to evolve; and 6) care coordination is not supported in the reimbursement structure.

In spite of the great potential for EHRs to help providers coordinate care, there is a dearth of tools for care coordination, and additional informatics research is needed to guide development of such tools. For example, EHRs lack adequate support for creating and maintaining accurate and up-to-date care teams of patients, a feature fundamental to collaborative care coordination.[35] The literature shows that the medical home model is not well-supported by health information technology (HIT).[36,37] Tools needed for medical home-based team care, especially for patients with complex care needs are not available in current EHRs. The need to understand who is involved in the patient's care team at any given time, what their role is, and how they can be contacted is crucial to coordinating care and to ensuring that each member of the care team is "on the same page". However, previous research has shown that this information may not be available for easy and efficient access and may be scattered across tools, documents and people.[38] To compensate for the lack of appropriate EHR-based functionality, workarounds that use a patchwork of solutions, including spreadsheets, text documents, hand-written notes, and refrigerator

magnets with facility and provider contact information are used. Needless to say, these multiple "shadow" systems are not integrated with one another, thus adding safety and quality concerns to the process of healthcare delivery.

Unintended adverse consequences of EHRs noted by Sittig et al. include unavailability of complete information at point-of-care and frustrating user experiences because of lack of innovation to make EHRs more user friendly.[39] Poor user interface designs can increase the cognitive workload of users resulting in diminished user satisfaction and ineffective workarounds.[40,41] Current EHRs particularly fail in supporting the complicated cognitive processes and unique needs of representing voluminous and diverse information of complex patients such as CYSHCN.[42-44] Researchers have recommended simplifying the presentation of information and facilitating navigation between functional modules such that it requires fewer clicks and screen switching.[45,46] Low satisfaction, poor usability, and lack of functionality have been reported by nurse informaticists.[47] EHRs also fall short in making relevant and complete information available to clinicians through cross-organizational information exchange.[46,48] Further, the lack of appropriate software functionality and poor user interfaces were linked to patient safety and quality concerns.[49,50]

Electronic personal health records (PHR) have been proposed as a strategy to support care coordination for CYSHCN.[51] However, few PHRs have been developed for pediatrics. The challenges include standards for pediatric content, unique privacy and confidentiality needs of the pediatric population, and the customizations needed for chronic conditions.[52] With the lack of appropriate tools to support care coordination, parents of CYHSCN bear the burden of maintaining, championing, and sharing information about their

child/children, repeating their "story", and coordinating care between clinical and nonclinical members as well as ancillary services that provide care to their CYSHCN.

2.6 Health Information Exchange (HIE) and Care Coordination

Health Information Exchange (HIE) is defined as the ability to electronically move health-related information among organizations according to nationally recognized standards.[53] A key motivation of HIE is enabling information to follow patients, wherever they seek care, in a secure and private manner such that clinicians can provide coordinated care by having access to the most current and relevant patient data.[54] Transitions of care can be common and risky for complex patients such as CYSHCN due to their age, fragile health status, and dependence on adult care-givers. A major facilitator to the use of HIE was the perceived improvement in care coordination.[55] Vest et al. note that HIE can improve care coordination among providers and can benefit the implementation of medical homes for CYSHCN.[56] Clinicians found HIE more valuable for patients who had multiple complex conditions and as a result had difficulty communicating or did not have the assistance of family members.[57] However, the design and implementation of HIE has faced barriers and challenges. Gaps in information necessary to provide patient care was cited as an important barrier by a number of studies.[58-60] The reasons for lack of key information included unavailability of certain document types and lack of understanding of what data needs to be made available to HIE. Additionally, multiple coexisting standards and insufficiently constrained specifications of existing standards was cited as a barrier to implementation of HIEs.[61]

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CHAPTER 3

INFORMATION NEEDS OF PHYSICIANS, CARE COODINATORS,

AND FAMILIES TO SUPPORT CARE COORDINATION

OF CHILDREN AND YOUTH WITH SPECIAL

HEALTH CARE NEEDS (CYSHCN)

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3.1 Abstract

3.1.1 Objectives

Identify and describe information needs and associated goals of physicians, care coordinators, and families related to coordinating care for medically complex children and youth with special health care needs (CYSHCN).

3.1.2 Materials and methods

We conducted 19 in-depth interviews with physicians, care coordinators, and parents of CYSHCN following the Critical Decision Method technique. We analyzed the interviews for information needs posed as questions using a systematic content analysis approach and categorized the questions into information need goal types and subtypes.

3.1.3 Results

The Critical Decision Method interviews resulted in an average of 80 information needs per interview. We categorized them into 6 information need goal types: (1) situation understanding, (2) care networking, (3) planning, (4) tracking/monitoring, (5) navigating the health care system, and (6) learning, and 32 subtypes.

3.1.4 Discussion and conclusion

Caring for CYSHCN generates a large amount of information needs that require significant effort from physicians, care coordinators, parents, and various other individuals. CYSHCN are often chronically ill and face developmental challenges that translate into intense demands on time, effort, and resources. Care coordination for CYCHSN involves multiple information systems, specialized resources, and complex decision-making. Solutions currently offered by health information technology fall short in providing support to meet the information needs to perform the complex care coordination tasks. Our findings present significant opportunities to improve coordination of care through multifaceted and fully integrated informatics solutions.

Key words: Children and youth with special health care needs, CYSHCN, Critical

Decision Method, information needs, care coordination.

3.2. Background and Significance

Comprising an estimated 15.6% of the pediatric population (approximately 11 million), children and youth with special health care needs (CYSHCN) are defined as "those who have or 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."[1] Special needs in children often result in increased need for medical, mental health, and education services, and use of specialized therapies and medical equipment,[2,3] leading to higher expenditures. Health care costs for CYSHCN are estimated to be 3 times higher than those of other children.[1,4]

Caring for CYSHCN is highly involved due to unique needs related to specific health care conditions, comorbidities and progression of disease, dependence of children on parents and caretakers, and the developmental and formative nature of childhood.[5] The American Academy of Pediatrics and the Committee on Children with Disabilities define care coordination for CYSHCN as "a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of the children and provide them with optimal health care."[6] Coordination of care for CYSHCN often involves a large number of people, such as clinicians, care coordinators, family members, home care professionals, and school staff; institutions such as clinics, hospitals, and community services; and various sources of funding. Inadequate care coordination can lead to wasted resources, delays in diagnosis and treatment, diminished patient and physician satisfaction, increased cost of care, and reduced quality

of care.[7,8]

Because CYSHCN receive care from many health care and nonhealth care professionals working in different settings, care-related data about these patients can be fragmented across multiple information systems. As a result, finding the information needed to provide the best care can be daunting. To develop tools that promote effective care coordination, designers must understand who needs the information, when they need it, what information they need, and how it can be made available.

Previous research has focused primarily on clinicians' needs for either medical knowledge from the medical literature or clinical information from patient records.[9,14] While these needs are important, they do not cover the full breadth of information needs that can arise in the process of care coordination. In addition, studies on the information needs of parents of children with conditions requiring chronic care have typically focused on specific diseases and coping with disease.[15-18] An integrative review on interactions between parents and providers of technology-dependent children elicited information needs focused on caring for patients in the home setting.[19] Most previous studies focused on 1 or 2 types of participants.[15-19] In order to characterize the complexity of care coordination for CYSHCN, it is necessary to assess the different perspectives of providers, care coordinators, and parents, because their varying roles largely determine the types of information needs they have.[5] Previous studies used methods such as surveys/questionnaires, observations, and focus groups. While these methods are useful, the critical incident technique leads to focused attention and better memory activation, which are necessary to reveal the layers of complexity in care coordination of CYSHCN.[20,21] The critical incident technique has been used successfully to understand

human behavior, information needs, and decision-making in prior health care research.[22-26]

Previous studies have discussed various care coordination interventions, such as multidisciplinary teams, case management, and establishment of a medical home for complex patient populations including CYSHCN.[5,27] Yet the studies have primarily focused on care process tasks or activities, such as care planning, that are or can be well defined.[28-31] However, much less is known about the information needs in the less predictable world of coordinating care for CYSHCN. To design tools for care coordination, it is important to uncover the underlying care goals. Research has shown that goals guide human behavior and influence perceived needs, actions, and evaluations of outcomes and consequences.[32] In this study, we aim to triangulate the information needs and associated goals that are important to physicians, care coordinators, and parents while coordinating care for CYSHCN. The study focuses on patient-centered medical homes that have implemented the coordinated care model,[33] because it has been increasingly accepted as a preferred care coordination strategy for CYSHCN.[5] Ultimately, our findings can be used to inform the design of informatics tools, policies, and processes to support and improve care coordination for CYSHCN.

3.3. Objectives

To identify and assess information needs of physicians, care coordinators, and families while coordinating care for CYSHCN and categorize the needs into associated goal types and subtypes.

3.4. Materials and Methods

3.4.1 Design

Semistructured in-depth interviews were conducted with physicians, care coordinators, and parents of CYSHCN (interview guide available as an online supplement). The interviews followed the Critical Decision Method (CDM),[20] an adaptation of Flanagan's critical incident technique[21] and a form of Cognitive Task Analysis.[20] The interview guide, developed by 3 of the co-authors (PRK, CW, and GDF), followed the CDM guidelines and was piloted with 4 subjects. The interviews were recorded and analyzed using a systematic content analysis approach proposed by Srnka et al.[34] and Ely et al.'s[35] method for categorizing questions asked by physicians. The study was approved by the University of Utah Institutional Review Board under protocol no. IRB00075524.

3.4.2 Participants and setting

We recruited a purposive sample[36,37] of 19 interviewees (8 physicians, 7 parents, and 4 care coordinators) from 6 primary care sites that participated in pediatric patient-centered medical home demonstration projects in Utah.[38] Our purposive sampling approach targeted participants with rich breadth and depth of varied experiences with CYSHCN through seeking (1) 3 key complementary roles for care coordination (physicians, parents, and care coordinators); (2) participants with experience across different clinical and patient conditions with CYSHCN; (3) physicians and care coordinators with a minimum of 2 years of (current) experience with care coordination of CYSHCN; and (4) parents of CYSHCN who are also "family partners" in the practice, serving as advisors regarding policies and quality improvement for the practice and providing support to other families of CYSHCN.

Participants were invited by e-mail to join the study by the project director and co-author CN. For phenomenological studies, 6-10 participants are recommended.[39-41] We determined the target sample size based on 2 criteria: (1) a diversity of participant roles were represented in the sample and (2) ongoing analysis indicated that we had reached saturation,[42] because no new information needs were being generated.

3.4.3 Procedure

The primary author conducted the physician and care coordinator interviews at the individual's work site and the family interviews at either the individual's home or workplace. The interviews were conducted according to the CDM method described in Table 3.1. The physicians and care coordinators were asked to open the patient's chart for reference to improve recall. The research team did not access the patient information directly.

3.4.4 Analysis

We systematically analyzed the CDM interviews, adapting Srnka et al.'s[34] content analysis guidelines for analyzing qualitative data to derive new theory and Ely et al.'s[35] method to analyze questions asked by physicians regarding patient care. The analysis was conducted in the following 7 stages:

- *Stages 1 and 2: Interview recording and transcription.* The audio recordings from the interviews were transcribed. The transcripts were deidentified to protect the research subjects' privacy.

- *Stage 3: Unitization.* The deidentified transcripts were split into units to facilitate

Table 3.1 – Phases of the critical decision method.

Phases[20]	Description[20]
Incident identification and selection	The interviewees were asked to recall a recent episode of care or *incident* for children and youth with special health care needs that they perceived to be challenging from the perspective of finding information related to care coordination. The interviewer asked questions to refine and/or clarify the *incident* further, as necessary. This step also defined the scope of the *incident* for the purpose of the interview.
Timeline verification	The interviewer obtained a clear, concise, and verified overview of the incident, identifying key events on a timeline. This step provided a crucial framework for the rest of the interview.
Deepening	The interviewer deepened into the key events, probing for details on each event in the timeline. This phase elicited implicit information, invoked cognitive processes, and created a picture of the interviewee's cognitive experience, skills, and knowledge. The interview guide prompted for content (what), goals (why), recipients (to whom), sources (from where), mode (how), and barriers in meeting the information needs.
"What-if" queries	In the final sweep, hypothetical *what-if* questions were asked to uncover implicit cues, and the interviewee was allowed to speculate on the knowledge, information, and/or tools that could have helped the incident.

coding. Each unit comprised a few sentences to a few paragraphs that captured a single "meaning." Typically, a unit started when a new topic was discussed and ended when the interviewee changed topics.

- *Stage 4: Coding of information needs.* In this stage, 2 researchers independently extracted zero or more information needs from each unit using a code book. The coding rules were proposed by author PRK and were refined through consensus. We defined an information need as an explicit or implicit request for any kind of information that was specifically related to the care of the child discussed in the

interview. Information needs included but were not limited to information that could be found in the child's health care record, parents' personal records, or the biomedical literature. Both explicit and implicit information needs were coded and represented as questions. Disagreements in coding were resolved through group consensus, with the help of a third researcher.

- *Stage 5: Coding of generic questions.* We transformed the specific questions identified in stage 4 into generic questions; eg, "What are the child's seizure patterns?" was transformed into "What is the pattern of symptom X?". First, authors PRK and GDF converted 50 randomly selected questions into generic questions to define and hone the process and create a code book. Then, 6 researchers (PRK, GDF, CW, GBB, DB, and VT) created generic questions from randomly selected and de-duplicated questions, for a total of 251 questions from all interviews. Disagreements were resolved by consensus throughout stage 5.

- *Stage 6: Development of a classification scheme for generic questions.* The generic questions were classified into meaningful information seeking goal types and subtypes. We initially attempted to use goal classification mechanisms from the literature[43-45] but found that they did not provide enough granularity and depth of meaning. PRK then grouped similar generic questions into categories according to information need goals. The preliminary classification was iteratively refined through group consensus by PRK, GDF, and CW. Precise definitions were developed for the information need goal types and subtypes.

- *Stage 7: Coding of generic questions according to the classification scheme.* Four investigators (PRK, GBB, DB, and VT) each independently coded a different and

random sample of 40 questions according to the classification developed in stage 6, with an inter-rater agreement (Cohen's kappa) of 0.81. The definitions of the information goal types and subtypes were refined for clarity through consensus. The remainder of the questions were then split among the 4 researchers for coding.

3.5. Results

The CDM interviews lasted 55 min on average, with a range of 42-70 min. They resulted in an average of 80 information needs per interview. Our analysis categorized them into 6 information goal types and 32 subtypes (Table 3.2). The goal type definitions were either adopted from the literature (when available) or derived based on inferences drawn from the data. Sample interview quotations for each information goal type are provided in Table 3.3. The information goal types and subtypes were common across the 3 roles, but the varied perspectives appeared to influence how information needs were discussed across roles, as demonstrated in Table 3.4.

Interviewees often described achieving *situation understanding* by reviewing complex and extensive health care records and through personal communication involving numerous clinicians and individuals across different care and community settings. This information goal spanned patients' social status, including concepts such as caregiver aptitude and family dynamic between parents who were separated or divorced. In some cases, clinical team members were unsure about the reliability of the information provided by parents and had to seek corroborating information. Interviewees described c*are networks* for CYSHCN that go far beyond the health care system, and including schools, community services, extended families, and friends. The need and urgency for

Table 3.2 – Information goal types, subtypes, and definitions.

Information goal type	Definition	Information goal subtype
Situation understanding	Creating a mental model of the patient by integrating pieces of information about the patient, environment, history, and preferences	Patient history
		Patient status
		Patient/family preferences
Care networking	Building a patient's care team or network, knowing team member identities and roles, and sharing pertinent information to enable activities/action as a team	Care team building
		Contact information
		Shared team action
		Shared team knowledge
		Team member identities
Planning	A process that starts with choosing health care goals, followed by evaluating alternate routes, and finally developing a specific *plan* (adopted from Montana and Charnov's definition of planning[46])	Emergency preparedness
		Episodes of care
		Identification of barriers
		Patient safety
		Resources
		Treatment
Tracking/ monitoring	The process of understanding adherence to and execution of the treatment plan, the patient's progression toward care goals, and the effect of treatment on outcomes	Administrative
		Clinical assessments
		Diet
		Episodes of care
		Medication
		Patient/family satisfaction
		Results
		Symptoms
Navigating the health care system	Understanding, supporting, and executing the logistical and process tasks that typically require *navigating the health care system* in order to accomplish continuous and comprehensive care	Care process
		Clinical trials
		Financial
		Health Insurance Portability and Accountability Act/regulatory requirements
		Resources
		Services
Learning	Seeking information about or education on the various aspects and methods of caring for children and youth with special health care needs	Condition/treatment for Condition
		Medication
		Procedure
		Symptoms

Table 3.3 – Information needs goals and corresponding representative quotations from interviews.

Information need goal	Interviewee	Representative quotations
Situation understanding	Physician	"So the challenges on the first visit, I'd say there were a few. First of all, no prior records available made it kind of tough. So not really having a good grasp of how was this kid growing, what kind of developmental assessment had been done in the past. There had even been some preliminary labs done by the outside neurologist and when the parents came, they had requested them ahead of time. They never arrived. We didn't have them and we couldn't get them."
	Parent	"And when we got there, come to find out that's when one of the doctors let it slip that she has a mild case of spina bifida. And that's been apparently diagnosed for about three or four years. That's where the first barrier of communication came out. That's when it [we] found out that all these issues are tied in."
	Care coordinator	"I don't know all the cases perfectly, so I might look into it a little bit and just educate myself and kind of look at what their past medical history is and then look at when they were last seen, even if it was when they were sick."
Care networking	Physician	"We need to have a clearer relationship with neurology and communicate more clearly with neurology so that they know what we're doing and we know what they're doing, so we can work together because we can't rely on a parent to pass on that information back and forth."
	Parent	"She's a very difficult stick, so we worked with her pediatrician to place an order that while she was inpatient for the surgery to have a blood draw that would then be provided to her geneticist … So [the] pediatrician worked with the geneticist, worked with the folks, the surgeon which worked really well."
	Care coordinator	"Speech did see her and felt that a swallow study in outpatient when she is well would be a good idea. That probably would be something we would follow up on, and end up ordering, because it does not look like it was done while she was inpatient."
Planning	Physician	"He has an emergency letter from the genetics department on what his required work up and treatment would be, in the event that he got very sick and had a prolong fasting state, which labs to be drawn, what type of IV fluids to administer, who to call, etc. So, we have provided the local

Table 3.3 – continued.

Information need goal	Interviewee	Representative quotations
Planning	Physician	EMS department, our local ER here as well as the school district with this letter. And then of course everybody down at the hospital, the ER, the metabolic department they all have access to this letter as well."
	Parent	"So we had to work out a time where with school and our personal commitments and work commitments that we could commit to having that much time that we needed to spend outside of work. So we had planned it about a year ahead of time. We looked at her school schedule and found out….she's on year round schedule…when she would be off track, and try to coordinate that with when she would be off track, so she would miss the least amount of school. We also had to look at coordinating with her school, because she's highly susceptible to getting sick. And so we didn't want to have to have a surgery cancelled due to illness and then basically interrupt both surgeries, because of one of them needing to be rescheduled."
	Care coordinator	"if they have any questions or resources that they would want before they come in to the appointment tomorrow or anything they might need help with, and then preparing those before they come in."
Tracking/ monitoring	Physician	"We've always been concerned about his growth and development because of his condition and we monitor that very carefully with the help of gastroenterology."
	Parent	"So, just to illustrate something, a scenario that we experience is a phone call or a note home from school saying, <patient reference removed> had the worst seizure she's ever had, or <patient reference removed> had this many seizures today, and us wondering, really? Was it the longest seizure she's ever had? Did she really have that many seizures? What did they look like? What kind of seizures were they? Just a lot of needing to ask questions in detail. Was there anything that could have caused the seizure? What was she doing before and after the seizure?"
	Care coordinator	"She did say that our little guy is on the schedule for October trach/vent clinic. I said, 'Well, it is not showing up on our schedule.' She said, 'That is because we need to confirm the time first.' I said, 'They are coming in to clinic today. Do you want me confirm that time with them?' She said, 'Yeah, that would be great!' I will confirm the time with them when they come in today, and then I will call her back and let her know."

Table 3.3 – continued.

Information need goal	Interviewee	Representative quotations
Navigating the health care system	Physician	"I can tell you the first document that she [mom] gave us was not properly stamped, so our legal team said, this is the deal but you need to get one that's properly stamped" (about parents' divorce decree)
	Parent	"Right now we have four different agencies involved. No one agency can provide all of her supplies and her durable medical equipment. So it's pretty frustrating. We're actually, I'm working with the insurance company to see if there's a way to find, even limit to two, because I have one vendor that provides one item. I have another vendor that provides five items. I have another vendor that provides three. It's just difficult to try and coordinate."
	Care coordinator	"This client does wear diapers. So being in our program, <name removed> will make a prescription for the diapers, and we'll order those because the funding – I mean they'll get paid through the home program Medicaid."
Learning	Physician	"I think we have the information we just need to translate it into something that the family can understand and emphasize just the gravity of it."
	Parent	"You know, I researched most things on my own because I just realize that doctors are only humans, and I know my daughter best. I know what she responds, what she likes, how she improves with her health. I know that she does much better without medication than with medication. So, I have chosen very nontraditional ways."
	Care coordinator	No quotations found.

Table 3.4 – Cross-role comparison of the information goal types.

Information goal type	Characteristics		
	Physicians	Care coordinators	Parents
Situation understanding	One of the foremost goals before providing care at the beginning of episodes of care, at key transition points (eg, onset of new symptoms, change of providers or setting, change in treatment), and whenever important new information becomes available	Part of preparing for and follow-up before and after scheduled episodes of care	Related to the understanding of assessments and goals of clinicians throughout the care process
Care networking	Coordinating care within the primary, specialty, and extended *care network*, understanding roles played by family members in the child's care, and building the *care network* over the span of patient's changing health care status	Communicating with the *care network,* including clinicians, other care coordinators, schools, and payer organizations, to fill in information gaps as required	Keeping a record of contact information of *care network* members, understanding their roles, responsibilities, goals, and feedback regarding their child's care.
Planning	*Planning* for potential life-threatening emergencies and overcoming barriers in providing care	*Planning* for resources and ensuring that parental questions and concerns are appropriately and timely addressed	*Planning* episodes of care such as complex surgeries and alternate treatment options
Tracking/ monitoring	*Monitoring* results of laboratory tests, radiology exams, and trends of clinical assessments and *tracking* parents' levels of satisfaction	*Tracking* episodes of care and tasks completed for patients	*Tracking* symptoms, diet, and response to medications

Table 3.4 – continued.

Information goal type	Characteristics		
	Physicians	Care coordinators	Parents
Navigating the health care system	Helping parents *navigate* the care process and clinical trials, meet regulatory requirements, and expedite critical services as needed	Assisting parents to ensuring insurance coverage, procure services, and meet regulatory requirements	Supporting care processes for their child, manage clinical trial participation, and procure needed services and resources
Learning	Helping parents *learn* about medication safety and preventing unfavorable outcomes	Not applicable	*Learning* about the correlations between medications, symptoms, and side effects; procedures, treatments, expected patient responses, prognosis, potential complications, complementary and alternative medications (CAMs), and resources on nutrition and safety

communication between members of the *care network* was reported as being elevated as compared to patients without special needs. Getting a comprehensive view of patients' current and past *care network* at a glance was described as daunting. The information goals of *planning* and *tracking/monitoring* took on a whole new level of importance for CYSHCN. The complexity of patient conditions, ages of patients, and volume of medical interventions and episodes of care made meticulous *planning* and *tracking/monitoring* essential to the care coordination of CYSHCN. Proactivity, vigilance in maintaining patient safety, attention to detail, and follow-up were described as cornerstones of effective *planning*. *Tracking/monitoring* was performed not only by parents and clinical teams, but also by extended care teams, including schools and other environments where the patients spent time. *Navigating the health care system* was depicted as arduous owing to the multistep, time-sensitive, and paperwork-intensive processes. Participation in clinical trials for various conditions was considered to be important, with physicians and parents working together to *navigate* logistics, such as trial identification and participation. The information goal of *learning* was salient for families and physicians. We found that parents were extremely engaged in their children's care and constantly sought to *learn* through the continuum of diagnosis, treatment, and management of their children's conditions.

3.5.1 Workarounds

To overcome the shortcomings in the tools that interviewees used for care coordination, they described several workarounds, such as using handwritten sticky notes and spreadsheets to track patient lists, orders, care network member identities, and contact information; using electronic health record (EHR) flags to mean something other than what

the flag was intended for; using blog entries to track patient care episodes; and carrying huge paper binders with patient history, current status, and emergency information.

3.5.2 Summary

Responding to information needs typically required considerable effort and involved various individuals and multiple information systems. Frustration reported by several interviewees with the care coordination status quo can be summed up by the following parental quote:

> "I basically left frustrated with the concern that I don't want to go back to neurology because there's no follow-up, and I'm not learning anything new. And I just realized as a mom I just have to take care of my own things. I just feel like it would be terrific if there would be a central system of communication, where I don't have to repeat myself over and over again. I feel, like, my daughter even though she has disability, if she hears her story over and over again, it's actually depressing for her."

3.6. Discussion

The overwhelming gestalt that emerged from our interviews was of care coordination processes that are hugely complex, diverse, and unpredictable, and that involve extensive multidisciplinary teams. CYSHCN are often chronically ill and developmentally challenged and thus require many varied and specialized resources. [2-4] Their care comprises multilayered clinical decisions, as well as intense emotional, social, and financial needs. We identified that caring for CYSHCN generates numerous and ongoing information needs that demand substantial effort from physicians, care coordinators, and parents, despite the wide adoption of health information technology. To our knowledge, this is the first study to triangulate in-depth information needs and associated information processing goals of physicians, care coordinators, and families in the care of CYSHCN.

The information goal types for care coordination of CYSHCN identified in this study align with the core domains in the care coordination measurement framework defined by the Agency for Healthcare Research Quality (AHRQ)[29] and with the key activities in Wagner et. al's[28] care coordination model. For example, the information goal we identified of *situation understanding* can be achieved through interpersonal communication and information transfer among entities involved in a patient's care. AHRQ's measurement framework defines this as the coordination activity of "communicate" and Wagner et al. group it under the model element of "connectivity". *Situation understanding* is a critical precursor for the execution of the broad approach of "teamwork focused on coordination" as defined in AHRQ's measurement framework. The information needs and associated goals are, however, more critical, complex, and voluminous in this vulnerable population of children and require intense support from physicians, care coordinators, and parents.

It was evident from our interviews that participants of all 3 roles actively worked together to serve their CYSHCN. Physicians routinely went the extra mile to accommodate patients' social and personal situations and to assist overwhelmed parents with all the information goal types we identified. The parents served not only as caregivers but also as advocates, decision-makers, and sources of information about their child. They relentlessly *plan*, *track, navigate, learn, manage their care network,* and *try to keep themselves up to date* with their children's history, current status, and future plans, doing so with no single source of information. Our parent participants were "family partners" and as a result of this role may be more aware of the processes and resources for care coordination than parents who do not serve in this role. We consider these individuals to be experts in care coordination who have developed optimal strategies that could be useful for any parent of

CYSHCN. The parents relied on the physicians and care coordinators to fulfill their clinical information needs because they did not have access to their child's EHR. Care coordinators often became the information conduits between physicians and parents, and also vigilantly filled care gaps. Each of the 3 roles plays a crucial part in leading the care coordination process at various times in a patient's care. However, corroborating the recommendation of integrating the clinician and parental roles as a care coordination strategy,[5] they ultimately worked together and strove to achieve comprehensive, continuous, and high-quality care for CYSHCN.

3.6.1 Potential informatics solutions

Prevalent EHR and personal health record systems do not adequately support all the needs of care coordination.[47-52] Usability of EHRs also falls short in supporting the high-level reasoning needed to help clinicians understand the context of complex patients.[53-56] To compensate for the lack of appropriate functionality, our participants used workarounds to adapt and overcome limitations in their information environment. The information needs and associated goals identified in this study provide a framework for guiding the design of effective and likely disruptive tools to support care coordination for CYSHCN. Caring for CYSHCN generates representational information needs that go far beyond typical EHR and personal health record design approaches of lists, alerts, and simple displays. These modalities do not support the integrated displays of information required to understand complex associations between clinical information, medical knowledge, and patient data and environments that extend beyond hospital/clinic walls. As a result, precious cognitive resources and time are used to sift through and find relevant information and integrate it

into a comprehensive mental model.[49,57] We discuss below our vision for tools to support the information needs and associated goal types that, to be useful, must be integrated with the EHR.[58].These suggestions were made by 2 co-authors (PRK and CW) and then iteratively refined among members of the research team.

Care coordination tasks and their associated cognitive processes can be described as having high-level mental representations such as goals, values, and expected outcomes as well as more specific associated behaviors. Innovative displays designed using cognitive engineering methods were shown to better support the cognitive needs of emergency department users by McGeorge et al.[59] A tool to support *situation understanding* would provide integrated and organized displays of information in the patient's record at multiple levels of abstraction and visually link these to goals and expected outcomes for each individual, just as mental representations are structured.

Care networking involves creating and effectively maintaining a complex *care network* across organizational boundaries. To support *care networking* we envision a Health Insurance Portability and Accountability Act-compliant social networking application that provides views of the patient's care team members, their roles, and contact information. This tool should also allow creation of a shared sense of common ground and tools to repair gaps in the same[60] through sharing of each other's goals, roles, and responsibilities. Examples from the literature include tools to support teamwork primarily within the same care settings[61] and social networking applications to support care coordination for patients undergoing chemotherapy.[62]

Tools for *planning* could support resource identification, dependency management, hypothetical perspective-taking and project-management type functionalities. A timeline

view of episodes of care, necessary resources, and dependencies between them not only could benefit the care team but also could be useful to help patients know what to expect in the future. Current EHRs support longitudinal care plans that can be used to document the results of *planning.* However, they often don't follow a standardized format and may have limited shareability across settings.[63]

Tracking/monitoring of complicated care processes is an essential part of creating and maintaining orderly and effective "joint systems."[64] *Tracking/monitoring* data is a cognitive task that humans do poorly[65] and becomes especially burdensome for complex patients. A customizable dashboard with innovative user interface tools for identifying unexpected changes in patient trends, enabling easy *tracking/monitoring* of the details of patient conditions and behaviors in multiple settings and facilitating decision-making in order to respond to changes efficiently, would be desired to support this goal. Examples of tools to support tracking/monitoring include tools to track post-discharge calls[61] and self-monitoring tools for mental health.[66]

Navigating the health care system involves recognizing where the patient is in the care process, anticipating needs, and recognizing the individual constraints that influence decisions. The information goal of *navigating the health care system* calls for an innovative tool similar to Google Maps™ for care coordination in health care that includes links to information about financial, regulatory, care, and legal processes. Because processes and rules can be dynamic, the ability to maintain a socially created and shared framework where members of the team can update their knowledge base is essential.[67,68]

To support the information goal of *learning*, a tool would have to support access to a variety of curated information sources and provide better search tools to support curiosity

and exploration by users.[69] Standards-based context-sensitive links (ie, "infobuttons") to information resources,[70,71] such as the biomedical literature and patient education websites, can be embedded in care coordination tools to support this information goal.

3.6.2 Strengths and limitations

This study has several limitations. The CDM relies on interviewees' memory of past events and is thus susceptible to recall bias. All interviews were conducted by the first author, hence the data collected may have been influenced by her manner of conducting the interviews. To minimize this potential bias, we created the interview guide based on the CDM procedure.[20] We also piloted and honed the interview guide and relied on the research team's experience with the CDM technique. Although we understand that there are limitations to any single method of research, our study is part of a program of research and lays a foundation for future work. The study has limited generalizability to other patient populations because it focuses on CYSHCN. It is possible that some of the information goals will exist in other medical home settings and with other patient populations, such as complex older adults. Also, getting the perspectives of physicians, parents, and care coordinators about the same critical incidents/patients could have been useful, but we believe that we were able to identify the differences in information needs of the 3 roles effectively because (1) our interviewees covered diverse incidents and information needs and (2) our ongoing analysis indicated that we reached saturation because no new questions were being generated. Our data collection was focused on individuals in the primary role of physician, parent, or care coordinator in a CYSHCN care network. However, through the interviews we discovered that CYSHCN have extended care networks that may include

therapists, nursing services, social workers, schools and allied settings, government agencies, charitable support services, and community resources. Future research should focus on the ancillary roles and care settings.

Strengths of the methodology include triangulation of information from physicians, care coordinators, and parents; rigorous and in-depth content analysis; and the CDM technique. Consistent with prior literature,[25] we found that the interviewees were much more informative and detailed when recalling specific events, because probing for challenging incidents allows for details, strategies, influences, and subtle cues to be discovered[20] that other methods used in similar studies may not allow.

3.7. Conclusion

We found that supporting care coordination of CYSHCN generates a large amount of information needs that require substantial effort from the physicians, care coordinators, and parents of these patients. The information needs were categorized into 6 information goal types and 32 subtypes. Today's health information technology falls short in providing the support to meet these information needs in terms of both the available information and tools that enable care providers to perform care coordination tasks. Our study's findings suggest significant opportunities to improve coordination of care through multifaceted, integrated, and innovative informatics solutions.

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3.9. Competing Interests

The authors have no competing interests to declare.

3.10. Author Contributions

- PRK: Study design; literature search; collecting, analyzing, and interpreting data; and writing and revising the manuscript.

- CW: Study design; collecting, analyzing, and interpreting data; and writing and revising the manuscript.

- CN: Study design and revising the manuscript.

- SAC: Analyzing and interpreting data and revising the manuscript.

- LAS: Analyzing and interpreting data and revising the manuscript.

- GBB: Analyzing and interpreting data and revising the manuscript.

- DB: Analyzing and interpreting data and revising the manuscript.

- VT: Analyzing and interpreting data and revising the manuscript.

- GDF: Study design; analyzing, and interpreting data; and revising the manuscript.

3.11. Supplementary Material

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

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CHAPTER 4

FORMATIVE EVALUATION OF CARENEXUS: A TOOL FOR THE

VISUALIZATION AND MANAGEMENT OF CARE TEAMS

OF COMPLEX PEDIATRIC PATIENTS

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4.1. Abstract

Complex and chronic conditions in pediatric patients with special needs often result in large and diverse patient care teams. Having a comprehensive view of the care teams is crucial to achieving effective and efficient care coordination for these vulnerable patients. In this study, we iteratively design and develop two alternative user interfaces (graphical and tabular) of a prototype of a tool for visualizing and managing care teams and conduct a formative assessment of the usability, usefulness, and efficiency of the tool. The median time to task completion for the 21 study participants was less than 7 seconds for 19 out of the 22 usability tasks. While both the prototype formats were well-liked in terms of

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usability and usefulness, the tabular format was rated higher for usefulness (p=0.02). Inclusion of CareNexus-like tools in electronic and personal health records has the potential to facilitate care coordination in complex pediatric patients.

4.2. Introduction

Children and youth with special health care needs (CYSHCN) generally have or are at a risk of developing chronic medical and mental health conditions, resulting in an increased need for specialized medical, therapeutic, equipment, family support, and other services[1]. 15.6% (approximately 11 million) of the pediatric population has special needs and accounts for about a third of the total healthcare spending associated with children[2]. Coordinating care for these medically complex patients is crucial for enabling efficient use of resources, reducing costs, enhancing communication between patient/family and provider, and improving patient/family and provider satisfaction[3–5].

Caring for CYSHCN often involves a large number of participants from disparate settings, working independently, and serving in various roles that may wax and wane in importance or need over the continuum of patient care[6,7]. The clinical care teams often include the primary care physician and a number of specialists, care coordinators, therapists, and social workers. However, the care teams of CYSHCN also extend far beyond the hospital/clinic walls and may include schools; community resources such as support groups and family advocacy groups; cultural and charitable organizations; multiple payers and funding agencies; and family members, neighbors, and friends[7]. In a previous study, we identified and described information needs of physicians, care coordinators, and parents to support care coordination of CYSHCN and categorized them into information

goal types[7]. One of the goal types we identified was *care networking* and we defined it as "building a patient's care team or network, knowing team member identities and roles, and sharing pertinent information to enable activities/actions as a team". Keeping track of who is involved in a patient's care at any given time, what their roles are, their goals and feedback, and preferred contact information; and finding new care team members to fit patient and family needs, was described as extremely challenging by the interviewees. Because they lacked appropriate tools, physicians, care coordinators, and parents of CYSHCN resorted to workarounds such as spreadsheets, hand-written sticky notes, refrigerator magnets, and memorization to store and track care team-related critical information.

In spite of the great potential for electronic health records (EHRs) to help providers coordinate care, current EHR systems do not adequately support the needs of care coordination[8–10]. Vawdrey et al. note that we need better tools to support care team-related information in commercial EHR systems[11]. Usability of EHRs also falls short in supporting the unique needs of representing information about complex patients[12–14]. A recent systematic review reported that lack of appropriate software functionality and poor user interfaces were linked to patient safety concerns[15]. Electronic personal health records (PHRs) have been proposed as a strategy to support care coordination[16]. However, few PHRs have been developed for the domain of pediatrics due to lack of standards for pediatric content and customizations needed for chronic conditions[17]. With lack of PHRs to support *care networking*, parents of CYSHCN bear the burden of maintaining information about their child's care team and repeating their "story" while coordinating care among a large and diverse *care network*.

In this study, we partner with care team members in key and complementary roles: physicians, parents, and care coordinators of CYSHCN, to gain insights into designing an application for clinicians and patients/families for the purpose of *care networking*. We iteratively design two alternative user interfaces to view, understand, share, and manage patient care team information. We then implement the designs and conduct a formative evaluation of the usability, usefulness, and efficiency of the user interfaces.

4.3. Methods

This study used a within-subject design comparing the interactions of physicians, parents, and care coordinators of CYSHCN with two user interface designs (graphical and tabular) of a prototype software we named "CareNexus" to accomplish goals and tasks related to creating and managing patients' complex *care networks*. The study involved both, granular tasks designed to assess usability, and high-level tasks focused on solving a care coordination problem described in vignettes. The study addressed the following research questions: 1) to what degree are features offered by CareNexus to create, understand, and manage *care networks* of CYSHCN *easy to use and efficient*?; 2) how *useful* are the features offered by CareNexus?; 3) how do the graphical and tabular displays of the *care networks* compare in terms of *usability and usefulness*? The study was approved by the University of Utah Institutional Review Board under protocol #IRB_00096357.

4.3.1. CareNexus tool design

The design of CareNexus was guided by Information Foraging theory[18], Shneiderman's principles for information visualizations[19], and Jakob Nielsen's heuristics for user interface

design[20]. The Information Foraging theory draws an analogy between a bird foraging for food and humans foraging for information. The optimal foraging effort seeks maximum "benefit" from minimal "cost" of information seeking by identifying rich *information patches*. We enabled users to optimize their information seeking effort by providing *information patch enrichment* (i.e. providing ways to get to the relevant content quickly and easily). We also applied Shneiderman's visualization principles by offering an *overview* of information at the first level, then implementing *zoom-in/zoom-out* functions for the information, and finally providing information *details on demand*. Additionally, we have incorporated Nielsen's principles for user interaction design to the CareNexus prototype.

The design of CareNexus followed an iterative design methodology based on rapid prototyping, analyzing, and refining cycles guided by feedback from representative users from each of the target user roles: physician, parent, and care coordinator. Tabular representation of medical data in the form of charts are common in current EHRs (e.g. Cerner™ uses tables to display patient care teams). This made the tabular design an obvious choice. A recent systematic review on innovative visualization of EHR data reported that color, lines, shapes, and visual diagrams have been effectively used to render patient data[21]. Thus, we opted to design a graphical interface that depicts the care team as a visual diagram as an alternative to the tabular format. We started off with "low-fidelity" prototypes in the form of whiteboard diagrams and software mockups. As the design matured, we transitioned to web-based "high-fidelity" prototypes using the AngularJS™ framework, Java™ RESTful Web Services, and MySQL™ database. We further incorporated the critique from human factors and usability experts into the mature designs.

The functional specification for CareNexus is derived from the results of our previous work focused on eliciting information needs and associated goals that are raised by physicians, care coordinators, and family members while coordinating the care for CYSHCN[7]. CareNexus is designed with the objective of supporting the information goal of *care networking*, specifically creating, understanding, and managing patient *care networks* or care teams. CareNexus does this by supporting previously identified goal sub-types of *care networking*: 1) care team building, 2) care team member identities, 3) contact information, 4) shared team knowledge, and 5) shared team action.

4.3.2. Participants and setting

Participants in the iterative design phase and the study were recruited from primary care sites that participate in pediatric Patient-Centered Medical Home (PCMH) Demonstration projects in Utah[22]. Each practice has a designated care coordinator and has one or more "family partners" who are actively-engaged parents of CYSHCN. The iterative user design phase included one of the co-authors (CN), one parent, and one care coordinator. For the formative evaluation, we recruited a purposive sample of 21 subjects (7 each of physicians, parents, and care coordinators) with the following criteria: 1) a minimum of 2 years of current experience caring for CYSHCN; 2) experience across a wide range of clinical and patient conditions; and 3) no previous exposure to the CareNexus tool. The participants were invited by email to join the study by the project director of the PCMH Demonstration and co-author CN. We determined the sample size by following recommendations from the literature[23,24].

4.3.3. Case vignettes

The two case vignettes used in the study were adapted from the "Essential Information for Children with Special Healthcare Needs" project headed by the HL7 Child Health work group[25]. The primary author contributed to this project by suggesting use cases and writing story boards for the selected use cases. The case vignettes were representative of the clinical conditions, information needs, and challenges that often face this cohort of patients and are comparable in complexity. Each case vignette consisted of a narrative about the patient's clinical and social context and a care coordination problem related to a current event or episode in her/his life that needed to be resolved using CareNexus. The two case vignettes were further customized to the role of the study participant (physician, parent, or care coordinator). The case vignettes and the associated data were synthetic and were approved by the users in each of the three roles who participated in the user interface design phase.

4.3.4. Procedure

The study was conducted either in an office setting at the work sites of the participants or at their homes. The two case vignettes and two interface designs resulted in four possible case vignette/display format combinations: 1) case vignette 1 + graphical format; 2) case vignette 1 + tabular format; 3) case vignette 2 + graphical format; and 4) case vignette 2 + tabular format. Each of the participants interacted with two of the four combinations in random order such that all participants interacted with both the displays and both case vignettes.

The study session began with a brief introduction of the study. In study part 1, the

participants were asked to complete the following steps for their first case vignette/CareNexus display format combination: 1) usability tasks: perform 22 tasks (Table 4.1) distributed over the 5 goal subtypes of care networking[7]; and 2) problem-solving: identify care team members to communicate with using CareNexus to resolve a problem related to care coordination for a current episode of care as posed by the case vignette. This was followed by a questionnaire that assessed the usability and usefulness of one display format of CareNexus. These steps were repeated for their second case vignette/CareNexus display format in study part 2. Finally, the study subjects were asked to rate the usefulness of a set of CareNexus features and provide open-ended comments and suggestions. The participants were not provided with a tutorial of CareNexus. The goal was to assess the intuitiveness, usability, usefulness, and efficiency of CareNexus without any prior exposure to the user interface of CareNexus. The user sessions were recorded using Hypercam, a screen capture software.

4.3.5. Data analysis

Using the video recordings from Hypercam, each of the usability tasks were coded for: 1) ability to carry out the usability task to successful completion, and 2) time to completion. Given that the data represented repeated measurements of ratings, where the user rated two different interface designs, a paired sample data analysis was used. Comparison between the ratings of the two interface designs was performed using mixed-effects linear regression, with repeated measurements nested within user, controlling for the covariates of perceived vignette complexity, experience of the study subject with the patient conditions in the vignette, and the sequence in which the interface designs were evaluated.

Table 4.1 – Usability tasks and time to completion (average, median, range; in seconds).

Usability task	Average time (s)	Median time [min-max]
Identify the "inactive members" of the patient's medical care team.	1 ± 0.2	1 [1-1]
Identify the "less active" member(s) of the patient's family network.	1 ± 0.3	1 [1-1]
Identify the "less active" member(s) in the patient's medical network	1 ± 0.3	1 [1-1]
Identify the patient's event timeline.	1.1 ± 0.3	1 [1-2]
Find the patient's conditions.	1.2 ± 0.5	1 [1-3]
How many total members are in the patient's family network?	2 ± 0.2	2 [2-2]
Identify the "active" member(s) of the patient's family network.	2 ± 0.2	2 [2-2]
Who are the medical specialists the patient is actively/currently seeing?	2 ± 0.2	2 [2-2]
What is the preferred contact number for the patient's main contact?	2 ± 0.2	2 [2-2]
Find the patient's name on the screen.	2.1 ± 0.4	2 [2-3]
Identify the care team action(s) of the currently logged in user.	2.4 ± 0.8	2 [2-5]
How many of the care team actions are "Done"?	2.8 ± 1.0	2 [2-5]
Find the patient's main contact person (by name or role).	2.8 ± 1.2	2 [2-6]
What is the contact information for an "active" care team member of the patient's nonmedical care team?	3 ± 0.2	3 [3-3]
Zoom in and zoom out on the event timeline.	4.2 ± 1.0	4 [3-6]
Identify the events related to the current patient episode on the timeline.	5.5 ± 1.6	5 [3-10]
Delete the care team member you added.	5.5 ± 0.8	6 [5-8]
What are the goals and/or feedback of any one of the active specialists in the patient's care team?	6.6 ± 2.7	6 [4-17]
How many care team actions are currently displayed?	6.7 ± 1.7	6 [5-10]
Search for a new care team member.	13.4 ± 2.3	14 [8-17]
Identify events on the timeline ± 6 months from today.	14.9 ± 5.1	15 [8-29]
Manually add a new care team member.	32.8 ± 5.2	31 [26-43]

We developed a 14-item questionnaire with Likert-scale response options (1=strongly disagree; 5=strongly agree) to assess the usability and usefulness of CareNexus. The questionnaire included five questions from the System Usability Scale[26] and nine questions that measured self-perceived ability to understand the gist, create, and manage *care networks* and related information. The individual questions were aggregated into two composite scales: usability (questions 1, 3, 8, 12, and 13) and usefulness (questions 2, 4, 5, 6, 7, 9, 10, 11, 14) to maximize reliability and generalizability. Reliability analysis was performed using Cronbach's alpha by aggregating ratings for the two user interface designs for the composite scales.

4.4. Results

4.4.1. CareNexus user experience

The design of the user interface of CareNexus required ten iterations that were performed before the formative evaluation. The resulting user interface of CareNexus with the graphical *care network* format for case vignette 1 is shown in Figure 4.1. Figure 4.2 shows the tabular *care network* display for case vignette 2.

The patient banner (section #1, Figures 4.1 & 4.2) gives a quick overview of the patient and indicates additional needs if applicable (e.g. need for a language interpreter). Section #2 below shows the event timeline with boxes intuitively labeled to indicate clinical events (e.g. outpatient, inpatient, and emergency room visits) and other significant events in the patient's life providing information-patch enrichment. The start and end of timeline defaults to six months before and three months after the current date respectively. The user can view a wider or narrower timeline range by using the navigation menu buttons or the
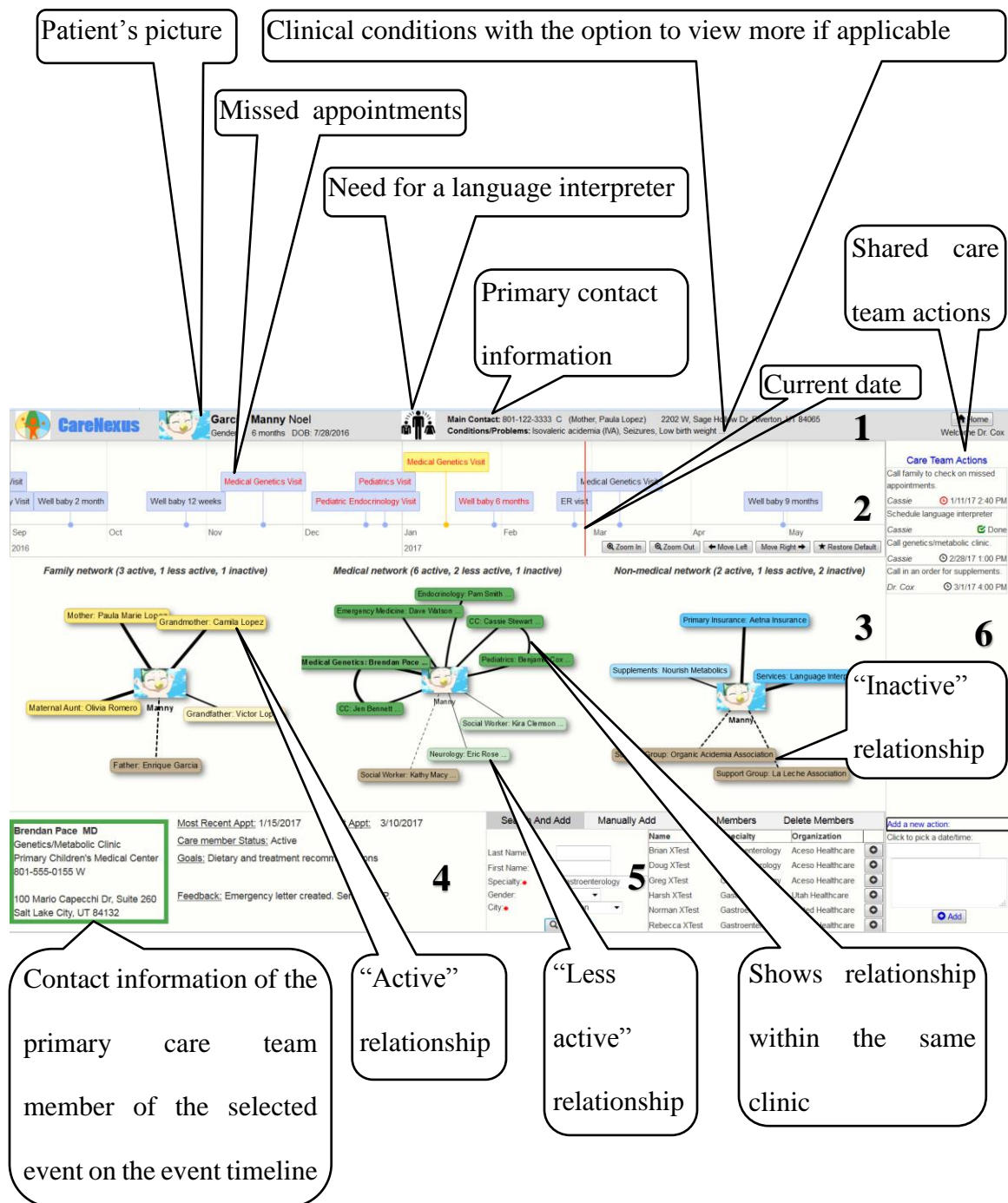
Figure 4.1 – CareNexus user interface with a graphical view of the care network for case vignette 1.
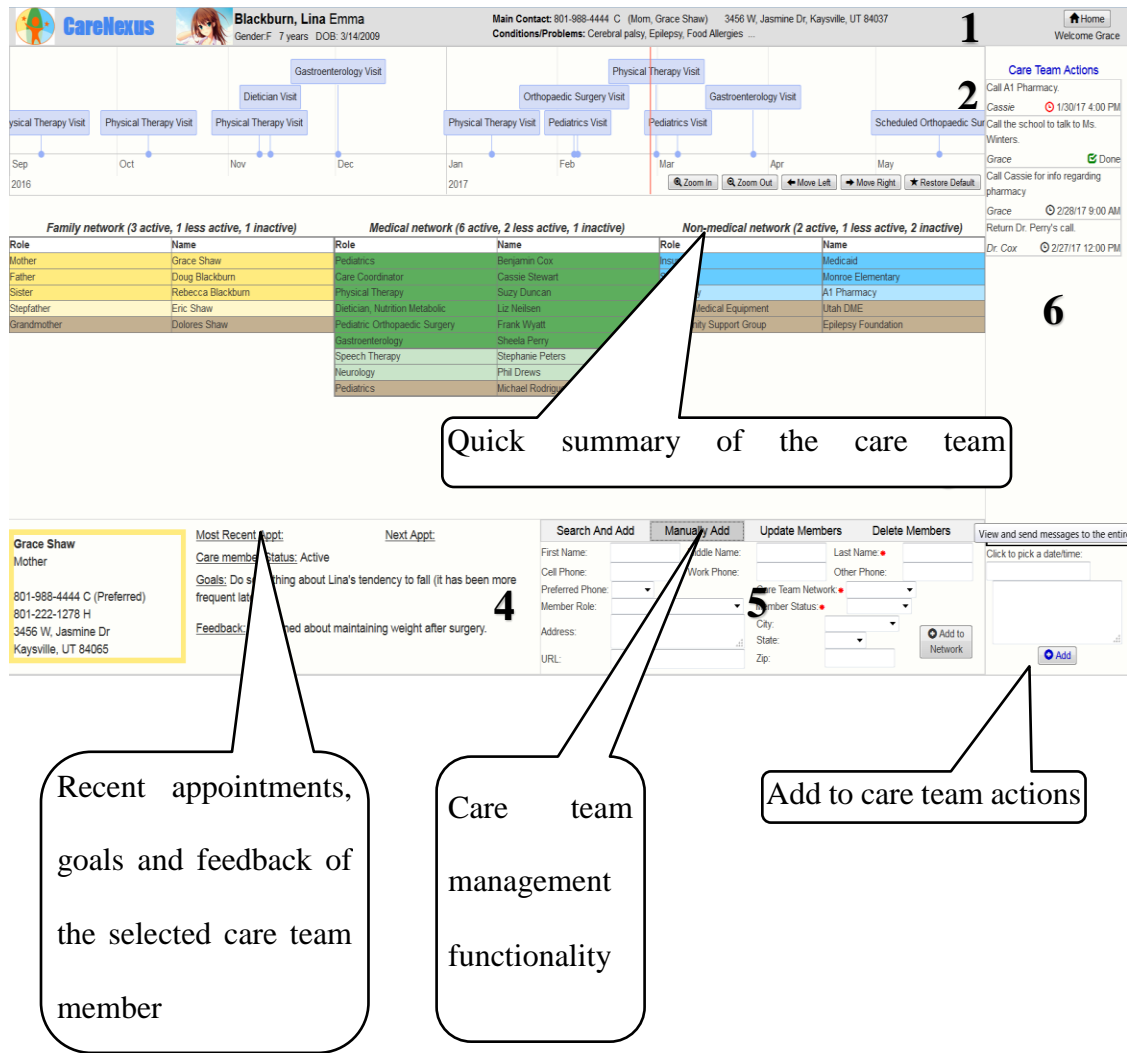
Figure 4.2 – CareNexus user interface with a tabular view of the care network for case vignette 2.

mouse wheel. Clicking on individual events, displays detailed information about the primary care team member involved in the event in the bottom left-hand side of the screen (section #4). Shared team knowledge of the patient demographics, clinical conditions, a quick reference to the contact information of the person most involved in the patient's care, and a quick summary of the patient's encounters aims to provide patient context efficiently and accurately.

Users can visualize the patient's *care network* in section #3 (Figures 4.1 & 4.2). Knowing who is currently involved in the patient's care, in what role, and how to contact them is vital to *care networking*. The *care network* is displayed either in a graphical (Figure 4.1) or tabular format (Figure 4.2). In the graphical format, the patient is shown in the center of the network and is surrounded by either the family (yellow), medical (green), or nonmedical (blue) *care network* member nodes. The tabular format displays the care team members in a table sorted by status ("active" at the top, followed by "less active", and finally "inactive"). The family network includes immediate and extended family members involved in the patient's care. Care team members belonging to a clinic setting are categorized as medical network members (e.g. primary care physician, care coordinator, neurologist, and social worker). The nonmedical team members include the extended *care network* such as the school, community support groups, and durable medical equipment providers. The color gradient of the nodes of the *care network* and the thickness and style of the connecting lines indicate closeness of the care team to the patient's care. There are three levels of closeness or importance: 1) active (color: darkest, connecting line: bold and solid); 2) less active (color: lighter, connecting line: medium and solid), and inactive (color: grey, connecting line: medium and dashed). The closeness or importance of a care team

member to the patient's *care network* can be manually assigned or can be inferred based on whether the team member has been involved in the patient's care within a certain time frame: 1) "active" indicates activity within the last 3 months; 2) "less active" indicates activity within last 6 months; and 3) "inactive" indicates no activity for over 6 months. The label across the top gives a quick summary of the number of active, less active, and inactive care team members. Our design goal was to provide optimal cues to users to help them understand the gist of the patient's *care network* and the ability to get more information on demand, per Shneiderman's visualization principles.

The bottom left of the screen (section #4) shows details of the care team member with the team member identity and contact-information of the selected care team entity (primary care team member involved in a timeline event or a member from the *care network*). This information display resembles a "business card" following Nielsen's design principle of matching real world and software system representations. Next to it we display the status, recent appointments, patient care goals, and feedback (if applicable and available) of the care team member. Building and managing a patient's care team (section #5) can be accomplished by using the search, add, update, and delete functionality conveniently co-located in bottom center of the screen. Users can update and/or delete only those care team members who have been added by them. Finally, shared care team actions are supported by providing information about who is responsible for which task, due date (if applicable), and the status of the task. The users can view all team members' tasks and add/delete/update their own task list. Following Nielsen's design principles, we have maintained simplicity and color/font consistency throughout the design of CareNexus and minimized the need for user recall by providing convenient tool tips.

4.4.2. Ease of use, efficiency and usefulness ratings

The study participants were able to successfully complete all of the 22 usability tasks (Table 4.1). The median time to completion was less than 7 seconds for all but 3 tasks (searching for and manually adding care team members, and identifying events took > 7 seconds). All users also successfully identified all the care team members needed to resolve the care coordination problems posed by the case vignettes. Users highly rated all CareNexus features with highest ratings for the timeline, team member business/contact cards, and most recent and next appointments (Table 4.2).

4.4.3. Comparison between CareNexus user interface designs

Cronbach's alpha for the composite variables of usability and usefulness are given in Table 4.3. There was a significant lower mean usefulness rating for the graphical interface compared to the tabular interface, after controlling for complexity, experience, and the sequence in which the interfaces were evaluated (adjusted mean difference=-0.12; 95% CI: -0.22,-0.01; p=0.02). Although statistically significant, the differences are very small and may not indicate clinical significance. There was a non-significant lower mean usability rating for the graphical interface compared to the tabular interface, after controlling for the same criteria (adjusted mean difference=-0.12; 95% CI: -0.26,0.03; p=0.12). Given our sample size of 21 we had 80% power using a two-sided alpha 0.05 comparison to detect a paired sample standardized mean difference of 0.64, which represents a moderate to large effect size by Cohen's criteria[27]. Table 4.4 gives the adjusted mean ratings for the individual questions and the composite variables assessing usability and usefulness of CareNexus.

Table 4.2 – Usefulness ratings of CareNexus features.

Feature description	Rating (1=not at all useful; 5=very useful)			
	Mean	Std. Dev.	Min	Max
Patient's primary contact on the patient banner	4.85	0.35	4	5
Timeline of events	4.95	0.21	4	5
Zoom-in/Zoom-out for event timeline	4.33	1.01	2	5
Display of three separate care networks	4.81	0.40	4	5
Display of number of care team members per network	4.67	0.58	3	5
Color-scheme supported display of "active", "less active", and "inactive" care team members	4.81	0.51	3	5
"Business cards" for the selected care team member	4.90	0.30	4	5
Most recent and next appointments for the selected care team member	4.90	0.30	4	5
Goals for the selected care team member	4.86	0.36	4	5
Feedback from the selected care team member	4.71	0.46	4	5
Search for new care team members	4.62	0.59	3	5
Add to (search and manual), delete, and update the care network	4.86	0.36	4	5
Care team actions	4.71	0.56	3	5

Table 4.3 – Cronbach's alpha for the composite variables.

User interface design format	Usability	Usefulness
Graphical	0.79	0.87
Tabular	0.83	0.94

Table 4.4 – Ratings of the CareNexus interface designs.

Measurement	Tabular design		Graphical design		P-value
	Adjusted Mean*	Std. Err.	Adjusted Mean*	Std. Err.	
Q1. I thought the system was easy to use.	4.72	0.10	4.55	0.10	0.21
Q2. I was able to grasp the gist of the patient's care network.	4.81	0.11	4.51	0.11	0.06
Q3. I found the various functions in this system were well integrated.	4.62	0.11	4.56	0.11	0.50
Q4. I was able to find the care team members relevant to the case vignette.	4.82	0.09	4.65	0.09	0.124
Q5. I was able to find the pieces of information I needed to accomplish the tasks in the case vignette.	4.85	0.08	4.76	0.08	0.18
Q6. It was easy to understand the meaning of the information presented.	4.86	0.10	4.61	0.10	0.05
Q7. I was able to find the contact information for the care team member(s) I need to communicate with.	4.85	0.08	4.77	0.08	0.20
Q8. I would imagine that most people would learn to use this system very quickly.	4.82	0.08	4.69	0.08	0.15
Q9. It was easy to search for new care team members.	4.82	0.10	4.69	0.10	0.21
Q10. I was able to find goals of the specialists working with the patient.	4.86	0.08	4.80	0.08	0.24
Q11. I was able to find feedback of specialists working with the patient.	4.86	0.08	4.75	0.08	0.14
Q11. I was able to find feedback of specialists working with the patient.	4.86	0.08	4.75	0.08	0.14
Q12. I think that I would like to use this system frequently.	4.82	0.08	4.79	0.08	0.64
Q13. I found the system very cumbersome to use. (reversed criteria)	1.08	0.09	1.33	0.09	0.04
Q14. Compared to the tools/workflow I currently use for care networking, I thought that CareNexus made it easier to accomplish care networking.	4.86	0.08	4.79	0.08	0.46
Usability (composite scale)	4.77	0.07	4.66	0.07	0.12
Usefulness (composite scale)	4.84	0.06	4.72	0.06	0.02
*adjusted for perceived vignette complexity, experience with patient conditions in the case vignette, and sequence in which the interface designs were evaluated.					

4.4.4. Open-ended comments

The study participants echoed their appreciation for CareNexus in their comments and offered suggestions for improvements (Tables 4.5 & 4.6).

4.5. Discussion

Pediatric patients with special needs have large care teams with members in various roles corresponding to different aspects of patients' lives, such as treatment and management of health conditions, developmental challenges, educational needs, and financial support. Previous research in the domain of patient care teams has addressed availability of care team-related information in the inpatient setting[11,28], supporting team work within the same care setting[29], and tailored applications for the needs of patients with certain conditions[30]. However, less has been done for designing clinician- and patient-facing applications to address the needs of medically complex patients that cross the boundaries of specific settings and conditions. The goal of our research is to address this gap by designing, developing, and evaluating two alternative user interface designs for a prototype of CareNexus, a tool to visualize, understand, share, and manage care team related information for complex pediatric patients.

The study participants highly rated the feature set and the overall user interface of CareNexus in terms of usability and usefulness. These findings are important based on the technology acceptance model (TAM) which stipulates that perceived usefulness and ease-of-use are predictors of actual use[31]. Several factors may have contributed to these findings, including deriving the requirements from a systematic information needs analysis[7], the early involvement of representative users, an iterative design approach based on the

Table 4.5 – Open-ended comments by participant roles.

Role of participant	Comments
Physician	"The care network was easy to use. It was extremely helpful to have the timeline to assess where the patient has been and where she is heading with her case."
	"This was quite easy to navigate."
	"Excellent tool."
	"Nicely divided into family, medical, and nonmedical."
	"Timeline is fantastic."
	"It is actually helpful to know the missed appointments. I have to go to two different screens to see the missed ones in my current EMR."
Care coordinator	"The visual timeline is a great way to help patients with appointments."
	"I like that it is all on one screen and there aren't a lot of tabs to navigate through."
	"I like the color coding."
	"I like that it is all in one place."
	"Nice interface compared to the current EMR."
	"I found the graphical visually more over stimulating or busy."
	"Well developed and user friendly. This app would replace our Excel registry. I can't say enough positive about the app – love it."
Parent	"I could use this on a regular basis finding what I need."
	"I currently do not have a tool for care networking other than a notebook."
	"Looks to be very exciting and useful."
	"CareNexus is very user friendly."
	"I love the display of goals and feedback."

Table 4.6 – Suggestions by participant roles.

Role of participant	Suggestions
Physician	"It would be nice to connect the timeline events to notes."
	"Let the user choose the interface format: tabular vs. graphical."
Care coordinator	None.
Parent	"It would be nice to have this tool available in languages besides English."
	"Being able to scan in documents, prescriptions, IEP documents would be helpful."
	"Reminders to schedule specialist appointments would be great."

information foraging theory[18], Shneiderman's visualization principles[19], and Nielsen's usability principles[20]. All users completed 100% of the usability tasks (time to completion for 19 out of the 22 tasks was less than 7 seconds). The problem-solving segment of our evaluation approach encouraged the users to quickly grasp the gist of the *care network*, identify the care team member(s) relevant to the problem, and access their contact information. The patient event timeline was the highest ranked component of the application. Users found it to be a very intuitive and quick way to gain shared team knowledge about recent visits, issues, and current status of the patient's care. The tabular format of the *care network* was preferred over the graphical format, however the differences in the ratings were small. Participants liked both the formats and users should be allowed to choose between the two formats, per individual preference, as suggested by one of our physician participants. Further research is needed to investigate if our findings regarding tabular versus graphical displays generalize to other applications as well as the different factors that may influence display format preferences. Display of three separate networks and the associated color coding made it easier for the users to identify care team members. Having the contact information along with the preferred contact readily available can be very beneficial, especially in emergent situations which was described as a need for this cohort of patients[7]. Sharing the goals and feedback provides a way to create a shared sense of common ground[32] between the team members. Finally, care team actions enable processes that require shared responsibility between care team members ensuring that members of the care team (including the parents) are "on the same page". Viewing the care team actions and their status is valuable for all team members and may reduce the need for time-consuming and sometimes unreliable person-to-person communication.

The results of our formative evaluation are promising and warrant future work on: 1) analyzing the information sources for the care team-related information displayed in CareNexus, 2) developing algorithms to automatically populate applications like CareNexus, and 3) integrating CareNexus into EHR and PHR workflows. Future studies should also focus on extending the findings in this study to other patient populations needing chronic care management.

4.5.1. Limitations

The case vignettes used in this study were adapted from the use cases identified by the HL7 Child Health work group. Although they are representative of clinical and patient conditions of children with special needs, it is possible that different conditions may require other design features. The formative evaluation assumes availability of accurate and up-to-date care team information. High-quality care team data may not be readily available in real world systems and that may influence users' perception of usefulness. Also, CareNexus is designed to be used in tandem with EHR and PHR systems. Further studies should investigate the usability, usefulness, and efficiency of CareNexus integrated in the user workflow.

4.6. Conclusion

We describe the design and formative evaluation of two alternative user interfaces of CareNexus, a prototype of a tool to view, understand, share, and manage patient care team information. We followed an iterative design approach guided by the information foraging theory, information visualization principles, and user interface design heuristics. In

addition, feedback from representative users was incorporated early into the design. Twenty-one users participated in the formative evaluation of the resulting graphical and tabular user interfaces. Users highly rated the usability, usefulness, and feature set of CareNexus, and were able to complete the usability tasks in a short amount of time. The tabular format was rated higher for usefulness but the difference was small indicating that the users liked both the formats. Tools that enable understanding the gist of a patient's *care network* across organizational boundaries, the temporal nature of care team relationships, details of contact information, goals and feedback of those involved in the patient's care, and ability to find providers to match patient/family needs have the potential to facilitate care coordination and team collaboration.

4.7. Acknowledgments

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CHAPTER 5

DATA STANDARDS FOR INTEROPERABILITY OF CARE TEAM INFORMATION TO SUPPORT CARE COORDINATION OF COMPLEX PEDIATRIC PATIENTS

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5.1. Abstract

5.1.1. Objective

Seamless access to information about the individuals and organizations involved in the care of a specific patient ("care teams") is crucial to effective and efficient care coordination. This is especially true for vulnerable and complex patient populations such as pediatric patients with special needs. Despite wide adoption of electronic health records (EHR), current EHR systems do not adequately support the visualization and management of care teams within and across health care organizations. Electronic health information exchange has the potential to address this issue. In the present study, we assessed the adequacy of available health information exchange data standards to support the information needs related to care coordination of complex pediatric patients.

5.1.2. Methods

We derived data elements from the information needs of clinicians and parents to support patient care teams; and mapped them to data elements in the Health Seven (HL7) Consolidated Clinical Document Architecture (C-CDA) standard and in the HL7 Fast Healthcare Interoperability Resources (FHIR) standard. Next, we identified C-CDA data elements and FHIR resources that include patients' care team members.

5.1.3. Results

Information about care team members involved in patient care is generally well-represented in the C-CDA and FHIR specifications. However, there are gaps related to patients' nonclinical events and care team actions. In addition, there is no single place to find information about care team members; rather, information about practitioners and organizations is dispersed in several different types of C-CDA data elements and FHIR resources.

5.1.4. Conclusion

Through standards-based electronic health information exchange, it appears to be feasible to build patient care team representations irrespective of the location of patient care. In order to gather care team information across disparate systems, exchange of multiple C-CDA documents and/or execution of multiple FHIR queries will be necessary. This approach has the potential to enable comprehensive patient care team views that may help improve care coordination.

5.2. Introduction

The Institute of Medicine (IOM) identified care coordination as one of 20 national priorities to potentially improve quality along 6 dimensions of making care safe, effective, patient centered, timely, efficient, and equitable.[1] Studies have shown that well-coordinated care improves patient outcomes across clinical settings, diseases, and patient/provider situations.[2] Yet, inadequate care coordination has been identified as a significant problem in health care, resulting in increased costs, resource waste, delayed treatments, and reduced patient/caregiver satisfaction.[3–5]

One of the essential components of effective care coordination is enabling communication between patients and their care team members.[2] In a previous study, we interviewed primary care physicians, care coordinators, and parents of children and youth with special health care needs (CYSHCN) to determine information needs related to the care coordination of these complex pediatric patients.[6] We found that identifying the members of a patient's care team, their contact information, details of care team member roles, temporal aspects of care team relationships, and their goals and feedback related to the patient's care is imperative for efficient and effective care coordination. Coordinating care for complex pediatric patients often involves a large number of participants in varied roles offering care in disparate settings and systems.[6] In fact, patients with chronic conditions may visit up to 16 physicians in a year, including up to 12 specialists working at 4 to 9 different practices.[7] Additionally, health records of CYSHCN are typically much more voluminous and complex than the records of other children.[8] Comorbidities, frequent changes in health status due to progression of disease, and having multiple health care providers may result in fragmentation of health care records of complex patients across

multiple information systems.

Health information exchange (HIE), defined as the ability to electronically move health-related information among organizations according to nationally recognized standards,[9] has the potential to improve care coordination by providing a source to fill gaps in information and generate a more comprehensive view of patients' health care data.[10–12] To facilitate the management of patients' care teams, information about care teams needs to be extracted from multiple information systems across different health care organizations. While standards-based HIE is a natural source to obtain care team information, it is not known how well the currently available HIE standards support the exchange of this kind of information. In the present study, we analyzed the adequacy of available data standards to support interoperability of patient care teams. Specifically, we 1) identified a set of HIE standards to exchange care team related information across systems; and 2) identified data elements within HIE standards that can be used to extract information about a patient's care team. We focused on standards that are required for Health IT Meaningful Use certification in the U.S., i.e., the Health Level Seven (HL7) Consolidated Clinical Document Architecture (C-CDA) standard [13] and the Fast Healthcare Interoperability Resources (FHIR) standard.[14]

5.3. Materials and Methods

5.3.1. Data standards

Clinical Document Architecture (CDA) is a document-based standard defined for the purpose of exchanging patient information between health care systems.[15] CDA was defined by HL7 [16] and is based on the extensible markup language (XML).[17] CDA

defines a *header* that contains metadata used to classify and manage the document; and a *body* that includes the clinical record. The CDA *body* consists of *sections*, and the *sections* in-turn include *entries*. The structure of *documents*, *sections*, and *entries* can be defined through CDA *templates*, which are sets of conformance constraints (e.g., data element cardinality, terminology bindings) designed to meet a specific purpose. The Consolidated CDA (C-CDA) specification defines 12 types of documents (e.g., care plan, progress note, continuity of care document) to support different care workflow processes and is required for EHR certification in the U.S.[18] HL7 CDA is the most widely adopted HL7 version 3 standard and is widely used in health information exchanges (HIE) across the U.S.[19]

Unlike CDA's document-based approach, the *FHIR* specification is a next-generation healthcare interoperability standard [14] that supports healthcare data exchange at the level of discrete data elements. FHIR's exchangeable content is defined in terms of building blocks known as *resources* that can be queried through web services. FHIR takes a design approach of composition – various *resources* can be combined to satisfy requirements of data exchange use cases. FHIR, like CDA, specifies cardinality constraints and terminology bindings for data representation. FHIR *resources* can be further customized through profiles and extensions to fit requirements of different use cases. The *U.S. Core* implementation guide, which is based on *FHIR Standard for Trial Use (STU) version 3.0.0*,[14] is a set of profiles that define the minimum conformance requirement for accessing patient data in the U.S.[20]

For the foreseeable future, it is expected that the CDA and FHIR specifications will coexist. Through initiatives such as *C-CDA on FHIR*,[21] which defines FHIR profiles to represent different C-CDA document types, CDA may eventually blend into FHIR. In the

present study, we have used the most current, stable versions of C-CDA and FHIR, i.e., the structural and sematic definitions in the C-CDA specification (http://www.hl7.org/implement/standards/product_brief.cfm?product_id=408) and FHIR STU 3 (http://hl7.org/fhir/) with associated FHIR profiles defined in the U.S. Core implementation guide (https://hl7.org/fhir/us/core/).

5.3.2. Procedure

To assess the adequacy of HIE standards to support care team management, we followed a systematic, four-step approach. *First*, we formally defined the data elements for representing patient care teams and related data. This step was informed by our previous work, in which we qualitatively analyzed in-depth interviews of physicians, care coordinators, and parents, and extracted information needs related to coordinating care for CYSHCN. The data elements address *who* is part of the patient's care team (care team member identities and contact information), *when* they provided care (patient events and care team actions), and *how* they are involved in the patient's care (e.g., role, specialty). The data elements have been incorporated into a data model for a care team management tool called *CareNexus* that we designed, developed, and evaluated in a separate study.[22] *Second*, we identified the FHIR resources that support the data elements. For this step, we first used profiles from the latest version of the U.S. Core implementation. For the data elements that could not be covered by U.S. Core, we referred to the FHIR STU 3 specification. We excluded resources that were still in draft status (e.g., *EnrollmentRequest*). *Third*, we mapped the care team data elements to the C-CDA specification. This work was informed by the *document*, *section*, and *entry* definitions and

examples provided in the HL7 implementation guide for CDA Release 2. *Fourth*, we identified additional data elements in the FHIR resources and C-CDA templates that may be used to procure care team member data. The intent of this step was to identify ancillary FHIR and C-CDA data elements that may contain care team related information. The mappings were performed by the primary author and then iteratively reviewed and updated through consensus with experts in those standards (GDF, GLA, and TC).

5.4. Results

5.4.1. Step 1 – Data elements

Table 5.1 describes the data elements representing a patient's care team. The data elements represent *care team members*; patient *events* with a designated main responsible party; and care team *actions*. Patient events are designated as *clinical* (e.g., clinic visit, hospital admission) and *nonclinical* events (e.g., the first day of school). Information about patient *events* helps with situation understanding and sharing information within the care team to enable shared team *activities*.[6] Care team *actions* are tasks that care team members rely on each other to perform and coordinate care for their patients (e.g., updating an IEP – Individualized Education Plan).

5.4.2. Step 2 – Mapping from the patient care team data elements to FHIR resources

Table 5.2 describes the mapping from the patient care team data elements to FHIR resources. All but the *nonclinical events* and *care team actions* mapped reasonably well to FHIR resources. Members of the medical care network and their care setting can be represented using the *Practitioner* resource (https://www.hl7.org/fhir/practitioner.html)

Table 5.1 – Care team data elements.

Category	Data Element	Description
Care Team Member	Name	Current name (first, last, middle etc.)
	Gender	Current gender
	Role/type	E.g., Primary care physician, step-father
	Qualification	Educational qualification(s)
	Specialty	E.g., Gastroenterology, physical therapy
	Affiliation organization(s)	Organizations the member is employed at or affiliated to
	Goals	Goals related to the patient
	Feedback	Feedback related to the patient's situation, progress etc.
Care Team Member Contact Information - Address	Address line 1	Street name, suite number etc.
	Address line 2	Additional address information
	City	
	State	
	Zip	Postal code
	Country	
	URL	Address of a website, if applicable
Care Team Member Contact Information - Other	Value	Details of contact information
	Type	E.g., email, phone
	Use	E.g., home, work
	Preferred status	Denotes the preferred method of contact
Clinical Events	Reason	Reason for the event (e.g., bone fracture). Includes outpatient, inpatient, and emergency events.
	Start date/time	Start time of the event
	End date/time	End time of the event
	Status	State of the event (e.g., in progress)
	Main responsible party	Person/organization responsible for the event
Nonclinical Events	Reason	Reason for the event (e.g., IEP meeting).
	Start date/time	Start time of the event
	End date/time	End time of the event
	Status	State of the event (e.g., in progress)
	Main responsible party	Person/organization responsible for the event
Care Team Action	Description	Describes the action
	Start date/time	Start time of the action
	Due date/time	End time of the action
	Status	E.g., Overdue
	Responsible person(s)	Person(s) responsible for/assigned to the action

Table 5.2 – Mapping between the patient care team data elements and FHIR resources.

Category	Data Element	FHIR resource	Version of FHIR implementation guide	Mapping type	Value Bindings/Constraints as per FHIR specifications/Comments
Care Team Member	Name	Practitioner.Name [@]	U.S. Core Profile Release 1	Exact match	N/A
		Organization.name [#]	U.S. Core Profile Release 1	Exact match	N/A
		RelatedPerson.Name [+]	FHIR Release 3	Exact match	N/A
	Gender	Practitioner.gender [@]	U.S. Core Profile Release 1	Exact match	Administrative gender (Required) E.g., male, female, other
		RelatedPerson.gender [+]	FHIR Release 3	Exact match	Administrative gender (Required) E.g., male, female, other
	Role/type	PractitionerRole.code [@]	FHIR Release 3	Exact match	PractitionerRole (Example) E.g., doctor, nurse
		Organization.type [#]	U.S. Core Profile Release 1	Exact match	OrganizationType (Example) E.g., healthcare provider, insurance company
		RelatedPerson.relationship [+]	FHIR Release 3	Exact match	PatientRelationshipType (Preferred) E.g., mother, neighbor
	Qualification	Practitioner.qualification [@] Practitioner.qualification.code [@]	U.S. Core Profile Release 1	Exact match	v2 table 0360, Version 2.7 (example) E.g., MD, PHD
	Specialty	PractitionerRole.specialty [@]	FHIR Release 3	Exact match	Practice Setting Code Value Set (Preferred) E.g., Endocrinology, Neurology

Table 5.2 – continued.

Categor y	Data Element	FHIR resource	Version of FHIR implementa tion guide	Mapping type	Value Bindings/Constraint s as per FHIR specifications/Com ments
	Affiliati on Organiz ation(s)	PractitionerRol e.organization @	FHIR Release 3	Exact match	N/A
	Goals	Careplan.activi ty.detail.goal		Exact match	Need to specify the performer.
	Feedbac k	Careplan.activi ty.detail.goal		No match	N/A
Contact informa tion - address	Address line 1, Address line 2, City, State, Zip, Country	Practitioner.ad dress @	U.S. Core Profile Release 1	Exact match	N/A
		Organization.a ddress #	U.S. Core Profile Release 1	Exact match	N/A
		RelatedPerson. address +	FHIR Release 3	Exact match	
	URL		No match	N/A	
Contact informa tion – other	Value	Practitioner.tel ecom.value @	U.S. Core Profile Release 1	Exact match	N/A
		Organization.te lecom.value #	U.S. Core Profile Release 1	Exact match	N/A
		RelatedPerson. telecom.value +	FHIR Release 3	Exact match	N/A
	Type	Practitioner.tel ecom.system @	U.S. Core Profile Release 1	Exact match	ContactPointSyste m (Required) E.g., phone, fax
		Organization.te lecom.system #	U.S. Core Profile Release 1	Exact match	ContactPointSyste m (Required) E.g., phone, fax
		RelatedPerson. telecom.system +	FHIR Release 3	Exact match	ContactPointSyste m (Required) E.g., phone, fax
	Use	Practitioner.tel ecom.use @	U.S. Core Profile Release 1	Exact match	ContactPointUse (Required) E.g., home, work

Table 5.2 – continued.

Category	Data Element	FHIR resource	Version of FHIR implementation guide	Mapping type	Value Bindings/Constraints as per FHIR specifications/Comments
		Organization.telecom.use #	U.S. Core Profile Release 1	Exact match	ContactPointUse (Required) E.g., home, work
		RelatedPerson.telecom.use +	FHIR Release 3	Exact match	ContactPointUse (Required) E.g., home, work
	Preferred Status	Practitioner.telecom.rank @	U.S. Core Profile Release 1	Exact match	Specifies order of use (1 = highest)
		Organization.telecom.rank #	U.S. Core Profile Release 1	Exact match	Specifies order of use (1 = highest)
		RelatedPerson.telecom.rank +	FHIR Release 3	Exact match	Specifies order of use (1 = highest)
Clinical Event	Reason	Encounter.reason	FHIR Release 3	Exact match	Encounter reason codes (Preferred) - includes content from SNOMED CT E.g., Fragile X Syndrome, Microcephalus
	Start date/time	Encounter.period.start	FHIR Release 3	Exact match	N/A
	End Date/time	Encounter.period.end	FHIR Release 3	Exact match	N/A
	Status	Encounter.status	FHIR Release 3	Exact match	EncounterStatus (Required) E.g., arrived, cancelled
	Main responsible party	Encounter.participant Encounter.participant.type Encounter.participant.individual	FHIR Release 3	Exact match	ParticipantType (Extensible) E.g., admitter, consultant

Table 5.2 – continued.

Category	Data Element	FHIR resource	Version of FHIR implementation guide	Mapping type	Value Bindings/Constraints as per FHIR specifications/Comments
Nonclinical Events	Reason			No match	N/A
	Start date/time				
	End Date/time				
	Status				
	Main responsible party				
Care team action	Description			No direct match	Can be loosely tied to CarePlan.activity.detail
	Start date/time				
	Due date/time				
	Status				
	Responsible person				

@ Practitioner - represents individuals engaged in the healthcare process. E.g., physicians, dentists.

Organization - represents grouping of people or organizations with a common purpose of achieving actions. E.g., institutions, healthcare practice groups

+ Related Person - represents persons involved in caring for the patient without a formal responsibility. E.g., spouse, neighbor

and the *Organization* resource (https://www.hl7.org/fhir/organization.html), respectively. Nonmedical care team members such as payers and pharmacies can be represented by the *Organization* resource. Care team members such as family members and care givers can be represented using the *RelatedPerson* resource, which can be referred within or back to the *Patient* (https://www.hl7.org/fhir/person.html) resource. Patient care team members can also be represented within certain resources as attributes. For example, the *contact* attribute of the *Patient* resource could be used to represent family members and other nonclinical personnel. The mapping of certain care team data elements would require the extension of terminology value sets. For example, the *v2 contact role* value set, which is bound to *Patient.contact.relationship*, would need to be extended to include other roles, such as those defined in the *PatientRelationshipType* value set (https://www.hl7.org/fhir/valueset-relatedperson-relationshiptype.html). Care team member roles can also be represented in various ways, such as the *PractitionerRole* resource and the *relationship* attribute of the *RelatedPerson* resource.

5.4.3. Step 3 – Mapping from the patient care team data elements to the C-CDA specification

Detailed mappings between the patient care team data elements and the C-CDA specification are included in Table 5.3. The nonclinical events and care team actions could not be mapped to any entity of the C-CDA specification. In addition, gender, qualification, specialty, goals, and feedback of care team members did not have an equivalent match in the C-CDA specification. Clinical events, such as admissions can be included in multiple entities. Only clinical events with an "active" status can be represented. There is not a simple way to represent clinical events with other statuses such as cancelled appointments.

Table 5.3 – Mapping between the patient care team data elements and C-CDA specification**.**

Category	Data Element	CDA element	Data type Mapping type	Value set/Comments
Care team members	All	Header.participant	N/A	N/A
		Header.componentOf.encompassingEncounter.responsibleParty	N/A	N/A
	Name	Header.participant.associatedEntity.associatedPerson.name	Exact match	N/A
		Header.componentOf.encompassingEncounter.responsibleParty.assignedEntity.assignedPerson.name	Exact match	N/A
	Gender		No match	N/A
	Role/type	Header.participant/@typeCode = IND and associatedEntity/@classCode= value	Exact match	INDRoleclassCodes E.g., NOK (next of kin), CAREGIVER
	Qualification		No match	N/A
	Specialty		No match	N/A
	Affiliation organization	Header.participant.associatedEntity.scopingOrganization.name	Exact match	N/A
	Goals Feedback		No direct match	Can be potentially mapped to either of these sections: the Goals, Health concerns, interventions, or health status evaluations and outcomes section of the Care Plan template.

Table 5.3 – continued.

Category	Data Element	CDA element	Data type Mapping type	Value set/Comments
Contact information - address	Address line 1, Address line 2, City, State, Zip, Country	Header.participant. associatedEntity.a ddr	Exact match	Value sets: PostalAddressUse, Country, StateValueSet, PostalCode
	URL		No match	N/A
Contact information – other	Value Type Use Preferred Status	Header.participant. associatedEntity.te lecom	Partial match. Preferred status cannot be specified	N/A
Clinical Events	Reason	Header.component Of.encompassingE ncounter.code	Exact match	CPT4, SNOMED CT
		Planned Encounter – encounter.code	Exact match	Value set Encounter Planned
		Encounter Activity - encounter.code	Exact match	CPT4, SNOMED CT
	Start date/time, End date/time	Header.component Of.encompassingE ncounter.effective Time	Exact match	N/A
		Planned Encounter – encounter.effective Time	Exact match	N/A
		Encounter Activity - encounter.effective Time	Exact match	N/A
	Status	Planned Encounter – encounter.statusCo de	Exact match	Status code SHALL contain @code="active". Does not represent all possible statuses.
	Main responsible party	Planned encounter – encounter.perform er.assignedEntity	Exact match	N/A

Table 5.3 – continued.

Category	Data Element	CDA element	Data type Mapping type	Value set/Comments
Clinical Events	Main responsible party	Encounter Activity - encounter.performer	Partial match – gives a set of responsible parties without designating the "main" responsible party	N/A
		Encounter Activity - encounter.performer.assignedEntity		N/A
		Encounter Activity - encounter.performer.assignedEntity.code		Healthcare Provider Taxonomy (HIPAA)
Nonclinical events	Reason		No match	N/A
	Start date/time			
	End Date/time			
	Status			
	Main responsible party			
Care team - action	Description		No match	N/A
	Start date/time			
	Due date/time			
	Status			
	Responsible person			

Terminology bindings to value sets defined in the specification are mostly sufficient.

5.4.4. Step 4 – Mappings from patient care team data elements to FHIR and C-CDA data elements

Both C-CDA and FHIR define entities that directly represent care team members of patients. However, we found that patient care team members can be represented by several other data elements. Tables 5.4 and 5.5 describe the FHIR resources and C-CDA data types, respectively, for identifying patient care team members. Inclusion of these entities while extracting members of a patient's care team may be needed to achieve more complete representations of a patient's care team.

5.5. Discussion

To our knowledge, this is the first study to identify and assess a set of data standards to enable extraction of a patient's care team and related data from standards-based HIE. Findings from our study suggest that the current versions of the C-CDA and FHIR specifications support most of the patient care team data elements. However, we discovered that information about patients' care teams can be spread over numerous FHIR resources and C-CDA data elements. Additionally most of the data elements that support patient care team management are optional. These issues can pose challenges during implementation. Complex patients such as CYSHCN often have large and diverse care teams that span patients' clinical, behavioral, developmental, and social needs.[6] Knowledge of who is on the patient care team, what their roles are, their contact information, goals and feedback related to the care they are providing or have provided, is crucial to effective and efficient care coordination.[6] An HIE-based approach that supports exchange of data elements

Table 5.4 – FHIR resources for identifying members of patient care teams.

FHIR resource	Description	Version of FHIR implementation guide
Account.subject	Entity the account belongs to	FHIR Release 3
Account.owner	Entity responsible for the account	FHIR Release 3
Account.guarantor.party	Entity responsible for the account	FHIR Release 3
Appointment.pariticpant	Participants involved in an appointment	FHIR Release 3
AppointmentResponse.actor	Participants involved in an appointment	FHIR Release 3
AuditEvent.agent.reference	Entity/actor involved in the event	FHIR Release 3
AllergyIntolerance.recorder	Values could be the Patient or the Practitioner	U.S. Core Profile Release 1
AllergyIntolerance.asserter	Source of information.	U.S. Core Profile Release 1
AdverseEvent.recorder	Patient, Practitioner, or RelatedPerson who recorded the event	FHIR Release 3
AdverseEvent.eventParticipant	Practitioner who was involved in the adverse event	FHIR Release 3
Basic.author	Basic is used for handling resources not currently defined in FHIR	FHIR Release 3
CareTeam	To be used to identify care team members for a patient	U.S. Core Profile Release 1
CareTeam.participant	Participants in a care plan.	U.S. Core Profile Release 1
CarePlan.author	Member and/or organization responsible for the care plan.	U.S. Core Profile Release 1
CarePlan.careTeam	Members involved in the care plan.	U.S. Core Profile Release 1
CarePlan.activity.detail	Defines members who are participate in and/or are responsible for activities in the care plan.	U.S. Core Profile Release 1
ChargeItem.participant	Individual who performed the service	FHIR Release 3
Claim.enterer	Author of the claim	FHIR Release 3
Claim.insurer	Target of the claim	FHIR Release 3
Claim.provider	Responsible provider of the claim	FHIR Release 3
Claim.payee	Party receiving the benefits	FHIR Release 3
Claim.careTeam	Members of the patient's care team	FHIR Release 3
ClaimResponse.insurer	Insurance issuing organization	FHIR Release 3
ClaimResponse.requestProvider	Responsible practitioner	FHIR Release 3

Table 5.4 – continued.

FHIR resource	Description	Version of FHIR implementation guide
ClaimResponse.request Organization	Responsible organization	FHIR Release 3
ClnicalImpression.asses sor	Practitioner performing the assessment	FHIR Release 3
Communication.recipien t	Information recipient	FHIR Release 3
Communication.sender	Information sender	FHIR Release 3
CommunicationRequest. recipient	Recipient of request for information	FHIR Release 3
CommunicationRequest. sender	Sender of request for information	FHIR Release 3
Composition.author	Authoring entity	FHIR Release 3
Composition.attestor.par ty	Entity who attested the composition	FHIR Release 3
Composition.custodian	Organization which maintains the artifact	FHIR Release 3
Condition.asserter	Values could be the Patient, RelatedPerson, or Practitioner.	U.S. Core Profile Release 1
Consent.consentingPart y	Who is agreeing to the consent	FHIR Release 3
Consent.actor.organizati on	Custodian of the consent	FHIR Release 3
Contract.authority	Authority of the contract	FHIR Release 3
Contract.agent.actor	Type of agent	FHIR Release 3
Contract.term.agent.acto r	Subject of contract agent	FHIR Release 3
Device.owner	Organization responsible for an implanted device	U.S. Core Profile Release 1
DiagnosticReport.perfor mer	Practitioner or Organization who produced the report	U.S. Core Profile Release 1
DocumentManifest.subj ect	Patient or Practitioner who is the subject of the set of documents	FHIR Release 3
DocumentManifest.auth or	Patient, Practitioner, Organization, or RelatedPerson who authored the set of documents	FHIR Release 3
DocumentManifest.reci pient	Patient, Practitioner, Organization, or RelatedPerson who are the intended recipients of the set of documents	FHIR Release 3
DocumentReference.sub ject	Patient or Practitioner who is the subject of the set of documents	FHIR Release 3

Table 5.4 – continued.

FHIR resource	Description	Version of FHIR implementation guide
DocumentReference.author	Patient, Practitioner, Organization, or RelatedPerson who are the intended recipients of the set of documents	FHIR Release 3
DocumentReference.authenticator	Practitioner or Organization who authenticated the document	FHIR Release 3
DocumentReference.custodian	Organization which maintains the document	FHIR Release 3
EligibilityRequest.enterer	Practitioner who authored of the request	FHIR Release 3
EligibilityRequest.provider	Practitioner who is responsible for the request	FHIR Release 3
EligibilityRequest.organization	Organization for the request	FHIR Release 3
EligibilityRequest.insurer	Target Organization of the request	FHIR Release 3
Encounter.participant	Practitioner and RelatedPersons involved in an encounter	FHIR Release 3
EnrollmentRequest.insurer	Target Organization of the request	FHIR Release 3
EnrollmentRequest.provider	Practitioner responsible for the request	FHIR Release 3
EnrollmentRequest.organization	Organization responsible for the request	FHIR Release 3
EpisodeOfCare.careManager	Practitioner care manager/care coordinator for the patient	FHIR Release 3
EpisodeOfCare.team	Practitioners (other than the care manager) involved in the episode of care	FHIR Release 3
ExplanationOfBenefit.enterer	Practitioner who authored the claim	FHIR Release 3
ExplanationOfBenefit.insurer	Responsible insurance Organization	FHIR Release 3
ExplanationOfBenefit.provider	Responsible Practitioner for the claim	FHIR Release 3
ExplanationOfBenefit.organization	Responsible Organization for the claim	FHIR Release 3
Flag.subject	Patient, Organization, or Practitioner to whom the flag is attributed to	FHIR Release 3
Flag.author	Patient, Organization, or Practitioner who created the flag	FHIR Release 3

Table 5.4 – continued.

FHIR resource	Description	Version of FHIR implementation guide
Goal.expressedBy	Patient, Practitioner, or RelatedPerson who created the goal	U.S. Core Profile Release 1
Group.entity.member	Patients or Practitioner group members	FHIR Release 3
ImagingManifest.author	Patient, Practitioner, RelatedPerson, or Organization who authored the artifact	FHIR Release 3
ImagingStudy.referrer	Referring Practitioner of the study	FHIR Release 3
ImagingStudy.interpreter	Practitioner who interpreted the images	FHIR Release 3
ImagingStudy.series.performer	Practitioner who performed the study	FHIR Release 3
Immunization.manufacturer	Manufacturing Organization of the vaccine	U.S. Core Profile Release 1
Immunization.practitioner	Practitioner(s) who performed the immunization	U.S. Core Profile Release 1
Immunization.vaccinationProtocol.authrority	Organization responsible for the vaccination protocol	U.S. Core Profile Release 1
ImmunizationRecommendation.recommendation.protocol.authrity	Organization responsible for the vaccination protocol	FHIR Release 3
List.source	Practitioner who authored the artifact	FHIR Release 3
MeasureReport.reportingOrganization	Organization reporting the results of a measure evaluation	FHIR Release 3
Media.subject	Practitioner recorded in the media	FHIR Release 3
Media.operator	Practitioner who created the artifact	FHIR Release 3
MedicationAdministration.performer.actor	Patient, Practitioner, or RelatedPerson administering the substance	FHIR Release 3
MedicationAdministration.performer.onBehalfOf	Organization on whose behalf the substance was administered	FHIR Release 3
MedicationDispense.performer.actor	Patient, Practitioner, or RelatedPerson who performed the event	FHIR Release 3
MedicationDispense.performer.onBehalfOf	Organization on whose behalf the event was performed	FHIR Release 3
MedicationRequest.requester.agent	Patient, Practitioner, or RelatedPerson who ordered the initial medication	U.S. Core Profile Release 1

Table 5.4 – continued.

FHIR resource	Description	Version of FHIR implementation guide
MedicationRequest.requester.onBehalfOf	Organization on whose behalf the order was placed	U.S. Core Profile Release 1
MedicationRequest.recorder	Practitioner who entered the request	U.S. Core Profile Release 1
MedicationRequest.DispenseRequest.performer	Organization that is the authorized medication supply dispenser	U.S. Core Profile Release 1
MedicationStatement.informationSource	Patient, Practitioner, RelatedPerson, or Organization that provided the information about the receipt of this medication	U.S. Core Profile Release 1
NutritionOrder.orderer	Practitioner who ordered the diet, formula, or nutritional supplement	FHIR Release 3
Observation.performer	Patient, Practitioner, RelatedPerson, or Organization who is responsible for the observation	FHIR Release 3
Organization	Organization associated with a patient or provider	U.S. Core Profile Release 1
Patient	Identity of the patient	U.S. Core Profile Release 1
Patient.generalPractitioner	Primary Care Provider	U.S. Core Profile Release 1
Patient.contact	Contact party for the patient (e.g., guardian, partner, friend)	U.S. Core Profile Release 1
Person.managingOrganization	Organization who is the custodian of the record	FHIR Release 3
Practitioner	Practitioner associated with a patient	U.S. Core Profile Release 1
Procedure.performer.actor	Patient, Practitioner, Organization, or RelatedPerson who performed the procedure	U.S. Core Profile Release 1
Procedure.performer.onBehalfOf	Organization on whose behalf the procedure was performed	U.S. Core Profile Release 1
ProcedureRequest.requester.agent	Practitioner or Organization who requested the procedure	FHIR Release 3
ProcedureRequest.requester.onBehalfOf	Organization on whose behalf the procedure was requested	FHIR Release 3
ProcedureRequest.performer	Patient, Practitioner, RelatedPerson, or Organization who has been requested as the performer	FHIR Release 3
Provenance.agent.who	Patient, Practitioner, RelatedPerson involved	FHIR Release 3

Table 5.4 – continued.

FHIR resource	Description	Version of FHIR implementation guide
Provenance.agent.onBehalfOf	Organization representing the agent	FHIR Release 3
QuestionnaireResponse.author	Patient, Practitioner, RelatedPerson who received and recorded the answers	FHIR Release 3
QuestionnaireResponse.source	Patient, Practitioner, RelatedPerson who answered the questions	FHIR Release 3
ReferralRequest.requester.agent	Patient, Practitioner, RelatedPerson, or Organization requesting the service	FHIR Release 3
ReferralRequest.requester.agent	Organization representing the agent	FHIR Release 3
ReferralRequest.recipient	Practitioner or Organization receiving the referral	FHIR Release 3
RelatedPerson	Person involved in the care of a patient, but is not a target of the provided healthcare and who is without a formal responsibility	FHIR Release 3
RequestGroup.author	Practitioner who authored the requests	FHIR Release 3
RequestGroup.action.participant	Patient, Practitioner, or RelatedPerson who should perform the action	FHIR Release 3
Results	*Refer Observation*	U.S. Core Profile Release 1
RiskAssessment.performer	Practitioner who performed the assessment	FHIR Release 3
Schedule.actor	Availability of the Patient, Practitioner, or RelatedPerson	FHIR Release 3
Sequence.performer	Organization responsible for the result of the test(s)	FHIR Release 3
SmokingStatus	*Refer Observation*	U.S. Core Profile Release 1
Specimen.collection.collector	Practitioner who collected the specimen	FHIR Release 3
SupplyDelivery.supplier	Practitioner or Organization who is the dispenser of supplies	FHIR Release 3
SupplyDelivery.receiver	Practitioner who collected the supplies	FHIR Release 3
SupplyRequest.requestor.agent	Patient, Practitioner, RelatedPerson, or Organization making the request	FHIR Release 3

Table 5.4 – continued.

FHIR resource	Description	Version of FHIR implementation guide
SupplyRequest.requestor.onBehalfOf	Organization representing the agent	FHIR Release 3
SupplyRequest.supplier	Organization intended to fulfill the request	FHIR Release 3
SupplyRequest.deliverFrom	Organization which is the origin of the supply	FHIR Release 3
SupplyRequest.deliverTo	Organization or Patient who is the destination of the supply	FHIR Release 3
Task.requestor.agent	Patient, Practitioner, RelatedPerson, or Organization requesting the task	FHIR Release 3
Task.requestor.onBehalfOf	Organization representing the agent	FHIR Release 3
VisionPrescription.prescriber	Practitioner who authorized the prescription	FHIR Release 3

Table 5.5 – C-CDA data elements for identifying members of patient care teams.

Data element	Example use
Author	ClinicalDocument.author
Authenticator	ClinicalDocument.authenticator
custodian	ClinicalDocument.custodian
dataEnterer	ClinicalDocument.dataEnterer
encounterParticipant	Header - recordTarget.componentOf.encompassingEncounter.encounterParticipant
guardianPerson	Header - recordTarget.patient.guardian.guardianPerson
Informant	Observation.informant
informationRecipient	Header - recordTarget.intendedRecipient.informationRecipient
legalAuthenticator	ClinicalDocument.legalAuthenticator
participant	ClinicalDocument.participant
performer	Encounter.performer

identified in this study would enable applications that provide a complete picture of a patient's care team regardless of location of care. Such applications could become a critical component for care coordination.

Our study has four major strengths. First, the patient care team data elements were derived from information needs identified through rigorous qualitative analysis of clinician and parent interviews of CYSHCN. We further implemented the data elements in CareNexus, an application aimed at visualization and management of patient care teams.[22] Second, rather than proposing a new standard for exchanging patient care team related information, we leveraged C-CDA, a standard required for EHR Meaningful Use certification. Prevalent HIEs are document-based for directed as well as query-based exchanges and C-CDA documents are the most frequently exchanged documents in HIEs nationwide.[23] Third, we mapped the data elements to FHIR, which is an emerging standard that is receiving rapid adoption and support from multistakeholder organizations such as the Argonaut project [20] and the Health Services Platform Consortium (HSPC).[24] Finally, our analysis went beyond the entities defined in the data standards that were designed to share patient care teams. We identified ancillary resources and elements (such as claims data) that can be used to extract additional care team members. Our work can be beneficial to promote the use of the ancillary areas in the standard specifications that can help enable applications (e.g., CareNexus) focused on patient care teams.

Most of the data elements mapped reasonably well to the data standards we examined. However, the nonclinical events (e.g., first day of school) and care team actions (e.g., call family to check on missed appointments) did not match directly to defined entities in either

of the data standards. While this is an expected finding, we believe that nonclinical events and care team actions should be supported by standard specifications because they may influence clinical and caregiver decision making. Care team actions are time-sensitive and may not be relevant across health care systems. But having a history of care team actions may be useful for supporting situation understanding of a particular patient. The authors intend to submit the data elements of nonclinical events and care team actions to HL7 for potential inclusion in future versions of the data standards.

Automatically extracting care team data would entail parsing available C-CDA documents and/or querying for appropriate FHIR resources. FHIR resources that encapsulate information about care team members (*Practitioner*, *Organization*, and *RelatedPerson*) can be represented as a reference within over 60 FHIR resources (e.g., *Encounter*, *Patient*, *CarePlan*, *EpisodeOfCare*, and *ReferralRequest*). Similarly, over 10 C-CDA data elements can be used to represent patient care team members. Thus in order to extract up-to-date and complete representations of care teams it would be necessary to exchange multiple types of C-CDA documents and/or send multiple FHIR queries for the various resources identified in this research. This adds complexity to the implementation. We also observed that the constraints specified by the data standards allowed a majority of the data elements to be optional. This may lead to additional problems during implementation. For example, one of the known barriers to HIE is patient identity matching.[25] The C-CDA specification states that the demographic data for a patient shall contain a birthdate. However, the patient date of birth is optional in FHIR STU 3, but is mandatory (if available) in the U.S. Core Patient profile. We contend that because date of birth can be a critical factor for patient identity matching between systems, implementers

should consider using the more constraining U.S. Core Patient profile.

EHR vendors and health care organizations may choose to implement some or all of the FHIR resources and C-CDA templates. In order to gather more complete care team data, implementers of patient care team applications such as CareNexus need to develop against both standards. The advantage of FHIR over C-CDA is a service-based approach for retrieving data that gives access to modular and computable data. On the other hand, the document-based C-CDA specification allows for exchange of not only the data related to the health care participants in specific encounters but also some of the ancillary data elements that may include care team related data (e.g., if allergy data is included in the CDA document, the person who entered the allergy may be a care team member who may not have participated in every patient encounter). We recommend making use of all data that are discoverable through available FHIR resources and C-CDA documents, especially because the data standards are likely to coexist in the near future.

For either data standard, the goal of extracting a complete patient care team can only be achieved if data sources involved in HIE implement and share the specific data elements identified in this study. Although the data standards provide ways to represent data of interest, the challenge is that the majority of the data elements needed to support care team management are optional. While this approach facilitates and presumably expedites creation of valid exchange artifacts (documents or resources), it falls short in promoting useful interoperability of the patient record. An approach to HIE that promotes going beyond the mandatory requirements for certification and encourages exchanging all patient data allowable within the realms of patient data privacy will help create a comprehensive representation of the patient record irrespective of the location of care. This suggests a need

for a policy change to require service level agreements between providers and consumers of patient data artifacts to achieve this goal.

5.5.1. Limitations

This study has several limitations. First, we focused on CYSHCN who tend to have large care teams with diverse roles over variable time frames. However, this research can be generalized to other patient populations, such as older adults, who have complex health needs and require support from a variety of health professionals and services. In addition, patient populations less complex than CYSHCN would still benefit from a subset of the data elements and mappings proposed here. Second, the mappings have not been validated in actual system implementations and there is wide variation in the implementations of health IT standards, which has been identified as a barrier to sematic interoperability.[25] Last, it is likely that patient care team data are duplicative or conflicted across health care systems. Future work should focus on algorithms to accurately adjudicate and prune patient care team related data. Additionally, applications such as CareNexus may benefit from creating a taxonomy of nonclinical events for CYSHCN.

5.6. Conclusion

We mapped patient care team data elements to FHIR resources and C-CDA templates to extract data from multiple EHR systems across healthcare organizations. Other than patients' nonclinical events and care team actions, the data elements mapped reasonably well to FHIR and C-CDA. However, there is no single place to find information about the patient care teams, rather it is distributed over several FHIR resources and C-CDA data

elements. In addition, most of the data elements required to represent patient care teams are optional. It appears to be feasible to extract comprehensive views of a patient's care team through prevalent and emerging standards-based HIE, but real implementations are needed to verify this perception. Health care provider systems and EHR vendors can help by implementing FHIR resources and C-CDA sections and entries identified in this study and maximizing data available for exchange, while maintaining patient security and privacy.

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CHAPTER 6

DISCUSSION

6.1 Summary

Care coordination is fundamental to delivering appropriate, timely, comprehensive, continuous, safe, cost-effective, and high-quality health care. This is especially significant for children and youth with special health care needs (CYSHCN) who have unique and elevated health care needs because of complex medical conditions, comorbidities, and age. In spite of the growing adoption of electronic health records (EHR), current state-of-the-art tools do not adequately support the needs of coordinating care for complex pediatric patients.

In this dissertation research, we uncovered a broad range of numerous, ongoing information needs raised by physicians, care coordinators, and families while coordinating care for CYSHCN. We categorized them into information goal types and subtypes, thus providing a framework for guiding the design of effective and likely disruptive tools to improve care coordination through multifaceted and innovative informatics solutions. We then investigated information displays and data standards to meet the information needs requirements and promote efficient and effective care coordination of CYSHCN. The findings and innovations from this research are envisioned to help guide the design and

development of next generation clinician- and patient-/family-facing applications to support care coordination of complex pediatric patients.

Our approach focused on users in three key and complementary roles involved in the care of CYSHCN: physicians, care coordinators, and families. In the course of three studies, we identified and described information needs, and explored and realized innovative information tools to facilitate coordination of care for CYSHCN. We started with understanding the information needs related to care coordination of CYSHCN because there is a significant gap in the amount and depth of research in this area. In addition, in order to create effective and efficient tools, designers must first understand the requirements of the target users. In our first study, we performed critical incident interviews, which are known to evoke focused attention and better memory activation, to elicit information needs (Chapter 3). This was followed by rigorous qualitative analysis to define and categorize the information needs into associated goal types and subtypes. We uncovered complex care coordination processes that require providers and families to collaborate, have up-to-date information about patients' care teams, communicate effectively, share information, rely on each other to provide medical and nonmedical care, and relentlessly plan, monitor, learn, and navigate the health care system. We then offered our vision for potential informatics solutions to support each of the information goal types.

In the second study, we designed, developed, and evaluated an informatics tool to support visualization and management of patient care teams (Chapter 4). This study provided evidence that the study participants found the user interface design of two innovative information displays to be highly useful, usable, and efficient. While both the designs were well-liked, the tabular format was rated higher for usefulness. These findings

are important based on the technology acceptance model (TAM), which stipulates that perceived usefulness and ease-of-use are indicative of actual use.[1] The functionality of the tool we developed was based on the systematic information needs analysis from our previous study described in Chapter 3. This, in addition to the iterative design approach with early user involvement, and guided by theory, may have contributed to the high user ratings for usability, usefulness, and efficiency. Tools like the one we designed and evaluated have the potential to facilitate communication between care team members of patients, in turn promoting effective and efficient care coordination.

The third study demonstrated the feasibility of using health information exchange (HIE) data standards to enable automated extraction of care team information from disparate systems and create a comprehensive view of a patient's care team (Chapter 5). The mapping approach presented in this study can be applied to different types of patient data. To enable tools like the one we described in Chapter 4 to be used in the real world to accomplish efficient care coordination, it is necessary to make the data available to them from all the information sources that capture and store patients' health care data. We used the data model for the tool described in Chapter 4 as our reference model for this investigation. We found that the prevalent standard required for EHR certification (HL7 C-CDA) and an emerging data standard that is gaining rapid adoption (HL7 FHIR) can support patient care team related applications reasonably well. However, EHR vendors and health care organizations may choose to implement only a subset of the data standard entities we identified in the study. In addition, although the data standards may be close to being comprehensive, the challenges are that a majority of the data is optional and the information from EHRs can be represented in more than one way. Thus, in order to achieve

useful interoperability of patient care teams, an approach to HIE that promotes exchanging all available patient data within the realms of patient data privacy is recommended.

In order for innovative tools such as the one described in Chapter 4 to have a positive impact in coordinating care for patients, they need to be integrated in user workflows. One way to achieve this goal is to integrate such tools with prevalent electronic health record (EHR) and personal health record (PHR) systems. To this end, the SMART (Sustainable Medical Applications and Reusable Technology) on FHIR platform provides promising opportunities to consumers, application developers, medical informaticists, and healthcare organizations.[2] Through its standards-based library of open source tools and resources, SMART on FHIR provides a useful application development environment. Additionally, the SMART on FHIR open application gallery provides an easy path to reach potential consumers. Users and healthcare organizations can benefit from innovative tools that can be incrementally added to existing systems, fostering market competition. Finally, by enabling access to up-to-date patient and administrative data from multiple and varied data sources, SMART on FHIR provides an interoperability platform for these applications.

6.2 Limitations

This dissertation research has several limitations. First, we focused on the domain of CYSHCN, so it is unknown whether the findings are generalizable to other patient populations. However, we believe that some of the information goals will exist in other medical home settings and patient populations, such as complex older adults, who share characteristics similar to CYSHCN (e.g., comorbidities, fragile health status, and dependence on caregivers). In general, patient populations with a larger care team and

requiring chronic care management may share some or all information goal types. Second, we used synthetic data to implement and evaluate a prototype of a tool for visualizing and managing care teams. Although we adopted the patient use cases from the Health Level Seven (HL7) Child Health Workgroup recommendations and designed the data to be representative of clinical and patient conditions of CYSHCNs, it is possible that real patient situations may pose additional challenges for displaying information. Third, the data standard mappings and HIE approach to exchange and extract patient care teams has not been validated in actual system implementations. This is important because errors, omissions, and variation in implementation of data exchange standards has been identified as a barrier to interoperability.[3] Real world system implementation will help understand the feasibility of using HIE components to automate the extraction of patient care teams from artifacts made available by prevalent EHRs. Although implementation is beyond the scope of this dissertation research, our study is part of a program of research and lays foundation for future work.

6.3 Future Research

This dissertation research suggests the following directions for future studies:

- Future studies could take advantage of the information needs analysis and associated goal types identified and described in this research to create tools to support care coordination of CYSHCN. In Chapter 4, we have described the design, development, and evaluation of a prototype to support one of the information goals, viz., *care networking*. Likewise, clinician- and patient-/family-facing applications can be developed and evaluated following a similar process for the other

information goal types identified in our study, i.e., *situation understanding*, *planning*, *tracking/monitoring*, *navigating the health care system*, and *learning*.

- The information needs research can be extended to ancillary roles participating in the care of CYSHCN (e.g., social workers, school personnel). The supporting care networks of CYSHCN will likely have unique information needs that may require a different set of tools.

- The SMART on FHIR platform can be used to develop and deploy innovative informatics tools (such as the one we described in Chapter 4) and integrate them with prevalent EHRs and PHRs to improve coordination of care.

- An important next step is to assess the impact of innovative informatics tools to support and improve care coordination in real world settings. Randomized controlled trials with a control group (usual care) and an intervention group (users given access to informatics tools designed to support care coordination) could be conducted to measure the impact of the technology intervention on efficiency, patient safety, and user acceptance.

- Future research could include implementing the recommendations from our study on data standards to enable automated extraction of patient care teams (Chapter 5) for commercial EHRs and PHRs. The exchange of data for patients served by more than one organization can lead to data duplication and uncovering of inconsistencies in the data. Data adjudication algorithms to resolve duplicates and discrepancies, and prune care teams based on characteristics of patient-provider relationships could be investigated. In addition, PHRs could incorporate input from patients and families to indicate relevancy of patient-provider relationships. The

resulting care teams could be evaluated for accuracy, timeliness, and completeness. This research can be extended further to investigate patient-to-provider and provider-to-provider networks to determine feasibility of inferring potential care team relationships.

- Sources other than EHRs and PHRs could be used to extract patient care team information. Further research could investigate data sources such as the All-Payers Claim Databases (APCD) that host medical and pharmacy claims data across payer entities, to synthesize a more complete and up-to-date care team.[4]

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