From Care Plans to Care Coordination: Opportunities for Computer Support of Teamwork in Complex Healthcare

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ABSTRACT

Children with complex health conditions require care from a large, diverse team of caregivers that includes multiple types of medical professionals, parents and community support organizations. Coordination of their outpatient care, essential for good outcomes, presents major challenges. Extensive healthcare research has shown that the use of integrated, team-based care plans improves care coordination, but such plans are rarely deployed in practice. This paper reports on a study of care teams treating children with complex conditions at a major university tertiary care center. This study investigated barriers to plan implementation and resultant care coordination problems. It revealed the complex nature of teamwork in complex care, which poses challenges to team coordination that extend beyond those identified in prior work and handled by existing coordination systems. The paper builds on a computational teamwork theory to identify opportunities for technology to support increased plan-based complex-care coordination and to propose design approaches for systems that enable and enhance such coordination.

Author Keywords

Care coordination; teamwork; care plan

ACM Classification Keywords

H.5.3 Group and Organization Interfaces: Computer-supported cooperative work

INTRODUCTION

The coordination of care for children with multiple, simultaneously occurring chronic conditions presents major healthcare challenges. These patients require care from multiple providers who are diverse in their expertise and work for different organizations. Despite widespread consensus on a need for greater coordination among providers, care for most of these children remains poorly coordinated [26]. As a result, they have high rates of unmet health needs, suboptimal physical functioning, and potentially preventable health care

crises, and they account for a disproportionate share of health-system use and costs [31, 26].

Healthcare research has shown that effective systems of care for patients with complex chronic conditions require an *integrated care plan* that addresses patient-centered health goals and provides context for treatment decisions for all members of the care team [28, 2]. To better understand the barriers to forming and using such care plans, we conducted a study of care providers for children with complex conditions. We interviewed and observed representative team members in the Complex Primary Care Clinic (*CPCC*) at Stanford's Lucile Packard Children's Hospital, including parents of children with complex conditions, primary care providers (PCP), medical specialists, therapists and administrators.

The study revealed five characteristics of complex care that raise significant challenges to effective teamwork:

- *Flat-structure of team with consensus-driven plan development.*

- *Loosely coupled plans of individual caregivers.*

- *Extended duration of plans over a child's life course.*

- *Continual distributed revision of caregivers' plans.*

- *Syncopated time scales of different providers.*

We more fully discuss each of these characteristics and their implications for care in the Discussion section. Taken together, they yield a teamwork setting, which we will refer to as *FLECS teamwork*.

FLECS teamwork differs fundamentally from the teamwork settings addressed by prior work in the social sciences and computer supported cooperative work (*CSCW*). A different approach is thus required for understanding and enabling effective FLECS teamwork. In this paper, we describe the use of a computational theory of collaboration, SharedPlans [19], which provides a specification of teamwork general enough to cover such teams. SharedPlans has been used in prior work to guide the design of computer agents operating as a team. We use it to identify mechanisms lacking in complex care teams and to suggest possible ways technology could provide such mechanisms.

The contributions of this paper are twofold: First, it presents a study of a broad range of members of care teams for children with complex chronic conditions. The study yields novel
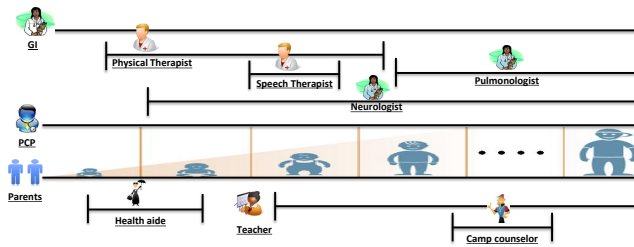
Figure 1. The complex care environment

findings specific to the challenge of implementing care plan–driven care and reveals the unique characteristics and complex nature of care teams. It also corroborates and extends prior general findings related to care coordination. Second, the paper draws on a formal computational teamwork theory to identify a set of teamwork mechanisms currently missing in teams caring for children with complex conditions, and it describes design implications for technology that could address these deficiencies and provide support for care teams' use of care plans. These design implications are also relevant to the design of technology for other teamwork settings with FLECS characteristics.

BACKGROUND AND RELATED WORK

This section describes the care environment of children with complex conditions and prior work on care coordination.

Care Teams

Children with complex conditions have multiple chronic, simultaneously occurring medical problems. Their care is significantly more complex than care for children with a single chronic disease (e.g., asthma), as it requires expertise from diverse medical specialists and other care providers whose treatments may interact. Care teams for such children are diverse and broad in scope, including not only physicians (PCPs and medical specialists) but also other types of healthcare providers (e.g., physical therapists) and people who work with the child in home and community settings (e.g., health aides, teachers). Henceforth, we refer to all caregivers who are not family members as *providers*. Providers differ in their expertise, and they address different aspects of a child's condition. Their involvement with the child's care may be continuous or intermittent, long or short term, as illustrated by the horizontal lines in Figure 1. The group of providers may change significantly over the years, either as a result of personnel changes or because the child's condition or a new developmental stage raise different needs.

Care Plans

The Chronic Care Model, which is the dominant blueprint for health-care solutions for adults and children with complex chronic conditions in the US, argues that effective patient care requires a collaborative health-care team, inclusive of an engaged, activated patient and family, supported by computer systems and with care framed by an integrated care plan [14]. According to this model, care plans should be organized around whole-person goals (e.g., school readiness) rather than organ-system goals (e.g., brain, lung).

A recent report by the Lucile Packard Foundation for Children's Health (LPFCH) [28] provides recommendations for the content of care plans and the process of developing them. It indicates that care plans should include clinical goals (e.g., feeding without a tube), family goals (e.g., going on a family trip) and "negotiated actions" (i.e., actions the team agrees upon) towards achieving the goals (e.g., starting occupational therapy, getting walking support device).

For example, a care plan might include a family-goal to travel in three months to Disneyland, and several actions toward this goal: (A1) optimize seizure medication; (A2) change feeding schedule from continuous to bolus to allow for at least 4 hours off a feeding tube; and (A3) get portable oxygen to be used during daytime naps at the park and train parents in its use. The patient status required to achieve this goal is reduced seizure frequency, lack of vomiting during bolus feeds, and parent comfort with using the portable oxygen. Persons responsible for these actions include the parent (A1, A2, A3), primary-care physician (A1, A2, A3), neurologist (A1), nutritionist (A2), lung specialist (A2, A3), home nurse (A3), and respiratory therapist (A3).

Inpatient and Outpatient Care Settings

Children with complex conditions receive most of their care in *outpatient* settings, and our study focuses on such settings. (When they need to be hospitalized their *inpatient* care is provided by a hospital-based care team.) The frequency with which these patients see particular medical providers varies depending on their conditions. The care team is distributed, and team members interact with the child and with each other less frequently than in inpatient settings. It is especially for outpatient periods that care plans need to be effectively deployed and care coordination mechanisms enhanced.

Care Coordination

Coordinated care leads to improved health outcomes for children with complex conditions and can reduce healthcare costs [15]. However, coordinating care across care teams is hard and care coordination is often not achieved [26]. O'Malley et al. [29, 10] studied medical practices' use of electronic medical records (EMR) to support care coordination. They found that while EMRs facilitate improved coordination within a single organization, they are ineffective for coordinating providers in different organizations and were also found to create information overload. According to the study, EMRs support linear processes rather than dynamic coordination processes and are optimized for billing uses rather than for provider and patient needs. In sum, current EMR systems do not provide mechanisms for supporting the coordination of team-based plans.

Human-computer interaction research has investigated systems to support patients in managing their own care [24, 6], but this work has focused on the patient alone and has not considered other care team members. The CSCW community has studied healthcare teams and developed tools for supporting them [16]. For example, prior work on coordination in inpatient settings has studied temporal and spatial coordination processes in hospital wards [7, 8], trauma-room coordi-

Role	N	Data Collection
Parents	13	Individual interviews with 4 parents (children ages ranged between 1.5 to 4 years old); focus group with 9 other parents who are also parent mentors (with children in their teens).
PCP	4	All were interviewed individually. Two of them were also observed for 2-3 hours.
Specialists	4	Individual interviews with a neurologist, pulmonologist, neonatologist and a cardiologist.
Therapists	8	3 focus groups with occupational and physical therapists (2–3 therapists in each interview).
Director of family-centered care	1	Participated in the parent focus group and in a meeting with the complex care program manager.
Care coordinator	1	Observation of 2 hours and informal conversations during that time.
Social Worker	1	Individual interview.
Program directors	2	Meeting with complex care program manager and medical director.

Table 1. Study participants.

nation [34], coordination of clinical and non-clinical staff [1], and collaborative information processes in care teams [32]. In outpatient settings, prior work has studied coordination in mobile teams (typically of therapists) and developed systems to support the loosely coupled work of such teams [30] and systems for supporting therapists' meetings [23]. While our work also addresses the need to coordinate care teams, our findings show that teamwork in complex care is significantly more complex than in these previously studied settings and thus requires new approaches for supporting coordination. We discuss these differences after presenting our findings.

RESEARCH SETTINGS AND METHODS

To better understand the challenges of care coordination and the barriers to implementing team-based care plans, we conducted a study over a period of 10 months during 2013–2014 that comprised observations and semi-structured interviews with parents and providers. Institutional Review Board approval was obtained. Most of the study was conducted in the Complex Primary Care Clinic (*CPCC*) at Stanford's Lucile Packard Children's Hospital, which operates a special complex care program. Interviews with physical and occupational therapists and a social worker were done at a nearby complex care clinic that shares many patients with the CPCC.

Participants

In the course of the study, we interviewed and observed representatives of different types of caregivers: parents, parent mentors (who are themselves parents of children with complex conditions), primary care physicians, medical specialists, therapists, a care coordinator, a social worker and administrators. Table 1 summarizes the participants by type and data collection methods. All parents we interviewed had children with complex conditions. The care teams for these children included 10–15 providers. For example, the care team for one family included a PCP, gastroenterologist (GI), neurologist, ear nose and throat doctor (ENT), a physical therapist (PT), occupational therapist (OT), speech therapist, and a school-based therapist. Another child's care team comprised 15 care providers including a PCP, cardiologist, liver transplant team, dermatologist, ENT, geneticist, GI, PT, OT, pulmonologist, and rehab specialist.

Data Collection

All interviews, focus groups and observations were conducted by the first and fourth author (some together and some separately) during visits to the CPCC in July 2013, November 2013 and March 2014. Notes were taken during interviews, focus groups and observations. The interviews with specialists and social worker and the focus groups with therapists were audio-recorded and transcribed.

Participants of the parent-mentors focus group, which lasted 2 hours, were asked to describe their experiences in managing the care for their children. They were asked to describe challenges that they face and the tools they use to manage their child's care and to brainstorm about tools that would help them better track and manage care.

In a one hour meeting with complex primary care program directors, we asked about care coordination processes and problems and about the types of support they thought would be useful to improve the use of care plans.

Individual interviews with parents lasted about an hour each. Parents were asked about the structure of the care team for their child, the use of care plans and care goals in their child's care, the tools they use to manage and track care, communication among team members and the challenges they face.

Interviews with PCPs and specialists and focus groups with therapists lasted about 45 minutes each. Interviewees were asked about their patient load, how often they see their complex patients, their use of plans and goals in care, the ways in which they gather information, their communication with parents and with other providers and the challenges they face.

In addition to interviews and observations, we collected relevant documents, including care plan templates, examples of specific care plans and patient information sheets.

Data Analysis

Analyses of interview and observation data (transcripts and notes) were done using affinity diagramming [11]. We iteratively clustered data into themes (e.g. "parents' frustration about lack of communication between providers", "physicians' view of care plans"). We discussed and revised these emerging themes over the course of several sessions.

STUDY FINDINGS

This section presents study findings on complex care teams and their use of care goals and care plans. The study revealed the complex FLECS nature of the teamwork in which care teams engage and resulting challenges to implementing long term team-based care plans. Extended duration and loosely coupled caregiver activities are inherent properties of such care. The section thus focuses on the main study findings with respect to other characteristics of FLECS teamwork. It also describes the communication deficiencies that were revealed as communication is key to teamwork.

Consensus-Driven Plan Development

Team-based care plans require that care teams, including the parents and patients (if they are old enough), reach consensus on goals for a child. Our findings indicate, to the contrary,

that at present care goals are typically defined separately by individual providers. Furthermore, their use varies among providers: while for some setting and tracking goals is a regular part of their practice, others set goals only at times of major health events (e.g., new diagnosis) or do not set goals at all. Conversations between providers and parents about goals vary greatly depending on the family and the provider. Some families have a clear idea of goals whereas others do not feel confident about setting goals. Some providers discuss goals with parents regularly while others do not discuss goals at all.

Of all providers, therapists (OT and PT) are most accustomed to working with care goals. They have a more standardized process for setting and tracking them than other providers. Therapists said that they usually set 2 or 3 goals related to mobility and feeding, which are challenging areas for most infants with complex conditions. A sample PT goal is that of a child achieving the transition from sit to stand, while a sample OT goal is that of a child no longer needing a feeding tube. Therapists often define subgoals (i.e., smaller steps) toward achieving a larger goal.

When asked how he works with a family to set goals, one specialist said: "I ask parents about seizures, skin infections. I ask about quality of life – Is the kid sleeping? Is the parent sleeping? Have they developed a strategy? I also ask the parents what is their top priority. I find that single question among the most helpful I ask." For another specialist, discussions about goals usually arise when there is a life shortening diagnosis, near the end of life or when the patient is hospitalized. In these situations she asks the parents "What are [your] goals for [your] child... How much would you put them through for treating this illness." They then decide on a treatment plan depending on the desires of the family.

Many providers discussed the difficulties of setting goals with parents. One therapist said that some parents have very specific goals such as the child not tripping when walking, while other parents have very vague goals such as wanting their child "to be better". A specialist commented, "different patients have a different idea about goals. Many patients are taken aback by it... I tend to give them ideas."

Some of our findings corroborated prior work. For instance, in a study on goal settings for elderly patients [35], providers said that patients sometimes feel uncomfortable discussing goals as they expect physicians to tell them what their goals are. On the other hand, some patients felt that physicians did not have time to discuss goals and did not engage in such high-level discussions.

Our findings also reveal substantial new challenges specific to complex care teams. In particular, the different processes and approaches to goals of various providers and the lack of joint goal setting by the team create significant difficulties for parents: They need to prioritize goals because "everyone wants to work on everything", and they also need to track the various goals. While parents frequently discuss goals with therapists, they said that with some doctors "goals don't come up at all" and that they would have liked to discuss the therapists' goals with other providers. These challenges are further exacerbated by the fact that parents have little experience in goal setting: they are often uncomfortable with the idea itself and when they do finally engage, they have difficulty articulating goals that are neither too specific nor too vague.

Continual Distributed Revision of Plans
Our study revealed that current care plans are usually individual provider plans, which are not well integrated into team plans. Parents have difficulties tracking these separate plans. Given the evolving condition of children with complex conditions, plans often become obsolete, and replanning is required. According to both parents and providers, however, even when team plans are implemented, they are rarely consulted or revised.

Furthermore, the nature of care plans varies, with some being simply a list of actions without any clearly specified connection to goals. For example, one PCP's care plan included a list of diagnoses, a high-level assessment of the patient and a list of low-level treatment actions (e.g., take new medication) and required tests (e.g., conducting a sleep study). This list was not organized around goals and was not coordinated with the plans of other team members. Parents expressed frustration at the use of such plans: "sometimes the care plan is a set of tests and it is not clear what the *plan* is [emphasis ours]."

To implement team-based care plans, "Pediatric Advanced Comprehensive Care Team (PACT) chats" are being held for patients in the complex primary care clinic. PACT chats include "core members" of the care team as identified by the family. They meet together to discuss care plans for the patient. PACT chats aim to facilitate a setting for the team to create a joint, centralized planning process. As one specialist reported, however, they are "totally not scalable" as they require getting all team members together at the same time, and the meetings themselves take a long time.

When a severe acute condition arises and a child transitions to inpatient settings (i.e., is hospitalized), a "care conference" might be initiated. In care conferences, a large number of team members meet together in one room to discuss the patient's condition and decide on next treatment steps. Care conferences greatly help everyone "get on the same page", but they occur rarely, usually only when there is a severe acute condition. They mostly involve team members from within the hospital and only some outpatient providers participate.

In outpatient settings, replanning is usually done in a distributed manner. Providers might revise their individual plans when they see a patient, but typically do not coordinate with other providers when they do so. To address this problem, the complex primary care clinic has established "status chats" with a smaller number of team members to follow-up on the patient's care plan. However, as with PACT chats, these meetings are hard to coordinate and do not scale well. One specialist described an additional problem with the ongoing tracking of plans: "One of the issues with the complex care initiative is that the PACT chats and all the status chats have to be provider initiated, and so if you don't remember to do it or there's no one coordinating it, it's like where is it going, where do you even look for it?".

These findings highlight the unique difficulties care teams of children with complex conditions experience in maintaining a coordinated care plan: While team members frequently revise their individual plans for addressing a particular aspect of the child's care, there are rarely opportunities for team members to discuss their plans together, and there are currently no effective processes or tools to support them in ensuring that their distributed activities are coordinated.

Syncopated Time Scales

Providers differ in their frequency and level of involvement in the plan. PCPs see their patients 3 to 4 times a year, and possibly more during times of acute conditions. Specialists typically see patients 2 to 3 times a year (and when an acute condition occurs). While PCPs are concerned with the overall status of the child, specialists are more focused on monitoring and treating the one facet of a child's condition related to their particular speciality. Therapists meet with patients one to three times a week and are thus more involved than physicians in the delivery of day-to-day care.

As a result of their different timescales and level of involvement in a child's care, providers require different information. Parents reported synthesizing and shaping information differently depending on the provider with whom they are talking. For instance, they might share information related to seizures with the neurologist and information related to feeding with the GI, shaping their choices by what they think is most closely related to that provider's aspect of care. In addition, even when asked similar questions by providers, parents felt that different answers were expected. As one parent said, "a doctor asks if she is walking and expects a yes/no answer; a PT will ask how she is walking and how much progress she has made." Another parent said that the medical team might monitor the child's progress through swallow studies that are typically done only 1 to 3 times a year, while the occupational therapists are much more involved in day-to-day feeding therapies, and that there isn't much conversation between the two.

Providers also differ in the timelines they set for goals and the ways they track progress towards those goals. Therapists set 6–12 month goals, monitor progress and explicitly document goals and progress toward them in their reports of an evaluation that typically occurs every 6 months. Specialists, on the other hand, said that they usually do not set goal timelines. One specialist said he does not do so, because of the uncertainty about the development of the child's condition: "The timeline is the next visit [...] So much of it is beyond their [parents'] control." As for tracking goals, some specialists said they revisit goals at each clinic visit (typically every 4 or 6 months). Another said, "I like seeing my patients quarterly, because then at the sick visits you can deal with just the illness, but when you have a visit where there's nothing going on and they're happy, then you have an opportunity to talk about what the goals are [...] being honest about things."

The different timescales in which providers operate and their different involvement in care pose additional challenges for care coordination. Each of the providers has partial information about the child's status and obtains it at different times. Therefore, it is hard to establish a complete picture of the child's condition at any moment. When providers obtain new information, they need to decide whether that information should be shared with other providers without having complete knowledge of others' plans. In practice, providers reported that such communication is often deficient.

Communication Among the Care Team

We also investigated the ways providers and parents communicate and asked them how they determined the information to communicate, because these processes are essential to effective team-based care plan formation and use.

Medical providers often belong to different organizations and frequently are unable to access to each others' medical notes. Hence, they seldom have the full picture of a child's condition. Team members with access to others' records are often overwhelmed by the massive amount of information confronting them. They reported that they often miss important information. One specialist said "I use my own savvy to figure out what happened to the patient since I saw them [...] It's all manual. If something big happened I'll get a phone call."

Providers described communication with other providers as slow and deficient. Most communication between providers is asynchronous, done through email, letters and notes. Providers who are within the hospital system can copy other providers on notes they enter into the EMR. However, one specialist remarked that "figuring out exactly what [the other provider] want[s] you to read requires that you read [their] whole [individual treatment] plan", and that there is lack of feedback when sending information: "You don't know if [other providers] read it... I get stuff all the time, too, and I don't always review my chart in a timely fashion."

As a result of these communication problems, parents find themselves responsible for transmitting information between providers, and are frustrated by this situation: "We need to relay information back and forth... We wanted [the providers] to be able to talk to each other in one room." One specialist noted a problem that arises when families transmit information between providers: "The family is telling me about what has happened [since the last visit] and they say 'this happened and we went to the doctor', and I really don't know what the doctor thought." Parents are often asked about meetings with other providers but do not remember all of the details from such past meetings. In addition, when new providers join the team or when parents call after-hours, they need to re-explain their child's condition. Parents also expressed frustration at providers not sharing information with them more proactively. According to parents, communication during transitions from inpatient to outpatient settings is crucial, but often lacking. Parents described transition times as especially stressful and said that they would like to have more information to prepare them and make them more confident about taking care of the child themselves.

Our findings corroborate many prior findings, including the ineffectiveness of EMRs [29], lack of communication among providers [37], and families' frustration with this lack [38]. Our study expands these results, showing that EMRs are even less effective when providers from multiple organizations are

involved, and that identifying relevant information is more difficult for providers in these settings. It also uncovered new problems, for instance, the difficulty of establishing common knowledge when communication is asynchronous and there are no means of determining whether other providers have seen information sent to them. It further identified a crucial communication gap at times of care transitions.

DISCUSSION

Our study reveals many challenges confronting care teams for children with complex conditions. In this section, we first reflect on these findings in the context of a recent report on the use of care plans in complex care [28], showing that many aspirations of the healthcare community are currently not realized. Next, we discuss the unique teamwork challenges for care teams for children with complex conditions that make the implementation of care plans especially hard in this setting. Finally, we discuss implications for design of technology support for care teams.

Care Plans: As They Are, As They Should Be

In support of the drive toward the implementation of integrated, team care plans for children with complex conditions, and to encourage their adoption and use, the Lucile Packard Foundation for children's healthcare (LPFCH) recently published a comprehensive report entitled "Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs". In their report, they outline the "10 Principles for Successful Use of a Shared Plan of Care" [28]. These principles, listed in the left column of Table 2, were identified by a panel of physicians, care coordinators and family advocates experienced in complex care and were informed by prior research on complex care coordination. This section reflects on our study findings in light of the aspirations for the use of care plans described in the LPFCH report.

Our findings reveal that many of the principles for successful implementation of care plans are currently not met, as summarized in the right column of Table 2, and that achieving them will require overcoming several barriers. These barriers cluster into four areas, which we order according to their focus on plans per se.

First, successful care plan implementation requires an integrated care plan with shared goals, implemented as a shared document that is monitored and revised over time (Principles 6, 7 and 9). Our findings reveal, however, that in current practice there are typically multiple individual plans formed by different providers, rather than a single shared team plan, and that providers are typically unaware of each other's plans. Even when team-based care plans are successfully implemented, they are rarely monitored or updated, despite the uncertainty in the outcomes of the initial plan and the inevitable, often unexpected, changes in the child's condition.

Second, successful use of care plans requires that communication among team members be clear, frequent and timely (Principle 2), as does care coordination in general. Our findings highlight many difficulties in achieving the requisite levels of communication and information sharing, including information overload, slow and unreliable communica-

tion channels and unclear communication between providers and parents. They show that providers cannot easily access or find all relevant information and thus do not have a full understanding of the child (Principles 3 and 5).

Third, care plans need to address the challenges of parent and family engagement and their integration into provision of care (Principle 1). Prior research on patient-centered care has found that patients and families are often not sufficiently engaged as a result of language barriers, cultural issues, the emotionally overwhelming situation, or providers' lack of experience with engaging parents [13, 9]. Our study revealed similar barriers (not reported in this paper as they largely replicate prior findings).

Fourth, care plans need to support transitions in care (Principle 8). In our interviews, both providers and parents described transition situations as very stressful, and families expressed the desire to be given more information and to be better prepared so they would feel more confident about meeting their new responsibilities.

Barriers to Effective Care Plan Implementation

Our study exposed the complex nature of teamwork in complex care, revealing five characteristics that, in combination, distinguish it fundamentally from other teamwork settings. In summary, these are,

- *Flat-structure, consensus driven plan development*: goal-setting requires consensus of multiple caregivers, with no single decision-maker "in charge".

- *Loosely coupled*: the activities of care providers are largely decoupled, but identifying interactions between their activities is crucial for preventing conflicts.

- *Extended duration*: care plans extend over months to years, during which a child's condition evolves.

- *Continual distributed revision*: care teams must create and frequently update well-coordinated care plans while rarely (if ever) meeting as a whole.

- *Syncopated time scales*: the timescales on which care providers interact with the child vary greatly from several times a week to once or twice a year.

These FLECS teamwork characteristics make the implementation of care plans in these settings particularly challenging. The extended duration of plans combined with uncertainty in outcomes of treatments and changes in the child's condition result in a need for ongoing revision of the goals and plans. The disparate timescales and involvement in the care plan pose difficulties for providers in keeping track of the child's current condition and plan status, and in coordinating their updated plans with others. Despite their different level of involvement in care, it is crucial that all team members reach consensus about the high-level care goals, as these goals guide their individual treatment plans. It is also important for them to be aware of changes in others' plans that might affect their own plans and to avoid undesired interactions when updating their plans. These challenges are further exacerbated by the fact that, for most providers, participating

	Principle	Study Findings
1	Children, youth and families are actively engaged in their care.	Engaging families is a complex process: families are overwhelmed by the child's condition; family engagement is a new concept and many providers do not feel comfortable with it.
2	Communication with and among their medical home team is clear, frequent and timely.	Communication is typically infrequent and slow. Providers often do not communicate among themselves, leading to lost information and to parents being responsible for transmitting information between providers.
3	Providers/team members base their patient and family assessments on a full understanding of child, youth and family needs, strengths, history, and preferences.	Team members are often focused on their aspect of the care and do not have a shared "big picture" view of the child's overarching goals.
4	Youth, families, health care providers, and their community partners have strong relationships characterized by mutual trust and respect.	Our study did not focus on this issue, but our findings show team members do not all know each other.
5	Family-centered care teams can access the information they need to make shared, informed decisions.	Team members cannot access all of the information about the patient. When they can access it, they are typically overwhelmed by the amount of information and have difficulties finding the *relevant* information.
6	Family-centered care teams use a selected plan of care characterized by shared goals and negotiated actions; all partners understand the care planning process, their individual responsibilities, and related accountabilities.	Different team members have different concepts and uses of care plans and care goals. There is no clear process for defining and revising team care plans.
7	The team monitors progress against goals, provides feedback and adjusts the plan of care on an ongoing basis to ensure that it is effectively implemented.	Progress towards goals is often not continuously monitored and care plans are not updated frequently. In addition, different providers set goals separately rather than as a team. Thus, even when monitoring is done it does not contribute much to achieving coordinated care.
8	Team members anticipate, prepare and plan for all transitions (e.g., early intervention to school; hospital to home; pediatric to adult care).	Parents feel they lack information in times of transitions, which they find especially stressful as responsibility shifts to them (e.g., in- to outpatient care) or when new providers join the team.
9	The plan of care is systematized as a common, shared document; it is used consistently by every provider within an organization and by acknowledged providers across organizations.	Different team members have different concepts and uses of care plans and care goals. Typically there are many different plans rather than a single team plan.
10	Care is subsequently well coordinated across all involved organizations/systems.	Care coordination is very hard to achieve, both between organizations and within organizations.

Table 2. Principles for successful use of care plans (left column) and findings from our study that point out the barriers in achieving them (right column).

on the care team for such patients is an exceptional situation, beyond the typical care they were trained to provide — most of their patients do not have multiple conditions nor require interaction and coordination with so many other providers. Some of the providers (e.g., PCPs in complex care clinics) are involved with many different care teams, each with a different team composition, and each operating over an extended period of time, often years.

The challenges faced by the care teams in complex care go beyond those previously studied in healthcare teamwork. In particular, the team coordination challenges they experience are not addressed by existing theories and tools. Prior studies of inpatient team coordination typically investigated the coordination of temporal activities (e.g., scheduling of operations [7]). In such settings the goals are clear (e.g., find a feasible, preferred schedule) and team members operate in the same timescale (plans are made for a specific day). When replanning is needed it is usually done in a centralized manner by a designated team member (e.g., the charge nurse might reschedule operations if an acute patient arrives [8]) and the changes are communicated by that person.

Prior work on outpatient settings has studied the coordination of mobile home care teams [30]. Such mobile teams share some characteristics with complex care teams, namely their activities are typically loosely coupled and they often do not meet together to coordinate. However, these teams are smaller than complex care teams and their high-level care plan is determined by single person (a case manager). Providers do not need to reach consensus about goals and their cooperation is not strictly required [30].

Foundations for Design of Systems to Support Complex Care Teams

For complex care teams to develop and successfully use long-term care plans, as well as for providers to operate as a team, requires systems able to support FLECS teamwork, and in particular, technology capable of supporting the collaborative, mutual consensus decision-making of a distributed, diverse team whose members operate on different timescales and seldom if ever meet as a full group. These systems must also accommodate team membership changing over the extended duration of complex-care plans.

The social science and CSCW communities have investigated teamwork extensively and developed theories and tools for supporting team coordination. Such work has studied teamwork in various domains, exploring various characteristics of the collaborative setting (e.g., mobile teams [30], co-located teams [32]), team structure (e.g., hierarchical and non-hierarchical teams [20], team homogeneity) and the nature of tasks performed by teams (e.g., loosely-coupled activities and highly interdependent tasks [22]). The FLECS teamwork characteristics exhibited by complex care teams distinguish it from the teamwork studied in prior work. As a result, existing tools and approaches do not fully address the challenges FLECS teams face.

In contrast, research in multi-agent systems (MAS) has developed several models of collaboration that more closely match the characteristics of FLECS teamwork. Each provides a formal specification for the design of computer agents able to robustly act collaboratively as members of a distributed team; they differ in the facets of teamwork they emphasize. The

Joint Intentions (JI) [27] formalization focuses on a specification of the mental attitudes required for teamwork. Planned Team Activity (PTA) [36] addresses issues of task allocation and team formation. The SharedPlans (SP) [19, 18] formalization directly represents partiality and evolution of plans. To analyze the opportunities for technology to support complex care, we chose SP, because it presumes only partial plans, distributed teams acting under uncertainty and the need for plans to evolve dynamically. (These assumptions contrast with JI and PTA which assume that the team has a complete, fully expanded plan.) SP requires certain group decision-making mechanisms, but not centralized replanning or complete knowledge of all team members' plans. It thus better fits the FLECS teamwork characteristics.

SP has been used to improve performance of multi-agent computer systems teams [39], as the model for intentional structure in dialogue systems [33], and as the basis of design for collaborative human-computer interface systems [5, 17]. While designed to guide the development of computer agents, it also provides a framework for identifying coordination mechanisms missing in complex care teams and needed to support their team-based plans.

SP is rooted in the observation that collaborative plans are not simply a collection of individual plans, but rather a tight interleaving of mutual beliefs and (coordinated) intentions of different team members. It specifies the beliefs and intentions required of team members for successful collaborative activities. In particular, SP requires that (SP1) each team member commit to (i.e., form specific intentions regarding) the team's performance of the group activity; (SP2) team members establish agreement on a "recipe" for carrying out the group action and establish mutual belief they are using that recipe; SP allows for recipes to be partial, expanded over time, and revised; (SP3) the group agrees on an allocation of tasks in the recipe according to participants' abilities to carry them out (i.e., decompose tasks and allocate work appropriately); (SP4) team members commit to performing tasks allocated to them (i.e., adopt intentions to do those tasks); (SP5) team members commit to the success of others in doing their tasks (i.e., adopt intentions that their teammates succeed).

According to SP, only the team members selected for doing a subtask determine and know in detail the recipe for that subtask. For example, the neurologist does not need to know the full details of the PT's plan for getting the child to walk, and the PT does not need to know the full details of the neurologist's plan for treating seizures. SP handles the problem of interaction among loosely coupled tasks through the required commitments to the overall team activity and to the success of teammates (SP1 and SP5) and general axioms of intention. These commitments result in several desired behaviors of team members. In particular, they necessitate communication among team members when any of them comes to believe that plans for subparts of the activity interact or when new information is obtained that could affect others' plans.

Thus, importantly, SP handles the tension between the low communication overhead of loose coupling (and the resultant lack of shared information about plan details) and coordina-

tion needs (sharing information that matters because of potential plan interactions) by requiring communication when essential, but not full sharing of all plan details by all participants. The need for such *efficient* communication was evident in our study: some of the providers we interviewed reported that when complete plans or notes are sent to them, they are unable to determine the information most important to consider, and they do not review the information in a timely manner as a result of this information overload.

We illustrate several desired behaviors engendered by SP with examples from complex care settings. The commitments to the overall team activity and to the success of teammates require that team members inform others if they learn that their plans are failing or likely to fail. For example, in the complex care domain, if the physical therapist learns in her session that the child's seizures have worsened, she should notify team members who are working toward the goal of optimizing seizure medication (in this case the PCP and the neurologist). Similarly, when team members update their plans, they should notify others about changes if their plans might affect others' plans. For example, if the GI decides to start feeding the child by mouth instead of through a tube, she should notify the nutritionist and occupational therapist who also address feeding issues. Further, although not directly involved in feeding, the respiratory therapist should also be notified because breathing and feeding often interact.

While such team behaviors and communication protocols are desired, they are hard to achieve in practice in complex care teams. The examples above assumed that team members had sufficient knowledge about others' plans and about the team's goals to realize that information should be shared. Our findings, however, show that care providers do not have this knowledge. Thus, it is unlikely that team members would exhibit the behaviors SP prescribes. However, SP also suggests ways in which technology could support care teams and help achieve desired team behaviors. The applications of SP in multi-agent systems demonstrate that it is in fact both feasible and efficient to allow individual team members to dynamically modify their individual plans and that only relatively limited communication is necessary to ensure that actions of a team members do not interfere with others' actions.

A SharedPlans-based analysis of complex care team needs suggests the following key roles for technology for supporting complex care teams:

- Make the care plan "ever present", adapting the content and form of its presentation to individual team members based on their involvement in the plan and context of use.

- Support efficient information sharing by team members.

- Enable care team members to easily adapt and expand parts of the plan, while ensuring their changes do not conflict with others' activities.

Making the care plan "ever present" will support team members in establishing and maintaining agreement and mutual belief about the high-level team plan and allocation of tasks (SP2 and SP3). Currently, these requirements do not hold in

complex care teams as there are no mechanisms to support them. While care providers want their teammates to succeed, they currently do not have sufficient information about others' plans to act in a way that supports others or at least does not conflict with their activities. Efficient information sharing will help team members act in a way that does not conflict with others' plans (SP5). The partiality and dynamic nature that SP assumes, and that complex care plans exhibit, leads to the need for enabling easy plan adaptation and expansion.

Providing this support for care teams likely requires the design of intelligent interactive systems that reason about the care plan and the context of each team member in the plan to determine the parts of the plan that should be presented and the information to proactively share with each team member. Specifically, adapting the presentation of the care plan to a particular team member and context of use requires reasoning about the role of that team member in the care plan, the context of interaction (e.g., clinic visit, quick review of the patient's status), and the history of interactions with the patient (when the patient was last seen) and with the system (e.g., what information is already known).

Deciding what information to proactively share with team members requires similar reasoning. In addition, such reasoning needs to consider the importance and urgency of information about the status of the plan and changes made to it to determine when to share that information (e.g., immediately or during the next clinic visit). These information sharing challenges are beyond the current state-of-the-art in multi-agent systems research [4]. Given the limited time of care providers, it is also important to reason about interruption management [21] when making decisions about the timing of sharing information.

Lastly, to reason about the importance of information to team members, such systems will need to get sufficient details from team members about their plans. Therefore, the systems will need to incorporate mechanisms for eliciting information in a manner that fits providers' workflows and does not require much effort. The representation of plans also needs to be flexible enough to allow for team members to provide incomplete descriptions of plans that can be easily adapted with time.

CONCLUSION

In this paper, we report the findings of a study of teams providing outpatient care for children with complex conditions, focusing on their conceptualizations and use of team-based care plans, which have been shown to improve care coordination and health outcomes. We identify the FLECS characteristics of teamwork in the complex care environment, which pose challenges to team planning and coordination beyond those considered by existing theories and tools from the social sciences and CSCW. We draw on SharedPlans, a computational theory of collaboration, to suggest ways in which technology could support complex care teams and to specify capabilities that such technology will need to provide.

Our study findings also raise additional opportunities for technology to support care teams, including systems for explaining and simplifying medical information [12, 25], sum-marizing providers' notes [3] and supporting low-level coordination activities such as scheduling appointments and ordering equipment. However, some of the challenges revealed in our study, such as the lack of experience of both providers and parents in setting care goals, will likely require better training for providers and mentoring for families and will not be solved by technology alone.

Systems able to support FLECS teamwork have the potential to improve the coordination and effectiveness of teams in many other settings within and beyond the healthcare domain. For example, teamwork in rescue and recovery efforts, software development projects and research collaborations all exhibit some or all of the FLECS characteristics, and would benefit from greater support of team coordination.

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