

From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring

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ABSTRACT

In families composed of parents and children, the health of parents and children is often interrelated: the health of children can have an impact on the health of parents, and vice versa. However, the design of health tracking technologies typically focuses on individual self-tracking and self-management, not yet addressing family health in a unified way. To examine opportunities for family-centered health informatics, we interviewed 14 typically healthy families, interviewed 10 families with a child with a chronic condition, and conducted three participatory design sessions with children aged 7 to 11. Although we identified similarities between family-centered tracking and personal self-tracking, we also found families want to: (1) identify ripple effects between family members; (2) consider both caregivers and children as trackers to support distributing the burdens of tracking across family members; and (3) identify and pursue health guidelines that consider the state of their family (e.g., specific health guidelines for families that include a child with a chronic condition). We contribute to expanding the design lens from self-tracking to family-centered health tracking.

Author Keywords

Personal Informatics; Self-Tracking; Self-Monitoring; Family Informatics; Families; Health; Children.

ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g., HCI).

INTRODUCTION

Self-management and self-tracking helps people understand their health, maintain wellbeing, manage a chronic condition, or engage in sense-making to change habits and improve overall health [59]. However, it is still widely regarded as

an individual practice. Self-tracking tools tend to be designed primarily for individuals, with the notable exception of commonly-included features for comparison, competition, and social sharing [10, 19, 39, 41, 48, 49, 63].

Although health tracking at an individual level is important, many aspects of health or health-related behaviors affect and are affected by other people. Prior research has examined how to support diverse forms of health-related collaboration. Examples include patient-provider interaction [7, 31], adolescents living with a chronic condition as they transition to adults [30, 56, 69], adult caregivers tracking information about a child (e.g., development [36], diabetes management [70]), and caregivers supporting adult family members with chronic conditions (e.g., cognitive impairments [57], depression [73], Parkinson's [51]).

In families, the health of parents and children can be interconnected [16]. Some health conditions are commonly experienced by both parents and children (e.g., ADHD [13], diabetes [46], poor sleep quality [77]). In many situations, the act of caregiving takes a toll on the health of informal caregivers [4, 55]. These interconnected health issues occur in families with a child living with a chronic condition, as well as in typically healthy families. Previous work on families has supported improving eating habits [61, 66], increasing exercise through family-focused exergames [64], and improving family awareness and health goals through online family portals and social networks [8, 37]. Our work expands family-centered design by examining how models of self-tracking can be expanded and applied to the family context, where family members are tracking together to improve the health of a family member or the entire family.

To inform the design of family-centered health technologies, we examined how family members living together manage their health. For the purpose of this study, we define family as: *“two or more people related biologically, legally, or emotionally who have lived together long enough to have patterns of interaction as well as stories that justify and explain these patterns”* [47]. We focused on families composed of parents and children living together because we were interested in age and development-related issues that may arise, but future work should also include other types of families (e.g., couples living together).

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Our study aimed to answer the following research questions:

- How do families with children, either with or without a chronic condition, manage their health together?
- What are common barriers that families encounter in managing their health together, and how might technology design help families overcome those barriers?

To answer these questions, we interviewed 24 families with young children living at home. Of these families, 14 were typically healthy (TH) families and 10 had at least one child living with Juvenile Idiopathic Arthritis (JIA). Our primary focus in the interviews was *sleep*. We chose sleep because it is one of the health issues that most impacts families [14] and both TH and JIA families experience poor sleep [77]. Therefore, sleep allowed us to compare and contrast families with a child with chronic condition versus families more focused on general health and wellness. Our interviews primarily took place at the family's home, with all family members living in the household present. Our goal was to elicit how family members support each other or work together toward health and wellness. We also supplemented interviews with three participatory design sessions with a cohort of children aged 7 to 11. We wanted to ensure children's perspectives on health, tracking, and family, without the interference or pressure of parents.

During our interviews, all participants connected sleep with overall health including mental health, physical activity, and diet. To triangulate insights from the interviews, our participatory design sessions with children covered both sleep and overall health and tracking. Our contributions identify themes in family health informatics that go beyond sleep:

- TH and JIA families want to identify ripple effects between family members.
- JIA families prioritize and collaborate toward the wellbeing of the child with JIA, while TH families try to balance the health of every family member.
- TH and JIA families want both caregivers and children to be able to collect data, in support of distributing the burden of tracking across family members.
- Children have a nuanced understanding of health, tracking, and technology and have privacy concerns.
- TH and JIA families want health guidelines based on families in a similar state (e.g., guidelines for families that include a child with a chronic condition, or guidelines for families with similar demographics).

In examining the needs, opportunities, and challenges that families experience around managing their health, we find that the current dominant paradigms of *self*-management and *self*-tracking are insufficient to guide the design of technologies to support maximizing health across the family. Our contributions inform the design of health tracking technologies that expand the design lens from a single person towards a family-centered approach.

In the remainder of this paper, we offer background on JIA and present related work. We then give an overview of our qualitative study, our participants, and our analysis. Finally, we present our results and discuss their implications for designing family-centered health tracking technologies.

BACKGROUND AND RELATED WORK

We first provide background on Juvenile Idiopathic Arthritis, then review and situate our research relative to prior work in designing for caregivers, designing for families, and designing for collaborative health.

Juvenile Idiopathic Arthritis

Juvenile Idiopathic Arthritis (JIA) is a chronic inflammatory disease, with no known cause and poorly understood underlying mechanisms [60]. An estimated 20% of children with JIA experience lifelong pain and chronic disability [24]. With early diagnosis and treatment, many children can live long lives. Symptoms vary, but children experience joint swelling, stiffness, tenderness and pain, limited range of motion, and poor sleep quality [77]. Children experience unpredictable episodes of active disease including joint inflammation, tenderness, and pain [54].

Designing for Caregivers

More than 34 million people in the US are unpaid caregivers who care for a relative [3]. Research in HCI and CSCW has examined a caregiver's role from the perspective of the care they provide [4, 67] and the impact of caregiving on a caregiver's wellbeing [42, 73]. Related work on caregiving covers a range of topics, such as supporting parents with premature babies [27, 42], the role of caregivers in managing the online accounts of older adults [57, 70], and designing technologies that support caregivers in providing better care for a person living with a chronic condition (e.g., cancer [32], Parkinson's disease [51], or autism [35]). Much of the related work has focused on settings where the family member with a chronic condition is increasingly transitioning toward dependence on the caregiver, such as with aging or a progressive condition. Work on children, however, often involves a transition toward independence [30, 56, 69]. An implication of this body of work is that health management designs need to consider the care recipient as well as the caregiver. We build on this thread of research by identifying opportunities and challenges to support both caregivers and children in collaboratively tracking.

Designing for Families

Designing for families spans a variety of topics. Prior work investigated the crucial role that calendars play in family coordination [52, 53], how parents coordinate to complete errands [68], improving a sense of connection [2, 74], and development of systems that learn routines to improve pick up and drop offs of children at afterschool activities [15].

Research has also examined how parents and children manage the use of personal digital devices [28] and the tensions around sharing of personal information. In the case of location tracking, even though people might be motivated by good intentions, having access to geographical location

traces can cause tension in family relationships [44, 72]. Examining the relationship between caregivers and children around monitoring a child's health, Toscos et al. present design suggestions for technology that enhances teenager self-care, considers caregivers, but avoids parent-child conflict around a child's ability to self-care according to parental expectations [71]. Our work expands this body of work by examining opportunities to balance caregivers tracking themselves, caregivers tracking children, and children self-tracking towards family monitoring of health.

Designing for Health Tracking

Increasing rates of chronic illness and interest in preventive health have led to an increased focus on home care [22]. In home care, it is often important for people to track behaviors, outcomes, and context to monitor and adjust their behavior, a process known as personal informatics [40]. Several models describe this process [6, 20, 40, 62]. Each describes the activities of tracking, integrating data, reflecting, and then acting on insights gained. Many products now support these activities for a variety of health and wellness concerns, including sleep, posture, physical activity, mood, and nutrition. The more recent lived informatics model describes the important role of deciding to track and selecting tracking tools, while also noting that people often lapse, sometimes abandon, and sometimes resume tracking [20].

These models describe the activities involved in tracking for health, but do not describe who will take on the roles. Instead, health tracking is primarily treated as an individual activity, hence the term "self-tracking". Some literature discusses social uses (e.g., [10, 19, 48, 49, 63]), collaboration between patients and providers (e.g., [7, 43]), or surveillance, particularly of older adults (e.g., [57]). As noted above, however, care and health activities are often collaborative and interdependent, especially among cohabitating family members. New research is needed to guide designers in creating tools to help families collaboratively track and act to manage their health.

Designing for Family-Centered Health

Prior research in health collaboration examines collaboration in the hospital among clinicians [1, 65], between clinicians and adult patients [7, 43, 45, 58], or between behavioral specialists monitoring various behaviors of children with different neurodevelopmental needs during school [35].

In the home setting, caregivers and care receivers work together to manage the health of care receivers [51, 57, 70, 80]. For example, sharing a child's glucose levels between parents and children can improve diabetes management [71]. Diet is heavily shaped by family, motivating work by Grimes et al. [25] to explore opportunities to support family diet and by Schaefbauer et al. [66] in *SnackBuddy*, a mobile application to help caregivers and children monitor their snacks. For physical activity, Saksono et al. [64] examined encouraging physical activity by creating exergames that focused on families. Last, Colineau [8, 9] and Kimani [37] thought to support family wellbeing through online family

portals and social networks. In these systems, family members review and reflect on family health goals and engage in these goals together. The results of this work show that health monitoring does not have to be an individual endeavor, that engaging the entire family can create family awareness on a particular health topic, and that technology can facilitate this group effort.

Research in personal informatics provides models describing describe the process of self-tracking [6, 20, 40, 62]. However, less work has examined applying these models in the family setting: where the same person can self-track and also track on behalf of another family member. Our work examines these models that describe the process and stages of self-tracking when applied into a focus on family tracking. Applying models of self-tracking to families will help researchers and designers understand how to account for the stages of tracking within family dynamics, accounting for multiple trackers with different family roles, expertise, and abilities working together toward family health goals. We examine these models with two types of families: typically healthy and families with a child with a chronic condition.

METHODS

Our study consisted of two activities: (1) semi-structured interviews with 14 TH families and 10 families with at least one child with JIA, and (2) three participatory design sessions with typically healthy children aged 7 to 11. This section explains our recruitment process, our participants, our protocol, and our analysis for each activity.

Family Interviews

We wanted to compare similarities and differences between TH families and families including a child with a chronic condition. Being able to compare the two cohorts allowed us to examine family-centered health informatics from both perspectives. Furthermore, comparing the two cohorts allowed us to reflect on families transitioning between typically healthy to managing a chronic condition for a child, and vice versa. We chose JIA as the chronic condition to study because we had access to families experiencing this condition.

Participants

We recruited families from two sources. The first was through a previous study on family sleep, which compared sleep between typically healthy families and families with a child with JIA [77]. We contacted families from both cohorts that consented to be contacted for future studies. The second participant source was through the University of Washington Communication Studies Participant Pool, which is a roster of people who have opted in to being contacted to participate in research studies. Our inclusion criteria from this list was to recruit families that registered as typically healthy. We defined typically healthy as families that do not have family members diagnosed with a chronic condition (e.g., cancer), or a neurodevelopmental condition (e.g., autism).

Family	Family Member	Age	Gender	Marital Status	Occupation
TH1	Father	31-40	Male	Married	Construction Management Stay at Home Mom
	Mother	31-40	Female		
	2 Children	7, 5			
TH2	Father	31-40	Male	Married	Banker Clinic Coordinator
	Mother	31-40	Female		
	2 Children	8, 5			
TH3	Mother	41-50	Female	Married	Nurse Practitioner Marine Maintenance
	Father	51-60	Male		
	3 Children	11, 7, 7			
TH4	Father	41-50	Male	Married	Research Scientist Clinical social worker
	Mother	41-50	Female		
	2 Children	12, 9			
TH5	Mother	31-40	Female	Married	Physical Therapist Assistant Nurse
	Father	51-60	Male		
	2 Children	12, 9			
TH6	Father	41-50	Male	Married	Marketing Consultant Physical Therapist
	Mother	41-50	Female		
	2 Children	15, 12			
TH7	Father	41-50	Male	Married	IT Manager Current Stay at Home
	Mother	31-40	Female		
	2 Children	8, 5			
TH8	Mother	41-50	Female	Married	Government (Civil Service)
	2 Children	11, 8			
TH9	Mother	31-40	Female	Married	Manufacturer Sales Business Owner
	Father	41-50	Male		
	2 Children	10, 7			
TH10	Stepfather	41-50	Male	Re-Married	Finance N/A
	Mother	41-50	Female		
	2 Children	14, 12			
TH11	Mother	41-50	Female	Married	Program Coordinator Dentist / Professor
	Father	51-60	Male		
	Child	16			
TH12	Mother	51-60	Female	Married	2nd Grade Teacher School Administrator
	Father	51-60	Male		
	Child	14			
TH13	Mother	51-60	Female	Co-Habiting	Nutrition Services Manager
	Child	13			
TH14	Mother	31-40	Female	Divorced	Marketing
	Child	13			

(a) Typically Healthy Families

Family	Family Member	Age	Gender	Marital Status	Occupation
JIA1	Mother	31-40	Female	Married	Instructional Coach Heavy Equipment Operator
	Father	31-40	Male		
	4 Children	10, 9, 6, 4			
JIA2	Father	41-50	Male	Married	Aircraft Mechanic Stay at Home Mom
	Mother	41-50	Female		
	3 Children	18, 16, 8			
JIA3	Mother	41-50	Female	Married	Health Assistant
JIA4	Mother	41-50	Female	Divorced	IT Consultant
JIA5	Mother	31-40	Female	Married	Nurse
JIA6	Mother	41-50	Female	Divorced	Nurse Electrical Engineer
	Father	41-50	Male		
	1 Child	5			
JIA7	Father	41-50	Male	Married	IT Consultant IT Consultant
	Mother	41-50	Female		
	2 Children	20, 17			
JIA8	Father	31-40	Male	Single	Sales
JIA9	Mother	31-40	Female	Married	Massage Therapist
JIA10	Mother	41-50	Female	Married	Stay at Home Mom
	3 Children	18, 16, 14			

(b) Families Including a Child with Juvenile Idiopathic Arthritis

Child	Age	Gender
PD1	9	Female
PD2	7	Female
PD3	7	Male
PD4	9	Female
PD5	7	Female
PD6	9	Male
PD7	11	Female
PD8	11	Female
PD9	11	Female

(c) Participatory Design Participants

Table 1: Overview of study participants. We conducted interviews with 14 typically health families and 10 families including a child with Juvenile Idiopathic Arthritis. We also conducted participatory design sessions with 9 children.

We interviewed 24 families that fit our criteria, 14 TH families and 10 JIA families. All children older than five were assented and had parental consent according to our university's IRB protocol. In all interviews, parental caregivers were present with their children. Of the 24 families, five identified as divorced, re-married, or single (TH=2, JIA=3). In one of the four divorced families, both parents participated in the interview (JIA=1). All families that consented to participate are heteronormative, though this was not criteria for inclusion. Table 1 summarizes participant demographics.

We interviewed all family members living in the same household together. Interviews lasted between 40 minutes and 100 minutes, focused on how families address sleep. Whenever possible, we interviewed families at their home, because we wanted them to be comfortable, in a location where they spend time together, and a location where they take part in activities related to health (e.g., diet, sleep). Of 24 interviews, 17 took place at the home of the family. Of 7 families we interviewed outside of the home, 3 were at the hospital after a medical appointment (JIA=3), 3 at a coffee shop (TH=2, JIA=1), and 1 at a school (TH=1).

Interview Protocol

We used suggested methods aggregated by Judge and Neustaedter for conducting research in homes [33]. Our interview protocol had four parts, with only the first different

between the two cohorts. In the first part of the interview we asked TH families about their health monitoring and priorities. For JIA families, we additionally asked how they manage their child's condition, how they monitor it, and how they address the challenges they face. We made sure to get answers from every family member. We also gave time for family members to build on each other's answers, allowing us to learn about their collaborative practices. Last, we also gave children coloring pens and paper to give them an additional means to express their thoughts.

To focus on sleep, the second part of the interview consisted of presenting data collection tools that are commercially available or have been published at CHI or CSCW that focus on issues related to sleep. Our goal was to elicit conversations about current tracking practices as a family and to identify opportunities. Our range of tools included pen and paper checklists, diet journals [12], self-report-based sleep journaling [5], and sensor-based sleep systems such as Fitbit¹, Jawbone², and Lullaby [34].

The third and fourth parts elicited conversations about data representation, sharing preferences, and privacy concerns. The third part consisted of family members sketching how

¹ www.fitbit.com

² www.jawbone.com

they would like to view their data. Families struggled to sketch out their ideas, and more than half of the families preferred not to sketch. They stated that because tools do not support family tracking they found it difficult to imagine how data would be represented. In the final part, we presented data representations generated from the tools presented in the second part of the interview. We presented sleep data for a single person and then hypothetical examples of sleep data with all family members visualized together. Family sleep representations were also adapted from prior work, such as using a metaphor of multiple fish in a tank (inspired by the Fish'n'Steps visualization of co-worker step activity [41]) or showing each family member's sleep data by day, month, and year (inspired by Froehlich et al.'s visualization of water usage by family members [23]).

Analysis

In an iterative process, the research team created an affinity diagram to identify emergent themes [29]. We identified themes as we processed the data, focused on family practices and challenges around family health management, making sense of health data as a family, and designing for tracking in the family context. The research team wrote memos using the identified themes that included comparisons between the two family cohorts. The lead author discussed findings iteratively with the research team.

Although our interview protocol focused on sleep, all participants connected sleep with overall health, including mental health, physical activity, and diet. Our results reflect these connections between sleep and other health topics.

Participatory Design with Children

Our family interviews consisted of interviewing parents and children together. We also wanted the perspective of children on health and tracking without the interference or pressure of their parents. Specifically, because families in our interviews struggled to sketch out how they wanted to view their data, we wanted to work with participants willing to design for health. We therefore, conducted three Participatory Design (PD) sessions with children in an intergenerational co-design group. We adapted the content of the interview protocol to the PD sessions to ensure we were covering the same topics.

Participants

The same cohort of children participated in all three PD sessions. Sessions were part of a yearlong, biweekly, intergenerational design group called *KidsTeam UW* [76]. Each *KidsTeam UW* session had six to nine children (total of two boys, seven girls) between the ages of 7 to 11 years old representing diverse ethnic backgrounds. *KidsTeam UW* works on a variety of co-design projects.

Although the children in this group are all typically healthy, we chose to engage with this specific group of children because of their domain expertise in design, critique, and communicating with adults [75].

Participatory Design Method

The PD method we implemented was Cooperative Inquiry [17, 18], a framework that focuses on adults and children as equal partners in co-design. We conducted three co-design sessions (one per month) that lasted 90 minutes each. Each session had six to seven adult design researchers working with the children. For each session, we began with a "Question of the Day" and presented the children with specific design and informant activities to understand their conceptions of health technologies. In Session 1, we used the "Big Paper" technique [26] to have children collaborate together to draw out what they considered healthy and unhealthy habits about themselves and about their parents. In Session 2, we implemented the "Line Judging" technique [78], where children voted on health technologies as *really like*, *really dislike*, and *not sure*. The room was divided into three spaces representing the three possible responses. Children voted on each technology by standing in the space in the room that corresponded to one of the three responses and gave a reason for their vote. We presented the children with 20 different health technologies for children and also the sleep tracking tools presented in the second part of the family interviews. Finally, to further explore sleep and associated technologies, Session 3 had children create "Bags of Stuff" low-fidelity prototypes [17] of their ideas for sleep technologies. All sessions included group discussion of the children's designs and critiques.

Analysis

For all three sessions, we collected observational field notes, photographs of children design artifacts, and video recordings of the entire session. The first step of our analysis consisted of writing summative memos for each session. Two authors then applied the themes identified in the family interview data to drive a deeper analysis of data from the PD sessions. Insights from PD were used to triangulate and corroborate our findings from the family interviews. Next, in the results sections, we present insights from the PD sessions with respect to the themes identified in the family interviews.

FAMILY PRACTICES AROUND HEALTH MANAGEMENT

The focus of our family interviews was on sleep. Through the course of the interview, all families expressed health concerns and practices with regard to diet, physical activity, and mental health, and connected them to sleep.

Motivations between the two family cohorts are different. TH families are motivated from the perspective of wellness and preventive health. JIA families focus on the wellbeing of the child with JIA. JIA families want to monitor anything that would improve wellbeing and management of JIA, including monitoring swelling, pain, and joint mobility.

The remainder of this paper references the TH families as TH[1:14], the JIA families as JIA[1:10], and states which family member we are quoting. We reference children from the PD sessions as PD[1-9], consistent across the sessions.

TH and JIA Families Manage Health Differently

Health practices of TH and JIA families are different. JIA family efforts center on the child with JIA, including structuring their days around appointments, medication, and sleep time of the child with JIA.

JIA10 (sister, 22 yo): ... kind of like the family system where we would just, "Okay, he's sick. We know that. Okay, let's just all take care of him first."

This approach comes from a real necessity and good intent, but also takes a toll on the rest of the family. Parents of children with chronic conditions struggle to attend to their self-care and are concerned other children are unintentionally a lower priority (e.g., siblings of the child with JIA).

TH families do not need organize themselves as much around the care of a particular family member. With respect to wellness and health, TH families tend to be less structured. TH parents make efforts to self-care (e.g., diet, exercise, sleep) and strive to balance self-care between work and family responsibilities. TH parents describe how they try to do healthy activities together with their children, and our PD sessions with children revealed the same theme. However, children in the PD sessions expressed a nuanced view on what they consider to be healthy activity they do with their family:

PD1 (female, 12 yo): ... watching a movie with my dad and eating candy, it's unhealthy and healthy at the same time.

The health of TH families imposes less constraints on how they manage their health and how they can manage their schedules. This gives them more opportunities to have planned and unplanned health activities.

TH2 (mother): ... we're sort of not as structured ... This week ... they were able to play outside ... we kind of like, 'Ah, forget about homework for now.' ... A lot involves us [parents] playing with them [children] basketball outside or baseball.

On the other hand, JIA family schedules are constrained by multiple doctor appointments per week and regular caregiving, which limits the time for family members to take part in healthy habits. When JIA children were in remission after an arthritis flare, JIA families made a strong and intentional effort to do activities they considered healthy together.

Family Members Collaborate to Manage Children's Health

In JIA families, family members collaborate to manage the chronic condition (including the child with JIA). Due to the demand of regular monitoring of pain, sleep, medications, as well as frequent medical appointments, family members organize themselves around caregiving responsibilities. One caregiver, usually a parent, organically turns into what we identified as a *primary caregiver* of the child with JIA.

JIA7 (primary caregiver, mother): ... I used paper and pencil. [To] date reaction or issues for the day, and if we treated it with painkiller or not, that kind of thing, or any other issues that we can observe. If it's a fever, change in appetite, or mood.

The *primary caregiver* becomes the most involved in caregiving, monitoring, tracking, mediating treatment, and facilitating information to the team of healthcare providers.

In two-parent families, the second parent, or an older sibling, takes on an assisting role, which we call the *secondary caregiver*. The *secondary caregiver* assists when needed, such as maintaining regular intake of medication and facilitating information management when the *primary caregiver* needs support.

JIA7 (secondary caregiver, father): I don't go along to every appointment ... I go when ... we go through the whole situation. The reason why, it's so much information ... I'm just kind of sitting here, the backup, and remind her [primary caregiver] of everything I know has been said or questions that we discussed.

TH families organize themselves similarly: one parent is the *primary caregiver*, and another caregiver, such as the second parent, is *secondary*. However, the intensity of these roles is lower because children do not require as much care.

These collaborative caregiving roles are based on practical reasons: having one family member be the main point of contact, maintaining records, and facilitating information coordination with healthcare providers. Existing designs support a *primary caregiver* tracking to manage their children's health. However, designing for just the *primary caregiver* makes it difficult for *secondary caregivers* to track or have access to the data collected to support the care of children. Consequently, only the *primary caregiver* can track, which can lead to tracking fatigue and sometimes leave this caregiver overwhelmed. Our work identified *primary and secondary caregivers* working together to care, monitor, and track the health of their children.

Viewing tracking and monitoring as a collaborative practice means personal informatics artifacts need to provide opportunities for other family members to be equally informed and better support the *primary caregiver*. Kimani et al. found that mothers and daughters tended to use a family-focused online social network for health at higher rates compared to their male family members, but stated that there is an opportunity to increase engagement of male family members [38]. Our results indicate that supporting primary and secondary caregivers will also support balancing family-health responsibility regardless of gender.

Children Can Collect Data and Collaborate with Parents

Children in TH families did not have health as a top concern (or even wellness). Instead, priorities such as school and socializing were more important. On the other hand, children with JIA are diagnosed at an early age and learn to manage their condition as they mature. In the process, they also begin to self-monitor, facilitate information to their health providers, and mediate their own treatment. One teenager described deciding which medication he would continue to take:

JIA7 (son, 16yo): *For six and a half years, I was on these meds. At this point, ... because of all that I have an incredibly weak immune system. I get sick incredibly easy It's out of the question for me to be on meds like that again.*

Children with JIA wanted the means to monitor their own condition and have access to their own data. When we discussed current tracking artifacts in our interview, children with JIA expressed the following:

JIA8 (daughter, 12yo): *I liked it [tracking artifact] because then I can have more control and it would be easier to use for me, it's my pain. I think I'd like it entering myself more.*

Supporting children in self-monitoring provides opportunities to improve collaborative monitoring practices that already occur in JIA families. One mother described repurposing a skeleton image with body joints from their doctor as a tracking artifact that would allow her daughter to track her own joint pain:

JIA4 (mother): *They have a skeleton that has lots of dots for joints, we used copies of that with a color crayon to indicate things that were 'ouchie' versus things that were not 'ouchie' ... just colors, so that it didn't have to be words.*

This single tracking artifact allowed the daughter and mother to collaboratively track joint pain and swelling. PD children further stated that the tracking artifact used by children does not have to necessarily be different from that of adults:

PD2 (female, 7yo): *It's a good idea to have it [tracking technologies] for kids but why can't kids just use the grown-up version?*

PD children noted that if the adult version was easy to use then they did not need a child version of the same tracking artifact. Children also reminded researchers of their ability to use devices that were not purposely designed for children, such as parent mobile phones. Although children and adults have different levels of knowledge and information processing abilities, the same tracking artifact can still support both of them. For example, a design might support varying granularity according to who is tracking: a parent might track at a fine granularity, while the same artifact might also support a child tracking at a more appropriate granularity.

Family Participation Makes Health Habits More Sustainable

In both family cohorts, health activities were considered more sustainable when the entire family was involved (e.g., diet, physical activity, sleep). In family TH13, the stepfather was diagnosed with sleep apnea and the oldest son also experiences poor sleep. To improve the sleep of the stepfather and oldest son, TH13 parents described moving every family member's sleep time to earlier (including the mother and younger son):

TH13 (mother): *Yeah, he's [husband] very sensitive to how much sleep he gets ... Now, [husband] helps me make sure [younger son] gets to bed earlier and because ... my older son's habits of not sleeping has cost him dearly, you know, we made a big deal of it [sleeping].*

Similarly, both TH and JIA families discussed diet changes as more sustainable when the entire family changed:

JIA7 (father): *It's actually brutal not to, because you have to create two sets of food. Cooking would mean two meals for every meal. It's better to do it this [everyone on same diet] way.*

Changing diet as a family was more sustainable: families did not need to prepare different meals for each member and they could empathize around cravings and struggles. However, when a single family member attempted to change their diet, they struggled to maintain it on their own.

Personal informatics technologies often allow social sharing of information between people and sometimes support group challenges. However, there is generally less support for tracking together as a family. Family-centered informatics would take advantage of shared daily experiences to allow one family member to add information on behalf of others. In the case of sleep, family members could share relevant tracked information, such as temperature, noise, light, or time spent watching TV before going to sleep. Allowing this type of data collection could reduce the monitoring burdens of individual, instead sharing the load among family members addressing the same health-related activity.

OPPORTUNITIES IN FAMILY HEALTH INFORMATICS

Of the 24 families we interviewed, ten had an adult family member who currently or previously used a personal informatics tool to track their health (all adults, including an adult child living at home). Of these, five had monitored sleep (TH=2, JIA=3). Among nine children in the PD sessions, one wore a pedometer regularly and four others knew of a family member wearing a pedometer to track their steps.

Families in both cohorts wanted to aggregate family data and explore ways to review the data for a sense of *family health*.

TH6 (father): *It would be a great app if you could see each of these [sleep data trends] individually and overlapped and then controlled for other factors.*

Designing from a family lens means to adjust and situate collected data from each member to fit the family context. This section describes design considerations to support family-centered health informatics.

Revealing Ripple Effects Between Family Members

Both adults and children expressed wanting to understand how the behavior of one family member affects others. Engaging the entire family in tracking means to go beyond individual tracking to leverage family data for comparison and to identify such ripple effects. In the case of sleep, one opportunity is to analyze ripple effects between co-sleepers:

TH11 (father): *You could see how the people in the same room, if they are affecting each other, if something I'm doing is waking her up, like kicking ... if [spouse] is doing something that wakes me up and that's why I woke up here.*

There are other forms of ripple effects that do not have an instant or visible effect. Families wanted how the mood or energy level of one person is affecting another:

JIA9 (mother): *Number one, to know what's happening to [daughter] but to see the relation between what's happening for [daughter] and what's happening to me. ... I think it would be interesting to see if there are differences or not.*

Focusing only on individuals falls short of identifying and addressing such issues, but contextualizing an individual in the family context can help identify positive and negative effects that can support families in taking action together.

Comparison Among Family Members Needs to Consider Appropriate Baselines for Each Family Member
In identifying ripple effects or otherwise comparing within families, designs need to account for appropriate baselines based on characteristics of each family member (e.g., age, chronic condition). In the case of sleep, the amount of sleep needed by each family member will likely vary:

TH4 (Father): *... for [son, 12 yo] ... if he gets less than 9 [hours], then I don't feel good about that and [daughter, 9 yo], I want her to be somewhere in the 9 to 10 range. For myself, I like to sleep pretty much exactly 8 hours ...*

Not considering such differences among family members risks confusing families when they are reviewing data to identify ripple effects. In our family interviews, caregivers and children expressed concern when sketching and viewing hypothetical representations of sleep at a family level.

TH4 (mother): *... I'm just going to be so confused. I also feel like there's no need because everyone's different, you don't need to compare.*

In the family context, presenting raw self-tracking data (e.g., hours slept, calories consumed, steps taken) without normalizing the values to appropriate baselines or otherwise designing for differences within the family will confuse family members and make it difficult for them to gather insights.

Supporting Family Health as a Value

The ultimate goal for families is to have a sense of overall family wellness, whether that be with sleep, diet, or mood:

TH14 (mother): *It would start great discussions on "Okay, look. Somebody is sleeping so much better. What are you doing that we're not doing?" Especially when you have multiple kids, like "Oh look, this kid's sleeping well, but this kid's not."*

Taking a family lens means to adjust and situate collected data from each member to fit the family context. This section describes perspectives that should be considered in designing to support family-centered health informatics.

Family Health Guidelines Based on Similar Families

Families have different health priorities, challenges, and opportunities. Taking care of a newborn is different than

caring for 10-year-old child. Similarly, experiencing JIA impacts the sleep quality of an entire family:

JIA7 (mother): *Starting with chronic illness ... They [health specialists] always talk about this is a sleep issue. The thing is, we don't know what the norm is? ... We don't know how much that chronic illness component has changed our sleep habits.*

Due to the circumstances experienced by JIA families, these families do not consider general sleep guidelines to be applicable to their situation. JIA families want sleep guidelines that consider the effect of the chronic condition. Overall, both family cohorts wanted comparisons with families of a similar composition (e.g., with children around the same age and gender, with parents around the same age and gender). This insight confirms prior research findings that people find social data comparisons more motivating, applicable, and informative if they are compared to demographically similar cohorts [79]. But current personal informatics designs that generally emphasize a single average or ideal that fails to account for such diversity.

HEALTH QUALITY OVER QUANTITY

To identify commonalities and opportunities to expand on differences between designing for personal versus family health informatics, our interviews presented families with existing self-tracking artifacts and representations of tracked data. This section summarizes some commonalities and the additional needs of family-centered informatics.

Both family cohorts wanted to move away from raw quantitative information to more qualitative insights. This is consistent with prior work calling to move the discourse from quantified self to *qualified self* [50, 59]. Similarly, both family cohorts did not want to be overwhelmed or misinterpret quantitative data. This concern was especially crucial to the JIA families, as they are constantly concerned for the child with JIA. Both cohorts therefore wanted data representations to be higher-level and easily interpreted, consistent with Consolvo's prior work on representation of self-tracked activity data [11].

Need to Know Why, Not Just What

Both TH and JIA families discussed wanting family sleep monitoring to help them understand factors that affect their sleep quality. Similar to prior individual-focused work by Choe et al. [5], families expressed wanting to relate sleep to: diet, physical activity, caffeine intake, stress, and mood. Families felt they are unequipped to take action on improving their sleep without such information regarding the specific factors that affect their sleep quality.

JIA families wanted to monitor data that could help healthcare providers assess and improve treatment. JIA families are told by experts that sleep needs to be a high priority for their child and that lack of sleep causes arthritis flares. Sleep continues to be a priority during a flare because it helps overcome the flare. Parents in JIA families do not sleep well because they wake up at night trying to

ease their child's discomfort and ensure they are sleeping well. Thus, for JIA families, monitoring sleep could provide family members with information on how the child with JIA is actually sleeping and could also provide specialists with information of whether sleep is the arthritis trigger.

JIA2 (mother): *If we figure out ... that she's actually getting a good night's sleep ... Now, is her arthritis still flaring? ... Now we need to start looking at other things like medication changes. Are there things we need to change? Right now, ... everything is blamed on her lack of sleep.*

Data could support investigating other possible triggers for an arthritis flare or adjustments in a child's medication.

Overall, both family cohorts stated that relating sleep to other aspects of health would create a sense of holistic health (e.g., motivating them to address not only sleep, but also the ramifications of poor sleep in other aspects of their health).

Identify Improvements and Support Normalcy

Along with providing takeaways and helping families set personalized goals, families want systems to highlight success (e.g., improvements made individually and as a family). In addition, families including a child with JIA commonly requested features highlighting aspects of normalcy:

JIA10 (mother): *I've made a choice not to make everything about a checklist [or numbers] because for one thing I don't want our whole focus to be on pathology or sickness or illness. I want it to be on our lives ... If the functioning is okay I'm not going to be spending a lot of time doing this.*

Families do not want the focus of tracking to be entirely on illness, but rather on making informed choices, balancing tradeoffs, and highlighting progress.

BURDENS AND TENSIONS IN FAMILY INFORMATICS

Focusing on the health of the family, rather than the individual, presents challenges with respect to making sense of multiple streams of data from multiple family members, concerns for protecting privacy, preferences for sharing among family members, and how to take action when tracking insights conflict with other important commitments. One common theme we identified across our interviews with families and in prior work on personal informatics is that insights revealed in tracked data can create negative reactions [10, 20, 21].

Too Much Family-Level Data is Hard to Make Sense Of

Interviews included both presenting families with hypothetical representations of family sleep data as well as asking families to sketch how they would like to review their data. During these portions of the interview, both parents and children expressed that it can be challenging to make sense of detailed sleep data overlaid from multiple family members. They noted such complexity of information presentation can be especially difficult for younger children to make sense of.

JIA9 (mother): *This just seems a bit too much for me to think about. ... my brain shuts off it's too much detail.*

A father who had experience tracking his own physical activity and sleep was interested in connecting his child's health state with his. The father found making sense of his own physical activity and sleep was difficult. He reflected on the difficulties of reviewing his tracked data in conjunction with his spouse and his child's tracked data:

JIA6 (father): *... Then you're overwhelmed with too much data. It's a lot of big data now.*

Self-tracking data is already complex and difficult to interpret, family informatics based in simple overlays of many streams will likely be too difficult to make sense of. Designs will instead need to simplify representations according to what information and benefits families seek in those streams.

Competing Commitments Constrain Family Health Action

Families struggle to balance the health of each family member with other life responsibilities (e.g., work, school). JIA families particularly struggle to make sleep a priority, especially because children with JIA do not want the condition to interfere with their daily activities. One JIA family participant with young children (all less than age 10) explained that better information about her daughter's sleep quality might help with prioritizing evening activities:

JIA1 (mother): *... we were going to do this [activity] tonight, but maybe we'll wait and come home and go to bed a little early.*

Family members in both cohorts also stated that feedback on poor sleep could cause tensions with other commitments, both at an individual level and at a family level:

TH9 (mother): *... It would be like, "Okay great, they didn't sleep" and that would be that. Because there's just too much going on ...*

Although barriers to action are a challenge in personal informatics, the family perspective also surfaces additional challenges. Taking action may require participation of more than one family member, adding both coordination needs and additional competing commitments. Change might also require both children and adults to address an issue, which may conflict with family member abilities or responsibilities.

Sharing Data within a Family Raises Privacy Concerns

Family members in both cohorts, as well as children in the PD sessions, expressed privacy concerns about sharing their data with other family members:

JIA3 (daughter, 16 yo): *... makes me not be able to hide anything. I couldn't watch a late-night Netflix binge ... I think I kind of hide how much sleep I get ... so it might be a good thing in the long run, but at the time, I might be, "Oh darn, I can't get away with anything."*

Children with JIA had an internal conflict, while they understood that sharing data about their sleep could improve assessment and treatment of their condition, they also did not want their family to have access to their habits all the time. TH families were concerned that sharing data

could cause unhealthy competition between family members or that information about a family member's lack of sleep could be misused to trick the tired family member into doing something harmful. To balance the tension around sharing, family members wanted the ability to control what days and what information to share with family members:

TH11 (daughter, 16 yo): *If you put it on, everyone gets the same app, it's all connected, but as a group, you can only see other people's general information ... Like how well they slept last night, but you can't really see ... That specific stuff.*

Although most of the families we interviewed were married, six included divorced parents. Divorced parents we interviewed struggled to handoff information, which was especially salient in JIA families attempting to help manage the arthritis consistently. Divorced parents also did not want data about themselves shared with the former spouse:

JIA8 (father): *... families that are split like ours. Is her mom and me going to be on the same one [data visualization]? I [don't want] to get a comment, "I see you didn't go to bed until 3 AM last night, where were you?"*

Prior work on location sharing and tracking in families has found low usage due to family member hesitation to share location continuously [72]. Accounting for privacy when designing for families is crucial, and a lack of privacy support will lead to non-adoption of family-centered informatics tools.

DISCUSSION OF FAMILY INFORMATICS

Our results illustrate needs, challenges, and opportunities that present themselves when designing for families to monitor and act on their health. Designs that work for families, not just individuals, are necessary because: (1) there is often a relationship between the health of parents and children [16, 47, 77], and (2) children, especially younger children, cannot always track for themselves and therefore depend on adult caregivers to do second-hand tracking.

Prior research has developed models of self-tracking to inform the design of personal informatics tools [19, 40, 62]. These models identify stages, challenges, and barriers in the process of self-tracking. Li et al.'s five-stage model characterizes personal informatics as an iterative process with five stages: preparation, collection, integration, reflection, and action. Each stage presents barriers, and failures cascade into later stages [40]. Epstein et al.'s lived informatics model expands upon this with additional stages: deciding, selecting, lapsing, and resuming tracking [20]. This section uses these models to discuss design challenges and opportunities for families. Families can include several types of trackers (i.e., self-trackers and second-hand trackers), with varying needs and responsibilities (e.g., due to differences such as age and family role), working together towards common goals (e.g., overall family health, helping managing a family member's chronic condition).

Deciding: This first stage is when a person decides they want to track. Epstein et al. describe self-tracker motivations

to include: behavior-change, instrumentation (e.g., tracking without a particular goal), and curiosity [20]. Family tracking often requires multiple people deciding to track, and our interviews reveal differences in family motivation for this decision. TH families were motivated by a sense of curiosity, because they want to verify that the health of family members is as well as perceived, or because they wanted to change a particular behavior. On the other hand, the decision to track by JIA families is based in improving the wellbeing of the child with JIA. JIA families have a strong motivation to collect and track with the intent to use gathered data to improve diagnosis and treatment. For example, caregivers are asked to track medication, reaction to medication, amount of sleep, and diet. However, as caregiving takes a toll on caregivers in JIA families, tracking technologies need to support not only monitoring the child with JIA but the wellbeing of the rest of the family. Differences in how families come to tracking suggest designing for these different needs and expectations.

Selecting and Preparation: In these stages, a person decides how they will track, including selecting what tools to use. Families face all of the same barriers as individuals, such as struggling to identify tools that will collect the data supporting insights they seek [20, 40]. Families also face additional barriers. In the case of young children, families need to determine if both adults and children can use the same tool. If not, they may need to determine if there is a similar tool designed for young children. Families collaborating with medical providers need tools that can track the information requested by providers and support appropriate sharing with those providers. There are also additional barriers and burdens in purchasing and maintaining multiple tracking devices, especially if a child version is more expensive due to a focus on child safety. These complex requirements for selection are currently poorly supported.

Collection: Families collect, capture, or record desired data using their selected artifacts. There will be generally be multiple family members tracking, either manually or using tools that automatically collect data. Prior work in individual tracking identifies collection barriers that include a lack of time, lack of motivation, not remembering to regularly collect, and difficulties with subjective estimation [40]. These barriers also apply in the family setting and may occur at greater scale considering the different cognitive abilities and knowledge of every family member.

Balancing collection of data from a family perspective will need to consider how shifts in motivation will change over time. For example, when a child with JIA is experiencing a flare, the entire family is focused on helping the child overcome that flare. Just as the competing commitments and health goals of other family members can be de-prioritized in this situation, tracking may also be de-prioritized. Tracking tools for families may benefit from improved approaches to automating tracking in times and contexts when tracking will be a lower priority.

In previous work, leveraging shared experiences within a family can lower the barriers to tracking diet [25, 66] and physical activity [64] as well as reflecting on health goals [8]. Designing for families can lower barriers to tracking by leveraging shared experiences and having family members track on behalf of each other. With respect to sleep, family members can track the perceived mood of other family members, environmental factors (e.g., noise), and daily events (e.g., stress) that could be affecting their own sleep as well as the sleep of other family members.

We have also seen that family informatics presents additional challenges surrounding self-tracking vs. second-hand tracking (e.g., a parent tracking on behalf of child). Current designs generally do not support a single person simultaneously self-tracking and second-hand tracking (e.g., a parent tracking their own sleep as well as the sleep of their children). The lack of multi-directional tracking makes it difficult to support health goals at a family level. The matter of who does the tracking also surfaces several additional challenges and opportunities. Tools that limit tracking to a *primary caregiver* both: (1) force the primary caregiver to bear the entire responsibility of tracking, and (2) present barriers to *secondary caregivers* utilizing tracked information (e.g., in collaborations with health providers). As children mature, they will also want to take primary responsibility for self-tracking. These challenges in coordinating and transitioning tracking are not well supported in current tools.

Integration: Integration entails preparing and transforming data for analysis and reflection. Our interviews found that visualization techniques that are effective with data streams of an individual can quickly become overwhelming when multiplied by the complexity of a family. Additional challenges can also result from different approaches to tracking by different members of a family. For example, a *secondary caregiver* might collect data at a coarser granularity or less frequently compared to the *primary caregiver*. Therefore, family health informatics systems will have to address the challenge of aligning or otherwise reconciling data from different sources.

Reflection: Reflection needs to be supported at the individual and family level. Toward this, designers need to consider when and how members of a family access data. This includes taking into account the type of family member that is reflecting when presenting insights and visualizations of collected data. In the case of children, the design of reflection needs to consider the devices they use and their cognitive ability to self-reflect.

Supporting reflection at the level of the family surfaces another set of challenges. Our interviews revealed families wanted guidelines and comparisons appropriate for the nature of their family (e.g., accounting for age and chronic conditions). Families also want systems to help account for the different needs and goals of each family member, and to help in identifying positive and negative ripple effects among family members. Addressing such needs requires

integrating data across family members. But families are complex and faced with many competing commitments, so designs need to be mindful of potential tensions and negative implications of tracking.

Action: Action can occur after collection, integration, and reflection [40], or it can be intertwined with these stages of tracking [20]. In addition to the challenges that individuals face in identifying what action to take and succeeding in that action, families face additional challenges presented by coordination and collaboration among family members. For example, if improving the sleep of a family member (e.g., an adult with sleep apnea) means that a child also needs to go to sleep earlier, then the family needs to reassess evening routines of both parent and child. Our interviews also found families were better able to maintain healthy practices if all family members were engaged. Appropriate action in a family informatics perspective therefore requires examining potential actions for every family member that account for sustainability and appropriateness.

Lapsing and Resuming: Lapsing is an inherent element of tracking [20]. It can include forgetting (e.g., not remembering to journal a meal), failures in upkeep (e.g., not charging a sleep sensor), skipping (e.g., choosing not to journal a meal), and suspending (e.g., deciding not to track while on vacation). Lapses sometimes cascade into abandonment, or people can decide they have obtained the value desired from tracking and explicitly choose to no longer track. These same activities occur in family informatics, although with additional coordination and collaboration. For example, the additional challenges of family tracking may make lapses more likely. A decision to resume tracking after a lapse may require collaboration among family members to restructure priorities to support a return to tracking. A decision to discontinue tracking entirely may be difficult depending on whether family members agree they have identified an actionable plan or otherwise gained desired knowledge.

At a more fundamental level, our results reveal that a family can continue tracking even when one or more individuals lapse. The roles of tracking are not statically assigned to a single family member (e.g., one family member could be collecting data, a second could be integrating, and reflection could occur as a family). This also corresponds to family members taking on different roles in managing family health (e.g., *primary caregiver*, *secondary caregiver*, self-manager). Although tracking together is poorly supported in current tools, we believe it is an important insight gained from the family informatics perspective. Sharing the burdens of tracking will not come without costs, as we have noted tools can present integration barriers and may create coordination overhead within families. Future designs should account for fluidity in family health when considering the stages of personal informatics in the context of family-centered design.

LIMITATIONS AND CONCLUSIONS

Personal informatics research has primarily focused on individual *self*-tracking and *self*-management, with much less investigation of how groups such as families collaborate in monitoring and managing their health together. Our research has examined practices, needs, and opportunities in families supporting and collaborating to manage family health.

We interviewed two cohorts of families: typically healthy families and families that include a child with a chronic condition. To help ensure an understanding of children's perspectives, we additionally conducted PD sessions with typically healthy children. We believe our results generalize well beyond the families studied in this work, and we have used prior models of personal informatics to help foreground more general insights into family informatics. Nevertheless, our studies still present some limitations. First, all families we interviewed included heteronormative parents, although this was not an inclusion criterion. Second, we were not able to interview caregivers other than parents, although these can play a crucial role in caregiving. Last, we did not explore other types of families, such as couples living together. Future work should further explore family informatics in additional family arrangements.

Our research examined models of personal informatics in the context of families tracking for health. We found similarities, additional challenges to account for, and opportunities that could lower barriers to family tracking. Family informatics technologies need to account for the case where a single person is simultaneously acting as a self-tracker and a second-hand tracker, need to account the different needs of family members (e.g., differences in the amount of sleep for adults versus children), and should take advantage of shared goals and contexts to support family members in tracking on behalf of each other. Expanding models of personal informatics to family-centered informatics provides designers and researchers with guidance in considering self-tracking and second-hand tracking in the context of family-centered health. Whether supporting a family working toward their collective health, or a family working to manage one member's health concerns, there are many opportunities for tools to better support coordination.

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