Beyond the Bulging Binder: Family-Centered Design of a Digital Health Information Management System for Caregivers of Children Living with Health Complexity

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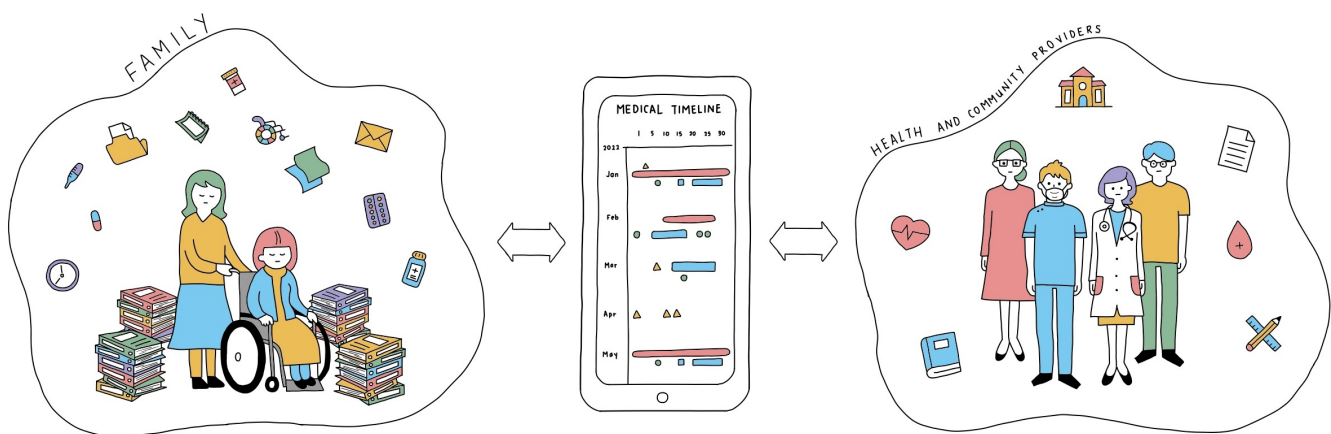
Figure 1: Futuristic vision of supporting families with information management, care coordination, communication and collaboration with health providers for Children Living with Health Complexity

ABSTRACT

Children Living with Health Complexity (CLHC), whose multiple, severe and chronic conditions differentiate them from those with "complicated" conditions, rely life-long on a vast and ever-shifting array of care providers. Their parent caregivers face a fragmented health care system, disconnected medical records, inter-stakeholder communication barriers and an impenetrable accumulation of documentation – from mundane to life-critical, and largely on paper. They must coordinate care while organizing, tracking and transmitting trends in many health parameters to myriad care providers. We engaged with parent caregivers of CLHC from 12 families through an iterative, 3-phase co-design process to understand their needs for a future digital management system. We share our deepened understanding of their information-centered challenges, a set of principles for how design best-practices need to shift when targeting this acutely high-needs group, and a medium-fidelity prototype user interface which from the ground-up prioritizes caregiver-centered data integration and humanization of the child and family, as well as integrated health record access.

CCS CONCEPTS

• **Information systems** → Data management systems; • **Human-centered computing** → *Visualization*; **User studies**.

KEYWORDS

health, design, user study, personal information management

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1 INTRODUCTION

A subgroup of children and youth with special and extensive health care needs cope with severe chronic conditions (interacting, unpredictable, and incurable; *e.g.*, mitochondrial disease, quadriplegic cerebral palsy or other severe neurological impairments), resulting in multi-organ and developmental impairments that influence cognition, function, mobility, and communication [3]. This complex and medically fragile group has been referred to as Children with Medical Complexity; or more recently, *Children Living with Health Complexity* (CLHC) [34].

One of the ways in which CLHC and their families are falling through the cracks of a fragmented health care system is the overwhelming information-management load that falls on their shoulders with no supporting system except what they devise on their own. Our current objective is to concretely envision an alternative digital solution to support CLHC families' information management needs.

Although under 1% of the pediatric population, CLHC numbers are increasing as life expectancy grows due to recent advances in pediatric care [10, 22, 73]. Intensive healthcare system users [14, 21], they utilize the majority of intensive care resources [15] and in some countries, one-third of child health spending [14]. CLHC rely on an average of 13 distinct sub-speciality physicians, and are repeatedly readmitted to hospital [14, 21].

However, when not in hospital, CLHC's functional and intellectual impairments together with patchworked external support mean near-total reliance on family resources for care and its coordination. This day-to-day life is filled with outpatient visits and dependence on multiple forms of medical technology assistance [22, 26]. Because of the nature of their multiple impairments, CLHC generally cannot access their own health records, help manage their own care, or even provide assent. It is their families who must be health domain experts, complex-care coordinators, managers and sharers of extensive health records, mostly kept on paper. The combined factors of *multiple* conditions that are *severe*, *life-long* and often *life-limiting* place CLHC in a different needs category than patients suffering from "complicated" conditions such as Type I diabetes, who are also negatively impacted by healthcare system fragmentation (Figure 2).

Others have analyzed problems in complex care coordination [14, 43, 46, 67]. For example, Amir et al. identified multiple issues with care coordination: relating to care plans being left behind the evolving condition of the child, provider-specific, not integrated into team plans and not centered around care goals, as well as to team communication challenges [4]. Sheerly from a data standpoint, this results in information inconsistencies and errors, and voluminous, non-navigable records, often stored by caregivers in large and numerous binders accumulated over their child's life [5, 26, 27].

The move away from paper-based records towards system transformations, digitization, ecosystem approach [52] and computer-supported cooperative care (CSCC) [23] has been explored using HCI techniques. This has ranged from user-centered design of record-keeping aids targeting a specific age or condition [36] to broad needs elicitation for cloud-based coordinated care plans for CLHC families [24].
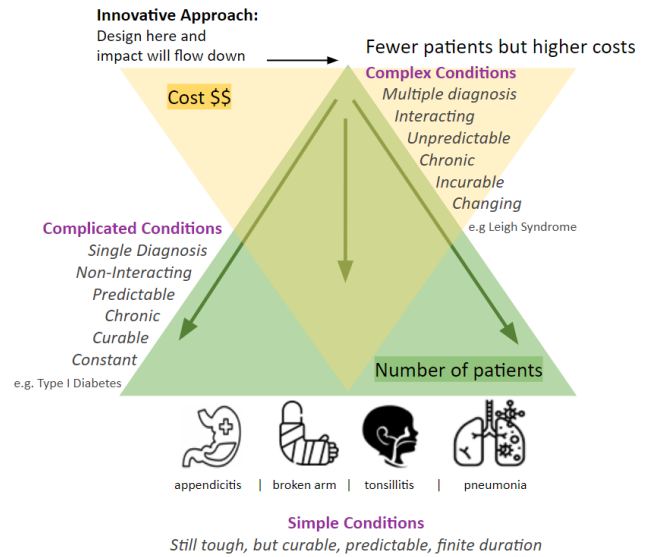
Figure 2: *Simple*, *complicated* and *complex* health conditions. Design innovations that support the many interlocking challenges of care for *complex* conditions can also inform support for complicated conditions.

Altogether, it is clear that individual systems and patchwork solutions designed for predictability have failed to address the constantly changing and complex landscape of children's health care and their information, as stated in Greenhalgh and Papoutsi's 2018 review documenting the need for a "long-overdue paradigm shift" [28]. This body of work also makes clear that the solution to these unique challenges – deriving from volume, duration and communication issues – will surely rely on an overhauled and centralized data infrastructure which currently does not exist in many countries. However, it is critical that as this infrastructure is implemented, it be informed by a deeply re-imagined interactive information management *ecosystem* that enables effective information sharing within and between many groups – parents, care providers, and other stakeholders. Therefore, the vision we present is futuristic and forward-looking: we target the time when the centralized database system is implemented and third-party applications could effectively access patient health records. Further, targeting design efforts towards systems for complex conditions and solving their challenges could also provide design solutions for complicated conditions (Figure 2).

1.1 Research Questions and Approach

Despite past problem definition and recommendation, the vision of the ecosystem remains fuzzy. How should requirements for such a tool diverge from those for less impacted populations? What aspects of complex care could it assist with? How should these intertwine holistically so as to be usefully comprehensive rather than over-ambitious and cumbersome? How would parents want this tool to be organized and presented to them? Can this be succinctly captured in actionable heuristics? These questions also lead to specifications for the backend system that will drive this access portal.

Our aim is to concretize a vision of what this kind of holistic change might look like, and represent the needs of CLHC caregivers after augmenting past work with an additional targeted investigation. While a solution that works for this population will likely be excessive for other under-served patient groups, it will demand creation of an interconnectivity and approach which can benefit these others in simplified form.

We built on past assessments of this group's general needs and obstacles to examine in an actionable manner:

(1) In terms of features, interactivity, content, information, and functional integration, what do parent caregivers need in a digital tool solution for information management? For this group, how might these capabilities interplay to *significantly* reduce information management burden, and what might they look like?

(2) To what extent are this group's health-coordination needs divergent from others? For non-generic (divergent) needs, can we identify principles that pinpoint where and how to tailor special solutions for this group?

In a caregiver-focused design process, we first sought to understand the main information-centric challenges for parent caregivers: what they hope to do with patient's information, their current strategies for managing such information, the drawbacks or advantages of these strategies, and their general feelings towards managing information through technology and their design feature preferences for a digital tool. We then devised designs that instantiated and evolved these ideas through three prototypes informed by several interviews with parent caregivers as well as domain expert consultations.

1.2 Contributions

We contribute three new resources to aid in the development and architecture of user-facing systems that support information management and care coordination for this population:

(1) A deepened and task-oriented understanding of challenges and strategies specific to CLHC caregiver information management to inform the design of targeted solutions **based on what caregivers want to do with health information**.

(2) A set of **caregiver-centered and forward-looking design principles** specifically targeting health information management derived from both past works and our own engagement with parent caregivers to guide the tool design.

(3) A **blueprint in the form of a prototype** for a caregiver-centered interface, which illustrates a way to implement these emergent design principles and caregiver-preferred features.

2 RELATED WORK

We examine in more detail literature that documents caregiver information needs, current technological obstacles to providing them, other tool-design efforts for health care coordination, and their capture in guidelines. The last two have received considerable attention from the human-computer interaction (HCI) and Computer-supported cooperative work (CSCW) communities; our sample aims to be representative.

2.1 Past Examination of Caregiver Information Challenges and Their Impact

When society relies on families to provide at-home and unpaid care for those with chronic conditions, the resources demanded from those familes are major [14]. Parent caregivers must wear multiple hats and take on many additional responsibilities and roles, including managing documents, chairing team meetings, engaging with researchers, writing letters to government officials, training other caregivers, scheduling appointments, and communicating with stakeholders [5, 46, 56, 67]. Parents regularly mention challenges with "working the system" or "navigating the system" and express frustration with health, social and school services [5, 7, 27, 56, 67]. Financial impact is often exacerbated when one parent has to leave the workforce [14, 41]. Consequently, parent caregivers can experience trauma, fatigue, frustration, anger, distress, depression and inability to continue to provide care [14].

Tennant et al. conducted a formative study to understand how family caregivers navigate information management and communication in complex home care and provided design recommendations for digital health care technologies. Some emergent information challenges from this study included continuous learning to provide care, maintaining records (identifying patterns, documenting, *etc.*), sharing the right information with the right person in the right way (summarizing information), teaching other caregivers about the care situation, and navigating bureaucratic systems [67].

Targeting design for pediatric populations, Kientz et al. created a record-keeping digital system (BabySteps) for parents of young children to track their developmental progress [36]. Their following study of parent-pediatrician relationships produced guidelines in designing health technologies [35].

More broadly, Desai et al. studied perspectives of CLHC parents and care providers for cloud-based care plans. They proposed requirements of shared care plans to meet the information needs of caring for CLHC, such as accessibility of care plans from various locations and devices, alert and search features, collaborative functions like secure messaging, and caregiver-controlled permission settings [24]. Later, Desai et al. employed user-centered design to determine content priorities and design preferences for longitudinal care plans among CLHC caregivers and care providers [25].

In analyzing the burden carried by CLHC families, Amir et al. identified five unique characteristics of complex care that cause challenges for teamwork: 1) goal setting requires consensus but there is no single decision-maker in charge 2) The activities of care providers are loosely coupled 3) care plans can extend months to years as the child's condition evolves 4) care plans need to be frequently created and updated by the care team while rarely meeting as a whole 5) care providers meet the child with varying frequency (*e.g.*, several times in a week or once a year) [4].

Unfortunately, research indicates a stagnant response to CLHC caregiver needs in health care systems: the studies cited in this paper span 2002 to 2022, and document a lack of change that is at odds with information systems progress in these two decades. An ecosystem approach [31, 52] rather than patchwork solutions is required to reduce burden on CLHC caregivers and their families.

2.2 The Existing State of Electronic Health Records

Despite the importance of care continuity for CLHC [49], a present lack of centralized and accessible data storage largely prevents flexible, timely and focused access to health information [1, 5, 9, 26, 27, 54, 67]. Disconnected systems between and within health care and community services especially impact these families because of care duration and complexity, and the high number of care providers who do not communicate effectively in the present system [4, 14, 43, 46].

Today's Electronic Health Records (EHR) are at the root of these data-connectivity problems. While commonplace in modern health authorities, existing systems lack standardization, a critical obstacle to start with. Beyond this, they directly inhibit care coordination. Most fundamentally, they are not interconnected and not comprehensive, often omitting "secondary" yet vital items like referrals and consultation reports [51]. Vawdrey et al. found that EHRs do not provide adequate information about individuals across the entire care team (physicians, but also social workers, dietitians, pharmacists, occupational therapists), as well as their reports, thus hindering cross-team as well as parent-team communication [69]. Horsky et al. adds the lack of document abstraction, aggregation and interpretation capabilities, while reliance for transmission on technologies such as email, mail, telephone, and fax inhibit collaboration and group decision-making [30]. Finally, errors caused by usability and application design of EHR systems are widely reported, affecting patient outcomes, safety and care quality [6, 70].

In short, little of what we propose could happen within existing EHR systems. The many obstacles to rebuilding or replacing them are far beyond our scope. Others have focused directly on how EHRs need to change: for example, Horsky et al. propose a web-based care coordination model which could potentially integrate with current EHRs, noting how updating even these capabilities should increase situation awareness through visit and event tracking, medication and problem list updates, and a two-way patient-facing portal for care instructions and requests [30], all consistent with what the families we consulted told us. Our intent is to show what could result if a more modern system did exist, and help to guide it.

2.3 Existing Tools and Technologies

Specialized Purposes: Among the small number of developed and tested prototype systems which specifically target patients of at least *complicated* conditions, the most extensive was reported by Cheng et al., who used human-centered design methods to create and test a mobile app for enteral tube care [16]. Participants identified requirements they felt crucial, such as a homepage, a child's profile, viewing and managing other users, a nutrition plan, displaying care routines, reminders, tracking inventory and health data, caregiver communication and troubleshooting. The application received positive feedback; caregivers cited benefits of flexibility in managing time, providing confidence and peace of mind, simplifying life and reducing error, and supporting the child as a person and not a diagnosis. They further wished to track and view longitudinal health data, organize and edit notes, personalize information in the child profile and highlight resources. While this application was refreshingly holistic in scope, its focus on a single situation makes

it unlikely to scale to a complex and comprehensive ecosystem for information management. We considered its requirements as we generated a CLHC set.

With a user-centered process, Kurahashi et al. developed a web-based system more narrowly focused on clinical collaboration and communication between care providers, patients, and caregivers called *Loop*. The system was tested by patients with chronic diseases, family caregivers and care providers. *Loop's* core functions are composing, posting and reading messages, filtering messages, and receiving email notifications; these features received positive feedback from the users.

Lin et al. examined the barriers and facilitators for family-centered technologies such as *GoalKeepr (GK)* which is used for setting measurable goals during CLHC visits with care providers then tracking them. Lack of integration into EHRs and care provider workflows were cited as barriers to its use.

Novel Interface Technologies: Novel technologies can help to address gaps; for example, Voice Assistive (VA) technologies applied to note-taking and home-care assistance. Sezgin et al. proposed VA technologies for care management and coordination of children with special health care needs [59] and studied feasibility of their SpeakHealth diary appliction prototype [60, 61]. SpeakHealth combined a graphical user interface with voice-enabled features, including voice-to-text note entry, searching, upcoming appointments, prescribed medication, mock care plans and EHR integration [60]. A preference survey (83 caregivers) highlighted tracking medications, appointments, and hands-free and voice interaction. Similarly, Tennant et al.'s study of caregiver expectations for VA in complex homecare indicated information recording, retrieval and reminders [66].

While a wholly VA approach is likely impractical, voice input/output is commonplace on contemporary mobile devices, and we wondered if this feature would be helpful. As a result, we asked our participants about their VA technology preferences. These studies of a specialized technology are also relevant because they ranked features in the context of studying caregiver challenges.

Personal Health Tracking Systems: Most of the vast HCI literature on tracking of personal health parameters is not suitable for CLHC needs due to the type and breadth of parameters needing tracking (a FitBit will generally not suffice), the interactions of concern, and longitudinal scale (for example, [32, 36–40, 44, 62, 64, 68]).

Some research has examined self-tracking tools [38], and caregiver-based health and behavior tracking for general pediatric populations [36, 37, 64, 68]. In an example, Jo et al. designed an app (Geni-Auti) to enable caregiver tracking of behaviors for autistic children which enabled caregivers to reflect on potential behavior causes, had emotional benefits when they saw improvements, and through use of data improved caregiver/care provider communication via easily-created tables and graphs [32]. However, even these are not adequate for CLHC caregivers who are keeping note of (as reported by parents in our own study) pain, diet, mood, medication side effects, menstruation, bladder spasms, chills, fever, gasping, appetite, muscle twitches, nausea, sleep, seizures, constipation, bowel and urine output, oxygen saturation, temperature, respiratory rate, heart rate, blood pressure, visual disturbances, fatigue, and behavioral issues.

Beyond medical symptomology, CLHC caregivers need to track a holistic information ecosystem encompassing the entire life of their child. To leverage such information capture to review and reflect on this data, they will also have unique visualization needs, as well as integrating this information in one platform to help understand interactions and changes over different time periods.

In summary, tools and technologies specifically targeting the CLHC population and their caregivers are rare, and those that exist have narrow foci which do not address the depth or breadth of information management challenges.

2.4 Design Values, Guidelines and Preferences

HCI and CSCW studies of health care technology applied to patients with complex conditions often provide design guidelines, frameworks and recommendations. While often considering collaboration in health care settings between care providers and relationships between patient and caregivers, most is underscoped for our needs, considering specifically in-hospital settings (*e.g.*, [48]) non-CLHC patients [33, 62], or patients who do not have cognitive or functional impairments [8].

A small, ambitious set connect holistic scope to patient-centered perspectives. Chute and French argue that an individual's health goes beyond what an electronic health record system holds and needs to include personal, social needs and lived experiences. The author proposes that in order to remove the burden of "health story-telling" for the patients, the patients should be the main point of integration, where they can share their information across care providers and stakeholders [19]. This group later presented 14 common user requirements from reviewing 52 co-design projects with patients with various conditions (*e.g.*, diabetes, multiple sclerosis) and contrasted them with previous works [20]. These include visualizing trends to assist decision-making and improve patient-care provider dialog.

This holistic sensitivity also appears in intelligent "agents" that help oversee medical and cloud-based digital tools. A digital "Guardian Angel" shifts the focus from designing for institutions to designing for individual patients [65], monitoring health, collecting data, customizing treatment plans, communicating and sharing information with care team, and maintaining reminders. Similarly, Bhattacharyya et al. built a digital health advisor for frail elderly patients with multiple chronic conditions and found approval of features like tracking and insights, advice and information, providing a holistic picture of the patient, and coordination and communication [11].

Of most direct relevance to our own study and prototype due to similar focus and scope, Desai et al. grounded their user-centered design of cloud-based longitudinal care plans by interviewing parents of CLHC and care providers to understand design preferences and content priorities [24, 25, 71]. Their high-level design guidelines include building in system redundancies, centralization, accessibility, consistency, balance between security and access, and collaborative support. Lower-level user requirement examples include table layout with search/sort/filter, familiar and customizable layout and control over permission settings [24, 25]. These works did not extend to envisioning an application, but their content priorities [25] and design guidelines [24, 25] informed our own system

concept map and prototype, which we iteratively developed with a similar demographic of users.

3 METHODS

Our data collection methods and analytical approach (3-phase approach overviewed in Figure 3) differed from Desai et al. [25] in two respects: we (1) omitted asking parent participants to draw or design their preferred system, finding this task infeasibly complex based on our own assessment (Figure 4); and (2) used [60]'s 5-point importance scale in our feature ranking activity. Our research protocol was approved by the University of British Columbia's Behavioral Research Ethics Board (H21-02184).

3.1 Participant Pool and Recruiting

In all stages of our elicitation and design, we sought insights from caregivers who self-identified as having a child with complex health needs that was currently and intensively engaging with the healthcare system. Because these parents are already heavily burdened, we attempted to minimize intrusion and the typical difficulty of recruiting members of this population by using opportunity sampling. Recruitment was ongoing via social media platforms, and opportunistic given the highly constrained pool. We consulted the same pool of caregiver parents for all of the user studies reported here, recruiting through a Facebook group that is specific to parents of CLHC and a local children's hospice email list (in British Columbia (BC), Canada) with the support of a pediatrician colleague.

For each phase (Figure 3, green columns), we enrolled 5, 5, and 4 parents (Groups A-C respectively). Two parents from Group A also enrolled in Group B, due to our ongoing process, their enthusiasm and general low participation capacity for CLHC caregivers. In all, 12 different parents from distinct family groups participated in three phases leading to input from 12 unique families. While data show that the burden of care usually requires at least one CLHC parent to work from home or be a stay-at-home parent [14, 41], six of our families (50%) reported having secondary caregivers (*e.g.*, nursing help, support workers, help from other family members), and 11 (98%) were composed of *two* primary parent caregivers.

Table 1 summarizes participant demographics and characteristics for all participant groups. All participants self-identified as mothers of CLHC (Question 4). Group A and Group B shared two participants. One participant (Group A and B) had moved their child to a group home. One participant (Group A and B) spoke a primary language that was not English. One Group C participant was a single parent and their child had an additional foster parent. All participants self-reported as a primary caregiver for their child. Although the children of the two mentioned above did not always reside with the parent participant, both of those parents said they were in constant communication with their child's caregivers and were involved in all care decisions. Out of twelve children, all but one child had cognitive and functional impairments, and one had declining cognition. Common conditions included seizures, gastrointestinal issues, behavioral issues, mobility issues and pain.

We discussed this work with two domain experts (recruited through other research teams) during the Explore Phase and another (co-author) throughout the project. They provided valuable insights about the demographics pool and helped to narrow down
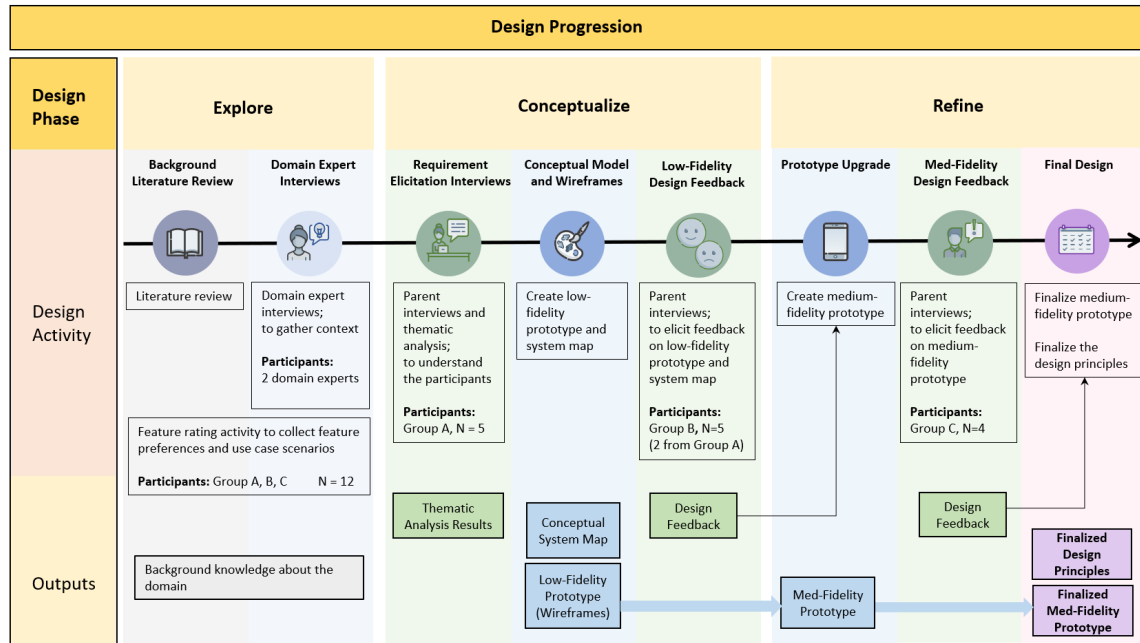
Figure 3: Phase diagram showing the Explore, Conceptualize and Refine phases, along with task and participant breakdown in each phase. Outputs of each phase are shown in the bottom row, in bold/saturated boxes.

Table 1: Participant demographics and characteristics. Data is pooled for all 12 participants in Groups A, B and C.

#	Demographics questions:	All Groups (N=12)		
		Mean	SD	N
1	Average age (years)	42.4	8.3	12
2	Average age of the child with medical complexity (years)	10.1	5.5	12
3	Do you currently manage the child's data? - Yes - No			10 2
4	Is English your family's primary language? - Yes - No			11 1
5	How do you identify your relationship with the child? - Mother - Father			12 0
5	To what extent do you rely on digital technology to organize your child's health information on a scale of 0-10? (0 = Not at all, 10 = Fully)	5.5	2.7	5
6	How comfortable are you with using digital technology on a scale of 0-10? (0 = Not comfortable, 10 = Very comfortable)	9.0	1.4	5
7	How comfortable are you with using smart phones on a scale of 0-10? (0 = Not comfortable, 10 = Very comfortable)	9.6	0.8	5
8	How skilled are you with organizing information electronically on a scale of 0-10? (0 = Not skilled, 10 = Very skilled)	7.8	2.6	5
9	How important is it for your family to have security of medical information on a scale of 0-10? (0 = Not important, 10 = Very important)	7.4	2.6	5
10	How important is it for your family to share medical information on a scale of 0-10? (0 = Not important, 10 = Very important)	9.6	0.8	5

the problem to "putting all patchwork design solutions into a holistic and integrated approach".

3.2 Phases of Participant Engagement and Prototype Design

Specific design activities and their outputs listed on Figure 3 are *highlighted in italics.*

Explore: To gain a better understanding of EHRs, the problem space, foreseeable future changes and our design goals, we conducted a *Background Literature Review* and two *Domain Expert Interviews* . The domain experts were a pediatric physician who leads a community-based facility that cares for CLHC in BC, and a senior researcher with expertise in health informatics. Altogether, our expert input provided information about the centralization

of EHRs and associated challenges, and clinician perspectives on current care coordination challenges for parents. We also received ongoing feedback and expert opinion from an occupational therapist who had extensive experience working with clinically complex patients and conducting research for different pediatric populations and their families (one of the co-authors, (Dr. Liisa Holsti). This input and feedback was very valuable in understanding the participant caregivers, designing the prototype and devising the design principles.

Conceptualize: For a high-level understanding of how the user interface should work, we conducted *Requirement Elicitation Interviews* with five parent participants (Group A in Figure 3) to understand their main challenges and strategies in managing health information, identify specific tasks that could be assisted with technology, requirements for a prospective management tool, and their general feelings towards using technology. We began the process of capturing design priorities as "design principles" (DPs) at this time and iterated on them thereafter.

We used this data to inform our first prototype, in the form of a *Conceptual System Map* accompanied by a *low-fidelity wireframe mockup* in Figma[1]. Then, we collected *Low Fidelity Design Feedback* from five parent interviews (Group B).

Refine: Input from the preceding phase informed our first *Medium-Fidelity Prototype* (Figma). We collected *Medium-fidelity Design Feedback* from four parents (Group C), then created a *Finalized Medium-Fidelity Prototype* (Figma) and *Finalized Design Principles*.

3.3 Data Collection and Analytical Approach

Feature Rating Activity: Over all three user study phases, we collected data on participants' feature preferences at the end of every interview (N=12). We created the initial list of possible features based on previous research on the same (or similar) population [2, 24, 25, 42, 58, 60, 63, 71] and the expert input.

We asked participants to rate the list based on importance, using a 5-point scale bounded as 0 (Not), 2 (Somewhat) and 4 (Very) Important. In addition, participants could assign the feature to an "Irrelevant bin" for any features that they believed would not be relevant to their situation. Finally, we asked the participants to explain their rating for each feature and/or to provide a scenario where it could be useful. We conducted this activity towards the end of the interviews so that parents would do this rating having been primed to think about features by the preceding discussion. Participants were further asked to add any additional features that they thought were important. Translation of ratings to feature rankings is described in Section 4.2.

Interviews: We conducted interviews remotely in 1-hour Zoom sessions; participants received $15 compensation for every hour of interview participation. Interview questions were open-ended and the interviewer asked follow-up questions if participants appeared to emphasize certain subjects. Participants were asked about their challenges, barriers, workflows and strategies for organizing medical information; about tracking symptoms, language barriers, updating information, and researching for information. After the question period, Group B and C participants were shown sections of

the prototype. Group B participants provided higher-level feedback as they walked through the prototype and the prototype conceptual map (Figure 4) with the researcher. Group C participants interacted with the prototype and were given certain tasks to complete. All participants were encouraged to think aloud and provide feedback for every prototype section. At the end of each interview, all participants completed the feature rating activity.

We recorded interviews, then three of the co-authors manually transcribed them. Seeking a list of actionable caregiver challenges and strategies, we analyzed our data using applied thematic analysis (inductive) with the method described by Guest et al. [29] and Braun and Clarke [12], utilizing NVivo Pro 12 software[2]. Three co-author coders deconstructed our qualitative dataset (interview transcripts) into smaller pieces and assigned a code to each piece of text. We defined a meaning for each code (*i.e.*, when to use or how to use) to keep code usage consistent; this generated a codebook. Using the software also allowed us to collect more quantitative data (*e.g.*, number of occurrences for each code). To improve inter-rater reliability, we coded each interview separately and then checked for convergence of the codes during one-on-one meetings. The codes and the codebook were revised again during team sessions. As we grouped codes into categories, overarching challenges emerged. Co-author domain experts not involved in the coding or the interviews also reviewed the codes.

4 FINDINGS

Our principle findings take the form of a set of overarching *challenges* (Section 4.1) derived from inductive thematic analysis on our Requirement Elicitation Interviews (Conceptualize Phase) with 5 parents/caregivers. In 4.2 we describe caregiver feature preferences in advance of Section 5's description of their instantiation in a prototype.

4.1 Caregiver Information-Centered Challenges

4.1.1 Having Limited Access to Health Information and Records. As expected, accessing health information and medical records (*e.g.*, reports, doctor notes, care plans, communications between doctors) is challenging for parents. Parents often need to go through many roadblocks to access needed information in their health records.

> "The more difficult [information] would be the conversations that the doctors don't tell you, so finding out what doctors have said to another doctor. I usually get that information from the archives of the hospital or need to ask the pediatrician." [P1]

Caregivers mentioned having to access disjointed records in many different places and formats (digital or physical). The lack of a centralized platform and associated challenges has also been documented by other research [1, 54]:

> "It's all in different places, and they all have different ways of access, some of the things you just don't access on a regular basis because either you forget, or you forget your password." [P1]

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[1]Figma: https://www.figma.com/

[2]Nvivo Pro 12: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

The strategies that caregivers use to overcome this requires continuous communication with care providers through e-mail, mail, phone calls or asking their pediatrician to access their health records. The main drawbacks to this strategy are that it requires reliance on memory, and errors of retrieval can occur because there can be multiple versions of the child's records:

> "I find there to be a lot of errors when it is not digital, because by the time I get the mail and there's an error, I have to call or email to get that corrected whereas if it's online I could edit it or add a 'look at me' note." [P1].
> "If I need to make changes to [the care plan], I have to e-mail back and forth... But it's not fully integrated and if I see practitioners outside of that hospital, it's not linked. So I'm keeping separate records from health-care practitioners" [P5].

This challenge directly relates to the broader problem that we are trying to solve and the assumption that we have made about the existence of a centralized database.

4.1.2 Finding Information About Resources. Caregivers can have difficulties with finding information about resources that are available to them, and there is no centralized place for such information. Parents reported significant time spent searching for complete and correct information, people, resources or services which they critically needed, such as new medications, wheelchair-accessible areas, social communities, available charities, therapies or funding sources [46, 46, 56, 57]:

> "I feel like everything is kind of detached, there's no one spot... maybe you want to be able to have connections with other families in the same area, maybe you want to see where is a wheelchair-accessible beach or trail, maybe you want to know about a new medication" [P4]

All 5 participants mentioned that their main strategy is to rely on word-of-mouth, information from the care team, online communities and researching, and some mentioned the problem of not knowing what to search for.

> "It is always through word-of-mouth, unfortunately, people and healthcare professionals are not aware of what's out there. Either parents talk to each other or this therapist passes information out to another therapist." [P2]

> "Care providers do not give a hand to guide you. You don't know what you can qualify for to even ask for it, so there isn't an example or a list that's a clear option of what is available." [P1]

P5 took a particularly active information-seeking strategy:

> "I set up an office and a fax machine. I'd just spend the whole day calling, calling, calling, calling. That's how I found out because it's not always provided to you. I tend to actually call every single organization whether I think I'm eligible or not. Because you always learn something new." [P5]

4.1.3 Becoming the Central Information Holder. Decentralized, difficult-to-access health records and unfamiliar care providers results in caregivers having to become the central, reliable source for their child's health information

 [30, 49, 67]. They must repeat their story endlessly to new stakeholders [1]. Their child's "story" may consist of events that happened during the last hospital visit, or how a specific care procedure should be done or the details of their diagnosis.

> "You're having to be the one answering all the questions... we've been in the trauma room and doctors are asking me what should be done." [P4]

> "Repetition of the same story is so traumatic for families like mine. You're reliving everything that you kind of dealt with over the years. And sometimes, even if you're not, you're repeating it, you're repeating it to a fellow, you're repeating it to a resident, you're repeating it to a nurse clinician…" [P2]

Being the main source of information, caregivers must be constantly vigilant and engaged to ensure collaboration effectiveness, and cross-connect people and information to make it holistic. Remembering important information and worrying about losing critical documents causes stress:

> "There were situations where a treatment started that can be detrimental for something else... and I need to be in the picture to say there are other things going on." [P4]
> "I wish I never got paper, I wish everything was emailed to me because then I have the electronic copy and I don't have to worry about losing it." [P3]

One parent mentioned that this process is laborious and said:

> "I want quality time with the person I'm caring for I don't want to keep track of papers and files." [P1]

Caregiver strategies for ensuring that they are sharing accurate information are often based on organizing, updating, maintaining, tracking, summarizing and converting documents, into summarized plans, on which they spend very large amounts of time:

> "I'm dealing with thousands of pieces of paper and having to manage them without any proper training. It is a lot of organizing, keeping reminders, re-referring, emailing and keeping up to date." [P1]
> "Let's say we just had a major surgery. I would write an overview of how the surgery went, what [my child's] current baseline is, what's their therapy plan. Then, I send individual emails to everybody and respond to everybody." [P3]
> "I had created that [care plan] as a document. I need to just include a brief summary for a new practitioner coming on board, kind of like an on boarding process." [P5]

They must also manage different document formats (physical and digital)., often converting between them.

> "We use Google Docs, so it can be shared with both health care practitioners and family members." [P5]

We compiled a list of what parents include in the parent-created care plans or summaries based on responses from all 12 participants:

dates of hospital admissions, diagnosis, when things/events happened, when medications started, current medication and doses, mobility, equipment list, how to interact with the child, expectations for support workers, how to use equipment and troubleshoot, seizure protocol, care team names, major surgeries, a general overview, contact information, family contacts, how to administer medications, feeding plan, water intake, signs of distress (protocol, triggers, prevention), daily living (dressing, toileting), play/leisure activities, sleep, favorite activities, positioning and movement (transfers, sitting, crawling, standing, walking, mobility), and communication.

4.1.4 Navigating the Health Care System. Issues with system navigation and stakeholder communication arise in different contexts [5, 7, 27, 56, 67]. *e.g.*, inexperience of the caregiver, their difficulty with medical jargon or their primary language.

> "I'm not a medical assistant so I don't understand the language and a lot of the abbreviations." [P5]

Caregivers with older children mentioned the amount of time that was required to learn how to communicate with stakeholders and how to navigate the system:

> "I would say that I am able to understand medical jargon now, er ..more easily and that was a learning curve... trying to figure out how and what to include and what it all meant." [P4]

> "This is 15 years in the making - this didn't happen overnight. There was a quiet yes-yes-yes person. Whatever the doctor said, I didn't challenge it." [P2]

They come to know which documents or pieces of information about their child should be shared with each stakeholder (*e.g.*, nurse, school, government, care providers, *etc.*) in a way that they can respond to it:

> "It was a lot of work and very time consuming if you don't speak a certain way to doctors or write emails to get a grant. I learned how to write these emails and what to say...but I know you'll get a roadblock if you don't say it a certain way." [P5]

They found ways to learn about and search systems they had to interact with. They also learned the language to use with care providers to result in actions. P5, speaking of system navigation, mentioned:

> "It's very very overwhelming, it's a full time job. Even researching your medical condition ... the school system the child care system, the health system, inpatient, outpatient, they all have a different systems... so much learning about the inner workings of a hospital I had to work there to figure it out." [P5]

> "As soon as I use the words that health care practitioners use, I get to where I need and navigate easier, but not a lot of people can do that. You actually need to talk in their [care provider] language." [P5]

Commonly, parents relied on paper to navigate the system, and some expressed that using paper could improve communication with care providers:

> "I like to take paper into the hospital with me, sometimes they get angry if you're staring at your phone." [P3]

> "[Care providers] don't have time to bring [the care plan] up, it's a lot harder to read, so I just print two or three copies. Also, if I have questions for them, I print it out. I print out everything when I go to the appointment. Because they're not going to open your email ... they don't have time for that. you've just got to put the paper in their hand ... Paper can go a long way." [P5]

They tracked and meticulously compiled data (symptoms or other variables, on paper charts and Powerpoint presentations) to present to stakeholders [20, 55], and mentioned the importance of having visualizations to present the data:

> "Our [child] has really low platelets and some of it is medicine induced... and there's a medication for reflux that causes low platelets as a side effect, but we never realized this until he was off the medication .. and now we put them back on and we noticed the same symptoms of low platelets. So then we compared the time that [child] was on it and when [child] was not... that's what's great about it. Also, it can be helpful for getting a special medical equipment." [P2]

> "When you talk to doctors, they don't want to see stacks of paper ... they want to see trends and a correlation... this way they can make a quicker diagnosis. So that's why I made PowerPoint presentations, which are very similar to a medical education presentation in rounds. I showed them the graphs and pie charts and the trends and I was able to communicate with the doctors. Um, but if you just show data on a symptom tracking app, it's not going to do anything. You have to actually translate that into some sort of graphing..." [P2]

We asked all 12 participants to list the parameters that they track at home and school. Examples were listed in Section 2.3.

In summary, many caregivers found that documenting symptoms, behavioral cues and other care events helped them with communication and system navigation. However, these strategies are stressful, time-consuming and greatly rely on the individual caregiver's experience and network.

4.1.5 Managing Finances and Financial Information. While mentioned less frequently, some caregivers emphasized spending significant time tracking all their finances and applying for insurance, government funding and charities. Other research has also reported caregivers' difficulty with managing finances [14, 41, 46]. Two participants explain the difficulty with managing information and obtaining funding. One parent explained the importance of advocacy, tracking who has advocated for the child, where the process is at and whether there have been any barriers:

> "So [the digital system] should have a list of unavailable items [*e.g.*, behavioral interventionist, specialized equipment]. These could be under 'advocacy', this is the number of letters or phone calls or emails I've

sent to [the government program] in regards to this formula, and then everyone on the care team can see that the doctor or social worker has put in a letter, and it still hasn't happened." [P1]

"I do all the ordering. And then when the invoice comes, my husband does all the paperwork for insurance. Because that's almost a part-time job. Yeah, a lot of cash going in and out." [P5]

P3 explains using spreadsheets to keep track of finances:

"I apply to different organizations for funding. Some things don't get covered through regular plans and they don't happen all at once, but it can take months from start to finish, so I need to keep track of them in a spreadsheet." [P3]

4.1.6 Humanizing The Child and Family. In the context of "information shared with stakeholders", four parents mentioned the need and importance of humanizing the child and family. Four of five parents mentioned having created an **"About me book"** or **"Communications Dictionary"** (named variously) for their child in paper format, which they share with school or care providers.

These documents are a way to introduce their child, provide information about how to interact with them, share their likes/dislikes, what they are like outside of the hospital, who is in their family, and their communication methods.

"I think everyone should have an [About me book], so your child doesn't become a subject or an object... the primary goal is to tell someone who doesn't know anything about your child, their cues. What does this look mean? My child is nonverbal so I took multiple different pictures for different scenarios. Scratching can mean multiple things to my child. It's not always -I'm bored or I'm tired... that's maybe the [child's] way of soothing [themselves]. It's [About me book] not something that I would give to a healthcare provider who sees [child] for five minutes."

P2 provided a practical example of how this information could be integrated during visits with care providers and how much time the caregivers could save:

But wouldn't it be wonderful if that whole thing comes up on the screen of the healthcare provider right before they see the patient. So they kind of get to know a little character ... a person. We would save so much time! ... This way you personalize the child. The child is actual human, the child has a family, and a story that goes with each picture ... like a photo book.

P2 mentioned that this information is also useful for communicating with other caregivers, and described how it can efficiently convey parent preferences for their child's care. They also felt that care providers sometimes provide a different level of care for the CLHC population:

And you pass it to every caregiver. My child is not a number, my child matters, and these are [child's] likes and dislikes. One example is my [child] can't see so putting [child] in front of a TV to stimulate [child] is never going to work. So [child] needs to work one

on one with an IPad, hand over hand activities. So that is outlined in the Communication book. So it explains... These are things [child] can and [child] cannot do. And focuses more on the positive, not [child's] deficit... Not a happy book but a realistic book ... care should be the same across the board...The fact that healthcare providers and therapists are putting this little population in a different category is just hard to swallow." [P2]

Another parent described the importance of this information and how it could help with care decisions:

"The about me and home life stuff is super important for people to understand where [child's] at and what [child's] general day to day surroundings are." [P1]

We asked all 12 parents about what they include in these documents. They responded with: how they eat and walk, language and what a sign means, how to read their body language, likes/dislikes, favorite color, short biography, what it looks like when they are feeling a certain way, child's interests, pictures, what does a look mean, what does crying/scratching mean, postures, gestures, expressions, communication devices, sounds, communication toys.

4.1.7 Other Challenges and Strategies. Other challenges were mentioned less frequently. These consisted of ordering supplies, tracking tasks (*e.g.*, who has done what during the day), tracking changes in appointments, tracking medications, and tracking changes in the care team. Similarly, some strategies that were mentioned included setting reminders, using calendars, and taking photos or videos.

4.2 Priorities and Feature Rank

We compiled 27 recommended features from previous research, and asked parent participants to rate them using a 5-point scale (Section 3). We used this data to prioritize our own design foci, and to inform and prioritize our Design Principles (Section 6.1).

All 12 parents rated desired features. We analyzed responses by taking the average and standard deviation of all ratings for each feature (N=12), then ranking features based on average rating (Table 2). We reference features by their rank. We compiled ranking results after each study phase, and used them on the next phase. For example, "sharing information about how to interact with the child" was ranked very highly by Group A, and thus we prioritized the Interactions book and Life Journal from the start.

Communicating with the Care Team and Maintaining Transient Records – The top-ranked item by 100% of parents (Rank=1, SD=0) was *(R1) maintaining a contact information list corresponding to care providers*; with *(R3) maintaining an updated medication list* close behind (SD=0.29). We heard repeatedly that it is very difficult and time-consuming to keep track of changes in care providers' contact information.

Maintaining a contact list might not seem a daunting task or beyond the capabilities of the wealth of contact management tools

already in existence. P5 (Table 2) explains their **health-care contacts' volatility** and linkage to an evolving, complicated, many-player care plan. Participants' unanimous agreement with this capability highlights the need for **specialized integration with a larger data system** in which **the concept of a care plan figures prominently**.

Streamlining the Facilitation of Positive Child Interaction – The ability to *(R6) share information about how to interact with their child* emerged as a high and widely agreed upon (SD=0.40) priority, with particular commitment from parents with a non-verbal child.

Tracking and Visualizing Things – Participants highly prioritized tracking *(R1) upcoming appointments* and *(R7) recent symptoms*. There was high variability for *(R20) tracking who has advocated for the child*: some found this very important, while others were unsure about the meaning or how it could be achieved. Unsurprisingly, they also wanted to easily see the tracking results, up-voting features related to data visualization: *(R9) symptom history, (R10) diagnosis history* and more modestly *(R16) laboratory test results*.

Health Records Access and Search – Participants wanted to be able to *(R4) interact with their health records at their care provider*, describing how this would allow them to show important details, take notes and make changes, emphasizing the need for **access to be real-time.** They emphatically wanted effective *(R5) search functions to find information*, signifying the overwhelming amount of information they are handling and once again, the need for an underlying data **integration** to support such search functions.

Other Notable Features – Setting reminders received some attention *(R14, R18, R19),* with comments and results that this is less valuable for routine tasks (*e.g.*, R22). *(R12) downloading and printing* was important to parents who felt that care providers are more likely to respond to paper documents. *(R27) translating medical information to other languages* was only rated highly by P1 whose primary language was not English; but others emphasized in their comments that this could be very important to non-English speakers and travelers.

Participant-Proposed Features – Three parents offered additional features: P7's were wide-ranging: nursing charts and orders, extensive supply inventory details, medication lists and prescription access connected to insurance coverage, schooling goal-setting, P9 focused on *medical equipment inventory management*, wishing to organize records for receipt, repair and maintenance. P1 requested *grant-funding resources*.

5 PROTOTYPE

This work culminated in a medium-fidelity prototype whose purpose was to first explore how a tool integrating this group's many information-management needs could work from their perspective, to elicit their feedback in its evolution, and finally to act as an aspirational target to motivate and help prioritize the development of enabling database, security and EMR technology. We illustrate the prototype through its conceptual map and with select detailed views.

5.1 Conceptual Map

Figure 4 overviews the system we designed (based on content priorities from [25], illustrating in a "birds-eye view" the prototype's functional sections and how data is shared between them. A core underlying idea is **re-use of integrated data** that has been entered by a busy person. This data might arrive by way of network and portal-available EMRs (*e.g.*, lab results), manual entry by the parent (symptom tracking, significant medical events, "how to interact with my child" items) or through some other connected systems (*e.g.*, prescriptions, connected care plans and contact lists). Once in the underlying database, **custom reports** can be generated by the parent, compiling the data for different purposes (a symptom log for a doctor; a version of the Interactions Book for a new caregiver or teacher). Similarly, key **visualizations** allow the parent to efficiently view and access data from a timeline perspective designed to **scale to years of data**, but be useful on a **small screen**. Unique views where we focused our design efforts are highlighted in Figure 4 and described below.

5.2 Selected Prototype Views

We selected several regions of the medium fidelity prototype to highlight distinctive ways in which it seeks to support the unusual needs of this group. The simple design of these prototypes aims for a shallow learning curve, low need for physical documentation and timely, easy information access to information [67].

The Medical Timeline – Visualizing and Accessing A Lifetime of Data on a Mobile Screen: Research suggests that visualizations can facilitate discussions and communication between caregiver and clinicians [39, 40, 44]. Such visualizations are critical for CLHC caregivers, and these features were ranked highly (Table 2). On the key Medical Timeline visualization page (Figure 5A), users can view medical history on a yearly, monthly or weekly basis. It provides an access point for entering tracking information; then visualizes data in a manner amenable to finding patterns, developing insights and showing and discussing with care team partners. The current design of these pages relies heavily on manual tracking; however, automated tracking and video tracking tools [50, 72] could be integrated to move towards semi-automated tracking [17, 47].

Figures 5B-C depict screens linked from the Timeline, a portal to greater detail and to logging data. The Timeline view also links lab EMRs and medication records.

Dashboard: The entry point of the whole system, the Dashboard connects to many other functions Figure 6A and is user-customizable in terms of which "easy access" pages it lists.

Life Journal: Parents wanted a way to document the life of their child outside of the hospital, in part to share with the constantly changing stream of people who are part of their child's life and who do not know them. The Life Journal (Figure 6B) is connected to the application's Child's profile section, and can also be used to track activities done working on caregoals. This type of journal can also be helpful to move towards family health informatics by identifying ripple effects between family members [53].

Interactions Book: This Life Journal adjunct is a place to collect parent-generated media showing how the child communicates through gestures and expressions which may be needed for teachers, sitters and care team members, and especially crucial for non-verbal children. These may be shown to others on the parents' own mobile device, printed via the summaries, or exported and sent

Table 2: Participant-Prioritized Features and Associated Design Principles, selectively supported with participant quotes. Rankings of 27 features were produced by averaging participants' 5-point ratings (N=12) where 0 = Not important and 4 = Very important. Rank of 1 is most preferred. Some features have N<12 because they were not ranked by all participants because the participant believed it was not relevant to their situation. Each feature is mapped to the a related design principle based on context and the design principles are prioritized based on the ranking of the feature.

Rank	Task/Feature	Mean	SD	N	DP
1	Maintaining a contact information corresponding to care providers (e-mails, numbers)	4.00	0.00	12	DP1 - Facilitate Communication and Collaboration
	"I have the master document of the contacts and emails for all the practitioners, and I have to maintain those records. What I find really frustrating is we have 20 different health care providers... and I have that document with all the phone numbers and emails so if I have to call some clinic, I need to find this document. I would love to have a digital solution where I could input this thing as part of the care plan with all those numbers in my phone. So it's all there and it's stemming from the care plan ... if you change practitioners or you add practitioners you want to have a master place where you don't have to change everything separately. That's why I don't program these numbers in my phone, because they are changing, and then I'll have to keep updating my phone contacts." [P5]				
2	Tracking upcoming appointments	3.92	0.29	12	DP1- Facilitate Communication and Collaboration
	"Appointments and referrals are super important because that's how stuff gets done." [P1]				
3	Maintaining an updated medication list	3.92	0.29	12	DP2-Capture History and Provide Insight
4	Interacting with personal health records at your provider (i.e. at hospital, family doctor)	3.91	0.30	11	DP1- Facilitate Communication and Collaboration
	"It was easier to communicate with the health care providers because they already had the information on their screen or on their binders so we could point to it." [P2] "There's been multiple times when my [child] has gone through emergency and they can't see something on [child's] file. So if I'm at the emergency room and the doctor is asking me questions, I can pull up the previous admission form or information that he doesn't have to show him." [P1]				
5	Robust search function to find information quickly	3.83	0.39	12	DP3 - Integrate Information to Provide a Holistic View
6	Sharing information about how to interact with the child	3.82	0.40	11	DP4 - Humanize he Child and Family
7	Tracking recent symptoms	3.75	0.45	12	DP2 - Capture History and Provide Insight
	"I was able to correlate [mood] to the medicine [they] were taking and then we took [my child] off the medicine because it's creating all these side effects ... so when we took [my child] off the meds, then we did see an improvement... and that's mainly what I'm tracking, the correlations. We need to understand when things are going uphill or downhil. But it is very difficult to track." [P7]				
8	Controlling permission settings in terms of who can view and modify the care plan	3.75	0.45	12	DP5 - Share and Access Confidentiality
	"I understand confidentiality has been always an issue to protect the patient. But what if the patient wants to get connections. What if the patient is authorizing it -- for me there is no secret in our family." [P2] "My concerns are that I don't want everybody accessing them [information], like anybody in the care team to access everything. [P6]				
9	Visualizing and summarizing the history of symptoms	3.58	0.51	12	DP2 - Capture History and Provide Insight
	"When you talk to doctors, they're don't want to see stacks of paper, they want to see trends, and they can make a quicker diagnosis. So I made PowerPoint presentations which had a similar format to medical rounds... I showed the graphs, the trends and pie charts. I had all these algorithms and calculations. So I was able to communicate to the doctors in this way... because I worked in medical education, I knew how these presentations are supposed to look like. So if you just show this app, it's not going to do anything ... you have to translate that into some sort of graph or pie chart and print it when you're talking to the care team." [P5]				
10	Visualizing and summarizing the history of diagnosis	3.50	0.67	12	DP2 - Capture History and Provide Insight
	"When you're dealing with any doctor, they want to know the history." [P4] "It would be good to see the progression of diagnosis connected to medical images" [P8]				
11	Outlining care goals to promote shared decision making	3.42	0.67	12	DP1 - Facilitate Communication and Collaboration
	"I had care goals for all of education when I was training all those support workers. So I had a PowerPoint presentation, which I went through and I had the care goals and the mission printed out in booklets for everybody." [P5]				
12	Downloading and printing feature for the care plan	3.42	0.79	12	DP6 - Customize and Allow Flexibility
13	Secure messaging system to contact care team members	3.42	0.90	12	DP1 - Facilitate Comunication and Collaboration
14	Reminder system for medications	3.42	0.67	12	DP6 - Customize and Allow Flexibility
15	Syncing appointment information with other mobile applications (e.g. personal calendar)	3.33	0.78	12	DP6 - Customize and Allow Flexibility
16	Visualizing and graphing laboratory test results	3.25	0.75	12	DP2 - Capture History and Provide Insight
	"Showing the differences between lab results is the most important, not a singular lab results, but how has it changed over time." [P3]				
17	Tagging specific team members to get their attention about an item	3.25	0.97	12	DP1 - Facilitate Comunication and Collaboration
18	Reminder system for therapy home program(s)	3.25	0.97	12	DP6 - Customize and Allow Flexibility
19	Reminder system for equipment maintenance	3.18	0.75	11	DP6 - Customize and Allow Flexibility
20	Tracking who has advocated for the child and how many times (e-mailing charities or government grants)	2.90	1.20	10	DP1 - Facilitate Communication and Collaboration
21	Sharing care preferences with the care team	2.83	0.72	12	DP1 - Facilitate Comunication and Collaboration
22	Reminder system for feeding	2.78	1.39	9	DP6 - Customize and Allow Flexibility
23	Notifications to alert changes in care	2.75	1.48	12	DP6 - Customize and Allow Flexibility
24	Tracking when and where users are accessing the care plan	2.75	0.97	12	DP5 - Share and Access Confidentiality
25	Recording conversations at care provider	2.75	1.14	12	DP6 - Customize and Allow Flexibility
	"When you're at the hospital or with a care provider, there's sometimes really stressful conversations that are emotional, and in the moment. You can't remember, or think about everything that you need to hear. Some care providers will say yes and some people will say no. But if that can be done in the app to keep it all together, that'd be awesome." [P9]				
26	Hands-free and voice interactive engagement with the app	1.45	1.21	11	DP6 - Customize and Allow Flexibility
27	Translating the medical information to other languages	4.00	-	1	DP1 - Facilitate Comunication and Collaboration
	"I'm hoping that there is translation options, because English is my fifth language ... people need to be able to translate to their family and friends ... In the first few yers, we would talk like we were second grade citizens until we found our voice. A lot of parents who have multiple languages, they're almost dismissed ... maybe 15 years into it, sure I've picked some jargon, but we don't speak medical." [P2]				

following secure protocols. The Interactions book also homes some data that can be re-usable elsewhere in the system; for example the data recorded in the Interactions Book can be integrated with the Medical Timeline to show changes in behavioral cues.

6 DISCUSSION

In this section, we first discuss a set of emergent design principles and then revisit our guiding research questions.
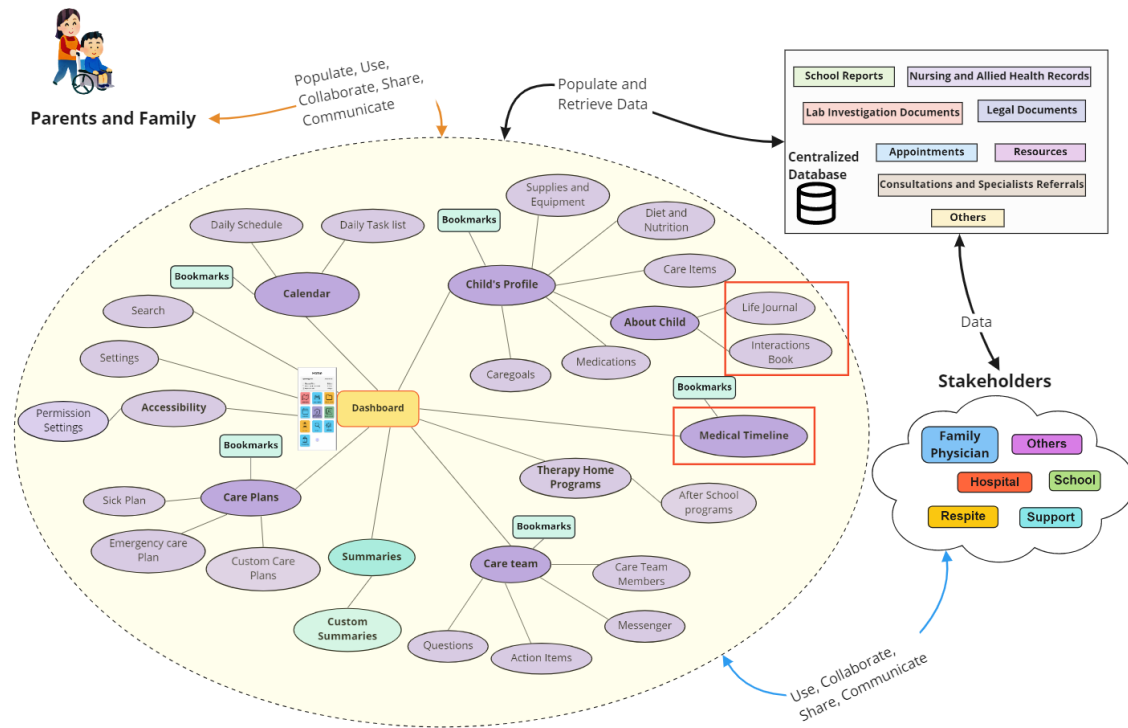
Figure 4: Prototype's Conceptual Map, showing the complexity of the medium-fidelity prototype and how the envisioned information management system fits into the bigger picture of the family and care team. The application itself resides within the yellow oval, centered on the Dashboard view (Figure 6). Lavender ovals indicate functional units of the application, accessed through one or more screen views. Central lavender nodes (Care Plans, Care Team, Medical Timeline, Calendar, Child's Profile) are emphasized. Turquoise items highlight the Summaries feature: data is integrated to generate custom summaries based on user-applied bookmarks. Many of the nodes received high-level participant feedback from Group B in the form of low-fidelity prototype. Nodes described in Section 5.2 are in red boxes and they received the most participant feedback (from Groups B and C).

## 6.1 Design Principles for CLHC Caregiver Health Information Management

Iterating over the duration of the project, we arrived at a set of six design principles that capture caregivers' information-centered challenges, their feature preferences and goals for using information. Crucially, each one is operationally centered in *parents' use of such information*. Here we describe the principles, how they manifest in our design approach and the ways that they uniquely apply to or are exceptionally needed by this group.

At the highest level, our findings clearly indicate that to ensure easy access and avoid fragmentation, **data, documents and information should be centralized, sharable, searchable, real-time, accurate, secure and interactive**. This over-arching objective cannot be addressed at the level of the interface until they have been accommodated by the underlying data structure of the digital health information management system. It is painfully clear that the best strategies caregivers have found cannot make the health information-wrangling part of their job manageable alongside their other responsibilities. An information system aiming to improve their situation needs to save time, reduce errors caused by using

numerous modes and formats of communication, drastically lower the need to remember information, and streamline communication between and with stakeholders. The principles should target the articulated caregiver challenges giving rise to ineffectual strategies (Section 4.1). They should be be potentially addressable with foreseeable technology.

6.1.1 DP1-Prioritize Communication and Collaboration In Underlying Structure.
Many health information management systems are intended for personal record-keeping and reflection, or communication with one or two care providers. CLHC, however, require a tool that will help them *continually* coordinate with a *vast, evolving care team*. Its communication affordances must be built into its underlying structure.

In our conceptual model (Figure 4), we are trying to enable an ecosystem which is fundamentally a collaborative and communication space for various aspects of care. A shared appointments Calendar, Contacts list and jointly developed Action Items are common tools but not usually part of a data tracking and document sharing app; while the primary purpose of the Child's Profile, Medical Timeline and custom Care Plans is sharing and communication.
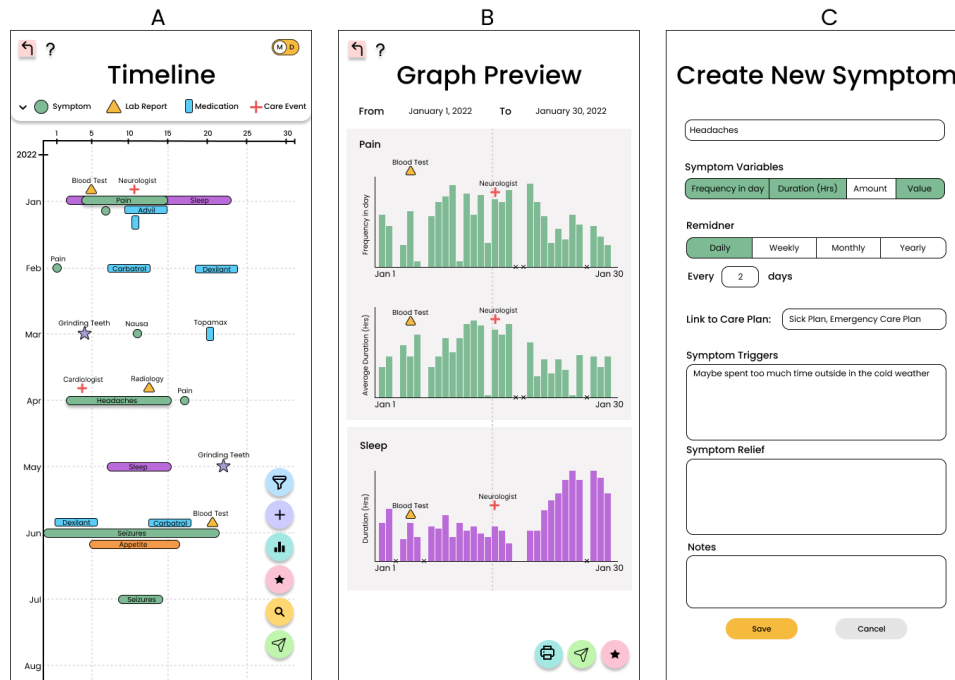
Figure 5: Selected Sections of the Medium Fidelity Prototype, sized to a smartphone screen. (A) Visualization overview: The Medical Timeline compactly renders a year's worth of four categories of data (symptoms, lab reports, medication and care events as well as sleep) on one screen scrollable up/down by year while day of month runs left-right. Each colored marker can be tapped to open and view associated details, records, contacts and history. B) Visualization detail: An example of a graph of user-selected variables could be accessed from the Timeline (green "graph" button on the Timeline view). C) Tracking things: How a new symptom (or variable) can be added to the Medical Timeline, accessed from the "+" button on the Timeline view.

The Accessibility settings crucially control who can access, view, and edit different sections of the ecosystem.

Effective communication and collaboration can be achieved through many methods in a cloud-based technology, with key requirements of data sharability and realtime interactivity, in particular to support direct discussion between family care provider with utility for both caregivers and care providers.

As others have noted, the interface should also limit medical jargon; once caregivers feel confident with terminology, their communication with care providers can improve. Desai et al. emphasizes using family-centered terminology in cloud-based longitudinal care plans [24]. Our own data confirms how jargon poses barriers to communication, especially for new parents.

6.1.2 DP2-Capture History and Provide Insight, at Scale and Across Many Personalized Parameters. As shown in Section 2, CLHC tracking and visualization needs are exceptional due to the volume of historical information that needs to be tracked, captured and integrated to provide insight for the caregiver and empower them in care decisions. Beyond complex and interacting symptomology, this includes information like medication changes, appointments with specialists and related notes, lab results, medical imaging and behavioral changes.

Tracking: Thus, the interface should support tracking and maintenance of an accurate and historical record of events. For example, parents have mentioned that their child's complex symptom patterns makes it difficult to discern symptoms of new acute problems from those of the complex disease progression [43], making it difficult for care providers to know when to escalate care.

Sharing and visualization: Once data is accessible and sharable, it also must be presented in a manner that is *comprehensible and usable* by caregivers and care providers (Figure 5 provides an example). Our data and previous research indicate parents rely on symptom tracking data to generate records to facilitate these exchanges: not with complicated graphs of lab results, but simple ways to view and track health details they know to be a priority, and to share their insights.

This principle addresses issues of access to health data and discussing data with care providers. It is a path to empowering caregivers and integrating data from at-home events with medical health records.

6.1.3 DP3-Integrate Fragmented Information for a Holistic, Provider-Spanning View. The interface should aim to include everything about the child's care, because all care aspects are holistically linked. Furthermore, the interface should integrate and link data elements in a way that offers a holistic view of the child, rather than showing
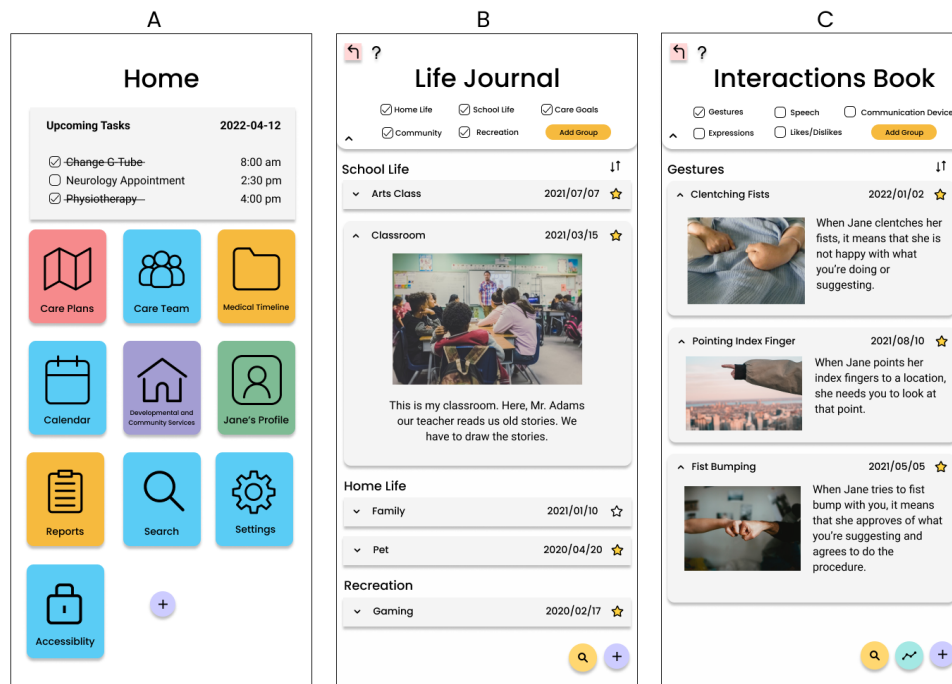
Figure 6: A) The main Dashboard. B) The Life Journal. C) The Interactions Book. Information cards can be tagged as bookmarks using the yellow star on the right top corner.

them as a set of symptoms. This principle relates to the reality (well-documented in the literature and in our data) that the current care system and decision-making fail to view the child's complex diagnosis as a whole.

This principle also addresses the issue with handling and sharing fragmented data in different formats and with different providers (another barrier to holistic views). Data integration is the key to buying time for busy parents. Information must be created or updated just once and in one place. When users can retrieve and link data items from different interface zones, they can share them with stakeholders in a suitable compilation – in contrast to the high degree of repetition built into crucial information-sharing with stakeholders responsible for different facets of the whole child's life.

Amir et al. emphasize that care plans need to be "ever present", with content and form adapting to each information receiver based on their care team role; and suggest intelligent interactive systems that customize these views [4]. Currently, caregivers do this customization themselves. Due to the highly specific knowledge and experience required, it may not be a realistic goal for intelligent systems.

However, caregiver-centered technologies could make it easier for caregivers to create goal-oriented summaries [18] by moving the central information-repository from the parent's head and paper binder to a shared-access digital system, then easing rapid information assimilation and integration. Our prototype includes this capability (Summaries page and bookmarks, Figure 4).

6.1.4   DP4-Humanize the Child and Family. Although rarely raised in the context of digital tools, our participants made it clear that this idea is crucial. Our data shows that caregivers care deeply about sharing how their child communicates, what their family looks like, their life outside of the hospital, care preferences and likes/dislikes. Previous research shows that increased technology and automatization has fragmented care and led to dehumanization and patient depersonalization [13]. Patients report being viewed as a "group of symptoms" rather than a human, which negatively affects their relation with care providers. While there is not a definition for "humanization of care", key elements include respect for a patient's uniqueness, individuality and humanity [13]. This is equally important for caregivers of CLHC, who are intensively exposed to the health care system.

Additionally, previous design guidelines suggest that adding better tracking tools may actually cause unnecessary anxiety over the child's progress. Adding sentimental sections to information management tools can counteract this [36]. Kientz also suggests that care providers' confidence grows with awareness of their patient's family life; and that the bond between parents and provider is strengthened through this personal connection [35].

Desai et al. propose supporting these aims with a section for personal information about the child, their home life and family [25]. Information about how to interact with the child and what their body language means helps understand children with atypical communication abilities: *"the focus should be on what the child can do,*

the positives, and not the negatives" [P10]. These ideas appear in our prototype in the Life Journal and Interactions Book Figure 6.

6.1.5 First, Access Easily; then if Possible, Share Confidentially. The interface should balance sharability, accessibility and confidentiality *according to the caregivers' prioritization.*

Desai et al. articulated a related principle ("Balance between access versus security") [24], and [4] included a guideline on information sharing. Our data support these suggestions, but go on to show that CLHC caregivers seem to *prioritize* sharing information over security (Table 1). Parents told us that it is a major task to provide consent to different organizations for using and accessing their data (*e.g.*, filling-in and signing forms), and described security barriers to accessing information either for themselves or other stakeholders.

Caregivers should not have to choose between access and security. The interface for a digital information application should prioritize accessibility and sharability *while* giving primary caregivers the ability to easily provide consent and control other user's access. Specific features should be designed to make this process painless and easy, *e.g.*, with the ability to change view/edit permission settings for different pages.

6.1.6 DP6-Build In (Rather than Add On) Customizability, Flexibility and Cross-Application Collatability. Because families and individual caregivers differ so much in their needs and how they prefer to organize complex information collections to reduce overwhelming cognitive load, the interface needs a degree of customizability and flexibility that has to be built in from the start, not added on at the end. Data needs to be shared across applications (not re-collected or entered multiple times), in a single platform that can generate pharmacy, medical testing, or physiotherapy reports from the same data records.

Other researchers have pointed to similar design guidelines [25, 67] and offered suggestions for increasing flexibility and customization, and this principle is sometimes used in different contexts. Our prototype testing with parent participants helped us solidify what this might look like. our design is architected such that information can be tagged for integration across application regions and views. For example, parents described the need not only to tag different kinds of information, but to make these collations memorable and findable or aligned with other conceptual elements, by further customizing color mappings (*e.g.*, for tags on Medical Timeline symptom categories or calendar events); and thereby reduce overwhelming cognitive load. They need to add their own custom data categories, *e.g.*, for their child's gestures, postures and expressions, or pages and page organization (*e.g.*, custom care plans) that match their own mental model for data organization.

We provided a menu option at the top of all the pages to enable addition of custom data categories (visible on Figure 6 B, C top menu). Table 2 ranks other customizablity and flexiblity features, such as reminders for various tasks and downloading/printing material.

6.2 Revisiting the Research Questions

6.2.1 RQ1: In terms of features, interactivity, content, information, and functional integration, what do parent caregivers need in a digital tool solution for information management? For this group, how might these capabilities interplay to significantly reduce information management burden, and what might they look like? Our progress on this question is captured in the feature ranking and challenges analysis, then abstracted in our Design Principles.

Parents' highest-rated features highlight their need to *integrate* the information they manage, then and cross-reference and access it in a multitude of ways: track appointments and symptoms, maintain a detailed and integrated contact list, control permission settings, visualize and summarize histories of symptoms (and other events), maintain a medication list, search with power (scope and speed), and share information about how to interact with the child.

Once information access and management burden barriers are reduced, the most important and unique caregiver "wants" are to obtain insights from health information and be empowered in care decisions, to humanize their child by sharing their life outside of the hospital, and be able to present a holistic view of their child to others by integrating information. Parents were enthused to see these features implemented. Our design principles reflect these requirements and align with a family-centered care model, integrating expertise and preferences of parents into the care system.

6.2.2 RQ2: To what extent are this group's health-coordination needs divergent from others? For non-generic (divergent) needs, can we identify principles that pinpoint where and how to tailor special solutions for this group? In Section 6.1's list, we explained how principles that seem generic, obvious and customary for other populations must, for this population, be: taken further (DFP1–collaboration with *really, really large* teams); given more scope and flexibility (DFP2 and DP3–capture, integrate, visualize and access a *lot* of information over a *long* time with *acute* consequences; or weighted differently (DP5–sharing may be more important than confidentiality).

However, underlying all of these principles is the need for fluently interconnected data system. Its existence, and the powerful leveraging that this approach will demand, will be valuable for patients with complicated or even simple health needs.

Finally, DP4's emphasis on humanization of patients and their caregivers are a value which needs traction at all levels of health concern, but has rarely been given expression in health-oriented information system design.

6.3 Limitations

Parents of CLHC are an overwhelmed and hard-to-access group. The participants that we reached were all mothers in a similar age range, comfortable with technology, living in the same part of the world (BC, Canada) and health system. Only one was a non-English speaker. The limited diversity may have introduced bias in our data and impacted design decisions, and understated the difficulties that non-English speaking users might face. The sample of 12 was considerable for a study of this type, but a larger group might expose a larger range of design preferences. Methodologically, in the future triangulating design-interview interactions with observations, analysis of caregiver-created documents, and even in-person, in-situ interviews might expand insights.

In this study, we also have not considered cases where children do not have cognitive or functional limitations and can partake in their own care as a stakeholder. These aspects can be considered and studied through child-centered designs [63] and collaborative care.

7   CONCLUSIONS

Building on previous recommendations, guidelines and findings, we have gone a step further by laying out an ecosystem which centers the caregiver at an information management hub: it shows how actually *addressing* information management challenges could look, helping to motivate the data-interconnectivity roadblock and provide an aspirational blueprint for a dashboard through which parents could access it.

Through engagement with parent caregivers and experts, we substantively honed and extended previous principles, to facilitate further development of digital information management and care coordination tools for caregivers of CLHC. The "extreme data" that this group is managing – integration, timescales, complexity – requires an exceptionally powerful solution. Although our initial target was all about information (what we informally call the "bulging binder" problem), our design expanded to other fields and challenges: team communication, cooperative care, data visualization and health care systems. As this vision is developed and refined, it should draw more deeply on all of these fields.

Bringing such an interface to reality is dependent on access to the data that it aims to integrate. Some zones of our blueprint could function today anywhere in the world – those relying on parent-provided or importable data such as the Interaction Book and Life Journal, and a Medical Timeline version focusing on parent-tracked symptoms, medication and medical events. At the next level of ambitiousness, a specialized organization such as an innovative pediatric center already organized around team-based care and which prioritizes within-team communication and centralization of data pertaining to care plans, contacts and calendars, might be able to support a pilot environment to nurture and explore these ideas, so long as the parent caregiver – the most important individual in the CLHC's care team – remains the primary stakeholder for this information hub.

Most of these ideas are in the future. A comprehensive solution to these complex communication challenges and care fragmentation will not only require a digital transformation, but also depend on changes in the health care system involving many entities and considerable inertia. Technical barriers include development of centralized health records databases for the right kind of access to patient health records. However, once our underlying health information system infrastructure makes it possible for a system enacting these principles to be constructed – a little sooner if motivated by concrete expressions of need, we hope – the "complex" solution will enable better and easier health information management by others with large but less totality of need. It will scale down beautifully to support subsets of functionality; but simpler, partial solutions do not scale up. When we address just part of the problem, it does not help with the big challenges because the needs are highly interconnected at the level of information management.

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