

Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care

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ABSTRACT

Adolescents with complex chronic illnesses, such as cancer and blood disorders, must partner with family and clinical caregivers to navigate risky procedures with life-altering implications, burdensome symptoms and lifelong treatments. Yet, there has been little investigation into how technology can support these partnerships. We conducted 38 in-depth interviews (15 with teenage adolescents with chronic forms of cancer and blood disorders, 15 with their parents, and eight with clinical caregivers) along with nine non-participant observations of clinical consultations to better understand common challenges and needs that could be supported through design. Participants faced challenges primarily concerning: 1) teens' limited participation in their care, 2) communicating emotionally-sensitive information, and 3) managing physical and emotional responses. We draw on these findings to propose design goals for sociotechnical systems to support teens in partnering in their care, highlighting the need for design to support gradually evolving partnerships in care.

Author Keywords

Families; Adolescents; Self-Management; Health Information Management; Personal Health; Chronic Illnesses

INTRODUCTION

Among teens, the burden of chronic illness is growing, as rates of cancer, diabetes, heart disease and other conditions are on the rise [49]. Chronic conditions, recognized by the Center for Disease Control and Prevention as a leading health concern for the nation, are still most common among older adults [57]. Yet, estimates of the number of adolescents in the U.S. suffering from *at least one* moderate or severe chronic condition recently reached 31% [64]. Even worse, many health care providers report that the complexity and range of health concerns in teenage adolescents

proves more challenging than for other age groups [50, 70]. Recent efforts to design technology to support patient participation in care [32, 39, 74], including efforts to improve personal health record (PHR) systems and patient portals show promise, but largely focus on ill adults [7]. Unanswered questions abound about the applicability of these efforts to younger patients as they represent a particularly vulnerable group with varying social, physical and cognitive abilities. For reasons that we describe in detail below, their involvement in care might be imperative one moment and unwise the next.

Recent computing interventions for chronically ill youth have demonstrated success with symptom recognition [78], promoting healthful physical activity [56, 75], and nutritional competency [29]. However, these efforts assume individualized health goals and view the patient as an independent user. We lack studies examining the role of technology to support *teenage adolescents' ongoing participation as partners in their healthcare*.

Research in this area is particularly important where it concerns complex chronic illnesses [22] (e.g., cancer [38, 71], sickle cell disease [11] and rare blood disorders [41]). People suffering from these forms of illnesses require special attention due to complicated, risky treatments and the unexpected nature of recurrence often leading to hospital readmission. Teenagers grappling with these illnesses face difficult transitions to adulthood [62], and their unique position as both dependent and emerging adult challenges the models of self-management and patient participation typically adopted in HCI research.

To gain a better understanding of common problems faced by teenage adolescents with complex chronic illnesses, we conducted a qualitative field study focused on three stakeholder groups. Informed by nine non-participant observations of clinical consultations, we conducted 38 semi-structured interviews across two pediatric health care settings: 15 interviews with adolescents with chronic forms of cancer and blood disorders, ages 13–17 (referred to henceforth as “teens”) along with 15 interviews with parents of these teens and eight interviews with participating clinical caregivers who treated patient participants and also routinely treat teens in the target group. Teens and parents faced

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challenges related to: 1) teens' limited participation in their care, 2) communicating emotionally-sensitive information, and 3) managing physical and emotional responses. Our findings allow us to distill goals for this group that can be addressed through design. In this paper, we:

- Characterize three primary challenges associated with teens' participation in the care of complex chronic illnesses.
- Examine the applicability of HCI research supporting chronic illness self-management to this group and identify opportunities to create teen partnerships with family and clinical caregivers.
- Discuss how technology can support these partnerships by outlining goals for the design of interventions to support teen involvement in their care.

BACKGROUND

We first provide background on the problem space by bringing in perspectives from health and social sciences related to teens' challenges in managing chronic illness. We then summarize the literature describing previous efforts to design technology for ill teens. In doing so, we apply the lens of self-management and related theoretical work to examine the applicability of existing HCI research to this group.

Participation in Care: Necessary but Difficult for Teens

There is now a growing consensus in the medical community that argues for the transformation of the "patient"—from a dependent recipient of care, to an activated participant [23, 28] who is a "whole person" with physical, psychological, social and emotional needs [8].

Teens' activation—and what it means for them to be whole—are complicated prospects. Their physical and psychosocial development vary. Yet, in the pediatric setting, clinical caregivers have limited means to assess the teens' level of psychosocial maturity. There is no clear clinical boundary that sets apart adolescence from adulthood since the patient's age does not reliably mark the progression of their transition to adulthood [60].

Young people often depend on proxy reporting of symptoms and experiences by parents and clinicians [48, 66]. Yet, parents and their children often differ in their assessments of function, behavior, and quality of life [18], place different importance on symptoms and their severity [62], and have different preferences for how they wish to receive medical information [65]. Unfortunately, teens also experience barriers to effective communication during clinical encounters: perceived attitude of the doctor, need for privacy, limited vocabulary or the presence of parents can inhibit discussions that could influence shared decision-making and plans of care [6, 80].

Often, pediatric practice does not even differentiate between childhood and adolescence [59] and the parent-clinician relationship is emphasized. Kientz found that even this relationship is often accompanied by tensions and ine-

qualities [34]. An unintended consequence of these dynamics is that the patient's role as a 'child' during care is perpetuated, while the parents' role as proxy is reinforced, contributing to the difficulties that adolescents face in assuming growing responsibility for their own health.

While there are ongoing efforts in the medical community to ease pediatric-to-adult care transitions, prior research has focused on broad systemic changes needed in healthcare delivery programs and resource management such as staff training and patient education [54] rather than on the role technology can play in supporting patients' participation in their care—an important gap that motivates our work.

Teens and Complex Chronic Illness

Complex chronic conditions, as defined in clinical studies [22], include a range of diseases that "can be reasonably expected to last at least 12 months and to involve either several different organ systems or one system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center" [22]. Recently, the HCI community has begun to address chronic illnesses that require special needs arising from such complexity [32, 38]. These forms of illnesses, such as cancer and sickle cell disease, have a cyclical nature—often characterized as having repeated cycles of recurrence and remission—even when patients are compliant in their therapies [9]. Their treatment regimens can include frequent blood transfusions, hormonal therapy, and chemotherapy, typically requiring the need to balance effectiveness of the dosage with side effects to the patient. Even when "under control" or in remission, follow-up and continued vigilance are necessary throughout one's lifetime [32].

For teens, these complexities prove especially challenging as their illness affects developmental processes and impacts psychosocial adjustment and quality of life [62]. For example, patients with a cancer diagnosis will typically go through different stages in their illness journey, starting from the initial diagnosis and onto treatment and survivorship, depending upon the recurrence of cancer [26]. As they are required to manage symptoms between visits, their normal daily routines and social roles (e.g., such as going to school and maintaining friendship) are re-established [38], while they are also expected to begin to develop health management skills. Cancer treatments can have a lasting impact on one's physical functioning and appearance, psychosocial wellbeing and other areas of health—with residual effects of chemo or radiation therapy manifesting years later [79].

Self-Management for Chronic Illness

Medical and social science communities alike recognize the importance of *self-management* of chronic illnesses: fostering one's ability to manage symptoms, navigate treatments and cope with the physical, psychosocial, and lifestyle changes they bring about [4]. Corbin and Strauss, guided by extensive ethnographic research with chronically ill pa-

tients, specified three sets of self-management tasks involved in living with a chronic illness: medical management, role management, and emotional management [16]. Lorig and Holman [40] and Schulman-Green et al. [63] further expanded on these task sets to identify categories of self-management processes for chronic illness, delineating a comprehensive list of associated skills. For example, chronically-ill people will need to learn to *focus on their illness needs* by monitoring symptoms, taking medications and making day-to-day decisions in response to their experiences, but they will also need to *activate* or effectively *utilize healthcare resources* by reporting accurately about the progression of disease, communicating with clinical caregivers and coordinating care services. In addition, they will need to *develop coping strategies* to deal with various aspects of living with the chronic illness. Our study investigates how we can support teens in partnering with family and clinical caregivers to perform such tasks.

RELATED WORK

Designing for Teens with Chronic Illness

A rich body of HCI research has offered insights into how technology can be designed to support self-management of prevalent forms of chronic conditions [29, 31, 41, 43, 56, 77]. Prior work focused on this goal either draws from theory (e.g., [14, 78]) or emphasizes the involvement of people in the design process (e.g., through user-centered and participatory-based design [45, 55]) with more and more attention being paid to bridging these two approaches [2, 27, 30]. Below, we discuss each approach further and highlight how each has been applied in efforts to design for adolescents.

Theory-based Approaches to Designing for Ill Teens

Behavior change theories feature prominently in self-management interventions aimed at modifying behavioral determinants of health over time. As such, they are well-suited to applications that promote self-management of behaviors to focus on illness needs, such as those related to diet [24], physical activities [13], and medication adherence [17]. While behavioral factors alone were neither the cause nor treatment for the illnesses we studied, it is reasonable to expect that acclimating to new responsibilities, such as recognizing problematic symptoms and administering one's own medications, has dramatic behavioral implications for teens.

Popular models of behavior change include the Transtheoretical Model (TTM), which characterizes an individual's readiness to change behaviors, defining the stages through which she can progress in modifying them and processes governing transitions between those stages [58]. While TTM can be useful in situations in which it is clear how to allocate someone to a stage, adolescents with complex chronic illnesses and their readiness to engage in behavior change is expected to be sporadic as they encounter unexpected illness experiences that are less controllable [9].

On the other hand, the Health Belief Model (HBM) posits that people's *beliefs* (with respect to the severity of their illness, perceived barriers and benefits of self-management) affect the way they behave [5]. Yun and Arriaga [78] advocate for the use of HBM in the design of interventions to increase awareness of symptoms and knowledge of disease process in adolescents, as it allows us to account for their *perceptions* rather than assuming a certain cognitive stage.

Both models have been used extensively in HCI research, but emphasize the individual rather than taking into account social influences such as peers and schooling that are unique to adolescent development. As such, peer-based social cognitive models of behavior such as social validation [12] and social comparison theory [21] have informed the design of persuasive systems for adolescents' health-related activities [46]. These models emphasize the tendency to assess one's abilities in relation to a social group to drive behavior change. For example, Chick Clique [68] made step counts of small groups of adolescent girls visible to each other to motivate physical activity. Other systems such as StepStream [47], AHPC [56] and iFitQuest [42] saw the benefits of school-based deployments as they can leverage existing social structures—rituals, space and time—to promote and sustain physical fitness.

While peer-based social models may work for adolescents who are similar to a target social group, teens with complex chronic illnesses are unlike peers in their existing social structures. They must balance large academic workloads with frequent hospital visits and other care activities. Their social and emotional well-being is challenged due to ongoing stress associated with diagnosis, treatment, social stigma and uncertainty about their future health status [62].

User-Centered Approaches to Designing for Ill Teens

While theories focus on outcome-driven processes mediating behavior, involving ill teens in the design process is critical to understanding their unique needs in various aspects of living with the illness. However, capturing design input from them poses challenges to researchers: the presence of clinicians and researchers can bias teens' reporting of their experiences and preferences [6].

Recognizing these challenges, Peyton and Poole introduced a participatory design research framework, inspired by 'reality TV', that advocates the use of participant-created videos to capture and share illness-related experiences with researchers, as a way to avoid biased responses [45]. Other work has approached this problem through cultural probes and dyadic interviews to mitigate the influence of the researcher [51].

Beyond the Self: Partners in Management

The "self" in self-management suggests a focus on the individual patient; however, the burden of self-management extends to family caregivers rather than the ill person alone [10, 61]. Chen et al. in particular cautioned that the HCI community has placed disproportionate emphasis on sup-

ID	Sex	Age	Disease (Stage of diagnosis/treatment)
T1	F	17	Alveolar Soft-Part Sarcoma (Remission)
T2	F	13	Ewing's Sarcoma (Neoadjuvant Chemotherapy)
T3	M	13	Osteosarcoma (Metastatic disease)
T4	F	17	Osteosarcoma (Neoadjuvant Chemotherapy)
T5	F	16	Alveolar Soft-Part Sarcoma (Remission)
T6	F	17	Clear cell sarcoma (Stage 4 Metastatic)
T7	F	15	Osteosarcoma (Remission)
T8	M	17	Metastatic Testicular Germ Cell (Remission)
T9	M	14	Giant Cell Tumor of Bone (Remission)
T10	M	17	Osteosarcoma (Remission)
T11	F	16	Juvenile Granulosa Cell Tumor (Remission)
T12	M	16	Germ Cell Tumor
T13	F	15	Chronic Idiopathic Thrombocytopenic Purpura
T14	F	13	Sickle Cell Disease
T15	F	14	Osteosarcoma, (Stage 2)

Table 1. Patient demographics and illnesses. Diagnosis and treatment are mainly categorized under therapy, remission, and metastatic stages. Patients in remission are off treatment and may not currently experience symptoms related to the illness. Metastatic cancer is cancer that has spread from the primary site to another part of the body.

porting the execution of caregiving tasks rather than the needs of caregivers themselves [10]. Ethnographic studies helped researchers understand conflicting demands and challenging experiences faced by family caregivers [36, 67, 76]. For example, in their study of bone marrow transplant caregivers, Kaziunas et al. found that, like patients, parents transitioning into the new role of caregivers experience inseparable information and emotion work in their actual caregiving [33]. In parallel, other studies have focused on caregivers' use of social media to better navigate complex information resources to suit their caregiving needs [1, 19].

Parents of ill teens face the typical demands of caregiving, while facing added challenges associated with supporting their teens' participation in care. Our study focuses on understanding both parents' and teens' experiences communicating about and managing health-related needs to better understand and respond to these challenges.

STUDY

Setting

With IRB approval, we conducted observations and semi-structured interviews with parents, teens, and clinicians recruited at Children's Healthcare of Atlanta (CHOA), in two Cancer and Blood Disorders Centers (one urban, one suburban). We recruited patients who were 13–17 years old, through convenience sampling guided by our inclusion and exclusion criteria and IRB-mandated clinician approval. Inclusion criteria included the mental capability to participate in the study (as determined by their oncologist), and the ability to speak English. Non-English-speaking patients, prisoners, and patients with a terminal diagnosis who would not be undergoing treatment or subsequent follow-up were excluded from participation in the study. Prior to the scheduled consultation, we obtained assent from patients, consent from their parents, and HIPAA authorization. Our study

ID	Role	Experience
C1	Physician (Fellow)	2 yrs
C2	Nurse Practitioner	< 5 yrs
C3	Primary Nurse	4 yrs
C4	Physician	4 yrs
C5	Child Life Specialist (Social Worker)	5 yrs
C6	Team Nurse	< 5 yrs
C7	Physician (Fellow)	3 yrs
C8	Physician	16 yrs

Table 2. Clinical caregiver demographics.

included teens with complex chronic illness for which frequent hospitalizations are common, routine diagnostic tests are needed to assess status and management, and treatment decisions involve the consideration of complex symptomatic experiences. Recruitment began in October 2014 and concluded when reaching data saturation in May 2015.

Interviews and Observations

We conducted 38 individual interviews: 15 with patients, 15 with their accompanying parent(s) and eight with clinical caregivers. For nine of the 15 patients, we also observed consultations to note behavioral patterns in the consultation room and contextualize interview responses. Consultations typically involved the reporting of diagnostic tests and an inquiry into patients' symptoms, such as pain levels and experiences with medication. They lasted approximately 15 minutes each, and researchers were present 5–10 minutes before they began (i.e., while patients and parents waited for the physician to arrive).

Interviews with teen patients and parents were conducted in private rooms or separated areas at CHOA: only the parent(s)—not their children or members of the care staff—were present during parent interviews, while only the teen was present during teen interviews. Interviews, conducted by two researchers (one in each room), were audio recorded, and took place after the scheduled consultation. Interviews with clinical caregivers were also audio-recorded and conducted individually. All interviews lasted approximately 30 minutes.

We kept interview topics consistent across the parents and patients while adapting specific question phrasing to each. Topics addressed 1) awareness of illness and diagnostic data, 2) experiences and challenges communicating about aspects of health at the clinic and at home, 3) teens' preferences related to the use of information technologies in their care (such as PHRs), and 4) whether and how commonly-available technologies were appropriated by parents and/or teens to support health management tasks. For clinical caregivers, topics addressed patients' and parents' participation in consultations and other care-related communication (e.g., electronic forms of communication with patients and parents). We also probed their experiences communicating diagnostic information with both patients and parents to learn their perspectives on the impact of computing systems on diagnostic reporting.

Participants

Teens

We conducted 15 interviews with teen patients (10 female). The majority were experiencing varying stages of cancer diagnosis and treatment (therapy, metastatic, or remission). One patient had a chronic form of Idiopathic Thrombocytopenic Purpura (ITP) and one had sickle cell disease. Table 1 provides details on patient demographics.

Parents

In addition to interviews with teens, we conducted in-depth, private interviews with parents of teen patients. Parents' ages ranged from 33–52 (mean=43). In ten cases of 15, the mother alone accompanied the teen and participated. In two cases, the father alone accompanied the teen and participated. In two other cases, both the mother and father participated. Finally, one aunt, who shared parental responsibilities for the teen, participated alone.

Clinical Caregivers

We conducted semi-structured interviews with clinical caregivers individually (details in Table 2). Participants included four physicians with varying levels of experience, two nurses, one nurse practitioner, and a child life specialist.

Analysis

Three researchers created observation notes through regular debriefings following fieldwork. After transcribing all interviews verbatim, we segmented responses by question-answer turn, cross-referencing clusters with observation notes. Together, we conducted affinity clustering with paper copies of the individual turns. We then applied a hybrid approach [20]: after inductive analysis yielding emergent clusters, we reconsidered as a group each cluster in a more deductive fashion. In this way, we together re-evaluated clusters based on our understanding of the domain and prior findings. This resulted in some refinements to cluster composition and resultant codes. Data analysis occurred in an iterative fashion from March 2015 to August 2015.

FINDINGS

We present combined data from both the interviews and observations when discussing themes resulting from our analysis. In reporting on findings, we refer to clinical caregivers with the label “C” and parents with the label “P” while teens are labeled “T” (e.g., C1, P2, and T2).

Teens' Limited Participation in Their Care

While we expected that power relationships between teens, their parents, and their physicians would influence communication about care management, we witnessed several examples of the specific influences of these dynamics on patients' reporting of their health status. Most physicians and nurses asked questions about the patient experience directly to the teen. Still, we observed behaviors indicating frequent deferral to the parent, such as looking to them when the teen was spoken to, speaking with hesitation, and waiting for parents to nod or otherwise give them permission. In

some cases, time constraints for parents, or perceived lack of time of clinicians, led to hurried consultations. In these cases, we witnessed more dominance by the parent, manifesting at times in interruption of the teen, and the taking of the teens' turn. Often, once the parent “took over,” the remaining portion of the medical consultation was tailored toward the parent.

When asked what they would do if they had a question about a health-related experience, nine out of 11 teens preferred to ask their parents first, before their doctor. Responses revealed two reasons why teens were hesitant to ask questions: previous experiences with explanations that they could not understand, and feeling as though they will not receive a comprehensive answer.

Some teens believed that their doctor perceived them as being unable to understand detailed explanations, and thus do not go into desired details. As T13 put it, “*Sometimes I tell my mom questions to ask them so that I don't have to ask them. [...] they don't want to explain everything to me because they think I won't get it. But if my mom asks a question they'll go into full detail. Because my mom has a strong personality so people usually explain everything to her.*” In contrast, T4 told us that she preferred asking her father questions because he spoke to her in ways that were easier to understand. She said, “*Mostly I don't pay attention because I can ask my dad. He explains it better. They [doctors] use too many big words and I don't know all of them, so I just wait 'til my dad tells me.*”

While the parents were responding to these preferences, as an unintentional consequence, teens often did not see a need to participate in clinical consultations. In fact, many parents worried that their teens deferred too much to them. P6 described an illustrative example of this, “*Like what you saw in there. Like how she always looks to me, and then I make her say something to whoever she has a question for.*” In contrast, T8 provided an illustrative example of the *other side* of this coin, “*I didn't ask too many questions because I knew they knew what they were doing and they definitely knew a lot more than I did.*”

Communicating Emotionally-Sensitive Information

The separate interviews revealed insights into how teens and parents handled emotionally-sensitive information. We present how they described preferences related to sensitive topics, as well as instances in which they each found the need to emotionally protect the other, which often resulted in “shielding” information.

Sensitive Topics

In many instances, teen patients and parents expressed the need for a private line of communication with their doctor. Some teens preferred to be seen by clinicians without the presence of their parents. We witnessed this with T3, who cited sexual topics as being the most challenging part of clinical communication. While he hesitated to discuss sex in front of his parents, he needed more clarification about

the long-term impact of his treatment on reproduction capability. T8 also preferred to have more private communication with clinicians, particularly concerning certain private parts of his body. As he stated, *"It's a lot easier when they [parents] leave the room. It's something about it's easier for me to talk personally to a stranger than it is to talk to somebody personally that I see everyday. Maybe I can just tell them my story and then never see them again. I guess that's what makes it easier."*

Shielding Information

In other cases, we saw that teens and parents needed a private communication channel for instances typically motivated by the desire to protect one another from emotional distress. Teens shielding information typically manifested as hiding symptoms from parents, not wanting to surprise or worry their parent, and not wanting to delay the parent. T7 expressed this concern, saying that he was hesitant to share details of pain or symptom that he is experiencing. He told us, *"I'll talk to my mom about my health, but only to tell her if I have a new pain or something in my leg. Then I'll be like, 'hey it hurts right here', and she'll say 'how does it feel?' like 'from 1-10', 'do you need medicine?' But like if I want to go into detail. I'll just look it up or see how this pain goes. I don't want to worry her with my problems because I know she'll go insane"*

T13 was protective of both her mother's time and mood, and was cautious not to cause her mom extra work noting that, *"We have to do a lot of extra steps because I'm older I guess [...] She cried a couple times so I feel bad."*

Parents similarly indicated a need for privacy, though the motivations behind it have some variation. Some parents were trying to avoid upsetting their children, hiding the results of a concerning MRI from them, for example, until time had passed and there was a more positive update. A physician, C1, helped to clarify why: *"The first conversation that we usually have with parents, when even we don't know what's going on [...] a lot of parents request we don't let the child know, and I think that's very legitimate because at that point no one knows what's going on, we don't know what it's coming out to be, we don't know what the prognosis is going to be like, we don't know what treatment he's going to get. But once the child is diagnosed, we really stress out that families should talk to their children, and we also talk to them."*

However, at times this approach conflicted with the teen's preferences and information needs. For example, T15 believed that understanding the potential consequences of a treatment could help her better prepare for the next step in her care. She explained, *"After that biopsy, my mom didn't tell me and I guess like, everybody else knew except me [...] I don't want anything held back [...] I really want to know what could be bad because that's how I prepare myself. Like this time, with the surgery, since everything is so close to my nerves, if I come out of surgery without a leg.. I want to be prepared for that. My mom's more like, 'let's just*

think positive'. But for me, I can't. Through all this, I just can't."

Managing Physical and Emotional Experiences

Uncertainty in the patient's health status and progression of disease led to increased tensions among teens, parents, and clinical caregivers. Specifically, difficulty in understanding and communicating about the patient's subjective experience (e.g., symptoms, pain level, etc.) seemed to amplify these tensions.

Understanding the Patient Experience

For many parents, talking about teens' experiences was the most challenging part of the communication with physicians. A cancer survivor, P4 lamented on her inability to sympathize with her child's painful experience while receiving chemotherapy, stating, *"It's difficult because all chemo is not the same ... I had like bumble bees stinging me from the top of my head all the way to my toes. She doesn't go through that. So it's kind of hard for me to know. I know she's going through something, but I just don't know what it is."* Seeing that even a previous cancer patient who underwent a similar treatment regimen is struggling to understand her child's experience shows the extent to which parents lack the means to fully ascertain the impact of chronic illness on the patient.

As a common reaction to this struggle, most parents had a persistent desire to probe their child's experiences. Yet patients often complained about inquiries into their physical or emotional state. T8, though he appreciated his parents' concern, tired of questions such as 'how are you feeling?' remarked, *"A lot of times I really don't want to talk to them about how I'm doing. The biggest question I hated being asked is, 'are you okay?' or 'how are you feeling?' I'm feeling fine until you come here asking me all these questions. I mean they want to know and I appreciated it, but if I've got a problem then I'm not afraid to tell anybody."*

C5, a child life specialist¹, shared her thoughts on how and why "prompting" teens every time with questions about their status was not effective. She told us, *"...in terms of sharing how they're feeling about things, that's gonna come in a conversation that's completely unrelated to kids having cancer [...] a lot of times teenagers are so over hearing, 'how are you doing?' or 'how are you coping with everything?' [...] I think the key is not to push it, and it does come out, just in a different way than it does with some of the younger kids who are a little more forthcoming with how they're feeling about things."*

Conflicting Interpretations

Limited means for understanding and empathizing with the patient's symptomatic experience often resulted in conflicting views between patients and their parents when com-

¹ Child life specialists are child development experts who work together with doctors, nurses, and other clinical caregivers. They work to assess and meet the emotional, developmental and cultural needs of each child and family.

municating the patient's experience to the doctor. We both witnessed and heard several accounts of teen patients assigning different levels of severity to what might be a symptom. As T5 remarked, "*Sometimes she doesn't really understand, like how I had a fever like a week ago and she was exaggerating about stuff and I was like it wasn't that bad, so sometimes I don't want her to talk because she'll totally make it a bigger deal than it is.*"

In these cases, parents require a means of discussing care with the care team without the child present. In fact, P5 took T5's experience to be more serious and addressed this concern to the doctor during the consultation. "*Now I can't say this is front of her because she gets mad, but she's been complaining a lot about her head being dizzy...anytime I say anything she's like "Stop complaining, Mom!" but she really does it at home.*" Such differing interpretations about the patient's subjective experience have the potential to influence the doctor's decision-making process toward the patient's treatment. Interestingly, we observed that these differences motivated teens to perceive electronic forms of medical records as a way to *resolve disputes or conflicting interpretations* over the patient's experience and health status. When asked why access to the patient portal might be useful, T8 commented that, "*That way we don't have to question or argue about anything that has happened. All we have to do is look.*"

Perspectives on the Role of Computing Technology

Both teens and parents were optimistic about the role of computing technology—such as electronic health records—in their care. When asked if they desired access to electronic medical record data, teens' and parents' views aligned: all parents in our study valued access to the electronic health record, while 12 of the 15 teens indicated that they desired the ability to see *more* of the information in their record and two of the remaining three commenting instead on the importance of electronic care plans and notifications detailing how to prepare for clinical visits.

For both teens and parents, reasons for desiring access to this data included the ability to *share health information in future care scenarios*, and to *make sense of the diagnosis and treatment progress*. In the following sections we explore these desires and bring in clinicians' perspectives on access to patient data.

Making Sense of Diagnosis and Treatment Progress

For patients in our study, the results of diagnostic tests, such as radiology scans of the site of osteosarcoma treatment, or lab results such as the white blood cell count, served to enhance their awareness of the diagnosis. Both teens and parents commented on their desire to access diagnostic data—for both review with clinicians as well as for personal archive and review.

In particular, radiology scans served as a powerful way to relate data back to the teens' physical experience. As T10 explained, "*[The scans] make me feel a little bit like I'm in*

there. I can see the tumor they point out in my body, so I can see what's wrong with me so they don't have to tell me in some weird way." These sentiments were echoed by T4, who remarked that he desired ongoing access to his radiology imaging data, "*the MRI—to see what they see—so I could better understand it.*"

Teens often commented on the value of visual information as a compelling medium for resolving certain aspects of uncertainty in their care. Several saw the utility of visual information in the context of understanding their illness and preparing for treatment or surgery. T13, when explaining her favorite doctor, commented that, "*she will be like, [this is] what's gonna happen inside my body—but it would be somewhere else. So I can picture it actually happening somewhere else. And sometimes she would draw something out [...] to answer questions about it.*"

In addition to the role that radiology scans serve as diagnostic data, they are also taken as salient signs of treatment progress. While it is not uncommon for patients and parents to experience some degree of uncertainty, photographic data was often used in evaluating progress.

Both teens and parents expressed a strong desire for having access to visual signs of progress of the care such as X-rays and MRI scans. P4 saw the need to access the scans to determine whether a treatment has been effective, commenting that, "*When they do an MRI on my daughter, I just like to see what they see. The first time I had to ask them. But I want to see after the chemo, that it [tumor] would disappear... So that's a big relief to see, the progress of what's going on.*" While T5 shared that, "*[I] want to see how my platelets have gotten better over time [...] how my MRIs have changed over time: how they were at the very beginning and how they are now—that would be interesting to me.*"

Teens were interested in how specific data types changed over time as well as when events unfolded over the course of treatment. As T5 illustrated, "*When I had my first round of chemo; It would have when I started [...] how much weight I lost maybe, and how they had to do blood infusions and all that stuff after that. I want to see that.*"

Clinicians' Perspectives

Despite teens' and parents' favorable view toward electronic health data however, a deeper analysis of our findings revealed that clinical caregivers' views related to the availability of this data differed from those of teens and parents. While the patients and parents appreciated having access to these records, care providers on the front line of delivering scanned images cautioned that automatic release of electronic copies is concerning.

Two nurses that we interviewed expressed concerns especially with regards to delivering the 'bad news'. They warned that scans, although seemingly intuitive, could be misleading at times and require careful reviewing of radiologists and oncologists. Both agreed that unless they indicate

signs of improvement, scans should not be released automatically and electronically to the patient and family members. Instead, they preferred that the information is communicated verbally via face-to-face or over a phone call prior to the release. Primary nurse, C3, remarked, *“I don't have a problem with them having the information after we've discussed it, but to me the worst thing that can happen is have a parent go in, and read a scan and it's a Friday night, and you're not gonna be able to talk to anyone on your regular team until Monday. [...] So be able to start that discussion so the parents have a time to process that.”*

Appropriating Commonly-Available Technologies

We were interested in exploring how families adopted commonly-available technologies to support health-management needs (e.g., internet search, online social networks). The most commonly appropriated technology was Internet search. Teens explained that they searched online during and after their initial diagnosis. Many searched for images online to help them prepare for a procedure or side effects of surgery. T15, an osteosarcoma patient, described that she searched for images to help her prepare for surgery on her leg. *“Pictures—like what the surgery is...I've just mostly been preparing myself—what I've done is preparing myself.”*

While we anticipated that teens might look for others like them on the Internet to evaluate their situation, we found that they set strong boundaries around sharing health-related information online. Teens were also specific about whom they would be interested in reading about. The treatment process can vary widely depending on what a patient is diagnosed with, and patients are not as interested in learning about or talking to patients who have gone through different illnesses. As T7 responded, *“I don't wanna hear from a 26 year old that everything's gonna be okay, who had a different cancer than me.”*

DISCUSSION

Both teens and parents in our study deal with the burdensome effects of illness while facing challenges unique to their situation. In this section, we discuss both the opportunities and complexities associated with our findings, drawing particular attention to the nuances we found that challenge typical models of self-management and patient participation. Finally, we highlight implications for the design of sociotechnical systems to address the opportunities we see.

Ownership of Health Needs

In Corbin and Strauss' [15] view—and in the view taken in subsequent work to operationalize management of chronic illness [40, 63]—the successful navigation of health management processes is achieved through mastery of a number of skills (e.g., taking medication, reducing stress, keeping appointments). Skills are acquired in service of self-management. Yet, the teens in our study are in need of both parental care and, simultaneously, experiences of autonomy. At times, they were incapable of representing their interests in communication with their physicians and parents

played a central role. At other times, the teens' lack of privacy inhibited their communication with physicians.

We can expect that teens will experience varying degrees of psychosocial and physical maturity and varying close relationships with their clinical caregivers and parents. Thus, we believe that designing with a view toward mastery of skills for *eventual* self-management can best guide efforts to this group.

Teens with complex chronic illnesses will likely acquire self-management skills more from parents or others who have navigated the experience, rather than from their peer group. Bandura's concept of observational learning [3] aligns with the navigation of health care we witnessed. According to Bandura, observational learning describes a form of role-model-based learning through observing the behavior performed by others and the outcomes that follow. In both the care and home settings of teens with complex chronic illnesses, parents are most likely to assume the role of a model as they directly set an example for communicating with clinical caregivers, navigating the healthcare system, and attending to illness needs. Thus, parents acting as representatives of these teens can be a necessary and important part of teens' acquiring health-management skills.

At the same time, parental involvement *alone* is problematic: while parents can ideally serve as a model for self-management skills, they themselves lack firsthand physical experience of the illness. Teens' participation in their care is essential; yet, as we witnessed in our study, parents often lacked knowledge and means to understand how to support teens' participation. To avoid an abrupt transition to adult care, teens' ability to practice management skills is essential [62]. Supporting eventual self-management for chronically ill teens means strengthening partnerships between parents and teens that allow *a gradual and dynamic process through which teens can learn to take ownership of health-management needs.*

As an overarching goal, we recommend that designers of sociotechnical systems aim to support both teens and parents to *acclimate to the role of partner in the teens' care.* Below, we highlight two particular areas in which we see opportunities for design to better support this goal.

Recognizing and Managing Body Responses

Recognizing when physical responses are present in the body has significant importance for patients especially undergoing long-term treatment cycles such as chemotherapy for which their successful recovery will largely depend on the careful balance between the effectiveness of treatment dosage and its toxicity to the patient. For most teens in our study, parents were predominantly in charge of tracking the patient's symptomatic experience and reporting them to clinical caregivers either remotely or during consultations with the doctor. We saw that parents had difficulty understanding the teen's experience at home while going through

chemotherapy treatment (as in the case of T5 and P5) and this led to discrepant interpretations about the patient experience and increased tensions between them.

While previous studies point to the lack of objectivity in proxy-reported health outcomes, proxy reporting by parents is still most common [66]. Teens' assessments and reporting on symptoms can differ qualitatively from their parents', yet our findings show that patients are less prone to raise health concerns directly to their doctors. We also found that, in a conscious effort not to worry the parents, some teens engaged in self-censorship of the symptom severity as they are reporting their experiences to the parents, and would independently decide to raise a health concern only when they felt it became alarming. One concern is that this degree of separation in doctor-patient communication can result in lower care quality as such care is based on approximations of the patient's health.

We recommend that future computing systems accommodate patient- and parent-reported assessments of symptomatic experiences and reconciliation of these assessments during long-term therapies. MacLeod et al. envisioned leveraging similar technology to capture symptoms to provide "evidence" to doctors to aid diagnostic processes [41]—in our case, the role of patient- and parent-reported data, collected in tandem, may contribute to better-informed decision-making after a diagnosis, based on richer data allowing for teens' input. For instance, doctors can consider regularly collected data; patients and parents can point to specific events of concern and provide clinicians with more context when needed.

How to design both the data collection experiences as well as the techniques for reviewing these data—suitable for *teens* in this scenario—is an important area for future work. Hartzler and colleagues have recently demonstrated the feasibility of incorporating patient-reported data into prostate cancer care, through dashboards reviewed collaboratively during consultations [25]. Patel et al. showed that real-time tracking tools for patient-collected data improved psychosocial comfort and symptom communication with clinicians [52]. This work provides starting points on which we can build to explore how a similar interface could be designed for teens and parents to review patient-collected data with physicians. Emerging methods for capturing patient experiences such as symptom severity [52], site of pain or representations of subjective experiences [33] and employing feedback mechanisms [35] to enhance awareness of health status show promise.

The act of collecting assessments periodically can encourage reflective activities, which have the potential to instill agency in health management. Self-reflection has been a proposed mechanism for helping the individual understand more about their behavior and adjust that behavior in response [14]. An important design consideration is that many technologies are designed based on "probe" methods to ask about the patient experience. It is unclear whether

teens will respond to these if they don't respond to the spoken equivalent: teens particularly disliked being probed directly about their symptomatic experiences and emotional well-being from their parents.

Our interviews with the Child Life Specialist (CLS) revealed valuable insights about how to encourage teen patients to talk about their health concerns such as, at times, steering the conversation to a topic unrelated to health. More studies are needed to understand these communication strategies, as teens tend to express their feelings in ways that are different from adults. A promising means to better account for these differences includes the **involvement of experts such as CLS's in the user-centered design process, in addition to the typical stakeholders we tend to include (historically, patients, family and clinical caregivers)** as they better understand the delicate communication needs of these teens.

Activating Health-Related Resources

Teens will need to learn how to effectively utilize the health management resources available to them, including non-clinical experts, clinical caregivers in addition to electronic forms of health data.

Connecting with a Community of Experts

Online social communities supporting the connection of patients to others with experience and knowledge (but who are neither clinicians nor caregivers) could potentially satisfy teens' information needs while also potentially reducing the burden on parents to act alone as role models for the teen. However, some teens in our study were not interested in the experiences of older adults—even a decade older. This poses challenges to designers of applications to connect patients with others who have already overcome similar experiences. This suggests that **basing these connections not only on condition but on skill-attainment goals** can allow teens to connect with others that they can relate to as peers, based on learned or desired skills, while easing the burden on a family caregiver to serve as role model alone. The "social scaffolding" approach holds promise as a learning environment on which to base a similar application. For example, MAHI [44] supported newly diagnosed diabetics in obtaining self-management skills by connecting them with diabetes educators who could provide personalized guidance.

Augmenting Clinical Consultations

As evidenced by the permission seeking we witnessed in the exam room, teens seemed hesitant to consider themselves an authority on their own experiences and needs. While doctors and other clinical caregivers were inclined to address important concerns to patients, they often did not tailor explanations to the patient's literacy level. Parents were entrusted—and expected—to encode important care information as teens had difficulty understanding medical terminology and plans. Sometimes, parents would unknowingly dominate the conversation as a result. These instances altogether suggest that teens, parents and doctors could be

lacking a general awareness of their own actions or beliefs that may interfere with the teen’s ability to participate.

We recommend enhancing the situational awareness in clinical environments through the inclusion of cues to action to allow multiple-stakeholder engagement. Multimodal interfaces [73] aimed at detecting nonverbal cues such as gesture and gaze orientation (e.g., teen turning head to parent) in the consultation room show promise because they allow for the capturing of data that could be used in modeling of appropriate moments for providing feedback to effectively inform each stakeholder about their behavior. For example, doctors can be notified during or after the consultation if they are found to talk more to parents than the patient. Of course, technology deployments in clinical consultations could introduce unwanted interruptions as each stakeholder engages in discussions that may have serious implications for the teen’s future health outcomes. While more studies are needed to explore the varied effects of feedback mechanisms on the quality of clinical consultations and acceptability of individual stakeholders, recent studies demonstrate this form of interaction is promising: Patel et al. found that clinicians had favorable attitudes toward reflective visual feedback that provided awareness of their nonverbal communication [53].

Augmenting Personal Health Records

Teens with complex chronic illness will undergo frequent hospitalizations and complicated therapies and electronic health record systems feature prominently in illness management and care. However, personal health records (PHR) systems are currently “one size fits all”—the experience is not different between the parent and adolescent user [7]. As most teenagers have limited prior experience with technologies that report on their personal health data, they must grapple with issues of data privacy, health literacy and emotional preparedness.

We found that medical terminology and teens’ limited health literacy presented barriers to their ability to effectively communicate with doctors. These language barriers can similarly transfer to their use of PHRs [37]. Teens favored radiology scans as they allowed for a familiar yet concrete means to make sense of the illness and evaluate the progress of treatment over time. T13 told us that her favorite clinical caregivers used drawings to communicate with her. Realizing teens’ strong preference [72] for using abstracted representations of medical information in making sense of their illness experience, we recommend that personal health records made available to teens **embody techniques to vary the level-of-detail of information and apply appropriate timing, linguistic framing and graphical rendering to these data to make their presentation meaningful.**

At times, making medical data more accessible to teens can also mean that there will be unintended consequences that are not in their favor. While electronic forms of health records prioritize the delivery of strictly medical data such as radiology scans and lab results, it is important to realize that

teens with chronic conditions are a particularly vulnerable group. As C3 cautions, data that carries any potential for emotional impact needs to be consulted with doctors before its release. However once released, teens will still need to be prepared to understand and process the information that they see. Teens might not only be vulnerable to upsetting medical data, but also while managing symptoms and emotions as they are going through multiple treatment cycles. Capturing and assessing the teen’s affective state during this period can help inform system designers to generate more personalized and context-sensitive resources. Work in this direction includes an early prototype of a teen-specific PHR that incorporates new types of information into the teens’ health record, including information on mood, peer interactions, aspirations, and goals [51].

LIMITATIONS

Our study has limitations. Like many qualitative studies, we included a relatively small number of participants. Also, we only focus on cancer and blood related disorders in our framing of complex chronic illnesses. Our presence as researchers could have affected certain observed participant behavior or responses during consultations and individual interviews. Finally, while findings of our study may not adequately generalize to a wider population, we expect that knowledge derived from our study can be transferable [69] to similar contexts or situations involving chronically-ill teens and their parents.

CONCLUSIONS

Teenagers grappling with complex chronic illnesses represent a particularly vulnerable population facing difficult transitions from pediatric to adult care. Our study identifies opportunities for teens and parents to develop gradually-evolving partnerships to promote their eventual self-management. First, we discussed the applicability of existing HCI research supporting chronic illness self-management. We then characterized challenges associated with teens’ participation in the care concerning specific complex chronic illnesses, including pediatric cancers and blood disorders. Finally, we discussed opportunities for HCI research to address these challenges by outlining a research agenda along with specific recommendations for the design of future sociotechnical systems to better support teens’ increased participation in their care.

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