

Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers

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ABSTRACT

Adolescents with chronic conditions must work with family caregivers to manage their illness experiences. To explore how technology can support collaborative documentation of these experiences, we designed and distributed a paper diary probe kit in a two-week field deployment with 12 adolescent-parent dyads (24 participants). Three insights emerged from the study that highlight how technology can support shared illness management: 1) provide scaffolds to recognize physical and emotional experiences in the context of daily activities; 2) help families reconstruct patient experiences; and 3) adapt to individual preferences for capturing, representing and sharing experiences. We discuss opportunities for HCI research that follow from these findings and conclude by reflecting on the benefits and limitations of using diary probes with adolescent patients and their parental caregivers.

Author Keywords

Family Informatics; Health; Diary Studies; Probes; Chronic Illness; Adolescents; Family-Centered Design, Co-Design

CCS Concepts

•Human-centered computing → Empirical studies in HCI;

INTRODUCTION

Over 10% of the adolescent population in western countries live with at least one activity-limiting chronic condition [28, 54, 84]. In addition to the negative effects of illness, chronic conditions can interfere with self-perception, emotion regulation, and one's capacity to engage in social activities [17, 66]. An additional burden of chronic illness is that young patients need to maintain awareness of their health by reflecting on



Figure 1. Diary probe kit used in our study. Participating patient-parent dyads received two kits to use for data entry, for up to two weeks. Each kit contained two weekly diary booklets, sticker sheets, markers and pencils, a self-addressed, stamped envelope, and an optional camera.

their physical, emotional, mental, and social experiences, and communicate these experiences to their formal and informal caregivers [54, 76].

Family members provide the daily setting for illness management—they often take active roles in supporting everyday activities. Indeed, family support is linked to better illness management and health outcomes [65]. On the other hand, family members also struggle to elicit emotionally-sensitive and difficult illness experiences from those they care for [83, 36, 74].

Cultivating an understanding of young patients' first-person, lived experiences poses several challenges to researchers [60, 6]. Young patients are still developing both the physical awareness and conversational skills required to articulate new sensations and emotions [35]. This leads to a number of challenges when involving people in collaborative design [12, 81]. First, it is not clear how much the researcher should dictate the course of a design activity. A second issue is mitigating the

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effect that the presence of authority figures (e.g., parents) pose to designing artifacts that are patient-centered.

Methods that incorporate elements of co-design [23, 34, 56, 35] and probes [71, 22] show promise in engaging youth in design activities. We drew from these methods to explore how to support adolescent patient–parent dyads in documenting their daily experiences throughout routine treatment regimens. We designed and distributed paper diary kits as probes to collect *in-situ* observational data from both the patient and their parents in natural settings. We used daily text messaging prompts to encourage participants’ use of various media technologies in conjunction with the diary. We subsequently interviewed patients and parents to understand their experiences appropriating the probes.

In this paper, we describe the design and deployment of a diary probe kit (Fig. 1) with 24 participants (representing 12 adolescent–parent dyads). Each adolescent was 12–18 years of age and had a chronic illness. In each dyad, both the patient and a parent kept individual diaries, in parallel, for at least two weeks. Six of these dyads included a child with cancer; the other six, a child with lupus. We focused on cancer and lupus patients because they are most likely to experience the benefits of reporting on their daily experiences during treatment and between visits to the doctor’s office [29].

In this paper, we contribute:

- A characterization of how patients and parents appropriated diary probes to document and communicate their illness experiences.
- Insights into how technology can support shared illness management for adolescents with chronic conditions: 1) provide scaffolds to recognize physical and emotional experiences in the context of daily activities; 2) help families reconstruct patient experiences; and 3) adapt to individual preferences for capturing, representing and sharing experiences.
- Discussion of the benefits and limitations of using diary probes with adolescent patients and their parents, and the opportunities for HCI research that follow.

DESIGN CONTEXT: PEDIATRIC CANCERS AND LUPUS

Cancer and lupus (a type of rheumatic autoimmune disease) are chronic conditions that severely limit pediatric patients’ everyday activities and overall quality of life [28]. Once diagnosis is confirmed, treatment for these conditions is expected to progress in a non-linear fashion, with repeated cycles of therapy, doctor’s visits, and remission or recurrence. For cancer care, each chemotherapy cycle consists of an outpatient or inpatient treatment visit (lasting one to five days), followed by two to four weeks of recovery at home. Patients may receive up to fourteen chemotherapy cycles according to established standard practice of care. Treatment regimens for lupus vary by individual patients, but usually require long-term monitoring with bi-weekly to monthly visits to the clinic.

Not all treatments for these conditions lead to positive outcomes, and patients need to manage difficult side effects of the treatment. For example, antimetabolite drugs—commonly

used in both cancer and lupus treatment—cause dizziness, fatigue, headache, mouth ulcers, and decreased appetite [52]. During each clinic visit, clinicians often rely on parents’ verbal reports to make an informed decision about the type of medication and dosage that is needed to counter the harmful effects of treatment. Yet these reports are susceptible to recall and observer bias.

While adolescent patients lack the needed skills to recognize, recall, and articulate their experience, parents lack the firsthand experience of the illness [36]. Hence, deferring to the parent alone would lead to an incomplete assessment of the patient’s health. For example, prior studies [45, 53] highlight significant discrepancies between patient and caregiver-reported symptoms in the clinic. Such biases can compromise clinicians’ decision-making, and patients’ ability to receive the best care.

Our study is motivated by this important gap. We designed our diary to understand how to best support cancer and lupus patients during a recurring, two-week treatment and recovery period. Designing for this critical period is important yet challenging, as clinicians require intensive monitoring and vigilance between each clinic visit.

RELATED WORK

Family health informatics

The CHI community has seen increased awareness of the role of families in shaping health behaviors, as well as concern for the burden of informal caregiving [15]. For example, the personal informatics field within HCI has seen a shift away from “self-tracking” toward family-oriented tracking, as there is a need for design to promote family health and distribute the work of tracking health information [59].

Work in family informatics has explored the benefits of using tracking tools to encourage positive family communication about health, while leveraging existing family routines [32, 67, 47]. Overlapping daily routines (e.g., dinner) among family members provide opportunities to set goals, raise awareness, and reflect upon health data [32]. Furthermore, journaling meals that are eaten apart can provide more value to families than those eaten together, suggesting an opportunity for journaling tools to complement, rather than compete, with family interactions [47]. However, dynamically changing treatment regimens are common barriers that interfere with family routines and patient involvement in illness management [69], requiring new approaches to design.

In addition, when patients’ privacy is at stake, sharing sensitive health information among family members can lead to negative feelings of surveillance and violation of trust [83]. For example, blood glucose monitoring technology can create tensions for adolescent diabetes patients when parents attempt to regularly “check in” with them based on their use of the technology [74]. On the other hand, sharing tracked data can help families avoid conflict while giving them space to indirectly discuss problems, thereby helping caregivers to initiate emotionally-sensitive discussions about depression with care recipients [83].

Our work expands on these studies and explores how patients and parents appropriated a diary probe to document and communicate about the patient's illness experiences during complex treatment regimens.

Health-focused collaborative design with families

Collaborative design studies with youth and their family members have made many types of contributions to HCI. Participatory [57] and co-design [25] approaches enabled researchers to elicit different perspectives on a design problem [78, 39] and co-produce prototype concepts [55, 33, 25]. Some studies found that the act of collaborative design supports development of empathy [79] and inspires changes in adolescent-parent communicative practices [78].

Collaborative design with young patients brings new considerations to the fore, as the act of design can affect the participant designers' well-being [49]. While some studies found that collaborative design can be empowering for youth participants [19], it can in fact be challenging to assess its actual benefits [26, 12]. Well-being considerations are especially important for youth who are grappling with the social, physical and cognitive challenges of illness [54]. These challenges bring about complex communication needs [36].

For people with complex communication needs, collaborative design activities can be a sensitizing experience as they can introduce new vulnerabilities for participants, and tensions in how researchers navigate power relationships [43]. In fact, cultivating a balanced design partnership with adult and child participants is a key ethical issue in participatory design with youth [51, 85].

When designing for and with ill children, these child-adult relationships are often patient-caregiver relationships, and navigating them can be particularly challenging. Berry and colleagues, while not looking specifically at young patients, found that care recipients can have different values from those of their care team [7]. In fact, we have only recently begun to address barriers to communication about patients' values [8].

Hong et al. [35] explored how co-design can mitigate patient-caregiver tensions, creating artifacts with adolescents and parents. In Miller et al.'s [55] work to design inpatient communication tools with hospitalized children, the authors highlighted the importance of incorporating first-person perspectives of patients' illness and care in the design process.

Such researcher-led design sessions can help guide creative activities. However, at a design workshop or interview, participants are often removed from immediate context and rely on memory of meaningful events. Furthermore, the presence of authority figures can discourage candid responses from adolescent participants [60]. For care situations that span daily life, there is a need to enable design processes to be incorporated into everyday contexts.

Probes for everyday health management

Over the past two decades, HCI researchers have adapted various versions of Gaver's Cultural Probes [27] to inform the design of new technology applications, or inspire new design opportunities in everyday contexts [10, 38].

Using probes for data collection and design allows participants to acquire and reflect on aspects of daily life that might not otherwise be accessible to researchers. Probes can also facilitate privacy by allowing participant control over which data they want to share with researchers [10]. For this reason, they are often used in design research in personal settings [21] (e.g., family communication in distributed homes [38], financially depressed communities [22], and chronic condition management [77, 48]).

While probes are often designed as a "packet" to be deployed in an everyday setting, they can also encompass diary studies [11] and longitudinal user studies supported by the increasing ubiquity of mobile devices [10]. In a foundational media elicitation study, photos best elicited participants' recall of people and locations related to important events in their lives [14]. Subsequent mobile photo-elicitation studies successfully adapted the diary study method for self-reporting of everyday health-related experiences, including foods eaten [20, 48], emotions [70], and physical activity tracking [30, 31].

We aimed to understand the affordances of various media formats, such as photo and video, combined with sketching and journaling, to support patients in capturing and reflecting on their daily illness experiences.

DIARY PROBE DESIGN

Our study sought an understanding of patients' and parents' illness experiences and related daily activities during the treatment period. This is in sharp contrast to studies that focus on the patient alone. Including the parent's perspective underscores that health behaviors and experiences of family members are intertwined [16, 59, 9].

We provided multiple diaries in two kits, for both the child and a parent, to allow families to appropriate them as they chose.

Our diary design draws on three goals: 1) provide scaffolds to reduce cognitive and physical burden in supporting reconstruction of experiences; 2) allow participants to document representations of varying experiences in personally meaningful ways and with maximum flexibility; and 3) prompt reflection through momentary engagement with medium probes. Below, we elaborate on how these goals drive our design decisions.

HCI studies informing the diary design

We designed our diaries based on insights from HCI studies, comprising storyboard, pictograms, paper diaries and probes.

Storyboarding [35, 34, 56]: Co-design studies have found that storyboard-based scaffolding techniques can be used to elicit daily experiences and difficult concepts for children. Hong and colleagues [35] adapted storyboarding techniques inspired by comic-boarding [34, 56, 63] to elicit context from adolescent patients who articulated their illness experiences during co-design sessions. Their study design choices accounted for the emotional sensitivity of the subject matter and the need to provide visual "scaffolds" (in their case, pre-created artifacts) to go along with free-form sketching. To support participants in composing narratives, we incorporated a storyboard-based diary template consisting of multiple panels as a vertical timeline (Fig. 2).

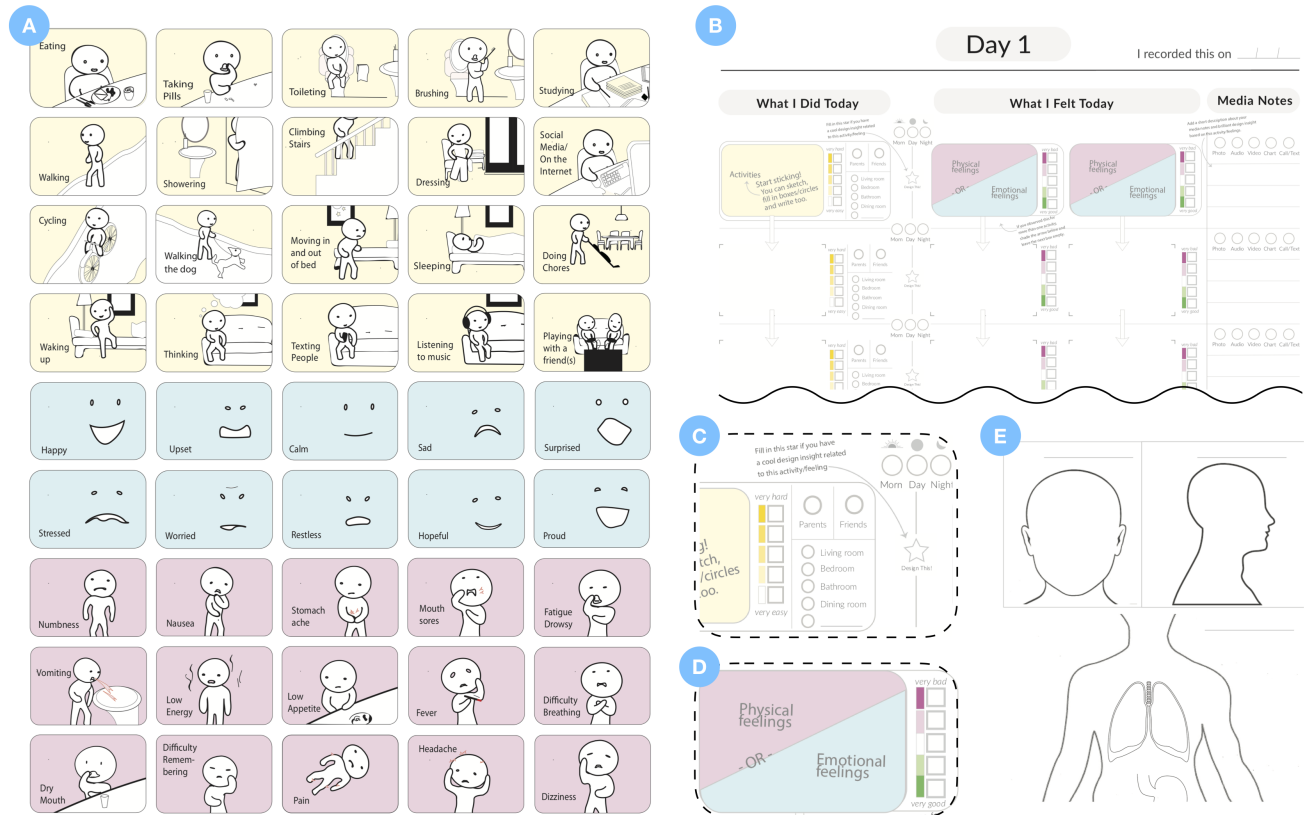


Figure 2. Features of the diary booklet. A: Experience sticker sheet contains representative pictograms of common activities (yellow), emotions (blue), and physical symptoms (pink); B: Daily entry template encourages participants to create a story of their day by placing experience stickers in respective columns (marked by matching color) in chronological order; C and D: Multiple response options enable participants to evaluate experiences, time of day, social context and location ; E: Outline of body diagrams are provided to scaffold sketching activities.

Pictograms [37, 72, 40, 73, 44]: Medical research shows that pictographic representations of health indicators can improve patient comprehension, particularly for those with limited literacy. They can also improve recall and adherence to medical instructions, as well as symptom expression, in ways that are consistent with existing clinically-validated measures [72]. We created a set of pictograms based on Visual ODLs [35] to help participants quickly identify activities and symptoms. Our goal was to support recognition of past activities and experiences, and use them as basic building blocks to construct daily narratives.

Paper diaries [5, 80, 82]: While digital diaries offer efficient reminders and sensing capabilities, *in situ*, recent studies have revisited the benefits of paper. Paper diaries can accommodate changing situations and needs. Paper provides the flexibility to customize representations of different types of experiences, while enabling reflection through easy entry review [5]. People with cognitive and motor disabilities were found to benefit from paper diaries over more advanced technologies: they built on people’s familiarity, enabled implicit reminders, and allowed for friction-free set-up and deployment [80].

Probes [10, 27, 38]: Rather than asking participants to create “copies of reality”, we looked to DiSalvo and Roshan’s concept of *medium probes* [22]. We examined whether participants

used different media to respond to prompts, without collecting their private responses (e.g., private photos). Our protocol asked participants to reflect upon their experiences using existing media technologies (i.e., cameras for photos and video) when using their diaries, and why they chose different media types to capture observations.

Diary kit features

We designed the diary kit (Fig. 1 and 2) through four iterations. During the iterative design process, we tested the intelligibility of the diary content with two families living with a healthy teenage child. This testing led to refinements to make activity and feeling categories more distinctive (Fig. 2A) (described below in Experience Stickers). We also learned that following the instructions to create entries on a daily basis was difficult. We included illustrated guidelines in each diary entry template (Fig. 2B). Finally, people preferred to give textual or multiple choice responses rather than using stickers to indicate redundant information. We removed all stickers that had a limited number of options for these categories and instead embedded multiple choice response options within the diary template (Fig. 2C and D). The resulting final diary kit (Fig. 1) included two diary booklets (for two weeks), experience sticker sheets, an optional instant camera and film packs, post-it notes, and pen and markers.

Daily entry template

Each diary booklet contained seven days worth of daily entry templates and asked participants to choose from a given set of stickers or draw to outline their daily activities (e.g., eating, sleeping, etc.) with the associated experiences (e.g., happiness, pain, etc.) on a vertical timeline (Fig. 2B).

Each row was designed to contain a single entry—a co-occurring activity and experience sticker pair—along with options for marking auxiliary details such as the time of day (e.g., morning) and immediate social context (e.g., alone, with mom, etc.) and setting (e.g., bedroom) (Fig. 2C). For symptoms, checkboxes were used to indicate the severity of the symptom and its interference with an associated activity (using an embedded 5-point Likert-style scale). Additionally, the template included space to capture written notes.

Experience stickers

The experience stickers consisted of three sheets containing a mixed sticker set of 16 activities, eight emotional experiences, and 12 physical experiences [35] and two sheets containing a repeating set of the 16 activity stickers (Fig. 2A).

Illustrated guidelines

In addition to the guidelines on each diary entry template, we included instructions in the beginning of each booklet, and participants were encouraged to freely elaborate on the template by adding their own annotations (e.g., duration of activities or symptom onset), drawings, and elaboration. Multiple body diagram outlines allowed participants to sketch their own representation of an experience (i.e., whole body, head, torso, organs, and individual limbs) (Fig. 2E).

Caregiver diary

We created a separate parent version of the diary to provide adolescent participants an option to maintain their privacy. Having two diaries allowed us to better understand aspects of the patient's life that parental caregivers attend to. The parents' version of the diary kit included a similar set of instructions, but asked that they record their observations of the child's illness experience.

Media probe

Participants were instructed to use digital media to capture moments of their daily living on their mobile phone or the camera included in the kit. Instead of sending or uploading the recorded data, they were asked to enter a time log at the end of the diary packet whenever they captured data with their mobile phone. We provided an instant camera¹ and two color film packs in case they had a defective phone camera or did not own a mobile phone. We did not require that the participants share the photos with us.

METHOD

Procedure

We recruited families at a large pediatric healthcare system, in cancer and rheumatology clinics from Aug 2018–Feb 2019. The protocol was authorized by the healthcare system's institutional review board (IRB). Inclusion criteria for the study

included specific patient ages (10–19 years), the ability to speak and read English, a diagnosis of cancer or lupus, an intent to receive routine treatment, and willingness to return to the clinic within 3–4 weeks. Through convenience sampling guided by our inclusion criteria, weekly screening assisted by nurse practitioners and a clinical research coordinator, and IRB-mandated clinician approval, we enrolled a total of 22 patient–parent pairs.

After obtaining clinician approval and patient and parental consent, a researcher described the study protocol and scheduled an exit interview with the participants on the day of their next clinic appointment.

Participants

Among those who consented, 12 patients and their parents remained in the study for our final analysis ($F = 8$; $M = 4$). Patients were 12–18 years old ($mean = 15.1$) (see Table 1).

Text messaging protocol

We sent three daily text messages to patient and parent participants' mobile phones—at 11 a.m., 5 p.m., and 9 p.m., to prompt diary use. The morning and evening reminder text messages included a unique task for the day that asked participants to capture an activity or an emotional or physical feeling using one of the five media probes (i.e., photo, video, voice, drawing, and written note). The tasks were designed such that all permutations were exhausted by Day 14 (the final study day). Participants were still allowed to log freely with their choice of medium outside of the task. An example task included the following:

"After reviewing today's entry, pick one PHYSICAL feeling and use your PHONE to capture how you (your child) felt about that experience with a PHOTO."

Data collection

The diary data collection period lasted 14 days for each participant. We retrieved the diary kits either by mail or in person before the interview. We were able to retrieve ten patient diaries and nine parent diaries (we lost contact with two families and one parent) after the exit interview. All paper diaries were scanned and transcribed for analysis.

After the diary data collection period, one researcher conducted semi-structured interviews with each patient–parent dyad. We used empty exam and conference rooms for interviews (one was conducted by phone). Prior to the interview, the researcher handed the participants their own diaries for reference and asked them to review it privately. Interview topics included: user experience and burden of diary entry, experience responding to different media technology probes, and preferences for sharing and communicating information captured in the diary. Each interview lasted 45 minutes, all audio files were transcribed, and patient and parent names were anonymized before further analysis occurred. After their completion of the study, all patient and parent participants received up to \$75 in total compensation.²

²Each participant received up to \$25 per week and an additional \$25 for completing the exit interview.

¹FujiFilm Instax Mini 9 or FujiFilm Instax Mini 90 Neo Classic

Child Age	Child Sex	Diagnosis	#DDays	#DEntries	Parent Age	Parent Sex	#DDays	#DEntries
15	F	Lupus	14	188	43	F	-	-
13	F	Cancer	14	171	41	F	13	126
13	M	Cancer	13	166	38	F	12	173
16	F	Cancer	14	152	46	F	14	152
14	F	Lupus	14	141	57	F	14	112
16	F	Lupus	14	129	41	F	14	84
18	F	Lupus	13	106	55	F	14	55
15	M	Cancer	10	81	35	M	14	113
15	F	Cancer	13	81	37	F	7	43
12	M	Lupus	10	46	34	F	6	45
16	F	Cancer	-	-	40	F	-	-
18	M	Lupus	-	-	52	F	-	-

Table 1. Demographic information of patient and parent participants, sorted by number of diary entries of adolescent participant. #DDays and #DEntries refer to the total number of days and entries each participant logged in their diary. Some participants completed exit interviews, but did not return their diaries. Patient ID's and specific diagnoses are obscured to preserve the privacy of study participants.

Analysis

We analyzed 720 minutes of interview data from all 24 participants and responses to the diary booklets from ten patients and nine parents. After transcribing and digitizing all responses to the paper diaries, we included a total of 237 days and 2164 diary entries in the final analysis.

In the analysis, we looked for common activities and patterns across participants and differences among child and parent responses. We also qualitatively analyzed participants' sketches of body diagrams in the diary, paying attention to distinct and similar features across patient and parent drawings. Any written comments provided in the diaries were cross-referenced with interview data and analyzed through the same thematic analysis process.

Following an iterative, inductive thematic analysis process [13], two researchers (R1 and R2) individually reviewed and conducted open coding on all interview and diary entry transcripts. After gaining a level of familiarity with the codes, they annotated keywords and phrases believed to explain a segment's particular topical relevance and independently constructed a master code set. Next, R1 and R2 met in person to compare and revise the master code set. R1 and R2 then independently reapplied the revised master codes to three interview transcripts. After several phases of iterative review and re-evaluation of themes and subthemes, both R1 and R2 determined that no new themes emerged from the analysis and R2 completed coding of the remaining transcripts. R1 and R2 met again to review all coding once finished, and to arrive at themes. In the end, the researchers arrived at six main themes and 26 subthemes.³ Data analysis occurred between March and June 2019.

FINDINGS

All 12 patients reported using the diaries during the two-week study period. On average, patients and parents entered data for 12.9 and 13.0 of the 14 days, totaling 129 days of entry for the patient and 108 days of entry for the parent. Our analysis of the diary entries (any sticker or added text labels) included a total of 1261 patient and 903 parent daily entries.

Our qualitative analysis uncovered three primary needs for personal and shared documentation, each detailed below. When

quoting participants, we code child, parent, and child-parent dyads respectively as C, P and CP. We include relevant results of our analysis of diary entry data throughout the findings, focusing on whether particular dyads converge or diverge in their documentation of activities, and use this information to contextualize the qualitative data.

Scaffolds helped patients recognize and document physical and emotional experiences

When asked about their overall use of the diary to narrate the illness experience, many patients appreciated the stickers, which provided guidance during acclimation to the diary. C8 remarked, *"I would have been like, what do I write, what do I do? The stickers helped guide me in the beginning and from then on I was like, 'Okay, I'm supposed to do this and this.'"*

Patients also told us that they have a difficult time understanding what exactly they were experiencing, but that using the stickers helped them develop more familiarity with bodily sensations. C12 commented that the stickers helped him develop the language needed to recognize and identify his emotional and physical feelings *"It [stickers] really ... put like a word to my emotions. [They] would help [me] come to a conclusion of how I feel."*

As they grew familiar with the initial set of experience stickers, some patients started adding their own personally-relevant experiences in place of the stickers (e.g., "mellow", "hanging in there", and "drained").

Becoming attuned to changing experiences

Some patients talked about the importance of focusing on small changes in their symptoms. C2 highlighted the fact that most patients, herself included, do not pay attention to changing symptoms until they worsen or a new symptom arises. *"If you want to see what's changing [...] [the diary] can help you keep track of really just what's happening with you. 'Cuz you really don't notice it [...] unless it's new or worse."* C15 commented that, as a result of filling out the diary, the stickers helped her describe her feelings for her doctor and family members. *"I learned to pay more attention to how I was feeling, because I didn't used to do that before. Then, if I were to have a flare up, and would have to go to the hospital and explain how I was feeling, I wouldn't know how to do that."*

³The full list is included in Supplementary Materials



Figure 3. Diary entry excerpt from C13

So this [diary] helped me explain how I'm feeling, a lot more."

Grounding experiences in activities

Many participants told us that the activity stickers in particular helped them recognize perceived emotional and physical experiences. C12 told us that thinking about the activities helped him better recall certain problematic symptoms. "Different activities, like what you are doing before the flare-up. That made me remember that day." Commenting on the mood stickers on his diary entry, C1 recognized relationships between activities and his mood during the study. "Sometimes when I get happier towards the end of the day, it's because I talked to my girlfriend or something [...] but if not then normally I'm just kinda calm, or stressed, or whatever." C13, a lupus patient, told us that comfort with activities served as an important indication of her physical condition. "I can only write for 15 minutes. My hands get stuck and they'll start hurting."

Adolescents and family caregivers need support to reconstruct the patient's experiences

Our analysis of interview data showed that adolescents' and parents' journal entries often *agreed* when it came to documenting everyday activities and routines. Patients also valued their parents' ability to reliably keep track of their daily activities. However, the diaries revealed discrepancies in adolescents' and parents' observations of physical illness experiences. Additionally, maintaining a mutually agreed-upon, open diary made it easier for some participants to share sensitive experiences.

Reconciling parents' perceptions and adolescents' lived illness experience

Consistent with earlier studies in family health management [36, 74, 83], parents had trouble assessing their child's internal experiences, but did not realize the extent. Parents often relied on external cues and previous observations that would hint at the patient's subjective experience of the illness. For example, when asked how she keeps track of her child's illness experience, P13 told us, "If it's like something bothering her at school or with a friend or something, she'll just be real quiet. Then you can notice that something's wrong, because she's [usually] always so hype."

However, we found that cues such as posture and facial expression can at times mislead parents. For instance, C1 stated, "I don't know if dad's ever noticed [the pain caused by ulcers] because I just kinda like curl up into a ball. Yeah, you've [P1] probably seen me curl up, lay down and get quiet." C8 added that she could better track her physical feelings and asserted that her parent's observations only reflect impressions, not actual assessments of the true experience. "I think I can track my feelings better [than my mom] because, from what she sees [P8] is what she's going to think I'm feeling, but I know what I'm feeling and how I'm feeling."

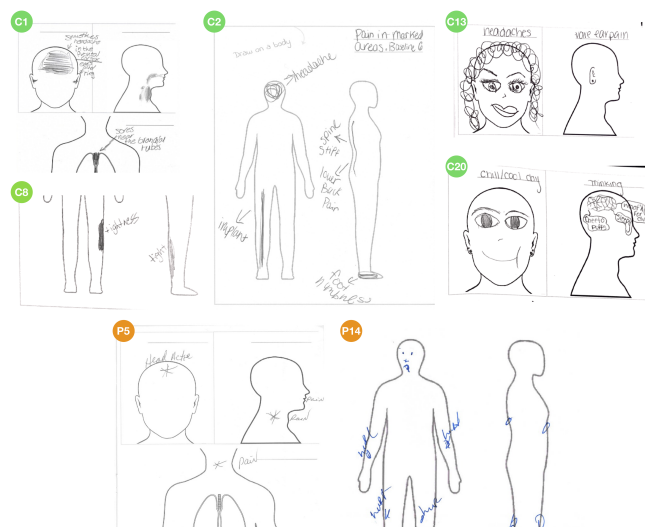


Figure 4. Various sketches produced by diary participants.

Although patients were aware of this mismatch between their observations and their parents', they did *not* realize how difficult it was for their parents to infer how they were feeling. P15 commented that she will usually ask her child to confirm her observation about an experience, gathered from reading her child's facial expression, yet C15 expressed her frustration that P15 had to ask. P15: "Outside of that [asking C15 directly], I wouldn't have known. Based on her facial expression, or how I saw her get up in the morning, I would figure maybe something was wrong, so I'd ask her, 'Are you in any pain?'" C15: "You can tell [how I feel] ... It's very obvious, after I take my injection!"

In our analysis of patient and parent entries, we saw that the most frequent activities reported by patients (sleeping, eating, taking pills, waking up, showering, and brushing) resembled those observed and reported by their parents. The dyads also similarly reported on certain emotional experiences (calm, happy, and sad).

While patients and parents shared similar activities and mood observations in the diaries, there was a difference in how patients reported their physical feelings. While stomachache, headache, pain, low energy, and nausea were more prominently observed and recorded by parents, patients focused on slightly different categories of illness—such as generalized pain, headache, mouth sores, low energy, and stomachache.

Patient and parent participants included 46 and 26 sketches, respectively. Further analysis of these sketches showed that parents identified the anatomical region of the affected area whereas patients were more likely to add detailed elaborations of sensations onto the diagrams beyond indicating the physical location (Fig. 4). For example, C8 utilized different shades of gray to indicate the degree of “tightening” she experienced on her right leg. C13 and C20 added facial features and illustrations of thoughts to personalize their drawings. In elaborating on one of his sketches (Fig. 4), C1 gave us an illustrative account of how methotrexate, the main acting chemical agent used in chemotherapy, physically affected his body during treatment. *“Once you get the [injections] this guy [inflamed uvula] just kind of droops in, and slaps everything around. Sometimes you can’t actually swallow because of it, and your whole nasal cavity gets inflamed too.”*

Developing mutual awareness for collaboration

We found that patients learned to pay attention to details of their changing illness experience. Yet many participants agreed that they could reliably document physical activities together. When asked about her experience using the diary, P2 lamented about her inability to understand C2, outside of keeping track of mundane activities. *“It was a little bit harder for her dad and I because we both have very busy, very hectic stressful jobs [...] And we couldn’t focus, but there is a lot of just the general activities that we knew. I mean she was doing enough sleeping, she slept a lot or we’d watch TV or do social media on her phone, but it was hard to pay attention to the detailed things.”* However, it was this ability of the parents to attend to routines that patients valued. C8 suggested that her parent could share the “workload” of documentation, by focusing on activities. *“She [P8] can track me better when I’m doing my activities... that would help split the workload.”*

Some families chose to use open diaries. One lupus patient–parent dyad (C13 and P13) appreciated how the shared diary helped them develop mutual understanding and effective communication about difficult physical experiences. C13 felt comfortable sharing even her severe illness experiences, which she said she could not do in the usual context of face-to-face communication. P13: *“She’ll write it in the diary when it [symptom flare up] happens or when she’s feeling it, but she won’t tell me until she really needs me, or if I pick the [diary] book up and go through it. All right, you was feeling like this on this day. She’s like, yeah. I think it helps her. She’s able to write it out, loudly, and not have to say it out loudly.”* C13: *“[It’s] like a silent cry for help. It would just be open.”*

Individual preferences drive observation-type, capture and representation of illness experiences

Through the use of diary probes, we discovered that there are individual differences in what illness observations patients want to capture and how they want to represent them. For example, when we asked patients if they used the embedded rating scales (Fig. 2C) with symptoms they logged, we received mixed responses. Most participants found the rating scales familiar, and thought that *clinicians* would better understand their feelings if represented this way. Others (C2, C5,

ID	Photo	Video	Audio	Sketch	Note
C1	x			x	x
C2	x			x	x
C3	x				x
C4	x	x	x	x	
C5	x			x	x
C8				x	
C12	x				
C13	x	x		x	x
C14	x	x	x	x	x
C15	x			x	x
C18				x	
C20			x	x	x

Table 2. Media technology used by patient participants. ‘x’ indicates the participant used the technology during the study period

C8) who experienced the same symptoms did not think the use of scales applied to their experiences.

C2 particularly had a strong reaction to the rating scales. *“I personally hate pain scales, [...] because honestly my pain scales are very different from other people’s.”* C2 continued, saying that instead of numeric scales, she describes her pain by asking others to imagine a relatable, but intensified, experience. *“I was like, ‘you know when you have to pop your knee because there’s just that uncomfortable pressure?’ Like bend down and pop? ‘Well that feeling is like 10, no 45 times worse in this leg.’ Then you can only really imagine, but that’s like how I describe it.”*

Patients also wanted to represent emotions using a combination of media technology. For example, some participants preferred to use photos to capture their facial expressions, in a “selfy” style, whereas other participants (C13, C20) took photos of objects (e.g., food) or activities (e.g., doing homework) that they associated with a particular emotion. C13 illustrated this point and remarked, *“[pictures] of things, that make me happy. My food, and I have pictures of my drawings.”*

Some participants suggested that videos would better help them represent their emotional experience. C13, who experimented with videography, suggested that videos could help the viewer see the true emotional experience of a person, instead of a desired state of expression. *“So, it’s like, don’t judge a book by its cover. I could be smiling, but, you know, when you actually go into depth into that picture ... you look at the details... kinda spot things. But versus a video, you don’t have to spot anything, you just watch it and you can see it.”* P15 concurred, speaking from her experience using live videoconferencing with her daughter, *“I feel video also helps to capture emotions. I can track better, her emotions, because I could hear it through how she speaks. I could see it when we FaceTime each other.”*

On the other hand, other participants, like C8, told us that using videos to capture their experiences was confusing. In an interesting contrast to her earlier comment on the stickering activity, P8 said, *“I don’t know what to do in the video though [...] Would I be like, happy, or something? I don’t know. I don’t want to be awkward in a video, so...”*

Finally, very few participants (C4, C14, C20) responded to prompts to document observations with audio. Some participants thought audio could provide an important signal of health status. C15 stated, *"You can also tell if someone's in pain, by how they sound."* However, the consensus among the rest of the participants was that it wasn't valuable because its function overlaps with video.

DISCUSSION

In this section we reflect on the insights that were present in our findings and bring in lessons learned from the diary probe study. This reflection is meant to start a discussion about how the HCI community can support chronically-ill patients and their family caregivers.

Scaffolding collaborative reconstructions of daily life

Diaries provided a unique view of how adolescents and their parental caregivers reported illness experiences. We learned that the visual design of the diary supported patients in recognizing and reconstructing these experiences. Our findings suggest a need to **design effective scaffolds to support patients in learning about and representing their illness experiences**, such as learning associations between signs of illness and daily activities. In particular, we found that a storyboard format and pictographic representations of activities, emotions, and physical experiences provided the needed scaffolds for patients to compose daily narratives.

The media probes helped our participants engage in momentary reflections of their experiences, and allowed them to provide insightful, design-related feedback on the role of different media (audio, video, and photos) to capture their feelings. While the paper diaries contained design elements (e.g., stickers, storyboard template, and body outlines for sketching), these scaffolds did not exist for digital media probes. For example, many participants told us they did not know how to respond to a video prompt. This finding is consistent with other media elicitation studies, which reported that participants were often confused as to what needs to be captured using camera technology [71, 86].

Future research should address how to design effective scaffolds to support collaborative reconstruction of the patient's daily experience with digital media technology. As research and design partners, young patients can be actively involved in the process of deciding how to design these scaffolds. Today, 95% of adolescents own or have access to mobile phones that are equipped with media tools to capture aspects of daily life [1]. A recent survey of teenage adolescents reported that video content platforms (e.g., YouTube, Instagram, and Snapchat) are among the top applications they use [1], motivating research on the role of Video-based methods [46, 64, 58] for design research with young patients.

In our study, many patients provided feedback on how they wanted to approach the use of various media technologies. For example, some participants used their camera to take pictures of their own face or objects and scenery to represent their mood. Collaborative design processes could build on these preferences to create additional scaffolds and enable

personal representations. The challenge will be to do so in an ecologically-valid manner.

From caregiver- to family-centered communication

Caregivers' observational accounts of illness experiences are susceptible to bias when interpreting their child's health status from physical cues such as their facial expressions and posture. In the clinic, there is potential for further influences such as recall bias [50] when reporting experiences. We discovered that patients and parents documented similar activities and emotional experiences, yet this was not always true for physical experiences (e.g., mouth sores). The specificity of drawings in patient sketches, in comparison to those of caregivers, also points to the extent to which personally-felt and third-person observations differ.

The prevalence of caregiver reports can mean that parents assume a burden to observe and keep track of their child's health between visits [36]. To mitigate this burden, technology should be designed to help patient families share the responsibility of observation and documentation. It will be important to account for discrepancies in observations and to give patients the means to review and contribute amply and flexibly to documentation.

Timing is an important factor in discussing and reflecting on patients' experiences. Grimes' [32] and Lukoff et al.'s [47] findings point to the value of shared co-located routines (e.g., dinner) for facilitating families' collaborative reflection on health data. However, for some patients, sensitive illness experiences were more comfortably shared after some time had passed and outside of the typical context of face-to-face communication. This has implications for designing shared patient and caregiver tools for collaborative review of health information [68, 4].

Rather than implementing a strict open or closed data access policy, our findings point to the need to account for much more nuance. We see important research opportunities to **identify the appropriate timing, types, and level of detail of health-related information to facilitate emotionally-sensitive discussions**. Furthermore, there are important opportunities to explore how to best support informal and formal caregivers and patients to choose data sharing models that maintain autonomy while ensuring patient safety. Families in our study had the flexibility to adopt their own approach to sharing, and they leveraged private, persistently shared, and progressively shared diaries as a result. As P13 beautifully illustrated, *"I like it [having an open diary]. She likes to try to figure out the puzzle [symptom] before she tells me what's wrong. She knows I don't know."*

From structured to adaptive experience representations

Clinical instruments often focus on standardizing illness representations, forcing patients to translate their experience into a numerical value [62]. Yet, our research shows that valuable information is lost in this translation. This is due, in part, to the individual variability in personally-conceived notions of 'normal' for each patient. Patients also need different levels of abstraction to represent their own experiences.

Reporting in the clinic should be patient-centered. Young patients who lack cognitive and verbal communication skills need illness representations that are familiar and personal [50]. Structured scales are valuable as they provide a consistent approach to eliciting data, across patients. Still, our study points to opportunities to balance the rigor and validity of established scales with the flexibility needed to accommodate the patient's developmental stage.

Findings from our study point to the need to **design artifacts that engage with the intersection of quantitative, repetitive, or predefined “tracking”, and more flexible, generative approaches** to capturing lived experiences, through probe-based methods. Our diary probe not only allowed us to collect data, it demonstrated how an artifact can bridge these two, traditionally separate, approaches. Indeed, “objective” quantified data can made personally meaningful through contextualization to communicate personal narrative, identity, and a felt sense of self (instead of creating copies or impressions of reality) [24]. In our case, we saw that using both paper diaries and media probes helped patients develop and articulate their personal illness narrative around objective data, in ways that support their autonomy in expression.

How to incorporate flexibility in expression into care processes remains an important question for the HCI community. For documenting pain, recent work has diversified the expressiveness of pain reporting using pressure-based [2] and haptic [61] sensing. It will be important to understand how to design and tailor patient-friendly representations for other types of illness data (e.g., nausea, fatigue, etc.) that do not lend themselves to structured scales. Adaptive approaches to documenting illness experience echo other recent work, such as tailored measures for pain reporting to enhance respondent motivation, minimizing the difficulty of self-assessment and encouraging care providers to consider individual differences more explicitly during encounters [3].

LIMITATIONS AND FUTURE WORK

While findings and implications from our study are transferable to other families living with a serious chronic illness [75], there are limitations of our approach. First, we had a relatively small sample size and only recruited one family caregiver from each of the 12 households. We also restricted study participation to adolescent cancer and lupus patients, to address gaps we saw in technology support for their unique treatment characteristics. More studies are needed with patients living with less severe chronic conditions or families living with multiple children with medical needs. There are also rich opportunities to study parents' and clinicians' needs associated with documentation.

Diary probe approach

Despite its advantages, we observed several limitations of the diary probe approach. We intentionally refrained from asking participants to electronically share digital photos, videos, and audio captured during the study. An advantage of medium probes [22] is that participants could exercise control over their data to preserve privacy.

Yet, retrospective review of their media data with researchers was challenging. Participants had trouble sorting through their digital libraries to differentiate specific study data, and had difficulty recalling events to contextualize their collection of media during the interview. For these reasons, we did not analyze contents of the media data and they were only used to prompt discussions about their value in capturing their illness experience. While we provided an alternative technology (i.e., instant camera) for capturing photos, participants struggled to obtain a clear image in low-lit conditions. Paper diaries allowed participants to quickly locate the data inside (e.g., sketches and annotations). Future studies should incorporate ways to collect insights from both paper and digital media in a coordinated and ongoing way, while enabling controls for personal and shared review.

Caring for parental caregivers

By focusing on observations of the *patient's* illness experiences, we did not probe parental caregivers' personal experiences coping as caregivers. Kaziunas et al. found that parents face heavy emotional burdens and intensive information work as they transition to the role of caregiver [41]. Better understanding *parents'* felt experiences would help us learn and account for their needs related to documentation and information sharing with the patient. It will be important to design technology that does not add to their information burden [15]. We must also account for the ways in which documenting illness observations can be a sensitizing experience—becoming too attuned to symptoms like pain could add strain to both the patient and caregiver [36].

Impact on clinical caregivers

Finally, introducing alternative means for patients to express their symptoms and other illness experiences could also increase the burden on clinicians' to review this information. Early research has identified opportunities to shift this burden, by leveraging existing clinical workflows, such as supporting physicians' elicitation of practice-specific questionnaires during patient interviews [18]. Supporting patients in leading the narrative is another promising approach [87], which could leverage shared displays in the clinic [42]. More research is needed to support such collaborative review.

CONCLUSION

In this paper, we described the design and deployment of our diary probe kit with 24 participants, representing 12 adolescents with a chronic illness, and their parents. We focused on cancer and lupus patients because they are most likely to experience the benefits of reporting on their daily experiences during complex treatment regimens. Based on patients' and parental caregivers' use of the diaries, we identified three needs for personal- and shared documentation to support families' collaborative health management. We further elaborated on the implications of these findings for future HCI research, and discussed the benefits and challenges of using diary probes with our study population.

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