

Integrating Patient-Generated Observations of Daily Living into Pediatric Cancer Care: A Formative User Interface Design Study

Udaya Lakshmi, MS
School of Interactive Computing
Georgia Institute of Technology
Atlanta, GA, USA
udaya@gatech.edu

Matthew Hong, PhD (c)
School of Interactive Computing
Georgia Institute of Technology
Atlanta, GA, USA
mhong@gatech.edu

Lauren Wilcox, PhD
School of Interactive Computing
Georgia Institute of Technology
Atlanta, GA, USA
wilcox@gatech.edu

Abstract— Patient-generated data, such as recorded Observations of Daily Living (ODL) and Patient-Reported Outcomes (PRO) data, are valued sources of information in oncology care. However, prior work largely focuses on capturing clinician-defined, patient-generated data in adult oncology care. Emerging research at the intersection of human-computer interaction and medical informatics suggests that *visual narratives* of patients' observations of daily living (Visual ODLs) could better support multi-party review of patients' everyday symptoms and quality of life, potentially improving patient-clinician communication. In this paper, we build on a prior study of Visual ODLs by describing a formative, two-phase study with 15 pediatric oncology clinicians. In Phase I, we analyzed data from ethnographic interviews in a pediatric oncology setting to capture the needs of nurses, nurse practitioners, and oncologists. In Phase II, we constructed two low-fidelity dashboard display prototypes, populated with Visual ODLs contributed by actual adolescent oncology patients, and we subsequently interviewed pediatric oncology clinicians who reviewed each dashboard design. Findings from our study contribute four key design objectives for presenting interactive Visual ODL dashboards in pediatric oncology, along with three use cases for using these dashboards for symptom tracking and communication.

Keywords— *Graphical user interfaces; health information management; oncology; pediatrics; chronic care management; healthcare informatics; user-computer interface; symptom assessment; patient-centered outcomes research; patient-generated data; user interface design*

I. INTRODUCTION

The use of patient-generated health data (PGD) in clinical communication is now being encouraged, fueled by the rising availability and affordability of mobile and ubiquitous sensing technologies [4,17,22]. The time is ripe for considering both whether and how data generated in non-clinical contexts can support patient-clinician communication, especially for tracking illness signs and symptoms [5,29].

In cancer care, collecting experiential accounts of patients' daily living between clinical visits could both inform treatment decisions and support planning for supportive care [40]. In pediatric cancer care, clinicians rely on patients and their parental proxies to provide narrative accounts of the patient's illness experiences between clinical visits [29]. However, eliciting these narratives presents several challenges.

First, the lack of comparable communication skills and the presence of adults can make it difficult for young patients to participate in clinical conversations [13]. Furthermore, clinicians often turn to parents to fill in the gaps in communication, which foregrounds the parents' observations of the patient's felt experiences [30].

Second, patients' and parents' observations often take the form of retrospective accounts, in which emotional, physical, and social experiences are reconstructed during the clinical consultation [28]. These narrative descriptions rely on episodic recall, often placing cognitive burden on patients who are suffering the toxic effects of therapy. As a result, the patient is hindered in recognizing and expressing details of their experiences in response to open-ended questions [31].

The beneficial role of visual illustrations for communicating health information is widely known by the medical community, as evidenced by the use of educational illustrations in medical communication [12,16,17,30,31,41]. Likewise, visual depictions have the potential to offer pediatric patients the means to convey nuances of their lived illness experiences.

Hong et al. explored how to design technology to allow adolescent patients to contribute first-person accounts of their illness experiences in clinical conversations [12]. They introduced Visual Observations of Daily Living (Visual ODLs), a library of illustrated prompts, to patients and family members, in a participatory design study. Visual ODLs enabled adolescents to articulate illness experiences through collaboratively-generated storyboards during co-design sessions. The visual library is informed by a framework for understanding patient activities and symptoms, and also interviews with pediatric clinicians [3].

In this paper, we report findings from a two-phase study in which we sought to understand how oncology clinicians would review such visual, patient-led narratives as PGD. Like other studies investigating clinician perspectives on adopting PGD for clinical contexts [33], these insights can inform the design of symptom communication tools to foster effective patient-clinician communication. In Phase I, we revisited data from the Visual ODLs study by conducting a secondary data analysis of the transcripts of 12 clinician interviews [12]. In these interviews, clinicians: 1) explained how they sought insights into *patients' daily activities* during the initial stages of treatment,

and 2) identified the *symptom communication challenges* they currently faced during clinical visits [12].

In Phase II, we created two low-fidelity user interface designs, each of which embodied a graphical, narrative-based, dashboard design for a collection of Visual ODL data. The Visual ODL data we used to populate our designs was directly generated by patients in Hong et al.'s study [12]. Eight clinicians then reviewed our designs, evaluating the represented data as legitimate PGD to answer questions probing the value of each of the two dashboard designs. Clinicians compared the merits of each design based on their potential to support: 1) symptom-tracking; 2) multi-stakeholder review, and 3) patient-clinician communication. Findings from our study contribute four key design objectives for interactive Visual ODL dashboards in pediatric oncology, along with three use cases for clinician dashboards presenting graphical PGD.

II. RELATED WORK

In this section, we outline the role of PGD in healthcare. We briefly explain the two kinds of PGD identified by Brennan and Casper, which are distinguished based on their use of language—specified by either the patient or clinician—to describe health phenomena from the patient's perspective [3]. Patient-defined, patient-generated data is "*uniquely defined and uniquely important to the patient*," whereas clinician-defined, patient-generated data are assessments that clinicians see as an important measure of the patient's health status [3]. Below, we describe both types of PGD and the challenges associated with integrating them into clinical care. We then situate our study with respect to recent efforts to use patient-contributed data in pediatric care communication.

A. Integrating PGD into Clinical Care Conversations

Patient-generated health data equip clinicians with information about patient experiences collected outside the clinical setting [34]. Clinician-defined, patient-generated data include Patient-Reported Outcomes (PROs), which are standardized measures for patients to report on their health and quality of life [9]. Though PROs may not reflect specifics about how a patient functions or feels, they provide a reliable method to capture some treatment effects on the patient's quality of life and their satisfaction with their care [8]. For example, PRO measures are helpful in determining cancer patients' health-related quality of life (HRQOL). These patients are likely to experience multiple symptoms as direct effects of multi-phased chemotherapy. When integrated into Personal Health Records (PHR) and patient portals, well-implemented PROs can empower the patient to take ownership in managing their health [21]. However, while there are concerted efforts by clinicians to adopt PROs in their practice, there are two barriers to integrating them into clinical care [25,35,38].

Clinicians are concerned that patients may not be able to provide complete, relevant, standardized data through self-reports of illness experiences [40]. Additionally, PROs are "static" measures [32]—typically taking the form of multiple-

choice questionnaires, which can fail to both capture and represent nuances of complex internal experiences [35].

Advances in personal informatics and the Quantified Self movement allow data collection through passive and active sensing [19,23,28,37]. However, to integrate these data into practice requires that we solve challenges not only in capturing and managing PGD, but also in displaying it in ways that support clinicians' interpretation of the data [40].

In the next section, we point to examples of human-computer interaction (HCI) research that explore the use of graphical information to engage patients in their healthcare.

B. Engaging Patients through Visual Communication Displays in Clinical Settings

Recent work in health informatics and HCI has culminated in the design of graphical information displays to support different use cases for patient-centered communication. Exploring the integration of personalized PRO dashboards in follow-up care, Hartzler et al. examined the design of graphical PRO information to effectively represent patient-generated HRQOL data following prostate cancer care treatment [10]. Since PRO measures are collected using standardized questionnaires [16,35], graphical presentation techniques are required to structure and present PRO data in graphical displays. Furthermore, even when presentation techniques are designed well to fit the data they depict, the standardized nature of PROs excludes details about everyday activities and situational contexts that are often important in order to "fill in the gaps" [1,40].

Most studies investigating the role of graphical information in patient-clinician communication focus on communication directed to the patient. For example, Hong et al. prototyped and pilot-tested a tablet-based interactive radiology report application that supports on-demand retrieval of patient-friendly explanations with anatomical illustrations [11]. AnatOnME demonstrated a projection-based handheld system that allows clinicians to display medical images onto the patient's body [26]. Closer to the study we present in this paper, the BodyDiagrams project demonstrates how patient-generated diagrams can be used to augment text descriptions of patients' pain symptoms to support symptom communication [15]. Extending the use of illustrative techniques to depict patients' symptoms, we explored the role of visual, patient-defined PGD in communication during pediatric cancer care.

C. Capturing Comprehensive PGD for Complex Chronic Illness in Pediatric Care

During cancer care, clinicians rely on comprehensive accounts of illness experiences to assess treatment effects on the patients' quality of life. Monitoring the effects of cancer treatment is especially important in the early phases of chemotherapy since successful treatment must balance the extent of therapy given with its toxicity to the patient [7]. This balance can be achieved through improved patient-clinician communication, which also influences patients' adherence to a treatment regimen [27].

In pediatric care, both patients and parental caregivers must monitor physical and psychological symptoms to create comprehensive reports for clinicians to review [14]. However, side-effects from chemotherapy treatment often interfere with the patient’s ability to observe, recognize, or recall these events [13] so the parents’ perspectives are vital in communicating observations to the clinicians [1,30].

Research on patient–clinician communication also suggests that patients managing chronic conditions wish to exchange both clinical and non-clinical information with providers [1,20,36]. On the one hand, parents can provide a limited picture of the illness experience by selectively sharing details that they alone consider relevant to the consultation [12,18]. On the other hand, eliciting responses to open-ended questions from adolescents is challenging, requiring novel methods to capture their symptom experiences [2,14].

Below, we provide further background on the study we present in this paper, by introducing and elaborating on Observations of Daily Living and a method that builds on them to elicit illness experiences from pediatric cancer patients.

D. Generating Visual Observations of Daily Living

The Observations of Daily Living (ODLs) proposed by Brennan and Casper are a type of patient-defined, patient-generated data and a framework for our study of PGD in pediatric care [3]. ODLs situate a person’s observations of health in their everyday life through self-captured observations of felt experiences, and can complement clinician-defined outcomes.

Hong et al. [11] translated ODLs into a visual language to form Visual ODLs, representing the patient’s lived health experiences through 72 illustrations, or pictograms. Each visual ODL represents either an everyday activity, its context (e.g., people involved, location), a symptom (emotional or physical indicators), or media preferences for sharing evidence of the patient’s reported experience.

In co-design sessions with 13 patients and families, the participants created collaborative storyboards relating a sequence of their everyday activities from morning to evening, along with symptoms occurring in the context of those activities. Each storyboard represented a day in the patient’s life. The study found that storyboards populated with Visual ODLs provided effective ways to relate first-person accounts of symptoms like emotional distress to their impact on performance of routine activities.

The study we present in this paper explores the potential to integrate visual narratives with other forms of patient-generated experiential data for clinician review. In the following sections, we present findings from two sets of interviews with clinicians in which they provided feedback on the role of Visual ODLs in pediatric cancer care.

III. METHODS

A. Study Setting and Participants

With IRB approval, we conducted 20 interviews over two phases with 15 clinicians at Children’s Healthcare of Atlanta (CHOA) in two Cancer and Blood Disorders Centers (one urban, one suburban). Clinical experience across participants

TABLE I: CLINICIAN PARTICIPANTS¹ AND STUDY CODES²

Codes	Phase I	Phase II	Role (years of practice)	Specialty
C1	●	●	Oncologist (35)	Solid tumor
C2	●	●	Nurse practitioner (24)	Solid tumor
C3	●	●	Oncologist (25)	Solid tumor
C4		●	Oncologist (NR)	Hematology & Solid tumor
C5	●	●	Oncologist (11)	Solid tumor & cancer survivorship
C6	●	●	Nurse practitioner (20)	Solid tumor
C7		●	Nurse (NR)	Pediatric cancer
C8		●	Oncologist (NR)	Solid tumor
C9	●		Oncologist (25)	Leukemia & lymphoma
C10	●		Oncologist (12)	Leukemia
C11	●		Oncologist (27)	Brain & spinal cord tumor
C12	●		Oncologist (26)	Leukemia & lymphoma
C13	●		Oncologist (7)	Hematology & cancer survivorship
C14	●		Oncologist (9)	Leukemia & lymphoma
C15	●		Oncologist (3)	Solid tumor

1. Clinician participants (n=15) and codes by role, specialty and length of time practicing.
 2. Presence or absence of a bullet indicates participation in Phase I (n=12), Phase II (n=8), or both. Use of “(NR)” indicates that years practicing were not reported in the interview(s).

ranged from 3–35 years (*median* = 22) (see Table I for participant details). We interviewed 12 clinicians between March and April 2017 for Phase I. After the patient-focused study [12], we began recruitment for Phase II in September 2017 focusing on solid tumor patients. We concluded when we reached data saturation, in November 2017. The second study includes design feedback from five clinicians who participated in Phase I.

B. Data Analysis

Each interview in Phases I and II was audio-recorded with clinician consent and transcribed verbatim for qualitative analysis. For both studies, we organized clinician quotes to iteratively generate themes until no new themes emerged.

For Phase I, we leveraged data collected by Hong et al. [12] and performed a secondary data analysis of interviews conducted after a design activity with adolescent patients. While Hong et al. present a subset of insights specific to the design of Visual ODLs for patient families in their paper, we apply

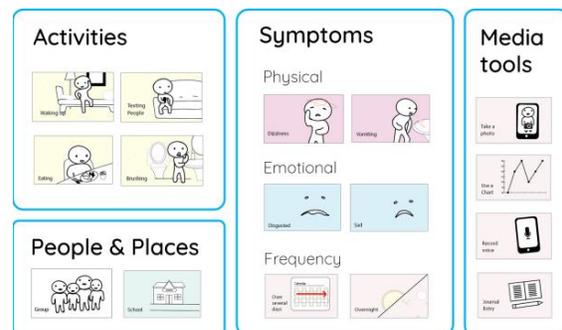


Figure 1. Sample Visual ODLs proposed by Hong et al. [12]

themes deductively to arrive at insights pertaining to their review by clinicians. Our deductive analysis focused on three themes that arose in Hong et al.'s participatory design study [12] with patients and their family members: *patient experiences of interest to clinicians, the role of symptom tracking in complex chronic care, and reconciling conflicting perspectives.*

In Phase II, we conducted an inductive thematic analysis of interview transcripts. We noted emergent themes through bottom-up coding, with two researchers evaluating subthemes to reach a consensus over three iterations. Clinicians recruited for Phase II to evaluate prototype dashboards are indicated in the table. In the interest of full disclosure, we would like to share that C1 is a clinician collaborator in ongoing studies.

In the Hong et al. study, analyzed in Phase I, the authors collected data in semi-structured interviews for 20–30 minutes with 12 clinicians (10 oncologists and 2 nurse practitioners) with clinical experience ranging from 3–35 (*median*=22) years [12]. These interviews were the source of our secondary data analysis.

Eliciting clinician perspectives at an early stage of the design ensured selection of realistic symptoms for the patient population, based on the Pediatric Memorial Symptom Assessment Scale (pMSAS) [39]. The scale guided domain-specific perspectives on patient behaviors that clinicians would prefer to track in solid tumor and leukemia patients. The pMSAS is a validated instrument that measures symptom experiences in cancer patients between 10–18 years old, across 30 items relating to physical, mental and other patient-rated factors. The interviews included questions probing clinician preferences for frequency of data collection, current practices, and motivation to use data in clinical decisions.

IV. PHASE I: FORMATIVE DESIGN INTERVIEW FINDINGS

Below, we detail findings from our Phase I analysis, organizing our findings from clinician interviews into two larger, overarching themes. We associate study insights with relevant quotes from the transcribed interviews. Each quote is attributed to the respective clinician by the code assigned in Table 1.

A. *Current Practices and Preferences for Collection of Patient-Generated Data*

Relating to our first deductive theme, *patient experiences of interest to clinicians*, we found that clinicians mentioned advantages of collecting PGD during multiple stages in therapy, for both leukemia and solid tumor patients. They attributed these advantages to the potential of PGD to help them gauge the toxicity of therapy. The initial stages of treatment are harder for adolescents and young adults than they are for children and adults with the same tumors. Treatment is also tough on parents, who often help the patient cope at home. C9 explains how during “[the] first six months—because parents are worried but they’re also burned out and it is an intensive kind of therapy—there are a lot of symptom problems at that time. So, parents tend to dichotomize into the people who either call all the time or the people who just occasionally [check in].”

Clinicians preferred to receive PGD from patients and parents during treatment, which can range from 6 months to a

year, depending on the severity of the cancer [C1–C3, C5, C6, C9–C15]. During this period, most clinicians preferred data collection while the patient is out of the hospital. Some preferred data two-to-three times a week [C3, C6, C14] or at a set of times related to the treatment stage [C1, C10, C15] and the symptom severity [C9]. Some clinicians also preferred daily-logged patient data [C1, C5, C10, C11]. For example, C5 reasoned that, “*I think ideally you would do it seven days a week because a lot of times kids are getting chemo on a specific day and so you expect their symptoms to change throughout the week.*”

Talking about their current process to track symptoms between clinical visits, clinicians mainly relied on verbal prompts and responses to parent reports of specific symptoms [C1, C3, C6, C14]. Their process includes a Review of Systems (ROS), collected by nurses and nurse practitioners to elicit symptom data at the beginning of each visit. ROS data is often an approximation and inadequate for clinicians to understand the entirety of the patient’s illness experience. C1 mentioned: “[If] you just pick a number—it doesn’t tell you what it is. High distress: ten. [But] there’s no scale that we’re handed that tells us what this [actually] is [for the patient].”

Clinicians ask patients and parents to keep diaries for tracking activities occurring as part of patients’ routines (for example, food intake) or persistent symptoms like headaches if these are reported by the patient and parent [C2, C3, C6, C9–C11, C13]. Specifically, clinicians mentioned headaches as a symptom connected to physiological and psychological effects of treatment, relying on in-depth data from patients to characterize and reason about them. To quote C6: “*If it’s a patient that is reporting pain or reporting issues with nausea and vomiting or having headaches, those sorts of things are the situations in which we will ask them to track their symptoms, so that we have more information.*”

However, clinicians perceived that parents and patients often filter details about daily activities. To some extent, the passage of time affects recall, and subsequently, what is filtered in communication [C2, C9]. At other times, such filtering is a result of patients’ and parents’ deliberately limiting the information shared with clinicians, to save time [18]. In C9’s words, “[F]amilies, I think, for a long time, didn’t want to burden the doctor [...]. They were here to talk about cancer, and so on the flip side, we’ll have patients coming off therapy and you want to talk about their obesity and the fact that their BMI is off the map, and they don’t want to talk about it because you’re their cancer doctor, you don’t need to tell them to go out and be physically active, you just need to tell them that they’re in remission from their cancer.”

B. *Perceptions of the Role of Patient-Generated Data in Prevention, Adherence and Reconciliation*

Regarding our second deductive theme, *the role of symptom tracking in complex chronic care*, clinicians were motivated to track symptom data to ensure prevention and management of the illness experience [C1, C3, C6, C9, C12]. They mentioned that information on gradual changes in the patient’s routine could guide them in understanding the required modifications to treatment, and to enlist the support needed from other resources. Talking about physical exercise

and medication, clinicians reported deviations affecting patient responses to treatment [C3, C9, C12]. While they do not rely on these patient reports to adjust chemotherapy [C1], clinicians mentioned the need to track anxiety and distress [C1, C3, C5, C9, C13]. Considering the current reliance on parent–patient-initiated reports of early signs, clinicians also faced challenges managing conflict, and reported that the types of conflict they face is not always between the patient and parent alone. C3 explains how: “*Sometimes [its] not a conflict between parents and [the] child, it can sometimes be a conflict between us and families. We want them to get out there and do stuff and they’re like, ‘no, I think he needs to stay home ...[to] protect himself.’*”

Finally, related to our third deductive theme on *reconciling conflicting perspectives*, clinicians consistently emphasized their need for both perspectives in a PGD dashboard display, and favoring one over another was family-specific—guided by their perception of the family and the individual patient [C11–C14]. Notably, some teenage adolescents may not be willing to share their experiences, depending on their personality, personal relationships, and other factors [C1, C11, C12, C14]. This is exemplified in C11’s opinion that, “*The problem, in that population, is that the veracity of symptom reporting is completely and totally linked to social, emotional and personality issues as well as socioeconomic issues.*”

Clinicians said that they preferred and encouraged the teenage adolescent’s perspective [C2, C3, C5, C9, C10, C15] in consultations. However, clinicians relied on parents to corroborate their accounts, as C10 says: “*Sometimes I’ll trust the parents more, because I know the teen [...] has a lot going on, and can’t even really grasp how often they really are taking pain medication, because they just are so ticked off that they have cancer and that they’re sick. It depends.*”

From this study phase, our main takeaway was that symptom tracking by patient families can be dynamic, reactive and self-selected. Clinicians focus on uncovering symptom details from both patients and their family members (often, a parent). Yet, these details are difficult to recall, explain, and elaborate on during clinical consultations. The patient’s articulation of their felt experience is highly valued and explicitly sought, but can also get lost. Incorporating multiple aspects of patients’ lived experiences—not just the specific manifestations of illness—could guide supportive care planning for families dealing with complex chronic illness management.

V. PHASE II: REVIEW OF PATIENT-GENERATED DATA

For our second set of interviews, we narrowed our focus to solid tumor patients, returning to a subset of clinicians recruited in the previous study. We elicited their responses to Visual ODLs structured in two narrative-based, PGD dashboard designs. The Visual ODLs represented self-reported symptom data that is expected for a sample patient profile, which we provided to them.

We used storyboards from the patient-focused study [12], collaboratively-generated with 13 adolescents (F=5; M=8) between 14–19 years of age, and their parents. Patients were

either currently undergoing treatment, or had treatments in the last three months for complex chronic illnesses related to solid or brain tumor ($n=11$) and sickle cell disease ($n=2$). Below, we further describe the dashboard designs for clinician review of patient-generated data in interview sessions with clinicians.

A. Designing Dashboards for Clinicians with PGD

Each of the two dashboard designs embodied a different stylistic approach to structure visual, narrative-based PGD. Patient storyboards were adapted to address role-based constraints faced by clinicians (i.e., time available for a consultation and access to data sources) [12,24,39]. The prototype dashboard designs met the four information objectives below.

- Display relationships between symptoms and activities, with visual representations of modifiers and auxiliary verbs such as “cannot do” an activity.
- Allow clinicians to access PGD in the form of media used to capture symptoms and other observations (e.g., photos, videos). Contextualize the data captured by indicating when they were captured with respect to ongoing patient-reported observations.
- Demarcate patient and parent contributions of observations of daily living, especially logged symptom data.
- Enable review of patient-reported symptoms by their frequency, severity and their interference with specific activities in the patient’s daily life.

We explored the last objective in a limited manner due to our access to only a single day of patient data.

We used a Wizard-of-Oz approach to demonstrate the expected interactions (e.g., *tapping*) for accessing media (Fig. 3 & 4). We showed sample patient-generated data on mobile devices to help clinicians experience each kind of media format type (charts, journal entries, photos or audio notes) indicated on the designed dashboards. The sources of the data collected are indicated by participant: logged by teens (green) or parents (light orange), and annotated with a fictional time of capture. Examples of activities and symptoms that patients would not like to share electronically with clinicians were shown with a red outline, and included for discussion purposes.

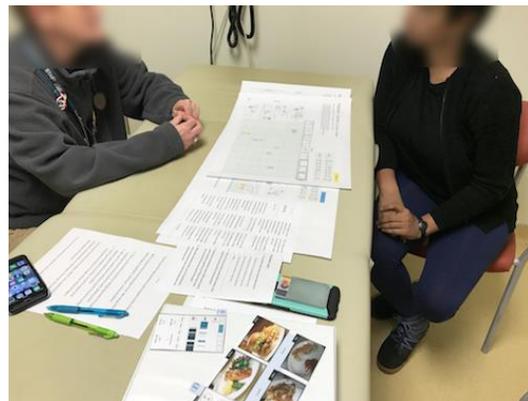


Figure 2. Researcher (right) conducts user interface design review and interview with field study participant (left) (Phase II).

a) Timeline

layout: This view structures patient-reported Visual ODLs in relation to the chronology of daily activities from waking up in the morning to sleeping at night. Retaining this narrative aspect, we created a timeline view arranging activities and symptoms across two rows and five columns. Symptom persistence is indicated by the lines from left to right, along a linear progression of activities performed by a patient on a day (Fig. 3).

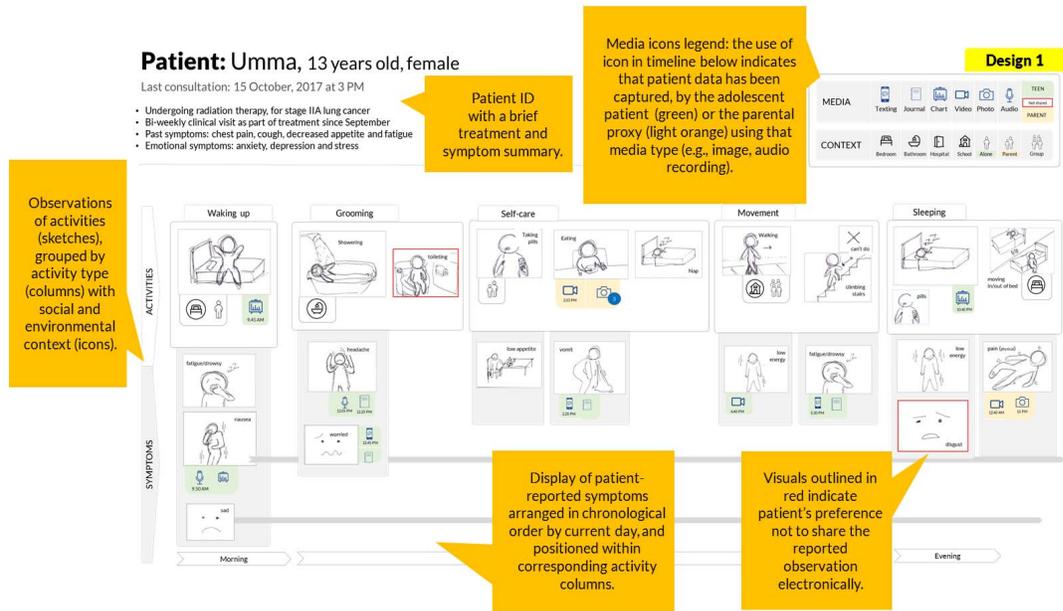


Figure 3. Design 1: Low-fidelity prototype shown to clinicians in Phase II, representing a daily timeline of patient-generated, Visual ODLs. Five call-outs were added to explain prototype components (shown in orange with black text).

b) Tabular layout: Taking into consideration the clinicians' need to review salient patterns in data, we arranged Visual ODL data in a tabular format to emphasize the interaction between symptom prevalence and associated daily activities. Here, we place symptoms in the order of frequency and PGD media with symptoms and activities (Fig. 4).

B. Clinician Review of Dashboard Designs

With informed consent, we conducted in-person design review sessions and semi-structured interviews, spanning a minimum of 30 minutes, with eight clinicians (Fig. 2). We showed clinicians a sample patient profile in the form of a personal, text-based vignette that included the sample patient's medical history. All clinicians routinely treated solid tumor patients, so the history was sourced from details in relevant public profiles of solid tumor patients on PatientsLikeMe¹. Storyboards with data generated by 11 patients with a diagnosis of solid tumor, from Hong et al.'s study [12] populated the prototype dashboard designs. (As described in the previous section, we produced a composite collection of Visual ODLs from these patients, to match the experiences typically felt by actual patients matching the patient profile.)

We oriented each review session with a brief, 10-minute introduction to the concept of Visual ODLs, and the two narratives for reading the fictional patients' data, one layout style per design (Fig. 3 & 4). Clinicians were encouraged to reflect on their own experiences communicating with patients with profiles similar to the sample patient profile. We provided interview questions to elicit information about the points in their clinical consultation flow that were opportune moments for

reviewing the visual data presented in the designs. We asked each clinician whether and how they would use each of the two proposed designs in clinical communication. Though we were prepared with a narrative verbal script describing the patient's data, all eight clinicians were able to read both visual designs without the need to refer to additional clarifications to guide their interpretation.

Each design included a short summary to identify the patient with details of their recent visits, and a legend to decode the visual media icons used in the visual narrative. The patient's socio-environmental context, such as location and presence of other people, were included and placed alongside *high-level* activities. For the purpose of this study, we coded recurring, *high-level* activities (e.g., waking up, grooming, illness-related self-care, movement and sleeping) from the storyboards generated by solid tumor patients. *Finer-grained activities* (e.g., teeth brushing and taking individual pills) were interchangeably arranged based on the patient's routine preferences. We grouped activities together to enable scanning from one set of activities to the next.

Symptoms most frequently reported by patients across physical and emotional indicators were placed in line with activities by time of day. PGD media preferences expressed by the adolescents and parents were placed closer to the relevant symptom, to appear like tabs (Fig. 3 & 4). They were placed next to the symptom to report the type of media the patient selected, to log that symptom.

We also inquired about other situations clinicians have encountered in their consultations, to learn what would motivate clinicians' use of Visual ODLs in their practice.

¹ Patient profiles sourced from <https://www.patientslikeme.com/>

We differentiated between parent- and patient-reported data based on findings from prior studies [13] (Fig. 3 & 4). In doing so, we delved deeper into the applicability of two different ways to structure the narrative view of Visual ODLs to reconcile reports by parents and adolescents.

After eliciting clinicians' initial responses to visual patient-generated data, we gauged the level of granularity of symptom data desired by clinicians in a dashboard design. From the use cases they suggested, we gained further design insights into how to construct digital dashboards for visual, narrative-based PGD.

C. Findings from Phase II

Once the clinicians were introduced to both layouts, they were able to make connections between activities and symptoms without the researcher's intervention. Between the two layouts, all clinicians preferred the tabular view (Design 2). They explained that this preference was related to their need to see an overview of the patients' experience between visits, which varies by the stage of treatment. C4 exemplified this finding well: "Yeah I like this [design 2] better. And I think especially if you're seeing them every two weeks, you know, if you could see if there would be, for example nausea and weight, you could see the specific light days. You look here [pointing to symptoms in design 2], you might say, you are nauseous on waking up four days last week."

Access to these narratives helped clinicians build a comprehensive history of descriptions of the patient's symptoms. This history is important because patients tend to set their illness experience in the background while going about their daily lives, foregrounding symptom information in relation to the onset of a clinical visit [24]. Parents may also selectively recall severity because of the time lapse between visits [C3–C5, C7, C8]. Clinicians saw value in reviewing data logged at a point in the past even if the symptom was resolved since the time of data capture. C3 expressed this view noting how, "[Its] great that they didn't really know, or they sort of forgot about it. But then the next time they get chemo and are feeling really crummy, we don't want them jumping off a bridge. You know, I mean, so I think it's important for us to know how bad they felt when we got something three weeks ago even though now they feel really good."

Clinicians mentioned their need to review three aspects of symptom-related data: *frequency, severity and persistence* of the symptom. Participation in evidence-based medicine requires tracking over long cycles of time. Clinicians expect

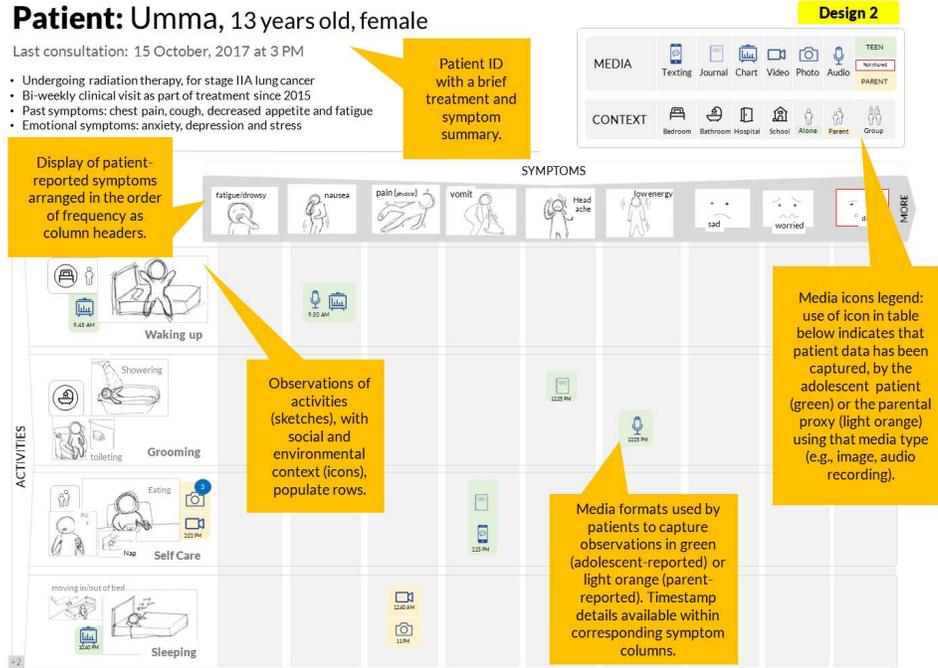


Figure 4. Design 2: Low-fidelity prototype shown to clinicians in Phase II, representing a tabular layout of patient-generated, Visual ODLs. Five call-outs were added to explain the components (orange with black text).

that over the course of their treatment cycles, patients will build up a history of narratives [C3, C6, C8]. They expected to see views summarizing data across visits—classified by each visit—to visualize progress over the course of treatment. For example, C3 stated that they desired: "...a way for us to dig deeper, but then we want to see a summary from one visit to the next."

The need to quickly glean the frequency of the symptom was mentioned in particular with reference to tracking physical symptoms [C2–C5, C7, C8]. As C5 mentioned: "...it's helpful to know how frequently they experience symptoms and what those symptoms are: intermittent vs. continuous vs. exacerbated by certain activities."

Physicians wanted to see both the recurrence of the symptom over time along with severity of the symptom reported in the data [C3–C5, C8]. C3 pointed this out in the context of emotional symptoms: "I think the severity of what would be here [for...] 'is pain greater than seven,' or the frowny face more than seven times. And down here, here's pain, three to five. When I'm [seeing] three to seven, [...] again you want [...] to know severity as well."

While pain has a standardized assessment scale [6,39], we learned from Phase I that clinicians evaluate most symptoms in a descriptive manner in conversation. We found that all clinicians (except C7, a nurse) relied on information about the activities affected in the patient's routine to assess the extent or severity of impact including pain. C3 mentioned how using this data could help them: "I mean we find out that every time they try to get out of bed and get up, showering for them is, like a major "to-do" "...I can't get my shoes off and my underwear off because my back hurts so much..."

Clinicians rely on activities to situate symptom experiences with respect to daily activities and socio-environmental context. The value of tracking how the symptom affects the patient in performing routine activities was validated in both layouts. C2 related how, “*It’s nice to know that the only time they have pain is when they’re walking up the steps vs. when they’re sleeping or when they’re trying to sleep.*”

Clinicians further saw the media shared by the patients as a way to learn how the patient experienced the symptom. However, they were cautious about what the process for reviewing these media would entail. C3 mentioned how “*It’s difficult [to review]—although we have plenty of folks who send us pictures now and even videos, just on the phone.*”

Another concern arose about video lengths and keeping these to a minimum [C1, C3–C5, C8]. C8 was enthusiastic about video to describe difficult symptom experiences and said, “*I think that again, if this is going to be something they use at home and they’re having a symptom that seems vague and unclear, [then] having a video... that would be revolutionary because, again, that’s a common problem here... I want them to describe it.*”

D. Use Cases for Tabular and Timeline Narrative Designs

In summary, clinicians were interested in and optimistic about the use of patient-defined PGD in their current practice, and the presentation of these PGD in visual, narrative formats. We organize findings in this section under three use cases for the use of dashboards as: *reviewing data before the consultation, reviewing data during the consultation, and remote follow-up between visits*. Below, we detail each use case and provide its rationale.

a) Use Case I: Preparing for the Consultation

We asked all clinicians about their desired uses of PGD in clinical communication. Seven of the eight clinicians (all except C5) mentioned specifically that they would review the data before they meet the patient and parent for the clinical visit. C5 also alluded to reviewing the summarized data as part of the ROS. This quote from C7 sums up the clinicians’ opinions: “*I mean it’s not necessarily something that I’m just going to get and flip through and read but they are going to give me an abbreviated version of what they have as I’m going through their Review of Systems.*”

Clinicians shared scenarios in which they would review the data and integrate it into their workflow [C3, C5, C7–C8]. The current flow of reviewing patient data involves referring to MyChart, an extension of the current Electronic Health Record (EHR) system in place at CHOA. Nurse practitioners collect information in-person before patients meet the physician [C3–C5, C7]. Quoting C5: “*I see it that the patient would fill this out, you know, once they get to the clinic part of their calling visit. They would enter it and then I would be able to receive it prior to going in and seeing the patient.*”

Clinicians conveyed concerns about accessing data from systems outside their current EHR workflow, which would add to the burden of review [C3, C5, C7, C8]. In the same context, C5 went on to explain this concern: “*We need everything in one place and if it’s not in one place, we’re not going to make the extra effort to go look for it elsewhere. So, there needs to be*

a link to it within our, you know, our other workflow. And I guess it would be preferable for me to have a link electronically that we could just pull it up versus risk losing paper or something.”

However, in terms of when to review Visual ODLs, clinicians mentioned that they preferred to use the narratives to update a mental model of the patients’ experiences before they met them. Being able to see this history beforehand would allow clinicians to prepare a plan for navigating the patient’s problems [C3, C4, C6, C7]. Clinicians could organize their conversations with details from the PGD narratives, as C6 mentioned: “*...it can certainly expedite a clinic visit because it can make it more problem focused. [...] These are the things we need to drill down and really evaluate today versus, getting this checklist and trying to review it real quickly before you go in the room. And then, you always end up [...] often end up veering off in a different direction.*”

Media shared by the patients could also provide evidence for clinicians to probe in discussion. Clinicians were favorably disposed toward images as observational PGD data, especially for nutrition intake and appetite tracking [C4–C6]. However, the media in these formats (images or video) need to be summarized, as C5 pointed out: “*Again as long as it’s something that I can look at and immediately get the information out that’s fine. I guess it’s: do I want to look at like 28 meals...so again, it depends on what the context is.*”

Overall, clinicians referred to shortlisting symptoms to attend to during their consultation with the patient [C2–C4, C8]. Having retrospective evidence gives clinicians an opportunity to prompt for details about the patients’ reported experiences. The Visual ODL narratives helped trigger responses as seen in C6’s observation that, “*sometimes we get very focused on why the patient is here that day and if it’s for chemo, we miss, kind of, what’s going on at home.*”

We found that the narrative PGD by itself would not inform the treatment plan, but could direct attention during the clinical consultation. As expressed by C5: “*I would change my descriptions after I talked to them all day long. I would never change anything based on just a log. So it’s really just a prompt to go through, you know, the symptoms at once, again most distressing for them.*”

b) Use Case II: Prompting for Details During the Consultation

Although clinicians commented on the value of using accounts of the patient’s illness experiences between visits to prepare for an upcoming consultation, they were enthusiastic about using the graphical dashboards in face-to-face consultation with the patients [C1–C4, C6, C8]. Through the shared viewing of Visual ODLs, clinicians suggested that they would prompt patient families to share specific details.

Access to data at both daily and summary levels lends itself to an interactive display of data. Without any prompts from the researcher, clinicians asked if data will be made available on a digital interface [C3–C4, C6, C8]. Clinicians alluded to personal computing devices [C3, C6], and preferred mobile [C6, C7], tablet [C4, C8] or larger screens [C3, C8]. The main aspect of data access was to see a snapshot or overview. C4

explained the rationale for using tablets: *"Yeah, I think a tablet would be especially... if you're looking at sort of big picture, frequency kind of things, and then you could [...] lead me to the actual experience. I think the tablet can be fine."*

Clinicians expected to use the tabular view as an anchor to effectively guide discussion. It could help keep track of talking points without distracting from the main topic (potentially identified from Use Case I). C8 illustrated this point with: *"You know sometimes when you're talking about symptoms it's not necessarily linear. They start talking about something else or this and that prompts discussion of another symptom. And sometimes when it's not written down or in concrete fashion. It's very hard to mentally keep track, if that makes sense. And so having something concrete like this would help to kind of come back to you know this is what [you logged]."*

The visual means of presenting PGD appealed to the clinicians. They saw its value in engaging young patients with by offering them the opportunity to create and navigate the first-person perspective of their illness experience, especially through the timeline view. C3 explained this with: *"You know I think for them to see what they're [logging], they have to pull it up on the screen to, kind of, go through it with you, you know. So, I think with a format like this, that you can visually look at it with the kids would be helpful."*

Some clinicians argued for the need to switch flexibly between tabular and timeline views so that they can direct patients, or be directed by patients to a specific instance of logged data. By doing so, patients can draw from a specific day to illustrate their self-collected data observations [C2, C4, C5]. C2 said: *"[Its] a way to identify, like, one day they're like off the chart for some reason. And then you can go back to that particular day and look at it and then you could also specifically ask the question about that particular day."*

c) Use Case III: Following Up After the Consultation

Supportive care for cancer requires coordination among a team of clinicians and clinical staff members, including (but not limited to) physiotherapists, psychologists, nutritionists, and family support specialists. Clinicians considered that the review of these visual narratives can contribute to identifying the involvement of the care team [C3–C6, C8].

Care team members [C4–C6] could be seeing data independently or in parallel. For example, independently during nurse triage, and in parallel for early interventions in nutrition or family support with psychological support teams when nurse practitioners and oncologists consider treatments before meeting with patient families. C8 said: *"I would want it to be something that was available for everyone to look at. So, they won't have to rely on me to tell them..., [and] they're thinking for themselves in the context of their roles."*

Nurses could intermittently follow up on how patients are coping with treatment effects by monitoring their daily reported entries of ODLs between visits [C4–C7]. One of the nurses, C7, told us that she prescribed a symptom diary for patients who have reported or exhibited signs of frequent symptom occurrence. While it is common practice for nurses to follow up with patients over a phone call a few days after their visit, C7 expressed a strong desire to see what the patient

logged through the timeline view. Describing further how the layout of PGD could inform the type of interaction, C7 said: *"It would be nice if this was already sitting in my queue. I'm dreading whatever it could be. Whenever they come in, I would already know how many times to date she [the patient] had diarrhea, [when] she began to drink... and it would be nice for them to be able to talk [about it]... 'Well, at this time she had this many ounces.' And it's very easy on a map here, or [to] here, from there [pointing to the symptom detail]."*

Nurse participants highlighted the need to track adherence to prescribed medications, and they expected to refer to the narratives to grasp the extent to which an intervention had impact on managing the symptom. In C7's words: *"And when I go back and ask them, all this time they were vomiting, 'did you get the medication?' They can have it flag the times that they [parents] gave the medicine."* Caregivers could refer to the collected data for a reference point in their past experience as C7 further added, *"...the parents could go back and see trends...so even for the parents to be able to 'trend' what was going on the last time he [the patient] was feeling this way, or might be able to help them manage things better at home."*

Keeping closer track of symptoms can help complement clinical data when clinical correlation is needed to assess and diagnose problems. As C6 mentioned, *"Information like this [points to media icons in the dashboard designs] may help us if we're trying to work on some kind of symptom management protocol, or we're trying to improve or collect data on symptoms and trying [to] correlate things or whatever."*

Having logged the data themselves, patients and parents are likely to access and review their own data, too. Clinicians mentioned that patients might find trends in these data that suggest particular support needs at particular times, and use this information to support care team coordination [C4, C5, C7] to ensure everyone is acting in concert. C4's comment described an example: *"As the medical oncologist we're sort of overseeing their whole treatment plan [...] in conjunction with all these other teams. But it's nice to have a discussion with them, and really know what's going on. And then have a discussion with the psychology providers, the psychiatry provider team that you're all on the same page because these all are really intertwined. So you want to make sure that everyone including the family and patient are on the same page [and that] is important. So, if it just said 'Go do this,' I think there would be a big disconnect for us."*

VI. DISCUSSION

Our study elicited clinician feedback to inform the design of patient–clinician communication technology that embodies the use of patient-defined and patient-generated data in clinical oncology practice. We set out to answer questions about the relevance of visual observations of daily living as a method for presenting symptom data to clinicians, in a formative user interface design study.

We asked clinicians to expand on patient-contributed visual symptom data, structured in two alternative narrative layouts, to elicit their detailed responses to each design. We then probed the perceived use of such patient-collected data in their functional roles as clinical caregivers.

In cancer care, clinicians often assess the patient's responses to therapy, and evaluate ongoing issues during survivorship, through retrospective, self-reported accounts of the experiences patients have outside of the clinic. From the patient's perspective, these experiences are often situated within their daily activities, spanning multiple facets of living with cancer. Through our study, we found that details requested by clinicians need not relate to patient-identified symptoms alone. For example, the adolescent's grades in school can reflect indirect indicators of psychological symptoms, social support, and coping. Thus, narrative layouts with multiple observations of daily living can help to surface concerns that could otherwise go undetected.

We also found that verbal reports alone may not sufficiently convey what the patient intends to communicate about their symptom-related experience. In these cases, clinicians valued visual narratives along with additional media captured by patients—in each format—to supplement verbal reports of illness experiences. Tools to elicit multimedia data from patients should provide guides for capturing rich formats (such as video segments) by attending to issues of image quality and length of recorded data. The adequate requirements can be judged ahead of time by clinicians and families, in concert.

Patient responses to treatments invariably differ, requiring adjustments in their treatment care plan. In the clinic, where their time and attention is the most constrained resource, clinicians can benefit from a summarized “snapshot” guiding their attention to problems. This need was reflected in clinicians' unanimous support and preference for the tabular layout of Visual ODL data. Our study highlighted several opportunities and potential scenarios of use for this tabular narrative design. First, this type of summary could aid clinicians in mitigating the burden of having to review patient data, by distributing the review task among members of the care team. In current practice, each patient encounter starts with the front-line nurse's systematic elicitation of the patient's medical history through the ROS symptom checklist, which the oncologists deem as inefficient. Still, they valued the ability to review a summary of the patient's health status between visits, surfacing symptoms and ordering them by *frequency*, *severity* and *interference with specific daily activities*.

Second, in the consultation scenario, the tabular view could enable clinician access to comprehensive patient histories of symptom data collected over time. Clinicians mentioned using these data to prepare for an upcoming consultation visit, to ground their in-person consultation and investigation of symptom experiences with patient families. Instead of reactive questions from clinicians, the tabular view could contextualize the discussion topics they would like to bring up during the consultation visit. Clinicians remarked on the positive potential to use visual PGD dashboard designs to engage adolescents, by prompting explanations of the data collected by them, on a shared in-clinic display.

While all clinicians valued the tabular dashboard layout, they also mentioned use cases for the timeline layout during in-person interactions with patients. Clinicians could refer to the timeline to note any deviations from the patient's routine, at the daily level if necessary. Though the timeline dashboard layout

was not their first preference, access to a sequential, granular display of a single day was deemed helpful during initial stages of cancer treatment, and for detecting early signs of the effects of therapy on the patient's quality of life.

Finally, our findings suggest that both narrative-based layouts: timeline and tabular, could support clinician-led communication with patient families by grounding the communication in the patient's observations, collected *in situ*. Clinicians suggested that patients could use the timeline to pinpoint symptom experiences, directing attention to a specific day's data, including the contextual observations surrounding their symptoms. Treatment care planning continues between clinical visits for long-term chronic illness management. After a consultation visit, care teams and patient families communicate remotely, tracking medication adherence, nutritional intake and other indicators of how the patient is coping with changes in treatment. Nurse practitioners in our study discussed the importance of monitoring trends in the symptom data logged by patient families, and saw many benefits of the timeline dashboard design to situate communication about treatment effects.

VII. CONCLUSION

We conducted a two-phase formative study with oncology clinicians, to gain insights into how adolescent patients' PGD related to symptoms should be structured for clinician review. Our study has limitations. Like many qualitative studies, we recruited a relatively small number of clinicians for short windows of time due to the demands on their availability. Our design prototypes represent a composite patient persona that was constructed based on actual patient data collected using Visual ODLs [12], but it is limited to observations spanning only one day of a realistic patient scenario from the collected dataset. Clinician reviews of patients' profiles with visual symptom data collected over a longer period of time is important to investigate in future work.

In a subsequent study, we plan to collect visual PGD narratives from patients using mobile technology. We will design clinician dashboards based on lessons learned in our study and we will use the deployment opportunity to investigate and validate the use cases presented here, by observing clinician interactions during consultations with patient families. Our design objective is to support shared decision-making in pediatric care [5] through inclusive, patient-centered technologies that support effective communication during care consultations.

ACKNOWLEDGMENTS

We thank our study participants and the clinical staff for their support. This study was funded in part by NSF #1652302.

REFERENCES

- [1] A.M. Barbarin, P. Klasnja, T.C. Veinot, Good or bad, ups and downs, and getting better: Use of personal health data for temporal reflection in chronic illness, *Int. J. Med. Inform.* 94 (2016) 237–245.
- [2] R. Bassett, B.L. Beagan, S. Ristovski-Slijepcevic, G.E. Chapman, Tough Teens, *J. Adolesc. Res.* (2008).
- [3] P.F. Brennan, G. Casper, Observing Health in Everyday Living: ODLs and Thecare-between-the-care, *Pers. Ubiquitous Comput.* 19 (2015) 3–8.
- [4] E.K. Choe, B. Lee, M. Kay, W. Pratt, J.A. Kientz, SleepTight: Low-burden, Self-monitoring Technology for Capturing and Reflecting on

- Sleep Behaviors, in: Proc. 2015 ACM Int. Jt. Conf. Pervasive Ubiquitous Comput., ACM, New York, NY, USA, 2015: pp. 121–132.
- [5] C.-F. Chung, K. Dew, A.M. Cole, J. Zia, J.A. Fogarty, J.A. Kientz, S.A. Munson, Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data, in: Proc. 19th ACM Conf. Comput. Coop. Work Soc. Comput. - CSCW '16, ACM Press, New York, New York, USA, 2016: pp. 768–784.
- [6] J.J. Collins, M.E. Byrnes, I.J. Dunkel, J. Lapin, T. Nadel, H.T. Thaler, T. Polyak, B. Rapkin, R.K. Portenoy, The Measurement of Symptoms in Children with Cancer, *J. Pain Symptom Manage.* 19 (2018) 363–377.
- [7] P.G. Corrie, Cytotoxic chemotherapy: clinical aspects, *Medicine (Baltimore)*. 36 (2008) 24–28.
- [8] P. Deshpande, Bl. Sudeepthi, S. Rajan, C. Abdul Nazir, Patient-reported outcomes: A new era in clinical research, *Perspect. Clin. Res.* 2 (2011) 137.
- [9] F.D.A. Food, Drug Administration draft guidance for industry on patient-reported outcome measures: use in medical product development to support labeling claims, *Fed. Regist.* (2006).
- [10] A.L. Hartzler, J.P. Izard, B.L. Dalkin, S.P. Mikles, J.L. Gore, Design and feasibility of integrating personalized PRO dashboards into prostate cancer care, *J. Am. Med. Informatics Assoc.* 23 (2016) 38–47.
- [11] M. Hong, C. Feustel, M. Agnihotri, M. Silverman, T. Olson, S. Simoneux, L. Wilcox, Supporting Families in Reviewing and Communicating about Diagnostic Imaging Studies, in: *Submitt. Publ.*, 2016.
- [12] M.K. Hong, U. Lakshmi, T.A. Olson, L. Wilcox, Visual ODLs: Co - Designing Patient - Generated Observations of Daily Living to Support Data - Driven Conversations in Pediatric Care Aflac Cancer and Blood Disorders Center, (2018).
- [13] M.K. Hong, L. Wilcox, D. Machado, T.A. Olson, S.F. Simoneaux, Care Partnerships, in: Proc. 2016 CHI Conf. Hum. Factors Comput. Syst. - CHI '16, ACM Press, New York, New York, USA, 2016: pp. 5337–5349.
- [14] P.S. Houts, C.C. Doak, L.G. Doak, M.J. Loscalzo, The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence, *Patient Educ. Couns.* 61 (2006) 173–190.
- [15] A. Jang, D.L. MacLean, J. Heer, A. Jang, D.L. MacLean, J. Heer, BodyDiagrams, in: Proc. 32nd Annu. ACM Conf. Hum. Factors Comput. Syst. - CHI '14, ACM Press, New York, New York, USA, 2014: pp. 1153–1162.
- [16] R.E. Jensen, S.P. Gummerson, A.E. Chung, Overview of Patient-Facing Systems in Patient-Reported Outcomes Collection: Focus and Design in Cancer Care., *J. Oncol. Pract.* 12 (2016) 873–875.
- [17] K. Lee, H. Hong, Designing for Self-Tracking of Emotion and Experience with Tangible Modality, in: Proc. 2017 Conf. Des. Interact. Syst. - DIS '17, ACM Press, New York, New York, USA, 2017: pp. 465–475.
- [18] C. Lim, A.B.L. Berry, T. Hirsch, A.L. Hartzler, E.H. Wagner, E. Ludman, J.D. Ralston, "It just seems outside my health", in: Proc. 2016 ACM Conf. Des. Interact. Syst. - DIS '16, ACM Press, New York, New York, USA, 2016: pp. 1172–1184.
- [19] X. Liu, L. Liu, S.J. Simske, J. Liu, Human Daily Activity Recognition for Healthcare Using Wearable and Visual Sensing Data, in: 2016 IEEE Int. Conf. Healthc. Informatics, IEEE, 2016: pp. 24–31.
- [20] G. Marcu, A. Dey, S. Kiesler, Designing for Collaborative Reflection, in: Proc. 8th Int. Conf. Pervasive Comput. Technol. Healthc., ICST, 2014: pp. 9–16.
- [21] L.S. Matza, D.L. Patrick, A.W. Riley, J.J. Alexander, L. Rajmil, A.M. Pleil, M. Bullinger, Pediatric Patient-Reported Outcome Instruments for Research to Support Medical Product Labeling: Report of the ISPOR PRO Good Research Practices for the Assessment of Children and Adolescents Task Force, *Value Heal.* 16 (2013) 461–479.
- [22] H.M. Mentis, A. Komlodi, K. Schrader, M. Phipps, A. Gruber-Baldini, K. Yarbrough, L. Shulman, Crafting a View of Self-Tracking Data in the Clinical Visit, in: Proc. 2017 CHI Conf. Hum. Factors Comput. Syst. - CHI '17, ACM Press, New York, New York, USA, 2017: pp. 5800–5812.
- [23] J. Mirkovic, Jelena, Utilizing emerging technologies to promote more efficient face-to-face patient-clinician communication, in: Proc. 2013 ACM Conf. Pervasive Ubiquitous Comput. Adjun. Publ. - UbiComp '13 Adjun., ACM Press, New York, New York, USA, 2013: pp. 1393–1396.
- [24] V.M. Montori, A. Gafni, C. Charles, A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes., *Health Expect.* 9 (2006) 25–36.
- [25] H.S. Murthy, W.A. Wood, The Value of Patient Reported Outcomes and Other Patient-Generated Health Data in Clinical Hematology, *Curr. Hematol. Malig. Rep.* 10 (2015) 213–224.
- [26] T. Ni, A.K. Karlson, D. Wigdor, AnatOnMe, in: Proc. 2011 Annu. Conf. Hum. Factors Comput. Syst. - CHI '11, ACM Press, New York, New York, USA, 2011: p. 3333.
- [27] L.M. Ong, J.C. de Haes, A.M. Hoos, F.B. Lammes, Doctor-patient communication: a review of the literature., *Soc. Sci. Med.* 40 (1995) 903–18.
- [28] R.A. Patel, A. Hartzler, W. Pratt, A. Back, M. Czerwinski, A. Roseway, Visual feedback on nonverbal communication: a design exploration with healthcare professionals, in: *Pervasive Comput. Technol. Healthc. (PervasiveHealth)*, 2013 7th Int. Conf., 2013: pp. 105–112.
- [29] R.A. Patel, P. Klasnja, A. Hartzler, K.T. Unruh, W. Pratt, Probing the benefits of real-time tracking during cancer care, in: *AMIA Annu. Symp. Proc.*, 2012: p. 1340.
- [30] L.R. Pina, S.-W. Sien, T. Ward, J.C. Yip, S.A. Munson, J. Fogarty, J.A. Kientz, From Personal Informatics to Family Informatics: Understanding Family Practices Around Health Monitoring, in: Proc. 2017 ACM Conf. Comput. Support. Coop. Work Soc. Comput., ACM, New York, NY, USA, 2017: pp. 2300–2315.
- [31] E.S. Poole, T. Peyton, Interaction design research with adolescents, in: Proc. 12th Int. Conf. Interact. Des. Child. - IDC '13, ACM Press, New York, New York, USA, 2013: pp. 211–217.
- [32] PROMIS, Patient-Reported Outcomes Measurement Information System: Dynamic Tools to Measure Health Outcomes from the Patient Perspective, (2015).
- [33] T.J. Reese, K. Kawamoto, G. Del Fiore, C. Weir, J. Tonna, N. Segall, P. Nesbitt, R. Waller, D. Borbolla, E. Moretti, M.C. Wright, Approaching the Design of an Information Display to Support Critical Care, in: 2017 IEEE Int. Conf. Healthc. Informatics, IEEE, 2017: pp. 439–443.
- [34] M. Shapiro, D. Johnston, J. Wald, D. Mon, Patient-generated health data, *RTI Int. April.* (2012).
- [35] C.F. Snyder, K.C. Smith, E.T. Bantug, E.E. Tolbert, A.L. Blackford, M.D. Brundage, What do these scores mean? Presenting patient-reported outcomes data to patients and clinicians to improve interpretability, *Cancer.* 123 (2017) 1848–1859.
- [36] A. Stevens, H. Pridham, S. Szigeti, S. Diamond, B. Arunchalan, The care and condition monitor: Designing a tablet based tool for visualizing informal qualitative healthcare data, in: 2014 IEEE Conf. Vis. Anal. Sci. Technol., IEEE, 2014: pp. 279–280.
- [37] M. Swan, Emerging patient-driven health care models: an examination of health social networks, consumer personalized medicine and quantified self-tracking, *Int. J. Environ. Res. Public Health.* 6 (2009) 492–525.
- [38] J.M. Valderas, A. Kotzeva, M. Espallargues, G. Guyatt, C.E. Ferrans, M.Y. Halyard, D.A. Revicki, T. Symonds, A. Parada, J. Alonso, The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature, *Qual. Life Res.* 17 (2008) 179–193.
- [39] J.W. Varni, M. Seid, P.S. Kurtin, PedsQLTM 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations, *Med. Care.* 39 (2001) 800–812.
- [40] P. West, R. Giordano, M. Van Kleek, N. Shadbolt, The Quantified Patient in the Doctor's Office: Challenges & Opportunities, in: Proc. 2016 CHI Conf. Hum. Factors Comput. Syst., ACM, New York, NY, USA, 2016: pp. 3066–3078.
- [41] Q. Zeng-Treitler, H. Kim, M. Hunter, Improving patient comprehension and recall of discharge instructions by supplementing free texts with pictographs., *AMIA ... Annu. Symp. Proceedings. AMIA Symp.* 2008 (2008) 849–53.