Just-in-Time Design: In Situ Methods for Capturing and Articulating Adolescents' Illness Experiences

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Abstract

During phases of treatment and between visits to the doctor's office, adolescent patients with complex chronic illnesses must recognize and communicate about illness-related experiences with a variety of caregivers. However, significant gaps exist in our understanding of how to design appropriate techniques for eliciting day-to-day, illness-related observations from these patients. To address this gap, we draw on qualitative research on the needs of adolescents with complex chronic illnesses to propose a new, in situ approach to eliciting participatory design input, called "Just-in-Time Design." Our approach draws inspiration from future breaching experiments and just-in-time intervention research, to both elicit adolescents' momentary experiences and couple these with participatory design feedback. In this position paper we discuss our work-in-progress including how we are currently applying Just-in-Time Design to design new symptom-tracking tools for adolescents with cancer and chronic blood disorders.

Introduction

Recognizing when an adolescent patient is experiencing physical responses to illness and treatment plays an important role in clinical decision-making. For adolescent patients undergoing long-term treatment, such as chemotherapy for cancer treatment, success requires a delicate balance between the effectiveness of treatment doses and their toxicity to the patient.[1] Symptom monitoring plays an important role in assessing treatment effectiveness. Designing tools that account for dynamic, spontaneous observations of the adolescent patient's illness experience—including symptoms—requires formative design research. Such research should incorporate the perspectives of patients, their caregivers, and their physicians, while being respectful of the needs of each stakeholder group.[2] However, there is limited research investigating how to conduct participatory design research with adolescent patients in this domain. In this paper, we describe our ongoing work on **designing interactive tools and methods for capturing adolescents' symptoms and other illness-related experiences, and articulating these experiences** in ways that align with the adolescent patient's needs.

First, we provide background motivating the need for our approach. We discuss practical challenges that occur when conducting formative and design-oriented research with ill adolescents. Finally, we introduce Just-in-Time Design, and situate our design approach with respect to complementary methods. Two questions drive Just-in-Time Design research: Can we progressively collect data about individuals' illness-related experiences in varied contexts and in near-real-time? Can we build on observational data we collect, to elicit direct, formative design input from patients in order to co-design solutions for articulating patient experiences?

Background

In pediatric care, caregiver-reported (most often, parent-reported) assessments are often relied upon, though pediatric patients experience symptoms directly.[2] However, to rely on caregiver's assessments alone engenders the risk of misinformation. In fact, studies have consistently found statistically significant differences between pediatric patients and parents' assessments of the patient's physical and psychological symptoms and behavior.[3,4] Yet in a recent field study, Hong and colleagues found that both tracking adolescent cancer patients' symptoms and reporting them to clinical caregivers were significantly difficult—for both patients and their parents. These difficulties were not due to a lack of communication *channels.* Instead, they arose from an inability to *capture* and *articulate* patients' illness-related experiences—both physical and emotional—as they unfolded in the patient's daily life.[2]

The direct *capture* and *articulation* of patients' health assessments, or Patient-Generated Health Data (PGHD), often occurs outside of typical care contexts (e.g., home, school, work, etc.), and is handled through electronic or paper-based instruments that patients can use to directly contribute observations related to illness severity, treatment experiences, and quality of life. Patient-Reported Outcomes (PROs), prominently through PROMIS measures, are a common form of PGHD which are gradually being integrated into clinical workflows as electronic health record systems evolve.[5] When integrated into Patient Health Records (PHR) and patient portals, well-implemented PROs have the potential to empower the patient to take ownership in managing their health through improved collaboration and communication with clinicians.[6,7]

However, existing PRO measures are insufficient when used alone to capture nuances of the adolescent patient's experience. First, concerns about methods used to achieve content validity and elicit momentary experiential data renders PROs an inadequate measure for understanding young patients' illness experience. For example, many commonly used child-reported measures have a recall period of the past 30 days.[8] This could be problematic for young patients who may not have yet developed the cognitive skills necessary for comprehending time frames.[9]

Regardless of the patients' age, the FDA PRO guidance[5] states that "*PRO instruments that call for patients to rely on memory, especially if they must recall over a long period of time … are likely to undermine content validity. Response is likely to be influenced by the patient's state at the time of recall. For these reasons, items with short recall periods or items that ask patients to describe their current or recent state are usually preferable."* Based on this guidance, a task force report on good research practices for pediatric PRO instruments has recommended recall periods of 24 hours or less.[9]

While the FDA encourages researchers to provide documentation of content validity based on patient input, a recent review of pediatric PRO instruments used in support for medical product labeling cautioned that content validity of child- and parent-reported pediatric measures has often been supported by input from parents or clinical experts rather than the children themselves.[9] Yet there is growing evidence that involving children in the content validation process can be more effective than doing so with clinical experts alone. For example, one study concluded that, when establishing content validity, involving adolescent patients as "experiential experts" resulted in greater relevance of the PRO for the target population.[10] Thus, there is justifiable reason to start including adolescent patients as content validity experts when developing PRO instruments targeted at adolescent populations.

Most importantly, PROs are designed in a "static" manner—comprising multiple-choice questionnaires—and often lack the expressiveness needed to convey complex internal experiences and the situational context surrounding a health assessment. Brennan and Casper recently highlighted this problem in a paper summarizing lessons from Project HealthDesign,[11] a national PGHD initiative research program funded through the Robert Wood Johnson Foundation, stating, *"the things that patients attended to, the language they attached to those phenomena and the ways in which becoming aware of this information stimulated health action, and the language used to describe those things was often substantially different from that used by health professionals. Indeed, not only were the traditional terminologies of health inadequate to express the phenomena of interest, but the very structure of the terms and the purpose they served in the individuals' lives were markedly different from the signs and symptoms terminology employed by clinicians to denote meaning in health."*[12]

In parallel, emerging research in Medical Informatics and Human–Computer Interaction (HCI) handles the direct capture and articulation of a patient's illness experience through mobile and ubiquitous sensing technologies.[13,14] For example, Pina and colleagues leveraged on-body sensing to capture stressful family situations and provide feedback, in situ, to parents of children with ADHD.[14] We can now collect a rich set of both personal and contextual information, where both the illness experience—and the "sampling" or "reporting" of that experience—occurs in a closely-coupled manner. The collection and reporting can now occur in near-real-time, across the user's natural settings (i.e., extending beyond the care setting to the home, workplace, school, and other non-clinical settings).[12]

Design Research with Ill Adolescents

Participatory Design (PD) methods, including interviews and participatory workshops, are often employed in formative design research with children.[15] Miller et al. recently adopted these methods to design inpatient communication tools for hospitalized children, by drawing on perspectives of multiple stakeholders involved in the pediatric patient's care.[16] However, these methods present notable limitations in our domain. The presence of authority figures (i.e., researchers, parents) can discourage candid responses from adolescent participants in interviews and workshops. Including adolescents' peers in formative studies can yield higher engagement.[17] Yet, even the presence of peers can inhibit candid responses, especially regarding sensitive topics related to personal, lived experiences of illness.

A key tenet of PD is to directly involve the intended users of an envisioned technology in the design process, and to conceive of the design in an iterative fashion via multiple design activities with user–participants. While in-person meetings offer irreplaceable value, especially for eliciting expressive feedback (e.g., arts and crafts, role-playing, etc.), coordinating these activities with ill adolescent patients often means removing them from context that is in fact vital to capture. Using retrospective methods to capture adolescents' experiences often means removing them from immediate context and relying on memory rather than actual events. Consequently, the design ideation that follows is, in part, removed from authentic experience. This tension between the need to elicit everyday experiences while

acquiring personally- and contextually-relevant design feedback—*directly coupled with those experiences*—calls for a new method within PD.

Table 1. We situate Just-in-Time Design research with respect to other complementary approaches that are often used to elicit formative design input from children and adolescents.[16–23] Circles (empty, half-full, and full) indicate the strength of the relationship between the class of design methods (one per row) and the features of the PD process that are essential in our domain (one per column). A full circle indicates a strong relationship, a half-full circle indicates a moderate relationship, and an empty circle indicates a weak relationship.

	Ethnographic observation	Participant-initiated data collection	In situ data collection	Breaching experiment	In situ design activity	Response to design
Workshops (e.g., Miller et al. 2016, Webster et al. 2015)	◐	○	○	◐	◐	●
Scenario-based (e.g., Davidoff et al. 2007, Odom et al. 2012)	◐	○	◐	●	◐	●
Probe-based (e.g., DiSalvo & Roshan 2014, Tsvyatkova & Storni 2014)	○	●	●	○	○	◐
Experience Sampling (e.g., Riekhoff & Markopoulos 2008, Colombo & Landoni 2014)	○	●	●	○	○	◐
Just-in-Time Design	◐	●	●	●	●	●

Table 2. Description of features of the PD process

Ethnographic observation	Studies involve observing a participant in ways that adopt the user's point of view in a natural setting.
Participant-initiated data collection	Data collection activity is driven by the participant.
In situ data collection	Data collection occurs near in time and in place to actual moment of experience.
In situ design activity	The participatory design activities are themselves situated in the user's natural setting.
Breaching experiment	Exploration of participants' reactions to envisioned technologies in future scenarios.
Response to design	Ongoing exploration of participants' reactions to design artifacts.

Just-In-Time Design

Our approach attempts to mitigate the challenges of collecting everyday symptom-related data from adolescents and engaging them in co-design activities to re-envision which symptom-related experiences should be captured, and how. As we describe below, Just-in-Time Design takes inspiration from just-in-time mobile experience sampling methods, future breaching experiments, and probes.[13,24,25]

Experience sampling

Recent mobile health (mHealth) research to support behavioral modification incorporates "just-in-time" detection of behaviors followed by timely health interventions tailored to the event.[24] We similarly aim to capture moments in which particular phenomena occur—in our case, patients' symptoms—through mobile experience sampling, which is often used to collect day-to-day experiences of patients. In place of interventions, however, contextually relevant design activities are triggered, which we describe further below.

Breaching experiments

Breaching experiments, first conceptualized by Garfinkel and later imported into HCI research via Crabtree, provide insight into expected practices around future ubiquitous technologies in the absence of prior practice.[26,27] Davidoff et al. demonstrated the utility of breaching experiments through scenarios.[25] Scenarios are depicting through storyboards that are designed to elicit participants' future needs relating to an imagined use of technology.[25] For example, scenarios in each fictional situation can convey varying degrees of system autonomy—reflecting the extent to which a technology "takes control" over a situation to support a human's goal: a robot can automatically provide meals for children, or instead only be involved in reminding and preparation tasks—leaving the actual task of cooking in the hands of parents. By exposing parents and children to multiple alternative scenarios to establish the

same goal, future breaching experiments help researchers determine where the boundaries of acceptable social norms lie.

Probes

Probes—cultural[28], technology[29], medium[19], and other variants of probes—play an integral role in HCI research to study the everyday lived experiences of informants. By introducing technology artifacts (e.g., camera, journal, etc.) into people's lives, probes invite people to become co-partners in the design process, by which control over data collection and design activities is transferred from researchers to participants of the study.[17,33] Several varieties of probes have been applied to study personal health management practices and both psychosocial and information needs. Mamykina and colleagues introduced cognitive probes[30] to investigate how individuals' diabetes management practices were tied to their approaches to interpreting and reasoning about their data. Wilcox introduced a probe to study the use of tools to complement automated methods for searching for and reviewing online health information[31] for uncovering how to accommodate patients in tracking pain and responses to therapies electronically during post-surgical inpatient care.[32]

Most relevant to our current work, recent studies adopted probes to understand adolescent's illness experiences, showing their favorable attitudes toward probe-based methods.[17,34] For example, Poole and Peyton saw the use of mobile video–based probing methods as means to capitalize on adolescents' familiarity with expressive media tools so as to empower them to "become co-producers of the data collected about them as part of requirements gathering processes" by contributing their self-reported illness experience data.

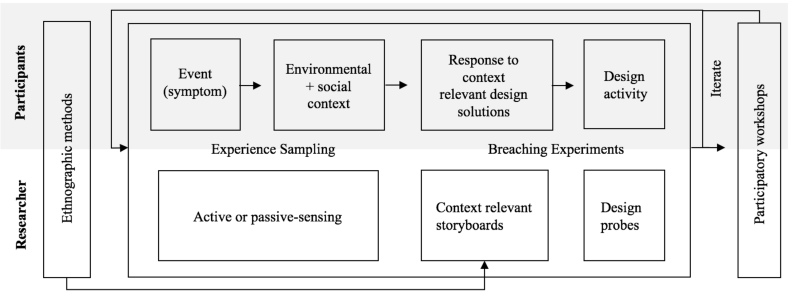

Figure 1. Just-in-Time Design research design. Boxed items on the top and bottom rows show research and data collection tasks expected to be completed by the researcher and study participants. Researchers can later decide at any point in time to hold PD workshops with all involved participants with illness experiences and design feedback captured over time.

Figure 1 shows an overview of Just-in-Time Design research. We rely on active self-reporting (both system-prompted and participant-initiated) as well as passive sensing of behavioral- and physiological correlates of specific symptoms, such as stress and interrupted sleep.

Once an illness-related experience is *captured,* participants are further prompted to describe it along with the immediate social (e.g., alone, with parent, etc.) and environmental (e.g., home, school, etc.) context.

Based on the provided context, a breaching experiment is initiated. System prompts elicit participants' responses (e.g., qualitative or quantitative impressions) to short, contextually relevant design ideas and possible alternatives, which they can review and engage with, if they wish. Our designs begin with graphical illustrations on storyboards (drawing on Truong et al.'s[35] guidelines for storyboarding) that adolescent participants can choose from, re-arrange, and help to complete in their own words, illustrations, and other media. Their choice of medium is guided by probe-based design activities and the captured context.

Design activities explore whether and how the current symptomatic experience might be *articulated* and *shared* with various caregivers (both formal clinical caregivers, and informal family caregivers). In this way, we capture characteristics of symptoms that the adolescent alone experiences, in ways that are anchored to the immediate social and environmental context. Parental caregivers, on the other hand, can also contribute to the data collection and observations of symptoms.

Conclusion

In our ongoing work, we are investigating how to design symptom-tracking tools in ways that engage adolescent cancer patients and their parental caregivers while respecting transparency and adolescent privacy.

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