
From Retrospective to Real-time: a Study of Patient Tracking Behaviors for Cancer Symptom Management

Rupa Patel

University of Washington
Medical School
Seattle, WA 98103
rupatel@uw.edu

Predrag Klasnja

University of Washington
Medical School
Seattle, WA 98103
klasnja@uw.edu

Wanda Pratt

University of Washington
Information School &
Medical School
Seattle, WA 98103
wpratt@uw.edu

Abstract

Much of the work patients with cancer have to do for their own care occurs at home and away from the clinic. To manage symptoms effectively, patients must accurately report the symptoms and side effects that occur between visits to clinicians. Current patient-reported outcomes (PRO) tools administer *clinician-focused, retrospective* questionnaires to patients to better assess symptoms between visits. Meanwhile, we believe that a personal informatics approach could generate *patient-focused, real-time* solutions that promote patient reflection and action. To assess patients' needs and behaviors in the area of real-time tracking, we analyzed a rich qualitative data source consisting of interviews and observations with 23 breast cancer patients in active treatment. Insights from our work can inform the discussion on the challenges and opportunities of integrating non-clinical, patient data into the clinical setting.

General Terms

Design, Human Factors.

Copyright is held by the author.

CHI'12, May 5–10, 2012, Austin, Texas, USA.

ACM 978-1-4503-1016-1/12/05..

Introduction

Symptom management is a major problem for patients with cancer. Patients with cancer experience many unanticipated symptoms away from the clinic and do not always communicate the full extent of their symptoms to clinicians [5]. Researchers have developed patient-reported outcomes (PRO) questionnaire tools [9] to address these problems. PRO tools measure health outcomes and quality of life periodically or prior to appointments using validated questionnaires. Today, computer-based tools periodically administer PRO questionnaires to patients and generate summaries for clinicians to review, typically at appointment times. Reported benefits of PRO tools in particular include improved patient well-being and patient-clinician communication [9]. Despite these reported benefits, we see several missed opportunities for PRO developers to design tools that move closer to real-time tracking, characteristic of personal informatics [1], and away from requiring patients to retrospectively recall symptoms.

First, personal informatics tracking can empower patients with cancer to take a more active role in symptom management than the current generation of PRO tools. In PRO interventions, the patient does the work of answering questions, but all reflection on this information is done by the clinician. Because PRO tools focus on providing self-reported patient assessment for *clinicians* to digest, the opportunity to foster *patient* reflection and action is missed. For example, patients might forget about intense pain episodes immediately after an infusion because they feel fine when they go in for the next one. Tracking pain and reflecting on the link between pain and toxicity monitoring could help them bring up forgotten pain episodes with clinicians.

Second, current PRO tools do not leverage modern tracking features from real-time tracking or sensing applications that could provide a more accurate picture of health status. The retrospective nature of patient-reported health status in a question-answer format causes recall bias in the data [6]. Many questions are framed in a manner that requires patients to recall events from the last few days or weeks, such as “how many times in the 7 days have you...” Also, patients with cancer frequently suffer from memory deficits as a result of “chemo brain,” so events that are less salient could be difficult to remember. To move beyond retrospective questionnaires, personal informatics tracking tools should capture the following: variability of symptoms, mood states, or behaviors over time; cyclical patterns; and co-occurrence of symptoms, environmental conditions, and psychological states [7]. Some personal informatics applications in the consumer market already have some of these capabilities:

- Mobile personal informatics applications like Tonic (www.tonicselfcare.com) can support flexible, recurring, real-time data capture for a configurable range of symptoms.
- Bathroom scales like FitBit’s Aria (www.fitbit.com) can track and automatically record weight on a real-time basis, a crucial indicator of progress for some cancer cases.

Patients with cancer who are motivated to be vigilant about symptom management could decide to use personal informatics applications for themselves. Individuals vary in their desired level of ownership over symptom management, and currently, we have limited understanding on what patients with cancer want from

Figure 1. HealthWeaver Mobile check-in entry screen.



Figure 2. Web-based HealthWeaver tracking history graph for symptoms.

personal informatics tools for symptom management. A small 2009 survey of 134 rural cancer patients and survivors showed that about one-third tracked health issues in some tool, such as a notebook or calendar [1]. Questions remain regarding why the majority of patients did not track and what their reasons were for tracking. In addition, tools used were computer-based in only 12 cases. Since cancer communities comprise a different demographic than “quantified self” power users, we have to determine what motivation they would have to take up self-tracking. To empower patients to be more engaged in their own care through use of tracking tools, we need a deeper understanding of their needs and behaviors.

Methods

We investigated the information management practices of 25 breast cancer patients. For this project, we undertook a secondary analysis of interview data that focused on the patients’ tracking behaviors. Findings have informed hypotheses and research questions for further investigation during the first author’s dissertation and beyond.

A team of researchers, led by the last author, collected data for two qualitative studies on the personal information management (PHIM) practices of breast cancer patients. Twenty-three women with breast cancer who were in active treatment were recruited for this research. Participants were interviewed at home, over the telephone, or observed during clinic visits for a total of 3 to 5 meetings over a 4 to 6 week period.

In one of the two studies, 10 participants had access to HealthWeaver, a web-based and mobile PHIM tool with personal informatics features that was implemented

based on a needs assessment with the other 15 participants. One module of HealthWeaver enables self-tracking parameters through a “check-in” feature that lets the patient to record her overall state and provides sliders to track symptom severity, well-being, and pain as frequently as the patient wishes to. The self-tracking module provided default health issues to track (‘metrics’), including nausea, stress, energy, and coping, but any of these could be disabled and new health issues could be added. See Figure 1 for a screenshot of mobile data entry and Figure 2 for a web-based graph of symptom history.

For this qualitative analysis, the first author reviewed raw audio and transcripts of interview data, field notes, and photos of artifacts for emergent themes using open coding [8]. Higher-level themes for the coding scheme spanned: (1) motivations, (2) barriers, (3) specific health issues monitored, (4) data capture, (5) review, and (5) sharing of tracked data.

Discussion of selected findings

Our findings provide insight into tracking needs and behaviors specific to patients with cancer in active treatment. Many, but not all, of our participants were motivated to do what they needed to do to fight this life-threatening condition. The overwhelming nature of cancer made symptom management difficult to achieve practically on one’s own. One participant had her partner ask her how she was doing every day, and the partner recorded this information in a long Microsoft Word document. Others tried to track symptoms in notebooks and diaries, often in list or narrative form, interspersed with other non-symptom-related questions and information. Re-finding information related to symptoms when it was needed posed a challenge.

Meanwhile, participants who used HealthWeaver tracked more metrics than required and found the application engaging. Furthermore, one participant said that showing her oncologist her tracking history helped him take her hip pain more seriously.

Leveraging real-time personal informatics applications to empower patients is not a new phenomenon within the CHI community. Patients could learn from their own symptoms and behaviors when they have chronic conditions, such as diabetes [4] and heart disease [3]. In these cases, condition-specific personal informatics applications were able to enrich patients' understanding of how their disease was progressing and shed light on opportunities where they could make lifestyle changes in the moment to modify that progression.

In contrast, patients with cancer have limited control over disease progression and often have trouble managing symptoms. Rather than the individual taking on the onus of figuring out what is relevant to track, we could design tools that foster a joint collaboration effort with the clinician expert, the home-based caregiver, and the patient self-tracker. In such a scenario, the clinician generates suggestions of what to track, while the patient decides what is sustainable and important enough to go through with, and the caregiver serves a support role at home.

Conclusion

Rather than emphasizing solely clinician or patient reflection, cancer symptom management requires *shared awareness with caregivers and clinicians* (not just the individual with cancer). This workshop can clearly continue the discussion.

Acknowledgments

We would like to thank the iMed group for their support, the breast cancer patients who took part in the studies, and the NLM training grant for funding.

References

- [1] Hermansen-Kobulnicky, C. J. (2009). Symptom-Monitoring behaviors of rural cancer patients and survivors. *Support Care Cancer*, 17(6), 617-26.
- [2] Li, I., Dey A., Folizzi, J. (2010). A stage-based model of personal informatics systems. In *CHI '10*, 557-566.
- [3] Maitland, J., Chalmers, M. (2010). Self-monitoring, self-awareness, and self-determination in cardiac rehabilitation. In *CHI '10*, 1213-1222.
- [4] Mamykina, L., Mynatt, E. D., Davidson, P. R., Greenblatt, D. (2008). MAHI: Investigation of social scaffolding for reflective thinking in diabetes management. In *CHI '08*, 477-486.
- [5] Rogers, M., & Todd, C. (2002). Information exchange in oncology outpatient clinics: Source, valence and uncertainty. *Psychooncology*, 11(4), 336-45.
- [6] Stone, A.A., Shiffman, S., Atienza, A. A., Nebeling, L. (2007). *The Science of Real-Time Data Capture*. New York: Oxford University Press.
- [7] Stone, A. A., Broderick J. E., Porter, L. S., Kaell, A. T. (1997). The experience of rheumatoid arthritis pain and fatigue: Examining momentary reports and correlates over one week. *Arthritis Care & Research* 10(3), 185-193.
- [8] Strauss, A. L., Corbin, J. M. (1998). *Basics of Qualitative Research*. London: Sage Publications.
- [9] Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., Selby, P. J. (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. *J Clin Oncology*, 22(4), 714-24.