© Copyright 2013

Rupa A. Patel

Design for Use and Acceptance of Tracking Tools in Healthcare

Rupa A. Patel

A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2013

Reading Committee:

Wanda Pratt, Chair

Donna Berry

Paul Gorman

Program Authorized to Offer Degree:

Department of Biomedical Informatics & Medical Education

University of Washington

Abstract

Designing for Use and Acceptance of Tracking Tools in Healthcare

Rupa A. Patel

Chair of the Supervisory Committee:

Wanda Pratt, Ph.D., Professor

Department of Biomedical Informatics & Medical Education

and School of Information

Tracking tools that collect patient-generated data can have a major impact on health outcomes and patient-clinician communication. The relationship between the patient and the clinician can be fundamentally altered when the patient uses a tracking tool. Clinicians can gain a more holistic understanding of patients instead of relying predominantly on clinic visits for input, and patients can better understand how to manage their condition tool use. Yet, acceptance of tracking tools remains low.

In my dissertation work, I investigated patients' use of researcher-driven electronic Patient-Reported Outcome (e-PRO) and patient-driven Personal Informatics tracking tools during cancer treatment. In one study, patients who frequently used PRO tools had lower end-of-study symptom distress than those who used the tool once or not at all. Patient attributes, such as age, gender, and educational attainment, were not found to be an indicator of frequent voluntary use.

In a second study, I analyzed self-tracking attitudes and behaviors of 25 women with breast cancer. Results showed that patients' tracking behaviors outside of the research context were fragmented and sporadic, compared to when they were given personal informatics tool. Participants used information they had collected on the tool to view patterns among symptoms, feel psychosocial comfort, and improve symptom communication with clinicians.

To better understand the reasons why most patients do not realize the opportunity of using a tracking tool as a path to these benefits and to further inform future tool design, I propose two theoretical models: (1) the Model of Use of Tracking Tools by Patients and Clinicians (MUTT-PC) and (2) MultiTrack. MUTT-PC illustrates factors in symptom communication and feedback in scenarios that use no tracking tools, a patient-driven tracking tools, researcher- or clinician-driven tracking tools, or, in a proposed future scenario, symptom tracking tools that are used collaboratively by the patient and clinician. MultiTrack provides a deeper understanding of tradeoffs in requirements for tracking tool developers, by enumerating multiple dimensions to be considered in design for use and acceptance: (1) the patient, (2) clinician, (3) data collected and presented, and (4) the tracking tool itself. This work contributes to health informatics, health services, human-computer interaction, and information and management science.

In this dissertation, I propose the use of a novel framework that separates clinical and personal usefulness of data from the perceived value of the tracking tool itself. Further, incorporating the context of healthcare into tracking tool development considerations promises that both clinicians and patients can realize the value of self-tracking as next-generation tracking tools are deployed.

Table of Contents

Acknowledgments

It took a village to support me in the completion of my Ph.D. program. I am deeply grateful to have so many wonderful people in my life making this village a fun and stimulating place to live in.

My advisor, Wanda Pratt, is amazing at providing a safe place for her students to grow as both researchers and people. I also have grown as a writer and a public speaker under her wise guidance. Other committee members have also had a hand in my academic development. I am grateful that Paul Gorman accepted the invitation in 2009 to serve on my committee, advising me during some difficult times and providing me with valuable resources, such as Kathryn Hunter's "How Doctors Think." Donna Berry has always been constructive with her feedback and provided great direction in pinpointing specific areas in which I could improve. Tom Payne, as my first rotation advisor, has always been gracious with his time and provided wonderful perspective. And finally, Beth Devine and I co-authored a paper in my initial year of the program that was my first foray into quantitative analysis.

The iMed lab, led by Wanda Pratt, has been a fun and intellectually active environment. Pedja Klasnja and Andrea Hartzler have been caring and intelligent academic "siblings" who have helped me develop as a writer and researcher by example. I have to include Eun Kyoung Choe, Jina Huh, Katherine Blondon, Logan Kendall, and many other iMed contemporaries in the acknowledgment list.

Other PhD students have been a great source of inspiration and help along the way. My cohort—Steve Rysavy, Denny Bromley, Melissa Clarkson, Wynona Black, Daniel Capurro, and Walter Curioso—are all brilliant and I have learned something from each one of them. Lauren

Wilcox Patterson has also a great sounding board for ideas and patiently listened to practice talks. Leila Zelnick tutored me in Biostatistics and was quite generous with her time. I also have to acknowledge Mary Czerwinski, who has provided me with an opportunity to extend ideas into Microsoft Research projects.

A balance of work and play keeps the spirit alive. I have many friends in Seattle to thank for this. Sharbani Roy and Tito Hubert have opened up their home on numerous occasions and have become family. I have also learned much about the holistic nature of my own productivity under Sharbani's great tutelage. Rachel Hanisch has also been a sister to me. In addition, I would like to thank Dasha, Alisher, Shannon Carney, Aisha Kaba, and Sameer and Jennifer Halai for coffee and fun times. Also, many friends made a special effort to listen to my dissertation practice talks, including Sarah Mennicken, Eun Kyoung Choe, Laurence Rohmer, Bas de Veer, Alan Au, and Jared Bauer. A heartfelt thanks also goes to Adrienne Andrew and McKenzey Bonart, who provided extra sets of eyes to proofread the dissertation draft.

And finally, my family deserves thank you for being who they are and always encouraging me to be my best self. Deepa, Alpa, my parents, Payal, and Neelam have all been supportive throughout this journey.

List of Figures

List of Tables

Chapter 1 : Introduction

People with serious illness such as cancer experience many unanticipated symptoms (1) and struggle to communicate them to clinicians during treatment (2). Patients with cancer contend with a variety of symptoms stemming from cancer progression, treatment regimens, and co-morbidities and many rely solely on clinic visits to get help with managing them. Yet these patients have difficulty conveying the full extent of symptoms along with chemotherapy infusions, surgeries, radiation treatments, and follow-up appointments (3,4) to clinicians. Although uncontrolled common cancer treatment-related symptoms, such as pain or fatigue, can have serious consequences if they are not controlled (5), clinicians frequently misjudge the intensity of patients' symptoms and undertreat them (3,6). In standard cancer care, patients find it challenging to prioritize and communicate urgency to clinicians (7). This problem is not unique to the context of cancer care.

Self-tracking of symptoms by patients can successfully address some of these problems. Patients who track symptoms at home as they occur can share symptom severity, frequency, and duration with clinicians. In turn, clinicians can better understand and address symptom burden. Additionally, cancer patients who initiate self-tracking can potentially experience benefits that have not yet been explored.

Outside of research settings, many patients do not typically have access to tools to effectively appraise and manage symptoms at home (8). Symptom tracking tools described in the literature review in Chapter 2 have shortcomings that may prevent wide acceptance in practice. At the same time, a proliferation of mobile and sensor-based technology that facilitates

tracking (9) provides an impetus to consider how employment of these technologies can help patients with a wide variety of chronic conditions to both manage their symptoms better and improve their quality of life.

In this chapter, I provide rationale for the importance of self-monitoring in symptom management for patients with cancer, define terms related to tracking tools that support symptom management, specify the major research question regarding patients' voluntary use of these tools, and describe how this dissertation addresses these questions.

Background and Significance

Part of this dissertation explores self-tracking in the cancer context. Cancers are complex diseases that arise from uncontrolled division of abnormal cells, often resulting in tumor growth. Patients with cancer often suffer from a more diverse set of symptoms than can be fully explained by disease characteristics and treatment side effects alone (10). Symptoms arising from cancer can include unexplained weight loss, fever, fatigue, pain, and skin changes, although it is possible to be asymptomatic (11,12). Patients diagnosed with cancer typically enter a treatment plan involving some combination of chemotherapy, radiation, hormone therapy, or surgery, often leading to worsened symptoms or additional side effects.

Symptom management, if implemented well, can have a major influence on patients' quality of life during cancer care. According to Jakobssen, symptom management is defined as an "intentional activity that depends on patient's subjective responses to experienced symptoms and can be initiated or performed by patients or healthcare professionals" (13). Dodd & Jansen described symptom management as both strategic and dynamic, influenced by patient outcomes, personal factors, the environment, and, of course, the illness itself (14). Although evidence-

based interventions exist for an increasing number of cancer-related symptoms, patients still suffer from untreated symptoms and do not receive enough assistance from clinicians in managing them (7). Studies identifying barriers to effective symptom management often narrowly focus specifically on one particular symptom or cluster of symptoms (3,15-17) such as pain, associated with both lower symptom and quality of life issues (SQLI) and survival rates from cancer treatment and palliative care (5).

The diverse and unforeseen nature of symptoms makes assessment and management of SQLI challenging (12). A major reason may be predominant use of medical interviews to assess symptoms in cancer care. When patients do not specify bothersome SQLI's during the clinic visit, clinicians assume that they are not a problem, even if they are brought up at prior clinic visits (13). Because symptoms typically increase over the course of chemotherapy treatment and then gradually diminish (15), this causes a misconception. As reviewed by Armstrong, frequency and intensity of symptoms is also difficult for clinical teams to assess in medical interviews (7). A significant number of cancer survivors experience a range of physical symptoms (nausea, weight gain, etc.) long after treatment ends, and uncontrolled symptom distress can persist over time (12).

Self-management is also quite difficult for patients with cancer. Although patients undergoing chemotherapy typically take few preventative actions to self-manage side effects at home (12), clinicians can play a definitive role in symptom management. The Institute of Medicine recommends that clinicians maintain a "continuous healing relationship" [p.66 from (16)] with the patient, rather than viewing cancer care in terms of short-term treatment. A recent study that took place in Sweden (13) explored barriers to clinicians' ability to help patients manage symptoms. Four major themes emerged: building a relationship with the patient,

understanding the patient, assessing symptoms, and collaborating with other healthcare professionals to ensure information exchange and clear responsibility (13). When patients used tracking tools and shared symptom data with clinicians, both were in a better position to assess symptoms and priorities. Tracking tools afford patients the potential to facilitate both self-monitoring and symptom management of their cancer (16), and healthcare in general (9).

Self-monitoring of cancer symptoms during treatment is not new. Patient-reported outcome (PRO) instruments and momentary experience sampling tools that support self-monitoring show benefit to patients, providing clinician awareness of potentially missed symptoms (17) and toxicity alerting (18). However, these tracking tools are often adopted in in academic medicine cancer care settings (19). In cancer centers throughout Ontario, Canada where the Edmonton Symptom Assessment Scale (20) has been used for years, nurses champion the benefits of PRO assessment for oncology patients, whereas only half of all physicians perceived PRO measures as improving care (21). These physicians were more likely to determine that care was more efficient when eliciting symptom priorities by talking with the patient than reviewing the PRO report (21). As a result of the predominant use of PRO tools in academic medicine, Glasgow calls for a pragmatic approach to PRO measurement that is instead informed by such implementation science models (22) as the Expanded Chronic Care Model (23). Rather than focusing on having clinics adopt PRO tracking tools, this dissertation investigates patients' voluntary use and acceptance of tracking tools are beneficial for cancer symptom management.

Definitions

In this dissertation, **self-tracking** is defined as the measurement or observation and self report of bodily symptoms and the impact on daily activities and cognitive processes (24). A **tracking tool** is used to support self-tracking of health issues. Tracking tools can be as simple as paper and pencil or as complex as an Excel spreadsheet including pivot tables and charts. **Real-time tracking tools** support capturing health issues in the moment, as they occur.

Dissertation Project Description

This dissertation extends prior work on types of tracking tools used in cancer care through analysis of actual voluntary use of e-PRO and personal informatics tracking tools, description of benefits that patients with cancer experience from personal informatics tracking tools, and proposal of a conceptual model that can help inform on tracking tool design and acceptance. The question that I attempt to answer is: **How do we design tracking tools that are used and accepted by patients?** Each chapter in this dissertation contributes to addressing this question as follows:

- Chapter 2 broadly reviews the current literature on three major types of tracking tools: those that consist of patient-reported outcome (PRO) instruments, ecological momentary assessment (EMA) tools, and consumer health informatics (CHI) tools in which the patient has control over tracking. The chapter concludes with theories that can help arrive at a deeper understanding of tracking tool use and acceptance.
- In Chapter 3, I analyzed voluntary use of an e-PRO tool by 372 people with cancer, characterized the relationship between frequency of voluntary use and symptom distress, and explored patient attributes related to frequent use. One-quarter of the patient

population used ESRA-C voluntarily two or more times over the course of cancer treatment. These patients had lower end-of-study symptom distress than those who used the tool once (significantly) or not at all (trending, but not significant). Patient attributes, such as age, gender, and educational attainment were not indicative of frequent voluntary use. Implications of study results are discussed in depth to conclude the chapter.

- In Chapter 4, I undertook a qualitative analysis of data collected on the personal information management practices of 25 women with breast cancer. For this study, a personal informatics tool was deployed as a technology probe to 10 women with breast cancer. Observational and interview data was analyzed to elicit the "in-the-wild" self-tracking practices of the 10 women before using HealthWeaver, as well as 15 other women with breast cancer. Results showed that, although "in-the-wild" tracking behaviors were fragmented and sporadic, tracking with use of personal informatics tools were more consistent. Participants also used tracked data to see patterns among symptoms, feel psychosocial comfort, and improve symptom communication with clinicians.
- Chapter 5 introduces a new conceptual framework intended to inform the design and acceptance of future tracking tools for cancer care. The two theoretical models in this framework are: (1) the Model of Use of Tracking Tools by Patients and Clinicians (MUTT-PC) and (2) MultiTrack. MUTT-PC illustrates factors in symptom communication and feedback in scenarios that use no tracking tools, a patient-driven tracking tools, researcher- or clinician-driven tracking tools, or, in a proposed future scenario, symptom tracking tools that are used collaboratively by the patient and clinician. MultiTrack provides a deeper understanding of tradeoffs in requirements for

tracking tool developers, by enumerating multiple dimensions to be considered in design for use and acceptance: (1) the patient, (2) clinician, (3) data collected and presented, and (4) the tracking tool itself.

- Chapter 6 specifies the contributions of the dissertation, implications of findings and the conceptual model, and directions for future work.

The dissertation supports convergence of tracking tool design for healthcare based on patient needs. By identifying and further understanding dimensions of importance for tracking tool design, I hope that future design of tracking tools will encompass greater benefits to patients and result in more integration into standard cancer care practices. If both patients and clinicians accept using tracking tools as an integral part of symptom management, we can move closer to continuous healing relationships that are the cornerstone of effective care.

Chapter 2 : Literature Review

"The approaches that are being used to develop e-Health technologies are not productive enough to create technologies that are meaningful, manageable, and sustainable."

- Julia van Gimert-Pijnen (25)

Patients have access to a variety of tracking tools for symptom management support. This chapter covers the use of two categories of tracking tools driven by clinicians or researchers, Patient-Reported Outcome (PRO) instruments, Ecological Momentary Interventions (EMI), and patient-driven tracking tools. Use of these tools have been associated with improved health and communication outcomes, but obstacles remain to widespread promotion of use and acceptance of tracking tools in standard cancer care. In this chapter, I discuss current types of tracking tool interventions and issues with their use by patients.

Most Americans do not use tracking tools to support their health. Although 7 in 10 track at least one health indicator, nearly half of this group use their memory, choosing to track "in their heads" instead of using a tracking tool (26). Of those who say they track, 34% report that they use paper and 21% say they use a computer to track health indicators (26). . Furthermore, the literature contains few studies on actual tracking behaviors of people with cancer. One 2009 survey asked 134 rural adult cancer patients and survivors to report their self-tracking behaviors (27). Results showed that nearly 1 out of 3 self-monitored symptoms during cancer treatment using some medium (27). Tracked data included treatment side effects (24%), trends in how they were feeling (worse, better...) (22%), effects of cancer on wellbeing (e.g., symptoms) (28%), and limits to usual activities (e.g., going to work, yard work...) (17%). A calendar or

datebook was the most common tracking tool, followed in popularity by a diary/notebook. Only 12 out of 134 subjects kept a diary on their computer (27). Although this survey suggests that a third of people with cancer track health issues during cancer treatment, the sample size was small and comprised of people from rural areas. Further, the survey did not address why they tracked and why the majority of people did not track. Knowledge is lacking about what cancer patients' motivation to engage in self-tracking and which tracking is beneficial enough to undertake.

Researcher- and Clinician-Driven Tracking Tools

In this dissertation, I study examples from two categories of tracking tools in which usage is driven by research use or for the benefit of clinicians: Patient-Reported Outcome (PRO) instruments and Ecological Momentary Assessment (EMA) tools.

Patient-Reported Outcome (PRO) Instruments

Patient-Reported Outcome (PRO) instruments have been historically used for patients' reporting of symptoms and wellbeing in clinical research settings (28,29). In the last 15 years, clinical informatics research has focused on how to promote PRO tool use in the context of standard clinical care (16,30-33). PRO instruments measure "any aspect of a patient's health status that comes directly from the patient (i.e., without the interpretation of the patient's responses by a physician or anyone else)" (29). These instruments are typically questionnaires that measure health status and quality of life, some of which are rigorously tested for psychometric properties (e.g., validity and reliability), and can be over 80 questions in length (11,30,34). PRO instruments are administered on a predefined schedule or immediately prior to appointments, either at home or in the clinic. The medium of administration could be paper-based (e.g., notebooks or diaries) or computer-based (e.g., interactive voice response (18), web-

based (17,35), or on a tablet computer (36,37). Figure 1 is an example of an e-PRO tool used for clinical care with a tablet interface for patients and a summary report for clinicians. In this dissertation, electronic computer-based PRO tools will be referred to as **e-PRO tools**.

Figure 2.1. Patient Care Monitor (PCM) Clinician Report (on the left) and Tablet Questionnaire (on the right) (38).

Patient self-reporting methods have been used for clinical research purposes as early as the 1920s in the form of paper-and-pencil diaries (28). Decades later, researchers devised PRO instruments to obtain symptom assessments for participants enrolled in clinical trials to be able to determine the impact of drugs or other interventions on patients' health status and quality of life (29,39). More recently, researchers have repurposed PRO tools, using them for routine symptom assessment and monitoring in clinical care, as well as raising clinicians' awareness of potentially

missed or underestimated symptoms (16,30-32). PRO results are occasionally an integrated part of the electronic health record (EHR) (33).

PRO Tools in Cancer Care

PRO instruments have a positive impact on patient outcomes when administered as an intervention for cancer symptom management in randomized controlled trials (17,18,35,40). Reported benefits of PRO tools include improved patient wellbeing (40-42), reduced need for symptom management support (41), lower toxicity during cancer treatment (18), and better patient-clinician communication (17,40,42). Other potential benefits include timely reporting and management of symptoms (43,44), reduced patient anxiety (42), fewer clinic visits or calls (45), greater patient adherence to advice (13), greater satisfaction with care (46,47), more effective self-management (41,42) and more efficient use of resources (13,16). In addition to raising clinicians' awareness of symptoms, many PRO tools in cancer care settings have evolved to provide alerts (18) and tailored advice to patients (17,35). In clinical settings, clinicians and practice managers could potentially use PRO instruments to measure outcomes that reveal quality of care, design system interventions, train health care personnel, and make administrative decisions given characteristics of a patient population (16).

Standard cancer care does not typically involve self-tracking with PRO instruments (30-32,48). Some researchers have explored why such tools do not appear more widely in practice (49,50). Ruland has examined use of web-based e-PRO tool WebChoice for cancer symptom management, deployed as part of standard care in Norway. WebChoice employs such patient-centered features as tailored self-management, discussion forums, and secure patient-clinician messaging. Tailored self-management allows patients to answer questions chosen from 19

problem categories and provides self-management material based on their responses. Two-thirds of users were considered active (2 or more uses) over the course of a year (41). Interviews with both active users and non-users of WebChoice revealed that active users perceived WebChoice to be more helpful than non-users, who just wanted to *"go about on with their lives"* and *"not be reminded of cancer"* (51). These findings demonstrate a need to accommodate patients' varying needs for support and diverse coping styles. A follow-up study investigating the use of WebChoice showed major disparity in individual patterns of feature usage between breast and prostate cancer patients (52). Breast cancer patients rated the discussion forum as very useful, whereas patients with prostate cancer found self-management features with symptom assessments had more value (52). A national Pew survey in the U.S. (26) supports some of these findings for patients with breast cancer from Norway. Peer support is a major reason that many patients with cancer use the Internet as opposed to to self-tracking symptoms (26, 53). This difference could occur either as a result of gender bias or the nature of the less straightforward disease treatment options of prostate cancer so contributing factors of perceived usefulness of self-tracking remain, in this case, undecided.

Barriers to PRO Tool Adoption

Despite reports of improved health and communication outcomes (17,18,35,41,55) from PRO tracking tools that were studied as interventions in randomized controlled trials, clinicians are generally resistant to incorporate them into clinical workflow (16,56). Some question whether instruments designed for research can be helpful in practice (16,48). I recognize several major reasons for their reticence: (1) cognitive bias in PRO instruments from retrospective recall, (2) obstacles to integration in an appointment-centric workflow, and (3) high patient data entry burden.

First, cognitive bias emerges in questions framed to require patients to recall events from the last few days or weeks, such as "how many times in the 7 days have you done X" (39). These questions assume that patients can remember all relevant symptom experiences over a specified time period and accurately represent them in the aggregate (39). In reality, patients who recall recent and salient symptoms self-report higher symptom distress over a 7-day period than their daily aggregated actual scores suggest, (57) making, temporal trends with a greater range more difficult to appraise retrospectively.

Second, clinicians or researchers usually administer PRO instruments prior to clinic visits, creating an extra burden on clinicians who must learn how to interpret the e-PRO score or summary report and find time to review it. With today's technology, self-tracking tools can capture signs and report symptoms in non-clinical contexts, providing a realistic picture of wellbeing and functioning *between* clinic visits. In spite of this, few PRO tools are deployed to take advantage of this.

Third, patients frequently find e-PRO assessments burdensome to complete. Psychometrically validated assessments are long and require that patients completely answer a full series of 80 or more questions (38), covering many more symptoms than any single patient experiences or cares to track. Tailored symptom assessments allowed patients to skip irrelevant questions, but current methods to analyze data for reliability and validity are complex and produce research evidence that can be inadequate for clinical decision-making (58). Because completing PRO assessments can be particularly arduous for patients in cancer treatment who are often emotionally overwhelmed and physically drained (51), patients who are depressed or experiencing pain are also less likely to track symptoms with questionnaires that feel burdensome, even in the context of research studies (39,59). One study of pain assessment

compliance among Italian cancer patients in an inpatient ward showed only a 58% compliance rate with daily pain reporting three times a day at least three times a week, when given a brief 4-question form (59). Reasons given for not completing the form included subjective psychological variables (44%), physical distress (26%), and absence of pain (16%) (59). Thus, variability in symptom reporting can be highly related to changes in patients' psychosocial condition.

In summary, although the use of PRO instruments in tracking tools for cancer care has benefits, such tools have not been deployed by most cancer clinics or adopted by patients on their own. In this dissertation, Chapter 3 includes an analysis of how e-PRO tools are voluntarily used when patients have access to them at home and how symptom distress or other patient attributes are associated with voluntary use.

Ecological Momentary Interventions (EMI) and Assessments (EMA)

An Ecological Momentary Intervention (EMI) is a program or tool that gathers repeated real-time measurements of phenomena in natural settings for the primary purpose of treating a patient's condition (60,61). The rationale for use of EMI emerged from Ecological Momentary Assessments (EMA), designed for researchers to better understand temporal phenomena in the real world. These interventions are termed "ecologically valid" because they take place in the natural environment and "momentary" because metrics of interest are measured at random or specifically identified moments in everyday life (60,61). The rationale for EMI and EMA rests on the major advantages for its use, which are: (1) minimizing recall, saliency, and recency biases through data collection in the moment, (2) collecting data in the context of daily life, and (3) being able to measure temporal concepts (39,61). Patients being studied can use Ecological

Momentary Assessment (EMA) tools to capture real-time health-related data in the context of their daily lives. EMAs provide a realistic representation of cues and experiences over time through time-sampled data collection, in which participants are notified at prearranged or random times to complete assessments or take measurements. Data collected could include open-ended entries in a diary, glucose monitor readings, or questionnaire responses (61). Variation in structure of collected data contrasts with traditional e-PRO data collection, which is questionnaire-based and often psychometrically valid. In the past, EMA protocols have been carried out on paper and subsequently using pagers. The prevalent use of smartphones expands possibilities for implementation by delivering interventions in real-time as symptoms happen and in real-world places or situations where interventions are most often needed.

Health-Related Use Cases of EMA/EMI Tools

The Experience Sampling Method (ESM), first introduced by Csikszenthmihalyi, aims to reduce bias from retrospective self-report diary studies (62). Csikszenthmihalyi used beepers and paper and pencil to develop his famous theory of "flow" to determine how participants' cognitive states contrast with their activities over time. Today, ESM is best known as "Ecological Momentary Assessment" (EMA), expanding the definition to cover assessment of both internal and external cues rather than just subjective experiences (60). EMA measures concepts of interest for researchers while EMI is a therapeutic intervention on its own and has been used to treat pain (63-66), anxiety and stress-related disorders (67,68), schizophrenia (69), smoking cessation (70), diabetes (71), and cancer-related fatigue (72). EMA tools have also been used to detect schizophrenia triggers, characterizing stress levels of individuals prone to psychosis prior to a psychotic episode (69). However, EMA methods have not been used in many multi-symptom cancer studies to date. Symptom monitoring studies using ESM often

focus on management of single symptoms (e.g., fatigue in breast cancer (72) or chronic pain (63,65). To date, studies use EMA in cancer care to understand the symptoms that patients have (72), rather than as deployment as an intervention (or EMI) that helps with symptom management during treatment.

Barriers to EMA/EMI Adoption

Like PRO assessments, EMI with self-tracking components also are not widely adopted for therapy or self-care in clinical settings (60). Evaluation of EMI has occurred through cross-discipline investigation of technologies for different clinical needs and using a range of methodological approaches (60). EMI are typically deployed using reminder beeps or notification messages that reach the patient in the middle of other activities. Although greater saliency of the symptoms being captured provides an advantage, frequent interruptions can be quite burdensome. When people are focused on tasks, they divert attention and affect productivity (73). In addition to the nature of the interruptions, current EMI data analysis methods are complex and make it challenging to interpret the data being captured (60,74). Often analysis of EMA/EMI data requires statistical techniques that allow for aggregation of within-person repeated measures and decisions to incorporate random or fixed effects across individuals. Even when EMI tools take these into account, it is best if patients and clinicians who read the reports know about underlying assumptions and implications.

Patient-Driven Tracking Tools

Patient-driven tracking tools come in many genres, including consumer health informatics (CHI) applications (75), personal informatics apps for health behavior change (76,77), e-Health applications (25), electronic diaries (78), or personal health records (PHR's)

(49). In this section, I describe such patient-driven tracking tools. Unlike other tracking tools, use of patient-driven tracking tools is initiated by the patient, as opposed to the patient being recruited as part of a research study or clinic intervention. The collected health data may or may not, therefore, be monitored by or shared with the clinician depending on whether the patient decides to do so. Patient-driven tracking tools also have potential to support cancer patients' understanding of how they should both handle particular symptoms and improve their self-management strategies.

Self-tracking of signs and symptoms is a major feature of many e-Health, e-Diary, and consumer health informatics (CHI) interventions (75). Few studies have produced evidence that patient-driven self-tracking is effective at improving health outcomes in cancer care. In one AHRQ-sponsored systematic review, of the 121 studies included, only 3 focused on supporting patients with cancer (75). Of these, only one study of breast cancer patients showed a significant positive impact. The authors also rated evidence for CHI's impact on outcomes as low for these studies (75). The scarcity of evidence extends to patient-driven self-tracking, especially because so many studies of e-Health and CHI interventions rarely separate effectiveness of tracking features or analyze the frequency of use outside of context of research studies. In the wild, we have limited understanding of how often e-Health and CHI interventions are used.

Although the research community is generally cautious about advocating use of patient-driven tracking tools in routine healthcare settings (79), grassroots interest in self-tracking as a hobby has emerged in the tech community (80). This interest, dubbed "Quantified Self" by *Wired Magazine* editor Gary Wolf, is designed to bring people together to discuss uses and features of tracking tools and provide community support for self-tracking endeavors (80). Tracking tools such as Fitbit (http://www.fitbit.com) and Moves (http://www.moves-app.com)

allow the average person to automatically collect data passively using sensor devices or even a mobile phone app that uses the phone's accelerometer. PatientsLikeMe (http://www.patientslikeme.com) and MedHelp (http://www.medhelp.com) not only provide web-based tracking tools, but also allow users to share data with caregivers and compare their own experiences with other patients in online communities. Currently, we are also witnessing a proliferation of mobile health applications (82).

In the field of human-computer interaction (HCI), study of Quantified Self tracking tools occurs in personal informatics, which involves investigation into the design and use of tracking tools that allow people to reflect and act based on data they collect on their habits, behaviors, and thoughts (76,77). People who use personal informatics tracking tools make the decision to track particular metrics that monitor achievement of goals for one's own health, wellbeing, and self-awareness through behavior change. Some HCI researchers have also designed condition-specific applications for diabetes (83) and heart disease (84) strive to enrich patients' understanding of how their disease is progressing and identify opportunities for patients to make lifestyle changes that could modify that progression. Although patients with cancer have less inherent control of the progression of their disease, accurately reporting symptoms and side effects to clinicians between clinic visits is no less important than condition-specific tracking tools that drive behavior change. In addition, because much of patients' work in cancer care takes place in "unanchored" settings on the go, and away from home and the clinic, mobile health (mHealth) applications might be able to meet this need as technology that runs on a device that patients are already carrying with them (85,86).

A model of personal informatics tool use describes the stages of self-tracking, describing what motivates and prevents people from engaging in self-tracking behaviors (77). Five stages

that users undertake when interacting with a tracking tool are: (1) determining what to track and which tool to use (*preparation*) (2) recording observations (*collection*), 3) combining and transforming data from any number of sources prior to reflecting on it, (*integration*), 4) reviewing and understanding integrated data in the short term or long term (*reflection*), and 5) choosing to do something given any newfound understanding (*action*) (77).

In personal informatics, limited knowledge exists about usage and engagement with current self-tracking tools among patients with cancer. It remains to be seen whether these patients will actually use tracking tools to help self-manage symptoms and communicate with clinicians. Cancer is not designated as the primary condition for users of PatientsLikeMe, a popular online community with condition-specific self-tracking features (http://www.patientslikeme.com). A search of PatientsLikeMe users conducted on April 3, 2013 revealed that, of the 189,376 total PatientLikeMe users who have created a profile, only 303 reported breast cancer as a primary condition. A number of apps on smartphone platforms have been developed, some which are sponsored by organizations such as the American Society of Clinical Oncology (ASCO) and cancer centers such as Dana-Farber in Boston. Nevertheless, how frequently these apps are used during the care workflow is unknown. In addition, people with cancer or caregivers might use familiar office software, such as Microsoft Excel or Word, to track symptoms, rather than searching for an app that could serve their needs. Further, most people living with cancer deal with their health offline and consult a healthcare professional for their information needs (27,8,53). The goal of research in this dissertation is to understand cancer patients' actual self-tracking behaviors and discuss how to design such tools to support patients' needs so that these tools are both used and accepted by patients.

Even among people who are not dealing with a serious illness such as cancer, Li and colleagues found that barriers to self-tracking include lack of motivation, lack of access to a tool when symptoms occur, forgetting to record, lack of time, poor organization of information, and suboptimal visualization (77). One limitation of Li's findings is that the data was collected from people who were recruited from self-tracking sites, rather the general population or people interested in achieving goals in a specific domain such as cancer. Li does not identify features of tracking tools that can help overcome barriers at these various stages of self-tracking.

In summary, patient-driven, researcher-driven, and clinician-driven tracking tools emerged from different fields. Despite similar ways in which these tools are supposed to help patients, they have tradeoffs that prevent them from gaining widespread acceptance. In Chapter 3, I will study researcher-driven tracking tool use. In Chapter 4, I examine the motivations and usage patterns of a patient-driven tracking tool. In the remainder of the dissertation, I aim to converge on a new paradigm for tracking tools that takes both use and acceptance into account in and outside of the clinic.

Chapter 3 : Investigating Use of an Electronic Patient-Reported Outcome (e-PRO) Tool

Introduction

Patient-reported outcome (PRO) tools facilitate self-tracking of symptoms by patients. With PRO tools, patients report symptoms using questionnaires typically on paper or a computer, although there is a recent trend toward deployment on mobile and tablet platforms (36). Electronic forms of PRO tools, or e-PRO tools, demand highly structured data entry from patients to generate a score or a summary report of symptoms and quality of life indicators (SQLI). Given the challenge of coping with symptom distress during cancer treatment, patients may find answering dozens of e-PRO questions in one sitting difficult. They could potentially be less motivated to complete e-PRO questionnaires if either they or their clinicians are not given access to the score or the report. Despite this patient data entry burden, there is value in deploying e-PRO tools due to research results indicating that patient-provider communication can be enhanced with regard to SQLI (17) and to recognize when patients in chemotherapy experience treatment-related toxicity {Bausch 2005}. In the literature review from Chapter 2, I described those and other benefits from the use of e-PRO tools in clinical care. However, *voluntary use of e-PRO tools by patients* has not often been evaluated.

In this chapter, I explored the relationship between symptom distress in patients with cancer and voluntary use of self-tracking and education features of an e-PRO tool. To further understand how this e-PRO tool was used, I addressed three main research questions:

(RQ1) How often do patients with cancer *voluntarily use* an electronic patient-reported outcome tool?

(RQ2) Is *voluntary use* of an electronic patient-reported outcome tool associated with *symptom distress levels* in patients with cancer?

(RQ3) What *attributes* of patients with cancer are associated with *frequent voluntary use* of an electronic patient-reported outcome tool?

ESRA-C In Action

The e-PRO tool that I studied for this chapter is called the Electronic Self-Report Assessment for Cancer (ESRA-C), developed at the Dana-Farber Cancer Institute and University of Washington. ESRA-C is a database-driven web portal that patients can access from any Internet browser. ESRA-C administers validated symptom self-assessment questionnaires to patients with cancer. The first version of the ESRA-C software was deployed in a randomized controlled trial, testing tool use plus a summary report to the clinicians as an intervention vs. tool use alone (17). In the intervention group, color graphic summaries of the patient report were delivered to clinicians just prior to a face-to-face clinic visit. The ESRA-C intervention significantly increased discussion of SQLI, facilitating conversations about more sensitive symptoms during clinic visits, such as sexual side effects (17).

In a second randomized controlled trial, Berry et al. deployed an enhanced version of the ESRA-C software (88). This version of ESRA-C goes beyond providing symptom assessment summaries to clinicians, as it also has patient-centered features: (1) Report My Experiences, in which patients take self-assessments for SQLI, (2) View My Reports, in which patients have

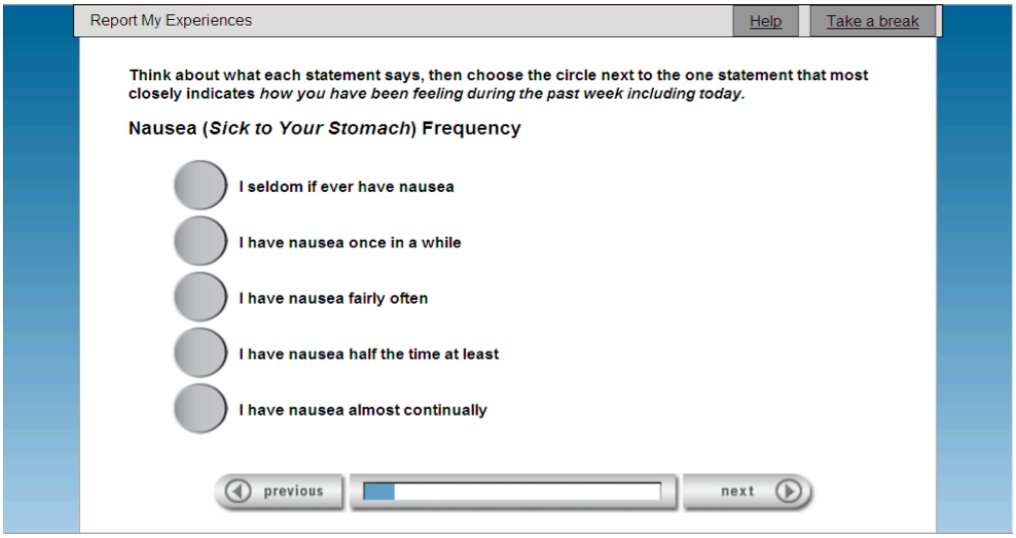
access to graphical summary reports of the self-assessment, (3) Teaching Tips, which contain tailored health education material, and (4) View My Journal Entries, which is a simple, open-ended feature that facilitates both entering and viewing journal entries, and (5) Share My Reports, which allows patients to share reports with trusted clinicians, caregivers, family members, or friends. These features are described further in the following sections.

ESRA-C Feature #1: Report My Experiences

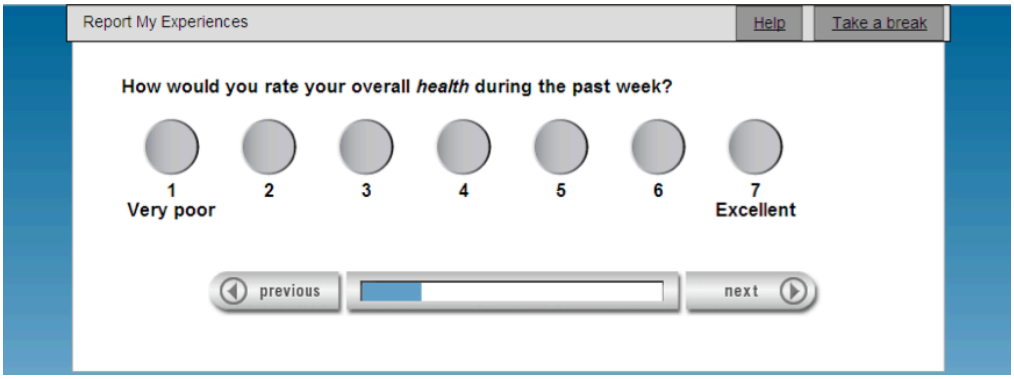
Patients use the Report My Experiences feature to complete self-assessments. This ESRA-C feature presents the user with a possible total of 77 questions from a series of validated instruments: (1) Symptom Distress Scale (89), (13 items, plus additional 2 items on impact on sexual activities and interests and fever/chills, which comprise the SDS-15 score) (2) PHQ-9 Depression Scale (9 items) (90), (3) EORTC QLQ-30 v.3 on Quality of Life (30 questions) (91), and (4) EORTC QLQ-CIPN20 on chemotherapy-induced peripheral neuropathy (20 questions) (92). In addition, the research team added questions on skin changes, spiritual concerns, and patient prioritization of SQLI. ESRA-C presents self-assessment questions to the user one at a time, as shown in Figure 3.1.

Figure 3.1. The Report My Experiences feature of ESRA-C. Patients are presented with a question at a time from various instruments. The questions cover a broad range of cancer and treatment-related SQLI.

(a) Nausea SDS-15 Question



(b) Overall health question

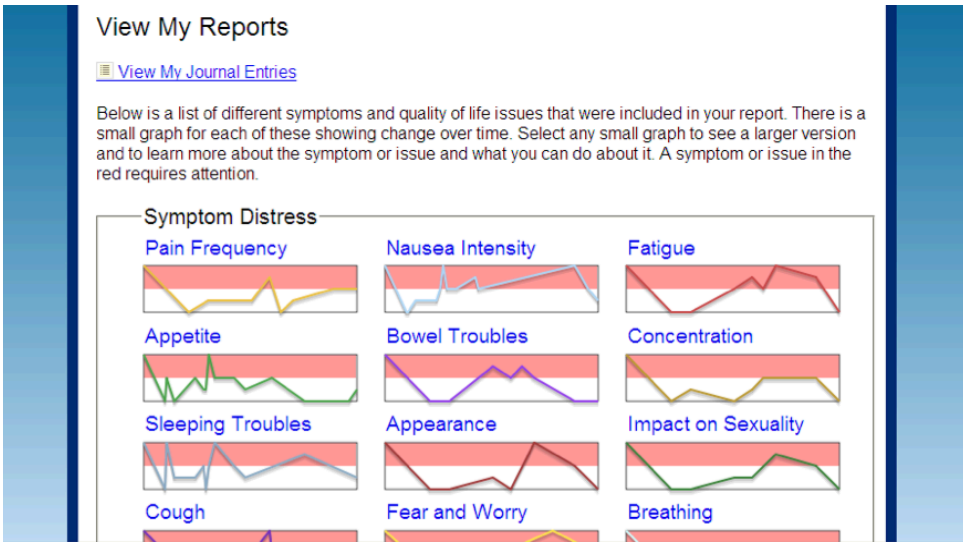


ESRA-C Feature #2: View My Reports

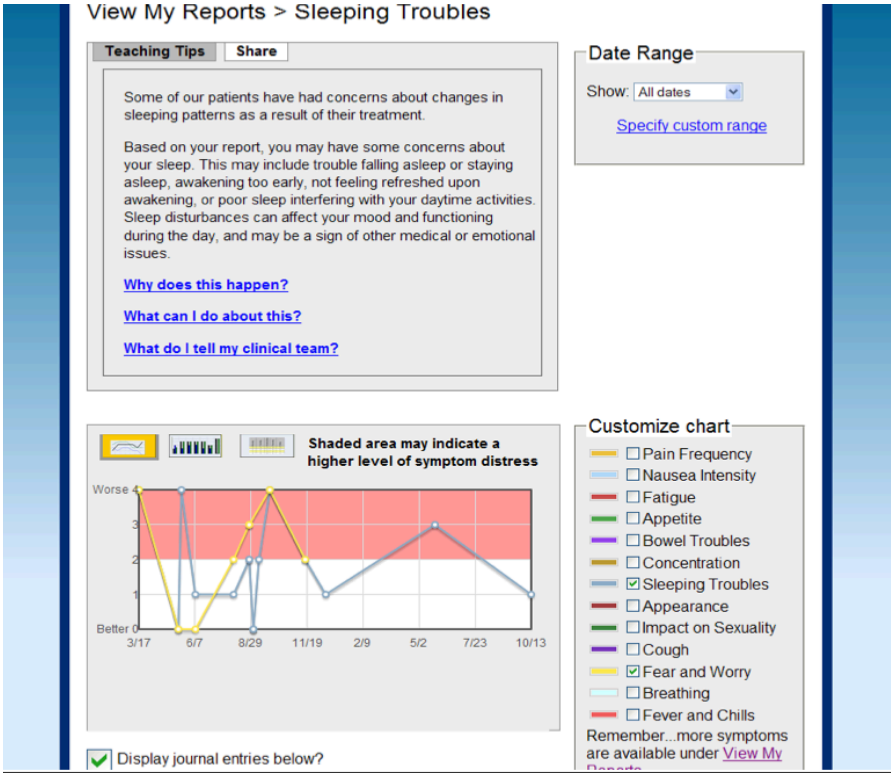
The View My Reports feature presents patients with graphical trends on 30 symptom and quality of life issues (SQLI) covered in self-assessments. Each SQLI has its own detail screen with graphs of SQLI history and ability to customize which SQLI are viewed simultaneously on the same line graph. Figure 3.2 contains exemplar screenshots of the overview and detail screens.

Figure 3.2. The View My Reports feature of ESRA-C. SQLI over a certain threshold are shaded in red on graphs, indicating a moderate or severe level for the SQLI. Patients can click on a particular SQLI graph in (a) to reveal more details on symptom status and teaching tips related to that SQLI as shown in (b).

(a) View My Reports overview screen



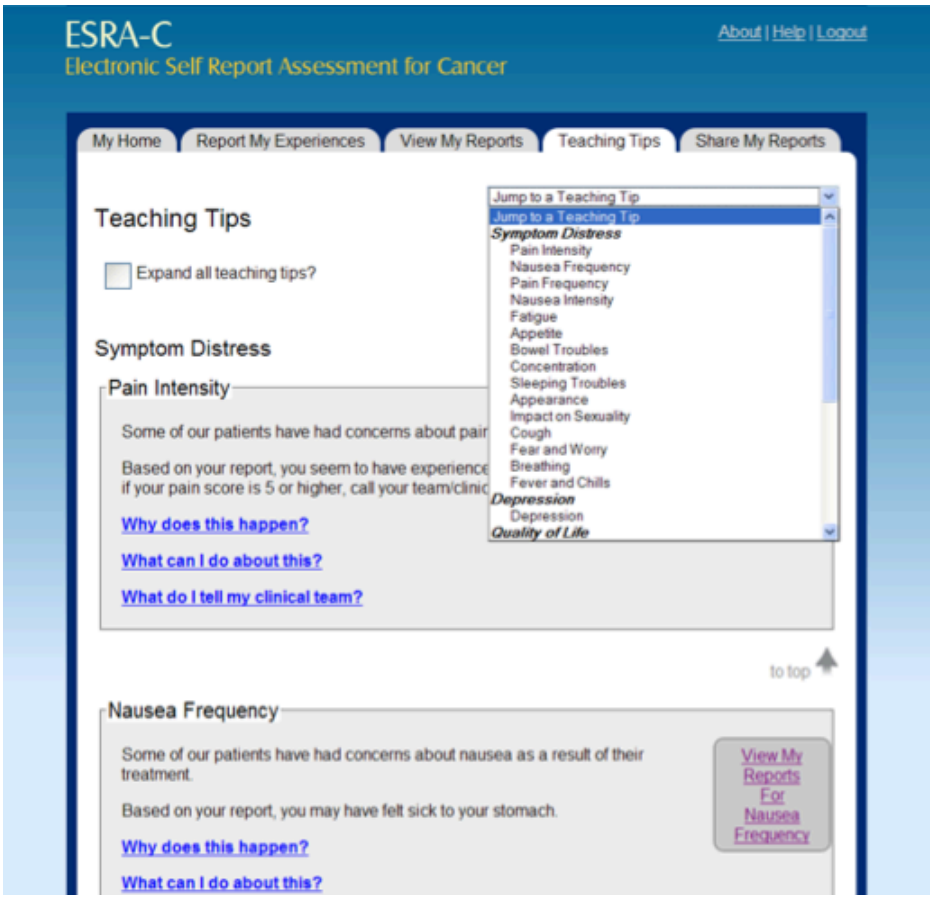
(b) View My Reports detail screen



ESRA-C Feature #3: View Teaching Tips

ESRA-C Teaching Tips feature provide patients with specific resources, advice, and other information tailored to each SQLI reported as a resource for patients to consult particularly when SQLI are above certain thresholds.

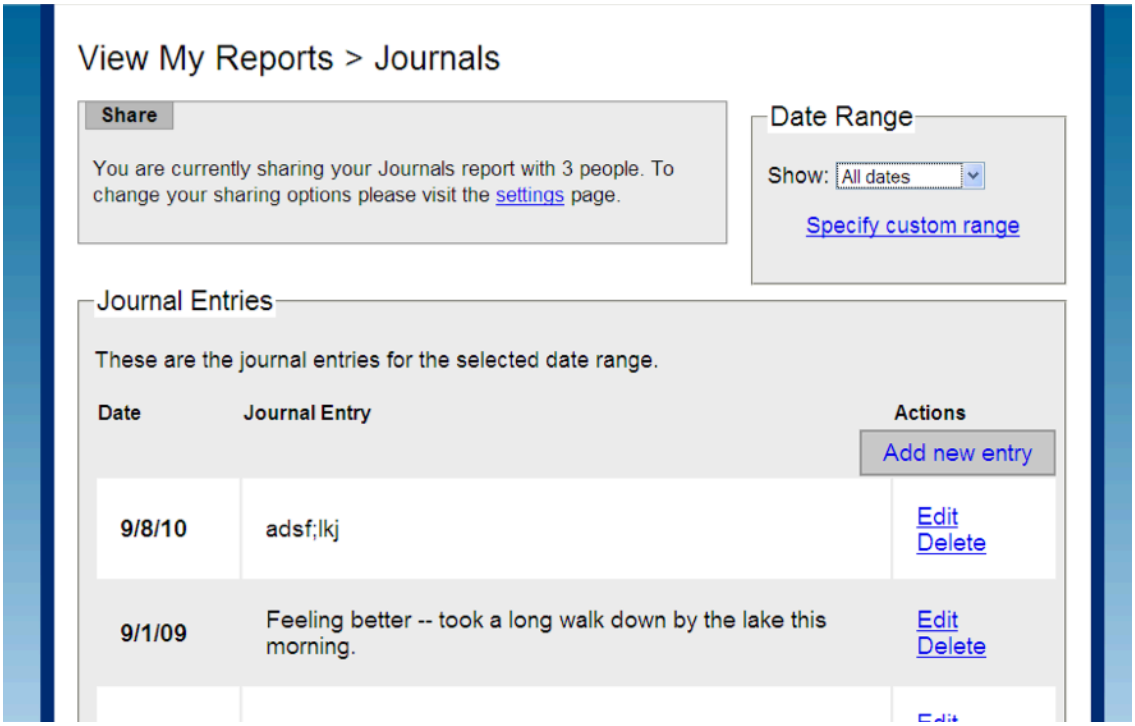
Figure 3.3. The Teaching Tips page for SQLI. The teaching tips contain links to credible resources and actionable advice to help manage particular SQLI.



ESRA-C Feature #4: Journals

ESRA-C has a simple journaling feature that can be accessed through the View My Reports screen. However, results of usage are not reported because a small minority of participants accessed the feature and fewer than 10% of participants completed a journal entry.

Figure 3.4. The Journaling feature simultaneously captures the date and a journal entry and presents it to users reverse chronologically.



ESRA-C Feature #5: Share My Reports

Participants could elect to share their symptom assessment reports with anyone with a valid email address, sharing either the entire report with the email recipient or deciding which particular SQLI histories the recipient is allowed to view.

Figure 3.5. Share My Reports feature enabled patients to specify email addresses of individuals who could view symptom assessment reports generated by ESRA-C.

Methods

The methods in this chapter describe data collection by Donna Berry's research team for a randomized control trial (88) and my secondary analysis of selected data to investigate voluntary use in the intervention group.

The original purpose of this trial was to compare symptom distress scores over the course of active cancer therapy for two groups (88). In the control group, patients reported SQLI on four occasions throughout therapy and received usual care support for SQLI. In the intervention group, patients reported at the same four occasions and clinicians received the summary report. Additional coaching and teaching tips were provided at each of the four study time-points, highlighted for the SQLI that was reported at a pre-determined threshold. Intervention group participants could determine for themselves how often to complete assessments and which SQLI to track receiving teachings and communication coaching as well. The primary analysis of the trial data revealed a significant reduction in symptom distress over time for the intervention group, establishing the efficacy of the full ESRA-C intervention (88). In this chapter, I hope to further unpack the reasons for this effect by demonstrating whether greater use of the tool—in other words, a higher "dose" of the intervention—was significantly correlated with end-of-study symptom distress.

Data Collection

A multi-site research team led by committee member Donna Berry collected data for this study at both the Seattle Cancer Care Alliance in Seattle and the Dana-Farber Cancer Institute in Boston (88). The research team recruited patients of any diagnosis or stage in medical oncology, radiation oncology, and transplant clinics prior to beginning a new cancer treatment. Symptom assessments were administered to all participants at the following time-points: initially at the consult prior to treatment start (T1), at the first on-treatment visit about 4 weeks after treatment start (T2), 6-8 weeks after treatment start (T3), and 2-4 weeks after the treatment end date (T4). At these study time-points, ESRA-C summarized participants' symptom assessment results for clinicians, providing information on 30 cancer symptoms and quality of life (SQLI) concerns.

Intervention group participants could take symptom assessments voluntarily any other time, and as per protocol, received a phone call a week after study enrollment to ensure that ESRA-C was working for them at home and encourage use of the intervention.

Data Analysis

I conducted a secondary data analysis on data from participants assigned to the *intervention group* only. The goal of this analysis was to gain a better understanding of patients' *frequency* of voluntary use of ESRA-C (RQ1), whether voluntary use was correlated with symptom distress (RQ2), and to uncover potential factors to explore frequency of voluntary use (RQ3). The intervention group comprised of 373 participants, but I excluded one outlier participant whose 66 voluntary uses of ESRA-C were far more than the 11 voluntary uses by the next most frequent user. As a result, the analytic sample included 372 participants.

In the initial stage of the analysis, I operationalized the constructs *voluntary use* and *symptom distress*. I determined each participant's voluntary use by counting page views of ESRA-C's patient-centered features (e.g. symptom assessment-taking, viewing reports, and viewing teaching tips) from the raw ESRA-C log data. To properly assess voluntary use, I grouped each time-stamped page view within a 2-hour timeframe into individual sessions. For example, if a page view for "View Reports" occurred within 15 minutes of a "Report My Experiences" page view, this is counted as one session. Each time a participant answered any assessment question(s) during a voluntary session, this was recorded as one voluntary use. Sessions that occurred within a day prior to a study time point were not entered as voluntary use because they may have been prompted. When both voluntary sessions and uses from page views

were tallied, I was able to obtain descriptive statistics that illustrated usage trends (see all Tables in Results section).

In addition, I operationalized *symptom distress* to address RQ2. I based symptom distress on the Symptom Distress Scale (SDS) as a broad indicator of common cancer symptoms. The original 13-item SDS was developed via literature review and patient interviews by oncology nurse researchers several decades ago (89). This SDS instrument was evaluated for internal consistency, construct validity, and test-retest reliability (93). Scores for SDS range from 13-65, with 13 questions asked on a 5-point scale. While cut scores to categorize levels of symptom distress have not been universally established, McCorkle suggests 25+ as an indicator of moderate distress and 33+ as an indicator of severe distress (93). For the trial with ESRA-C, the PRO tool included what we called an SDS-15 score: the original SDS measure, plus a question each about impact on sexual activities and interests and fever/chills. We re-set cut scores to be 26+ for moderate distress and 35+ for severe distress, due to the addition of the two questions. Selecting the symptom distress questionnaire during a voluntary use session and answering all questions resulted in a complete SDS-15 score.

I employed various statistical techniques to analyze data collected from research questions. Descriptive statistics were used to address RQ1, summarizing voluntary use of ESRA-C. Meanwhile, for RQ2, I conducted a between-group, one-way ANOVA to assess whether the dependent variable *end-of-study symptom distress* varied significantly among groups with different *frequency of usage*, the independent variable. The sample contained three groups of participants' voluntary usage: those with 0, 1, or $\geq$ 2 voluntary uses of ESRA-C. The ANOVA test is one-way because there is only one independent variable. This test of association identifies

how the variables are associated with consideration of variance and not causation. However, a between-group ANOVA can test an associative hypothesis if the following assumptions are met:

- The populations from which the samples were obtained should be normally or approximately normally distributed
- The samples are independent
- The variances of the populations should be approximately equal

These assumptions were tested. A plot of scores for each group over time was created for visual inspection of the data.

To answer questions about patient attributes (age, gender, stage, baseline symptom distress at T1, end of study symptom distress) and their relationships to different categories of frequency of use, I compiled categorical contingency tables and generated p-values to determine the significance of differences between the groups. I used a t-test to determine the variance in baseline symptom distress between participants who completed study time-points and those who dropped out for any reason.

Results

Demographics

Demographics for the 372 intervention participants are shown in Table 3.1. Just 14.5% of participants used ESRA-C only in the clinic, whereas 85.5% used ESRA-C independently at home. Nearly 78%, or 289 of the 372 participants, completed all study assessments.

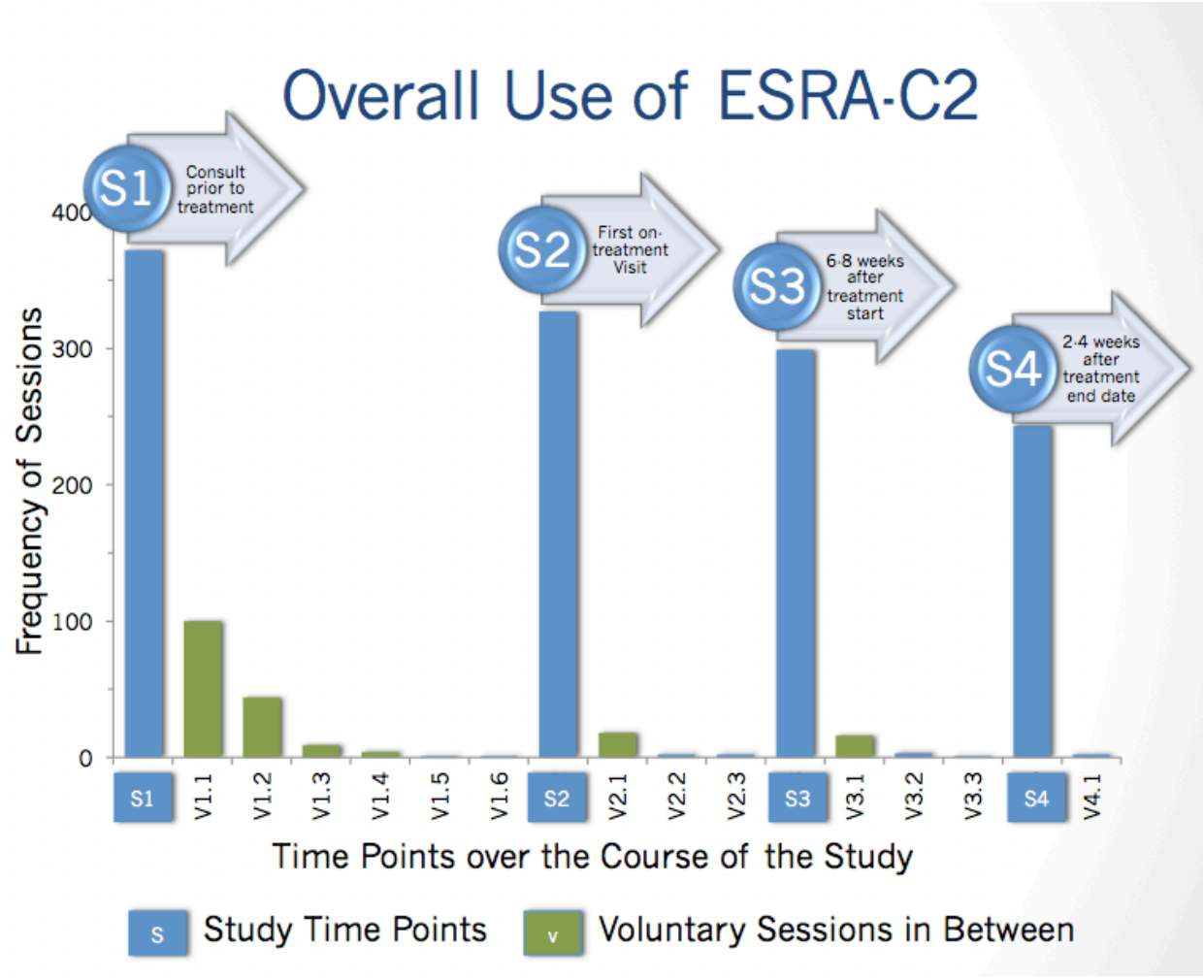
Table 3.1. Demographics of Intervention Group Participants.

CATEGORY	VARIABLE	FREQUENCY	%
Location of assessment	Clinic	54	14.5%
	Home	318	85.5%
Clinical Service	Medical Oncology	210	56.5%
	Radiation Oncology	125	33.6%
	Stem Cell Transplant	37	9.9%
Study Status	Completed all study time-points	289	77.7%
	Lost to follow up	37	9.9%
	Voluntary withdrawal	30	8.1%
	Other	16	4.3%
Clinic (Diagnosis)	Dana-Farber – Genito-urinary	89	23.9%
	Dana-Farber – Gastrointestinal	65	17.5%
	Dana-Farber – Head & Neck	26	7.0%
	Seattle Cancer Care Alliance - Transplant	37	9.9%
	Dana-Farber – TBD	3	0.8%
	Dana-Farber - Breast	104	28.0%
	Dana-Farber - Sarcoma	22	5.9%
	Dana-Farber - Lymph	17	4.6%
	Londonderry	9	2.4%
Age Group	20-29	14	3.8%
	30-39	32	8.6%
	40-49	81	21.8%
	50-59	98	28.0%
	60 or above	144	38.7%
	Missing	3	0.8%
Gender	Male	185	49.7%
	Female	187	50.3%
Use Computer at Home	Never	19	5.1%
	Rarely	23	6.2%
	Sometimes	43	11.6%
	Often	63	16.9%
	Very often	219	58.9%
	Missing	9	2.4%
Use Computer at Work	Never	49	13.2%
	Rarely	22	5.9%
	Sometimes	33	8.9%
	Often	55	14.8%
	Very often	208	55.9%
	Missing	5	1.3%
Stage	1	54	14.5%
	2	91	24.5%
	3	69	18.5%
	4	106	28.5%
	Missing or N/A (leukemia)	51	13.7%
TOTAL PARTICIPANTS		**372**	**100%**

(RQ1) How often did patients with cancer voluntarily use an electronic patient-reported outcome tool?

Figure 3.6 illustrates participants' voluntary usage of ESRA-C at various study time-points. The "T" study time-points are higher than voluntary sessions because the research team member requested self-reports by email to home and/or provided a touchscreen computer in the clinic waiting room for each time point visit immediately preceding visit with a provider.

Figure 3.6. Frequency of ESRA-C sessions by at both study "T" time-points and voluntary time-points. Study time-points are labeled T1-T4, with each successive voluntary session numbered after each "T" sessions. Voluntary sessions that included SQLI reports are highlighted in green. T1 took place initially at the consult prior to treatment start, T2 occurred at the first on-treatment visit, T3 occurred 6-8 weeks after treatment start, and T4 occurred 2-4 weeks after the treatment end date.



After study time-points T1, participants initiated more voluntary sessions of ESRA-C than after later time-points. Most intervention group participants received a reminder phone call a week after study enrollment at the T1 consult to ensure that ESRA-C was working for them at home. Sessions that occurred a day prior to any "T" study time-points were excluded from analysis, as these were prompted by automated reminder emails.

Table 3.2. Sessions initiated by all 372 participants and by the 289 who completed all study time-points.

	Sessions Initiated by *All* Participants (n=372)	**Sessions by Participants *Completing* Study (n=289)**
Study Time Point Sessions (T1-T4)	1241	1105 (89.0%)
Voluntary Assessment-Taking Sessions	203	178 (87.7%)
Voluntary Sessions without Assessment	147	133 (90.4%)
All Sessions	1591	1416 (89.0%)

Completing assessments was a method by which participants could monitor symptoms on and engage in self-tracking. Participants took 1241 study assessments in the "Report My Experiences" feature. The participants began 350 voluntary sessions, 203 included SQLI reporting and 147 in which they viewed reports and teaching tips without making additional reports. Eighty-three of 372 participants did not complete the study, for an attrition rate of 22%. However, these participants initiated only about 10% of sessions, as shown in Table 3.2.

Table 3.3. Percentage of full SDS-15 scores generated during voluntary and study time-point sessions.

	# of Sessions *with* Full SDS-15 Scores	**# of Sessions *without* Full SDS-15 Scores**	**% of Full SDS-15 Scores from all Sessions**
All Assessment-taking Sessions by those who completed study	1151	132	89.7%
Voluntary (NonT) Assessment-taking Sessions	135	43	75.8%
Study (T) Assessment-taking Sessions	1016	89	91.9%

ESRA-C also gave patients a choice of what SQLI questionnaires to take and whether or not to answer all items. As shown in Table 3.3, of the 178 voluntary assessments, 135 of these (75.8%) produced full SDS-15 scores from a completed assessment. The proportion of full SDS-15 scores was, by design, significantly higher for the study time point sessions than for the voluntary assessment-taking sessions, by Fisher's exact test, $p < .0001$).

(RQ2) Is voluntary use of a patient-reported outcome tool associated with symptom distress levels in patients with cancer?

To answer question RQ2, I defined three groups of voluntary use as 0, 1, and 2 or more voluntary uses of ESRA-C throughout the study period.

Table 3.4. Frequency of voluntary use by all participants. Includes patients who completed study time-points and by those who did not.

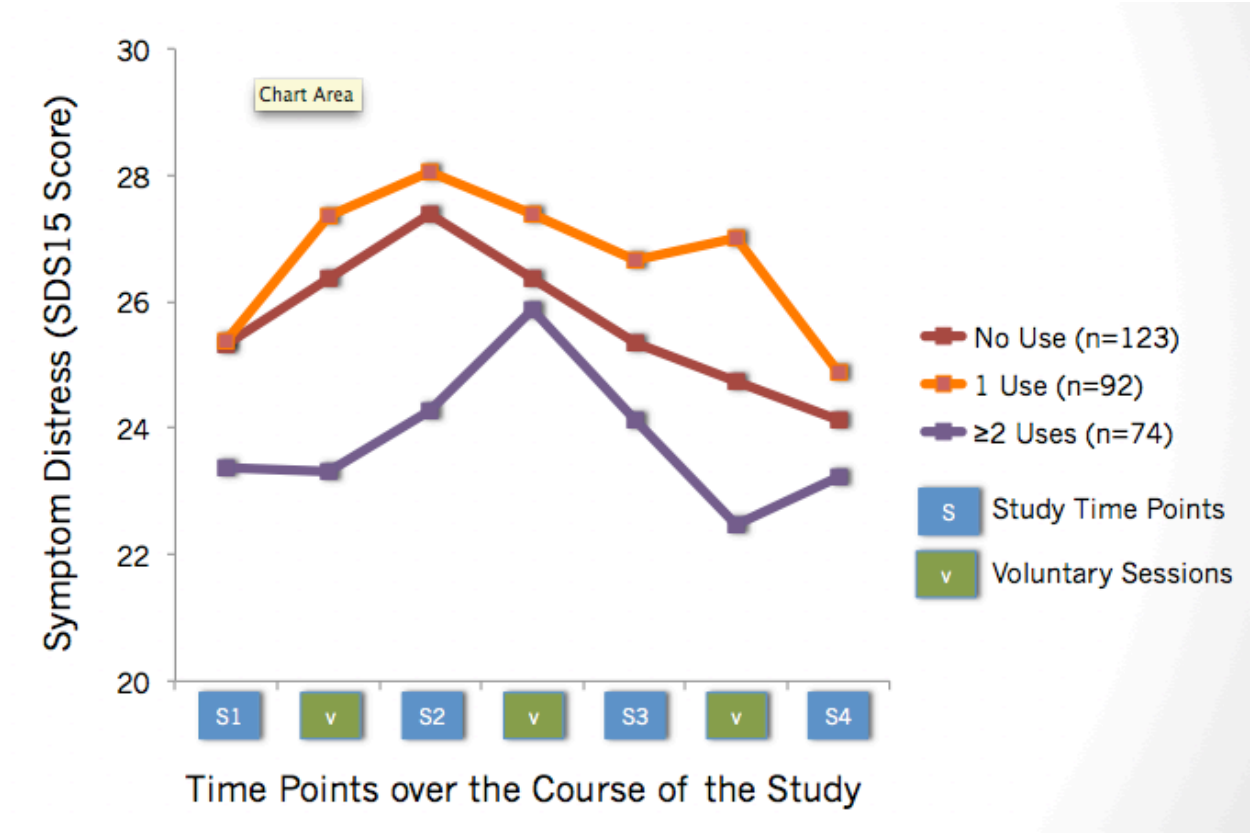
	All	Completed study	Attrition	Baseline SDS-15	End-of-Study SDS-15
# of voluntary Sessions	# of participants	# of participants	# of participants	mean (SD)	mean (SD)
0	179	123	56 (31.3%)	25.3 (SD=7.4)	24.0 (SD=7.0)
1	110	92	18 (19.7%)	25.4 (SD=7.0)	25.4 (SD=6.8)
2	51	44	7 (16.0%)	23.4 (SD=6.8)	23.0 (SD=5.8)
3	18	17	1 (5.9%)		
4	5	4	1 (25.0%)		
5	2	2			
6	3	3			
7	0	0			
8	2	2			
9	1	1			
10	0	0			
11	1	1			
Total Patients	**372**	**289**	**83**		

First, I computed descriptive statistics for voluntary usage and average end of study SDS-15 scores. Table 3.4 shows the number of participants at each level of voluntary usage. Nearly half of all participants (n=179) did not use the tool outside of "T" study time-points, but this

percentage dropped to 42.6% when accounting only for those who completed all study time-points (n=123). Of 289 participants who completed all study time-points, 74 (25.6%) were frequent users with 2 or more voluntary sessions.

Second, I checked assumptions prior to running a one-way between-group ANOVA: approximately independent samples, normal distributions, and approximately equal variances. Participants with different levels of voluntary use were independent because they were in groups that were mutually exclusive. Upon visual inspection, the distribution of end-of-study SDS-15 scores was skewed left for all three groups of voluntary usage, showing a higher proportion of patients with lower-than-average symptom distress. However, there were very few outliers in all three groups. Finally, the variance was 33.7 for participants with ≥2 voluntary uses, while it was 48.5 for those with no voluntary use and 46.7 for those with just 1 voluntary use. Due to the difference in variances and the non-normal distribution, I ran the Kruskal-Wallis one-way ANOVA, with a result of $H=6.07$, $d.f.=2$ ($p < .05$). Thus, end-of-study symptom distress was not identical for all 3 levels of voluntary usage. Post-hoc pairwise analysis of groups with t-tests showed that that the group of participants with 2 or mores voluntary uses was significantly different from the group with only 1 voluntary use ($p < .02$). None of the other pairwise comparisons were significant.

Figure 3.7. Average symptom distress (SDS-15), grouped by category of voluntary usage frequency. Lines are purple for those who were frequent users, orange for those who used ESRA-C once, and red for those who had no voluntary uses.



Average SDS-15 scores at each time point plus voluntary uses of participants who completed all study time-points are shown in Figure 3.7. Participants who had 2 or more voluntary uses also on average report lower symptom distress from T1 to T2 compared to other participants. However, these participants with frequent voluntary use still experienced increased symptom distress between T2 and T3, just as the participants with 0 or 1 voluntary use did.

(RQ3) What attributes of patients are associated with frequent voluntary use of a patient-reported outcome tool?

Aside from lower overall symptom distress compared to those with one use, what did the most frequent users have in common? Firstly, primary outcome analysis showed that intervention had a more robust effect on symptom distress in participants who were 50 years of age or older (88). However, frequency of voluntary use, or the "dose" of the intervention, was not associated with age in this secondary analysis. There were no meaningful relationships between age, gender, stage, or end of study SDS-15 score, and the number of times that they voluntarily used ESRA-C. Baseline symptom distress scores were significantly higher ($t = -2.47$; $p < .02$) in those participants who dropped out, compared to those who completed the study.

Discussion

Results from this analysis show how frequently one e-PRO tool was voluntarily used in the intervention arm of a randomized controlled trial. About one-quarter of the 372 patients with cancer could be considered frequent users because they initiated 2 or more voluntary sessions of ESRA-C. These frequent users had significantly lower end-of-study symptom distress scores than those with just one use. Yet there were no demographic attributes associated with frequency of use that stood out.

At first glance, it may seem incongruous that those with just one voluntary use of ESRA-C had the higher end-of-study symptom distress than those with no voluntary uses. Perhaps those completing the study felt less bothered by symptom distress and had little need to log in except to participate in study time-points. This could also explain the spike in symptom distress scores between T2 and T3 for the frequent users, as shown in Figure 3.7. It is plausible that participants

did not use ESRA-C between study time-points unless they experienced higher symptom distress than what they normally experienced.

Findings are consistent with other studies outside of the context of cancer that show active users of tracking tools are healthier than non-users (94,95). Chronically ill people are also reported to be less e-Health-literate (25). Thus, they might not regard Web-based interventions a suitable solution for them. Alternatively, they could be too ill to benefit, making it more difficult to provide self-tracking tools those with a higher illness burden. Børøsund and colleagues confirmed, after controlling for type of diagnosis and age, that the only factors significantly predicting active voluntary use of the e-PRO tool WebChoice were high levels of computer experience and not having other illnesses (52). The WebChoice study's findings in patients with breast and prostate cancer complement conclusions from this chapter's analysis. Two-thirds of WebChoice users had 2 or more sessions during one year, which the authors characterized as frequent voluntary use (52). Though this is unsurprising, high frequency users perceive tracking tools to be more useful than low frequency users (51). Which features patients used appeared to been an indicator of patients' needs. For men with prostate cancer, use of symptom assessments, advice, and the discussion forum was directly associated with symptom distress (52). Meanwhile, symptom distress had limited impact on the use of WebChoice for women with breast cancer (52). Women with breast cancer preferred discussion forums, whereas men with prostate cancer preferred using symptom-tracking assessments (52). In summary, limited social support and depression were associated with WebChoice use for women with breast cancer, whereas physical symptom distress was associated with WebChoice use for men with prostate cancer. The only variables that were associated with frequent use by both men and women were previous computer experience and having additional illnesses (52). Use of e-PRO tool

WebChoice revealed that lower levels of social support, higher levels of symptom distress, and higher depression were associated with high use of messaging with oncology nurses (51). Because ESRA-C did not have a discussion forum or secure messaging, we could not corroborate these findings on WebChoice in this analysis. Yet use of ESRA-C did help patients remember to bring up issues during clinic visits, which likely was part of the intervention's impact on lower symptom distress at the end of the study (88). In addition, the ESRA-C II study included more than twice the number of patients from a broad spectrum of cancers beyond breast and prostate, increasing the ability to generalize the findings.

Perceived usefulness could have been another barrier to patients completing questionnaires to arrive at full SDS-15 scores. Although we did not analyze detailed data on this for individual patients, reasons for not completing voluntary assessments are certainly of interest. Possibly, participants initiating a voluntary assessment questionnaire did not feel like finishing all 15 questions or did not perceive that the completing the SDS-15 assessment would help them if the clinicians did not review the report. Another reason could be patients' desire to focus on a particular symptom (e.g. depression, skin changes, or quality of life). Those who dropped out may have died or been so ill that they could not or did not want to finish study assessments. It is likely that those most burdened by symptom distress were unlikely to use the tool or complete the assessments. Designers of e-PRO tools must consider that patients' symptom distress may be too high to finish questionnaires. ESRA-C administers validated measures and allows patients to choose individual SQLI items or questionnaires to report. ESRA-C does allow granular, even daily, approach using broad categories that are selectable and fewer question items could be easier to adopt and incorporate into a patient's routine. Still, the design of the tool should correspond to a lower user burden, whether through passive sensor-based monitoring of signs or

asking fewer questions, even at the risk of compromising psychometric validation in PRO symptom assessments.

Which demographic factors truly influence acceptance could have strong associations with the nature of the features that make up the intervention (96). Age seemed to be a factor in this study, as the RCT findings also indicated a reduced symptom distress effect that was more robust in patients over 50 years of age (88). However, older users were not necessarily more frequent users of ESRA-C than those under 50. Nevertheless, highlighting teaching tips and problem areas through any use of ESRA-C could make it easier for older users to raise the subject of problematic symptoms in face-to-face consultations. In a study conducted by Meropol, education level, and not age, has been shown to be associated with satisfaction with consultations. This trial of a Web-based communication aid delivered prior to cancer consultations and reported an association between patient education level and satisfaction with post-intervention discussions about diagnosis/prognosis, use of community services and communication in general. As a result, supplementing face-to-face consultations with communication aids like ESRA-C could be more effective in some specific demographic groups over others. The nature of the communication aid interventions and its relationship to which patients benefit from them needs to be explored further in future studies.

This analysis has its own limitations. I did not analyze explicit reasons for participants' voluntary use whether less frequent voluntary users found the tool less acceptable or were simply had high symptom distress. Second, although study time-points were relative and took symptom distress trajectory into account, length of treatment varied based on the patient's cancer diagnosis and care plan, which could have influenced usage patterns. Third, we do not have specific reasons for missing data from those who started but did not complete the SDS-15 assessments.

Fourth, it would be useful to explore which reported symptoms benefited the most from frequent voluntary use, rather than focusing on a general cancer symptom distress measure.

Conclusion

Despite the benefits shown in research studies (17,35,42,88), patient-reported outcome assessment was not an expectation of patients in cancer treatment (40). This analysis suggests that keeping patients with cancer engaged with e-PRO tools at home is a worthwhile endeavor because it has potential to influence symptom distress. Still, we cannot assume that all patients with cancer will *want* to use e-PRO tools—or any tracking tool for that matter. We should consider which aspects of tracking tools for symptom monitoring in cancer care are robust and for what demographic of patients. In this dissertation on the whole, my goal is to converge on optimal design of tracking tool features that both patients and clinicians can accept and benefit from. Future work into tracking tool design and adoption could move us closer to establishing their role in standard cancer care.

Chapter 4 : Exploring Benefits to Self-tracking during Cancer Care

Introduction

The literature contains a limited number of studies on how patients with cancer track their symptoms during treatment "in the wild." To address this gap in knowledge, I analyzed study data on the natural tracking behaviors of 25 patients with breast cancer and their behaviors after deployment of a personal informatics tool with real-time tracking features to 10 of these patients. This tool could be considered a *technology probe,* which is a technology that is *"deployed to find out about the unknown"* and combines *"the social science goal of collecting information about the use and the users of the technology in a real-world setting, the engineering goal of field-testing the technology, and the design goal of inspiring users and designers to think of new kinds of technology to support their needs and desires"* [p.18, (97)] and not just to evaluate whether a technology is effective in a prescribed setting. This type of study is particularly valuable for the design of consumer health technologies, which tend to be used in a variety of settings and where the full spectrum of users' needs cannot be identified effectively in lab studies.

To understand potential benefits of such tools, I studied the tracking behaviors of 25 women with breast cancer. Ten of these participants had access to a real-time tracking tool that served as a "technology probe" to uncover behaviors and benefits from voluntary use. Findings showed that while patients' tracking behaviors without a tool were fragmented and sporadic, behaviors with a tool were more consistent. Participants also used tracked data to see patterns

among symptoms feel psychosocial comfort, and improve symptom communication with clinicians. I conclude with design implications for future real-time tracking tools.

Methods

This work is a part of a larger project on the personal information management practices of breast cancer patients during treatment (85,86,98-102). This analysis of 25 patients' tracking behaviors came from two smaller field studies from the larger project. The methodological approach for both studies was similar to one used by Paepcke (103), as most interviews and observations took place in the participant's home or the clinic. This approach facilitated interaction with participants and enabled observations in their natural 'work' setting with the supportive artifacts they use (e.g., tracking tools, personal information collections, calendars, email, browser bookmarks, online communities).

The purpose of the work presented in this chapter was to describe patients' tracking behaviors as well as the benefits and barriers to tracking health issues during treatment both without and with a personal informatics tool that enabled symptom tracking. For the first study, I assessed 15 participants' natural symptom tracking behaviors during cancer treatment "in the wild," without access to the personal informatics tracking tool. During the second study, I investigated tracking behaviors and benefits that emerged when 10 participants used HealthWeaver, our personal informatics tool, that included real-time tracking features. Our university's internal review board approved both studies and the study team recruited a convenience sample of local patients with breast cancer through flyers, and word-of-mouth. Each participant enrolled in only one study and all were compensated. Following are details on each study and the way I analyzed the data.

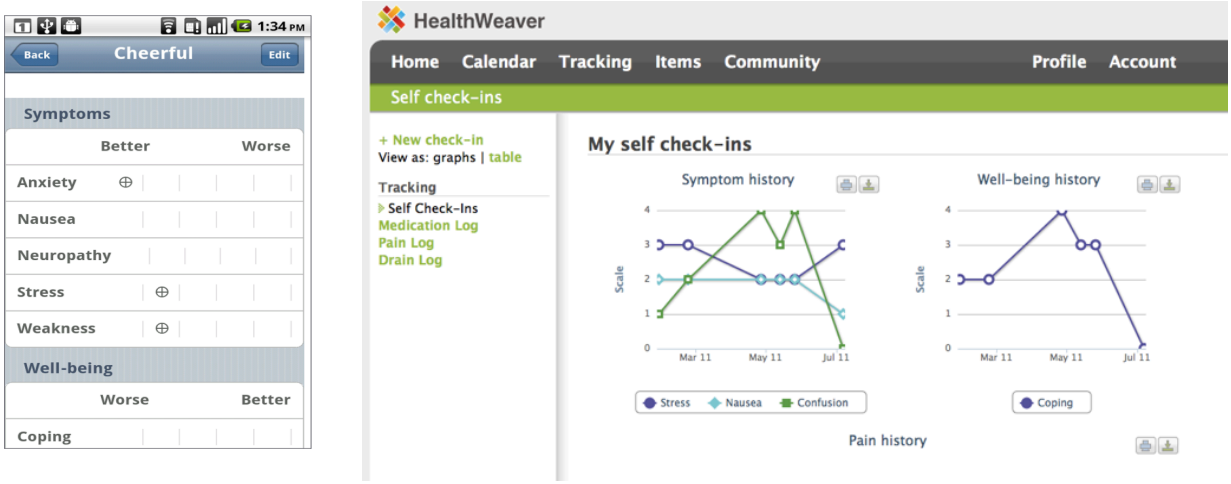
In-the-wild Study Procedures: Needs Assessment

The overarching goal for the "in-the-wild" Study was to understand patients' personal health information management needs (98) during treatment for breast cancer. Each participant was followed by the study team for six weeks. Data collection included two 60-90 minutes interviews and observations in the home, an observation of a clinic visit, and two critical incident interviews over the telephone, as described in (85). In this chapter, I refer to these "in-the-wild" participants as P1 through P15.

HealthWeaver Study Procedures: Technology Deployment

Based on findings from the in-the-wild study, the study team led participatory design groups (101,102) that resulted in the development of a personal health informatics tool called HealthWeaver to help patients manage their personal health information during treatment. HealthWeaver consists of a website and a companion mobile phone application. The study team conducted 45-minute interviews 3 times over 4 weeks as described in (86). The initial interview took place before any tool use, while the second and third interviews focused on participants' use

Figure 4.1. (a) Mobile and (b) Web-based versions of the HealthWeaver check-in. The check-in feature lets the patient track patient-selected symptom, well-being and pain issues ("metrics") on a 0 to 4 scale.



of HealthWeaver for symptom tracking over the study period. In this paper, I refer to the HealthWeaver study participants as HW-P16 through HW-P25.

HealthWeaver enabled real-time tracking through a time-stamped ”self check-in” feature, a drain log, and a medication intake log. HealthWeaver came with a set of 4 default metrics (nausea, stress, energy, coping), but the user could disable any default metrics as well as add custom metrics relevant to her situation. In addition, the check-in feature let the user record her overall state, weight, blood pressure, and minutes of exercise. Users could log check-ins as frequently as they wish and could view graphs of their tracked metrics over time (see Figure 1 for the web interface). Another feature, the drain log, provided a way for users to record drain fluid levels after surgery. Similarly, the medication intake log provided users with a way to log the medications they take. To learn about patients' experiences with using a tracking tool, in this study the study team asked participants to use HealthWeaver to track at least 1 physical or psychosocial issue, but we did not prescribe how often they should check in or what issues they should track.

Data Analysis

All interviews were audio-recorded. I used open coding (104) to identify emergent themes in de-identified transcripts (P1-P15) and detailed field notes from audio-recordings (HW-P16 to HW-P25). I coded situations illustrating behavior related to self-tracking and symptom management to illustrate typical self-tracking behaviors, benefits, and barriers, until saturation was reached. I examined log data to verify usage patterns reported in interviews. During this analysis, I also enumerated the health issues brought up by participants during interviews and

clinic visits. Two study team members who collected the data verified the coding scheme and findings in discussions.

Results

In the sections that follow, I describe how participants used self-tracking to manage their care, both without and with a personal informatics tool. I begin by briefly describing our participants' demographics and the range of health issues participants had experienced in comparison to the health issues they actually tracked. I then describe how patients tracked their symptoms "in the wild"—when they did not have access to HealthWeaver or a similar tracking tool. Finally, I discuss how the tracking behaviors differed for patients who were given access to HealthWeaver and the benefits they experienced from using the application.

Participant Demographics

Our participants varied in age, occupation, and education level, use of technology, and extent of their support networks. One participant identified herself as Hispanic, one as Native American, and the remaining participants identified themselves as Caucasian. Eleven participants were experiencing breast cancer for the first time and four were experiencing it for the second time. Eleven participants were receiving chemotherapy, 7 went through a surgery, 3 were receiving radiation therapy, and 1 was receiving hormone therapy. The 15 women who took part in the in-the-wild study ranged in age from 37-73 (median=53). The 10 in the HealthWeaver deployment study ranged in age from 48-68 (median=58). Treatments included chemotherapy, radiation therapy, surgery, hormonal therapy, or some combination of these. Among their occupations were grocery store clerk, airline operations employee, homemaker, and a retired biomedical researcher with advanced degrees. One participant described herself as homeless.

Complex Range of Symptoms Managed

Cancer is a tremendously complex disease with a broad range of symptoms and side effects. Many cancer patients also have comorbidities that further complicate their health. We identified 47 distinct health issues that participants mentioned that they experienced during their care (Table 1). These health issues included physical symptoms, psychosocial problems, and vital signs that were out of the normal range. Although tracking such a breadth of health issues posed a significant challenge, a few participants did choose to track a subset of these issues with a tool, such as a notebook or calendar. More commonly, participants did not use tools to track symptoms that they had to manage, instead relying on memory.

Table 4.1. Health issues experienced by participants (*indicates one or more participants tracked issue with a tool).

Acid Reflux	Cloudy vision	Fatigue*	Insomnia*	Pain - Back	Sores – Mouth
Anemia	Constipation	Fever	Loss of appetite*	Pain - Bone	Sore Throat
Anxiety	Dehydration	Hair loss*	Lump size change	Pain - Headache	Swelling - Arm
Bloating	Depression	Heart rate	Lymph edema	Pain - Joints	Swelling - Foot
Blood count*	Diarrhea	Hives*	Memory deficits	Pain - Leg	Swelling – Seroma*
Blood pressure*	Dizziness	Hot flashes*	Migraines	Pain - Mouth	Vaginal tear / dryness
Blood sugar*	Drain fluid*	Infection - Bladder	Nausea*	Pain - Stomach	Weight gain / loss*
Bruising	Dry cough	Infection - Thumb	Neuropathy	Rash	

Natural Self-tracking Behaviors of Patients with Breast Cancer

Although patients with breast cancer often deal with a large number of symptoms, when they lack a dedicated tool to track these symptoms, their tracking behavior tends to be sporadic and incomplete. In this section, we present data showing that the most common practice was to try to keep track of symptoms by relying on one's memory, without using any kind of tool at all. We then show that those participants who did use tools to track symptoms often develop their own idiosyncratic, self-devised systems, which were both cumbersome and incomplete. Finally, we argue that the chief difficulty that patients with cancer face in trying to track is the lack of

knowledge about what they should be tracking and how to track. The healthcare system typically offers little support in this regard.

Patients rely on memory to track most health issues

Patients with cancer often experience a great deal of pain, stress, and anxiety, as well as "chemo brain,"—all of which make it hard for them to concentrate and think clearly (105). In spite of such cognitive difficulties, our participants monitored most health issues by memory. Although participants talked about the importance of writing health information down *during* visits to make sure no information communicated by clinicians was missed, 18 participants (68%) did not write down any symptoms that they experienced between clinic visits.

During clinic visits, participants relied on memory to discuss their symptoms and other health issues that occurred at home. Because the time between visits varied depending on the phase of treatment, participants had to recall the frequency and intensity of health issues that occurred anywhere from a couple of days to months before.

P5's experience provided an illustrative example of the difficulties patients experienced with trying to remember symptoms. P5 and her oncologist were trying to diagnose her irregular heartbeat from the previous week during a clinic visit. The oncologist believed was related to P5 not feeling well during that time but the patient could not say for sure how at that time to corroborate the oncologist's theory. In addition, because P5's irregular heartbeat was intermittent and they had not yet ordered an ECG, it could have been useful to know what was happening outside of the clinic to determine what events were co-occurring and how P5 felt in general, to see if the irregular heartbeat was due to stress, anemia, or some other cause. Unfortunately, P5

couldn't offer the oncologist any symptom history data other than the limited information that she remembered.

This incident is characteristic of others that participants experienced, in which patients' secondary symptoms were challenging to diagnose because they lacked real-time data of those symptoms. Some participants said that it was easy to be inaccurate about how they felt in the past. P11 expressed that she *"loses track of what happened when."* Most participants answered questions about past symptoms during the clinic visit from memory, but the accuracy of these assessments is unknown. Relying on memory by patients who experience memory deficits is problematic; yet it is the predominant way that patients with cancer report symptoms.

Patients devise their own systems using familiar tools when they track

Across both studies, 8 of 25 participants tried to track symptoms on their own using some kind of tool—paper or electronic. When patients used tools to track health issues, they usually appropriated familiar tools such as notebooks, calendars, and Microsoft Word documents, few of which were intended to be used to systematically track health issues in real-time.

For a small number of highly proactive participants who tracked health issues, tracking was a time-consuming and not typical activity. For example, prior to her use of HealthWeaver, HW-P21 was in the habit of spending significant time aggregating her data from a paper-based journal where she tracked side effects, sleep, vitamins, food intake, medications, exercise, and blood sugars for diabetes. On a weekly basis, she transferred the data to Microsoft Word. When she had a clinic appointment, she typed up 4-6 page summaries of the data for her doctor. Although she estimated this effort taking 4 to 8 hours, HW-P21 found the task important enough to do *"because I feel like the more information they [doctors] have, the better off I am going to*

be." She had always taken this detailed tracking approach, starting with her diabetes. HW-P21 valued informing clinicians accurately about her symptom history enough to continue this time-intensive, self-devised tracking system over the long term. Yet HW-P21 was unusual in the thoroughness of her tracking practice.

Other participants who valued self-tracking had suboptimal systems in place and did not always know how to improve them. Before HW-P17 had access to HealthWeaver, her partner undertook tracking on her behalf by recording HW-P17's health issues in a Microsoft Word document *"of the size that would frighten the Word team*." The partner asked her how she was doing and noted when she complained. HW-P17 described her partner's process and its limitations:

"After I haven't been complaining about something for a week, she'll ask 'are you still having this' so she can draw out a pretty clear picture of when things started and stopped, but I don't know….There is no particular thing to remind her [the partner] that four days in a row I complained about X and on the fifth I didn't."

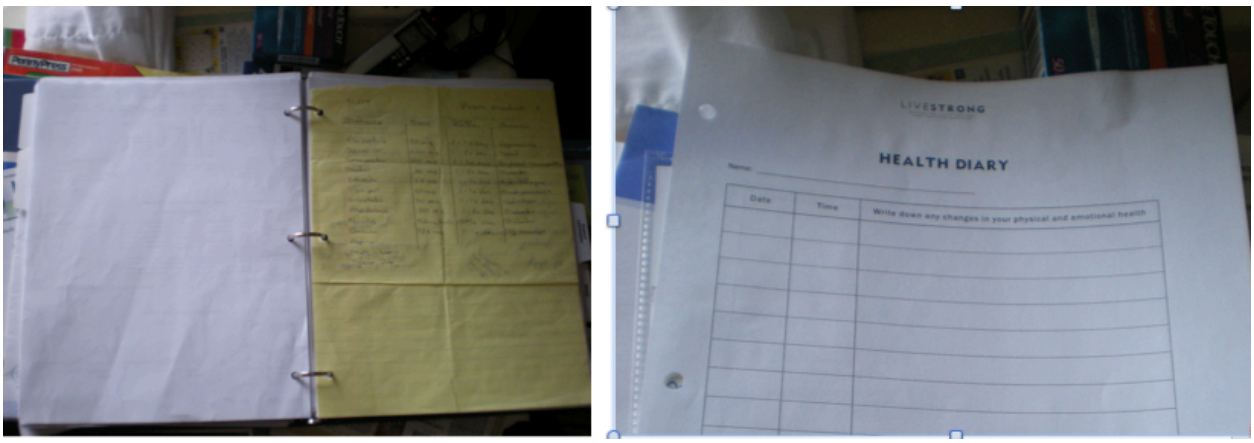
HW-P17's partner had to read back through the document every so often to prevent issues from slipping through the cracks. HW-P17 and her partner's tracking system worked well enough to assess how HW-P17 had been doing recently. But her partner had to parse a large electronic document to recall HW-P17's historical health issues, searching for specific terms that may have been called something else earlier.

The self-devised tracking systems of other participants were even more fragmented and sporadic. P2, a diabetic going through treatment for a recurrence of breast cancer, strove to collect her health information in a binder (Figure 2) and jot down issues as they came up in a

black notebook beside her bed, but instead she ended up with many locations for this information. She had a computerized spreadsheet in which she sporadically recorded insulin levels, a health issue tracking diary in a LiveStrong handbook (Figure 2), and a Patient Orientation Guide where she recorded her blood pressure in chart format. P2 wanted to but had not yet begun using the LiveStrong diary. Some of these artifacts were at her mother's house and others at her significant other's house, limiting easy access to her tracking system. P2 was motivated to track and had some structured tracking tools at her disposal; yet she still had trouble consistently collecting all the data in one accessible place.

Another participant, P3, had a calendar that she sometimes used to jot down dates of symptom occurrences (e.g., hair loss) and a journal notebook where she recorded symptom information in narrative form alongside other observations about her life. For many participants like P2 and P3, such fragmentation of previously tracked data made it difficult to reflect upon different aspects of how they were feeling or to re-find data when they needed to.

Figure 4.2. Self-devised tracking tools used by P2: medication list in binder (left) and LiveStrong diary (right).



In conclusion, self-tracking activities of participants who tracked 'in the wild' were time-consuming, fragmented, and sporadic. Aggregating the tracked data for reflection remained a

challenge for all participants except HW-P21, but her ability to access and reflect on her data came at the cost of a significant time investment in her tracking process.

Patients have little guidance in deciding what and how to track

A major reason why patients have difficulties with tracking is that they often work out for themselves what they need to track and how to track it (106,107). With cancer, knowing what to track is particularly difficult because there are so many possible health issues that can arise and some occur unexpectedly. Similarly, lacking dedicated tools, patients are left to design their own tracking systems, with varying success. For instance, notebooks, Word documents, and health diaries—such as the one used by P2—can easily capture the breadth of symptoms patients deal with. However, reflecting upon data in these tools was a challenge that few participants did successfully.

In terms of knowing *what* to track, clinicians sometimes suggested that patients track specific health issues to gauge likelihood of infection or toxicity. For example, some participants were asked to track drain fluid, blood sugar, or temperature at home. However, patients often experienced many more symptoms than were covered by clinicians. It was patients themselves who figured out which additional signs and symptoms were important and which they needed to track systematically.

In terms of knowing *how* to track, support from the clinicians was even more lacking. Clinicians provided some participants with formatted paper logs for tracking drains, but for most other health issues, patients created their own logs on paper or in a spreadsheet. HW-P23 reflected, *"Doctors do recommend it to you, but how are you going to do it? It was recommended in the mass amount of the paper you get at the beginning. So you read it later, and*

they don't provide the system." Although clinicians suggested that participants track particular health issues, this recommendation often came without guidance on how to track or was buried in the paperwork that participants took home. As a result, participants devised their own systems with minimal guidance from clinicians.

Benefits of self-tracking for patients with breast cancer

The deployment of the dedicated tracking tool in the HealthWeaver study group revealed relatively high usage by participants, and accordingly exposed key benefits of having access to a tracking tool. Some benefits directly related to the problems that patients experienced when they tracked on their own. First, participants used HealthWeaver frequently because tracking preserved important symptoms and treatment-related events without having to rely on memory. This tracked data allowed patients to see patterns when diagnosing problem symptoms and monitor issues surrounding intense health events. Second, using HealthWeaver enabled participants to unify tracking data with other care-related information, making it easier for them to track consistently and to access their tracking history. Third, because HealthWeaver came with a set of default and optional metrics based on our previous research, our participants had a starting point for figuring out what to track. Finally, regular use of HealthWeaver by participants also uncovered new benefits to tracking, such as better communication with clinicians and psychosocial comfort derived from consistent collection and occasional reflection on the data.

HealthWeaver use was more popular than anticipated. When an easy-to-use tracking system was available to them, participants used it more than was required for study participation. Participants were only required to track 1 health issue, but ended up tracking an average of 8.8 metrics. HealthWeaver was set up with 4 default metrics and a dozen other metrics were

available for them to choose from. If participants wanted to create their own custom metrics, they could do so by customizing the tool's settings. Four out of the 10 participants who used HealthWeaver created their own custom metrics to track health issues, including "did all stretches", "surgical discomfort", and "knee pain." Some participants even employed workarounds to generate new custom metrics in units that weren't supported by HealthWeaver. For example "took all pills" was a well-being parameter that one participant created on the 0-4 scale, because she preferred using check-ins more than the medication log feature. These participants actively made their own decisions about what was useful to track and varied greatly in what they chose to track in HealthWeaver.

Patients appreciated having tracking data and information related to their cancer care unified. HW-P18 thought that having information such as her health calendar, clinical contacts, and tracking data *"all in one place, without shuffling any papers"* was very important. HW-P21 agreed: "*I definitely feel more empowered. Instead of having 50 pieces of paper all over, I have it all right in front of me."* Rather than tracking on a standalone device disconnected from the rest of the cancer care experience, patients were able to use HealthWeaver to track symptoms and manage other care-related information in one place. The unification of data made it easier for patients to collect all the information they needed to share with clinicians during appointments and to feel confident they could find a piece of care related information when they needed it.

Patients use a tracking tool to reflect on patterns and overcome memory deficits

When patients tracked data in HealthWeaver, they could reflect on symptom patterns in the spirit of personal informatics. Tracked data provided better answers than relying on memory alone because the check-in graphs provided an interactive visual representation of historical data

that facilitated pattern finding. Half of HealthWeaver study participants stated how useful the tool was for capturing and graphing symptoms to understand and problem solve health issues.

For example, HW-P19 thought surgery was a major enough event that she decided to undertake tracking. Tracking pain after surgery helped her figure out that she developed an infection. "*So I was able to look back and see, I wasn't feeling this bad, what's going on now?"* After her post-surgical drains were taken out, fluid was not being absorbed, causing swelling. HW-P19 was able to see the relationship between her post-surgical pain and when the swelling developed. When she visited her clinician, she confirmed that the cause of her pain was a seroma, a common side effect of surgery, as she had suspected. Given her newfound understanding of her symptoms, HW-P19 said she thought the check-in graphs were the most valuable HealthWeaver feature.

Another participant, HW-P23, tracked her symptoms during radiation therapy. She knew extreme fatigue was a common side effect of radiation, but she often had insomnia as well. She started tracking sleep and fatigue to see if they were related: *"How am I gonna figure out what [the fatigue] related to, but if I put down did I have a bad night or not, then I can see it's pretty clearly related to that [sleeplessness] rather than radiation."* Although she said she suspected it before, *"it was more black and white there [on the HealthWeaver graph], so that was useful."*

Patients use tracking to support communication with clinicians

Regular tracking with HealthWeaver enabled participants to recall symptoms during clinic visits and discuss specific health issues with clinicians. Participants were able to capture symptoms and their intensity on a regular basis close to the time that the symptom occurred. Thus, they could provide a more accurate picture of symptom history to their clinicians. In one

case, HW-P17 had an appointment with the oncologist coming up, so she had been trying to carefully monitor her symptoms. Because she was in a 2-week break from chemo, her symptoms had changed and she wanted to accurately recall these changes. HealthWeaver enabled her to share her symptoms with her doctor. Also, having a concrete tracking history of a particularly troublesome symptom—hip pain—helped her clinician address it more readily:

"It was very useful for me to be able to lay out what was going on to my doctor, to show this is what's happening. I was able to show her that my hip was getting worse over time and that she should take it a little more seriously, [given] the fact I had it [tracked data] for day after day after day and I could show her what was going on."

HW-P23 also thought tracking would be beneficial for supporting communication with her doctor, especially because her clinic visits were often weeks apart, and without a tool, she could not accurately answer her doctor's questions about how she had been doing. In addition, HW-P18 pointed out that having access to HealthWeaver on the smartphone was particularly valuable to her during clinic visits. This access increased her confidence that she could answer any question the clinician might ask because she could easily look up the information she was asked about.

In summary, a tracking system such as HealthWeaver supported communication with clinicians in three ways: by enabling patients to keep accurate and concrete data about their symptoms, by helping them preserve symptom history over long periods of time, and by giving patients confidence that they can accurately answer clinicians' questions during appointments even if they had not prepared the needed information in advance.

Patients take psychosocial comfort in regular tracking

Finally, even patients who are not looking to resolve specific health issues derive psychosocial benefit from using tracking tools. HW-P17, for example, found tracking in HealthWeaver helpful for her emotional wellbeing, specifically for reminders that she still had positive moments even when things were going poorly. She relayed the benefit she saw in tracking:

"This might be really goofy, but adding something good that happened, any good news, might be helpful to go back and remember that there have been improvements [good things happening]. I usually summarize, so you can look over the last couple of weeks and see how things are going…Day to day it doesn't look like much has changed but then you look back after a couple of weeks and you see, 'oh cool, there has actually been an improvement, or even it's getting worse, you know you need to push it. Being encouraged to log every day and be able to see a summary of those logs isn't the part I would have thought would be the coolest, but really has been the part I relied on the most."

HW-P23 also found herself relying on HealthWeaver's tracking features to capture how she was feeling. She liked the journal and used it to track her exercise as well as to record experiences—the "ups and downs" of cancer:

"If I had it for the whole year, it would have been really useful. It was a roller coaster, overwhelming at times, from the beginning. Tracking helps with that, with the ups and downs."

Cancer treatment is a psychologically difficult experience, and one potential benefit of tracking is to highlight positive moments interspersed with the inevitable challenging periods.

For patients dealing with a life-threatening illness, awareness of the good aspects of their lives serves as an important source of comfort.

Discussion

Although self-tracking is very difficult for patients with cancer to initiate, it could be more beneficial than anticipated. Although the study team that designed HealthWeaver had a minimal preconception of how the tracking feature should work, users overcame inherent barriers that patients encountered trying to track symptoms on their own. Nearly all HealthWeaver users were motivated enough to engage in more self-tracking than required, which in turn fostered enjoyment of these unexpected benefits.

Table 4.2. Summary of key findings and related implications for tracking tool design.

Summarized findings	Implication from HealthWeaver tracking feature use
In-the-wild: barriers to tracking	
Limited clinical guidance	Pre-populated metrics helped patients decide what to track.
Fragmentation of data	Patient preferred unified information on cancer care in one system.
Time & energy burden	Ease of use enabled from intuitive, aesthetic, multimodal interface.
With HealthWeaver: benefits to tracking	
Augmented memory	Patients did their own reflection and customized metrics to remember trends.
Psychosocial comfort	Patients owned the tracking process and took comfort in routine.
Communication support with clinicians	Patients could show tracking data to clinicians and help prioritize symptoms.

Characterizing a Complex Symptom Burden

Designers and developers of real-time tracking tools for patients with cancer need the ability to understand the great burden of a life with symptoms related to disease and treatment. In Chapter 4, participants with breast cancer related that it took great effort to track symptoms, and they also acknowledged benefits from tracking symptoms in real time.. The process requires a choice from many symptoms they may experience of what to track, and then follow through as

they occur. Although HealthWeaver supports real-time tracking in the technical sense through time-stamped check-ins, most participants did not utilize the tool to report immediate symptoms. Other studies have shown that, despite the best of intentions, making a decision to track specific metrics generally does not correlate with actually self-tracking (77). Given all the symptoms that people with cancer experience, it is difficult for them to determine on their own which metrics are worthy of tracking, particularly when data entry is manual rather than passive. It is also challenging to analyze and interpret the very noisy channel of information that is the result of passive monitoring. Further, ethical implications of passive monitoring include revealing potentially the patients' uncomfortable patterns of symptoms and activities.

A limitation of this work is that, while HealthWeaver can theoretically support time-stamped self-tracking in real time as symptoms occurred, participants tracked daily or sporadically. This may have resulted HealthWeaver's design limitations, such as all new metrics being calibrated on a 0 to 4 scale. Additionally, the check-in entry screen displaying a full page of web form fields such as minutes of exercise and sleep did not get filled out for many patients. Future design adaptations could support more in-the-moment data capture through effective and intuitive interface elements, rather than through cumbersome HTML forms commonly implemented on the web and mobile versions of HealthWeaver (101).

Self-Tracking Behaviors Gravitate towards the Familiar and Easy

Findings on participants' tracking behaviors in the wild correspond to those from the Pew Report "Tracking for Health." Seven in 10 Americans track health indicators in some way (26). Of these tracking individuals, 34% used paper tools, 5% used a computer program, 1% used a website, 7% used an app or mobile tool, and 8% used a medical device. Half of these tracking

individuals did not use any tracking tools at all (26), supporting the finding in this chapter that patients with cancer rely heavily on their memory to track symptoms (108).

Ideally, tracking tools for cancer, or any serious illness, capture the following information in as close to real time as possible: (1) variability of symptoms; (2) mood states over time; (3) behaviors over time; (4) cyclical patterns; and (5) co-occurrence of symptoms, environmental conditions, and psychological states (39). Akin to capturing the categories of data collected in ecological momentary assessments and interventions described in Chapter 2, obtaining a detailed picture of a person's health requires either a heavy data entry burden on the patient to report how they are doing. Alternatively, patients wearing devices or download sensing mobile apps that employ sophisticated algorithms analyzing multiple messy streams of passive data. For most people without smartphones or the knowledge of the value of an app that works to help improve their health, finding a viable solution is quite a challenge. With so many choose from, it is not surprising that even the savvy among us have trouble separating the worthwhile apps from those that have limited use (79). Clinicians could fill this gap by prescribing valuable apps (or "suggesting" choices to allay concerns about medical liability or malpractice suits).

Upfront investment in tracking tools and their maintenance—in terms of time and expense—are costly for both clinicians and patients. The perception that self-tracking is a burdensome endeavor prevents either party from considering incorporation of the practice. The benefits patients experienced through use of HealthWeaver also correspond to the Pew survey on tracking tool use: 46% said self-tracking changed their overall approach to health, 40% asked new questions or sought a second opinion, and 34% said that self-tracking affected their treatment decision. Despite these promising numbers 37% said that self-tracking had no effect on their lives (26). As a result, approaches to self-tracking tool development should evolve to help

those who receive minimal or no benefit from self-tracking. Note that these statistics do not apply to cancer only, a context that is quite different situation than for the general population.

Conclusion

People with cancer experience a broad range of symptoms during treatment, and do not always see the benefits of real-time tracking. In the wild, participants with breast cancer rarely invested time in the tracking process, and those who did typically made do with fragmented and sporadic self-devised systems. Almost all participants with breast cancer were not aware of the benefits of tracking prior to participating in the study where we deployed HealthWeaver as a technology probe. Participants who used the program augmented their memories, supported communication with clinicians, and derived psychosocial comfort from tracking. Due to its positive aesthetic, customizable metrics, and opportunities it provided for reflection, we found that HealthWeaver motivated participants, with or without clinicians, sufficiently to make the effort to track symptoms—. Further investigation into cancer diagnoses, stages, and treatments that can best be served by self-tracking—and how to ensure that well-designed tools are accessible and used—will help patients realize their full benefit during cancer treatment. When carefully designed, such tools could help patients to better manage their treatment, communicate with their providers, and maintain control over their care and their lives.

Chapter 5 : Discussion

"Medicine strives for causal simplicity."

- Kathryn Montgomery Hunter (109)

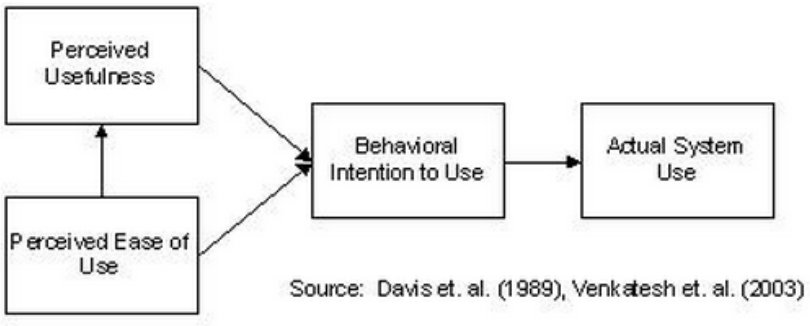
The relationship between the patient and the clinician has potential to be fundamentally altered when the patient uses a tracking tool to document symptoms and details of their care particularly one with monitoring or sharing features. Instead of clinic visits serving as the only information source about the patient's condition, tracking tools that gather patient-generated data can foster clinicians' continuous understanding of the patient's condition including. For patients with cancer, tracking tools could support symptom management, self-care, and communication. In this dissertation, I studied two tracking tools—ESRA-C, an e-PRO tool, and HealthWeaver, a personal informatics tracking tool, to understand how often such tools are voluntarily used by patients in cancer care, what benefits are experienced from their use, and how attributes of patients (e.g., symptom distress) relate to use and benefit.

To understand further what drives use and acceptance of tracking tools, this chapter covers existing theoretical frameworks and a new conceptual model that could influence the design of future tracking tools. Existing conceptual models help inform explanations for low use and acceptance of tracking tools in today's clinical environment. As a result, I developed a new model that incorporates outside empirical literature and includes findings from secondary analyses from Chapters 3 and 4.

Theories of Technology Acceptance Applied to Tracking Tool Use

The Technology Acceptance Model (TAM) (110,111), the continued use model (112) and its derivatives (112) from the management science literature can help us understand patients' tracking tool use. Aspects of health status and treatment decisions likely influence patients' decisions on what is useful to track. Empirically grounded theories can explain motivations and barriers to self-tracking and inform patient-centered principles that designers should follow to develop tracking tools for patients. In this section, I will explain these foundations and relevant extensions of these theories.

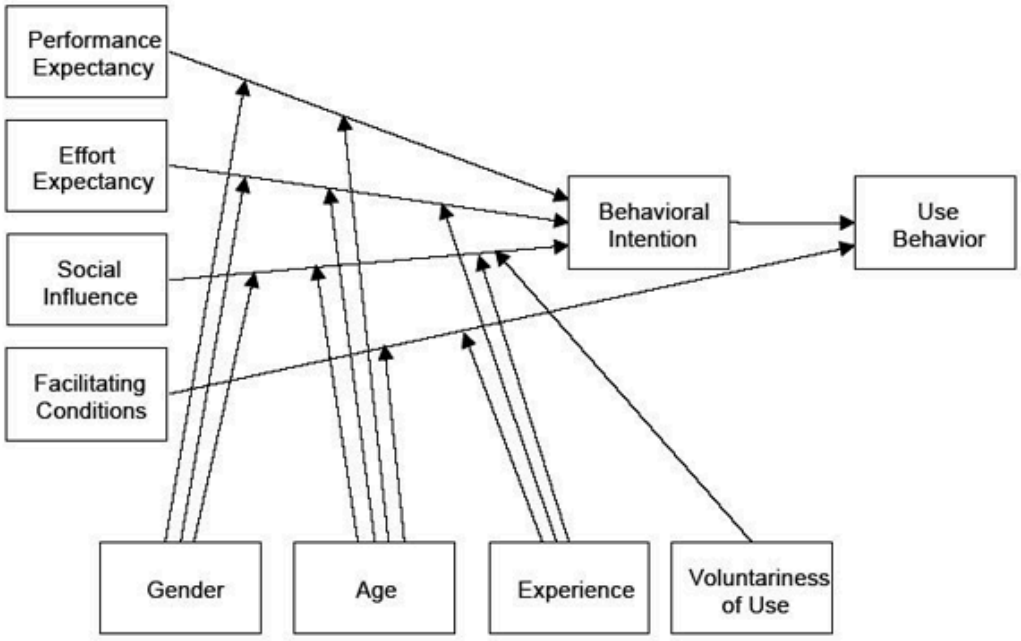
Figure 5.1. Technology Acceptance Model (TAM). In the original TAM theory from the management science literature, perceived usefulness (PU) and perceived ease of use (PEOU). PEOU positively influences PU, according to TAM.



The original TAM was derived from the Theory of Reasoned Action (TRA), which suggests that a person who intends to undertake an action is likely to actually carry out that action, which is also referred to as behavioral intention (113). Although both TRA and TAM assume rational decision-making, TAM theorizes that one's intention to voluntarily use a technology plays a vital role in their actual use of it. In the original TAM, belief factors that are the most predictive of the decision to use a technology are perceived usefulness (PU) and perceived ease of use (PEOU). PEOU positively influences PU, according to TAM. Mediating

factors of behavioral intention such as age and gender have been described in many extensions to TAM, such as the Unified Theory of Acceptance and Use of Technology (UTAUT) (110). The UTAUT also defines variables such as age, gender, experience, voluntariness of use, expected performance, expected effort, social influence, and facilitating conditions as influencing intention to use a technology tool, these factors mediate the theory that human beings are not rational actors.

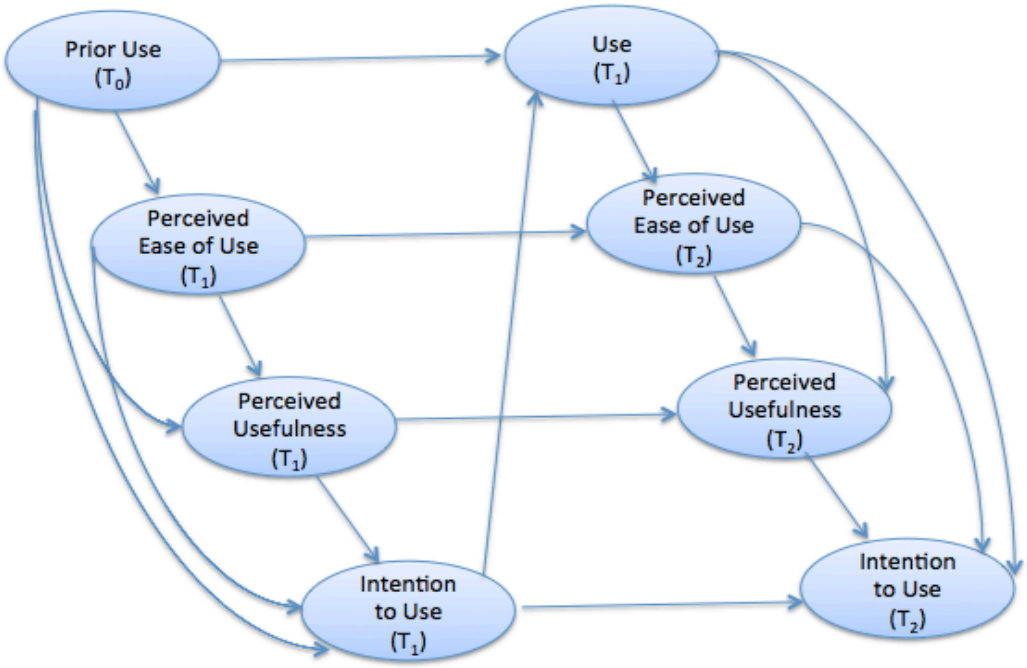
Figure 5.2. Unified Theory of Acceptance and Use of Technology.



TAM and its successors have been used to predict adoption of electronic medical records and telemedicine by clinicians (114), provider-delivered e-Health applications (46) and patient use of consumer health information technologies (115). Although TAM extensions could be used to predict one-time adoption, understanding the use of tracking tools by cancer patients demands application of *continued use* technology acceptance models. Because tracking health issues over time yields the most benefit, relevant theories must explain how to motivate

continued use of tracking tools. For example, entering weight into a tracking tool once is not as helpful for reflection as much as capturing weight daily over a multi-week period. The continued use model by Kim and Malhotra expands upon TAM by instantiating causal links between PEOU, PU, intention to use IT, and actual use of IT at different times (112). This model addresses how intent to use IT evolves over time. If the first few uses of a tracking tool are perceived as a chore without benefit to one's health, then patients will likely abandon the tracking tool.

Figure 5.3. Continued Use Technology Acceptance Model (116). Prior use of a tool at T_0 generates perceptions about ease of use and usefulness, intention, and actual use at T_1 that theoretically influences intention the next time one intends to use the tool at T_2.

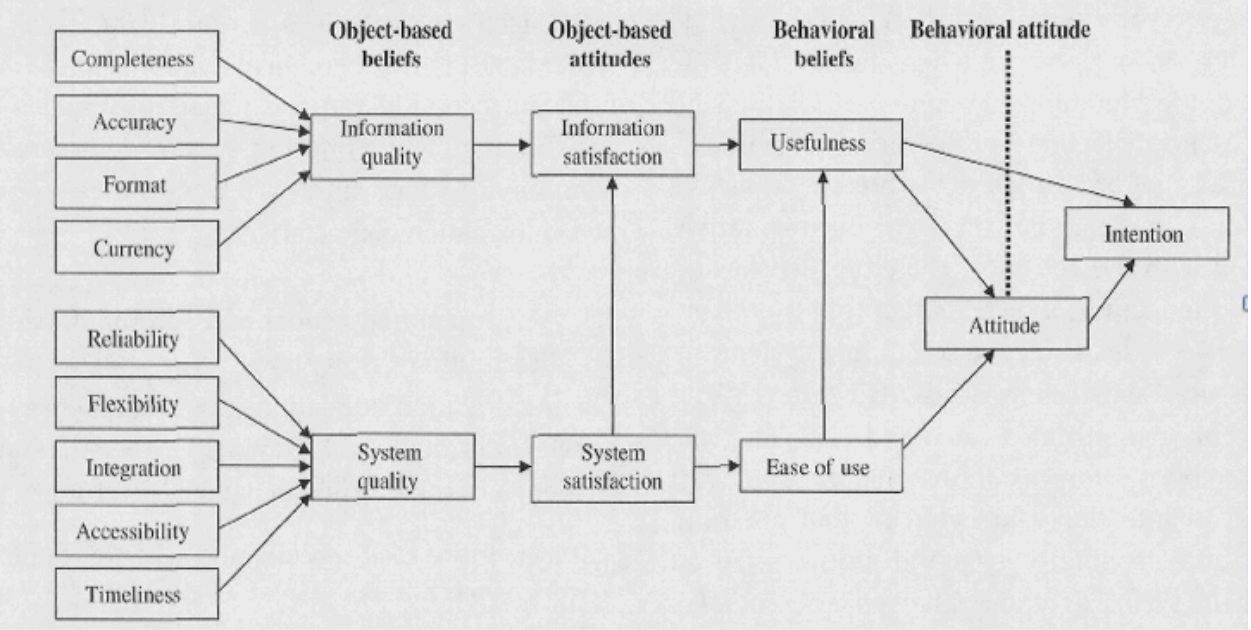


TAM itself is a parsimonious theory, but it does not explain what designers and developers should optimize to encourage patients' acceptance of tracking tool technologies. Thus, researchers have extended TAM in the healthcare context to predict adoption of different

types of technology by healthcare professionals (47,117-120). Others have used TAM-related theories to determine whether patients will accept e-Health technologies delivered by providers (46,47,115,121,122). These studies often take the perspective of the behavioral intention of the patient (e.g. health information-seeking behavior) and subjective environmental norms along with perceived usefulness and ease of use, as factors in whether a patient uses a technology. However, researchers in this area provide minimal detail about what makes technology perceived to be easy to use or useful. Designers and developers do not have guidelines to clearly define requirements for its use.

Rather than focusing on perception of technology as a key driver, Van Gemert-Pijnen advocates that patients adopt a holistic approach to e-Health acceptance (25). A review of existing e-Health frameworks demonstrated that many focus on identifying individual, organizational, and technological dimensions that contribute to acceptance and impact of the e-Health technology (25). Many of these frameworks are developed from the fields of human-computer interaction (HCI), health services, and management science. In general, the HCI frameworks suggest that a participatory approach involving multiple stakeholders including patient, clinician, payer, and healthcare organization management will lead to a more acceptance. Based on these attributes, health services and management science approaches typically highly emphasize a summative evaluation that relates to overall technology acceptance or success outcomes. However, specific e-Health technologies vary quite widely in how frameworks can be applied. Systems designers and developers of patient-driven tracking tools certainly need to involve patients and clinicians, and be aware of payers and healthcare organizations constraints that deliver cancer care to define what supports—and enhances—patients' perceived ease of use and perceived usefulness of any given tracking tool.

Figure 5.4. Integrated model of technology acceptance and user satisfaction (123). Factors influencing object-based beliefs (information quality and system quality) lead to object-based attitudes (information satisfaction and system satisfaction), which influence a user's behavioral beliefs about usefulness and ease of use of an IT system.



In contrast to TAM's focus on predicting information technology adoption through behavioral intention, the field of information science is more focused on improvements in user satisfaction as a predictor of a technology's success. As a result, attributes of information system design affect users' adoption. Integrating technology acceptance and user satisfaction models, Wixom differentiates object-based attitudes and beliefs that a user has about IT from the behavioral beliefs that lead to intention to use it. This integrated model is represented in Figure 5.4, which explains how the attributes of an IT system can influence beliefs about the IT system and ultimately intention to use it. Identifying attributes of tracking tools that impact usage by a specific population can be a practical path to understanding how to design them.

Clinicians, researchers, and even technology companies develop frameworks to better understand uptake of specific components of e-Health interventions (124,125), electronic symptom-reporting (126), chronic care interventions (127), and personal health records (PHR)

integrated with the electronic health record (EHR) (49). Han applied Johnson's Comprehensive Model of Information Seeking (CMIS) (128) to determine three main groups of factors that influence interactive cancer communication system use (124): demographics, psychosocial needs, and disease-related factors. Although the extension of CMIS explained why cancer patients used a specific tool in their cancer journey, the framework focuses on only dimensions of the patient, rather than aspects of the technology or the clinician using the communication system. However, none of these frameworks specifically separate what aspects of patient-generated data and the technology capturing the data need to be taken into consideration.

Theoretical frameworks fall short of identifying factors contributing to acceptance of any particular tracking tool by patients and cancer care clinicians. Frameworks such as TAM (129) and its derivations do not effectively describe technological elements whose objectives include capture, presentation, and sharing of patient-generated health data. The Stage-Based Model of Personal Informatics (77) focuses on tracking tool acceptance but does not adequately describe enough factors that designers should consider when defining characteristics of tracking tools, and doesn't involve clinician team members with an interest in interpreting patient- tracked data.

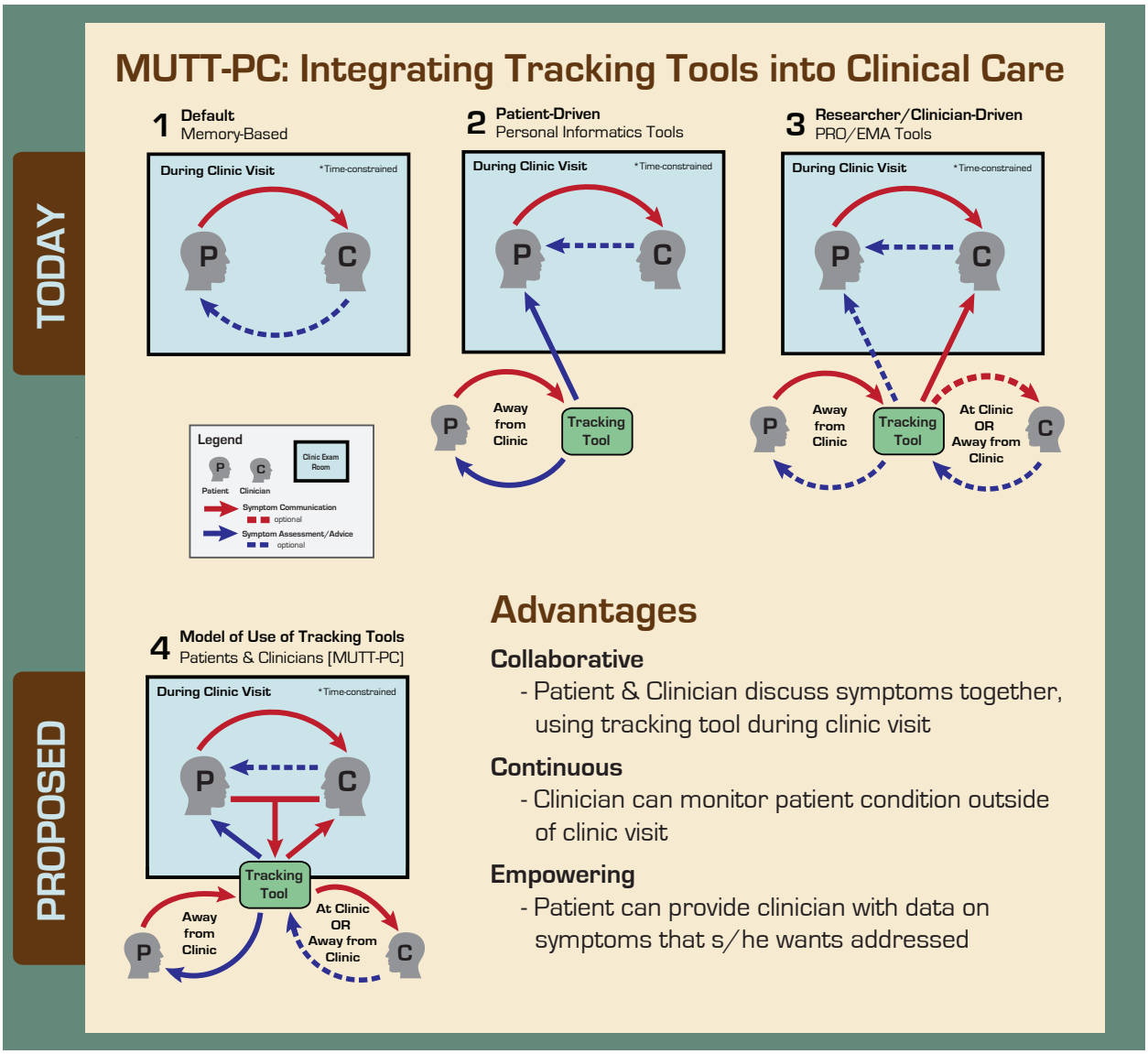
Other theories about chronic illness interventions like the Chronic Care Model include the broad health system and community as settings for care-based interventions (127). If tracking tool use is viewed as clinical intervention, self-management support that it provides should certainly fit into the patient's everyday life and clinical workflow. However, I argue that to be informative for patients, clinicians, and tool developers, a theoretical framework for use of tracking tools in cancer care should incorporate unique aspects of tracking tool design, adhere to patients' needs in the context of their lives, *and* have clinically relevant goals. For *both patients and clinicians* to use and accept the tracking tool, we need to identify the breadth of goals before

tracking tools can gain widespread acceptance. Acceptance of tracking tools cannot be easily understood in isolation from the *usefulness of the data* that it collects.

Conceptualizing a Model of Tracking Tool Use in Healthcare

Chapter 2 described the differences between various types of Patient-Driven and Clinician/Researcher-Driven tracking tools. In this section, I provide a conceptual model to visualize the context of the clinical setting and symptom communication flow when each type of tracking tool is used. The diagrams in Figure 5.5 depict four different scenarios in which symptoms are communicated to a clinician: (1) memory-based (default scenario), (2) personal informatics tracking tool (patient-driven scenario), (3) patient-reported outcome (PRO) or ecological momentary assessment (EMA) tracking tool (researcher/clinician-driven scenario), and (4) newly proposed tracking tool (future scenario).

Figure 5.5. Model of Use of Tracking Tools by Patients and Clinicians (MUTT-PC).



The memory-based symptom communication scenario in Figure 5.5(1) is quite common. Half of all American self-trackers—one-third of the population—monitor health indicators only "in their heads" (26), so clinic visits become the main source of symptom communication for most clinicians. For example, internal medicine clinicians elicit patients' chief complaints, ask for a history of the present illness, and undertake a review of systems (130). During the process of asking questions and conducting the physical exam, internal medicine physicians are able to

draw out current symptoms, but rely on patients to accurately recount symptoms that occur between visits. As discussed in Chapter 2, this process is subject to recall bias and other cognitive distortions.

The second scenario, shown in Figure 5.5(2), is one in which the patient uses a personal informatics tracking tool outside of the clinic visit to inform communication during the clinic visit. With Quantified Self, a movement encouraging self-tracking, in full force, people are initiating health-related tracking outside of clinics and hospitals. Of all American self-trackers studied, 34% use paper, 5% percent use computer programs, 1% use websites or other online tools, and 7% use apps (26). Thus, Quantified Self may still be considered a "fringe" movement popularized among tech enthusiasts, hobbyists and educated individuals with chronic illness (). Additionally, studies that prove that personal informatics tracking tools lead to better health outcomes are rare (75). However, one recent Mayo Clinic study showed that Fitbit physical activity tracking among heart disease patients decreased hospital readmission rate (132). The clinic's heavy involvement in procuring and distributing Fitbits made the study possible, as well as clinicians recruited to review the data. Scenarios are quite different where individuals chooses to purchase a tracking tool or create one with previously owned media/software, yet symptom communication during the clinic visits typically occurs just as it did in the default scenario. Importantly, the patient might feel more informed and able to communicate tracked symptoms accurately. Thus, if patients are empowered, they may bring tracked data to clinic visits, although such data might not be reviewed by clinicians on a tight schedule.

A third scenario, shown in Figure 5.5(3), occurs when a clinician-manager or researcher integrates a Patient-Reported Outcome (PRO) or Ecological Momentary Assessment (EMA) tool into clinical workflow to help facilitate a dialogue about symptoms and self-management

between patients and clinicians during the clinic visit. Here, a patient typically receives specific instruction on when and how to use the tracking tool and in some cases is given a tracking device, which can be tablet or phone-based or can use software apps on their own mobile device or computer. Due to the nature of PRO and EMA tools, patients answer questionnaires to generate a score or take measurements to populate the tracking tool. There is not always a choice of questionnaires or measurements to be filled out, and requirements of some EMA/PRO tools are perceived to be onerous, as described in Chapter 2. However, the clinician receives validated information about the patient's symptom status, which in turn allows the clinician to make more informed clinical decisions (130).

Finally, in the future proposed scenario shown in Figure 5.5(4), the patient and clinician collaborate, using tracking tools for symptom communication. Here, the tracking tool is a symptom communication aid during the clinic visit. First of all, it provides feedback to patients on how to manage problematic symptoms both in and outside the clinic, as ESRA-C had done and the PRO/EMA scenario illustrated. Second, it could provide a summary patient symptom report to clinicians inside the clinic, as ESRA-C and other patient-reported outcome tools do. Third, the tracking tool could gather in-the-moment symptom data from the patient outside of the clinic, which happens in the personal informatics scenario and EMA/PRO scenario as well.

Thoughtfully designed tracking tools can facilitate supportive and collaborative communication between patients and clinicians. What makes this scenario unique is that feedback to patients—and clinicians' suggestions of high-priority clinically relevant symptoms—is incorporated continuously throughout the interaction cycle. Specifically, during the clinic visit, the patient and clinician collaboratively discuss symptoms currently bothering the patient, signs and symptoms the clinician observes, symptoms the clinician expects to be

problematic for the patient in the near future, and how the patient can manage symptoms at home. This future scenario also has the clinician providing feedback outside of the clinic in cases when it is clinically necessary. Clinicians can assess clinical necessity using a quality of life dashboard of a patient population (a feature of some electronic medical records or practice management software suites). More sophisticated but technically difficult solutions for assessment of clinical necessity would include alerts generated from remote monitoring data passing a previously specified threshold.

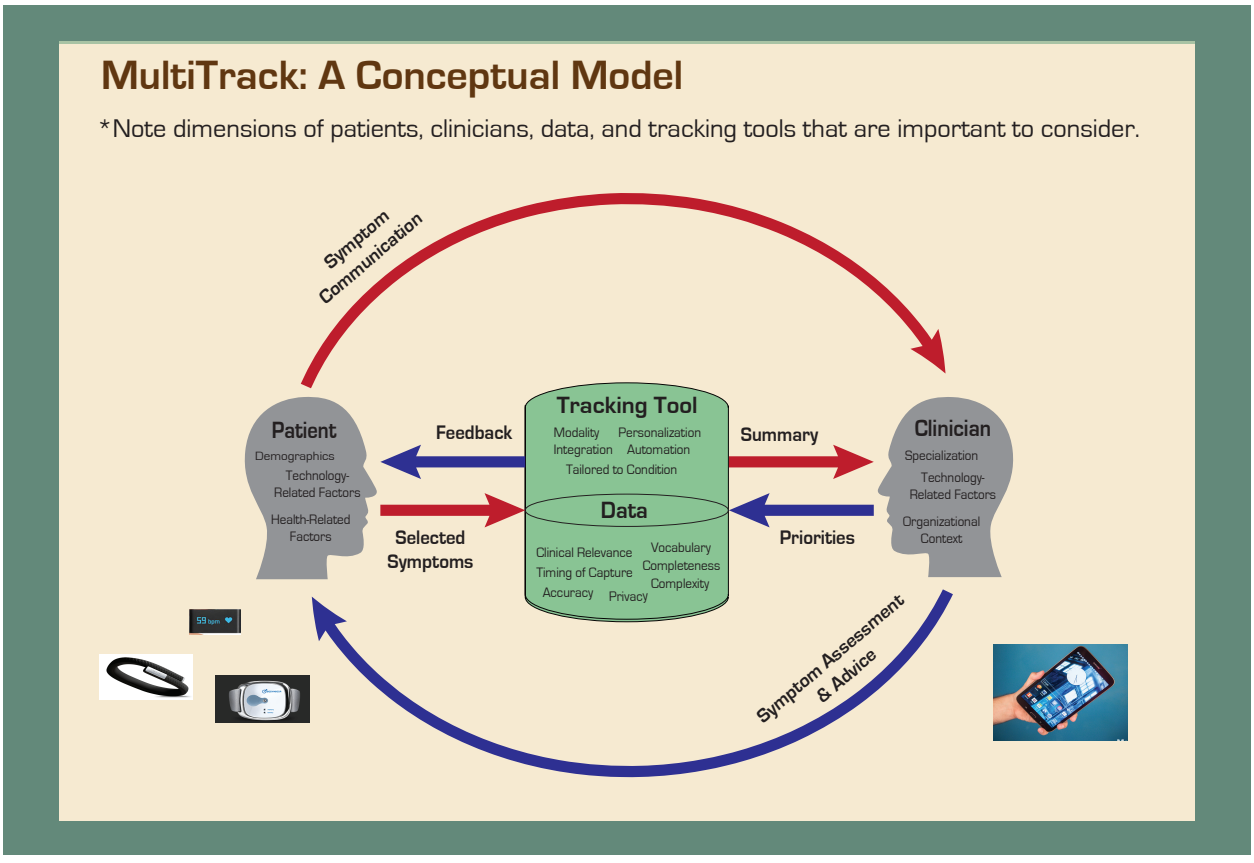
One caveat to heed on passive remote monitoring: alert fatigue is a common complaint of clinicians when using computer-based decision aids based on PRO assessments (30). To help busy clinicians, dashboard visualizations could provide quick and accurate insight into a large population of patients' symptom conditions. These visualizations would have to be designed to be quickly reviewed but also trustworthy in representation of the underlying data.

MultiTrack: A Conceptual Model of Tracking Tools

Technology acceptance model-derived theories described earlier do not provide a basis for understanding of both technology attributes and context that facilitates voluntary use and acceptance by patients and clinicians. To address the deficits of the conceptual models for tracking tools described earlier, I developed a conceptual model that incorporates clinician's perspectives and explicitly separates attributes of the data and tracking tools. This new conceptual model describes dimensions of four major components of self-tracking in healthcare: (1) the patient, (2) the clinician, (3) the tracking tool, and (4) data captured. Each component has several key dimensions to consider in terms of design tradeoffs. Taking these dimensions into account for appropriate use cases could increase the likelihood that patients and clinicians use

and accept the tracking tool for symptom management in cancer care. Ideally, patients would reveal their health priorities from specific metrics that they collect in tracking tools, and clinicians can prioritize clinically relevant metrics for patients to track. Both parties would have to accept the tracking tool if the tool were to be effective and clinically relevant. In the following sections, I describe dimensions of the four components: patient, clinician, tracking tool, and captured data.

Figure 5.6. Conceptual Model of Tracking Tools that collect patient-generated health data. The curved arrows between the patient and the clinician represent the continuous healing relationship the clinician and patient should both foster whether a tracking tool is used or not. The tracking tool and the data it collects are meant to support the relationship between the clinician and patient. Tracking tools that are used to monitor patients' signs and symptoms between visits still might not be accepted by either the patient or the clinician.



Patient Dimensions

Patients have attributes that lend themselves to using tracking tools related to demographics, technology, and their health. These tools should strive to enhance the patient's wellbeing first and foremost. Tool use by itself is not a measure of its success for health purposes. Factors that influence a patient's decision to use a tracking tool during cancer care that are health-related, demographic, and technology-related are detailed in the following sections. If these factors are not developed with careful forethought, patients could remain uninformed about which self-care management practices are worthwhile for their condition. Focusing on these factors could help patients feel a greater sense of control over their illness when using tracking tools.

Health-Related Factors

Health-related factors have a major impact on what patients feel like and whether they derive benefit from use of tracking tools (41). Two such factors that affect use in particular are symptom distress and disease state.

Symptom Distress

Patients have varying levels of symptom distress over the course of treatment, which can impact use of tracking tools. High symptom distress might leave patients physically unable or too fatigued to use a tracking tool. In Chapter 3, I described low symptom distress associated with relatively frequent use of the e-PRO tool ESRA-C. Results were inconclusive about whether a high range of symptom distress or a sharp increase prompted someone with relatively low baseline symptom distress to voluntarily use ESRA-C. Though further exploration is needed to determine when and how symptom distress plays a role in voluntary use of tracking tools,

promising study results suggest an association between level of symptom distress and frequency of use.

A Norwegian study found that some breast and prostate cancer patients using an interactive tailored health assessment tool called WebChoice were too ill to benefit, and thus used it less frequently than expected (52). In a study looking at user perceptions of the initial ESRA-C system (preceding the ESRA-C system used in Chapter 3) (133), more symptomatic patients with cancer found ESRA-C less acceptable. In addition, Han's investigation of characteristics of users of a system called CHESS concluded that such disease-related factors as symptom distress, factored into interactive health communication system use (124). The framework resulting from the work mentioned earlier in Chapter 2 focuses on only patient dimensions related to tool usage, despite the influence of both the data collected and the tool itself.

One strategy to mitigate the problems of data entry during periods of high symptom distress calls for patients to enlist caregivers to record physical or psychosocial symptoms. A caregiver who uses a tracking tool on a patient's behalf might have to perceive or ask about symptoms rather than having the ability to record symptoms as they happen. Regardless of the caregiver's role, it is worthwhile to consider patients' symptom distress as a factor influencing tracking tool use and acceptance. Patients could be too debilitated by high symptom distress to engage in self-tracking or, conversely, motivated to troubleshoot difficult symptoms. Patient burden and lack of awareness of availability are clearly obstacles to tracking tool use. Patients with cancer are often too overcome with a broad range of symptoms to research what benefits can be derived from initiating tracking tools use (108). In the study in Chapter 4, participants tracked a limited set of symptoms, if any. Altogether, participants described suffering from 47

signs and symptoms during the course of breast cancer treatment. Thirty-two percent of these participants tracked thirteen symptoms in a tool. Most often the tool was familiar and informal, such as a paper calendar, a spreadsheet or a Microsoft Word document.

In summary, symptom distress affects the motivation and ability of patients to undertake self-tracking, even with knowledge of benefit. When people have debilitating symptom distress, they conserve energy for activities that are more basic to their lives. Particularly without social support, self-tracking could feel like a joyless chore not central to one's wellbeing (134).

Disease State

Disease state refers to the number and quantity of health conditions of a patient. Based on findings from Chapter 4, patients with multiple well-managed chronic conditions that are under control are more likely to be able to track and manage cancer in addition to other life functions. In one example a woman with diabetes was used to tracking and summarizing her progress in Word for her primary care physician. After receiving a diagnosis of cancer, she was able to easily track symptoms. However, her case was atypical of most people with other multiple conditions. One study found that a high number of health conditions could be associated with lower use of interactive health communication tools (124). This trend corresponds to studies on self-tracking in diabetics, a condition that is commonly tracked. Blondon showed that people with diabetes are 24% less likely to be smartphone users, even when adjusted for age, race, SES, and ethnicity (134); they more often used traditional methods of tracking health metrics, such as pen and paper (134).

People who have to manage comorbid chronic conditions are likely to have anxiety and other psychosomatic manifestations of their disease state. Patients in other studies disliked using

tools that were a "constant reminder" of their ill health (39). Similar findings emerged from Grimsbø's interviews with patients suffering from cancer (which were analyzed as a "bricholage" quilt of findings) (51). Patients worry when they feel unwell—and might choose to socially isolate themselves—and when tracking tools use numbers and risk profiles that show them in a terrible disease state. According to Grimsbø:

"Discovering unwanted statistical information about diagnosis, survival rates and prognosis 'upset' and 'worried' some of the cancer patients in our study. When they became worried, they also felt alone. It became apparent to them that they were only interacting with a computer program, and there was no one to calm them down, support them or offer comfort in that period of anxiety that the unwanted information from WebChoice had created."

Use of tracking tools in such a way could degenerate into a self-perpetuating cycle—leading to abandonment of the tool rather than acceptance, or anxiety instead of wellness. When tracking tools reflect back illness to chronically ill people (sometimes in more concrete terms than they actually should be reflected), without informing a clinician or caregiver of signs and symptoms over time, the benefits to patients using the tracking tool could deteriorate into a psychological trigger. Clinicians' monitoring patient-generated health data of the seriously ill is more desirable, with appropriate thresholds for alerting of dangerous signs and symptom levels. In addition, caring, well-informed, honest explanations should frame the tracking tool charts and recommendations. When tracking tools like ESRA-C also provide contingency instructions, patients are likely to realize more benefit than absolute use suggests. People likely become more aware of symptoms they should communicate about with clinicians because the tool subtly reminds them. A basic tracking tool like ESRA-C can nudge people into proper symptom communication or self-management practices. This explanation could account for why a

randomized controlled trial showed an association between voluntary patient-centered use of ESRA-C and lowered symptom distress (88).

In summary, health-related factors can prove to be a strong motivator as well as an obstacle to effective self-tracking.

Personal Demographic Factors

A large number of such personal demographic factors as age, gender, socioeconomic status (SES), educational attainment, race, geographic region, marital status, number of children can influence tracking tool usage (134,26,52,27). Meanwhile, informatics researchers conducting empirical investigations into e-PRO tool usage among different sub-groups have uncovered associations between tool usage and demographics (52). In this section, I discuss age, gender, and SES—three demographic factors that influence use and acceptance of health-related tracking tools.

Table 5.1. Pew "Tracking for Health" survey results (26).

Tracking Tools

Among those who track health indicators for themselves or others, the % who keep track in the following ways

		Paper	Computer Program, e.g. Spreadsheet	Website or other online tool	App or mobile tool	Medical device	Keep track in head
All trackers (n=2,183)		**34%**	**5%**	**1%**	**7%**	**8%**	**49%**
a	Men (n=926)	28	6[b]	1	8	7	54[b]
b	Women (n=1,257)	40[a]	4	2	6	8	44
Race/ethnicity							
a	White (n=1,286)	35	5	1	7	8	50
b	Black (n=372)	40	3	2	8	9	45
c	Hispanic (n=271)	33	4	1	8	6	43
Age							
a	18-29 (n=323)	28	6[d]	1	16b[cd]	1	55[cd]
b	30-49 (n=547)	33	6[d]	3[cd]	9[cd]	5[a]	51[d]
c	50-64 (n=604)	36[a]	5[d]	1	3[d]	14[ab]	45
d	65+ (n=670)	41[ab]	2	-	1	12[ab]	44
Education attainment							
a	< High school (n=160)	31	1	1	1	13[d]	51
b	High school grad (n=575)	37	3	1	4[a]	9	49
c	Some College (n=592)	36	4[a]	2	10[ab]	7	49
d	College + (n=842)	32	9[abc]	2[b]	9[ab]	6	48
Household income							
a	< $30,000/yr (n=599)	35	3	1	4	10[cd]	48
b	$30,000-$49,999 (n=402)	39[d]	4	1	9	10[c]	48
c	$50,000-$74,999 (n=287)	37[d]	9[ab]	2	8	4	44
d	$75,000+ (n=509)	28	7[a]	2	10[a]	5	54[c]
Parent of minor							
a	Parent (n=514)	33	8[b]	3b	10[b]	5	48
b	Non-parent (n=1,668)	35	4	1	6	9[a]	49
Urbanity							
a	Urban (n=795)	34	5	2	8	8	48
b	Suburban (n=1,038)	36	5	2[c]	7	7	48
c	Rural (n=287)	33	3	-	5	10	49

Source: Pew Research Center's Internet & American Life Project/CHCF Health Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2.4 percentage points for results based on trackers.

Note: Percentages marked with a superscript letter (e.g., [a]) indicate a statistically significant difference between that row and the row designated by that superscript letter, among categories of each demographic characteristic (e.g. age). Those who responded that they use another method are not included – about 2% of trackers.

Age

People are considerably more likely to track their health in some way as they get older (134,26). As shown in Table 5.1, middle-aged and elderly people use paper for self-tracking and are unlikely to utilize technology for this purpose (26). Young people between 18 and 29 were more likely to own a smartphone, but tracked health indicators the least (134,26) . When they did track health, the medium of choice for this age group was likely to be computer-based (i.e., a mobile app or a computer program) (26). However, in Kaiser Permanente's patient portal usage study, educated older adults with "sufficient computer access to request a password" were more likely to log into the patient portal than younger users, presumably due to greater healthcare and self-management needs (135).

The primary research question from Chapter 3 showed age being directly associated with use of ESRA-C, the e-PRO tool investigated in Chapter 3 of this dissertation. The majority of older participants who used ESRA-C did so 1-2 times, so even relatively low "dose" of an e-PRO tool can be effective. Potentially, this means that older patients with cancer could benefit from even minimal self-tracking on their own. Perhaps participants could react to teaching tips and remember to bring up bothersome symptoms during clinic visit conversations (55). This communication effect was similar in the earlier version of ESRA-C (17), in which user studies showed that older users (> 60 years of age) were more likely to find ESRA-C to be more acceptable than younger users in terms of time required to complete assessment questionnaires (133). As people age, they may feel a greater need to use health-related self-tracking for managing chronic illness. It is possible that older patients felt that they could use a technology with a straightforward design that allowed taking assessments, isolated poorly understood symptoms, and provided teaching tips for taking action. In addition, ESRA-C follows 508-

compliant guidelines for people with disabilities in terms of color contrast and readability (136). People with dexterity impairments are more able to use a straightforward website on a computer than type in an app loaded on a small touch-sensitive smartphone. In addition, even the earlier version ESRA-C found to be acceptable by older users required little (if any) configuration (133). One caveat to note on ESRA-C acceptability study results is a ceiling effect, as most respondents rated ESRA-C's acceptability to be quite high (4 out of a 5-point Likert scale) (133).

Smartphone self-tracking apps are unlikely to reach the many chronically ill older people, as the elderly are far less likely to use smartphones (134,137,79). Yet some medical futurists suggest that remote monitoring and self-tracking with smartphones could eventually replace doctors' visits (138). Following this line of reasoning, many developers have created simple yet sophisticated smartphone apps that facilitate tracking of health indicators by chronically ill people. Still, there are opportunities for improvement. Although smartphone use currently decreases with age, 16% of Americans 51 to 64 years of age own smartphones. This group is experiencing the second fastest growth rate in smartphone ownership (139).

In summary, before we decide which tracking tools are likely to be accepted by elderly users, we must consider potential physical or cognitive impairments. In addition, we cannot assume that the majority of people who benefit from tracking tools will own smartphones, and it will be necessary, therefore, to continue to develop apps for a variety of platforms.

Socioeconomic Status (SES)

SES is a challenging demographic factor to consider when designing tracking tools. Chronic conditions such as diabetes and kidney disease strike low SES groups at a

disproportionately high rate (140). Barriers to tracking tool use are compounded because disparities in health-related technology use are quite pronounced in this population. Before contemplating acceptance, many informatics researchers are struggling with how to encourage initial use among a population characterized by low health and technical literacy (135,141-143). Even with Internet access, low SES individuals have far lower rates of logins and active use of patient portals (135), interest in telemedicine consultation (143), and adoption of health self-management technologies (141). People with low SES have major constraints that prevent them from seeing tracking tools as healthy activity: (1) difficulty learning about and trusting health-related technologies (143); (2) lack of regular Internet access (144); (3) low rates of smartphone use in every age group but the young (134); (4) limited reading, technical, and health literacy (145) (5) social isolation or limited social support (146); (6) limited free time (147).

Age and race interact with the adoption of health-related tracking tools. Low SES decreases rates of technology adoption among middle-aged and older adults especially (135). Although smartphone adoption rates are higher among young blacks and Hispanics, including those who are less educated, they are still less likely to use health-related apps than their white and Asian peers (134). In a study on Kaiser Permanente patient portal usage, African-Americans and Latinos were more likely to not log on, even having obtained a password, compared to Caucasians (135). Those most at risk for poor diabetes outcomes may fall further behind as health systems increasingly rely on the Internet and limit current modes of access and communication (135). Meanwhile, people with higher educational attainment were more likely to both request a password and log on to patient portal. However, Kaiser-insured low-SES people from this study are doing even better than those who are uninsured and living in poverty. This study did consider income, which could play a larger role in the adoption of such technologies

than educational attainment. Blondon did look at income, and found that controlling for all other demographic factors, it was associated with smartphone adoption far more than educational attainment (134). In summary, low SES individuals are far more likely to have serious chronic diseases and need the health-related guidance the most, but the vast majority are not using the tools that were designed to help them manage their conditions better.

In the face of these many constraints, clinicians and administrators have to see value in engaging with this population to help them realize benefits of health-related self-management. However, the problem of e-health adoption in low SES populations requires a complex systems theory approach, going beyond simple advocacy and prescription of self-tracking tools. Many low SES individuals feel disenfranchised and spread too thin in their ability to move up from their station in life. For example, among low-income African Americans, interest in telemedicine consultations over in-person consultations is lukewarm, because distrust of the American medical community runs deep, stemming from prior generations' beliefs and their historical roots in slavery and segregation (143).

Sarkar suggests that consumer health interfaces require simple navigation, because the complex navigational skill required to use a portal could deterred low SES individuals who logged on from using it (135). Instead of designing "best-in-class" solutions, informatics professionals developing tools for this population need to choose a tracking tool system that relies on cheap and accessible technology (e.g., using SMS over Internet-based solutions). For this population, designers need to provide users with an interface that enforces straightforward navigation and use of simple language.

Gender

A first glance at Pew Tracking for Health survey results suggests that tracking health indicators is an activity that American men and women do at similar rates (Men, 65%; Women, 72%) (26). Upon closer examination, more women (n=1,677) responded to the Tracking for Health survey than men (n=1,377), so it stands to reason that men who declined to participate in the survey were uninterested in the topic and therefore did not track health indicators. Gender also influences tracking tool use in terms of medium choice. Of all female self-trackers, 40% describe themselves as using paper when tracking their health, as opposed to just 28% of male self-trackers. The demographics were reversed when asked about who tracked mentally, as men were more likely to say they tracked using memory (Men, 54%; Women 44%). This could be due to women generally taking a large interest and role in taking care of their own health and that of their family.

Women were also significantly more likely to report enjoying using version 1 of ESRA-C, the patient-reported outcome tool described in this dissertation (133). Other researchers have found subtle differences among PRO feature use by men and women. Børøsund's secondary analysis on the use of WebChoice among breast and prostate cancer patients and found that male prostate cancer patients were more likely to take symptom assessments than use community forums that are popular among women. This effect was more pronounced among men who had minimal social support (52).

Summary of Personal Demographic Factors

Many studies support the idea that demographics are important when designing tracking tools that will be used and adopted. Some people hold the view that mobile apps and other

Quantified Self-like tracking solutions seem to help the young and fit, the worried well, and higher income individuals (145) more than a broad population of people with serious health conditions. As Neter points out, "the Internet reinforces existing social differences" (145). Many of the commercially viable self-tracking tools strive to keep people who can afford to buy the tracking tools youthful, energized, and slim, rather than focusing on clinical management of chronic disease (148). To achieve maximum public health benefit, self-tracking tools need to reach people who are chronically ill as well as individuals from low SES groups, older people, and those with minimal social support.

Technology-Related Factors

Tracking tool designers and developers should take patients' relationship to technologies into account when designing a tracking tool. In this section, I describe patients' attitude towards technology and digital literacy.

Attitudes toward Technology

Attitudes toward technology are shaped by awareness, desire to use, and actual use of the technology. Limited awareness of specific tracking tools for health purposes is perhaps one reason that people do not engage in self-tracking (27,149). Knowledge of tracking tools makes it easier to choose a tool that is sustainable for people with certain health conditions and lifestyles. However, one most also factor in desire to use a tool—which, according to the original technology acceptance model (TAM), is driven by *perceptions* of usefulness and ease of use. Simply being aware of the benefits of health-related self-tracking does not entail active use of tracking tools. One researcher found that users had to both be aware and want to obtain a tool before they would adopt it (150). Even dedicated users who go to Quantified Self meetings have

trouble sticking to self-tracking regimens despite knowing what tools are available (131). In addition, it is possible that health information technologies optimally designed for people with specific health needs are more likely to be adopted if they are fun to use or have personal meaning.

Being aware of general fitness tracking devices for active people is quite different than having the ability to find the right symptom tracker for an individual personal health situation. Portable motion-sensing, self-tracking tools are becoming mass consumer devices available in retail outlets. Today's price point could still discourage many from buying fitness trackers, particularly since attrition rate is high even among Quantified Self members (131).

Digital Literacy & Prior Experience

"Want" or "desire" to use a tool does not necessarily correspond to long-term engagement (150). Digital literacy and prior experience with technologies can also have an impact of tracking tool use. Digital literacy is "the ability to effectively and critically navigate, evaluate and create information using a range of digital technologies" (151). Prior experience with technologies can impact the attitude that patients have toward using tracking tools during cancer care, as skill and exposure allow users to transcend the learning curve faster. The TAM Continued Use model introduced earlier in the chapter illustrates the cascading effect of regular use of technology. The more one uses technology, the greater one's perception of ease of use and usefulness (112). Active smartphone app users have quite a different perspective on what makes a tracking tool app useful and intuitive to use than people who have never used smartphones, such as many elderly people (152). Many advanced Quantified Self users are more concerned about the robustness of features and experimentation rather than basic quality of life issues

(131). Meanwhile, novices to intermediate users have difficulty navigating the quality of 650,000 apps in the Apple Store (79). A new smartphone user could initially download a tracking tool app and forget about it or have to put effort into figuring out how to incorporate tracking tool app use into everyday life.

Clinician Dimensions

As discussed in Chapter 2, most tracking tools have not been integrated into standard clinical workflow, whether in cancer care or other clinical settings. In this section, I discuss factors that influence a clinician's use and acceptance of a tracking tool, including his or her professional specialization, organizational context, and prior experience with technology.

Professional Specialization and Role

Clinicians of diverse specialties might want to see different levels of granularity or types of patient-generated health data. In cancer care, oncology nurses who triage patients' concerns have to monitor symptoms that patients experience at home more frequently than radiation oncologists, who often see patients at clinic visits in between radiation treatments. Meanwhile, surgeons might prefer a coarser representation of the data tracked between clinic visits because they want to know if the patient is fit for surgery in the preoperative stage, and require less follow-up postoperatively. For this reason, the type and specialization of the clinician is important. In another example, primary care physicians and medical oncologists maintain a longer-term relationship with patients than surgeons do, so long-term psychosocial symptoms are more important to them than to a surgeon performing an operation. Triage nurses of any specialty may need to monitor patients more closely and escalate problems that they cannot help the patient resolve to physicians on a case-by-case basis.

Although rare in practice, clinicians could suggest tracking metrics for a patient to help them prioritize self-tracking practices at home. Metrics to track are often guided by the physician's specialty and the patient's condition. Regardless of what the clinician suggests to track, ideally the patient provides input by adding metrics that are personally important but not suggested. In the case of medical oncologists who see patients with cancer undergoing chemotherapy, both monitor a complex array of symptoms in parallel. Thus, it becomes important for the clinician who suggests self-tracking to work with the patient to prioritize metrics carefully to make it less burdensome. Deciding on symptom metrics together also could prevent an overwhelming number of metrics from being tracked and provide a clinically-informed perspective on how self-tracking can be helpful. Additionally, this practice reduces the chance of unnecessary over-sharing of information that makes the patient uncomfortable and increases clinician workload. For primary care physicians or endocrinologists who care for patients newly diagnosed with diabetes, more fine-grained glucose monitoring and symptom tracking is likely to be clinically beneficial. As time goes on and the patient's glucose level stabilizes, frequent tracking is less likely to be useful (unless to diagnose an related problem or during an unusual period of activity). Physicians who see many patients with diabetes in their practice could eventually be attuned to effective tracking practices of their patients overall.

Organizational Context

The organizational context of clinical care can influence a clinicians' likelihood of accepting a tracking tool in everyday workflow (153). Traditional clinical care workflow allocates little time and place for analyzing patient-generated data gathered from tracking tools. The organizational contexts of most clinic settings have not yet evolved enough to support such patient data collection and collaborative review. Clinicians are often concerned about how

review of patient-generated health data will affect their time allotment for reimbursable activities and clinical documentation, without a proven improvement in patient outcomes or efficiency (154). Practicing clinicians are often skeptical of unproven or confusing patient-reported outcome measures, are unsure about how to interpret the meaning of scores and question whether they have the time and resources to collect such data in clinical practice (79,155). Time constraints in hospitals and clinics prevent patients and clinicians from discussing self-tracking practices or reviewing tracking data together. In addition, most patients avoid "bothering" clinicians if they—or the staff—appear rushed (156). Participants from Chapter 4 did not expect guidance or receive many suggestions from their clinicians on which metrics to track or what tools to use (108).

Despite these obstacles to clinician acceptance, incorporating a patient's tracked data into a care plan can enhance patient-clinician communication even if outcomes are difficult to measure precisely (157). Many stakeholders do recognize benefits of using tracking tools to address patients' priorities and monitor symptoms more frequently than at strictly at clinic visits (33,158,159). A deep application of Chronic Care Model practices enable systematic embedding of patient-centered communication routines within clinical workflow. Integrated health systems and academic medical centers in particular are open to incorporating patient self-report data into practice because they recognize that review of patient-generated data can lead to a "learning health system" that can reduce costs (160). Administrators can further support review of patient-generated data through drafting of patient safety policies and resource allocation. Clinical champions can push patient-centered use of tracking tools at a high level, even though acceptance of and attitudes towards new practices must be felt at many levels and functions within the organization to be effective (22,47).

In addition, most tracking tools used today are rich with medical information but not FDA-approved, and as such could be couched as real threats to patient safety, driving fear of medical liability. Fear is great for individual clinicians in particular. A healthcare organization could operate in the red or go bankrupt, and a clinician could lose his license in deemed liable for a specific incident—thus threatening a livelihood and reputation.

Technology-Related Factors

Clinicians' perspectives on technology influence how likely they are to accept tracking tools into their workflow. In this section, I describe how technology access, ownership and attitudes toward technology play a role in workflow.

Technology Access and Ownership

Clinician-driven remote monitoring systems are likely to be funded by academic medical centers and cancer centers (Dana-Farber, SCCA, Memorial Sloan Kettering, etc.) and be backed by research funding. Because of federal legislation mandating multiple phases of meaningful use of IT in healthcare, smaller entities like community hospitals and private group practices lack time and funding to support novel patient-centered initiatives, such as incorporation of patient-generated data into workflow, which goes above and beyond basic electronic medical record implementation (161). For these organizations, skilled informatics and IT professionals are in short supply to build basic electronic health record infrastructure, let alone support novel collaborative patient-generated tracking tool systems (161).

Attitudes towards Technology

A study predicting clinicians' acceptance of a new patient telemonitoring system demonstrates that clinicians' review of self-tracking data is a factor in a successful intervention for patients (118). Other work I have undertaken assessing attitudes of clinicians shows that self-assessed computer knowledge was positively associated with an e-prescriber's attitudes towards use of a new e-prescribing system pre-rollout and post-rollout. (162). Home-based computer usage also had a similar impact. By extension, since review of tracking tool data adds another element into workflow for clinicians, it is quite important to gauge their likelihood to accept this change.

Tracking Tool Dimensions

Tradeoffs are made when designing, developing, and using tracking tools. Dimensions of tracking tools covered in this subsection include whether the tool is (1) condition-specific, (2) automated, (3) multimodal, and (4) integrated with existing systems.

General vs. Condition-specific

Individuals who decide among the many tracking tools available may do so on the basis of their health conditions. The health reason for which a tracking tool was developed could be specific to a condition or a set of conditions or appropriate for the general population. ESRA-C and HealthWeaver, the tools described in Chapter 3 and Chapter 4 respectively, are condition-specific tracking tools designed for people who are undergoing cancer treatment. Such aThis specific situation means that long-term engagement with tools is not mandatory. However, eight patients in the study outlined in Chapter 4 were using at least one other tracking system prior to enrollment in the study. Thus, adding a condition-specific tool to the patent's tracking burden is

worthwhile only if the patient finds the tool beneficial enough to warrant the extra work. For ESRA-C participants, tailored advice was generated for patients with problematic symptoms, and that advice could provide incentive for using it.

However, today many people suffer from co-morbid conditions and might have difficulty tracking health issues for multiple conditions in more than one tool. Use of WebChoice, for example, was higher among people who only had cancer—without any other additional conditions (52). Design of general all-purpose tracking tools need to be directed by clinical guidelines to avoid being lost in a sea of mobile apps of lesser quality (79). Also, the more apps or websites one uses for health-related reasons, the harder it is to manage them all. One participant from Li's Personal Informatics survey commented that a barrier to use of tracking tools was that "it was a bit cumbersome going to so many different sites [for visualizations]" (77).

Manual vs. Automatic

Both automatic sensor-based data and manual self-report data from patients can be valuable for cancer symptom management. Most tracking tools in cancer care rely on subjective self-report metrics and questionnaires like HealthWeaver and ESRA-C. Patients have to manually enter or configure what they are tracking. Despite the necessity to add metrics to track in HealthWeaver, participants tracked more metrics than required for the purposes of the study (108). This indicates that particularly motivated participants overcome the barriers of manual data entry if the benefit of tracking is perceived value over time. However, showing benefit is not always enough to persuade a person to use a tracking tool. Although evidence comes primarily from paper diaries (163), studies show that tracking food eaten helps people lose weight (164).

However, our current generation of tracking tools to monitor food intake are notoriously difficult to maintain over long periods of time. People have trouble remembering to track the food they eat—every meal, snack, and drink—over the course of a day.

The future of self-tracking could be in tools that detect activities through passive sensors, which complement the goals of those manual tracking tools. For example, HealthWeaver users also said that they want to be able to indicate the amount of exercise and sleep in their check-ins. The study team listened to this request and added a field in the check-in that allowed the users to record minutes of exercise and hours of sleep. Meanwhile, today, sleep and exercises activity sensing could occur passively by wearing sensor devices, such as Fitbit (http:///www.fitbit.com), and integrating the data with tools like HealthWeaver or ESRA-C. Tracking tools that facilitate passive monitoring are easier to incorporate into one's life. Today, wearable wireless sensors like Fitbit (http://www.fitbit.com) contain accelerometers, altimeters, and Bluetooth connectivity. Although users must remember to wear and charge these devices, data such as step count, distance, and floors can be wirelessly transmitted, to a computer and synced with a website. Passive monitoring systems are easier to use than those that rely on manual data entry, but their use does not come without tradeoffs. Use of passive monitoring incites privacy and trust issues because data collected through such systems resides on computer-based storage that has to be secure enough for the patient to feel comfortable using the tracking tool. Benefits of automated self-tracking need to be weighed against potential privacy issues and mindfulness that comes with manual entry of health data.

Modality

Modality of a tool refers to the communication pathway between computer and the person using it. Specifically, a modality is the sense through which a human can receive the output of the computer or the sensor device through which the computer can receive input from the human. Multimodal interfaces combine inputs and outputs from different human senses and technological sensors. For example, a state-of-the-art anxiety monitor could consist of consisting of two modalities: (1) a standalone software on your computer detecting keyboard stroke speed and (2) galvanic skin response sensors. Compared with mobile app manual entry, this multimodal application could be more effective at getting people to use it consistently.

Although paper diaries were used as initial symptom reporting tracking tools for research purposes, multimodal interfaces are becoming increasingly common. Mobile, web-based, tablet and sensor device platforms can all provide different data entry inputs into a central database. Furthermore, each platform affords a different presentation of symptom reporting to clinicians and patients. Tracking tools could use hardcopy, on-screen, mobile, audio, and tactile cues to deliver feedback to patients and clinicians. Most patient-reported outcome tools have multimodal interaction beyond web-based data entry and presentation (e.g., tablet computers (36) and mobile text message reminders (60,69,101)). Today, paper is by far the most common mode used for self-tracking (26).

Choosing the appropriate modalities of tracking tools is a very important decision. Even as the number of devices supported can increase the power of the solution, a high number can also increase the complexity of the solution for both the tool designer and the user (165).

Level of Personalization

Instead of deploying a universal interface designed for the entire user population to use, a personalized user interface can be a powerful technique to encourage patients to use a tracking tool. HealthWeaver's customizable metrics that I described in Chapter 4 is one example of a way that users tailored tracking experiences to suit their needs. For example, a patient who wanted to track hip pain was able to focus on that priority, even if hip pain was not among the list of symptoms common to patients with breast cancer.

Although tracking tools can enable simple personalization by asking users to manually fill out profiles, this practice often discourages initial use (166). Tracking tools can also employ machine learning or recommender systems that tailor the user's experience based on his or her preferences and usage patterns. Yet machine-learning algorithms often mask complexity of the filtering process and do not make obvious how the interface was personalized (167). Thus, automated personalization through recommender algorithms in health-related systems should be carefully thought through in terms of perceived usefulness, accuracy, and transparency.

Integrated vs. Standalone

Integration with existing systems is key for both patients and clinicians' acceptance of tracking tools. Patients have to make sure that use of a tracking tool fits into their lifestyle or is important enough to warrant a change. Meanwhile, clinicians who use electronic medical records are loath to use a standalone system that slows them down during the workday.

Patients are often resistant to adding another tool to their everyday routine, even if it benefits their health, unless they see positive effects of use early on (77). Personal Health Records (PHR's) are designed to hold electronic versions of patient medical records in

conjunction with patient-generated data that theoretically could be shared with participating healthcare institutions. The PHR has to have a relationship with the healthcare institution before the integration can occur, so patients outside of major health systems might not realize the benefits of PHR medical record storage and integrated tracking without a lot of printing, scanning, and annotating. PHR efforts like Google Health have shut down due to lackluster consumer response (168). Standalone PHR's are still perceived as requiring too much work for to maintain over time (169).

Clinicians do not expect to review patient-generated data as part of their duties, as most e-Health interventions are not integrated with electronic health records (EHR). Tolerance for patient-generated data review is largely dependent on the specialty of the clinician. For example, nurses likely find e-Health interventions more useful than physicians because symptom monitoring of patients can be central to their role (137).

Inclusion of patient-generated health data in electronic health records happens in very few healthcare institutions. Many institutions are concerned about medical liability on the part of healthcare organizations due to accuracy issues with data entry, and the additional time necessary to enter, format and review data. Meanwhile, patients with cancer have shown a willingness to be open about privacy concerns to implement health information exchanges to support care coordination (170). Sharing patient-generated health data in a formal manner with clinicians could improve the clinical decision-making process between visits, when the patient has issues at home and cannot come in for a visit for a variety of reasons.

Data Dimensions

What, how, why, and when patient-generated data gets collected varies immensely among tracking tools for health. Tracking tools have to make tradeoffs in complexity, completeness, presentation, clinical relevance, accuracy, vocabulary, timing of capture, and privacy. In this section, I describe these tradeoffs.

Complexity of Data

The structure of patient-generated health data can be discrete or continuous, qualitative or quantitative, or some combination thereof. Patients often wish to interpret health data collected at different levels of structure that are meaningful *and* actionable. Complexity of structure or format of patient-generated health data can lead to tradeoffs that affect interpretation and action-ability. A greater amount of data through a tracking tool collected can increase the likelihood that a solution is validated and efficacious in the target patient population. However, if patients and clinicians are not using the tool, it is more efficient to agree upon a minimally viable set of data, in lieu of exacting too high of a user burden on the patient, clinician, or tool designer (165).

To illustrate this point, let us consider how a tracking tool could capture the concept of "anxiety." The PHQ-9 scale asks 10 questions about feelings and activities during the patient's last two weeks as they remember (171). This subjective self-report rating suffers from recall bias because it goes back two weeks. Alternatively, we can estimate anxiety from a statistical model of a continuous stream of audio data that passively detects anxiety from high-pitched speech. However, sensor-based visualizations are hard to create accurately because it is very difficult to set non-arbitrary thresholds of pitch and the sequences of pitch changes must be analyzed algorithmically. Although the initial 10-question instrument was not 100% accurate, there is less

effort and cost for the clinician to find out if the patient is suffering from anxiety. As a result, deciding which system clinicians should use often comes down to practical considerations such as cost and effort expenditure.

Clinical Relevance

Data is clinically relevant when it leads to a diagnostic or treatment decision made by a clinician. In his 2011 AMIA keynote, Gregory Abowd predicted that within five years the majority of "clinically relevant" data would be collected from non-clinical settings, at home and on the go, outside of hospitals and clinics (172). Given the rise of mobile applications and sensing devices, consumers can generate a great deal of health data on their own without the support of clinicians. However, how much of this health data is important for clinicians to review in order to take clinical action is questionable. The low adoption rate within clinical settings could be due to in part to resistance from clinicians, who report that they prefer to rely on their own subjective judgment in assessing symptoms and feel that patient-reported outcome measures for health-related quality of life lack clinical relevance (155).

Completeness

Patients who are self-tracking for research purposes are more likely to meet tracking tool data collection demands than patients who initiate self-tracking in everyday life on their own (108). Many PRO instruments prohibit missing data because this often invalidates the interpretation of the score, making it impossible to accurately assess validity and reliability. In Chapter 2 results, missing SDS-15 data was not quite as common as in practice. When use of ESRA-C was voluntary, participants completed the 15-item SDS instrument about 75.8% of the time, and 91.9% of the time for study time point sessions. However, such a high rate of

completed PRO questionnaires is difficult to achieve in a variety of settings. HeathWeaver did not attempt to require or remind users to make entries, and its usage was relatively high. Even though data validity can be called into question, patients can still use data as partial insight into troubleshooting problematic symptoms at home or with a clinician. However, some HealthWeaver metrics patients used were not considered clinically relevant enough by patients to bring up in clinic visits, and they remained unaddressed by clinicians.

Patients rarely enjoy taking symptom assessments, and oftentimes a great many questions do not apply to the patient. As a result, Item Response Theory (140) and Interactive Tailored Patient Assessments (ITPA), like Web Choice in Norway (58), attempt to fill the gap by allowing use of non-psychometric instruments to assess patients' condition in clinical care. Item Response Theory is applied to many clinical domains in an initiative by PROMIS (http://www.nihpromis.org/), in which questions are selected from a domain item back to assess symptoms and severity using psychometrically valid methods.

Type of Vocabulary

Vocabulary for symptoms, descriptions for Likert scale ratings, and other terms used in tracking tools must make sense to both the patient and clinician. Controlled vocabularies have a number of advantages because they allow clinicians to compare symptoms across patients and could constrain the patient to use the same term over the long term. Symptom vocabularies (i.e., ICD-10, Unified Medical Language System (UMLS) are quite complex and difficult to integrate into systems that patients would be able to interpret at home (173). As a result, these vocabularies do not get used in standard tracking tools for health.

Rather than constraining patients with cancer to use of standardized metrics, HealthWeaver suggested common metrics and allowed users to name other metrics that they wished to track. In the system described in Chapter 4, allowing patients to choose their own metric names has its advantages: (1) patients can relate to a term that they are comfortable with and feel that they want to track, as opposed to numerous choices that sound like medical jargon, and (2) patients can add and thus prioritize symptoms that are not common to their condition. Yet use of a symptom vocabulary driven by patients could lack medically specific terms that clinicians use to communicate with each other.

Timing of Capture

Timing tracking closer to when symptoms occur can provide a fuller picture of symptom experience, though this does not mean that more frequent self-tracking is sustainable. This is illustrated in Chapter 2. Because "frequent" users only used ESRA-C twice or more over the course of cancer treatment, voluntary assessment taking did not paint a granular picture of day-to-day health status of these patients. In contrast, for the HealthWeaver study, some participants tried to incorporate tracking into their daily routine, although rarely were check-ins more frequent than daily. Some participants used HealthWeaver tracking only when suffering a symptom that they wanted to troubleshoot or share with clinicians. Meanwhile, other ecological momentary assessment (EMA) studies were more constantly asking for data from participants, to the point of ovarian cancer patients saying that using the tool caused them a "constant reminder" that they are going through such a scary life-threatening illness. As a result, there are compromises to be struck between informational value of frequent assessments and the desire for patients to incorporate tracking into their routine.

Private vs. Shared

A patient is more likely to share data that is valuable for the clinician too. However, some data generated by the patient could benefit the patient more than anyone else. For example, mood journaling can help the patient keep track of how they are progressing through cancer treatment. A large quantity of journal entries could be prohibitive to realistically share openly with clinicians but specific journal entries or any associated metrics could be of clinical interest. In addition, symptoms like sexual dysfunction might be difficult to share for patients because of embarrassment. The tradeoff is that we would generally want the clinician to be able to discover symptoms that are difficult to elicit from the patient interview rather than hide data from the clinician who makes treatment decisions given their limited knowledge of the patient.

Conclusion

This chapter begins with a discussion of use and acceptance theory that has limitations when applied to use and acceptance of tracking tools in a healthcare setting. Technology acceptance models are explanatory in many contexts in which use of a technology is required of clinicians or employees (114,117), but do not explain what attributes of the technology drive continued voluntary use. In this chapter, I describe a framework consisting of two theoretical models: MUTT-PC (illustrating the context of health information technology) and MultiTrack (illustrating the dimensions of patients, clinicians, data, and tracking tools to consider during development of tracking tools). These models have the potential to transform how we think about tracking tools' role in the clinical context and provide concrete guidelines to consider how tracking tools should be implemented in the future.

Chapter 6 : Implications & Contributions

Contributions of this dissertation include a deeper understanding of benefits of and factors associated with use and acceptance of tracking tools for health. In this final chapter, I begin with a summary of findings from Chapters 3 and 4, followed by a brief description of the MUTT-PC and MultiTrack models described in Chapter 5. Next, I describe the contributions of this dissertation to four disciplines: health informatics, health services, information and management science, and human-computer interaction, providing rationale for the specific contributions to each discipline. Subsequently, I offer implications for patients, clinicians and systems designers to consider regarding future tracking tool design, use, and acceptance. Finally, I conclude with suggestions for future work in this area.

Overview of Study Findings

In Chapters 3 and 4, I demonstrate how collection and review of patient-generated data using tracking tools can help patients with cancer feel better, through decreased symptom distress, enhanced psychosocial comfort, and enhanced communication with clinicians.

The analysis from Chapter 3 addresses questions related to voluntary usage of e-PRO tools by patients with cancer. Even though e-PRO tracking tool use by patients with cancer positively affects symptom distress (18,41,42) and communication of symptoms with clinicians (17,41), there is limited information about *voluntary usage* by patients. To address this knowledge gap, I undertook an analysis of 372 cancer patients' voluntary use of the e-PRO tool ESRA-C2 described in Chapter 3. I found that lower symptom distress was slightly associated with patients who frequently used ESRA-C2, compared to patients using ESRA-C2 once or not at all, by running a between-group ANOVA test. Because this was a one-sample secondary

analysis without prospective data collection, I could not establish causation. Thus, participants with low symptom distress either felt healthy enough to initiate use of a tool on their own, or frequent voluntary tool use helped participants lower their symptom distress. Still, because baseline symptom distress of the frequent users was lower than less frequent users, the former conclusion is more likely to be the case.

Chapter 4 provides insight into *why* people use tracking tools during cancer treatment—and why they rarely do outside of research settings (27). In the study described in Chapter 4, I analyzed the tracking practices of 25 women with breast cancer "in the wild." Ten of these women who were given access to tracking tool as a technology probe in the midst of undergoing treatment. Results indicate that while the majority of participants relied on memory "in the wild," one-third of participants tracked health issues in a physical tool (108). Nevertheless, participants' tracking practices "in the wild" were fragmented across media, sporadic in timing, and, quite overwhelmingly, not guided by clinicians. When using HealthWeaver's self-tracking features, ten participants with access tracked health issues far more than anticipated. They reported benefits such as psychosocial comfort, establishing an understanding of patterns by counteracting memory deficits, and support for communicating priorities to clinicians. The study draws attention to the need to design future tracking tools for cancer care that meets patients' needs.

New Conceptual Models

Tracking tools can help people manage many health conditions even when not undergoing cancer treatment. By self-tracking worrisome issues, people could feel more empowered to share priorities through open communication with clinicians, rather than waiting

until symptoms get worse to report them. In Chapter 5, I describe new models MUTT-PC and MultiTrack that provide a basis for the integration of tracking tools into healthcare workflow and sharing of patient-generated data with clinicians. MUTT-PC consists of a set of workflow diagrams that describes memory-based, patient-driven, researcher/clinician-driven scenarios in and outside of clinic visits. MultiTrack describes dimensions of four components that tracking tool developers will need to consider: (1) the patient, (2) the clinician, (3) the tracking tool, and (4) the data. MultiTrack illustrates the activity of self-tracking as affecting symptom communication between the patient and clinician and providing a data-driven basis for clinicians' recommendations of treatment and self-management advice. These models frame the issue.

Implications

Patients, clinicians and systems designers are all key stakeholders in the design, use, and acceptance of tracking tools. In this section, I explain how each of these stakeholders could approach development and acceptance of next-generation tracking tools.

Implications for Patients

Patients have a great number of tracking tools to choose from in the form of mobile apps, websites, and journals, in addition to more generic options such as calendars, word processors, and spreadsheets. In this section, I describe implications derived from components of this conceptual model—in cancer care and other settings. Use and acceptance of tracking tools by patients are influenced by the following: (1) trust in technology, trust in the patient-clinician relationship, (3) logistics of use, and (4) health-related quality of life (HRQoL).

Lack of Trust in Technology

Patients often have difficulty trusting technology, and in some cases, the advice of their clinician, when it contradicts their personal beliefs or understanding of their condition. Technology-related reasons cited for low patient acceptance of consumer health informatics technologies in general include poor usability, limited training, and lack of computer skills (115,174).

As discussed earlier, inaccurate data can lead to lack of trust and a negative attitude toward use of tracking tools (77). Although Fitbit and other fitness tracking devices are not 100% accurate, Fitbit has been shown to improve clinical outcomes in heart disease patients at Mayo Clinic (132), and smartphone-based accelerometer apps have been shown to increase physical activity among older sedentary office workers (175). Perhaps well-educated patients recognize that just about any clinical test has measurement error. If the data collection is easy and the trend is correct rather than 100% accurate, it could still be beneficial to use tracking tools to gain another data source to triangulate across and share with trusted clinicians.

Lack of Trust in Patient-Clinician Relationship

Although in the past, the patient-clinician relationship has been based on a paternalistic model in which the "doctor knows best", shared decision-making is becoming a central component of policies that improve patient-clinician communication (127). Even as the advent of tracking tools and home health devices allows patients more continuous insight into their own health, personal insight that contradicts formal medical advice could undermine patients' trust in their clinician. Clinicians who are trained to use "evidence-based" guidelines fit patterns of phenotypes seen within a similar population of patients to arrive at a diagnosis. Clinicians

consistently make micro-decisions in the patient's best interest, but these decisions could be at odds with their own financial and legal interests. The question-and-answer templates that cover review of systems rarely, if ever, consider what tracking data the patient has collected (109,176). When a patient's tracking tool data is dismissed because of lack of time or interest on the clinician's part, the patient could thereby lose trust in the clinician. To avoid such a situation, the patient should prepare a summary before each clinic visit or choose tools that have a clinician view. Patients have to learn how to assess trust in clinicians for an improved patient-clinician relationship. To do so requires careful judgment, knowledge of how the healthcare system works, and observation skills that most patients may not possess intrinsically.

For patients to accept tracking tools and derive clinical benefit, patients have to either demand that clinicians review the data they collect or go see clinicians that already are open to reviewing such data. Practically speaking, the latter option is harder to enforce for people in underserved populations and those with limited provider choice given their insurance coverage.

Logistics of Use

Prior work by Klasnja and Pratt has found that patients do need to be able to capture signs and symptoms in unanchored settings, away from the bundle of health information that patients have captured (85,86,101). In Chapter 4, participants said that HealthWeaver mobile component helped them to capture signs, symptoms, and context in the moment as well as incorporate the process of using tracking tools in their everyday routines.

When people have serious illnesses such as cancer, a self-tracking regimen becomes harder to initiate and manage in the context of daily life. Many people with chronic disease have debilitating symptoms, such as pain and fatigue, that make it difficult to function every day.

Even though self-tracking can help, it is a difficult process for even healthy individuals, like the tech-savvy and curious in the Quantified Self community. Encouragement from others, such as providers and caregivers, is more likely to influence self-tracking practices among patients with cancer. In one study, of 134 rural patients with cancer, the 38 who were self-tracking signs and symptoms did so when suggested by doctors (34%), a nurses (47%), or non-clinical family members/friends (44%) (27). In case of serious illness, patients have to be proactive and seek out support they need to help with self-tracking from clinicians and caregivers.

Patient Outcomes

A grand challenge of patients' continued use and long-term acceptance of tracking tools is being able to see a marked improvement in their health that they attribute wholly or in part to self-tracking. Although not directly tied to health outcomes, a 2013 Pew survey is showing evidence that people are making positive health-related changes because of their self-tracking (26). Of 2,183 Americans who identify themselves as self-trackers, 46% say that the practice changed their overall approach to health, 40% asked new questions of their doctor or sought out other clinicians' opinions, and 34% said tracking affected a treatment decision. Nevertheless, seeing benefit was not the case for everybody, as 37% reported no effect on health-related routines from self-tracking.

Yet some signs and symptoms are more helpful to manage through self-tracking than others. For example, people are more likely to lose weight when they are self-tracking [King]. In fact, when feature usage of a Internet-delivered weight loss intervention was analyzed to determine which were the predictive of weight loss, self-tracking was the only one associated with a reduction in weight (meal planning and social networking were not) (177). Properties of

measurement are one reason that this is the case, such as for weight and insulin. Weight is a discrete number that is easy to measure by stepping on a scale, whether it is at home or at the doctor's office. Also, diabetics who have to measure insulin get used to being able to read glucose monitors and interpret A1C levels.

Implications for Clinicians

Whether clinicians are open to tracking tools as part of the domain of routine patient-clinician communication duties remains to be seen (79,178,179). Providing patients with guidance about what metrics could be clinically helpful to track at home can take the guesswork out of the tracking tool experimentation for patients. Yet, as discussed in Chapter 4, many people would be able to pick out metrics that are important to them to track, but are not aware of which are clinically relevant, or useful to share with the clinician. In this subsection, I discuss clinical workflow issues, such as information coordination challenges, implications of prescribing patients apps to deal with specific conditions, and contextual and organizational issues that prevent people from adopting tools already adopted by patients.

First, I argue from multiple perspectives that thoughtfully and collaboratively executed patient tracking has the potential to inform clinical decision-making and improve patient health and wellbeing. To make benefits even more concrete in this subsection, let us take the example of pain control during cancer care. Many patients with cancer pain suffer quietly or use alternative therapies without sharing the full extent of their pain with clinicians, since they are concerned about side effects from use of prescribed analgesics such as opioids and other painkillers (180). If oncologists did not proactively screen for pain, the symptom would not be addressed adequately. Tracking tools could aid patient-clinician communication about severity

and trajectory of cancer pain. Furthermore, clinicians' consumption of tracking tool data can inspire trust in patients and enhance the patient-clinician relationship (108). Patients may actually share how they are really feeling without holding back. The clinic visit could theoretically take the same amount of time if the discussion is focused on patient priorities and clinicians consume information outside of the clinic visit, taking less time to repeat questions that have already been answered elsewhere, which is a common problem in typical clinical workflow.

From a clinicians' standpoint, understanding of the patient's patterns, however mundane, provides insight into their overall functioning. In a typical outpatient setting, use of secure tracking tools could enhance the bond between clinician and patient. Each patient visit gets stored as a narrative, both in the clinician's long-term memory and in the medical record, which can be sparse in terms of current and/or relevant information. As Montgomery states:

"The case narrative serves as a repository of events. Written or oral, it not only assembles the history of the patient's illness but also preserves the traces of judgments made, hypotheses eliminated and confirmed, actions taken and discontinued. The case both accommodates the multifactoriality of cause in individual instances of illness and works to normalize events as it records them for later use, including when necessary, their reinterpretation."

-Kathryn Montgomery Hunter (109)

In today's clinical setting, the need for reinterpreting data is far too common, whether driven by a misdiagnosis, a need for a second opinion, a medical investigation, or a postmortem autopsy. Health-related sign and symptom data may be of limited clinical relevance when it is not

continuously gathered—or at the very least more often than at appointment times where the symptoms are recalled with cognitive biases, as described in Chapter 2.

Clinical judgment is at a crossroads with the advent of patient-generated data. The physical information workspace does not have to be the exam room (99). Self-tracking helps people in the Quantified Self community to achieve the noble objective: "Know Thyself." All clinicians who treat patients should heed the adage: "Know Your Audience." Yet, it is not easy to achieve in the current flow of medicine, where clinicians have to glean as much understanding of the patient as possible within the brief clinic visit and using relatively objective evidence in the form of imaging and lab test results. Physicians in particular are used to being authoritative decision-makers, trained in the science of medicine (109). According to medical humanities professor Kathryn Montgomery, physicians need to use an inherently nonlinear clinical judgment process to be able to generate "a linear cause and effect to explain to the patient." Despite training in the field of biological science, clinicians "habitually omit activities that might be expected of a science." For the purposes of the dissertation, such omitted activities include review of patient self-tracking data.

Realistically, developing time-saving strategies to incorporate clinicians' consumption of patients' tracking tools into their typical workday requires an understanding of information coordination practices in the clinical setting. Yet information coordination is a challenge to document in clinics and hospitals, and most studies in this area have quite heterogeneous methods and findings (181). Unertl's empirical study on three primary care practices exhaustively mapped the information artifacts, stakeholders and coordination processes of three group practices through a visually complex diagram. How to incorporate tracking tools in each setting requires initiative by the clinician in such situations where workflow practices are

antiquated or inefficient or poorly understood. Outside of integrated health delivery settings like Kaiser Permanente, adoption of tracking tools in clinical settings is usually up to the individual clinician to decide whether they want to either take extra time to review patient's tracking data during clinic visits. Allowing patients to bring in tools that do not fit into workflow might make already time-pressed clinicians fall even further behind in their schedule. Clinicians could actually spend more time reviewing data that is not clinically relevant (79), because few standards for the way patient-generated data from tracking tools exist to make it easy to interpret the data. Although more research is needed, it is difficult to generalize from studies of individual group practices. Comparisons to community hospitals and integrated delivery systems and academic medical centers would be challenging and futile to undertake.

Organizations that successfully deploy tracking tools are likely to have a culture that drives adoption by clinicians from top-down and bottom-up strategies. Suggesting or prescribing tools that do fit in workflow requires careful forethought, planning, and outside IT expertise. Occasionally, clinician-owned practices can decide to bake in a practice redesign solution that is based on continuous tracking data and passive alerts or perhaps become a concierge service that does so. In such situations, the clinical practice can license a tethered patient portal or suggest a set of tracking tools for patients with particular conditions. Adopting flexible tools that are **not** organization specific could mean that clinicians have to navigate a crowded health IT market, which is not typically something that many clinicians in private practice have the expertise to do. However, clinicians and payers—not healthcare administrators or IT—need to drive change in delivery models and workflow.

Widespread integration of tracking tools across organizations requires clinicians to take on a new perspective on how they conduct their work and interact with patients. For many

clinicians, they have to somehow mitigate or reduce existing competing demands on their time and attention to incorporate review of patient-generated data into their workday. Clinicians are required to be constantly "on," which makes it difficult for many to absorb this responsibility. Relearning a new mindset and workflow is not easy. When clinicians decide to prescribe tracking tools, they need to learn how to accept data on patients' symptoms. Use of patient-generated data challenges the "evidence" in Evidence-Based Medicine, which now consists predominantly of gold-standard randomized controlled trials that are taught as scientific fact in medical school (109,176). Yet, Montgomery points out, practicing EBM is problematic because so many diseases cannot be traced back to a simple cause-effect relationship:

"Illness potentially engages a similar complexity of cause, and biomedical science has done much to pare it down. To questions about how an individual fell ill, germs and viruses and genes—the advances of biomedical science—provide ready answers." (109)

Patient-generated data collected from tracking tools is not simple either. Yet Quantified Selfers are making self-experimentation popular and conducting "n of 1" studies (131) on topics as diverse as caffeine consumption and tree nuts' effect on weight loss. Given that many patients are tracking on their own and want to learn about their patterns/symptoms, clinicians should take the opportunity to provide them with oversight and guidance. Patient-generated data could suffer the same fate as useless lab tests or even promote anxiety—or worse, mistreatment—if clinically-unrelated metrics are tracked by the patient. Still data collected in real-time suffers less from the biases affecting many PRO solutions that rely on questionnaire instruments. Clinicians have an opportunity to lead the way and develop guidelines on patients' self-tracking practices and suggest ways that they can ingest patient-generated data in and outside the clinic.

I acknowledge that this challenge is harder than it sounds. Balancing out how tracking tools impacts workflow requires ethnographic-level examination of the many micro-decisions clinicians make throughout their workday. Micro-decisions, a concept borrowed from behavioral economics, affect people's ability to carry out long-term behavior change goals. Although this term has been applied to patients' healthy decision-making, I also see the impact of individual clinicians' micro-decisions on others' perceptions of their patient-centeredness in decision-making and communication style. Clinicians' conscious (and subconscious) micro-decisions affect practice workflow. In the moment, clinicians make decisions that correspond to policies, rules, clinical guidelines, and insurance recommendations, or subconsciously display nonverbal communication gestures that open up or shut down the patients' ability to talk about their symptoms. Every micro-decision a clinician makes in day-to-day clinical care can be with patients in mind (e.g., health outcomes, inconvenience, expense), but also these micro-decisions can be influenced by external factors (e.g., avoiding insurance fraud, malpractice, and prolonged documentation time) or intrinsic factors (e.g., empathy, exhaustion, greed).

Today, medical training emphasizes physician autonomy and knowledge over that of their patients. Unfortunately, tracking tool acceptance in healthcare might not occur without a cultural paradigm shift from paternalistic and hierarchical to patient-centered and equitable. Despite progress in medical informatics in the last 50 years, medicine has been very slow to innovate in terms of technology adoption. For clinicians to embrace patient-centered tracking tools, we need to undertake deep ethnographic research in diverse clinical settings to inform systems design, educational, and policy decisions. Finally, we must hope that fear of loss of privacy, ethical considerations, and demographic factors do not prevent widespread use of clinically useful patient-generated data from being shared with the population at large.

Implications for Tracking Tool Developers

Tracking tool developers have recently encountered many pitfalls to mainstream adoption in healthcare that acceptance is not even a near-term goal. MobiHealthNews announced that digital health has fallen into the "trough of disillusionment" in Gartner's hype cycle {Linden 2003}. As mentioned earlier, hundreds of thousands of health apps are rarely used {Linden 2003}. The rationale for non-adoption of tracking tools could be derived from insights gleaned from literature on medical device design and development as well as traditional software engineering standards and processes. Users engage with technology based on factors related to usability, usefulness, and aesthetics (183). However, too often in health IT, developers do not make an upfront investment in user needs assessment or continue to examine how user needs evolve over the course of software engineering life cycles (153,184). In addition, usability professionals do not make the required investment in gaining knowledge of complex domains that they are generating recommendations for (185). A recent study engaged medical device manufacturers on their opinions of the optimal way to develop technologies. Although academics and standards agencies cite successful deployments in settings where a strong user needs assessment occurred, industry manufacturers are reluctant to employ such formal user research methods. Their hesitation comes from the following reasons: difficult-to-navigate human subjects protocols, the time-consuming nature of user research, short-circuiting the process of soliciting input from lower-ranked personnel because a belief that the perspective of clinical champions sufficed and that such personnel cannot provide valuable and actionable input (153).

Given the current state of real-time tracking tools, I offer the following suggestions for the design of future tracking tools: (1) create intuitive, multimodal interfaces with a positive aesthetic to support real-time tracking, (2) pre-seed metrics based on the patient's diagnosis and

treatment, (3) enable customization for unusual and unanticipated symptoms that matter to patients, (4) maximize benefits to patients by supporting reflection and communication with clinicians and caregivers, and (5) give patients ownership over the tracking process.

Create intuitive multimodal interfaces with a positive aesthetic.

The field of human-computer interaction (186) has much to inform tracking tool developers in the domain of healthcare and wellness. Contextual inquiry, user experience strategy development, participatory design, and usability testing are all resource-intensive yet valuable processes to undertake when developing a tracking tool (187).

Designers and developers of any technology have to make tradeoffs between aesthetics and usability (183). According to Tractinsky, designers who pay attention to aesthetics do more than to satisfy the individual who is using the technology – they also fulfill social needs as well (188). Meanwhile Norman argues that many designers get caught up in ideal aesthetic forms that lack affordances and fail fundamental usability principles (183). User experience professionals should recognize that aesthetics matter in the short term but usability matters more in the long term. Too often, tracking tool developers fail to take into account the drudgery associated with regular tracking, whether or not benefits are realized. Without rigorous and deep needs assessments, they treat humans as rational actors, paying superficial treatment to the role of emotions and fallibility even with the best of intentions. Intentions to track without a supported structure are still merely intentions – as true as the falsehood "if I build it, they will come." Designers and developers who do not tend to the emotional side of using technologies do so at the risk of having technology remain unused by the very users that they were targeting.

The original ESRA-C system was reviewed for acceptability through a self-report survey (133), showing differences among users in acceptability of time allotment requirements. Making ESRA-C easy to use was one of the criteria for use. The primary outcome of Chapter 3's randomized control trial showed that ESRA-C was quite successful in improving symptom distress in the patients who used it, particularly among older users (55). It is possible that if the system also had a mobile component, younger users who prefer use of smartphones or tablet PC's as their main computing device would choose to use the tool more.

In Chapter 4, HealthWeaver's interface design was intentionally designed to be aesthetically uplifting. No participants said that tracking constantly reminded them of cancer, as ovarian cancer patients did after being alerted to log metrics with an EMA tool (39). HealthWeaver did not provide reminders to track, which could have been less burdensome than the EMA tool. In addition, participants also found value in accessing tracking data along with the calendar and notes in one place, which made their cancer-related information less fragmented. The positive aesthetic of the interface combined with the usefulness of HealthWeaver features made the tool engaging enough to drive consistent tracking even with the effort required to enter check-in entries and log medications.

To decrease the effort that tracking takes, the most valuable future tools will take a multimodal approach. HealthWeaver's mobile interface facilitated convenient data entry in the moment. Klasnja showed that such unanchored patient health data capture using mobile devices could be critical to the patient's wellbeing (86). Future mobile applications could also enable voice-based data entry with voice recognition to allow patients to record symptoms or annotate individual check-ins with more detailed contextual information.

Pre-seed metrics based on diagnosis and treatment.

Patients have difficulty deciding on what signs and symptoms they should tracking when they have cancer or some other condition, or simply want to maintain a healthy lifestyle.

Given findings from the dissertation chapters on of ESRA-C and HealthWeaver use, pre-seeded metrics made a major difference in whether patients were likely to use a tracking tool during cancer treatment. ESRA-C had 30 symptom and quality of life metrics that patients could choose among to see if they had problematic signs and symptoms that warranted clinical attention. During voluntary sessions, outside of the study time-points, they had to choose which signs and symptoms made sense for them to assess and could take those questionnaires as time allowed.

In addition, participants with breast cancer in the wild, without access to HealthWeaver, received little guidance on what to track. Profiling individual patients based on their diagnosis and treatment plan would provide some guidance to patients who do not know what symptoms to look for during cancer treatment. Personalized default symptom metrics—based on diagnosis and treatment profile—could be supplemented with optional metrics from a list that covers the breadth of symptoms that patients experience.

Enable customization for symptoms.

HealthWeaver allowed participants to customize which symptoms to track and name the symptom terms themselves. Users could define new symptoms that they have a personal interest in monitoring instead of just choosing among the many already provided in HealthWeaver. This feature allowed patients to further personalize the tracking tool to meet their own needs. For

example, HW-P17, the patient with hip pain, could track that symptom, even though it was not a typical symptom of patients with breast cancer.

Maximize benefits for patients by supporting reflection and communication with clinicians.

In HealthWeaver, users have the ability to choose metrics to overlay in graphs and see co-occurrences of symptoms or other patterns. We found evidence that patients prefer tools that support this type of functionality. Studies in Norway suggest that patients wish to engage in reflection at home on the data that they enter in PRO tools available to them (51,189). Supporting reflection by patients, and not just clinicians, is one step closer to personal informatics tools that provide individuals with transparent ways to use the data that they collect. Patients need to be able to understand what the data collected means to find use of a tracking tool worthwhile, especially if clinicians are not always reviewing the tracked data. Patients also need the option to review the data with clinicians when it is hard to determine what action should be taken on one's own.

Give patients ownership over the tracking process.

People valued ownership over their data in HealthWeaver since they had freedom to express what mattered to them. They did not necessarily need or want to share everything with clinicians or caregivers. Some patients, such as HW-P17, specified sharing was helpful but not necessary to find value in tracking. With control over who could see what data, patients could record sensitive issues, but only share selected issues. In contrast, for most PRO tools or interactive tailored patient assessments, the clinic or research team—not the patient—drives PRO tool use and clinicians see all the data.

In summary, patients need to remain engaged and aware to manage symptoms that emerge during outpatient treatment. Symptom tracking could be considered a self-care activity that also engages the patient in becoming aware of what they need to manage symptoms at home and how to communicate their needs to clinicians.

Contributions

This dissertation makes specific contributions to the fields of health informatics, human-computer interaction, health services, and information management sciences. The contributions to each field are discussed in this section.

Contributions to Health Informatics

Large sample size in study of frequency of e-PRO tool use during cancer care

The sample size of patients with different types of cancer who had voluntary at-home access to e-PRO tool ESRA-C was 372. This comprised the entire intervention group of a randomized controlled trial and is twice the size of a previous trial done with people with breast or prostate cancer, who used the interactive e-PRO tool WebChoice (35,52).

Characterizing voluntary use of tracking tools during cancer treatment

Even though some randomized controlled trials show that e-PRO tools can have a positive effect on symptom distress (35) and communication outcomes (17), few studies have broken down exactly *what features of the e-PRO tool* leads to better symptom management and *for which patients*. This dissertation takes us one step closer to reaching this understanding, by (1) studying and modeling relationships between patient attributes and tracking tool use

(Chapters 3 and 5), and (2) gaining insight into why people would voluntarily use personal informatics tools in cancer care, when available (Chapter 4).

Chapter 3 focuses on investigating whether voluntary use of an e-PRO tool was associated with symptom distress or any other demographic factors. The analysis in Chapter 3 corroborates findings from other studies that show that people with less pain (59), or a relatively recent first-time cancer diagnosis (189), are more likely to voluntarily use an e-PRO tool more frequently. The analysis from Chapter 3 also suggested that age, regardless of symptom distress, could influence voluntary use of an e-PRO system.

Furthermore, this dissertation converges on design principles for future tracking tools that build on the successes of prior tools steeped in PRO and EMA traditions. The conceptual framework in chapter 5 models attributes of patients, clinicians, data and tracking tools to make explicit which factors influence voluntary use and acceptance.

Contributions to Human-Computer Interaction

Describes a theoretical perspective of what drives tracking tool use for health purposes

Theoretical modeling of use and acceptance can feed into the user-centered design process of personal informatics self-tracking tools for serious health conditions like cancer. However, theories in personal informatics often focus on collecting data to create knowledge that supports action and behavior change. In cancer care, symptom awareness for both clinicians and patients might simply an end in and of itself.

User researchers in human-computer interaction identify a problem in need of a solution, conduct needs assessments with a purposively chosen cross-section of stakeholders, and devise

contextual design principles arising from data analysis and prior knowledge from the literature. Although Li and colleagues undertook this process to develop the stage-based model of personal informatics (77), the problem they were addressing—how people gain knowledge and take action from data collected on themselves—was not specific to health.

Contributions to Health Services

Suggests how to adapt tracking tools within today's clinical workflow

Theories of technology acceptance look at the tool on the whole as the entire solution. We need to be more precise than that when it comes to self-tracking in cancer care. The focus of systems design is not only on the adoption of the tracking tool itself, but also on the use of the *data* that is collected and presented by the tracking tool. Self-tracking in cancer care is useful only when the data is useful. Thus, models that conceptualize tracking tool design and acceptance should separate tool acceptance and data usefulness explicitly.

The Quantified Self Community uses the tagline "Know Thyself." If self-tracking helps patients achieve this objective for their health, then clinicians treating patients should be left with, "Know Your Audience." This is not easy to achieve in the current flow of medicine, where clinicians have to glean as much understanding of the patient as possible within the brief clinic visit and using relatively objective evidence in the form of imaging and lab test results. Physicians in particular are accustomed to being authoritative decision-makers, trained in the science of medicine (109). According to medical humanities professor Kathryn Montgomery, physicians need to use an inherently nonlinear clinical judgment process to be able to generate "a linear cause and effect to explain to the patient." Despite training in the field of biological

science, clinicians "habitually omit activities that might be expected of a science." For the purposes of the dissertation, such omitted activities include review of patient self-tracking data.

Contributions to Information & Management Science

Adapts current technology acceptance models to apply to tracking tools for health.

Use and acceptance of tracking tools for health theoretically could be predicted through existing technology acceptance models. However, existing models of technology acceptance and user satisfaction do not take technology attributes, the clinician's work context, and the patient's health situation into account. MUTT-PC describes the work context of future tracking tools, while MultiTrack represents tradeoffs about the technology, data, patient attributes, and clinician attributes intended for developers to design requirements to optimize use and maximize acceptance.

Future Work

Collaborative use of tracking tools by patients and clinicians has the potential to improve symptom management, patient-clinician communication and, ultimately, health outcomes. With tracking tools that collect patient-generated data, clinicians can gain a more holistic understanding of patient's condition, instead of relying predominantly on the clinic visit, and patients can better understand how to manage their condition. Despite benefits to patients shown in this dissertation and in the literature, most people do not tracking use tools for their health. To maximize patients' benefits from self-tracking and to further inform future tool design to promote use and acceptance among patients and clinicians, I propose two theoretical models. In this dissertation, I describe a novel framework that separates the clinical and personal usefulness of the data from the perceived usefulness of the tracking tool. Furthermore, incorporating the

context of healthcare into the tracking tool development considerations promises that with the deployment of next-generation tracking tools, both clinicians and patients can see the value of self-tracking in their lives.

Future work could validate the conceptual model through tracking tool development based on converging ideas from various fields—such as validated e-PRO questionnaires from health services, real-time data capture from use of ecological momentary assessment, and patient-initiated self-tracking tools facilitating personal choices and preferences. In addition, interviews and surveys with patients and clinicians can further strengthen knowledge of what matter to both parties when in comes to symptom management and the patient-clinician relationship. Not all tracking tools that patients use in the future will be sanctioned by healthcare organizations. Thus, we still need to consider how to enable patients to bring in tools that do not fit into workflow to have their tracking be useful, clinically relevant data be considered without taking too much time out of the clinician's workday. For tracking tools to be welcomed into the exam room and supported by clinical administrators, a cultural and organizational shift needs to happen in parallel to the development of next-generation of tracking tools. In the future, patients will be able to present their symptom history through continuous data of health metrics that are clinically relevant and/or priorities for their quality of life. Even as a movement towards patient-clinician collaboration through use of self-tracking data is fermenting, we must consider a wide range of dimensions of what makes self-tracking effective and efficient for both patients and clinicians.

In conclusion, it is important to discuss implications for patients, clinicians, and tracking tool developers that provide insight into how tracking tools should function for optimal acceptance for patients and clinicians and organizations in the future. Building a tracking tool

solution that is accepted in healthcare and at the patient's home requires a holistic perspective. Making such a holistic perspective explicit requires vision, advocacy, collaboration, and execution. Absent any one of these, tracking tools are destined to remain a promising technology that will be unlikely to reach full potential.

References

1. Gandhi M, Oishi K, Zubal B, Lacouture ME. Unanticipated toxicities from anticancer therapies: Survivors' perspectives. Support Care Cancer 2010, Nov;18(11):1461-8.

2. Rogers M, Todd C. The 'right kind' of pain: Talking about symptoms in outpatient oncology consultations. Palliative Medicine 2000, Jul 1;14(4):299-307.

3. Cleeland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA, Pandya KJ. Pain and its treatment in outpatients with metastatic cancer. N Engl J Med 1994, Mar 3;330(9):592-6.

4. Davidson JR, Feldman-Stewart D, Brennenstuhl S, Ram S. How to provide insomnia interventions to people with cancer: Insights from patients. Psychooncology 2007, Nov;16(11):1028-38.

5. Palmer JL, Fisch MJ. Association between symptom distress and survival in outpatients seen in a palliative care cancer center. J Pain Symptom Manage 2005, Jun;29(6):565-71.

6. Laugsand EA, Sprangers MAG, Bjordal K, Skorpen F, Kaasa S, Klepstad P. Health care providers underestimate symptom intensities of cancer patients: A multicenter european study. Health Qual Life Outcomes 2010;8:104.

7. Armstrong TS. Symptoms experience: A concept analysis. Oncol Nurs Forum 2003;30(4):601-6.

8. Purtzer MA, Hermansen-Kobulnicky CJ. 'Being a part of treatment': The meaning of self-monitoring for rural cancer patients. Cancer Nurs 2013, Mar;36(2):93-103.

9. Paton C, Hansen M, Fernandez-Luque L, Lau AYS. Self-tracking, social media and personal health records for patient empowered self-care. Contribution of the IMIA Social Media Working Group. Yearb Med Inform 2012;7(1):16-24.

10. Novy D, Berry MP, Palmer JL, Mensing C, Willey J, Bruera E. Somatic symptoms in patients with chronic non-cancer-related and cancer-related pain. J Pain Symptom Manage 2005, Jun;29(6):603-12.

11. Reilly CM, Bruner DW, Mitchell SA, Minasian LM, Basch E, Dueck AC, et al. A literature synthesis of symptom prevalence and severity in persons receiving active cancer treatment. Support Care Cancer 2013, Jun;21(6):1525-50.

12. Brem S, Kumar NB. Management of treatment-related symptoms in patients with breast cancer. Clin J Oncol Nurs 2011, Feb;15(1):63-71.

13. Jakobsson S, Ekman T, Ahlberg K. Components that influence assessment and management of cancer-related symptoms: An interdisciplinary perspective. Oncol Nurs Forum 2008, Jul;35(4):691-8.

14. Dodd M, Janson S, Facione N, Faucett J, Froelicher ES, Humphreys J, et al. Advancing the science of symptom management. J Adv Nurs 2001, Mar;33(5):668-76.

15. Byar KL, Berger AM, Bakken SL, Cetak MA. Impact of adjuvant breast cancer chemotherapy on fatigue, other symptoms, and quality of life. Oncol Nurs Forum 2006, Jan;33(1):E18-26.

16. Donaldson MS. Taking pros and patient-centered care seriously: Incremental and disruptive ideas for incorporating pros in oncology practice. Qual Life Res 2008, Dec;17(10):1323-30.

17. Berry DL, Blumenstein BA, Halpenny B, Wolpin S, Fann JR, Austin-Seymour M, et al. Enhancing patient-provider communication with the electronic self-report assessment for cancer: A randomized trial. J Clin Oncol 2011, Mar 10;29(8):1029-35.

18. Cleeland CS, Wang XS, Shi Q, Mendoza TR, Wright SL, Berry MD, et al. Automated symptom alerts reduce postoperative symptom severity after cancer surgery: A randomized controlled clinical trial. J Clin Oncol 2011, Mar 10;29(8):994-1000.

19. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. BMC Health Serv Res 2013;13:211.

20. Dudgeon DJ, Knott C, Chapman C, Coulson K, Jeffery E, Preston S, et al. Development, implementation, and process evaluation of a regional palliative care quality improvement project. J Pain Symptom Manage 2009, Oct;38(4):483-95.

21. Bainbridge D, Seow H, Sussman J, Pond G, Martelli-Reid L, Herbert C, Evans W. Multidisciplinary health care professionals' perceptions of the use and utility of a symptom assessment system for oncology patients. J Oncol Pract 2011, Jan;7(1):19-23.

22. Glasgow RE, Phillips SM, Sanchez MA. Implementation science approaches for integrating ehealth research into practice and policy. Int J Med Inform 2013, Jul 30.

23. Wagner EH, Davis C, Schaefer J, Von Korff M, Austin B. A survey of leading chronic disease management programs: Are they consistent with the literature? Manag Care Q 1999;7(3):56-66.

24. Wilde MH, Garvin S. A concept analysis of self-monitoring. J Adv Nurs 2007, Feb;57(3):339-50.

25. van Gemert-Pijnen JEWC, Nijland N, van Limburg M, Ossebaard HC, Kelders SM, Eysenbach G, Seydel ER. A holistic framework to improve the uptake and impact of ehealth technologies. J Med Internet Res 2011;13(4):e111.

26. Fox, Duggan M. Tracking for health. Pew Internet & American Life Project. Jan 28, 2013. http://www.pewinternet.org/Reports/2013/Tracking-for-Health/Summary-of-Findings.aspx. Accessed Nov 24, 2013.

27. Hermansen-Kobulnicky CJ. Symptom-monitoring behaviors of rural cancer patients and survivors. Support Care Cancer 2009, Jun;17(6):617-26.

28. Favill J, Rennick CF. A case of family periodic paralysis. Archives of Neurology and Psychiatry 1924;11(6):674.

29. U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health. Guidance for industry: Patient-reported outcome measures: Use in medical product development to support labeling claims: Draft guidance. Health Qual Life Outcomes 2006;4:79.

30. Bennett AV, Jensen RE, Basch E. Electronic patient-reported outcome systems in oncology clinical practice. CA Cancer J Clin 2012;62(5):337-47.

31. Lohr KN, Zebrack BJ. Using patient-reported outcomes in clinical practice: Challenges and opportunities. Qual Life Res 2009, Feb;18(1):99-107.

32. Marshall S, Haywood K, Fitzpatrick R. Impact of patient-reported outcome measures on routine practice: A structured review. J Eval Clin Pract 2006, Oct;12(5):559-68.

33. Snyder CF, Blackford AL, Wolff AC, Carducci MA, Herman JM, Wu AW, PatientViewpoint Scientific Advisory Board. Feasibility and value of patientviewpoint: A web system for patient-reported outcomes assessment in clinical practice. Psychooncology 2013, Apr;22(4):895-901.

34. Cella D, Hahn EA, Dineen K. Meaningful change in cancer-specific quality of life scores: Differences between improvement and worsening. Qual Life Res 2002, May;11(3):207-21.

35. Ruland CM, Andersen T, Jeneson A, Moore S, Grimsbø GH, Børøsund E, Ellison MC. Effects of an internet support system to assist cancer patients in reducing symptom distress: A randomized controlled trial. Cancer Nurs 2013;36(1):6-17.

36. Abernethy AP, Herndon JE, Wheeler JL, Day JM, Hood L, Patwardhan M, et al. Feasibility and acceptability to patients of a longitudinal system for evaluating cancer-related symptoms and quality of life: Pilot study of an e/tablet data-collection system in academic oncology. J Pain Symptom Manage 2009, Jun;37(6):1027-38.

37. Wilkie DJ, Kim YO, Suarez ML, Dauw CM, Stapleton SJ, Gorman G, et al. Extending computer technology to hospice research: Interactive pentablet measurement of symptoms by hospice cancer patients in their homes. J Palliat Med 2009, Jul;12(7):599-602.

38. Abernethy AP, Zafar SY, Uronis H, Wheeler JL, Coan A, Rowe K, et al. Validation of the patient care monitor (version 2.0): A review of system assessment instrument for cancer patients. J Pain Symptom Manage 2010, Oct;40(4):545-58.

39. Stone AA, Shiffman S, Atienza AA, Nebeling L. The science of real-time data capture. Oxford University Press New York:; 2007c.

40. Velikova G, Awad N, Coles-Gale R, Wright EP, Brown JM, Selby PJ. The clinical value of quality of life assessment in oncology practice-a qualitative study of patient and physician views. Psychooncology 2008, Jul;17(7):690-8.

41. Ruland CM, Holte HH, Røislien J, Heaven C, Hamilton GA, Kristiansen J, et al. Effects of a computer-supported interactive tailored patient assessment tool on patient care, symptom distress, and patients' need for symptom management support: A randomized clinical trial. J Am Med Inform Assoc 2010;17(4):403-10.

42. Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, Selby PJ. Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. J Clin Oncol 2004, Feb 15;22(4):714-24.

43. Heyn L, Ruland CM, Finset A. Effects of an interactive tailored patient assessment tool on eliciting and responding to cancer patients' cues and concerns in clinical consultations with physicians and nurses. Patient Educ Couns 2012, Feb;86(2):158-65.

44. Heyn L, Finset A, Ruland CM. Talking about feelings and worries in cancer consultations: The effects of an interactive tailored symptom assessment on source, explicitness, and timing of emotional cues and concerns. Cancer Nurs 2013, Mar;36(2):E20-30.

45. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at kaiser permanente through e-mail between physicians and patients. Health Aff (Millwood) 2010, Jul;29(7):1370-5.

46. Wilson EV, Lankton NK. Modeling patients' acceptance of provider-delivered e-health. J Am Med Inform Assoc 2004;11(4):241-8.

47. Agarwal R, Anderson C, Zarate J, Ward C. If we offer it, will they accept? Factors affecting patient use intentions of personal health records and secure messaging. J Med Internet Res 2013;15(2):e43.

48. Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice: Lack of impact or lack of theory? Soc Sci Med 2005, Feb;60(4):833-43.

49. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: Transformative tools for consumer-centric care. BMC Med Inform Decis Mak 2008;8:45.

50. Jones JB, Snyder CF, Wu AW. Issues in the design of internet-based systems for collecting patient-reported outcomes. Qual Life Res 2007, Oct;16(8):1407-17.

51. Grimsbø GH, Engelsrud GH, Ruland CM, Finset A. Cancer patients' experiences of using an interactive health communication application (IHCA). Int J Qual Stud Health Well-being 2012;7.

52. Børøsund E, Cvancarova M, Ekstedt M, Moore SM, Ruland CM. How user characteristics affect use patterns in web-based illness management support for patients with breast and prostate cancer. J Med Internet Res 2013;15(3):e34.

53. Fox S. Cancer 2.0: A summary of recent research. Pew Internet & American Life Project. Dec 13, 2010. http://www.pewinternet.org/Reports/2010/30--Cancer-20/Report.aspx. Accessed Nov 24, 2013.

55. Electronic self-report assessment for cancer: Results of a multisite randomized trial; J Clin Oncology. 2012n.

56. Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, et al. The impact of measuring patient-reported outcomes in clinical practice: A systematic review of the literature. Qual Life Res 2008, Mar;17(2):179-93.

57. Schneider S, Broderick JE, Junghaenel DU, Schwartz JE, Stone AA. Temporal trends in symptom experience predict the accuracy of recall pros. J Psychosom Res 2013, Aug;75(2):160-6.

58. Ruland CM, Bakken S, Røislien J. Reliability and validity issues related to interactive tailored patient assessments: A case study. J Med Internet Res 2007;9(3):e22.

59. Caraceni A, Galbiati A, Brunelli C, Gorni G, Martini C, Zecca E, De Conno F. Cancer patient compliance in the self-administration of a pain assessment tool. J Pain Symptom Manage 2004, May;27(5):417-24.

60. Heron KE, Smyth JM. Ecological momentary interventions: Incorporating mobile technology into psychosocial and health behaviour treatments. Br J Health Psychol 2010, Feb;15(Pt 1):1-39.

61. Stone AA, Shiffman S. Ecological momentary assessment (EMA) in behavioral medicine. Annals of Behavioral Medicine 1994;16:199-202.

62. Csikszentmihalyi M, Larson R. Validity and reliability of the experience-sampling method. J Nerv Ment Dis 1987, Sep;175(9):526-36.

63. Marceau LD, Link CL, Smith LD, Carolan SJ, Jamison RN. In-clinic use of electronic pain diaries: Barriers of implementation among pain physicians. J Pain Symptom Manage 2010, Sep;40(3):391-404.

64. Stone AA, Broderick JE, Shiffman SS, Schwartz JE. Understanding recall of weekly pain from a momentary assessment perspective: Absolute agreement, between- and within-person consistency, and judged change in weekly pain. Pain 2004, Jan;107(1-2):61-9.

65. Litcher-Kelly L, Stone AA, Broderick JE, Schwartz JE. Associations among pain intensity, sensory characteristics, affective qualities, and activity limitations in patients with chronic pain: A momentary, within-person perspective. J Pain 2004, Oct;5(8):433-9.

66. Cruise CE, Broderick J, Porter L, Kaell A, Stone AA. Reactive effects of diary self-assessment in chronic pain patients. Pain 1996, Oct;67(2-3):253-8.

67. Yoshiuchi K, Yamamoto Y, Akabayashi A. Application of ecological momentary assessment in stress-related diseases. Biopsychosoc Med 2008;2:13.

68. Broderick JE, Vikingstad G. Frequent assessment of negative symptoms does not induce depressed mood. J Clin Psychol Med Settings 2008, Dec;15(4):296-300.

69. Oorschot M, Lataster T, Thewissen V, Wichers M, Myin-Germeys I. Mobile assessment in schizophrenia: A data-driven momentary approach. Schizophr Bull 2012, May;38(3):405-13.

70. Rodgers A, Corbett T, Bramley D, Riddell T, Wills M, Lin R-B, Jones M. Do u smoke after txt? Results of a randomised trial of smoking cessation using mobile phone text messaging. Tob Control 2005, Aug;14(4):255-61.

71. Kwon H-S, Cho J-H, Kim H-S, Lee J-H, Song B-R, Oh J-A, et al. Development of web-based diabetic patient management system using short message service (SMS). Diabetes Res Clin Pract 2004, Dec;66 Suppl 1:S133-7.

72. Curran SL, Beacham AO, Andrykowski MA. Ecological momentary assessment of fatigue following breast cancer treatment. J Behav Med 2004, Oct;27(5):425-44.

73. Speier C, Valacich JS, Vessey I. The influence of task interruption on individual decision making: An information overload perspective. Decision Sciences 1999;30(2):337-60.

74. Schwartz JE, Stone AA. Strategies for analyzing ecological momentary assessment data. Health Psychology 1998;17(1):6.

75. Gibbons MC, Wilson RF, Samal L, Lehman CU, Dickersin K, Lehmann HP, et al. Impact of consumer health informatics applications. Rockville, MD: Agency for Healthcare Research and Quality (US); 2009g.

76. Understanding my data, myself: Supporting self-reflection with ubicomp technologies; Proceedings of the 13th international conference on ubiquitous computing. ACM; 2011h.

77. A stage-based model of personal informatics systems; Proceedings of the SIGCHI conference on human factors in computing systems. 2010.

78. Aarhus R, Ballegaard SA, Hansen TR. The ediary: Bridging home and hospital through healthcare technology. ECSCW 2009 2009:63-83.

79. van Velsen L, Beaujean DJMA, van Gemert-Pijnen JEWC. Why mobile health app overload drives us crazy, and how to restore the sanity. BMC Med Inform Decis Mak 2013;13:23.

80. Wolf G. Know thyself: Tracking every facet of life, from sleep to mood to pain, 24/7/365. Wired.com, 2009.

82. Klasnja P, Pratt W. Healthcare in the pocket: Mapping the space of mobile-phone health interventions. J Biomed Inform 2012, Feb;45(1):184-98.

83. Mamykina L, Mynatt E, Davison P, Greenblatt D. MAHI: Investigation of social scaffolding for reflective thinking in diabetes management; Proceedings of the SIGCHI conference on human factors in computing systems. 2008.

84. Maitland J and Chalmers M. Self-monitoring, self-awareness, and self-determination in cardiac rehabilitation; Proceedings of the SIGCHI conference on human factors in computing systems. 2010.

85. Hartzler A, Unruh KT, Pratt W. Blowing in the wind: Unanchored patient information work during cancer care; Proceedings of the SIGCHI conference on human factors in computing systems. 2010.

86. Klasnja P, Hartzler A, Powell C, Pratt W. Supporting cancer patients unanchored health information management with mobile technology; Proceedigns of the AMIA Annual Symposium 2011.

88. Berry DL, Hong F, Halpenny B, Partridge AH, Fann JR, Wolpin S, et al. The electronic self report assessment for cancer and self-care support: Results of a multisite randomized trial. Journal of Clinical Oncology 2013.

89. McCorkle R, Young K. Development of a symptom distress scale. Cancer Nursing 1978;1(5):373-8.

90. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD. JAMA: The Journal of the American Medical Association 1999;282(18):1737-44.

91. Osoba D, Aaronson N, Zee B, Sprangers M, te Velde A. Modification of the EORTC QLQ-C30 (version 2.0) based on content validity and reliability testing in large samples of patients with cancer. The study group on quality of life of the EORTC and the symptom control and quality of life committees of the NCI of canada clinical trials group. Qual Life Res 1997, Mar;6(2):103-8.

92. Postma TJ, Aaronson NK, Heimans JJ, Muller MJ, Hildebrand JG, Delattre JY, et al. The development of an EORTC quality of life questionnaire to assess chemotherapy-induced peripheral neuropathy: The QLQ-CIPN20. Eur J Cancer 2005, May;41(8):1135-9.

93. McCorkle R. The measurement of symptom distress. Semin Oncol Nurs 1987, Nov;3(4):248-56.

94. Kelders SM, Van Gemert-Pijnen JE, Werkman A, Nijland N, Seydel ER. Effectiveness of a web-based intervention aimed at healthy dietary and physical activity behavior: A randomized controlled trial about users and usage. Journal of Medical Internet Research 2011;13(2).

95. Verheijden MW, Jans MP, Hildebrandt VH, Hopman-Rock M. Rates and determinants of repeated participation in a web-based behavior change program for healthy body weight and healthy lifestyle. Journal of Medical Internet Research 2007;9(1).

96. Eysenbach G. The impact of the internet on cancer outcomes. CA Cancer J Clin 2003;53(6):356-71.

97. Hutchinson H, Mackay W, Technology probes: Inspiring design for and with families; Proceedings of the SIGCHI conference on human factors in computing systems. 2003.

98. Pratt W, Unruh K, Civan A, Skeels MM. Personal health information management. Communications of the ACM 2006;49(1):51-5.

99. Unruh KT, Skeels MM, Hartzler A, Pratt W. Transforming clinic environments into information workspaces for patients; Proceedings of the SIGCHI conference on human factors in computing systems. 2010.

100. Hartzler A. Locating patient expertise in everyday life; Proceedings of the ACM 2009 international conference on supporting group work. 2009.

101. P, Hartzler A, Powell C, Phan G, Pratt W. Healthweaver Mobile: Designing a mobile tool for managing personal health information during cancer care. Proceedings of the AMIA Annual Symposium. 2010.

102. Skeels MM, Unruh KT, Powell C, Pratt W. Catalyzing social support for breast cancer patients; Proceedings of the SIGCHI conference on human factors in computing systems. 2010.

103. Paepcke A. Information needs in technical work settings and their implications for the design of computer tools. Computer Supported Cooperative Work (CSCW) 1996;5(1):63-92.

104. Corbin J, Strauss A. Basics of qualitative research: Techniques and procedures for developing grounded theory. Sage; 2008.

105. Boykoff N, Moieni M, Subramanian SK. Confronting chemobrain: An in-depth look at survivors' reports of impact on work, social networks, and health care response. J Cancer Surviv 2009, Dec;3(4):223-32.

106. Rogers A, Mead N. More than technology and access: Primary care patients' views on the use and non-use of health information in the internet age. Health Soc Care Community 2004, Mar;12(2):102-10.

107. van Limburg M, van Gemert-Pijnen JEWC, Nijland N, Ossebaard HC, Hendrix RMG, Seydel ER. Why business modeling is crucial in the development of ehealth technologies. J Med Internet Res 2011;13(4):e124.

108. Patel RA, Klasnja P, Hartzler A, Unruh KT, Pratt W. Probing the benefits of real-time tracking during cancer care. AMIA Annu Symp Proc 2012;2012:1340-9.

109. Montgomery K. How doctors think : Clinical judgment and the practice of medicine. Oxford ; New York: Oxford University Press; 2006.

110. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: Toward a unified view. MIS Quarterly 2003;27:425-78.

111. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. Management Science 1989, Sep;13(3):319-40.

112. Kim SS, Malhotra NK, Narasimhan S. Research note?Two competing perspectives on automatic use: A theoretical and empirical comparison. Information Systems Research 2005, Dec;16(4):418-32.

113. Fishbein M, Ajzen I. Understanding attitudes and predicting social behavior. Journal of Experimental Social Psychology 1980;22:453-74.

114. Hu PJ, Chau PY, Sheng ORL, Tam KY. Examining the technology acceptance model using physician acceptance of telemedicine technology. Journal of Management Information Systems 1999;16(2):91-112.

115. Or CKL, Karsh B-T, Severtson DJ, Burke LJ, Brown RL, Brennan PF. Factors affecting home care patients' acceptance of a web-based interactive self-management technology. J Am Med Inform Assoc 2011;18(1):51-9.

116. Kim SS, Malhotra NK. A longitudinal model of continued IS use: An integrative view of four mechanisms underlying postadoption phenomena. Management Science 2005, May;51(5):741-55.

117. Holden RJ, Karsh B-T. The technology acceptance model: Its past and its future in health care. J Biomed Inform 2010, Feb;43(1):159-72.

118. Gagnon MP, Orruño E, Asua J, Abdeljelil AB, Emparanza J. Using a modified technology acceptance model to evaluate healthcare professionals' adoption of a new telemonitoring system. Telemed J E Health 2012;18(1):54-9.

119. Asua J, Orruño E, Reviriego E, Gagnon MP. Healthcare professional acceptance of telemonitoring for chronic care patients in primary care. BMC Med Inform Decis Mak 2012;12:139.

120. Ketikidis P, Dimitrovski T, Lazuras L, Bath PA. Acceptance of health information technology in health professionals: An application of the revised technology acceptance model. Health Informatics J 2012, Jun;18(2):124-34.

121. Or CKL, Karsh B-T. A systematic review of patient acceptance of consumer health information technology. J Am Med Inform Assoc 2009;16(4):550-60.

122. Kim J, Park H-A. Development of a health information technology acceptance model using consumers' health behavior intention. J Med Internet Res 2012;14(5):e133.

123. Wixom BH, Todd PA. A theoretical integration of user satisfaction and technology acceptance. Information Systems Research 2005;16(1):85-102.

124. Han JY, Wise M, Kim E, Pingree R, Hawkins RP, Pingree S, et al. Factors associated with use of interactive cancer communication system: An application of the comprehensive model of information seeking. J Comput Mediat Commun 2010, Apr;15(3):367-88.

125. Shapiro M, Johnston D, Wald J, Mon D. Patient-Generated health data white paper. Office of the National Coordinator for Health Information Technology, 2012.

126. Vickers AJ, Salz T, Basch E, Cooperberg MR, Carroll PR, Tighe F, et al. Electronic patient self-assessment and management (SAM): A novel framework for cancer survivorship. BMC Med Inform Decis Mak 2010;10:34.

127. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: Translating evidence into action. Health Affairs 2001, Nov 1;20(6):64-78.

128. Johnson JD, Johnson DJ. Cancer-related information seeking. Hampton Press Cresskill, NJ; 1997p.

129. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: A comparison of two theoretical models. Management Science 1989;35(8):982-1003.

130. Elstein AS, Shulman LSJA, Sprafka SA. Medical problem solving : An analysis of clinical reasoning. Cambridge, Mass.: Harvard University Press; 1978b.

131. Choe EK, Lee N, Lee B, Pratt W, Kientz J. Understanding quantified-selfers' practices in collecting and exploring personal data. CHI 2014 (in press).

132. Cook DJ, Thompson JE, Prinsen SK, Dearani JA, Deschamps C. Functional recovery in the elderly after major surgery: Assessment of mobility recovery using wireless technology. Ann Thorac Surg 2013, Sep;96(3):1057-61.

133. Wolpin S, Berry D, Austin-Seymour M, Bush N, Fann JR, Halpenny B, et al. Acceptability of an electronic self-report assessment program for patients with cancer. Comput Inform Nurs 2008;26(6):332-8.

134. Blondon K. The potential of improving care in diabetes through mobile devices, patient empowerment and financial incentives. Dissertation, University of Washington. June 2013.

135. Sarkar U, Karter AJ, Liu JY, Adler NE, Nguyen R, López A, Schillinger D. Social disparities in internet patient portal use in diabetes: Evidence that the digital divide extends beyond access. J Am Med Inform Assoc 2011, May 1;18(3):318-21.

136. Resources for understanding and implementing section 508 : Accessed 24 November 2013.

137. Van Velsen L, Wentzel J, Van Gemert-Pijnen JE. Designing ehealth that matters via a multidisciplinary requirements development approach. JMIR Res Protoc 2013;2(1):e21.

138. Topol EJ. The creative destruction of medicine : How the digital revolution will create better health care. New York: Basic Books; 2012.

139. Christiansen C, Grossman JH, Hwang J. The innovator's prescription. New York: McGraw-Hill; 2008.

140. King AC, Hekler EB, Grieco LA, Winter SJ, Sheats JL, Buman MP, et al. Harnessing different motivational frames via mobile phones to promote daily physical activity and reduce sedentary behavior in aging adults. PLoS One 2013;8(4):e62613.

141. Alpay L, van der Boog P, Dumaij A. An empowerment-based approach to developing innovative e-health tools for self-management. Health Informatics J 2011, Dec;17(4):247-55.

142. Health literacy, ehealth, and communication :Putting the consumer first : Workshop summary. Washington, DC: National Academies Press; 2009c.

143. George S, Hamilton A, Baker RS. How do low-income urban african americans and latinos feel about telemedicine? A diffusion of innovation analysis. Int J Telemed Appl 2012;2012:715194.

144. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: Internet use patterns, ehealth literacy, and attitudes toward computer/internet use. J Med Internet Res 2013;15(5):e93.

145. Neter E, Brainin E. EHealth literacy: Extending the digital divide to the realm of health information. J Med Internet Res 2012;14(1):e19.

146. Choi NG, Dinitto DM. Internet use among older adults: Association with health needs, psychological capital, and social capital. J Med Internet Res 2013;15(5):e97.

147. Montague E, Perchonok J. Health and wellness technology use by historically underserved health consumers: Systematic review. J Med Internet Res 2012;14(3):e78.

148. Versel N. Report: Clinical apps look promising for asthma, diabetes, but questions persist. MobiHealthNews 2013, Nov 2011.

149. Cantwell MM, Millen AE, Carroll R, Mittl BL, Hermansen S, Brinton LA, Potischman N. A debriefing session with a nutritionist can improve dietary assessment using food diaries. J Nutr 2006, Feb;136(2):440-5.

150. Liang T-H. Matrix analysis of the digital divide in ehealth services using awareness, want, and adoption gap. J Med Internet Res 2012;14(1):e11.

151. Wikipedia.Com : Accessed 24 November 2013.

152. O'Brien R. Smartphones struggle to connect with the elderly. Cnbc.com 2013, Sep 22.

153. Money AG, Barnett J, Kuljis J, Craven MP, Martin JL, Young T. The role of the user within the medical device design and development process: Medical device manufacturers' perspectives. BMC Med Inform Decis Mak 2011;11:15.

154. Wolpert M. Do patient reported outcome measures do more harm than good? BMJ: British Medical Journal 2013;346.

155. Gilbody SM, House AO, Sheldon TA. Psychiatrists in the UK do not use outcomes measures. National survey. Br J Psychiatry 2002, Feb;180:101-3.

156. Sainio C, Lauri S, Eriksson E. Cancer patients' views and experiences of participation in care and decision making. Nursing Ethics 2001, Mar 1;8(2):97-113.

157. Wald JS, Businger A, Gandhi TK, Grant RW, Poon EG, Schnipper JL, et al. Implementing practice-linked pre-visit electronic journals in primary care: Patient and physician use and satisfaction. J Am Med Inform Assoc 2010;17(5):502-6.

158. Mohr DC, Cheung K, Schueller SM, Hendricks Brown C, Duan N. Continuous evaluation of evolving behavioral intervention technologies. Am J Prev Med 2013, Oct;45(4):517-23.

159. van den Berg SW, Peters EJ, Kraaijeveld JF, Gielissen MF, Prins JB. Usage of a generic web-based self-management intervention for breast cancer survivors: Substudy analysis of the BREATH trial. J Med Internet Res 2013;15(8):e170.

160. Greene SM, Reid RJ, Larson EB. Implementing the learning health system: From concept to action. Ann Intern Med 2012, Aug 7;157(3):207-10.

161. DesRoches CM, Worzala C, Joshi MS, Kralovec PD, Jha AK. Small, nonteaching, and rural hospitals continue to be slow in adopting electronic health record systems. Health Aff (Millwood) 2012, May;31(5):1092-9.

162. Devine EB, Patel R, Dixon DR, Sullivan SD. Assessing attitudes toward electronic prescribing adoption in primary care: A survey of prescribers and staff. Inform Prim Care 2010;18(3):177-87.

163. Burke LE, Wang J, Sevick MA. Self-monitoring in weight loss: A systematic review of the literature. J Am Diet Assoc 2011, Jan;111(1):92-102.

164. Tate DF, Wing RR, Winett RA. Using internet technology to deliver a behavioral weight loss program. JAMA 2001, Mar 7;285(9):1172-7.

165. Chen F, Ruiz N, Choi E, Epps J, Khawaja MA, Taib R, et al. Multimodal behavior and interaction as indicators of cognitive load. ACM Transactions on Interactive Intelligent Systems (TiiS) 2012;2(4):22.

166. Wærn A. User involvement in automatic filtering: An experimental study. User Modeling and User-Adapted Interaction 2004;14(2-3):201-37.

167. A user-centric evaluation framework for recommender systems; Proceedings of the fifth ACM conference on recommender systems. 2011b.

168. Dolan B. Official: Google health shuts down because it couldn't scale adoption. MobiHealthNews 2011, Jun 24.

169. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2006;13(2):121-6.

170. Beckjord EB, Rechis R, Nutt S, Shulman L, Hesse BW. What do people affected by cancer think about electronic health information exchange? Results from the 2010 LIVESTRONG electronic health information exchange survey and the 2008 health information national trends survey. J Oncol Pract 2011, Jul;7(4):237-41.

171. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: Validity of a brief depression severity measure. J Gen Intern Med 2001, Sep;16(9):606-13.

172. Abowd G. Industry day keynote. AMIA Annual Symposium Oct 24, 2011.

173. Smith CA, Wicks PJ. PatientsLikeMe: Consumer health vocabulary as a folksonomy. Proceedings of the AMIA Annu Symp Proc 2008:682-6.

174. Kaufman DR, Patel VL, Hilliman C, Morin PC, Pevzner J, Weinstock RS, et al. Usability in the real world: Assessing medical information technologies in patients' homes. Journal of Biomedical Informatics 2003, Feb;36(1-2):45-60.

175. King AC. Behavioral medicine in the 21st century: Transforming "the road less traveled" into the "American way of life". Ann Behav Med 2013, Oct 5.

176. Greenhalgh T. How to read a paper: The basics of evidence-based medicine. Wiley. com; 2010b.

177. Brindal E, Freyne J, Saunders I, Berkovsky S, Smith G, Noakes M. Features predicting weight loss in overweight or obese participants in a web-based intervention: Randomized trial. J Med Internet Res 2012;14(6):e173.

178. Lorenzi NM, Novak LL, Weiss JB, Gadd CS, Unertl KM. Crossing the implementation chasm: A proposal for bold action. J Am Med Inform Assoc 2008;15(3):290-6.

179. I love the systemi just don't use it!; Proceedings of the international ACM SIGGROUP conference on supporting group work: The integration challenge. 1997b.

180. Potter VT, Wiseman CE, Dunn SM, Boyle FM. Patient barriers to optimal cancer pain control. Psychooncology 2003, Mar;12(2):153-60.

181. Unertl KM, Novak LL, Johnson KB, Lorenzi NM. Traversing the many paths of workflow research: Developing a conceptual framework of workflow terminology through a systematic literature review. J Am Med Inform Assoc 2010;17(3):265-73.

182. Linden A, Fenn J. Understanding Gartner's Hype Cycles 2003.

183. Norman DA. The design of everyday things. New York: Basic Books; 2002a.

184. Vincent CJ, Li Y, Blandford A. Integration of human factors and ergonomics during medical device design and development: It's all about communication. Applied Ergonomics 2013.

185. Understanding usability practices in complex domains; Proceedings of the SIGCHI conference on human factors in computing systems. 2010f.

186. Lazar J, Feng JH, Hochheiser H. Research methods in human-computer interaction. Chichester, West Sussex, U.K.: Wiley; 2010f.

187. Wolpin S, Stewart M. A deliberate and rigorous approach to development of patient-centered technologies. Semin Oncol Nurs 2011, Aug;27(3):183-91.

188. Tractinsky N, Katz AS, Ikar D. What is beautiful is usable. Interacting with Computers 2000;13(2):127-45.

189. Ruland CM, Maffei RM, Børøsund E, Krahn A, Andersen T, Grimsbø GH. Evaluation of different features of an ehealth application for personalized illness management support: Cancer patients' use and appraisal of usefulness. Int J Med Inform 2013, Jul;82(7):593-603.