

Blowing in the Wind: Unanchored Patient Information Work during Cancer Care

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ABSTRACT

Patients do considerable information work. Technologies that help patients manage health information so they can play active roles in their health-care, such as personal health records, provide patients with effective support for focused and sustained personal health tasks. Yet, little attention has been paid to patients' needs for information management support while on the go and away from their personal health information collections. Through a qualitative field study, we investigated the information work that breast cancer patients do in such 'unanchored settings'. We report on the types of unanchored information work that patients do over the course of cancer treatment, reasons this work is challenging, and strategies used by patients to overcome those challenges. Our description of unanchored patient information work expands our understanding of patients' information practices and points to valuable design directions for supporting critical but unmet needs.

Author Keywords

Personal health informatics, user study, mobile computing.

ACM Classification Keywords

H.5.2 User Interfaces; J.3 Life and Medical Sciences: Medical information systems.

General Terms

Design, Human Factors.

INTRODUCTION

Cancer care requires a great deal of information work on the part of the patient [19]. Beyond the psychological stress of dealing with a life-threatening illness, patients must manage a range of personal health information to play an active role in their health-care [16]. For example, patients

often gather and integrate their medical records, web pages, notes, and articles to make treatment decisions. They then must coordinate with various institutions and clinicians where they receive care (e.g., surgeons, oncologists, nurses, and other hospital personnel). In addition, to cover treatment costs and secure sufficient time off from work for cancer care, patients often exchange health information with their insurance companies, managers at work, and benefits departments. All the while, patients monitor their health as they move through treatment and share this information with their clinicians, family, and friends.

Clearly, to play active roles in their health-care, patients must practice effective information management. Yet, patients perform this information work under various conditions of support. Some information management is anchored with sustained time, dedicated space, and focused attention. For example, patients can spend considerable time on their home computers researching cancer treatment options and comparing their effectiveness. However, a range of important care-related needs arise while patients are away from such support. In these 'unanchored' settings, patients often lack the informational, physical, and attentional resources needed to effectively engage in required information activities.

When we examine the times when patients face difficulties managing health information, we find that often the need for patient work arises while the patient is away from her home, computer, or personal health information collection. For example, while walking through the grocery store, a patient might remember that she needs to ask her physician about a supplement she is considering for chemotherapy side effects. She needs to write this question down before she forgets it, and then add it to the collection of information she is preparing for her next appointment. In other cases, the patient might anticipate an information activity but may not have attentional resources to engage in it effectively. For example, it can be challenging for a patient to understand and write down what the oncologist is explaining when the patient is foggy-headed from chemotherapy drugs and the oncologist is speaking rapidly using unfamiliar technical vocabulary.

We use the term '**unanchored work**' to refer to the full range of such information activities that the patient must do

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without access to sufficient supporting resources. In this paper, we describe how patients undergoing treatment for breast cancer engage in critical, but poorly understood and ill-supported, unanchored information work. Based on repeated in-depth interviews and observations with 15 breast cancer patients, we describe the types of unanchored work that patients do, the causes that lead to the unanchored nature of these information activities, and the workarounds that patients develop to manage unanchored information work. Finally, we outline design directions for technologies that could help to anchor many of these critical activities and greatly ease the difficult work of being a patient.

RELATED WORK

As health-care moves increasingly to outpatient settings, individuals must coordinate their care among multiple clinicians and act as main custodians of their health information. To do so, patients manage a broad range of personal health information that comes in different forms and is fragmented across locations and devices, making its effective management challenging. To support these information activities, Pratt et al [16] have called for a user-centered approach to studying individuals' personal health information management (PHIM) practices. Prior research on PHIM finds that health information management often takes place in shared areas of the home and that individuals maintain specific files and workspaces (e.g., stacks on the kitchen counter or the desk in the study) to manage their health information [14]. Moen & Brennan outline common strategies for managing health information in the home, distinguished by information visibility and importance. The main type of technological support for PHIM activities has been the personal health record (PHRs). These tools, usually web-based, enable patients to have a single location for their medical history, lab results, medications, and immunizations, and often connect to hospital records [10].

While research on PHRs and home-based information management strategies have yielded valuable insights, patients' health information needs when they are away from their computers and home health collections remain largely unstudied. One exception is work on mobile technologies for chronic disease management to enable mobile collection of health-related information (e.g., blood glucose readings, images of food) [6,13]. However, the focus of this work has been on fostering reflection when the user is back at home and in front of her computer, rather than supporting needs that arise under unanchored conditions. The work described in this paper tries to fill this knowledge gap.

With regards to information practices in cancer, prior work has mostly focused on how patients seek information about their illness [9,11]. Recent work shows that these information seeking activities are increasingly moving online, especially among younger patients [18]. Our paper extends this literature by examining other types of information needs inherent in day-to-day work of cancer care management.

Methodologically, there has been a growing realization that the design of effective personal health technologies requires a deep understanding of what individuals do in their role as patients and how their health activities relate to other aspects of their lives. For example, Ballegaard et al [1] argue that healthcare systems are traditionally designed from a "clinical perspective," which focuses solely on what the technology needs to do to improve the patient's health. With this they contrast their "citizen's perspective," which pays close attention to the personal goals of patients and how technology fits within the context of their daily lives. Similarly, Unruh & Pratt [19] suggest that the work patients do during care remains largely invisible. They argue that study of patient work is necessary to increase patient participation, reduce medical errors, improve information provisioning, and design effective health technologies.

Although the emphasis on the clinical perspective is still dominant, there are notable exceptions. In HCI, work on elder care [3,15] has employed in-depth user studies to ground technology design in a deep understanding of elders' daily lives, their caretaking networks, and the needs of both. Similarly, Hayes et al [8] used extensive qualitative work with patients and clinicians to provide an overview of the cancer treatment process and develop design ideas on how pervasive technology can support patients at different stages of care. Our work extends this important research and follows a similar approach to provide a more detailed description of cancer patients' information management needs during one specific stage: active treatment.

Finally, although not specific to health, several studies address mobile capture and use of notes in everyday life [2,4,12]. This work finds that individuals create a large number of 'information scraps' [2] that have a number of functions, including temporary storage, cognitive support, archiving, and reminding. These studies conclude that electronic support for mobile note-taking is promising and that it should focus on enabling lightweight capture as well as flexible representation and organization of content.

It is not known how much of what has been found in the studies of mobile note-taking in everyday life carries over to the health domain. Although the importance of such factors as lightweight capture and flexible organization are likely to hold true, the health setting could introduce additional constraints not found in prior work of other settings. In our work, we take a user-centered approach to explore this issue by providing a descriptive account of patients' unanchored information work. Filling this gap in our understanding of patient work will help to ground the design of supportive technologies that can further help patients play an active role in their health-care.

METHODS

Our findings are a part of a larger study of the breadth of information management work of breast cancer patients. In a six-week field study, we conducted interviews and observations with fifteen breast cancer patients during their

cancer treatment. In this section, we describe how this fieldwork was conducted, who our participants are, and how we analyzed the data for this paper.

Study procedures

From November 2007 through August 2008, we conducted semi-structured interviews and observations with fifteen breast cancer patients. Each participant was asked to take part in two home visits, two telephone interviews, and a clinic observation, roughly evenly spaced over a six week period. Two participants became too busy with their cancer experience to complete the second home interview.

Home visits

We conducted 90-minute interviews and artifact walk-throughs in participants’ homes about how they managed their health information. During the visits, participants showed us their personal health information collections and the tools they used to manage this information. We also used the critical incident technique [5] to get specific information about a salient recent information management task. We audio recorded and transcribed all interviews and photographed the information management artifacts.

Phone interviews

During 30-minute phone interviews, we followed up on issues participants raised during the previous interview and asked them about the information they were managing for upcoming events. As in the home interviews, we also asked about a specific recent information management activity and how exactly the participants handled it. We audio-recorded and transcribed all phone interviews.

Clinic observations

We accompanied each participant to one clinic appointment of her choosing. During the appointment, we directly observed the participant using information and information tools to interact with clinicians. We took field notes and audio recorded and transcribed discussions that took place during the clinic observations.

Participants

We recruited a convenience sample of 15 patients who were undergoing treatment for breast cancer. Participants were recruited with flyers through local cancer treatment centers and cancer support organizations. All participants were women. They ranged in age from 37 to 73 (mean 50, median 51) and were highly diverse in socioeconomic status, level of education, experience with technology, and extent of their support networks. For example, one participant described herself as homeless while another was a retired biomedical researcher with advanced degrees. Other occupations included a grocery checker, a nurse, an acupuncturist, a retired military information specialist, a stay at home mom, a wealth advisor, a consultant, an auditor, an airline professional, and a poet.

Participants’ education ranged from some high school (1 participant) to post graduate (4 participants). One participant had a vocational degree, two had some college, and seven were college graduates. One participant identified herself as Hispanic, one as Native American, and the rest as Caucasian. Eleven participants had breast cancer for the first time and four were experiencing it for the second time. Participants received different treatments during the field study, some more than one type. Eleven participants were undergoing chemotherapy, 7 underwent surgery, 3 were undergoing radiation therapy, and 1 was undergoing hormone therapy.

Analysis

In our analysis, we focused on participants’ unanchored information management work. We created a case report for each participant made up of interview transcripts, field notes, and photographs. The authors worked together to analyze interview transcripts through open coding and iteratively identified emergent themes [17]. Table 1 shows the codes that make up the coding scheme that evolved from our analysis. Once the coding scheme was finally formalized, we used it to recode the interview transcripts.

Code	Definition
Critical information capture	<i>Tracking and recording personal health information when a need arises, often while engaged in unrelated activities away from one’s health information collection</i>
Critical information retrieval	<i>Looking up and referencing critical information when the need arises, often while engaged in unrelated activities and away from one’s health information collection</i>
Life situation	<i>Contextual factors in a patient’s life that shape unanchored nature of her work</i>
Anchoring through environment	<i>Shaping the environment to ground unanchored work (e.g., post-its hung on the wall as reminders)</i>
Repurpose	<i>Use of time, tools, or spaces intended for one purpose of unrelated personal, professional, or health-related work</i>
Collaboration	<i>Receiving help for health information work from other people</i>
Mobile collection	<i>Set of personal health information items taken from place to place</i>
Unanchored implement	<i>Tangible resource used to support unanchored work</i>
Break-down	<i>Problem that occurs due to unanchored nature of work or due to ineffective strategies for unanchored work</i>

Table 1: Coding scheme for unanchored patient work

RESULTS

In this section, we first outline a range of unanchored information work that our participants engaged in during the field study. We then describe the causes of unanchored

work that make this form of patient work so challenging. Finally, we describe the strategies that our participants adopted to overcome these challenges.

Unanchored Information Work: A Brief Sketch

During the course of their treatment, our participants engaged in numerous unanchored information activities to manage their health. These activities do not share one single trait that readily distinguish them from other forms of patient information work. Rather, unanchored work is a result of the circumstances under which patients engage in information activities, such as where the activity takes place. For example, some information needs arose away from home (e.g., in the car) while other unanchored activities took place while the participants were at home but away from their work areas—in the bathroom or in bed.

Unanchored work spanned both *information capture* and *information retrieval*. On the capture side, the following activities were commonly performed in an unanchored way: (1) tracking symptoms and side effects, such as wound drainage and post-surgery pain; (2) collecting information for upcoming clinic appointments, such as questions for clinicians; (3) recording clinicians' explanations and advice during appointments, and (4) capturing information in unexpected situations, such as receiving a phone call from the clinic after a long phone tag.

On the retrieval side, the two most common unanchored activities related to (1) planning and scheduling treatments, appointments, and help (e.g., a ride to the clinic), and (2) retrieving health information at the clinic, such as medical history as well as the medications taken and their doses.

In what follows, we describe the causes that made these information tasks challenging and the forms these activities took during cancer care.

Causes of Unanchored Work

The information activities that cancer patients perform become unanchored due to four main characteristics of the cancer care context: (1) diminished attention, (2) lack of familiarity, (3) necessity for mobility, and (4) inadequate work environments. We explain these factors below, and describe their effects on patients' information work.

Diminished Attention

The need for information capture and retrieval frequently arose when our participants were not in an optimal state of mind. In particular, participants in early stages of treatment experienced a great deal of stress and anxiety that interfered with their ability to focus. After treatments, participants also often experienced side effects (e.g., pain, fatigue, nausea, "*chemo brain*") that affected them both physically and mentally. Diminished attention due to stress, anxiety, and the effects of treatment reduced the ability of participants to concentrate, and to capture and process information effectively.

Recalling and recording information in clinical appointments was one significant area where diminished attention was a major problem. P8 describes one such appointment: "*We had gone over a few questions I had had and it was hard for me to kind of remember what I had wanted to ask.... I was not in a good state of mind to remember all that.*" Replying to physicians' questions could be equally difficult. P4 explains: "*...with the particular drugs I have, it seems to really interfere with my being able to think, particularly if somebody asked me a question and I'm just sitting there like a deer in the headlights just because my brain doesn't seem to process that kind of thing that well.*"

Diminished attention also made it difficult for participants to accurately understand and remember the information that physicians presented during appointments. Unless they immediately captured this information, many of the issues they discussed were soon forgotten.

Outside clinic appointments, the urgency to capture a question or a thought relevant to cancer care as soon as it first occurred was intensified by participants' state of mind. For example, given the importance of clinic appointments, most participants prepared in advance by creating lists of questions to ask and collecting materials such as magazine or research articles to discuss. Capturing this information was extremely important, but their diminished attention made it more difficult. As P4 explained: "*...if you have questions, just write them down. To write them down when you're thinking of them... because for me I'll forget it and I suspect a lot of people are that way too. You have so much on your mind and so many decisions to make and you could be feeling really crappy.* {P4}

Thus, their diminished attention made it vital for participants to be prepared for information capture at any time because they could not count on being able to remember what they needed to write down once they were back at home.

Lack of Familiarity

Eleven participants were first time cancer patients. For this group, the newness of the cancer experience added challenges to their information work. For example, during consultations and other clinical visits, participants were often required to provide a wide variety of personal health information. Examples included: (1) medications they were taking and their doses; (2) medical history, including family history and history of cancer-related issues (e.g., when the cancer was discovered, what tests and consultations the participants had, what etc.), and (3) sequence and severity of treatment side effects. Lack of familiarity meant participants were unsure of what would be required from them, and they sometimes came unprepared to appointments, having to rely on memory. As they progressed through treatment and became acquainted with the operations of the cancer clinic, participants learned what

information they would need during different types of appointments.

Similarly, those participants who knew little about cancer often experienced difficulty understanding what clinicians conveyed during appointments. This situation also made it challenging to recognize what portions of the conversation were most important and what they should record in their notes. As P11 described: *“But then the oncologist came in and holy cow... that’s a foreign world.... It was all completely new and I don’t have a science background and so I was just like oh, what is she saying?”*

This problem sometimes led to misunderstandings that impacted the participant’s ability to make treatment decisions. In one case a participant decided not to pursue care at an excellent regional cancer center after she misunderstand her doctor as saying that receiving treatment there would require her to enroll in a clinical trial.

Necessity for Mobility

The need to record and retrieve information often occurred when participants were away from home or their primary health information collection. Participants thought of questions for their doctors and remembered other issues when they were out and about, in their cars, or at work. For example, P13 carpooled with her sister to work every day, and during this time they often talked about P13’s treatment. Many of P13’s thoughts and questions about her care were generated during these discussions. Being able to record such questions and thoughts as they occurred was extremely important to all of our participants.

Similarly, participants routinely played long phone tag with clinic staff. To finally connect, participants needed to take phone calls at inconvenient times, for example, while running errands or in the car. During these calls participants had to schedule appointments and answer questions about procedures or cancer care history. All this required ready access to their calendars and at least some health information. Thus, they needed to carry this information with them to ensure these interactions were effective.

For a third of our participants, the need for mobile information management was even greater due to their living situation. Two participants traveled long distances for treatment and spent several hours a day in their cars. For them, their car became their primary working space. Three other participants lived part time with friends or relatives while receiving treatment and their health information collection was generally split among different homes.

Finally, analogous information issues arose even when participants were in their homes, but separated from the dedicated spaces where information work was typically anchored. For example, participants sometimes woke up in the middle of the night with a question or a thought they wanted to write down before they fell back asleep and forgot it. Similarly, after surgery participants needed to keep a ‘drain log’ to track fluid that drained from their

wounds. Participants usually emptied their drains in the privacy of their bathrooms, away from their primary collection of health information. Needing to track drain information meant that participants either had to record it in the bathroom or they had to wait until they were back at their desks to record this information. For many, capturing information in the bathroom was the easier option. As P8 explains: *“This is when I got home from the hospital I had those drains and would have to empty the fluid that would come out of them. And we had to keep track of it as far as you know, how much came out, what color it was. You know, just to kind of keep track of how things went... And it just, I kept it [the drain log] up in the bathroom with everything else because that’s where I changed and I didn’t want to go up there, remember and then come down here.”*

Much like information needs outside the home, such situations involved information work while participants were away from their information collections and workspaces where they usually managed their health information. The demands that such unanchored situations created were thus very similar to those when patients were mobile and away from home.

Inadequate Work Environments

Information work was often made more difficult due to inadequate environments in which participants were expected to understand important health information. As noted above, critical information encounters happened during clinical appointments. Yet, those interactions often happened while participants were sitting on an exam table without access to a writing surface and far away from the personal items they brought to take notes. This kind of environment made it harder both to focus on what the clinician was conveying and to record that information. One participant even reported not taking any notes during an appointment because her notepad was in her purse in the corner of the room, and she did not want to interrupt her clinician to get off the exam table to retrieve it. Unruh et al [20] provide more details about challenges of exam rooms as patient workspaces.

Similarly, for participants who traveled long distances for treatment, their car became their primary work environment. P10, for example, drove three hours to get to the clinic. She made and received phone calls to arrange care, took notes, and completed forms all while in her car. If a phone call came in, she would pull over, deal with the situation, and then get back on the road. For her, this way of managing her care was the norm, not an exception.

Finally, a number of our participants lacked technical resources such as fast internet connections, computers, or printers needed for effective information work. This made researching their health condition and available treatments more difficult, requiring them to do this work at libraries, homes of friends and relatives, at work, or over the phone, and to integrate the information they found with their other personal health information at a later time.

Strategies and Workarounds

To do their health information work under such unanchored conditions, our participants developed a number of strategies and workarounds. We describe these next.

Mobile information collections

To make it easier to capture and retrieve information when away from home, when a need arose at an unexpected time, and when they were not feeling well, our participants tried to make their information and information tools mobile. Three types of mobile information collections were particularly common:

Appointment bundles. All our participants created special information collections that they took to clinical appointments. Following Gorman [7], we have termed these task-specific information collections *appointment bundles*. The content of appointment bundles varied by the type of appointment. For consultations with clinicians, for instance, bundles typically included lists of questions, copies of magazine or research articles to discuss, bottles of currently taken medications, and labs or test results relevant to the visit. In contrast, for chemotherapy several participants brought items such as books, crossword puzzles, or portable DVD players for passing time. One participant even brought her taxes to work on during the infusion (Figure 1).

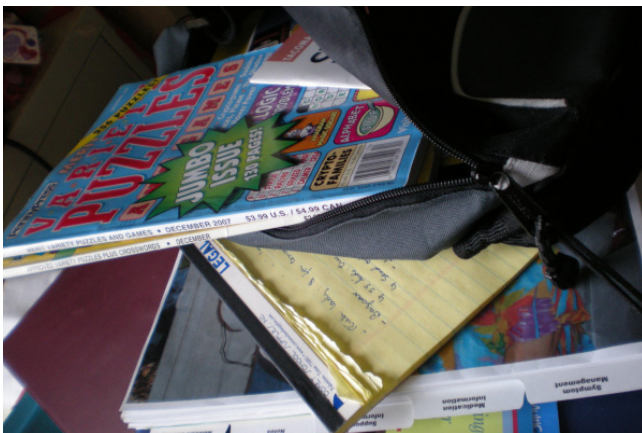


Figure 1: P2's chemotherapy appointment bundle included a question list, puzzle books, her taxes, and her cancer folder.

Appointment bundles were generally constructed over time as participants added to them when they thought of new questions or issues. For example, P8 started with a “patient itinerary,” a clinic-provided schedule of the visit, and then added to it questions that she and her husband thought of over several weeks. When he thought of something, the husband would email the questions from his Blackberry and P8 would add it to her list. Often, such questions were later triaged and revised shortly before the appointment to make sure the question list was current and contained all the important issues the patient wanted to raise. This was typically done a day or two before the appointment and participants often went through their bundles collaboratively with family members. Appointment bundles helped ensure that participants remembered to ask all their

questions, discuss their concerns, and had all the relevant information with them to make the clinical visit as effective as possible.

Mobile reference collection. In addition to appointment bundles, nearly all participants also carried a more general mobile collection of important information. For example, several participants carried a list of the medications they took, since they were “asked that all the time” {P8}. As P12 told us, “always keep a list of all your meds... You might remember the name of the drug but you might not remember individual dosages.” Mobile reference collections took different forms, from pocket calendars stuffed with business cards and loose paper to Blackberries (Figure 2). These collections allowed participants to schedule appointments and coordinate care whenever and wherever the need arose. As we explain in the Discussion, mobile reference collections are very similar to the just-in-time strategy identified by [14] in home-based PHIM.



Figure 2: P3's mobile reference collection included her calendar, business cards, and notes.

Carrying everything. Finally, some participants dealt with not knowing what information they needed and having to spend a large amount of time in transit by carrying entire or large portions of their collection of cancer-related information with them. Several participants who were in the early stages of treatment described carrying their whole collection of cancer-related information (e.g., their “cancer bag” {P15}) with them. This strategy was also common for participants who had to travel or split their time between several residences.

Capture, then Triage

Another common strategy, alluded to earlier, was capturing information whenever the need arose, and then leaving sorting, triaging, and deciding what exactly to do with the information for later when the patient could devote time and resources to information management. Our participants kept note-taking implements in locations where they thought they would need to capture information quickly. At home, notepads were kept in the bathroom, next to the phone, and beside the bed (Figure 3). Participants also carried post-it notes, notebooks, and pieces of loose paper

in their purses so they could be sure to write things down while away from home. Finally, if a need to capture information arose in a situation in which they did not have any of their standard note-taking tools, participants used any scrap paper they could find. These included envelopes, backs of unrelated business cards, post-it notes, and margins of documents unrelated to cancer.

The information quickly captured in this way was later triaged and sorted, transferred to question lists, and added to special purpose collections, such as appointment bundles, when participants had sufficient time, attention, and access to their personal health information collection. The triage process was often triggered by an upcoming appointment, the need to pay bills, or some other similar acute event.

Asking Others for Help

Getting help from others was another common way our participants dealt with the need to do information work while their attention was diminished or they lacked necessary resources. For example, nearly all our participants had taken another person to a clinic appointment. This strategy helped ensure that their questions were addressed even if they did not feel well. It also helped to simply have another set of ears in the room. Finally, those appointment companions often took notes, freeing the participant to focus on the conversation with her clinician. Several participants believed that bringing another person to appointments was absolutely crucial.

Formulating questions and issues to raise in appointments was also often done in collaboration with others. P13 thought of questions while commuting with her sister and talking to a colleague at work who was a nurse. P8 and her husband emailed questions to one another whenever one of them would think of one. Further, P11 explicitly sought advice from other people on important questions to ask: *“I talk to other people to find out what questions they would ask. My sister asked a nurse practitioner if she knew what she would ask related to...what does it mean that this tumor is disappearing and so this woman had some questions related to that that I wouldn't have thought of asking.”*



Figure 3: P4 left a notepad in the bathroom because questions for the doctor often came to her there.

Finally, participants who did not have the resources to do the information gathering due to old computers, slow internet connections, not owning a printer, or simply feeling ill, sometimes asked others to help them by doing research, or letting them use their computers to gather information.

Repurposing Resources for Health

Our participants dealt with the challenges of unanchored work by repurposing resources from other domains of their lives for personal health information management. Doing research about cancer treatments from work is one example of this strategy. However, repurposing extended to various artifacts as well. P11, for example, wrote poetry and always carried her poetry notebook, which she referred to as *“my baby.”* During cancer treatment, this notebook became a mixed-use artifact, containing not only poetry but notes related to cancer as well. She used the notebook, for example, to make and annotate a list of people who might be able to help her get to and from the hospital while she was living away from home for treatment. Similarly, P4 began making notes about cancer in the same notebook where she wrote recipes and practiced watercolor. P12 added the numbers for nurses and clinics to speed dial on her mobile phone, so they would always be handy even if she could not find the business cards or did not have the energy to look for them. In these cases, our participants appropriated information tools they were already actively using and always had with them in order to make unanchored capture and retrieval of personal health information easier and quicker.

Using Environment for Anchoring

Lastly, our participants commonly anchored their work by placing post-its, notes and other artifacts in their environment to act as reminders and for awareness [c.f. 12]. As in prior work, our participants used the environment for anchoring by keeping appointment dates on post-its stuck to the bathroom mirror, leaving medication bottles out to remind them to fill prescriptions, and keeping calendars out in the open for easy access both by the participant and other household members. This strategy made it easier to quickly find information when a phone call came in and remember important tasks and events when participants felt ill.

However, the unanchored context in which our participants did much of their information work meant that this strategy was also used beyond the home. Sticky notes were also kept in the car, and on artifacts that participants carried with them, such as their purses and mobile information collections. Participants who split their time between residences, or even between work and home, often maintained multiple calendars, one for each location. The ease of access and awareness that such calendars provided made it worthwhile to try to keep all of them up to date.

Interestingly, this strategy extended to emotional support as well. Get-well cards were routinely kept out to remind participants that they were cared for, and some participants

even carried such cards or printouts of supportive emails with them to chemotherapy.

Breakdowns

While the strategies that our participants employed enabled them to deal with the conditions of unanchored work, they did not always work. Breakdowns occurred for all strategies that we have discussed. Here we summarize the types of breakdowns we observed.

Even though our participants carried different types of mobile information collections with them, they did not always have all the information they needed. For example, P13 discussed how she needed to make treatment-related phone calls from work, but could not since the contact information she needed was in her cancer binder at home. P15 describes getting “yelled at” by a clinician for not bringing all her medication bottles to her appointment. In spite of preparation, not all needs could be anticipated.

Capture and triage can fail as well. Our participants sometimes took notes that they later failed to find or interpret. This was often due to jotting down a note on an unrelated item (e.g., on a business card for a chiropractor) or cramming too much into a small space (e.g., in margins of a date in a pocket calendar). Furthermore, the triage process sometimes just did not happen after information was successfully captured.

Even bringing another person to an appointment can fail. P11 describes bringing her sister to an appointment and then having an argument with her later about a point they understood differently. In the absence of a recording or a third person, it can be difficult in such situations to determine who heard the information correctly. Finally, notes get misread or forgotten even if they are in plain view. P4 describes, for example, thinking that a meeting was on a different day even though the right date was clearly written on a note posted on her bathroom mirror. Diminished attention can make it difficult to process even information designed specifically for that purpose.

DISCUSSION

Our analysis of unanchored work extends prior research on PHIM and mobile information management and points to design directions for technologies aimed at facilitating patients’ personal health information work. We discuss these contributions of our work below.

Characterizing unanchored information management

Our description of patients’ unanchored work contributes to our growing understanding of patients’ needs. Our findings extend PHIM research by broadening the scope of investigation to incorporate a class of vital yet previously understudied activities that individuals do as part of personal health management while away from home. At the same time, we show that mobility is just one of multiple conditions that can make information work ‘unanchored’ for patients. Other factors, including diminished attention,

unanticipated needs, and inadequate work environments lead to similar problems and practices. We thus conceptualize the whole class of such information practices as unanchored patient information work.

Our findings also shed additional light on the strategies identified in the research on health information management in the home [14]. We found that during cancer care, the just-in-time information management strategy can be heavily influenced by information needs that arise at unexpected times and places. Moreover, our work shows that in complex health situations, such as cancer, the just-in-time strategy appears to be employed with a significantly broader range of information than is observed in the general patient population. The mobile reference collections our participants carried contained far more than insurance cards and emergency information, such as allergies. These collections included business cards (often a host of them), medication lists, pathology reports, as well as scheduling information. In addition, special purpose collections, such as appointment bundles, can be viewed as a form of just-in-time collections as well, albeit ones that need to be right there and quickly accessible just in specific situations.

The uncertainty surrounding what information will be needed also meant that our participants routinely applied the just-in-case strategy as well. With many participants this strategy manifested in the form of a “*cancer bag*” {P15}—a bag with a larger set of cancer-related information which they also carried to some clinical appointments. For the participants who traveled for treatment or had split living arrangements, however, the strategy could also manifest in keeping their entire personal health information collection in the car.

Our research also confirms the importance of lightweight capture identified in the work on mobile note-taking in everyday life [2,12], as well as the importance of flexibility of information organization afforded by electronic note-taking systems [4,12]. However, as we discuss below, our findings show that note-taking and other quick capture in the context of health-care requires more functionality—primarily functionality around integration with health information—than general purpose mobile note-taking tools currently offer. These criteria suggest that supporting unanchored patient work will probably require at least some dedicated applications (privacy considerations related to having health information on a mobile device point in the same direction). It is quite possible, on the other hand, that some of the same features needed to support unanchored work of patients could prove useful in other domains as well. For example, smooth integration of information across different information collections and flexible conversion of data into different types on the fly seem like they could be useful in many different situations.

Designing for Unanchored Information Work

As we have seen, although our participants developed a number of strategies for dealing with the problems of

unanchored information work, those strategies often proved insufficient. Notes get misplaced, what a doctor says is misremembered, and not all information is there when the patient needs it. The breakdowns in these potentially critical activities suggest that there is a need for supporting patients' information work in unanchored settings.

Existing technologies for personal health information management focus almost exclusively on anchored information work—the work that individuals do while sitting at their desks and in front of their computers. Personal health records (PHRs) are the most prominent example of such technologies. PHRs allow individuals to keep all of their health information in one place, automatically import data about procedures, tests, and lab results, and, if the PHR is controlled by the patient, to keep ownership of the health record even if they change providers or move across the country [10]. Yet, PHRs and other common health information technologies (e.g., web sites like WebMD or applications for tracking fitness) do little to help with the kinds of unanchored work that our participants needed to do.

Our findings suggest six design elements for effective support for unanchored patient information work. First, tools for unanchored patient work should support *easy capture of a range of more informal information* than what health information has traditionally been taken to mean. Participants wrote down questions, notes, and to-dos, kept track of phone calls, jotted down names of supplements, and tracked who would take them to chemotherapy or help them with household chores. The highly structured data model of traditional PHRs is poorly suited for such information. Applications that support unanchored patient work should enable quick capture of free text notes, lists, images, and to-dos—information types that better match what patients do every day as they manage their care.

However, when participants needed quick access to this data, it was often alongside more traditional, structured health information. During an appointment, for example, a patient might need to access both her questions and notes, and her medication list and test results. Moreover, some of the questions and notes were explicitly *about* medications, test results, and other traditional health information. This suggests, second, that support for unanchored work requires *smooth integration between informal data, such as questions, and notes and traditional health information*. Mobile access to a PHR is not enough; but neither is a simple notes application on a mobile phone. Unanchored patient work requires that various types of data can be related to one another, and that these relationships can be both formulated at the time of capture and used as a means of retrieval. What this means is that mobile health applications should support creation of explicit links between various bits of information, and that linking should span the full range of information types, from formal health information to pictures and to-dos.

Third, our participants' efforts to create mobile reference and special purpose collections, such as appointment bundles, suggest the need for the *ability to flexibly create subsets of information*. The user should be able to act on these sets of related information as a unit—for example, bringing up all notes, images, and questions connected to an appointment just by opening the appointment. Since at least some of the information in these mobile bundles is used repeatedly (e.g., a medication list can be a part of both an appointment bundle and a mobile reference collection that the patient carries all the time), the application should support linking of information items or collections to multiple other such items. Similarly, since patients often create similar collections (e.g., appointment bundles), the application should provide collection templates that can easily be customized to specific needs.

Fourth, since patients often know the purpose for which information is being captured (e.g., a question for an upcoming appointment), it would be helpful to *enable information linking and collection creation at the time of capture*. Adding a question to an appointment right from the mobile device, for example, would at least to some extent reduce the need for the breakdown-prone triage process. On a mobile device, such linking could be enabled through either auto-complete lists of the user's other information or through free-text tagging that is interpreted by a server back-end. In either case, the emphasis has to be on the speed and ease of information entry.

Fifth, our participants routinely annotated their information, turning notes into to-dos, attaching notes to calendar entries and business cards, and using different symbols to indicate different stages of progress on a task. *Making it easy to change the role of a piece of information* would make a system for unanchored work much more useful. Enabling users to select a piece of text and assign it to a question list or turn it into a to-do would make it easier for patients to do process and reflect on their information.

Sixth, since unexpected needs arise, a mobile system for unanchored work should *allow searching and on-demand access of the user's larger information collection* beyond the mobile bundles the user created. This suggests a need for an always connected mobile system and some form of server-based back-end, rather than relying on desktop applications and local synchronization. Even though this is the general direction in which technology is moving, this implication—as well as the larger issue that health information would be located on mobile devices that are easily misplaced or stolen—introduces important privacy considerations that should be seriously considered. Mobile devices get lost; a phone is often seen or used by another person. Such circumstances suggest that health applications should be both separately protected from the general security model of the device itself, and that their integration with the more general purpose applications such as the calendar needs to be carefully thought through.

Finally, even though technology promises to greatly ease unanchored information work of patients, our data suggest that paper is unlikely to go away in the foreseeable future. This is not only because much of the information that patients receive in the course of their treatment is on paper—business cards, printouts of chemotherapy appointments, etc.—but also because arguably paper is still better suited for some contexts in which patients do their information work. We suspect that drain logs and questions jotted down in the bathroom are still more likely to be done on paper, as are notes jotted down in the middle of the night. However, in many contexts a technical system could be of great help, and even an incomplete solution could substantially ease a critical but difficult aspect of the work that patients have to do to manage their health.

Limitations

While we believe that our work yielded valuable findings about information management practices of cancer patients, we need to acknowledge its limitations. Our sample included only women and only breast cancer patients. It is an open question how much of what we observed generalizes to a larger population of cancer patients or patients with other health conditions. In addition, although we tried to get an accurate picture of our participants' practices, our reliance on interviews makes it possible that some recall bias has colored our data. Future work will, hopefully, triangulate our findings using different methods.

CONCLUSION

In this paper, we described an aspect of the often invisible information work that cancer patients do as part of their care. We make two chief contributions. First, we provide an account of critical unanchored information activities that patients do during treatment and that have remained poorly understood and largely unrecognized by health information management research. Further, we describe causes that make these activities particularly challenging to patients. Second, we describe a set of guidelines for the design of systems that could significantly ease these challenging unanchored information activities. Such technology, we believe, could have a profound impact on patients' lives, freeing more of their time and energy to focus on things that truly matter: their loved ones and getting better.

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