

Transforming Clinic Environments into Information Workspaces for Patients

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ABSTRACT

Although clinic environments are a primary location for exchanging information with clinicians, patients experience these spaces as harsh environments to access, use, exchange, and manage information. In this paper, we present results from an ethnographic-inspired study of breast cancer patients actively interacting with information in clinic environments. Through observations and interviews, we observed information interactions in awkward physical positions; inefficient use of existing clinical space; separation of patients from their information and lack of support for collaborative document viewing. These factors compromised patients' abilities to manage their information work when they experienced bursts of information exchange, lack of advance information, fragmented attention, and heightened stress in clinic environments. To overcome these challenges, we identify formative strategies to focus attention, encourage collaboration, and improve communication in clinical settings.

Author Keywords

Workspaces, personal health informatics, collaboration, CSCW, surface computing, medical informatics

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. J.3 Life and Medical Sciences: Medical information systems

General Terms

Design, Human Factors

INTRODUCTION

Going to the doctor is a major health activity. For example, United States residents attend 1.1 billion outpatient visits to the doctor annually [26]. Medical advances have made hospital stays shorter and specialty care done in the

outpatient setting has increased. In the domain of oncology, many patients who are undergoing active treatment spend the majority of their time away from the clinic without immediate access to their clinicians. This time away from the treatment center is punctuated by visits to the treatment center and bursts of information exchange with their clinicians. These visits occur in clinic environments, such as exam rooms and treatment areas.

When patients enter clinic environments, they are expected to access, use, learn, communicate, and remember information while interacting with their clinician. Despite these expectations, clinic environments have been designed without adequate understanding of patients' work—particularly their information work—necessary to meet these expectations. Although we see the results of patients' work (e.g., questions asked, information about side effects communicated, treatment plan placed in purse) we do not see the work itself. Thus, patients do what Star and Strauss call background work: a type of invisible work where “the workers themselves are quite visible, yet the work they perform is invisible or relegated to a background of expectation” [30]. To lift the veil from patients' information work in clinic environments, we report results of an observational study of breast cancer patients in exam rooms and treatment areas during active cancer care.

PATIENTS AS UNDERSTUDIED ACTORS IN CLINIC ENVIRONMENTS

Recognizing the influence of physical environment on clinical workflow, researchers study clinic environments to identify and remove barriers that impede clinicians' work [14,22]. For example, by re-designing patient-care rooms and installing acuity-adaptable beds in a cardiac care unit to accommodate a range of cardiac services—from coronary critical care services to coronary step-down services, Henrich et al. [13] dramatically improved nursing workflow. Findings demonstrated 90% reduction in patient transports, 70% reduction in medication errors, and improvement in patient satisfaction with clinical care. From a patient's perspective, studies of clinical settings have largely focused on stress [29], noise [1,6], and aesthetics [24] of clinical environments. For example, one well-known study suggests that rooms with a window to the outside may influence recovery from surgery [32].

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CHI 2010, April 10–15, 2010, Atlanta, Georgia, USA.

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Researchers also have investigated patient-physician communication in clinical settings. Medical studies document the challenges of remembering information after clinical interactions. Relying on memory alone is not a viable strategy because patients remember as little as 50% of what clinicians tell them during clinical encounters [17]. Yet, when patients are provided with recordings or notes from a consultation with their clinician, at least 60% of patients read or listen to those materials [23]. Within medical informatics, studies of how technology in clinic workspaces influences patient-provider communication were prompted by the introduction of computers into the exam room [9,25]. Frankel et al. [9] described how the technology created a barrier to communication when the screen was visible only to the clinician, but could become a shared artifact if the screen was re-oriented so the patient could also see it. Technology has been envisioned that would facilitate discussion between patients and clinicians during a consultation by enabling shared multimedia health information and interactive tools [31]. Yet, no studies have taken a deep look at patients' information work in clinical environments or how these environments support or inhibit that work.

Studies have been done of patients' information work outside of the clinic, examining what patients do in their everyday lives to manage their health and how their efforts can be supported [20]. For example, Frost and Smith [10] suggest that when diabetics supplement the blood sugar levels they collect with pictures they take of their dietary behavior, the reasons for shifts in their blood sugar levels are made more apparent. Mamykina et al. [19] highlight the value of having patients monitor their routine dietary activities and then share those records with their clinicians to encourage reflective thinking about their dietary choices. Other research looks at supporting the needs of the elderly and their family care-givers. For example, Consolvo and Towle [7], by observing *in situ* interactions between elderly and their family caregivers rough home-based ambient displays, identified a range of unsuspected dynamics and contextual factors that such technology must accommodate. Lastly, other researchers highlight the critical role that supportive technologies can play in the day-to-day lives of patients for both routine personal health management [20] and for critical health problems, such as cancer [12].

In contrast to most studies done within clinical settings, the above studies examine patients' needs by interacting with patients directly rather than (a) relying on secondary measures (e.g., patient satisfaction) or (b) focusing largely on clinicians' work and workflow to improve patient care. Although this user-centered approach to studying patients has not been widely adopted in the field of medicine, researchers in the design community have called for active study of patients and their needs [3], especially in clinical contexts [4].

Adopting this user-centered perspective of studying patients, but in clinical environments, we answer two

questions: (1) What is it that patients actually do—or try to do—to maximize their work in clinic environments such as exam rooms and treatment areas? (2) What are the implications for design directions to improve patients' capacities to work in clinical environments?

Answering these questions will help us devise new ways to support a patient's ability to access information, learn, and communicate in clinic environments and thus enhance their ability to understand and play an active role in their care. We begin by describing our study context and methods. Then, we describe our findings in three sections: (1) challenges preparing for clinic visits (2) clinical environments as harsh information workspaces for patients, and (3) post-visit challenges. We end by discussing three design directions to mitigate the challenges of information interactions in clinical environments.

METHODS

Through flyers and word-of-mouth, we recruited a convenience sample of 14 patients (referred to as P1, P2, etc.) actively undergoing treatment for stage 0 to stage 3 breast cancer. At the time of the study, patients were undergoing surgery, radiation or chemotherapy treatment. Participants ranged in age (37-73) education (no high school diploma to post-graduate degree), career (unemployed, blue-collar and white-collar jobs) and socioeconomic status. Thirteen (13/14) participants described themselves as Caucasian.

We followed each participant for 6 weeks through multiple methods as part of a larger study of personal health information management. For each participant, we conducted an initial home visit, two telephone interviews, a clinical observation, and a final home visit. During the home visits we conducted in-depth interviews and artifact reviews (e.g., personal notes taken during clinic appointments) to document patients' experiences in clinic environments. We conducted 30-minute telephone interviews between in-person contacts (e.g. home visits and clinic observations). The spacing of the home visits and telephone interviews allowed us to probe issues related to clinic appointments over time, capturing information activities before, during, and after clinic observations. We asked open-ended questions (e.g., 'How will you prepare for your next appointment?') and probed patient-raised issues specifically in subsequent interactions (e.g., 'How well did your question list work during your appointment?')

The observations occurred in exam rooms and chemotherapy infusion areas. We audio recorded the communication, recorded field notes, sketched the physical environment, and took pictures—as appropriate—during observations. Transcripts of observations were time-stamped. We also conducted post-observation debriefings to clarify and extend observational findings as part of the observation. These debriefings occurred in ad-hoc locations (e.g., exam rooms while patients waited to be seen, waiting rooms after appointments, hospital coffee shops).

Transcripts of exam-room communication and post observation interviews and field notes were analyzed for barriers that inhibit patients' information interactions during clinic visits as well as information activities that occurred preparing for and following up from clinic visits.

CHALLENGES IN PREPARING FOR CLINIC VISITS

Patients emphasized the importance of interaction time with their clinicians during clinic visits. They conceptualized clinicians as interactive, expert resources who were critical to their current and future health, but to whom they had limited access. For example, P4 emphasized how these clinical interactions were *"very important"* because *"there's a limited period of time that I get to spend with them [clinicians]."* Clinic environments—either exam rooms or chemotherapy infusion areas—became the default setting in which these interactions occurred during active cancer care.

Patients prepared in advance to maximize their interaction time with clinicians. As P2 explained, *"when I went into the doctor to talk about [her health status and potential treatments]...I'd be armed with a little bit of information."* The better she could prepare, the more she could get out of the interaction.

Acknowledging the importance of working together with their clinician, patients provisioned information for clinicians in advance. Patients created lists of questions they wanted to ask because, as P4 noted, *"for me I'll forget [the questions when] I'm just sitting there like a deer in the headlights just because my brain doesn't seem to process [it]."* Patients compiled personal health histories and health status reports to update clinicians on their evolving health status while away from the treatment center. Patients who received care from multiple clinicians compiled updates on care procedures and recommendations they received from other providers involved in their care. The general perception was that in a distributed system of cancer care, patients were responsible for ensuring the continuity of their own care because clinicians do not always have a complete view of patients' health and treatment status.

Patients also developed strategies in advance of appointments to reference and capture information during clinical interactions. They typically compiled portable 'bundles' of information that contained three types of artifacts (1) questions to ask, (2) information to provide clinicians, and (3) paper and pens to capture portions of information exchange for future reference. Patients like P3 and P13 pursued a different strategy for information capture. They arranged to bring another person along to their appointment to help them remember what was discussed or to take notes for them. We returned to these strategies throughout the results and discussion sections.

CHALLENGES DURING THE CLINIC VISIT

Given these strategies, how well could patients leverage information to maximize their interaction time with clinicians in clinic environments? None of the 14 patients in our study implemented all of their information

management strategies well all of the time. During our observations, we identified two sets of challenges that inhibited patients' capacities to use information effectively while interacting with clinicians in clinic environments: (1) physical challenges of clinic environments and (2) demanding characteristics of patients' information work in these settings.

Physical Challenges of Clinic Environments

Our findings point to four types of challenges of clinic environments that interfered with patients' abilities to carry out their important information work in clinic environments. In this section we detail these challenges from the patients' perspective, using anonymized photos, field-note sketches and illustrative quotes from participants.

Interacting with Information in Awkward Physical Positions

While clinicians used desks and counter space to lay out their information, patients had no such space for managing their information. Consequently, they struggled to carry out their information work in awkward physical positions. We identified four ergonomic poses in which patients conducted their information work.



Figure 1. Upright exam table pose

The first pose was the 'upright exam table pose' (Figure 1). For example, of her 60 minutes on the exam table, P8 spent 57 minutes sitting upright on the exam table while different clinicians cycled through the exam room. Balancing her question list and her pencil on her lap, P8 attempted to maintain eye contact with clinicians, record notes, communicate with hand motions, track her list of questions, and collect documents—which she held in place with her thigh—from clinicians.

The second pose was the 'reclining exam table pose' (Figure 2a). For example, between exams, P1 laid back on the exam table to review documents in preparation for her impending discussion with her surgeon: *"the closer the proximity to reading the document to the actual discussion of the document, the better the result is [for] personal communication."* After several minutes, her hands and arms began to shake from holding up the papers. Moreover, she lacked easy access to annotation functionality, stating that

she should have had a pen and a surface to write on because, “*I think that’s a better form of document review.*”

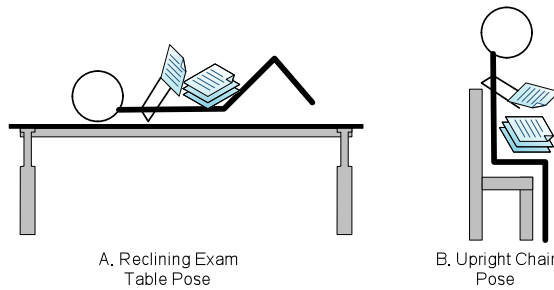


Figure 2. (a) Reclining exam table and (b) Upright chair pose

The third pose was the ‘upright chair pose’ (Figure 2b). For example, during her 60 minute pre-mastectomy consultation, P3 sat in a chair asking and answering questions, referencing her calendar, and tracking her question list in her notebook. In the midst of dialog—and holding multiple papers on her lap—P3 fumbled through her handbag to retrieve her calendar to reference precise appointment dates to aid discussion of her treatment plan.

The fourth pose was the ‘reclining chair pose’ (Figure 3). For example, while balancing her lunch and papers on her lap and side-tray, P13 underwent chemotherapy treatment, received and reviewed a copy of her lab results, queried her clinician about her test results, discussed emergent side effects, underwent an examination to determine extent of deterioration of her toe nails, and discussed a plan to monitor and manage the side effects with her clinicians.



Figure 3. Reclining chair pose

Separation of Patients from Their Information

The alternative to handling calendars, notebooks, and papers in awkward positions is to position them elsewhere in the room. However, placing these information resources elsewhere separated patients from their information during clinical communication. Thus, patients either (a) conducted communication with their clinician without the benefit of their information artifacts, or (b) broke their attention with ongoing information exchange to retrieve their out-of-reach information artifacts. Examples of the latter case included:

- **Retrieval from counter top:** In the midst of responding to questions from an oncology nurse assessing the patients’ current health status, P9 reached precariously over from the exam table in an attempt to reach her notebook (Figure 4). After teetering on the edge of the exam table, she obtained the notebook but only after it fell to the floor in the process.



Figure 4. Retrieval from counter top

- **Retrieval from floor:** With no obvious location to place her briefcase that contained material she prepared to reference, P1 set it on the floor next to the exam table. Midway through the consultation, P1 breaks her attention with the surgeon to retrieve her pathology report and question list.
- **Retrieval from hook behind door:** While receiving an unexpected treatment recommendation, P14 jumps off the table to retrieve her calendar and notebook located in her bag hanging from a door hook. She took significant time to re-settle herself to take notes. The clinicians’ explanation of health status and treatment options continued without pausing.

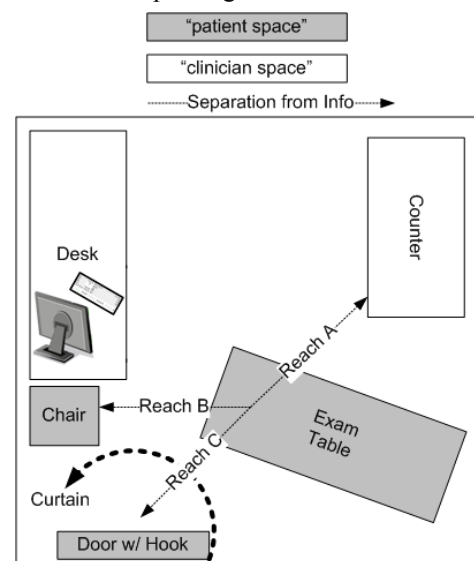


Figure 5: De-facto division of space

Inefficient Use of Space

We observed that all 14 patients used only a small portion of available space in clinic environments. Whether based on instructions from clinic staff or social norms, patients occupied chair(s) and the exam table, whereas clinicians utilized desks and counter space. Figure 5 illustrates the de-facto division of space that we observed. Despite the presence of flat surfaces for writing and internet-enabled computers, patients and their family members interacted with information in constrained spaces in awkward physical positions. Even when chairs were placed next to counter-tops which could be used as a writing surface, they only accommodated either left-handed or right-handed patients, but not both.

Lack of support for collaborative document viewing

Recognizing the importance of visual information to clinical explanations and collaborative problem-solving, patients and clinicians tried to work with documents together. Constrained by space, they struggled to position themselves and documents for collaborative viewing and interaction. For example, we observed:

- P1's surgeon perched on a stool, straining to hold documents in the air, pointing to illustrate his points, and drawing diagrams upside down so they would be right-side up to explain detailed surgical options for P1 and her husband.
- P9 squinted over her clinician's shoulder at a small screen as her clinician demonstrated—via hand and mouse movements—how to navigate an NIH-funded website relevant to her question.
- P15 was pleased that her surgeon illustrated his clinical logic on paper—*“he gave it to me a lot more thorough [than oral presentation]”*, but had difficulty viewing the document upside down while the surgeon illustrated his verbal points.

Demanding Characteristics of Patients' Information Work in Clinic Environments

The physical challenges represent only one facet of the problems patients encountered interacting with information in clinical environments. Another important facet is the demanding characteristics of the information work that patients need to perform in clinic environments. These characteristics exacerbated their problems interacting with information. These characteristics must be considered before new technology can be designed to help patients carry out their work in clinic environments. In this section, we detail these characteristics and describe the negative impact they have on patients' abilities to carry out their important information work.

Bursty Nature of Communication with Clinicians

A key characteristic of patients' information work in clinic environments is 'bursty' communication with clinicians. Patients experienced bursty-ness in two forms. The first form is the sheer speed of information conveyed during oral conversation. We observed how patients encountered bursts

of highly technical information at rates upwards of 200 words per minute. For example,

- P5's medical oncologist explained the plan to mitigate side effects of treatment at 195 words per minute.
- P11's surgeon detailed available knowledge of her current health status and recommended procedures at 200 words per minute.
- P12's medical oncologist presented details of a clinical study for which she was eligible, at 210 words per minute.
- P14's surgeon described clinical treatment options, including the option of enrolling in a clinical trial, at 204 words per minute.

The rate at which patients received this information exceeds normal conversational rates (i.e., 125-175 words per minute) and also exceeds recommended instruction to ensure comprehension [34]. Unfortunately, as the amount of information clinicians convey increases, so does the amount that patients forget [17].

The negative impact of these bursts of information was painful to observe. For example, P14 radically misunderstood the treatment options presented to her. She eventually refused treatment at that institution because she was convinced that the only way she could be treated there was to enroll in the clinical trial being described to her: *“I ain't gambling with my boob... I don't like the radiation lottery.”*

The second form of bursty-ness is the quickness with which clinicians enter clinic environments—where the patient is waiting—and commence information exchange with patients. We observed a repeated pattern where patients sit an exam room, hear a knock at the door, and were immediately engaged by a clinician on oncology topics with little ramp-up time. To illustrate, consider the following exchange between P11 and her clinician that occurs suddenly after a 9-minute wait in an exam room.

[knock at door & clinician enters]

Clinician: *Hello.*

Patient: *Hi, how are you today?*

Clinician: *Good, how are you?*

Patient: *Who are you?*

Clinician: *My name is [name removed]. I'm one of the oncology fellows working on the team. I'm going to talk to you and examine you and then [another clinician] will come in. So I had a chance to look what has been happening, what the left side of breast cancer and it was node positive and it was, estrogen receptor positive and HER-2 negative, Nottingham 3[inaudible] seeing you for neoadjuvant CMF which is chemotherapy -*

Patient: *Okay, before neoadjuvant, what did you say? I missed it entirely.*

Although the rate of communication in this exchange occurs at a manageable conversational rate, P11 still has trouble ‘catching up’ to the conversation. The clinician had been reviewing her information outside of the exam room and was well-prepared for a quick entry and launch into a detailed discussion of the patients’ health status and treatment. In contrast, P11 was in a kind of resting state in the exam room. She tried—but failed—to keep up with the initial conversation in the context of the unpredictable entrance of the clinician. P11 also lacked information about how the conversation would start and which clinician(s) she would see.

Lack of Information before Entering the Clinic environment

The second characteristic of patients’ information work is the lack of information before entering clinic environments. Patients’ capacities for managing bursts of communication were negatively influenced by lack of information prior to entering the clinic environment. Without knowledge of what specific information would be discussed, patients operated in reactive—instead of proactive—modes of interaction. Consequently, patients experienced:

- **Unexpected requests to recall information:** In response to the question: “How much Cytosin are you taking?” Unprepared, P11 responded: “Um, I don’t remember what it is.” Nurse asks P11: “400 [mg]?” Laughing nervously, P11 says: “I don’t even know.”
- **Inability to prepare:** P7 explained how she could not prepare for her appointment with her oncologist because: “this isn’t an area I have any expertise in at all and I’m not even sure what’s appropriate [to ask or discuss].”
- **On-the-fly information seeking:** Without knowledge of what would be discussed in advance, P7 noted that “questions will just sort of come out of just being there and listening to [oncologist] and answering her questions. That’ll trigger other questions.”
- **Unexpected switching of clinicians:** P4 noted how her oncologist and the nurse “switch back and forth.” Although they played different roles in her care and she targeted topics specifically for her oncologist, he sometimes “just walked in” unpredictably.

Fragmented Attention and Distractions

Patients’ capacities for managing bursts of information exchange were further complicated by multiple, concurrent activities unfolding in the clinic environment. Specifically, patients experienced fragmented attention when attempting to:

- **Receive instructions, reconstruct past events, and answer questions while undergoing physical exams:** For example, P11 attempted to respond to questions about her treatment schedule and medication refills, receive detailed instructions on side effect management, and

discuss treatment options and upcoming diagnostic tests while undergoing a physical exam.

- **Tracking and recording information while concentrating on communication with clinicians:** For example, we observed P8’s ongoing attempts to focus on verbal information exchange with her surgeon, while simultaneously tracking a checklist of her questions and recording notes in a notebook held in her lap (see Figure 1). Post-observation analysis of her checklist revealed that she failed to track her agenda consistently. Specifically, P8 failed to check off some items the surgeon addressed and checked off other items even though they were not addressed. After the surgeon left, P8 exclaimed: “I forgot to ask [breast surgeon about] my bandages.”
- **Scanning and referencing material during clinical assessments:** For example, we observed P9 fumbling with her notebook and flipping pages while trying to answer specific questions about treatment dates, current medications, and side effects. In a post-observation debriefing immediately after this interaction in the exam room, P9 admitted to multi-tasking: “No, I wasn’t actually looking [for details about health history]... I was actually looking for my note page when she was [asking] about the dates... I wanted to have my questions ready to ask... I was moving on my questions, not hers.”

These findings are problematic because fragmented attention (e.g., task switching between listening, note-taking, tracking agendas, reaching for information) reduces that amount of information that is assimilated and later recalled [5].

Heightened Stress Associated with Clinic Environments

Patients sometimes experienced heightened stress when interacting in clinic environments. Patients described stress in relation to a wide variety of factors including the physical environment itself and activities—such as physical exams, discussion of sensitive topics, or delivery of ‘bad news’—that occur in this environment. Through observations and interviews we documented how patients experienced stress associated with:

- **Anticipatory anxiety:** P1, a CEO of a financial services firm, described how “you walk into an appointment already scared, already having half convinced yourself that the worst is about to happen...you can’t listen as fully... the stress of being in these meetings, even for someone like me that functions well in high stress environments, whoosh.”
- **Unexpected information:** The hands and arms of P14, an airline professional, shook (she was visibly upset) as she heard the unexpected news that she would require radiation in addition to surgical treatment, while she tried to listen and take notes on the exam table.
- **Unpleasant surroundings:** P9, a small business owner, noted the challenges of communicating in an exam room:

“It’s kind of sterile... And you’re in a gown... You start feeling like a piece of meat.”

- **Time pressures:** P4, a registered nurse, —said *“I have to be quick and I better know what I’m talking about because they only have so much time to spend with me and so I think I get a little more anxious, maybe a little more flustered or nervous probably.”*

These perceptions of the clinic environment as a highly-charged and stressful atmosphere further exacerbate known challenges of processing information conveyed by clinicians, such as anxiety [18], level of technical language [15], and treatment side effects, such as “chemobrain” [11].

POST-VISIT CHALLENGES

Given the constraints of the physical environment and characteristics of patients’ information work, what were the impacts on patients after returning home? During post-observation debriefings and subsequent interviews, we documented the downstream impacts of trying to do their information work in harsh clinical environments. For example, we documented:

- **De-contextualized notes:** Asked to explain her notes, P11 couldn’t remember why she had recorded information about a genetics book in her notes from her doctor’s visit. Did the doctor recommend it? Was there a particular chapter to look at? How did this book relate to her specific health condition?
- **Information fragments:** Reviewing her notes at home with the interviewer, P2 realizes that she took notes on multiple scraps of paper that were hard to keep together after she left the appointment.
- **Unanswered questions:** P8 was leaving the treatment center when she realized she forgot to ask an important question about how to manage her surgical drains embedded in her body.
- **Conflicting Memories:** Debriefing at home, P4 and her friend discovered that they remembered the doctor saying different things about P4’s treatment regimen.
- **Needs for clarification & new question formulation:** P11 noted how *“it takes a lot to process it so I don’t even know if I have a question related to it [until later]...I need to get back in touch with her to ... make sure I understand the information about the probability of ...these other [genetic] mutations.”*

As researchers, we watched these impacts unfold in clinic environments. However, the patients usually didn’t identify them until after they returned from the treatment center. Thus, they were left with the responsibility to fill in the information gaps for themselves or to make phone calls to the clinic to request additional consultation.

DESIGNING EFFECTIVE INFORMATION WORKSPACES

How can we transform clinic environments into effective information workspaces for patients? Although we identify two obvious solutions—(1) physical re-design of clinical environments and (2) increasing the number and duration of

clinical appointments—we believe these solutions are impractical. Instead, we propose technology-based design directions based on common information spaces, surface computing, and meeting capture to focus attention, encourage collaboration, increase preparation, and improve information interactions given existing constraints. In addition, we suggest strategies to mitigate—either directly or indirectly—the challenges patients’ encounter in clinic environments, including fragmented attention, lack of advance information, and the negative impact of emotions on information interactions.

Common Information Spaces for Bridging Perspectives

Effective information interactions in clinical environments require a shared patient-clinician perspective on what and how information is discussed. Researchers in the field of CSCW note that cooperation of different actors requires the construction of a common information space where information and expectations are shared [28]. Adopting the concept of common information spaces helps to guide design thinking because it (a) reframes the challenges patients encounter in clinic environments in terms of clinician-patient collaboration, (b) acknowledges the challenges of fostering shared knowledge and problem-solving efforts among actors distributed across space and time, in this case patients who spend the majority of their time away from the treatment center and interact only periodically with clinicians, and (c) encompasses design solutions that leverage the interaction space before, during, and after appointments to maximize face-to-face interactions.

To support a common information space between patients and their clinicians, we propose three design directions to mitigate specific challenges. First, to improve patients’ access to advance information and reduce the impact of bursty communications about unexpected topics, we propose a suite of lightweight applications to facilitate collaborative agenda creation and management. Prior to appointments, patients and clinicians could push agenda items and relevant information to a shared application space. Patients and clinicians could use this information to prepare, thereby reducing the reactivity patients experience and maximizing information exchange during the appointment. This feature capitalizes on—and extends—patients’ ongoing efforts to prepare by facilitating awareness of patient and clinician actors’ agenda and information prior to face-to-face interactions.

Second, to improve information sharing and collaborative document viewing during appointments, we propose strategically-placed interactive displays to integrate data from different sources and make information visually accessible in constrained exam-room environments. For example, collaborative agendas prepared in advance could be pushed automatically to large displays within the clinic environment, thus increasing shared responsibility for the agenda, minimizing patients’ anxiety associated with communicating their concerns, and reducing patients’ urges

to multi-task (e.g., monitor the progress of their agenda while listening) during clinical communication. Further, patients and clinicians could continue to co-create information drawn from in-house clinical medical records (e.g., treatment plan) and personal health records (e.g., side effect trends) to align their two perspectives of the patient's health status and treatment plan. Thus, interactive displays extend the virtual common information space into clinical environments, bridging perspectives across pre-visit preparation and in-situ information access during the visit. Building this feature set requires surface computing strategies for collaboration.

Third, to free patients from the burden associated with learning and recording new information during intense clinical interactions, we propose systems to help patients clarify information after they return home. Using a common information space especially designed for this purpose, patients could review information and post targeted follow-up questions with clinicians. The questions could be contextualized with explicit links to supporting information captured from the information exchange in the clinic. Such functionality has the potential to reduce the burden of asking all questions on-the-fly as new information is presented in a distracting clinical environment. Building this feature set requires meeting capture strategies to facilitate information re-use.

Surface Computing for Collaborating

Surface computing has the potential to address the many challenges patients face during their clinic visits and encourage patient-clinician collaboration around visually-accessible information. For example, exam rooms are small and often have one small monitor set up on a desk that is ideal for viewing and use by one person, usually the clinician (see Figure 2). However, exam rooms also contain considerable surface area (e.g., walls, counters, cabinets, and pull-out trays) that could be transformed into surfaces to display and manipulate information. A small device that projects large images and uses computer vision to enable touch-based interactions could potentially turn exam room surfaces (e.g. wall, cabinet sides, exam table) into collaborative, visual workspaces [35] accessible when sitting or lying down. Enriching conversation with visuals—especially if patients and clinicians review, diagram, or annotate artifacts together—is a potentially powerful means to improve comprehension and facilitate shared understandings. For example, incorporating a visual representation (e.g., flow chart of options) into the discussion of clinical trials might have helped identify and correct P14's radical misunderstanding of her treatment options.

Moreover, researchers studying surface and tabletop systems have already developed solutions for two types problems that occur during interactions in clinical environments. The first problem is fragmented attention patients experience when attending to emergent conversation and information artifacts at the same time.

Physicians and patients both struggle to make eye contact during discussions and simultaneously capture notes, look up information, or remember to track questions on a question list. Wang et al. [33] found tabletop solutions that allowed collaborators to make eye contact while still interacting with the information on the virtual surface. We believe such strategies can be adapted to surface computing applications in exam rooms and treatment areas.

The second problem is inefficient space utilization in exam rooms. In our study, patients inhabited small 'territories' of available space, often in awkward physical positions, even when space better-suited to the information interaction remained unutilized. Availability of large interactive displays could help clinicians and patients make better use of available space and break down existing territorial boundaries between clinician space and patient space in clinical environments. For example, instead of P9 'hanging back' behind her oncologist straining to gaze over her shoulder to view a small screen as the oncologist explains how to navigate through a chemotherapy website, she could view the website on a large, easily seen surface display while standing side-by-side with her clinician. Sitting or standing in space usually occupied by clinicians (e.g., desk area, counter-top area, or back-wall area—see Figure 2), the patient could navigate the website herself—collaborating with the clinician—facilitating memory and her ability to re-find the information later. She could also save or send the website to herself for use at home or to share with others. Thus, strategic placement of interactive displays to maximize ease-of-use can help patients and clinicians better utilize available space in clinic environments. Techniques such as clearly labeled patient-designated controls and dedicated virtual workspaces for patients within the displays could encourage patients to use the technology, even in spaces that they do not usually occupy [33,27].

Meeting Capture for Information Re-Use

To address the demanding characteristics of patients' information work in clinic environments, patients require tools to capture and re-use information exchanged in time-limited appointments. One of the biggest dilemmas for patients is how to record oral information amidst distractions (e.g., undergoing physical exam), competing demands (e.g., listening to new information), and heightened anxiety in clinical environments.

Automated meeting capture in co-located environments has largely been studied in workplace settings, but we anticipate that both explicit and implicit capture strategies developed in these studies could be invaluable in the clinic environment. Ju et al [16] demonstrated how small interactive group spaces—not unlike clinical environments—can be instrumented for explicit, user-initiated capture of white-board activity and ongoing implicit capture of audio and image data over time. In clinic environments, implicit capture strategies could aid anxious or overwhelmed patients. At the very least, such patients would leave the clinic with a complete record of the

agenda, audio, and visuals used during the visit that they can review later. Explicit capture will help reassure patients that they are in fact capturing important moments, such as the current state of the white board at a particular point in time.

After capture, further research should explore how to help patients efficiently recall and re-use information after returning home. For example, P14 might be reluctant to listen to the entire visit. Instead, they might just want to replay information about specific treatment options discussed during that visit. In workplace settings, people rarely want to sit through a meeting for a second time and research is underway to provide better summaries of meetings and more robust ways to locate when action items were addressed in a recorded segment [8]. Clinic visits have enough similarities to workplace meetings that the technology developed for meetings also applies to this new setting. However, clinic visits have substantial differences that make the need for this technology, and the potential impact, much greater. For example, patients struggle to document their consultations with clinic staff and recognize that doing so jeopardizes their abilities to fully participate in the conversation at the moment. Patients routinely walk away with questions that we hypothesize they would seek to answer with the appropriate meeting capture technology.

Designs for automatically inferring agenda items and helping people quickly re-find segments addressing specific health topics could tremendously improve the patients' experiences. Allowing patients to find the section of the meeting they have questions about without forcing them to review, and relive, the entire meeting will lower the barrier to information re-use. The current techniques for identifying agenda items require training data and this will be a challenge in a setting where it is difficult to further burden specific patient-physician pairs with training during meetings. Post-meeting review and annotation is a possibility, but carries the emotional burden previously mentioned. The techniques used by Ehlen et al. [8] could potentially be used to train on a particular oncologist's meetings to annotate meetings patients have with that oncologist. While more research is done on automatic identification, implicit capture coupled with explicit capture holds promise for patients who are currently unable to simultaneously devote all their resources to participating in conversation and to documenting for later.

LIMITATIONS OF THE STUDY

Our ethnographic-inspired study of patients in clinic environments has several limitations. For example, our participants were women with breast cancer diagnoses. Patients confronting other health problems may encounter different problems. Nevertheless, the clinic environments we observed were remarkably generic. For example, exam rooms were similar in layout and size to exam rooms used in primary care. The infusion areas we observed served as treatment areas for all diagnoses requiring infusion, not just breast cancer. Another limitation is that we observed a

small set of patients (n=14) who were enrolled in a larger study on personal health information management. These patients were actively involved in discussing personal health information management during data collection. Our participant observation methodology meant that patients enrolled in the study knew the topic and interests of the researchers. It is possible that this knowledge biased their actions and interview responses.

CONCLUSION

Clinic environments are harsh information environments that often prevent patients from interacting with information effectively. From patients' perspectives, awkward physical positions, bursts of information exchange, separation from information artifacts, lack of advance information, and heightened stress inhibit their capacities to access, use, learn, communicate, and remember information effectively. The negative impact of these factors on collaboration and information exchange with clinicians thwarts efforts to improve quality of care. Physicians rely on patients to focus their attention, communicate effectively, and recall information accurately. To maximize patients' capacities to partner effectively with clinicians, we need to transform clinic environments into effective information workspaces for patients.

ACKNOWLEDGEMENTS

We would like to thank all of our patient participants, and the clinic staff who facilitated our study. Thanks to NLM R01LM009143 for our funding.

REFERENCES

1. Baker, C.F. Annoyance to ICU Noise: A model of patient discomfort. *Critical Care Nursing Quarterly*, 16, 2 (1993), 83-90.
2. Baker, C.F., Garvin, B., Kennedy C.W., & Polivaka, B. The effect of environmental sound and communication on CCU patients' heart rate and blood pressure. *Research in Nursing & Health*, 16, 6 (1993), 415-421.
3. Ballegaard, S.A., Hansen, T.R., & Kyng, M. Healthcare in everyday life: designing healthcare services for daily life. *CHI 2008*. ACM press (2008), 1807-1816.
4. Berg, M. Patients and professionals in the information society: what might keep us awake in 2013. *International Journal of Medical Informatics*, 66, 1-3 (2002), 31-37.
5. Broadbent, D.E. *Perception and Communication*. London: Pergamon Press, 1958.
6. Cabrera, I.N., & Lee, M.H.M. Reducing noise pollution in the hospital setting by establishing a department of sound: A survey of recent research on the effects of noise and music in health care. *Preventive Medicine*, 30, 4 (2000), 339-345.
7. Consolvo, S. & Towle, J. Evaluating an ambient display for the home. *CHI 2005*, ACM Press (2005), 1304-1307.
8. Ehlen, P., Purver, M., Niekrasz, J., Lee, K., & Peters, S. Meeting Adjourned: Off-line Learning Interfaces for

- Automated Meeting Understanding. *IUI* 2008, ACM press (2008), 276-284.
9. Frankel, R., Altschuler, A., George, S., Kinsman, J., Jimison, H., Robertson, N.R., & Hsu, J. Effects of exam-room computing on clinician-patient communication: a longitudinal qualitative study. *Journal of General Internal Medicine*, 20, 8 (2005), 677-682.
 10. Frost, J. & Smith, B. 2002. Visualizing health practice to treat diabetes. *CHI* 2002, ACM press (2002), 606-607.
 11. Hafner D. Lost in the fog: Understanding "chemo brain". *Nursing*, 39, 8 (2009), 42-45.
 12. Hayes, G.R., Abowd, G.D., Davis, J.S., Blount, M.L., Ebling, M., & Mynatt, E.D. Opportunities for Pervasive Computing in Chronic Cancer Care. *Proc. Pervasive Computing* 2008, 262-279.
 13. Henrich, A., Fay, J., & Sorrells, A.K.. Effects of acuity-adaptable rooms on flow of patients and delivery of care. *American Journal of Critical Care*, 13, 1 (2004), 35-45.
 14. Hignett, S. Physical Ergonomics in health care. In Carayon, P. (Ed). *Handbook of human factors and ergonomics in health care and patient safety*. Lawrence Erlbaum, Mahwah, New Jersey, USA, 2007, 309-321
 15. Jackson, L. Information complexity and medical communication: The effects of technical language and amount of information in a medical message. *Health Comm* 4, 3 (1992), 197-210.
 16. Ju, W., Ionescu, A., Neeley, L., & Winograd, T. Where the Wild Things Work: Capturing Shared Physical Design Workspaces. *CSCW* 2004, ACM press (2004), 533-541.
 17. Ley, P., & Llewelyn, S. Improving patients' understanding, recall, satisfaction, and compliance. In Broome, A., & Llewelyn, S. (Eds.) *Health psychology: processes and applications*. Chapman and Hal, London, 75-98.
 18. Ley, P., & Spellman, M.S. Communications in an outpatient setting. *British Journal Soc Clin Psych*, 4 (1965), 114-116.
 19. Mamykina, L., Mynatt, E., Davidson, P., & Greenblatt, D. MAHI: investigation of social scaffolding for reflective thinking in diabetes management. *CHI* 2008, ACM press (2008), 477-486.
 20. Moen, A., & Brennan, P.F. Health@Home: the work of health information management in the household (HIMH): implications for consumer health informatics (CHI) innovations. *JAMIA*, 12, 6 (2005), 648-656.
 21. Morris, M.R., Paepcke, A., Winograd, T., & Stamberger, J. TeamTag: Exploring Centralized versus Replicated Controls for Co-located Tabletop Groupware. *CHI* 2006, ACM press (2006), 1273-1282.
 22. Page, A. *Keeping Patients Safe: Transforming the Work Environment of Nurses*. 2004, Institute of Medicine of the National Academies Press, Washington, D.C., USA.
 23. Pitkethly, M., MacGillivray, S., & Ryan, R. Recordings or summaries of consultations for people with cancer *Cochrane Database of Systematic Reviews* 2007, Issue 1. Art. No.: CD001539.
 24. Rice, G., Ingram, J., & Mizan, J. Enhancing a primary care environment: a case study of effects on patient and staff in a single general practice. *British Journal of General Practice*, 58, 552 (2008), 465-470.
 25. Rouf, E., Whittle, J., Lu, N. & Schwartz, M.D. Computers in the exam room: differences in physician-patient interaction may be due to physician experience. *Journal of General Internal Medicine*, 22, 1(2007), 43-48.
 26. Schappert, S.M., & Rechtsteiner, E.A. Ambulatory medical care utilization estimates for 2006. *National health statistics reports*, 6, 8 (2008), 1-29.
 27. Scott, S.D., Sheelagh, M., Carpendale, T., & Inkpen, K. M. Territoriality in collaborative tabletop workspaces. *CSCW* 2004, ACM press (2004), 294-303.
 28. Schmidt, K., & Bannon, L. Taking CSCW seriously: Supporting articulation work. *Computer Supported Cooperative Work*, 1, 1, (1992), 7-40.
 29. Shumaker SA, Reizenstein JE. Environmental factors affecting inpatient stress in acute care hospitals. In: Evans, G.W. (Ed) *Environmental stress*, 1982. Cambridge University Press, New York, USA, 179-223.
 30. Star, S.L., & Strauss, A. Layers of Silence, Arenas of Voice: The Ecology of Visible and Invisible Work. *CSCW*, 8, 1-2 (1999), 9-30.
 31. Sullivan, F., & Wyatt, J.C. How computers can help to share understanding with patients. *British Medical Journal*, 331, 7521 (2005), 892-894.
 32. Ulrich, R.S. View through a window may influence recovery from surgery. *Science*, 224, 4647 (1984), 420-421.
 33. Wang, H. & Blevis, E. Concepts that support collocated collaborative work inspired by the specific context of industrial designers. *Proc. of CSCW*. ACM Press (2004), 546-549.
 34. Williams, J. R., Guidelines for the Use of Multimedia in Instruction, *Proceedings of the Human Factors and Ergonomics Society 42nd Annual Meeting*, (1998), 1447-1451.
 35. Wilson, A.D. PlayAnywhere: A Compact Interactive Tabletop Projection-Vision System. *UIST* 2005, ACM press (2005), 83-92.