The Invisible Work of Being a Patient and Implications for Health Care: "[the doctor is] my business partner in the most important business in my life, staying alive."

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In a distributed system of care, patients shuffle among many clinicians and spend the majority of their time away from the treatment center. Although we see the results of patients' work (e.g., medication taken, arrived at appointment) we do not see the work itself. By failing to see this work, industry overlooks issues with vital implications for their business. To lift the veil of invisibility from patients' work, we conducted a longitudinal field study to uncover the invisible work breast cancer patients do to obtain information, bridge inter-institutional care, manage dependencies and resolve inconsistent recommendations. In this paper we provide detailed examples of this work and explore the impact on patients and health-care operations; identify patterns of work with implications for patient-centered research and design; and propose common information spaces to improve patients' work through designs that highlight dependencies, preserve state information, link recommendations to justifications, and track task progress.

Motivation: Why Study Patient Work?

In a distributed system of outpatient care, patients shuffle among many clinicians and spend the majority of their time away from the treatment center. Although we see the results of patients' work (e.g., medication taken, arrived at appointment), we do not see the work itself. Consequently, 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 (1999:15)."

By failing to "see" the invisible—yet essential—work that patients do when undergoing care, the health-care industry struggles to answer key questions with vital implications for their business:

- How to increase patient participation? Despite evidence that people who participate in their care achieve better health outcomes (Laine and Davidoff 1996), research suggest that many patients do not achieve their preferred level of involvement in their own care (Degner and others 1997).
- How to improve information provision? Patients require accurate and timely information to participate effectively in their care. However, patients continue to express unmet information needs (Boberg and others 2003; Kravitz and others 2002) that inhibit their ability to proactively manage their health care.

- How to reduce medical errors? Although researchers call for inclusive approaches to reducing medical errors that include input from all stakeholders (Kohn and others 2000; Unruh and Pratt 2007), patients' knowledge of their personal health situation (e.g., evolving needs, extenuating circumstances) remain largely untapped in error-reduction strategies.
- How to leverage information technology? Despite projected benefits of information technology in health-care organizations, adoption rates of clinically-oriented information systems—from electronic medical records to online personal health records—remain low (Burt and others 2005) (Tang and others 2006).

Despite their central role in answering these questions and addressing these challenges, patients remain understudied actors in health-care. Without knowledge of the work patients actually do in the socio-technical system of health-care, any evaluation is incomplete and organizational improvement will suffer. Of particular importance is patients' 'invisible work.' We define patients' invisible work as the portion of their effort that remains hidden because it occurs behind the scenes (e.g., performed at home), between clinical encounters (e.g., scheduling, trouble-shooting side effects), or amidst multiple distributed actors (e.g., communicating with people in multiple roles or multiple people within a role). Although patients' invisible work is spawned by clinical care concerns, this work is rarely acknowledged—much less supported—by existing information systems or organizational processes designed to support the work of clinicians at the treatment center.

Methods: Lifting the veil of patients' invisible work

Making work visible requires careful study of the invisible work being studied (Suchman, 1995). Unlike other patient-centered research, we could not study patients in a single location (e.g., the treatment center) or clinical encounter (e.g., consultation or treatment session) because we sought to characterize patients' work in a holistic sense as patients undergo outpatient cancer care. Thus, we targeted patients' work that remained at least partially concealed because it occurs away from the treatment center or dispersed across clinical interactions.

To lift the veil of invisibility from patients' work, we conducted a 3-part field study of cancer patients' in-situ work while undergoing outpatient cancer care. In Part 1, we conducted in-depth interviews with 18 cancer patients; 16/18 were actively receiving cancer care; 8/18 were undergoing chemotherapy. In Part 2, we conducted demographic surveys and in-depth interviews with 8 breast cancer patients. Then, we followed these patients for 12 weeks during active treatment, conducting 76 critical incident interviews to understand their work as it unfolded over time. In Part 3, we conducted demographic surveys, in-depth interviews, personal health information collection reviews, and photo diaries with 9 breast cancer patients. Then, we followed these patients for 12 weeks during active treatment conducting 151 critical incident interviews. To supplement this data, patients kept logs of their information interactions and constructed a photo-diary of their experiences. In sum, we studied 35 cancer patients conducting a total of 35 in-depth interviews, 17 demographic

surveys, 227 critical incident interviews, 9 personal health information collection reviews, and collected over 200 photos from patients' photo diaries.

Findings: Patients' Invisible Work and Why It Matters

Patients' invisible work is difficult to grasp in the abstract. Therefore, to ground our discussion we describe four concrete examples of patients' invisible work, explore the impact on health-care operations, and examine the ramifications for patients themselves. Although we present specific examples from critical incident interviews and information logs in phase 3, they illustrate overarching themes that emerged in each phase of this study.

Obtain and maintain state awareness: What's going on?

To be informed participants in distributed care contexts, patients require information about their evolving health status vis-à-vis their specific cancer care trajectory. In our study, patients struggled to obtain information about their current health situation, a concept we call "state awareness." When patients failed to obtain state awareness—and update this awareness as their health situation evolved—patients experienced knowledge deficits that inhibited their ability to understand their health situation. Patients responded in ways that drained staff resources and created institutional inefficiencies at the treatment center.

To illustrate, consider the case of Lois, a 56-year bookkeeper, diagnosed with invasive breast cancer. After undergoing a bilateral mastectomy, she recuperated at home waiting for information from the clinic about pathology results and subsequent care procedures indicated for her cancer. When Wednesday—the latest day she was told she would receive the information—passed, Lois's anxiety elevated. She tried to obtain information about her health status from the treatment center but her efforts devolved into a morass of 19 communication episodes resulting from:

- Unclear communication channels: "I didn't know exactly who I needed to call, if I needed to call over there [the university] or the [offsite breast] clinic or where. So I thought I'd try [people at both locations].
- Lack of responsiveness: "I didn't hear anything [back from messages she left]… I tried every single number on that [business card] and I couldn't get a live person. So I thought …[raises voice] I'm just going to call and leave a message everywhere!
- Ambiguous answers and information gatekeeping: "[the nurse] called me back this morning and she told me that she knew that they had met, all the doctors, and discussed me. And that…she would rather have me talk to [the breast surgeon] rather than-you know-her telling me things that maybe she shouldn't be telling me."
- Duplicate effort: Staff from three different departments attempted to untangle the problem. Actors included the clinic coordinator, breast surgeon's nurse, breast surgeon, medical oncologist, nurse advice line staff, medical oncologist's scheduler, and the receptionist. The work included impromptu hallway conversations, notes left on keyboards, messages left on voice mail, messages forwarded through clerical

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staff and unneeded follow-up appointments squeezed into the surgeon's full schedule.

Lois illustrates four findings in our study of patients' invisible work: First, lack of information stimulated emotional distress. Without information, especially when this information is expected (e.g., Lois was told that she would receive news by Wednesday) and they are away from the treatment center, patients experienced a surge of emotional distress. Second, emotional distress stimulated action. In multiple instances, patients acted by engaging in rapid-fire communication to obtain information, understand the status of their requests for information, and discern logical next steps. Consequently, staff in different clinical specialties (e.g., surgery, medical oncology) across a range of roles (e.g., schedulers, clinical coordinators, nurses, physicians) worked in parallel—routinely duplicating effort—to understand the problem and communicate with the patient. Moreover, patients' expressed that their anxiety increases in proportion to the lack of responsiveness to their requests for information. Third, successful information provision and responsive communication has potential to ameliorates patients' distress by reducing uncertainty about the status of what is known institutionally (e.g., this is where you are in our institutional process) and clinically (e.g., pathology still under review). For example, once she receives the basic information Lois's tone changes dramatically (e.g., she uses the word 'happy' multiple times to describe her situation and interactions with clinic staff) even though nothing clinically has been resolved. For example, Lois remarked: "I kind of know which direction [to go] now."

Bridge Inter-Institutional Care: Caught In Between

A key task for patients who receive care at multiple treatment centers is to bridge inter-institutional care. This work is particularly important for patients who live away from large urban centers and thus lack access to cancer centers with cutting edge research and clinical care. Such patients regularly receive some care at cancer centers with follow-up at local institutions. However, these patients must work to maintain continuity of care between different institutions.

To illustrate, consider the case of Nancy who attempts to bridge surgical care between the nearest cancer center 5 hours away—where she underwent a mastectomy—and her local hospital. Nancy is distraught because "there are drain tubes stuck inside me and they need to be taken out." Although staff at the cancer center suggests an expedient strategy to get the drains removed locally, she encounters an unexpected glitch. The local hospital demands additional information about her drains before proceeding. She spends the day on the telephone trying to reach people with technical information required and relay that information to the local hospital.

Nancy demonstrates three barriers patients experience when trying to bridge care between multiple institutions. First, patients experience variations in operating procedures between health-care organizations. Nancy encounters unexpected problems because unlike the cancer center, "it's not as easy as just calling up and walking in…to get an appointment. [the local hospital] wants to know the drain tube brand so they make sure that they have

everything they need to take it out." Consequently, Nancy becomes a de-facto information courier shuttling medical information from one institution to another.

Second, patients lack procedural information to manage inter-institutional care given these variations. Nancy discovers that she received only partial task information. Although she receives medically valid task information (e.g. remove surgical drains locally is medically expedient), it lacks actionable specificity given the diversity of health-care operations in different organizational settings. Although it is unreasonable to expect staff at the cancer center to know other hospitals' operating procedures in detail, patients require procedural information (e.g., every institution is different, you may need to provide additional information, contact them in advance to establish a plan) in addition to clinical options.

Third, patients experience inefficient communication which inhibits their ability to communicate information across institutional boundaries. By the time we conduct the critical incident debriefing, Nancy is seven voice mails, three telephone conversations, and over 24 hours after her initial phone call to the treatment center. Nancy's drains remained unnecessarily embedded in her chest.

Manage Dependencies: Tripping Over Interrelationships

Another key task for patients is to manage dependencies between inter-related actions and events during cancer care. The challenge for patients is that they discover dependencies during emergent events, with little or no time to plan in advance. To illustrate, consider the case of Emily, a sales executive with a graduate degree, who is undergoing neoadjuvant chemotherapy for breast cancer and is also planning for upcoming surgery, the next phase in her treatment plan. Emily arrives at her planning appointment with her tightly-scheduled surgeon only to discover that she lacks key diagnostic information necessary for treatment planning:

> "[surgeon rifles through her file] 'Where's your genetic test?' And I'm like, 'Well, I thought I'd do it later.' And she's like, 'Well, do you realize that if it comes back positive, we'll probably want to do a bilateral mastectomy?' and I'm like: 'no, you know. Nobody told me that,' you know, so … I felt really dumb and bad, but it's like you don't know what you don't know."

In this case, the clinical team neglected to inform Emily that the results of her genetic tests could influence the type and timing of the surgery they would recommend. Thus, although they recommended the test and the patient intended to have it done, she did not understand the interdependency between one part of her plan (to get the genetic test) and another part of her plan (to have surgery to remove the cancerous tumor). The impact on Emily is significant because the genetic test takes three weeks to process and she must try to re-schedule with an already over-scheduled surgeon.

Resolve Inconsistent Recommendations: Reconciling Invisible Justifications

In a distributed system of care, clinicians' recommendations sometimes vary and patients must resolve inconsistent recommendations. To illustrate, consider the case of Donna, a 39 year old project manager. After undergoing chemotherapy and bilateral mastectomies at a cancer center, she returns to her local hospital system for follow-up consultations. Despite recommendations from the cancer-center surgeon that she required no further treatment, her local medical oncologist referred her to a radiation oncologist within her local health-care system for further evaluation. When the local radiation oncologist recommended radiation, Donna was shocked because she had already started the breast reconstruction process, which would interact with the proposed radiation treatment:

> "I kind of have to weigh the two [opposing recommendations] against each other. [local radiation oncologist] told me that…she had she felt compelled to recommend that I have the radiation therapy…[cancer center surgeon] goes: 'you absolutely do not need radiation.' He said um-he said we got such wide margins with you!'"

Patients like Donna illustrate how patients lack resources to resolve inconsistent recommendations. First, patients lack explicit justifications for clinical recommendations. Without evidence to contextualize the recommendation (e.g., research studies, institutional protocols, and diagnostic results), patients cannot evaluate individual recommendations. In this example, Donna appeared to receive only partial justification for the respective decisions and these justifications came predominately in oral form. For example, without explicit access to her pathology report or the specific study cited during the consultation, Donna could not understand the specific details the local radiation oncologist used to justify her recommendation.

Second, patients lack means to discuss details of competing recommendations with different clinicians. In this case, Donna discussed the competing recommendations with her surgeon with little mention of the justification behind the recommendation provided by her local radiation oncologist. Moreover, Donna did not appear to make an evidence-based decision. After listening to the cancer center surgeon repeat his recommendation, Donna simply decided not to have further radiation treatment without fully understanding differences between the two recommendations.

Patterns of Patients' Invisible Work: Implications for Patient-centered Research and Design

As we studied patients' invisible work and tracked their hidden tasks, four overarching patterns emerged that inform future patient-centered research and design. The first pattern is that patients' invisible work is reactive and bursty. An unexpected event occurs (e.g., Betsy receives competing treatment recommendations, Lois fails to receive health status

information, Nancy requires new technical information, Emily fails to complete diagnostics in time for treatment planning) which is followed by a burst of patient activity to understand and address the problem. Many of these bursts occurred while patients were away from the treatment center, required patients to communicate with clinical actors distributed across time and space, and transpired between periods of inactivity. One implication of this finding is that researchers require sustained data collection strategies that are not tied to specific location, focused exclusively on clinical encounters with individual clinicians, or single shot data collection. For designers, the implication is that patients require tools to help them 'even out' their work, making it more predictable and sustainable over time.

The second pattern is that these bursts of activity consumed patients' precious personal resources. Instead of spending time and energy on healing, relationships, and everyday life—patients continued at home/work with personal/professional responsibilities as well as being a cancer patient—patients expended their limited personal resources to obtain information, maintain continuity of care, managing dependencies, and reconcile inconsistent recommendations. Moreover, these tasks were emotionally charged and patients blamed themselves or others (e.g., the clinic, specific clinicians), which poisoned their perspective and exacerbated existing stress. The implication of this finding for researchers is twofold: researchers (1) require elicitation techniques that target patient actions—and ways to support those actions—masked by understandably strong emotions and (2) should explore means to collect data that minimizes the cognitive and emotional load on patients who are already overloaded. For designers the implication is to remain cognizant of the role of emotion in patients' work and the potential of emotion to influence the use of designed artifacts (c.f. Norman 2004).

The third pattern is that these reactive bursts of work remain under articulated and difficult to study. Over the course of this research, we relied on extended conversations and structured critical incident debriefing sessions to drill down into work that patients did not readily discuss. For example, patients generally responded to initial questioning (e.g., What's occurred since we last talked?) by describing their experience emotionally (e.g., I'm exhausted, I'm stressed out) or dismissing their effort (e.g., Well, not much, really). Persistent, structured probing over time unmasked the details of their work and how much effort they actually expended, even when patients initially downplayed their work-as-a-patient. To supplement verbal descriptions provided during critical incident debriefings, we also asked patients to log their actions related to bursts of activity in an abbreviated information log. Together, these techniques proved especially valuable for studying patients' invisible work. Another well-aligned strategy for both researchers and designers is to involve patients through participatory research and design methodologies, further integrating patients into the data collection and analysis process to unveil the intricacies of patients' under articulated work.

The fourth pattern is that reducing the burden of patients' work necessitates cooperation between patients and clinicians. Without professional expertise in cancer care, patients require interaction with clinicians to address their clinical concerns during cancer

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care. Similarly, clinicians require interaction with patients because clinicians remain removed—in time and space—from direct patient experience in which many problems are initially detected. These two forms of expertise—patient expertise and clinical expertise— are different (c.f., Civan and Pratt 2007). Unfortunately, these two forms of expertise rarely interact because patients and clinicians act largely independent of one another with few tools to support ongoing cooperation. Therefore, patients create workarounds that could be solved more efficiently if they received assistance from clinicians. Moreover, as Lois and Nancy demonstrated, ineffective communication systems thwart patients' efforts to notify clinicians and work together with them to resolve problems efficiently. One implication of this finding is that researchers, designers, and health-care operations managers should explore means to support required cooperation between patients and their clinicians. To conclude, we explore initial requirements for common information spaces and its potential impact on patients' invisible work.

Common Information Spaces: Improving Healthcare through Design

How can we support cooperation through design? Researchers in the field of CSCW note that cooperation of actors distributed in time and space requires: (1) "the active construction by the participants of a common information space where the meanings of the shared objects are debated and resolved (Schmidt and Bannon 1992:27)" and (2) [that] both the producer and the receiver [of information] consciously make an effort to understand each other's context - of production and use, so that even though the efforts may be distributed over time and space, there is a form of communication, of 'putting in common', going on in [cooperative] activity (Bannon 2000:5)."

Extending their conceptual work on common information spaces (CIS), we provide an initial set of functional requirements for CIS designed explicitly to ease patients' work in cancer care through cooperation with clinicians. Specifically, CIS must provide an interactive information space in which patients can cooperate with clinicians to highlight dependencies, preserve state information, link recommendations to justifications, couple clinical options with procedural task information, and track progress of clinical and logistical tasks. To illustrate, we return to three cases and present a brief formative analysis to examine the potential of CIS in the cancer-care context. For example:

- Betsy's local radiation oncologist could use a CIS to construct a lightweight representation of his justifications for additional radiation treatment by (1) posting the pathology report on line (2) linking specific data in the pathology report to the research study influencing his decision and (3) annotating that link with his personal recommendation based on his professional opinion. This representation is preserved so Betsy can reflect on it further at home. Moreover, she can share this representation with the cancer center surgeon (who disagrees with the local radiation oncologist) who provides his own links to studies and explains his differing professional opinion via annotations. Thus, Betsy could use the CIS to learn the competing recommendations and make an informed decision regarding

> further treatment through explicit representations that both clinicians and patients build, share, and modify within the CIS.

- Lois's clinicians could aid her work by using a CIS to (1) post the status of their deliberations (e.g., surgeon consulted with clinician A but still needs input from clinician B) to update Lois on the status of the organizational process involved in addressing her pressing information need, (2) provide a representation of dependencies (e.g., these diagnostics would indicate surgical option A, other diagnostics would indicate surgical option B), and (3) link each clinical options with task information about next steps (e.g., who to contact and how to contact them) once a decision is reached. In turn, Lois could use the CIS to track the decision-making process and review logistical tasks for different scenarios without relying on inefficient voice communications.

- Nancy could post a question about getting her drains out locally to the CIS, which sends an alert to a nurse who reads the question. Using the CIS, the nurse indicates that the question had been read and links the question to the surgeon's response. At discharge—still days before the drains need to be removed—a nurse links the option to get the drains out locally with procedural task information (e.g., she should contact the local hospital in advance to set up a plan). As she recovers, Nancy consults the CIS to review next steps and discovers the nurse's suggestion. As Nancy develops a plan with the local hospital, she posts a representation of that plan, including the request for additional information about the surgical drains. In turn, the nurse receives an alert, finds the appropriate information, and links a technical description of the surgical drains to her plan with her local hospital.

In these examples, the CIS provides two critical services that remain poorly supported in the current cancer-care environment. First, the CIS facilitates cooperation through underline explicit representations constructed by either the patient or their clinician. In the current cancer-care environment, patients and clinicians rely on heavily on oral communication to communicate their respective views on the patients' evolving health situation. Second, the CIS facilitates cooperation through interaction by allowing both the patients and their clinicians to develop shared understandings of each others' needs and perspectives through iterative refinement of these representations. In the current structure of cancer care, clinicians' time constraints and ineffective use of voice mail inhibit nuanced interactions required to construct a shared representation of the patients' evolving health situation.

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