

# Barriers to Organizing Information during Cancer Care: “I don’t know how people do it”

Kenton T. Unruh<sup>1</sup>, PhD, Wanda Pratt, PhD<sup>1,2</sup>

<sup>1</sup>Division of Biomedical and Health Informatics; <sup>2</sup>Information School  
University of Washington, Seattle, WA

## Abstract

*Patients need support to help them organize and manage the vast amount of health information they now receive, particularly in their increasingly active roles. Clinicians can be frustrated by the perceived failure of patients to use the information given to them, and patients express frustrations with the daunting organizational task of their health information. Yet, few studies have examined the barriers that patients face in organizing and thus effectively retrieving and using their health information. In this paper, we report on a qualitative, longitudinal field study of cancer patients’ in-situ organizing behavior where we uncovered four types of barriers to organizing: emotional, scalable, temporal, and functional. We provide detailed suggestions for how these barriers could be reduced by either technological or social changes. Our analysis of barriers provides empirical guidance for health-information providers, technology designers as well as patients and their caregivers.*

## Introduction

People organize their personal information to conceptualize what they know, enhance information retrieval in the future, and cue or remember tasks in everyday life.<sup>1</sup> However, studies also suggest that organizing is difficult and people fail to use their information effectively for emergent tasks.<sup>1,2</sup> In the health-care domain, patients face grave consequences if they cannot access and use information effectively.<sup>3</sup> Arguably, patients have access to more information about their health than at any previous point in history. However, information access is only the first step to managing health care needs. Patients must organize it effectively to support the underlying tasks required to manage their health proactively. Ironically, ever-increasing access to information exacerbates the challenges patients face in using information effectively. In this paper, we describe four classes of barriers patients encounter when organizing their information effectively for use during cancer care. We describe each barrier using rich examples culled from our triangulated data set, and conclude with four detailed recommendations for reducing those barriers. This study was approved by

the university IRB. For reporting purposes, we changed participants’ names to protect their identity.

## Methods

To understand barriers to organizing information, we analyzed data conducted in a 3-part field study of cancer patients’ in-situ information interactions through 35 in-depth interviews, 17 demographic surveys, 227 critical incident interviews,<sup>4</sup> 9 personal health information collection reviews, and over 200 photos from patients’ photo diaries.<sup>5</sup> 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<sup>4</sup> to understand their in-situ information interactions. In Part 3, we conducted demographic surveys, in-depth interviews, personal health information collection reviews, and photo diaries<sup>5</sup> with 9 breast cancer patients. Then, we followed these patients for 12 weeks during active treatment conducting 151 critical incident interviews.<sup>4</sup>

## Class #1 - Emotional Barriers

Patients’ emotional response to information influences their ability to interact with that information meaningfully. When information interactions feel unmanageable, patients simply set information aside in no particular order. Two emotional reactions inhibited patients’ ability to organize information.

### *Emotional Reactions to Accumulating Information*

Consider the case of Sarah, who describes why she keeps health information—ranging from claim forms to appointment slips—in unorganized stacks:

Sarah: “It’s just because I just got a lot of other stuff going on that it kind of just builds there, and I just can’t quite put it together and get organized and pay my portion and then just kind of do it on a weekly basis or something so it doesn’t get overwhelming and I just look at it.”

For Sarah, organizing her information feels unmanageable for two reasons. First—like many patients—her health situation exacerbates the time pressures she already experiences in her personal life (e.g., she cared for her 5-year old son) and professional life (e.g., she works outside the home). She can barely keep up with her everyday routine, and organizing health information becomes yet another task to accomplish in an already packed schedule. Second, Sarah experiences the additional burden of knowing that her unorganized stack of health information continues to grow. She wants to organize the information “more regularly” because otherwise “it just piles up.” Nevertheless, she also feels overwhelmed by the awareness that her organizing task grows each week, but she does not organize her information. Thus, Sarah articulates how emotional responses to accumulating information inhibit her ability to organize it effectively, even while the organizing task worsens as her information grows.

#### *Emotional Reactions to the Organizing Task*

In contrast to Sarah—who explicitly described her distress in relationship to growing piles of information—other patients expressed vivid emotional experiences associated with the process of organizing information. For example, when we first met Martha she explained how she experienced prolonged periods during which she placed information in a desk-drawer without examining it because she “just couldn’t deal” with all the information. Despite holding a graduate degree and working as an information professional, Martha was distressed enough that much of the financial information she received accumulated in unorganized piles. Two months after entering the study, Martha opened an interview with the following statements about her experience organizing information:

Martha: “Oh, you should just see me at this moment. It’s really gruesome. I’m going through my bills. It’s so awful. Yeah. It’s just pathetic. I hate doing this. It’s worse than going to a chemotherapy appointment I think...this huge stack of bills that have been accumulating for a long time and I’m finally plowing through it. It’s just awful, I hate this...I’m opening up the things that I haven’t opened yet for a long time. And then I’m ripping apart—you know—I mean I’m putting them in stacks of stuff that’s from [the hospital] to pay potentially and stuff’s that’s from my [insurance company]...and then the other stuff is about like: ‘we’re going to not pay this unless you tell us why, why-was this the result of an accident or injury?’ It’s like: ‘I’ve got cancer you big dummy!’”

For Martha, organizing her information is unmanageable for two reasons. First, her own emotional response to treatment creates a mindset in which she feels unable to interact with any information related to her cancer, much less organize it. Second, the very act of organizing the accumulated information produces additional anxiety; so much so that she uses powerfully negative descriptive terms to convey her experience: gruesome, pathetic, awful, hate, and dummy. Moreover, her anxiety heightens as she discovers that time-sensitive tasks with financial implications hidden within the unorganized collection remain unaddressed: “[exclaiming] it says: ‘no further payments will be made on your claim until we receive this completed form from you.’”

#### **Class #2 – Scalable Barriers**

Sarah and Martha highlight emotional reasons for not organizing their personal health information. Although Sarah and Martha encountered difficulty organizing their information as it accumulated over time, their concerns were more emotional—how they personally perceived their information—than any particular quality of the information itself. However, we observed other patients in this study store their information with little or no organization because of concrete qualities of their information, especially the size of their collections. When their information collections were small, they could easily access and use the information that they needed. As their information collections grew, organizing their information became more important to facilitate effective retrieval.

To learn how scalability influences patients’ tendency to organize information, we turn to Carol. At the time of her initial interview, Carol encounters a burst of new information related to both her phase of care—she required follow-up surgery and was exploring breast reconstructive options—and a logistical switch to a new treatment center for care. Previously, she kept her personal health information in a single folder, but she was now confronted by a surge of new oral and written information from staff at her new treatment center and her insurance. The information accumulated in a pile on the kitchen table. This lack of organization was a problem for Carol because “when I need to look for something I have to go through that whole pile.”

Carol illustrates an important theme in our data: personal health information accumulated during cancer care until patients experienced problems accessing and using that information. Even patients who displayed skills in organizing information exhibited reactive behavior by allowing information to accumulate and then trying to organize it after they

experienced retrieval problems. The challenge for these patients was that the accumulation of information was associated with bursts of clinical activity, during which they rely on information to participate in their care. Thus, a problem emerged: patients realized the importance of organizing information at a time when they (a) required effective information access for emergent tasks and (b) needed to focus attentional resources on clinical activities, rather than information management.

### **Class #3 – Temporal Barriers**

Time is a scarce resource for patients. Many patients—especially those who work or care for children—already experience extreme time pressures to which they must add the tasks of managing their cancer care. The task of organizing new and unfamiliar information is particularly taxing because patients require time to learn new content, devise an organizational strategy, and maintain their information organization over time. Patients must carve this time out of an already tight schedule and then devote keen attentional resources to the organizing task. In our study, two temporal barriers inhibited patients' ability to organize effectively.

#### *Time Compression*

One situation in which patients experience time compression—when patients lack time to understand bulk information adequately—is during early visits to the treatment center. In this study, patients experienced a rush of new information from multiple clinicians in a short period of time. For example, Norma described her initial visits as a mechanical process; one in which she was on auto-pilot, simply gathering all available information without a clear understanding of its purpose or how it related to her specific health situation:

Norma: "It's something when information is coming and it's fast and furious and you're saying 'OK' and you're making your little pile and you're walking out with something feeling like, um—I'm sure staff feels like 'OK, we've given them information.' You know? And then [pauses] I, I think I'm a practical enough person that I did review at some point how to uh, how to get to the clinic or what time I had to be there or whatever. But in terms of useful information specific to my condition?"

Norma illustrates the impact of time compression on her ability to establish a personal organizational scheme. First, she received new and unfamiliar information in bulk form while concentrating on the basic tasks of communicating with clinicians and collecting documents. Like many patients, she lacked additional time to engage deeply with the information

to begin learning the content in earnest. Consequently, she left the treatment center with little knowledge of either the meaning of her information or organizational strategies to facilitate its use. Second, the organizing task occurred largely in personal rather than clinic environments. Thus, her attempts to organize the information into an effective information system occur at home without access to clinical staff or other patients with whom they could ask questions or ask for help prioritizing information.

#### *Task Fragmentation over Time*

In addition to time compression, patients confront the problem of organizing ongoing and fragmented streams of information. To illustrate, consider the case of Tracy who lamented her inability to implement two of her own organizational schemes. First, despite organizing quick reference information into a notebook, she struggled to make time in her busy work and personal schedule to keep the notebook updated with the new information that emerged during cancer care. Instead, the quick-reference information devolved into multiple post-it notes scattered across various locations. Second, despite creating folders for documents she received during her cancer care, her information accumulated in another folder.

In contrast to Norma's experience, Tracy's problem is that although she established an effective organizational scheme, she experienced difficulty organizing information into that scheme over time. Tracy lacks resources to help her manage the continuous organizing task that becomes fragmented across time and her daily activities.

### **Class #4 – Functional Barriers**

Even if patients avoided the emotional, scalable, and temporal barriers identified in the previous sections, patients still encountered functional barriers to organizing information when they lacked an understanding of how to use that information in the future. Without working knowledge of how they will use the information in their cancer care, patients defaulted to storing information with minimal organization, instead of organizing information to facilitate its use. For example, when asked how she keeps track of all her cancer-related paperwork, Diana explains her default strategy to store her paperwork in a single folder:

Diana: "The file is intense. I'm, uh, you know, I don't know how people do it. The file is intense, and still I'm paying on things from July because I'm kind of waiting for the insurance to uh, do whatever they do. That, I don't totally understand either. You know. So all my stuff is in a file folder."

A major problem is that Diana lacks understanding of how to use the documents or when—if ever—she might need them. Although Diana is familiar with these documents—she receives them frequently—they lack context to help her understand their meaning. Diana cannot organize the information without supplemental information on the role of her health insurance in her care and on how the documents relate to procedures embedded within her particular insurance policy. A critical component of the additional information Diana requires is the division of labor between herself and her insurance company. What tasks (e.g., monitoring dates, submitting paperwork, etc.) is she responsible to undertake? What tasks will the insurance company complete on her behalf? What tasks require action by both her and the insurance company? Without understanding the functional purpose of the information she receives—in her case derived from both the content of the documents she receives and contextual information about her insurance policy—Diana cannot effectively organize that information in a way that facilitates retrieval and use. Consequently, Diana relegates the documents to storage in a folder without further organization, thus limiting her ability to effectively find and use that information.

### **Discussion and Implications**

Why do patients sometimes not organize their information? To answer this question, we identified four classes of barriers that inhibit patients' ability to organize information during cancer care: emotional, scalable, temporal, and functional barriers. Given these findings, what can be done to reduce the impact of these barriers on patients' ability to organize information effectively during cancer care? To answer this question, we discuss high-level functional requirements for electronic patient-health information management (PHIM) tools.

#### *Prevent unorganized collections from accumulating*

Patients require resources to organize personal health information prior to the point where linear searching, visual scanning, or unstructured browsing an unorganized collection of personal health information becomes untenable. One solution is to provide a rich, intermediate structure to information until patients can overcome emotional, functional, and temporal barriers to personalize that organization. The intermediate structure bootstraps the organizing process so that patients can navigate their information collections even when they lack the time, energy, or knowledge necessary to customize that organization to suit their particular circumstances. These intermediate organizations have two requirements. First, these intermediate organizations should embed

pre-organized links to other personal information related to health information (e.g., personal calendar, insurance information). Second, these intermediate organizations must be customizable because information management is a highly personalized process that is most effective when tailored to one's personal situation.<sup>1,2</sup> Unlike paper-based tools (e.g., binders, schedules), electronic PHIM tools have potential to prevent unorganized collections from accumulating through (a) efficient capture of content organized initially by others and (b) semi-automated transfers from clinical systems (e.g., clinical scheduling, medical records) to PHIM tools that integrate clinical information with personal calendar and task management systems.

#### *Provide functional views of information*

Patients require functional views of information consistent with the patient's experience of undergoing cancer care. To support functional views PHIM interfaces should meet three requirements. First, PHIM interfaces should help patients integrate descriptive information (i.e., the 'what') and procedural information (i.e., the 'how', 'when', 'why', 'where', and 'who'). For example, PHIM interfaces could help Diana—who struggled to organize her insurance information—to assess current coverage status, pending reimbursements and task information including expected time windows within which she, the insurance company, or the treatment center will perform particular tasks necessary to complete payment for services rendered. Second, interfaces should help patients distinguish information required for active tasks from the rest of their information. Researchers in the field of Personal Information Management have noted how information in personal collections is overlooked when needed for active tasks.<sup>2</sup> Martha illustrates the high stakes for patients when she discovers that she overlooked time-sensitive information with financial implications. This discovery added to her already high levels of anxiety. Effective PHIM interfaces will emphasize information needed for active tasks and de-emphasize information not directly related to current events reduce scalability barriers by helping patients attend to a smaller set of high-priority information. Other information not needed for active tasks can accumulate in the background without overwhelming the user or masking time-sensitive material. Third, PHIM interfaces should help patients navigate their information from the patients' perspective. For example, Martha would benefit from being able to sort incoming information by the date that her tasks are due, instead of the date services were rendered or the date insurance companies were billed. In sum, effective PHIM interfaces will help

patients integrate descriptive and procedural information, emphasize information related to active tasks, and provide navigation tools consistent with patients' experience of cancer care to provide an action-relevant view of information that reflects their tasks as they move through treatment.

#### *Leverage assistance from others*

One of the most viable PHIM strategies is to help patients is leverage assistance from others. By involving people from their social network in their organizing work, patients can potentially overcome all four classes of barriers. For example, patients can ask others to: (1) organize information for them when they lack time to organize it; (2) work with them if they experience adverse reactions to the process (e.g., engaging the information stimulates negative emotional reactions) or product (e.g., organizing the information highlights potentially negative outcomes) of organizing their health information; and (3) guide their understanding of why particular information is important, how the information can be used, and what organizational strategies might facilitate retrieval and use given their particular situation. Thus, by leveraging personal assistance from others, patients can avoid problems associated with accumulating unorganized information. To meet this requirement, PHIM tools must provide support for multi-user collaboration.

#### *Incorporate emotions into research and design*

Emotional considerations play an important, yet overlooked, role in informatics research and system design.<sup>6</sup> For example, researchers have developed a broad literature on clinician-patient communication and the delivery of bad news,<sup>8</sup> but such evidence is poorly suited to address the psychological distress experienced in the home away from clinicians and the treatment center. One particular concern is that a negative feedback loop might exist in which patients' own awareness of accumulating information—and the potential impact of not organizing it—paralyzes patients in a recursive cycle of distress during treatment when information management is essential to facilitate patient involvement in their care. For example, without functionality to help her, Sarah postpones organizing her information but lives with the angst that her organizing task grows with continued postponement.

Studying this feedback loop will provide new insights into the role of information in stress management during breast cancer care. A potential outcome of this research is the design of calm technologies<sup>7</sup> to allow patients to engage their information meaningfully in the midst of psychological distress that inevitably

accompanies patients during active treatment. For example, clinicians and designers could collaborate to explore links between common stress reduction approaches used in cancer care and interface design. For example, designers embed cognitive cues based on stress-reduction techniques in mindfulness, relaxation, or cognitive behavioral therapy into PHIM interfaces. This approach extends known stress-reduction techniques and supports continuity of strategies already employed to manage stress during cancer care.

#### **Conclusion**

Patients struggle to organize their health information, despite recognizing the clear benefits to organizing that information. In this paper, we have described, with rich examples, four types of barriers these patients face: emotional, scalable, temporal, and functional. Although we studied cancer patients exclusively, many patients likely face similar barriers, but the intensity of those barriers probably vary depending on the severity and duration of their health condition. Nonetheless, all patients could benefit from efforts by health-information providers or technologists to reduce these barriers. As healthcare moves increasingly online, PHIM tools could allow patients to focus their valuable time and attention on improving their health, rather than struggling to manage their health information.

#### **Acknowledgements**

Thanks to NLM Training Grant #LM007442 & NLM Grant #1R01LM009143 for supporting this work.

#### **References**

1. Jones W, Bruce H, Foxley A, Munat, CF. Planning personal projects and organizing personal information. Proc. 2006 ASIST Annual Meeting.
2. Boardman R, Sasse AM. "Stuff Goes Into the Computer and Doesn't Come Out": A Cross-tool Study of Personal Information Management. Proc 2004 SIG CHI, 583-590.
3. Unruh KT, Pratt W Patients as actors: The patient's role in detecting, preventing, and recovering from medical errors. *Int J Med Inform.* 2007;76:236-244.
4. Flanagan JC. The critical incident technique. *Psych Bulletin.* 1954;51:327-358.
5. Brown BAT, Sellen AJ, O'Hara KP. A Diary Study of Information Capture in Working Life. ACM CHI '00. The Hague, The Netherlands; 2000. p. 438-45.
6. Norman DA. Emotional design: why we love (or hate) everyday things. New York: Basic Books; 2004.
7. Weiser M, Brown JS. The Coming Age of Calm Technology. In: Denning PJ, Metcalfe RM, editors. *Beyond Calculation: The Next Fifty Years of Computing.* New York: Springer-Verlag 1997.;
8. Fallowfield L, Jenkins V. Communicating sad, bad and difficult news in medicine. *Lancet.* 2004;363: 312-9.