

User Experience Considerations for Patient-Centered Handoffs in Surgical Oncology

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Abstract. Handoffs, the transfer of care responsibility from one provider to another, commonly occur in intra-disciplinary silos that exclude patients. Little is known about patient preferences about handoff participation in surgical oncology and key information needs including user experience (UX) considerations. This exploratory, descriptive study was conducted at a cancer center in the western United States using a purposeful sampling technique to select 20 surgical oncology in-patients. The team used methodological pluralism for data collection: naturalistic observations, interviews, field notes, and artifact capture. Data analysis included systematic steps and content analysis consistent with accepted qualitative research methods. The analysis resulted in 356 codes synthesized into 15 categories and 3 themes: Depends Upon How Sick I Am, I Want To Know Everything, and My Life Is In Their Hands. Fifteen participants expressed varying levels of interest in participating in handoffs, and 18 of the 20 wanted to know "everything" about themselves. Initial categories of patients' information needs were developed. An opportunity exists to expand health informatics tools to inpatients and their families and design them from patients' perspectives. UX considerations are outlined to expand informatics tools for collaborative decision making to inpatient activities and include person-centered applications, electronic white boards to consider user diversity and tasks as well as context-sensitive information design.

Keywords: Handoffs, user experience, qualitative research.

1 Background

Communication breakdowns between providers are recognized as a predisposing factor in medical error. [1] Standardized information exchange protocols, such as SBAR (situation-background-assessment-recommendation), are viewed as a solution for these kinds of communication breakdowns that include patient care handoffs. Unfortunately, the complex, interruption-filled, healthcare environment is not conducive to providers focusing on a single event even with a tool such as SBAR. This has

led to workarounds and limited adoption of standardized methods of information exchange during patient care handoffs and other communication activities.

The patient is, arguably, the most vested member of all involved in the process of patient care. This recognition has resulted in a move toward patient-centered care and has become the focus of many healthcare safety and quality improvement initiatives. [2] Despite the recent acknowledgement of patient engagement needs, handoffs or the transfer of patient care responsibility from one provider to another commonly exclude patients and occur in intra-disciplinary silos. Yet, including patients in handoff processes would support shared decision making while respecting patient autonomy. Patient participation in handoffs also would reflect the right for them to partner in their own care as well as having the potential to improve care outcomes, communication accuracy and informed decision-making. [3]

Family-centered multidisciplinary rounds [4] and bedside nursing shift change report [5,6] have been implemented in many hospitals as a way to include patients and family members in the information exchange process. In the United States, government initiatives have mandated the adoption of electronic health records (EHR) and patient access to their health information. [7] An important component of these initiatives is commonly referred to as the Meaningful Use mandate. This mandate addresses specific uses of EHRs and electronic access to health information by patients. Although these mandates currently focus on the outpatient setting, a natural next step is developing tools to assist with patient access to clinical information in the inpatient environment. These tools are needed to enhance patient involvement during the provider handoff process.

Appropriate information content for collaborative handoffs, where patients are active participants, has not been determined. [8] Social roles, demographic factors such as age, physician authority and the fear of being labeled “difficult” have been shown to be obstacles for patient participation. [9] Little is known about patient preferences regarding handoff participation in surgical oncology and key information needs including user experience (UX) considerations. The purpose of this qualitative study was to determine patients' preferences about handoffs, identify current tool use and specifications for patient-centered information tools including UX requirements.

2 Methods

This exploratory, descriptive study was conducted on a 25-bed patient care unit at a cancer center in the western U.S. Using a purposeful sampling technique across demographics, levels of care, types of surgical procedures and recovery course, 20 adult surgical oncology patients were selected and agreed to participate.

Institutional Review Board approval was obtained. The team used methodological pluralism for data collection: naturalistic observations, interviews, field notes, and artifact capture. The scripted interviews used standardized questions with probes. Three areas were the focus for the interviews: preferences about participating in

handoffs, patients' information requirements and tools patients or families currently used to track care. Interviews were transcribed by a professional transcription company, checked for accuracy and uploaded into Atlas.ti for analysis. The team analyzed data using systematic steps [10] and content analysis. [11] First cycle coding, completed jointly, allowed definitions and boundaries to be created. Second cycle coding was completed by defined pairs of coders across all transcripts, and third cycle coding consolidated the generated categories into themes.

3 Results

The mean age of the 20 participants was 58.4 with a range from 28-85, and both genders were equally represented. One-half of the sample completed at least some college-level coursework although two had not graduated from high school. The patients underwent a variety of surgical procedures typically seen on this patient care unit.

The analyses resulted in 356 codes synthesized into 15 categories and 3 themes: Depends Upon How Sick I Am, I Want To Know Everything, and My Life Is In Their Hands. [8] This paper focuses on the first two themes because they are more relevant for user experience considerations. For the first theme, 15 participants expressed varying levels of interest in participating in handoffs. Six were neutral about their participation with statements such as, "Yes, I might." A small subset saw handoffs as the sole purview of providers while as many others had strong sentiments about participating, saying "It's my body and my health." The types of handoff participation patients wanted varied from just listening to being very active in the handoff process. Most participants wanted to be invited into the handoff process by being asked questions.

For the second theme, five categories were identified: patient tools, shared electronic health record information, information needs, discharge information and patient preferences. None of the participants currently used electronic tools or had EHR information shared with them while they were in-patients. Most tracked information in their heads or had family members act as information managers.

Ten of the 20 used hospital provided in-room white boards to track information (names of their nurses, family contact information and/or medications). Examples of whiteboards are in Figures 1 and 2 below. As may be seen in the figures, the whiteboards had a variety of uses from minimal (caregiver names or family contact information) to more information including scheduled medication times or the number of times the patient ambulated during a shift. One patient tracked his stated daily goals and his progress toward those goals on the whiteboard. None of the patients used the pain scale available on these artifacts. Four participants/families used hand-written records of varying depths. These records spanned in-patient, home and out-patient settings.

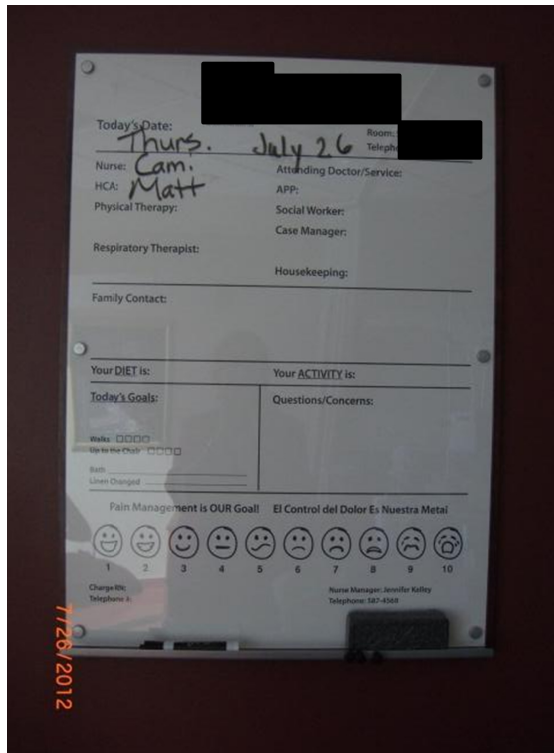


Fig. 1. An Example of a Whiteboard with Minimal Information

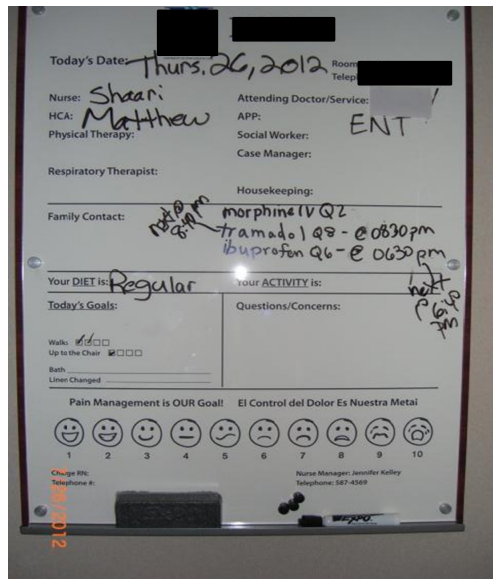


Fig. 2. Examples of Whiteboards with More Information

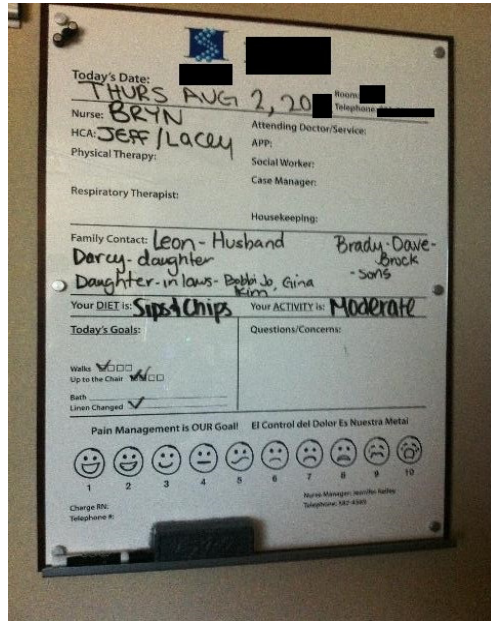


Fig. 2. (continued)

Sample information needs from the participant interviews are represented in Table 1. From the variety of sources, overall information needs were identified including initial categories of patients' information needs. Common categories were: medications, wound care, appointments (both in-patient and out-patient) and discharge information. However, most participants (18 of 20) wanted to know

Table 1. Exemplar Quotes about Patients' Information Needs

<p>“I would love to know everything about me.”</p> <p>“I want to hear what’s going on. This is my life.”</p>
<p>“What’s going to happen to me, about my incision? When are the staples supposed to come out? What time am I supposed to meet with the doctor? What doctor am I supposed to meet with? Everything.”</p> <p>“I think it would help me understand more what’s going on with me. More of what I can do for myself. Make me more aware of how severe my problem is or how not so severe.”</p>
<p>“I have a notebook that I keep. I have people, pain control...and the things that I should and shouldn’t eat. The different type of chemo treatment they’re supposed to give, different medications.”</p>

"everything" about themselves including their prognosis, saying for example, "I think you should be aware of everything," and "This is my body and I want to be aware of what's going on..."

Participants were evenly divided on the need for an electronic in-patient tool for oncology. Quotes on this topic ranged from "I know what's going on. It's nothing I have to write down..." to "...I need to be aware of everything."

4 Discussion

No patients used electronic tools, not even to take simple notes or write questions for providers to answer. This was surprising given the general public's use of smart phones and mobile devices such as iPads. In contrast to this lack of tools, the vast majority of participants wanted to know everything about themselves, which would imply tool usage to track information. Therefore, an opportunity exists to expand health informatics tools to inpatients and their families and to design them from patients' perspectives. Most important, these tools need to support collaborative decision-making in the inpatient setting. User experience (UX) considerations need to be created even before initial prototyping begins.

A long-term goal would be to create person-centered health records that manage health data in a longitudinal manner, beyond the current notions about personal health records (PHRs) or episodic, inpatient personal health records. These new longitudinal electronic tools could provide support for collaborative activities that include, for example, patient-centered handoffs and facilitated participative information management in other settings including the ambulatory care or home care arenas. While it may be tempting to create inpatient records tethered to acute care EHRs as a more permanent solution, this move would be short-sighted. Much like current personal-health records with limited data availability and requirements to manually enter information, [12] tethered person-centered health records would include only limited data and information centered on organizations or a subset of providers instead of more person-centered data and information.

Long-term, these new tools would follow precepts outlined by Cortese [13] about a "keep you well" health system: (1) care wherever the person is (home, work, school), (b) by an integrated, multidisciplinary team, (c) with whatever device, (d) providing information at the point of care. The longer-term focus would shift to home or work while allowing collaborative decision making activities such as handoffs in an acute care setting. Most important, individuals need health records that allow interoperability and data access across settings, i.e., records centered on them versus providers and organizations as is the current method. With the individual as the center of data and information management instead of organizations, supporting informatics tools would need to be redesigned. This vision would require years of development. In the meantime, other options may be fruitful.

5 Context-Sensitive Information Design and Tools

First steps may include a patient-centered tool tethered to the EHR and to expand the use of the whiteboards in patients' rooms. A tethered, person-centered healthcare record would include pertinent data from the EHR related to the current course of stay but would need to be robust enough also to allow data input by patients and their families, e.g., preferences, family contact information, questions for providers. This represents a change from current capabilities as patients are not allowed access to inpatient EHRs. These could be designed using either the patient care summary or the multidisciplinary plan of care to push information to an application useful for handoffs in surgical oncology. This kind of summary could guide shared decision-making among providers, patients and family members. Pertinent information could be sent to other devices such as electronic white boards in patients' rooms to display key information as discussed below.

Typical information would be available to the patient as well as the patient and nurse collaborations during handoffs: medication information, daily care goals such as ambulation or pulmonary activities, test results, and discharge planning. Handoff content would include collaboratively-set care goals for discharge and for the day or shift, information related to the problems with interventions and progress toward these goals and/or problem resolution. At discharge, a summary of care, home care requirements such as medications and wound care, would be electronically sent and/or printed for patients. Portions of this record could allow data entry by patients to update emergency contact information, care preferences or restrictions such as a do not resuscitate order or to pose questions to nurses or physicians.

Another promising method may be to expand white boards to an electronic means that allow information input as well as viewing by patients/family members and providers. The whiteboards could include basic information such as collaboratively set care goals including collaborative pain management goals, medication times with patient response and next dose information as well as patient progress toward shift or daily goals. Specific interventions, such as wound care every eight hours, and scheduled inpatient procedures, such as MRIs, could be listed. For both of these options, interoperability with the local electronic health record would be an obvious requirement. Ideally, inpatients and families would be able to bring their own devices such as iPads to use. Clearly using mobile devices would offer an optimal method for the opportunity to participate in care and flexibility for patients and family members.

5.1 Users and Tasks

Potential surgical oncology inpatient users will have diverse characteristics so designs would be similar to mHealth applications targeted for use by the general public. Because inpatients may not feel well enough to participate in collaborative activities, defined users must be expanded to include family members as well as the inpatients themselves. Both inpatients and their families will be diverse in technology experience and education levels as exemplified in our exploratory research. Thus, future devices and applications need to be targeted to accommodate individual

characteristics representative of the general public. Using mHealth design considerations may be helpful. [14,15]

Task-related information for surgical oncology inpatient records includes: ability to access information about the specific type of cancer including educational material, the type of surgery performed with diagrams or illustrations, length of time since surgery, ability to access medication information such as time of last dose, next dose and a pain effectiveness rating. These last two could be trended over time and plotted against each other. Certain fields should allow patient input as discussed above.

Task representation for whiteboards may be more limited: time and name of last pain medication, time next pain med is due, patient care goals for the day such as number of times to ambulate or an intake goal of, say, 2000 cc's, family or emergency contact information and patients' progress toward daily and discharge goals. If space is available, including any scheduled appointments or activities would also be useful.

6 Conclusions

Inpatient tools and their HCI considerations represent a new area of inquiry. A potential exists to improve patient outcomes, care satisfaction and smooth transitions from acute care to ambulatory and home care especially when the user experience is considered as these new tools emerge.

This exploratory study is, to our knowledge, the first to outline initial information content and UX considerations for patient-centered handoffs. This initial study showed patients' willingness to participate in handoffs, outlined information needs and uncovered potential tools for person-centered applications of the future. Inpatients typically want access to robust information about themselves. UX considerations are multiple. Stakeholders need to include family members and any designs need to be targeted to use by the general public with varying education levels, technology experience and abilities. Tasks are designed based upon patient care goals/problems, interventions and progress toward goals. Context-specific information for surgical oncology specifically includes pain management, wound information, follow-up cancer care and appointment schedules.

6.1 Limitations and Future Research

Limitations to this study include: (1) the sample was slightly more well educated overall than most and (2) the study was completed in a cancer specialty hospital, potentially limiting the generalizability of the findings. Future research may be to develop user experience requirements in more depth, to create a pilot project for electronic white boards and to expand decision aids to the inpatient arena and handoff activities. The user experience requirements could be validated using an initial prototype electronic whiteboard or handoff tool that is interoperable with the institution's electronic health record. A diverse set of inpatients and their families could be tested for the feasibility and design of this new tool in oncology.

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