

Comparing Health Information Sharing Preferences of Cancer Patients, Doctors, and Navigators

Maia Jacobs, James Clawson, Elizabeth D. Mynatt

College of Computing

Georgia Institute of Technology

Atlanta, GA 30332, USA

mjacobs30@gatech.edu, {jamer, mynatt}@cc.gatech.edu

ABSTRACT

As technologies such as personal health records and symptom trackers become more common, we are seeing an increase in patients actively engaging in health tracking behaviors. Patient collected data can provide valuable insight for healthcare providers, particularly in the area of breast cancer. Thus far, little work has examined whether the health information that patients are willing to track and share aligns with the information needs of healthcare providers. Our work provides a comparison between the health information sharing preferences of breast cancer patients, doctors and navigators. We identify discrepancies between stakeholders' preferences, such as patients' hesitation to share feelings of loneliness, signifying where technology can play an important role in helping patients prioritize the health information shared with providers. We present design implications from this work to guide the development of future health information sharing tools that consider the differing needs of healthcare stakeholders.

Author Keywords

Health Tracking; Physician-Patient Communication; Cancer Care; Cancer Navigation

ACM Classification Keywords

H.5.3 Group and Organization Interfaces: Collaborative computing, Organizational design; J.3 Life and Medical Sciences: Health, Medical Information Systems

INTRODUCTION

Personal health tracking is changing the landscape of healthcare. Patient-centered tools such as personal health records (PHRs), and symptom trackers are allowing people to actively engage in their personal healthcare. With these changing practices, health systems have the opportunity to utilize patient collected data to tailor and improve the care provided to their patients.

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Breast cancer care provides one area of healthcare that could greatly benefit from patients tracking and sharing health information. Cancer care is often modified for individual patients and one's symptoms and side effects can heavily influence the treatment plan [7]. Cancer treatment can often encompass a complex trajectory, distributed across multiple healthcare organizations. Thus, patients become responsible for communicating vital health data to help the medical teams monitor treatment impacts.

While patient self-monitoring and sharing of health information has the potential to benefit patient care, little work has identified whether the health information patients are willing to track and share aligns with the health information needs of the providers. By considering the relative needs of these distinct stakeholders, future tools could encourage patients to prioritize reporting health information that is of particular importance to their healthcare providers. Further, these patient centered tools may expand to provide greater collaboration between patients and providers.

In order to enhance our ability to develop tools that consider the needs of these multiple user groups, we compare the health information sharing preferences of breast cancer patients, doctors, and cancer navigators (professionals who help cancer patients navigate the complex healthcare system by providing individualized support and resources). We aim to call attention to the need for future health information sharing tools to promote greater collaboration between patients and their healthcare network, an area where CSCW researchers can have a significant influence on improving patient experiences. Our work provides the following contributions:

- We examine the health information sharing preferences of patients, doctors, and cancer navigators across 23 distinct health factors relevant to the breast cancer journey. Our results highlight the willingness of those involved in the cancer care process to utilize tools that encompass a robust set of health factors.
- We reveal discrepancies between patients, doctors, and cancer navigators' health information sharing preferences. Misalignment was particularly evident in regards to sharing emotional health factors. The finding points to an opportunity for technologies to bridge the

gap so that patient tracking behaviors align with the informational needs of their healthcare network.

- We identify four design implications to guide the development of future health sharing tools that will consider the needs of patients and providers.

RELATED WORK

Benefits and Challenges of Health Tracking

Patient Perspective

Patient engagement is becoming increasingly recognized as a significant aspect of healthcare, particularly in the cancer care process. Personal health tracking can allow patients to receive the necessary help in stressful situations, directly influence treatment decisions, and improve health outcomes [13,19,22]. Health tracking practices can help mitigate limitations in the existing health system, in which a patient must recall as much information as possible during time-constrained meetings with their providers [2].

Continuous patient engagement brings new challenges alongside the benefits. Patients often must share basic medical information with concerned family members and friends. In parallel, patients may also track side effects to share with their oncologist to help in determining future steps and influence health outcomes [22]. Overall as the network of care enlarges, the burden falls on the patient to share the appropriate information with each person within their formal and informal healthcare networks [17].

Provider Perspective

For healthcare providers, including doctors and cancer navigators, the increase in patients tracking their own health provides a wealth of information. Such information can help doctors and cancer navigators to more efficiently focus their time [6]. While doctors and navigators will often work to assess patients' health status during appointments, a more accurate understanding of a patient's health situation can be gained by the patient providing his or her own assessments [21]. Receiving this health information prior to appointments can also allow a more direct focus on areas that require a doctor's or a navigator's attention during in-person patient meetings.

The challenge with utilizing this information is that these valuable data are not yet regularly incorporated into healthcare treatment [2]. Providers have discussed viewing the information that patients track and add to PHRs as medically useful, especially when patients' medical records are not available [24]. However, these same providers did not have access to electronic records that could interoperate with the patients' own records. By providing more detailed insight into which specific health factors could benefit cancer providers, we hope to encourage the development of tools that support both patient health information sharing as well as the incorporation of the patient collected health information into cancer care.

Perceptions Toward Sharing

Social computing research has identified many scenarios in which a person may wish to share different pieces of information, or provide different levels of access, to others [5,10,18]. In the health field, we see a desire from patients to share subsets of health information with selected groups. For instance, one study found that users of mobile health tools opted to share more information with strangers than with friends or family [16]. The Digital Family Portrait provides another example in which a subset of personal information was shared with family members [12]. These studies demonstrate the importance of understanding the social context that can influence sharing behaviors. In addition, a study examining diabetes patients found that these preferences and attitudes towards health information privacy can change over time [14].

Such studies help us gain an understanding of the personal beliefs and desires that underpin health information privacy. We aim to expand on this work by investigating the social and medical implications of health monitoring for the cancer care system, as the severity and complexity of the disease can bring additional challenges.

Personal Health Tracking Tools

Emerging technologies are encouraging patients to actively engage in tracking their own health. PHRs provide one such technology. PHRs provide a single location for patients to collect information about their medical history, treatments, and medications [23]. The challenge with many existing online medical records, as discussed in a recent study, is that these records utilize an all or nothing access model that does not consider the various levels of sensitivity intrinsic in certain health information [3]. Thus, while patients may engage more directly with their health records, they do not necessarily have tools that support their preferred health information sharing practices, nor the preferences of those receiving the information.

Symptom trackers provide another tool that allows patients to actively manage their healthcare. Patel et al. found that utilizing real-time tracking tools helped cancer patients keep more accurate symptom data and enhanced communication between patients and their doctors [15]. Patel's work also called for future health trackers to provide patients with greater ownership of their data, and the freedom to specify which data to share with different individuals.

Mobile technologies are also emerging as useful tools for patients' health management. The HealthWeaver mobile project used a mobile phone application to allow cancer patients to capture ad hoc symptoms and questions for their doctors [11]. Similarly, the My Journey Compass project used tablets to provide cancer patients with a symptom tracker and provider contact information within a broader suite of cancer related applications [8].

While technologies such as these help patients track important health information, they have yet to provide features that allow providers to incorporate health information sharing preferences as a way to focus patient behaviors. We aim to provide a comparative study examining patient, doctor, and cancer navigator preferences, ensuring that future tools are beneficial to all those involved in cancer care.

METHODS

We designed this study to better understand health-sharing preferences of breast cancer patients, doctors, and navigators. We utilized surveys, interviews, focus groups, and a card sorting activity to elicit information from our participants. All of our participants were a part of the cancer care system in a residential town in the southern United States. The town consists of a community that spreads across the full socio-economic spectrum. The health system serves a geographic area of over 500 square miles with a population around 100K. In 2013, the health system treated 260 breast cancer patients. To date, the local cancer care system utilizes a process in which patients decide if they want to track and share their personal health information with their providers. Our study provides foundational information to improve this process, alleviate some of the responsibility from the patients, and make available more relevant information to providers.

Patient Surveys

To understand patients' willingness to share health information with various groups in the cancer care network, we developed a survey that asked patients to identify whether or not they would feel comfortable sharing 23 different health information factors with 7 different groups of people. The health information factors include basic biometric information, physical side effects, and emotional issues pertinent in a cancer journey. Through discussions with cancer navigators, doctors and patients, we selected the health information factors that were relevant for breast cancer patients. To further ensure the appropriateness of the list, we asked participants of this study whether any important factors were missing. Participants commented that the list was comprehensive.

The final list of health factors included two biometric factors, fourteen physical health factors and nine emotional factors. Biometric factors included height and weight. Physical health factors included pain, nausea, constipation/diarrhea, fatigue, hot flashes, sleeplessness, hair loss images, medication adherence, surgery details, cancer stage, survival statistics, scar images, breast images, and diet. Emotional factors included stress, anxiety, loneliness, fear, seeking support, 'I am having a good day' and 'I am having a bad day'. Height was used as an initial factor that possessed few emotional implications as a way for patients to get acclimated with the survey questions.

In the survey, patients were asked to indicate for each factor whether or not they would feel comfortable sharing the information with the following groups: Me, Caregiver, Navigator, Oncologist, Social Media, and Society.

'Me', as explained to participants, was a way for a person to indicate whether each health factor would be something they were interested in monitoring themselves throughout their cancer journey. 'Caregiver' was used to represent any person in the patient's health network who helps look after the patient (usually a close relative or friend).

'Navigator' was used for asking whether or not patients would share health factors with their cancer navigator. Cancer navigators provide patients with individualized support to mitigate barriers to care, including emotional, financial, and logistical issues that typically arise during the cancer journey [9]. Barriers can vary based on a number of factors, including diagnosis, treatment plan, and socioeconomic status. Thus, navigators offer a range of services, including answering health related questions, providing emotional support and therapy, and accessing vital resources such as gas cards (for those who can't afford the increase cost of driving to daily treatments) or health insurance. In Rome, GA, cancer navigators play a central role in the breast cancer care process. The navigation organization exists outside of the network hospitals and cancer clinics but works with these health institutions to provide personalized support for cancer patients. Navigators will typically meet with patients at their first meeting with the general surgeon and continue to meet with them throughout their treatment.

'Social Media' represented any social networking sites used by participants. Many of our participants engaged to a various degree with Facebook and other social media. For participants who did not, we asked them whether or not they thought they would feel comfortable sharing the information online. 'Society' was used as a means to ask patients if they would feel comfortable sharing certain health information in public settings, such as a public forum or open cancer awareness event.

We asked about these distinct groups in order to gain a more holistic view of patients' health information sharing preferences as they relate to their entire healthcare network. For the purpose of this study we focus on their preferences for sharing health information with their doctors and navigators.

Patient Interviews

To compliment the survey, we wished to gain a deeper understanding of the thought process used to decide what information patients were willing to share with the various groups. We developed a card sorting activity that mirrored the information collected in the survey. In the activity, the health information factors and groups were written on cards. The groups were placed along the top of a table to create individual columns. Patients would then receive the

health factor cards. For each group, the patient would place the health factor card in one of two piles below the group heading to indicate whether they would or would not be willing to share that health factor with that group. During the activity patients were encouraged to think aloud and the interviewers would occasionally ask probing questions to better understand the thought process. Table 1 shows a sample of data collected after a patient went through the first four health factors. Figure 1 shows a photograph of the activity after all of the health factors had been laid out.

All interviews took place in the cancer navigation office and lasted 1-2 hours. We found that responses from the interviews were comparable to the survey responses, while providing some additional information about the thought process behind the results.

Patient Participants

The survey was sent out to 67 breast cancer patients in the Rome, GA community. We also ran interviews with four additional patients (represented in this paper as P1-P4). All patients were female and had been diagnosed with breast cancer within the past year. Patients’ average age was 60 years old. Patients had varying stages of breast cancer and treatment plans, but all received treatment in Rome, GA.

We received 20 survey responses (a response rate of 29.9%). Three of the survey responses were removed from the analysis because the participants marked the same answer for each question. When combined with the responses from the four patients who participated in the interviews, we analyzed a total of 21 patient responses.

Participants who were interviewed had participated in previous interviews with the researchers for a separate study. We hoped that this on-going relationship would result in open, honest conversation, which could otherwise prove challenging due to the personal and sensitive nature of the information discussed.

Doctor Focus Group

In addition to understanding how patients felt about sharing health information, we wished to get a sense of the types of patient information doctors would be interested in monitoring. We ran a focus group with three doctors: a medical oncologist, a radiation oncologist, and a general surgeon. All three doctors work with the breast cancer

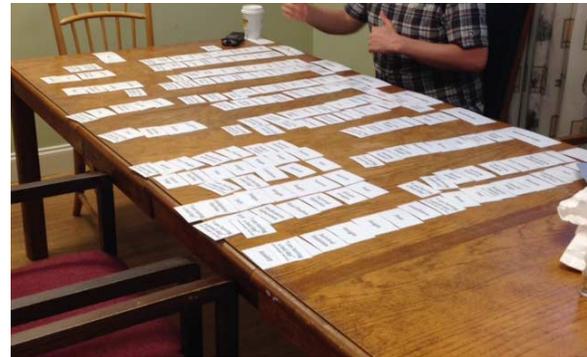


Figure 1: Image of a completed card activity

patient population described above. We conducted a focus group as opposed to individual interviews due to the preferences and availability of the doctors.

With these doctors we ran an activity similar to the card activity used with patients. For every health factor, each doctor stated their interest in receiving and monitoring information about that factor collected by their patients, and whether or not they currently collect that information. Upon completion, we asked the doctors to rank the health factors they were most interested in monitoring. This ranking allowed us to gain an understanding as to which features would be necessary on future health monitoring tools to encourage provider use.

Cancer Navigator Interviews

We ran the same card activity with two of the cancer navigators (represented in this paper as N1 and N2). Both navigators were nurse navigators. Nurse navigators’ work straddles the medical and emotional aspects of the cancer journey and they deal directly with many of the health factors included in the patient survey. Interviews were conducted with each of the navigators individually due to their differing availability.

Data Analysis

Two researchers reviewed the survey and interview data. The researchers used an iterative analysis to cluster segments from the survey responses and transcripts and develop thematic concepts. Researchers focused on preference reasoning, discrepancies between sharing

Willing to Share?	Me	Caregiver	Oncologist	Navigators	Social Media	Society
Yes	Height, Weight, Pain, Nausea	Height	Height			
No					Weight, Pain, Nausea	Weight, Pain, Nausea

Table 1: Sample of data collected after a patient completed the first four health factors

preferences, and technology design implications. The two researchers reviewed each other's analysis and came to a consensus on the themes.

FINDINGS

In this section we provide an overview of the doctor, navigator, and patient responses, summarized in table 2. We then examine some interesting factors that influenced patient preferences, including patient assumptions, cancer identity, and concerns about imposing on others. Finally, we examine the misalignment between patient and doctor responses.

Doctor Responses

The focus group activity with the medical oncologist, radiation oncologist and general surgeon revealed that eleven of the health factors would be important to all three doctors for continuous monitoring. These factors included both biometric factors (height and weight), four physical factors (nausea, constipation/diarrhea, hot flashes, and medication adherence), and five emotional factors (stress, anxiety, loneliness, fear, and seeking support). The medical and radiation oncologists were interested in an additional four physical factors: pain, fatigue, sleeplessness, and diet. While this list includes many distinct factors to track, all three of the doctors emphasized that the combination of information across many factors would be important in allowing them to better understand the context when issues do occur.

When asked to rank the factors in terms of their importance, each doctor agreed that pain, nausea, and constipation/diarrhea are typically the most important as they can greatly influence a patient's daily life. However, the doctors also stated that these can change depending on the patient, and anything that could negatively impact quality of life will be important for the doctor to monitor. As the general surgeon noted:

"The quality of life issues [are most important]. Most patients, if you ask them, their goal is to have some semblance of a good quality of life. Well, you can't have a good quality of life if you're in pain all the time, if you're sick, if you're having diarrhea... These are things that really impact their day to day." - surgeon

Thus, based on the doctors' feedback, health tools that monitor a range of quality of life factors, including both physical and emotional factors, will be most beneficial to them, despite the large amount of information.

Navigator Responses

Both navigators stated that they currently talk to patients about eleven of the health factors. These include six physical factors (pain, constipation/diarrhea, fatigue, medication adherence, surgery details, and cancer stage) and five emotional factors (anxiety, stress, loneliness, fear, and 'I am having a bad day'). In the future, the navigators

discussed a desire for health tracking tools to include these factors. Both navigators were also interested in including nausea and sleeplessness to their practice through future tools. N1 expressed interest in monitoring additional health factors, including height and weight (due to their impact on BMI), diet, seeking of support, hair loss images and scar images. N2 stated an interest in monitoring hot flashes.

The main similarity between the two rankings is that loneliness is viewed as critical to both of the navigators, ranked first and second in their individual orderings. However, when looking at their top ten ranked health factors we can see differences emerge. N1's top ranked health factors included (in order) loneliness, surgery details, pain, medication adherence, constipation/diarrhea, nausea, fatigue, stress, sleeplessness, and weight. N2's top ranked health factors included cancer stage, loneliness, anxiety, fear, stress, surgery details, fatigue, diet, pain, and constipation/diarrhea.

Looking at these rankings side by side, N1 focused more on medical issues while N2 ranked the emotional issues higher. These differences were primarily due to the fact that the navigators work with different groups of patients. N1 works with a wider range of cancers than N2, who works exclusively with breast cancer patients. A broader array of health challenges result from the additional cancer diagnoses. Ultimately, such variations demonstrate the need for health tracking tools designed for cancer navigators to include both physical and emotional health factors. Further, tools must be agile so that they may be tuned to best serve the individual journey of the patient.

Patient Responses and Motivations

Table 2 shows the percentage of respondents who indicated a willingness to share each health information factor with their oncologist and navigator. The table shows that overall patients are willing to share their health information with doctors and cancer navigators. The interviews provided some additional context around these responses, particularly into how patients make health information sharing decisions. Here we discuss three influential factors that arose during our conversations with patients.

Assumptions

Two assumptions made by the patients seemed to drive information sharing preferences. The first assumption dealt with the perceived interest of the receiver, while the second assumption focused on the receiver's ability to help the patient. When looking at these assumptions alongside our conversations with the doctors and navigators we begin to see that these patient assumptions do not always align with the beliefs of doctors and navigators.

1. Perceived Interest

The first assumption that influenced information sharing was whether or not the patient thought the receiver cared about the information. For example, P2 specifically stated

that she would not share feelings of nausea on social media because her friends on social media “don’t really care.” Perceptions of interest also motivated the sharing of information. P2 stated that she was willing to share her fear with her family and cancer navigators:

“Caregivers, they really want to know that because they’re afraid, they’re very afraid for you. Navigators, they want to be there [for you].” - P2

2. Ability to Help the Patient

The second assumption patients mentioned involved the ability for the receiver to help the patient with her issue. In general, this was discussed in interviews as a reason for not sharing health information. For example, P3 discussed a previous experience in which she chose not to tell the doctors about the side effects of her treatment:

“I never usually have swelling but the first time I took

Tamoxifen, I took it on a Friday night. The next morning I woke up and my hands were like the Pillsbury Doughboy’s. My fingers were swelled together. I’ve never seen anything like it. And doctors said ‘you should have come to the emergency room.’ And I said ‘Well, and what would you have done? Nothing.’ So I just kind of watched it.” – P3

In this situation, an assumption led a patient to not share health details with her doctor. Such an example demonstrates the need to make the ways in which doctors can help with managing certain symptoms and side effects clear to patients. These perceptions help explain why patients and doctors did not always concur on what information ought to be shared with one another. In the next section, we explore this finding in greater detail, describing how this misalignment can hinder a patient’s cancer care and how future technologies may help ameliorate this gap in care.

Health Factor	Percent of patients willing to share		General Surgeon	Medical Oncologist	Radiation Oncologist	N1	N2
	(Doctors)	(Navigators)					
Height	100	100	X	X	X	X	
Weight	95	81	X	X	X	X	
Pain	100	95		X	X	X	X
Nausea	100	90	X	X	X	X	X
Constipation/diarrhea	100	90	X	X	X	X	X
Fatigue	100	95		X	X	X	X
Sleeplessness	100	95		X	X	X	X
Heat Flashes	95	90	X	X	X		X
Hair Loss Images	90	76				X	
Medication Adherence	100	90	X	X	X	X	X
Surgery Details	100	95				X	X
Cancer Stage	100	100				X	X
Survival Statistics	90	90					
Scar Images	90	86				X	
Breast Images	90	71					
Diet	86	90		X	X	X	
Stress	71	86	X	X	X	X	X
Anxiety	76	81	X	X	X	X	X
Fear	71	76	X	X	X	X	X
Loneliness	76	71	X	X	X	X	X
Seeking Support	86	86	X	X	X	X	
Good Day	90	86					
Bad Day	86	81				X	X
Totals:			2 biometric 4 physical 5 emotional	2 biometric 8 physical 5 emotional	2 biometric 8 physical 5 emotional	2 biometric 11 physical 6 emotional	9 physical 5 emotional
Top Ranked:			Nausea, constipation/ diarrhea	Pain, nausea, constipation/ diarrhea	Pain, nausea, constipation/ diarrhea	Loneliness, surgery details, pain	Cancer stage, loneliness, anxiety

Table 2. The percentage of patients who indicated a willingness to share the health factor with their doctor and navigator, and the health information sharing preferences of each of the providers.

Cancer Identity

A surprising result that emerged from discussions with cancer patients was the association between a patient's assumed cancer identity and the willingness to share health information. N1 described to us how she has witnessed patients adopt varying cancer identities:

"Sometimes cancer is a small part of their lives, and they'll say 'cancer is a small part of my life and I'm not going to let it dictate my future, it's not my whole life.' And then sometimes cancer becomes... they get stuck in that. That's their whole life." – N1

Our conversations with patients helped to reveal the way in which they perceive their cancers differently. For example, P2 described her cancer as a small hurdle:

"I feel like this is a bump in the road, you get over it, and you move on down." – P2

When examining P2's sharing preferences, she spoke of being open and willing to share symptoms such as nausea, fatigue, and pain with her doctors, caregivers, and navigators. She was also comfortable sharing some information on social media, such as feelings of stress, anxiety and her diet. For society at large, P2 said she would be willing to share her experiences with hair loss, stress, anxiety, diet, and seeking support. The dialogue centered on sharing in an effort to overcome the disease and to help others. In contrast, P3 seemed to disassociate herself from the cancer:

"I just didn't want any one to know. Except my own children know, and my brother and sister in law know... I try to act like I don't have it I guess. I don't want to be my cancer." – P3

This perspective also seemed to affect her willingness to share health information. In general, P3 was less comfortable sharing health information. She was less willing to share information with the cancer navigators and said she would not discuss some personal health details, such as weight or constipation/diarrhea side effects with her caregiver. Further, she would not share any health information on social media or society at large. P3 also said that throughout treatment other people in her life, such as her boss, did not know about her diagnosis because she didn't want to be seen as a cancer patient. When discussing her sharing preferences for health information generally, P3 focused mainly on protecting her privacy.

These contrasting viewpoints help to provide a glimpse into the types of personal traits that can influence a patient's willingness to share health information. Future research could delve deeper into the influence of a patient's cancer identity on daily behavior and relationships with others.

Imposing on Others

The desire to not impose one's problems on other people seemed to cause some patients to share less personal health

information. P1 specifically stated that she tries to keep her pain to herself because she doesn't want to bother other people. P4 also stated that her desire to not "whine and complain" caused her not to share information on social media or to society at large. Further, P4 stated:

"I tend to even with [my husband and children], not want to complain, put a pretty good face on it... And you know, not wanting to trouble them or worry them, so a lot of times I just won't share things that I think will hurt them or upset them." – P4

Other studies have noted similar results in which patients wished to "maintain positive impressions" around the people close to them [1]. Interestingly, a patient taking on this burden to deal with issues and side effects by herself was apparent to the cancer navigators. N1 described a conversation she has with numerous patients. When she asks patients "why have you been hurting for two weeks and you didn't tell me?" A common response from the patient is "I didn't want to bother you."

Patient/Provider Discrepancies

Through our results described above, and summarized in table 2, we can see that some misalignments between patient, doctor, and navigator preferences exist. For instance, we can see that some health factors were only of interest to the cancer navigators, and yet fewer patients were willing to share this information with their navigators than with their doctors. This misalignment can be seen in the responses to health factors such as hair loss images and 'I am having a bad day'. Also apparent in table 2 is the willingness and interest patients possessed to share health factors that were not of interest to any of the providers. This can specifically be seen in the breast images factor, in which 90% of patients said they would be interested and willing to share these with their doctors. These misalignments begin to show the need for technologies that help focus patients' health tracking and sharing behaviors, so that they may better support the needs of their healthcare network.

The health information sharing preferences surrounding the emotional factors lead to some interesting discrepancies as well. As we discuss below, we have found inconsistencies dealing with loneliness and patient satisfaction.

Loneliness Gap

Our findings revealed that 24% and 29% of patient participants stated they would not share feelings of loneliness with their oncologist or navigator, respectively. P2 stated she would not share loneliness because "doctors really don't care if you're lonely." Other patients discussed not sharing emotional factors, such as loneliness, because they did not feel that doctors could help in coping with these emotions. However, the medical oncologist gave an example of a recent patient to describe why communicating feelings of loneliness can be so important:

“If any one of these [factors] is off the charts it could be bad. It could be loneliness. I had a woman today. I was like ‘how are we going get her home?’ She won’t reach out to her best friend. And because of that she’s scared to death, and because of that she’s scared about coming in to treatment and doesn’t know if she wants to do it. And it all stems from loneliness.” – medical oncologist

The navigators also brought up loneliness as an issue. Both navigators ranked loneliness high on their list of important health factors to monitor, but recognized that patients do not always share this information outright. Sometimes it falls on the navigator to identify hints that loneliness may be an issue for a patient. As N1 described:

“Loneliness is something that is very shameful and embarrassing to them. So if I sense that this person is alone I need to be there a lot more then.” – N1

This “loneliness gap” begins to show that some misalignment exists between what patients, doctors, and navigators each feel are important health factors to share. The navigators noted that emotional issues are generally the most challenging for patients to share, specifically referencing loneliness, fear, and anxiety.

Addressing this gap carries two main challenges. First, in order to track loneliness or other emotional issues, a useful measurement must be utilized. As the general surgeon noted: “I don’t know how you would define loneliness.” The second challenge involves increasing patients’ willingness to share loneliness issues with their doctors and navigators. This may be possible if health-tracking tools highlight doctors’ interest in emotional issues and how they may be able to help the patient.

Tracking Patient Satisfaction

Although we did not specifically ask about patient satisfaction, stories concerning their satisfaction with the health system came up frequently in our conversations with patients. For instance, P2 shared one memorable moment with us:

“I remember one time I was going through a depression. I remember going to [my doctor], and he was busy writing, he had his back turned to me and I was on the exam table. And I said things are pretty rough, I feel pretty sad. And he never even looked at me.” – P2

Following this situation, P2 told her doctor directly that their interaction had upset her and received positive results in return. She stated that following that incident and subsequent discussion her doctor makes a more concerted effort to shake her hand and focus on her during appointments. However, not all patients are as willing to confront their doctors. For example, P3 shared that she once felt extremely upset with her care when she felt that she could not reschedule one of her radiation treatments:

“I don’t like being treated like that. I like having a choice. And it was never made clear to me why I didn’t have a choice. [My doctor] would want me to tell him, but I just, I just can’t. Because, number one, they’re not going to change.” – P3

Clearly, experiences like these can leave lasting impressions on patients. P3 finished treatment several months prior to the interview, but got visibly upset when sharing this story, showing the long-term emotional impact of patient satisfaction during the cancer journey.

Interestingly, patient satisfaction also leaves lasting impressions on the doctors. In the focus group, the doctors also brought up patient satisfaction and their desire to have patients share their feelings and negative experiences with them earlier. The general surgeon discussed his desire to improve the cancer care experience for his patients:

“You find out sometimes after you’ve gone through the entire process that somebody early in the course of care was unhappy about something... It would be nice if somewhere they were keeping a log that we had access to that says how happy are they with the way things are going. It gives us a chance early on in the care to realize [we have a problem]. But we can solve it. What happens is the problem has already occurred and three months later comes to my office. Well, I could have fixed that. Give me real-time data. Let me affect the patient’s experience by knowing their not having a good experience. I can do something about that. Give me an opportunity.” - surgeon

Similar to the issue of loneliness, some patients revealed feeling hesitant to share dissatisfactions about their healthcare to their doctors. Notifying doctors of satisfaction issues through technology may help alleviate the challenge of confronting the doctors directly. Ultimately, a more defined process for tracking and sharing emotional issues and enhanced communication between doctors and patients may help to address these contrasting preferences.

Summary

Table 2 provides an overview of the health information sharing preferences across patients, doctors, and navigators. To our surprise, all of the providers indicated a need to receive a set of both physical and emotional health factors. Further, they all preferred receiving a wide range of health factors, which provide greater context but take more time to monitor and understand. We also found several factors that can influence patients’ willingness to share, including assumptions about others’ interest and ability to help, patients’ cancer identity, and concerns about imposing on others. Through a comparative analysis, we identified discrepancies between patient, doctor, and navigator health information sharing preferences. Such misalignments point to the need for future tools to help bridge the needs of healthcare providers with the behaviors of patients engaging in personal health tracking.

DISCUSSION

Cancer care is becoming an increasingly collaborative process between patients and providers. While existing tools such as PHRs and symptom trackers help patients collect health information, research has yet to examine whether this information aligns with the health information needs of healthcare providers, such as doctors and cancer navigators. We examined the health information sharing preferences of cancer patients, doctors, and navigators in order to explore how future tools can incorporate the needs of these stakeholders and enhance the utility of patient collected information in their healthcare.

In reflection, our findings highlight four specific design implications. These implications aim to reduce discrepancies between patients, doctors, and navigators' sharing preferences. For these design opportunities we also discuss challenges that ought to be considered in the development of future health information sharing tools.

Allow Recipients to Select Important Health Factors

Undoubtedly, patients need control of their health tracking tools. Providing control not only to the patient but also allowing those in a patient's healthcare network to select which factors they want to receive may help increase the utility of health trackers. The main motivation for this feature is that we saw discrepancies between each of the doctors and navigators regarding which features they were interested in monitoring. Today, health information tracking and sharing tools place the responsibility on patients to decide with whom to share [3]. Providing this feature to a patient's healthcare network may also help to reduce the concern patients felt about sharing health information with people who did not care about that particular information. Allowing recipients to select the information they wish to monitor may help alleviate the burden placed on patients of trying to guess who in their healthcare network should receive select health information.

Challenge: Determining Frequency of Sharing

Allowing both the sharer and recipients of health information to influence the sharing process does bring additional questions that ought to be considered in future designs. Determining how often patients should share health information with their doctors and navigators remains an open question for health tracking processes. Capturing and sharing health information more frequently requires a greater time commitment from patients. However, less frequent sharing hinders the potential benefit of health tracking tools to provide early warning signs that health problems are hurting a patient's quality of life.

When asked about current sharing processes, each of the doctors and navigators stated that patients brought up health factors "when there is an issue." While all of the participants agreed that more frequent sharing would benefit the cancer care process, the appropriate pace of health information sharing was not identified. Examining

how different sharing frequencies influence health-tracking practices could greatly help the design of future health tracking tools.

Support Sharing of Past Experiences

An important feature for future health information sharing tools and processes is the ability for patients to learn from the past experiences of providers and other patients. This need falls under broader requirement to educate patients about how providers can use the information they share. We found that some patients hesitate to share information if they don't think the person receiving the information can help. Demonstrating how sharing health information with others can benefit the patient will be important for showing the full value of such tools to patients. Previous work has examined how peer support can be enhanced in cancer care [4, 20]. There remains an open opportunity for tools to allow new patients to learn from the experiences of doctors, navigators, and other patients. Particularly, revealing experiences in which health information sharing behaviors benefited the patient can help provide context around the importance of these practices. Such tools may help to eliminate the discrepancies between health information sharing preferences identified in this research.

Challenge: Permanency of Shared Information

In the development of tools that allow patients to learn from others' previous experiences, designers must consider the permanency of the information being shared. The benefit of retaining health information is that such information could be used to help future cancer patients. Several of our participants described a willingness to share information in an effort to help others. Thus, if the health information that patients share with doctors, navigators, and the broader society can be maintained past their cancer treatment, it may provide valuable insight for newly diagnosed patients who are experiencing similar situations. However, sharing personal health information can also have negative lasting consequences.

P3 discussed with us the negative impact sharing health information had on her life. Prior to her own diagnosis, P3's husband had been diagnosed with terminal cancer. P3 shared with us that because everyone in the community knew about her husband's diagnosis and the negative symptoms of his disease, she felt as though his cancer unwillingly became a part of her identity. P3's feeling that people identified her as "the cancer patient's wife," prevented her from sharing with others her own cancer diagnosis, even years after her husband's diagnosis. This story provides one example of how health information permanence negatively influenced one patient's cancer journey. Similar to selecting the types of information shared, patients may need control over the permanency of the information being tracked, and possess the freedom to change the information that is shared over time.

Minimize the Burden of Sharing

One surprising result that emerged from this study was the broad range of health factors all of the doctors and navigators wished to receive from patients. Each of these stakeholders requested at least eleven distinct factors. This desire for extensive health information sharing conflicts with the general desire to reduce the time that patients must spend focused on health tasks. As previously stated, all stakeholders, including patients, doctors, and navigators ought to influence the information that is shared between one another. Once these preferences are set, however, scaffolding sharing processes to minimize the burden may help provide doctors and navigators with rich context while reducing the need for patients to continually think about which information ought to be shared with whom.

Challenge: Respecting Patient Privacy

Previous studies have shown that patients prefer to share different health information with the various people in their lives [14]. Tools may need to provide this level of control to patients in order to encourage continuous use. However, this control over information sharing can also threaten patient care if patients opt not to share important health information with their doctors. Thus, a significant issue with health tracking is respecting patients' sharing decisions even when such decisions may impede on their cancer care. Including explanations within health tracking tools of how and why providers may use shared information to improve the cancer care process for a patient may help alleviate this challenge. Future work should look at how the health information sharing preferences of patients, doctors and navigators can be made more transparent to each other, as this may help to align sharing preferences.

Utilize Healthcare Network Collaboration in Design

Our discussions with doctors, navigators, and patients made apparent the need to include all of these stakeholders in the design process of future health information sharing tools. In our conversations, participants suggested interesting design ideas based on their own experiences. For example, N1 shared a typical discussion about pain:

"I always ask them on a scale of 1 to 10, and can you describe the pain to me. That helps me a lot. Is it throbbing, is it a dull ache, is it over here, is it shooting through the abdomen. The location of it helps a lot. And they are usually pretty descriptive." – N1

Integrating design features that mimic these types of conversations could help health tracking tools provide greater context about a patient's health situation. Further, such features may be easier for doctors and navigators to monitor as they correlate with their existing methods for understanding patient symptoms and side effects. Doctors also brought a unique background, posing a new set of possible future designs. They presented ideas such as combining health-tracking tools with the existing psychosocial distress screening (a 2015 healthcare

requirement). The diverse design ideas posed by navigators, patients, and doctors highlight the significant help each can provide to the design of health tracking tools. We strongly encourage researchers to consider their input throughout the design process. Involving these and other stakeholders may also encourage a sense of ownership over tools, helping to remove the ever-present challenge of engaging users over an extended period of time.

Challenge: Developing Standard Measures

In our discussions with these stakeholders, the challenge of measuring many of the health factors in a meaningful way came up frequently. Survey respondents also commented that measuring some of these factors would be difficult. For example, as the radiation oncologist noted, "how do you collect pain?" A Likert scale selection of 7 most likely does not provide enough context around how the patient is feeling. We found our participants held different opinions on how best to measure specific health factors. A challenge for future technologies will be to utilize standard measurements for complex factors such as pain or loneliness that are meaningful for all of the users involved in the design and the use of such tools.

CONCLUSION

Our goal with this study is to support the development of useful health information sharing tools that will allow providers to more easily utilize information shared by patients. Our results indicate a general interest by doctors, navigators and patients to utilize health-tracking tools that include a range of health factors. Both doctors and navigators preferred robust tools despite the potential increase in complexity. The importance of context in understanding cancer patient health issues motivated this need for a broader range of health information.

While patients revealed an overall comfort level in sharing personal information with their doctors and navigators, we identified some discrepancies between health information sharing beliefs. Specifically, emotional issues such as loneliness and satisfaction with care provide challenges, as patients are not always comfortable sharing these issues. Future health-tracking tools may be able to better align the sharing preferences of doctors, navigators, and patients, allowing for health information tracked by patients to be better integrated into the care they receive. To support their development, we identified design implications and challenges to be considered in the design process.

We have focused our efforts for this study in a single cancer care community. Due to the focus on breast cancer, we also experienced gender and age biases (all of our participants were women and the average age was 60). While this scope limits the generalizability of our findings, it also allows us to provide a holistic qualitative account of the issues currently affecting patients' care from multiple perspectives. The findings and challenges we present here may be useful for identifying important questions to address

in other cancer care sociotechnical systems. A key challenge with managing longer health journeys is the lack of available ubiquitous care. This study contributes to our understanding of how technologies may help provide more continuous care during people's everyday lives.

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REFERENCES

1. Benjamin, A., Birnholtz, J., Baecker, R., Gromala, D., and Furlan, A. Impression Management Work: How Seniors With Chronic Pain Address Disruptions in Their Interactions. *CSCW '12*, (2012), 799–808.
2. Berry, D.L. Patient-reported symptoms and quality of life integrated into clinical cancer care. *Seminars in oncology nursing* 27, 3 (2011), 203–210.
3. Chen, Y., Hall, B., and Xu, H. Privacy management in dynamic groups: Understanding information privacy in medical practices. *CSCW '13*, (2013), 541–552.
4. Civan, A., McDonald, D.W., Unruh, K.T., and Pratt, W. Locating Patient Expertise in Everyday Life. *Group '09*, (2009), 291–300.
5. Consolvo, S., Smith, I.E., Matthews, T., Lamarca, A., and Tabert, J. Location Disclosure to Social Relations: Why, When, & What People Want to Share. *CHI '05*, (2005), 81–90.
6. Ferguson, T. Online patient-helpers and physicians working together: a new partnership for high quality health care. *BMJ (Clinical research ed.)* 321, 7269 (2000), 1129–32.
7. Hayes, G., Abowd, G., Davis, J., Blount, M., Ebling, M., and Mynatt, E.D. Opportunities for pervasive computing in chronic cancer care. *Pervasive Computing*, (2008), 262–279.
8. Jacobs, M., Clawson, J., and Mynatt, E. My Journey Compass: A Preliminary Investigation of a Mobile Tool for Cancer Patients. *CHI '14*, (2014).
9. Jacobs, M., Clawson, J., and Mynatt, E.D. Cancer Navigation: Opportunities and Challenges for Facilitating the Breast Cancer Journey. *CSCW '14*, (2014), 1467–1478.
10. Karlson, A.K., Brush, A.J.B., and Schechter, S. Can I borrow your phone? Understanding concerns when sharing mobile phones. *CHI '09*, (2009), 1647–1650.
11. Klasnja, P., Hartzler, A., Powell, C., and Pratt, W. Supporting cancer patients' unanchored health information management with mobile technology. *AMIA 2011*, (2011), 732–741.
12. Mynatt, E.D., Rowan, J., Jacobs, A., and Craighill, S. Digital Family Portraits: Supporting Peace of Mind for Extended Family Members. *CHI '01*, (2001), 333–340.
13. Ong, L.M., De Haes, J.C., Hoos, a M., and Lammes, F.B. Doctor-patient communication: a review of the literature. *Social science & medicine* 40, 7 (1995), 903–18.
14. O'Kane, A.A., Mentis, H.M., and Thereska, E. Non-Static nature of patient consent: Shifting privacy perspectives in health information sharing. *CSCW '13*, (2013), 553–562.
15. Patel, R. a, Klasnja, P., Hartzler, A., Unruh, K.T., and Pratt, W. Probing the benefits of real-time tracking during cancer care. *AMIA '12*, (2012), 1340–9.
16. Prasad, A., Sorber, J., Stablein, T., Anthony, D., and Kotz, D. Understanding sharing preferences and behavior for mHealth devices. *WPES '12*, (2012), 117–128.
17. Pratt, W., Unruh, K., Civan, A., and Skeels, M. Personal health information management. *Communications of the ACM* 49, 1 (2006), 51–55.
18. Singh, S., Cabraal, A., Demosthenous, C., and Furlong, M. Password Sharing: Implications for Security Design Based on Social Practice. *CHI '07*, (2007), 895–904.
19. Skeels, M.M., Unruh, K.T., Powell, C., and Pratt, W. Catalyzing Social Support for Breast Cancer Patients. *CHI '10*, (2010), 173–182.
20. Skeels, M.M., Unruh, K.T., Powell, C., and Pratt, W. Catalyzing Social Support for Breast Cancer Patients. *CHI '10*, (2010), 173–182.
21. Slevin, M.L., Plant, H., Lynch, D., Drinkwater, J., and Gregory, W.M. Who should measure quality of life, the doctor or the patient? *British journal of cancer* 57, 1 (1988), 109–12.
22. Street, R.L., Makoul, G., Arora, N.K., and Epstein, R.M. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient education and counseling* 74, 3 (2009), 295–301.
23. Tang, P.C., Ash, J.S., Bates, D.W., Overhage, J.M., and Sands, D.Z. Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *JAMIA* 13, 2 (2006), 121–127.
24. Witry, M.J., Doucette, W.R., Daly, J.M., Levy, B.T., and Chrischilles, E. a. Family physician perceptions of personal health records. *American Health Information Management Association (AHIMA)* 7, (2010).