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Using Health Information Technology to Foster Engagement: Patients' Experiences with an Active Patient Health Record

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ABSTRACT
Personal health records (PHRs) typically employ "passive" communication strategies, such as non-personalized medical text, rather than direct patient engagement in care. Currently there is a call for more active PHRs that directly engage patients in an effort to improve their health by offering elements such as personalized medical information, health coaches, and secure messaging with primary care providers. As part of a randomized clinical trial comparing "passive" with "active" PHRs, we explore patients' experiences with using an "active" PHR known as HealthTrak. The "passive" elements of this PHR included problem lists, medication lists, information about patient allergies and immunizations, medical and surgical histories, lab test results, health reminders, and secure messaging. The active arm included all of these elements and added personalized alerts delivered through the secure messaging platform to patients for services coming due based on various demographic features (including age and sex) and chronic medical conditions. Our participants were part of the larger clinical trial and were eligible if they had been randomized to the active PHR arm, one that included regular personalized alerts. We conducted focus group discussions on the benefits of this active PHR for patients who are at risk for cardiovascular disease. Forty-one patients agreed to participate and were organized into five separate focus group sessions. Three main themes emerged from the qualitatively analyzed focus groups: participants reported that the active PHR promoted better communication with providers; enabled them to more effectively partner with their providers; and helped them become more proactive about tracking their health information. In conclusion, patients reported improved communication, partnership with their providers, and a sense of self-management, thus adding insights for PHR designers hoping to address low adoption rates and other patient barriers to the development and use of the technology.

Introduction

This study investigates participant experiences of and satisfaction with an active Personal Health Record (PHR). In our parent study design (a randomized controlled trial), we differentiated between "active" and "passive" PHRs, in line with previous research in this area (Fischer et al., 2013; Hess et al., 2014). The "passive" PHR included problem lists, medication lists, information about patient allergies and immunizations, medical and surgical histories, lab test results, health reminders, and secure messaging. Such "passive" PHR designs typically provide both information and the capacity to make contact with providers, but only to patients who actively pursue these elements (Pagliari, Detmer, & Singleton, 2007, pp. 330–332; Tang, Ash, Bates, Overhage, & Sands, 2006). The active arm included all of these elements but added personalized alerts to patients for services coming due based on various demographic features (including age and sex) and chronic medical conditions (Fischer et al., 2013; Hess et al., 2014).

Our hypothesis in this paper is that "active" PHR designs may have the capacity to address the gap that exists between "information-only" (Bodenheimer, Lorig, Holman, & Grumbach, 2002, pp. 2473–2474) approaches that treat patients as "passive" consumers of information (described by Bodenheimer, 2005, p. 319; Bodenheimer et al., 2002, p. 2470; Charles, Gafni, & Whelan, 1997, pp. 682–683; Roter, 1977; Wagner et al., 2005) and those that inspire patient agency, action, and self-management (Roter, Stashefsky-Margalit, & Rudd, 2001; Rubinelli, Schulz, & Nakamoto, 2009; Wagner

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et al., 2001, 2005). They may also provide an impetus for "patients [to] become active participants in their own health care" (Tang & Lansky, 2005, p. 1291; see also; Tang et al., 2006), thus transcending the more common and often less efficacious "passive role" that fails to inspire patient autonomy, engagement, activation, and shared decision-making (Alexander, Hearld, Mittler, & Harvey, 2012, pp. 1201–1203; Bodenheimer, 2005; Dutta-Bergman, 2005, p. 292; Greenfield, Kaplan, & Ware, 1985, p. 526).

As active PHRs with personalized alerts delivered through a secure messaging platform are a relatively novel technology and patients have had few opportunities to interact with them, their benefits and drawbacks remain unclear (Ammenwerth, Schnell-Inderst, & Hoerbst, 2012; Archer, Fevrier-Thomas, Lokker, McKibbon, & Strauss, 2011; Chaudhry et al., 2006; Fischer et al., 2013; Goldzweig et al., 2013; Pagliari et al., 2007; Tang et al., 2006; Tang & Lansky, 2005; Zarcadoolas, Vaughon, Czaja, Levy, & Rockoff, 2013). In addition, given the problem of low adoption rates and the fact that many studies have focused primarily on provider experiences, more work is needed to understand how patients react to PHRs (Ammenwerth et al., 2012; Archer et al., 2011; Goldzweig et al., 2013; Zarcadoolas et al., 2013). Hence, we set out to answer the question: *What are patient perceptions of and satisfaction with active PHRs that offer personalized alerts?*

To answer this question, we designed and tested a PHR, known as HealthTrak, as part of a randomized controlled trial to assess its value for patients at risk for cardiovascular disease (Fischer et al., 2013; Hess et al., 2007, 2014). The active version of HealthTrak used in the trial was compared to a passive version that did not include personalized alerts. In order to better understand patients' experiences of and satisfaction with the active version and to provide insights for future research into the implementation of similar systems (questions in keeping with the *Affordable Care Act's* focus on patient-centeredness, see Koh, Brach, Harris, & Parchman, 2013), we conducted a series of focus group discussions with participants in the active arm. For these analyses we focused on whether participants experienced improved communication with their providers and a better sense of engagement with the healthcare system compared to their experiences before they had access to this active PHR.

Personal Health Records: Activating Patients Through Health Information Technology

The 21st-century medical practitioner is overburdened. Chronic care, health maintenance, and preventative healthcare require significant time and effort, often exceeding what primary care practitioners can offer in time-constrained office visits (Yarnall, Pollak, Østbye, Krause, & Michener, 2003). By one estimate, only 50% of recommended acute, preventative, and chronic care is effectively delivered to U.S. adults (McGlynn et al., 2003) and the quality of care received by many Americans falls well below the established guidelines (Asch et al., 2006; Bodenheimer, 2005; Wagner et al., 2005; Wright et al., 2012). Health information technology (HIT) is viewed as one potential remedy for time constraints and other barriers to the provision of care (Glasgow, Bull, Piette, & Steiner, 2004; Yarnall et al., 2003). HIT provides multi-modal pathways for enhancing information delivery and patient–provider communication (Bodenheimer, 2005; Bodenheimer & Grumbach, 2003; Marchibroda, 2008; Matusitz & Breen, 2007; Shortliffe, 2005; Tang & Lansky, 2005; Winkelman, Leonard, & Rossos, 2005). Such elements of care delivery are especially important to patients dealing with behavior-related illness (Glasgow et al., 2004; Hess et al., 2007; Lyden et al., 2013; McTigue et al., 2011; Robinson, Turner, Levine, & Tian, 2011).

Accordingly, research that focuses on uses of HIT to enhance the patient–provider relationship (which may reduce provider burden and enhance patient health outcomes) is especially needed (Bodenheimer & Grumbach, 2003; Chaudhry et al., 2006; Glasgow et al., 2004; Lyden et al., 2013; Matusitz & Breen, 2007; Roter, Larson, Sands, Ford, & Houston, 2008; Shortliffe, 2005; Walters, Adams, Nieboer, & Bal, 2012). Developing such HIT applications requires an understanding of how they fit into the larger healthcare system. As the *Chronic Care Model* (CCM), sometimes shortened to *Care Model* (Koh et al., 2013), elucidates, HIT applications should augment the overall healthcare system by enhancing "self-management," synergizing "clinical information systems," and providing "decision support" tools (Wagner, 1998, p. 3; see also; Koh et al., 2013; Wagner et al., 2001). By involving the patient in healthcare decision-making and providing resources for self-management, such HIT applications might enhance "patient activation," a concept emergent from the CCM (i.e., the "informed, activated patient"—Wagner, 1998, p. 3) and developed by numerous scholars invested in patient engagement and empowerment (Bodenheimer, 2005; Bodenheimer et al., 2002; Bodenheimer, Wagner, & Grumbach, 2002a; Hibbard & Greene, 2013; Rief et al., 2012; Roter, 1977; Roter et al., 2001; Rubinelli et al., 2009; Wagner et al., 2001).

PHRs are an emerging HIT application that may address some of these concerns and promote innovation in all three domains of the CCM previously highlighted. Specifically, PHRs allow patients to access their own health records ("clinical information systems"), utilize health-tracking tools ("self-management"), and engage in health-related messaging and shared decision-making with providers ("decision support") (Wagner, 1998, p. 3; see also; Koh et al., 2013; Wagner et al., 2001). Some PHRs also provide patients with opportunities to communicate with their providers via secure messaging, schedule appointments, request medication refills or other health services, and receive health alerts that keep them apprised of needed health services based on their demographic and health characteristics (Earnest, Ross, Wittevrongel, Moore, & Lin, 2004; Fischer et al., 2013; Pagliari et al., 2007; Tang et al., 2006; Tang & Lansky, 2005; Vishwanath, 2009; Wallis & Rice, 2006; Wright et al., 2012). One over-arching hypothesis of our research is that PHRs combining all of these elements stand the greatest chance of supporting practice changes and enhanced patient activation at multiple levels of the CCM (e.g., health systems, clinical sites, and patient–provider relationships).

Methods

Study Participants

All focus group participants were recruited from the larger randomized controlled trial that compared an active PHR to a passive PHR (Fischer et al., 2013; Hess et al., 2014). Participants were included in this parent study if they had at least one of the following conditions: coronary artery disease, congestive heart failure, or either hypertension or hyperlipidemia for which medication requiring laboratory monitoring was taken. Potential participants in the focus groups consisted of those randomized to the active PHR arm of the randomized controlled trial. This arm consisted of 584 participants, all of whom received an email from the project coordinator about participating in a focus group discussion. Focus group participants each received a $25 honorarium as compensation for their time. This study was approved by the University of Pittsburgh and Weill Cornell Medical College's Institutional Review Boards.

Focus Group Discussion

In order to better understand the reactions of participants to the experience of using the active PHR, we chose to employ the data collection method of focus group discussions. Focus group participants provided written informed consent and completed a demographic questionnaire. A single trained moderator (CN) with 5 years of experience in moderating led all of the focus groups. The open-ended script was developed by the study team in coordination with the qualitative expert (SLZ) and was refined based on team feedback.[1] Each focus group discussion lasted approximately 60 minutes and was audio-recorded and transcribed verbatim by the qualitatively trained staff member (DL) for use in the data analysis. As there was no passive PHR arm of the focus group study, we focus here on the experiences of patients interacting with the active arm as well as capturing feedback about any element of the PHR whether active or passive.

Qualitative Analysis

The analysis was guided by the qualitative "editing" approach developed by Crabtree and Miller (1999) for research that is conducted in the context of clinical medicine. Two coders, the moderator and the transcriptionist, worked with a qualitative expert (SLZ) to iteratively develop a codebook that captured key themes emerging from the focus group discussions. Once the codebook was complete and tested, the two coders analyzed each focus group transcript independently, using an adjudication process to resolve discrepancies that arose between them. The software computer program Atlas.ti (Scientific Software Development GmbH, Berlin) was used to capture and manage all qualitative coding data.

The two coders double coded 100% of the transcripts. Cohen's Kappa statistics were used to calculate intercoder reliability between the two coders. The Kappa statistics scores ranged from 0.71 to 1.00, or what Landis and Koch (1977) describe as "substantial" (0.61–0.81) to "almost perfect" (0.82–1.00) agreement (p. 165).

For the purposes of this analysis, our goal was to capture the experience of using the active version of the PHR known as HealthTrak, and, thus, our study is not tied to the outcomes of the randomized controlled trial ("parent study").

Results

Study Sample

Forty-one participants were organized into five separate focus group sessions. The total number of participants per focus group ranged from 5 to 11. Participants had an average age of 62 years and were predominantly female and Caucasian (Table 1). Over half of the participants completed college or trade school. Of those providing income information, more than one-third earned less than $50,000 annually.

Qualitative Themes

Thematic analysis focused on whether the active receipt of PHR messages helped participants to feel more engaged with their providers and their healthcare system. Three main themes emerged from the focus group discussions: (1) patient-driven communication; (2) partnering with providers; and (3) increasing awareness and proactivity in tracking.

Theme 1: Patient-Driven Communication

Many study participants felt that the active reminders and tracking tools they received in HealthTrak prompted both more frequent and improved communication with their providers. In particular, participants noted that the chronic disease self-management enabled by the tracking features facilitated their communication with providers both online and during office visits. For example, one participant described the process of cultivating questions and preparing topics for conversation during office visits based on test results available on HealthTrak:

> And I think, also getting the test results before you see the doctor, again, are very good because it allows me to think of some

Table 1. Characteristics of focus group participants (n = 41).

Age in years (mean ± SD)	62 ± 9
Gender (% female)	66%
Race (% Caucasian)	93%
Education (% for each category)	
High school degree	2%
Some college or trade school	17%
Completed college or trade school	51%
Graduate degree	29%
Annual income (% for each category)	
<$20,000	2%
$20,000—$34,999	15%
$35,000—$49,999	22%
$50,000—$74,999	12%
$75,000—$99,999	10%
$100,000 or higher	7%
Prefer not to respond	22%

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[1] A version of the focus group interview script is available by request from the corresponding author, John Rief (riefj@duq.edu).

> questions rather than just sitting there and confronting this in the doctor's office.

This comment indicates that for this participant, receiving information at the right time (i.e., getting test results ahead of an office visit) cultivated the experience of higher-quality clinical conversation. In addition, having access to test results ahead of speaking with a physician enhanced the perception that more relevant and useful information exchange was happening.

Participants also reported that they received timely responses from their providers regarding questions about their conditions. In particular, many participants reported the ease and convenience of using the secure electronic messaging feature. For example, one participant opined:

> My physician is great, she would always call me back—but it's really nice to know that I can just send her a quick email, you know: 'this is where we are, you know, and we talk about this is what's happening, what should I do?' You know, that is, it's almost like another level of comfort. She's just an email away.

This participant highlights how the immediacy of secure messaging cultivated a sense of comfort and ease of access. In part, this is due to the availability of feedback from and interaction with an expert at the moment *when* such information is critical. "This is what's happening, what should I do?" is just the type of question that may need an answer before the next available clinical appointment. Reinforcing the insights above, another participant noted:

> I live in a senior building, and we're asking a lotta questions, medical questions, so I go online, go right on here and type it in … Within maybe a half an hour, maybe the next day, I get an answer. Straight from the doctor…I really like it 'cause…some things you don't have to go, like they said non-emergency question. And so even though it goes in your folder or whatever, but I, I really enjoy doin' it because it informs me that my doctor is on top of things.

This comment highlights the importance of time and space as potential barriers to receiving relevant and actionable health information. Several participants reported that HealthTrak provided at least some resolution to this problem by allowing immediate (or at least comparatively fast) turnaround of information.

Similarly, some participants reported that they received responses to questions over secure messaging that they perceived as better than those delivered on the telephone. In part, this appears to be due to the fact that electronic messages can be written at a more leisurely pace. For example, one participant said:

> Yeah, and I find email better because I can get more detail. When we are talking on the phone, usually, the nurse, the doctor doesn't have that kind of time. But with email, what should I do with my mother?…I can get examples of what is happening and so I find that to be better.

Thus, while patients have traditionally been able to access their doctors in the clinic and over the telephone, many participants found secure messaging preferable. The reported ease of sending a message to a provider (i.e., your provider is "just an email away"), and directness of being able to do so without first leaving a message with office staff, seemed to improve participant experiences of making contact with their providers. Many participants felt that they could impart more information in this written mode than their providers had time to handle in an office visit. In addition, receiving a prompt response to such detailed information increased participants' trust in their physicians. Finally, the active nature of this PHR, which sent reminders regarding what types of routine care were needed, allowed participants to go into an office visit feeling better prepared for the interaction.

Theme 2: Partnering with Providers

Many participants described benefits well beyond improved communication, including feeling that HealthTrak helped them to be more engaged partners with their providers. For example, some participants described how it allowed them to cultivate relationships with their providers that they perceived as more robust and effective. Such relationships appear to have been based, at least in part, on participants feeling more knowledgeable about and responsible for their own healthcare rather than waiting passively for provider instructions. One participant stated:

> As a patient dealing with health care I feel … a need to be a part of that [the process], so I like that … it provides me with, you know, a check point…so I can be in partnership with, with my doctors. So I'm not relying on them to tell me when this is [occurring]. I keep on track with them.

The information and tools made available helped this participant feel like an active interlocutor and collaborative decision-maker. This lends credibility to the notion that patients informed about and aware of their own health status may establish a stronger and more productive patient–provider relationships (a theme we develop more fully in the next subsection).

Additionally, participants stated that HealthTrak reduced their feelings of time-related pressure on short clinical visits because these were no longer the sole source of needed health information:

> One of the things that I think with health care, the direction it's taking seems like that, you know, doctor visits are shorter and shorter. You know, access is such an important issue so you're in and out…Partnering with your health care providers in your health care, I think, is really important. So this allows, you know, us, as patients to do that to a better degree.

Being able to track health information allowed participants to feel that they were working with their providers to maintain their health on a regular basis. Tracking tools were also helpful in providing collaborative opportunities that remained grounded in the daily decision-making routines of participants. In short, according to reports by focus group participants, access to HealthTrak extended the patient–provider relationship beyond the bounds of increasingly time-constrained office visits and cultivated opportunities for active involvement by participants in their own care.

Theme 3: Increasing Awareness and Proactivity in Tracking

In addition to the communication and partnering benefits of using HealthTrak, participants articulated how it increased their sense of awareness about their health and the steps necessary to maintain or improve it. For example, one participant described HealthTrak in the following way:

> I think that HealthTrak, what it's really good at, is making you be aware of your own health. And be a participant … in taking care of yourself. And being aware of what is out there that you need to do.

Working effectively with providers to promote better healthcare (partnership) is only one part of the puzzle for this participant. Also crucial to the experience is feeling more aware of critical and relevant information so that action might be taken even in the absence of direct, face-to-face contact with a provider. In other words, the perception of a more robust patient–physician partnership gave these participants the feeling that they were moving toward decision-making independence and effective self-management.

Furthermore, participants described how HealthTrak made them feel as though they were more active in monitoring their health. This increased their self-perceived awareness and provided them with insights they felt helped them to be more proactive in achieving their health-related goals. One participant noted:

> I think, overall, HealthTrak makes you—or I think the whole object of HealthTrak, to me—is to make yourself more proactive in taking care of your health. You know, because if you don't wanna use it, well then it's really not HealthTrak's fault. You know what I mean? You've got the option now to do preventative health … To know that this needs to be done, and um, if you say, well you know what, I'm skippin' these reminders, I don't need to go to the doctor's for another 6 months, you know, that is your choice then. But I think the HealthTrak is trying to encourage you to be proactive in keeping your health at its optimum level.

Crucially, the provision of health reminders through HealthTrak played a central role in enhancing self-management. In this respect, participants felt that they were better able to communicate with their providers and, perhaps more importantly, take greater ownership over their own health.

In addition to activation and awareness, participants found that HealthTrak instilled a sense of being more knowledgeable. It also provided tools that they felt helped them to track, manage, and "own" their specific medical conditions. Participants explained that the use of the organizational structure and tracking features were critical to this experience and their overall satisfaction. One participant explained:

> Initially I signed up because I thought it was a good tool to communicate with my physician, but as time goes on I realize that, along the lines that you're saying, overall, I think the best part is that it helps me to be aware and it keeps in my mind what I'm doing right because you see the results in the lab work. And that works for me, seeing it concrete. I can say that that's a way for me to be as healthy as I can be.

In addition to general comments such as the one above, many participants with chronic conditions (including cardiovascular disease and diabetes) noted that from their perspective the tools were helpful in enabling them to become knowledgeable about health maintenance and decision-making. One participant stated that HealthTrak reinforced "if I'm doing something right or wrong. Not that I always make the right choices, but that reinforcement helps to make great choices."

Other participants felt that the information made available to them helped them to better research and understand elements that were unclear during clinical visits. In this way the tools made available to the participants promoted the perception that they could supplement the information they received from providers and take action on their own. In short, participants felt that HealthTrak enhanced the scope and fluidity of information typically delivered only through face-to-face patient–provider communication.

Discussion

Comments from our focus group discussions indicate that patients at risk for cardiovascular disease felt that an active PHR helped them to enhance communication with their providers, cultivate robust partnerships with them, and develop a more proactive role in their own care. In particular, the health information and communication technology combined in the active PHR decreased participant-perceived access barriers to health information while promoting communicative encounters that participants felt were crucial to engaging them in their own care. Furthermore, our themes overlap with major areas of HIT and chronic care research, primarily patient–provider communication, the CCM, and patient activation.

Patient–Provider Communication

Significant research suggests that the tools made available through PHRs may enhance patient–provider communication. Access to medical records and health-related messaging services through PHRs may increase the quality of patient–provider communication and amplify the activation of patients in their own care (Ammenwerth et al., 2012; Archer et al., 2011; Earnest et al., 2004; Tang & Lansky, 2005; Wright et al., 2012). Access to information that has been traditionally provider controlled and managed may improve the quality of office visits with benefits to overall patient–provider communication (Delbanco et al., 2012). In addition, including "secure messaging" in PHR design might improve outcomes and enhance the quality of the overall experience with the technology (Ammenwerth et al., 2012). As Fischer et al. (2013) note, the addition of personalized alerts to patients may improve their overall engagement in their care. All of these insights are given enhanced credibility by our participant comments and qualitative themes.

Previous work in the area of patient–provider communication sheds light on our participants' perceptions and gives added context to the interpretation of our themes. Major barriers to effective patient–provider communication include a lack of adequate "information sharing" (Charles et al., 1997, p. 682), inadequate preparation ahead of clinical encounters, and the inability to ask appropriate and relevant health-related questions (Bodenheimer, 2005; Greenfield et al., 1985; Heisler, Bouknight, Hayward, Smith, & Kerr, 2002; Roter, 1977; Rubinelli et al., 2009; Thompson, Nanni, & Schwankovsky, 1990; Winkelman et al., 2005). Without relevant and timely information, patients are unlikely to be prepared for the topics that their providers bring up with them in clinical visits and are less likely to advance their own topics of concern (Bodenheimer, 2005; Rief et al., 2012; Roter, 1977; Rubinell et al., 2009; Thompson et al., 1990). Addressing this information gap can both support patients in the practice of communicating about their health goals with providers and improve health outcomes (Bodenheimer, 2005; Dutta-Bergman, 2005; Earnest et al., 2004; Gordon & Edwards, 1995; van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003; Wagner et al., 2001). Furthermore, as indicated by growing research into the importance of online interactivity (Bodenheimer & Grumbach, 2003; Delbanco & Sands, 2004; Glasgow et al., 2004; Levine, Turner, Robinson, Angelus, & Hu, 2009; Lin, Wittevrongel, Moore, Beaty, & Ross, 2005; Roter et al., 2008), PHRs that allow patients to send and receive messages with their providers may promote timely communications and improved delivery of care as opposed to the unfortunate silences and other barriers to care delivery that emerge between visits to the clinical site (Delbanco & Sands, 2004; Earnest et al., 2004; Glasgow et al., 2004; Hess et al., 2007; Matusitz & Breen, 2007; Winkelman et al., 2005).

While our themes do not establish that patient–provider communication was improved by the use of an active PHR, they do indicate the degree to which participants in our focus groups felt that their communication with providers was enhanced in a variety of ways. Crucially, the online environment cultivated by HealthTrak provided an avenue for developing "a continuous healing relationship" as "a two-way interaction" (Tang & Lansky, 2005, p. 1290) unbounded by the "traditional space and time relationships" of face-to-face clinical encounters (Robinson et al., 2011, p. 131; see also Matusitz & Breen, 2007). In short, our focus group participants felt that time was being used more efficiently due to the active PHR. In addition, the sequencing of information (e.g., releasing test results ahead of a clinical visit) seems to have given participants the sense that their clinical encounters were more effective and more likely to yield the kinds of outcomes they expected.

The CCM: A Model for Collaborative Care

As noted in our introduction, active PHRs may be most useful in the ongoing effort to address the ever-increasing financial, professional, and health burdens of chronic disease (Bodenheimer et al., 2002a; Marchibroda, 2008). Wagner et al.'s CCM (Wagner, 1998; Wagner et al., 2001) highlights several important conduits for improving outcomes for chronic patients (i.e., those with long-term conditions that require ongoing monitoring and management such as diabetes, hypertension, and cardiovascular disease). These include the need to coordinate "informed, activated patient [s]" with "prepared, proactive, practice team[s]" through the cultivation of "productive interactions" (Wagner, 1998, p. 3; see also; Bodenheimer, 2005; Bodenheimer et al., 2002a; Marchibroda, 2008; Rief et al., 2012; Wagner et al., 2001; Wagner et al., 2005), which may be achieved through technological solutions ("clinical information systems"—Wagner, 1998, p. 3) such as PHRs (Hess et al., 2007; Wagner et al., 2001; Walters et al., 2012).

Crucially, according to Wagner et al. (2001), addressing access barriers to patient health information and facilitating active and ongoing communication with providers is one of the most important modalities for improving "self-management" in the chronic care setting (see also Bodenheimer et al., 2002a, 2002b). Hence, the implementation and use of the CCM tend to foreground the production of "collaborative" care rooted in a "patient-centered" conception of health in which providers work together with patients to address their particular needs and aspirations, including the provision of adequate "decision support" (Wagner, 1998, p. 3; see also; Bodenheimer, 2005; Bodenheimer et al., 2002a; 2002b; Gordon & Edwards, 1995; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997; Von Korff et al., 1998; Wagner et al., 2001; Wagner et al., 2005). Additionally, active patient "collaboration" in health care (Bodenheimer, 2005; Bodenheimer et al., 2002; Lorig et al., 1999; Von Korff et al., 1997, 1998; Wagner et al., 2001) and patient self-monitoring of chronic conditions (Glasgow et al., 2002; McTigue et al., 2011; Von Korff et al., 1997; Wagner et al., 2001), both critical features of PHRs as defined in this study, have been linked to better health outcomes. For example, in one study, health maintenance reminders delivered through an electronic PHR improved patient "adherence to guideline-based care recommendations" (Wright et al., 2012, p. 85) for mammography screening and influenza vaccination.

The comments made by our participants provide insights about the potential for PHRs to enhance clinical care across the domains of the CCM, and, in particular, the value of personalized alerts in cultivating more active encounters with the healthcare system. Their comments indicate perceived improvements in collaboration with their providers (patients with more information who are now active in their care), a sense that their daily health decision-making had become more effective ("self-management" and "decision support"—Wagner, 1998, p. 3), and a clear satisfaction with the functionality of the PHR. This lends credibility to the idea that active PHRs with personalized alerts delivered through a secure messaging platform might address some of the problems that have led to low adoption rates (Archer et al., 2011; Fischer et al., 2013; Goldzweig et al., 2013). It also indicates a level of satisfaction with this active PHR that could be translated into future iterations of the technology in our setting and beyond.

Patient Activation

While the CCM includes the promotion of "informed, activated patients" (Wagner, 1998, p. 3) in its design, researchers working beyond this model have developed a more robust conception of "patient activation." Placing our qualitative results in the context of a textured account of patient activation may highlight the most important component of the active PHR we are evaluating—personalized alerts.

As previously noted, active PHRs with personalized alerts stand a chance of getting patients involved in their own care in ways that passive platforms might not (Fischer et al., 2013). This insight is supported by previous work to develop and test the concept of patient activation. Hibbard, Stockard, Mahoney, and Tusler (2004) have developed a conception of "patient activation" that involves four primary elements which can be viewed as markers for its development: "beliefs about the importance of the patient role," "confidence and knowledge," "taking action," and "staying the course" (p. 1016; see also Hibbard & Greene, 2013; Hibbard, Mahoney, Stock, & Tusler, 2007; Hibbard, Mahoney, Stockard, & Tusler, 2005). These four elements are now viewed as critical to effective intervention design and evaluation for studies with primary outcomes such as self-management and health maintenance (Greene & Hibbard, 2012; Hibbard & Greene, 2013; Hibbard et al., 2007, 2005, 2004; Remmers et al., 2009). These markers for enhanced patient activation emerge in all three primary themes noted in our analysis (with particular import in the proactivity theme). This should come as no surprise given the deep connections between communication, partnership, and active patient engagement in care already described in the literature (see previous subsections).

First, as previously noted, patient-driven communication is an increasingly important element of effective chronic care delivery and has been linked with activation (Alexander et al., 2012; Bodenheimer et al., 2002; Hibbard & Greene, 2013). Our participants reported feeling as though improved communication with their providers allowed for shared action to address health maintenance reminders and other health concerns. Second, "partnership" provides patients with opportunities to work with their healthcare team to address problems and achieve desired health outcomes (Bodenheimer et al., 2002; Gordon & Edwards, 1995; Rubinelli et al., 2009; Von Korff et al., 1997; Wagner et al., 2001). Feeling like a partner seems to have enhanced our participants' perception of the importance of their own *role* in the promotion and maintenance of their health. Third, awareness and proactivity enhance the patient–provider relationship. When physicians can offer patients an active PHR integrated with their electronic health records system, they can maintain a schedule of active personalized alerts for their patients (Fischer et al., 2013). Finally, the ability to take ownership over one's own care is essential, especially among chronic patients who may have to take action (based on what they have learned from their providers) on their own to maintain their health or improve it on a daily basis (Alexander et al., 2012; Hibbard & Greene, 2013; Roter et al., 2001; Wagner, 1998; Wagner et al., 2001). In short, our themes indicate key areas of overlap with a more robust and textured conception of patient activation, especially the development of "confidence, beliefs, knowledge, and skills" (Greene & Hibbard, 2012, p. 521) necessary for successful self-care.

Patient Concerns with PHRs

Our qualitative results also address some concerns that have been raised about the use of technology to supplement direct, face-to-face clinical encounters including questions about the quality of the content being provided (Woods et al., 2013). As Shortliffe (2005) notes, "technology might interfere with an almost sacred relationship between physicians and their patients, potentially dehumanizing the care process and encouraging impersonal 'cookie cutter' approaches to the deep human problems that emerge in the context of disease and its management" (p. 1223; see also Matusitz & Breen, 2007). Crucially, our themes indicate that these common "anxieties" (Peters, 1999) about technological change do not seem to have played a role in participant experiences with this active PHR. In fact, quite the opposite appears to have been the case. This is likely due to the fact that the active element of the PHR under investigation here was the delivery of personalized alerts (Fischer et al., 2013; Hess et al., 2014) as opposed to general health information (or passive access to information). Hence, the personalized messages being sent to participants during their time in the active arm of our study seem to have contributed significantly to the overall participant experience of and satisfaction with this PHR (as one participant noted, the "reminders" he or she received "encourage you to be proactive in keeping your health at its optimum level").

Our Themes in Context

Our themes overlap with and expand upon themes and results from several previous studies. One pre-implementation study of a PHR identified similar themes, including the "promotion of a sense of illness ownership, of patient-driven communication, of personalized support, and of mutual trust" (Winkelman et al., 2005, p. 306). A post-implementation study that included a qualitative component also found that participants noted not only greater activation in their healthcare due to increased knowledge about their condition but also improved medical decision-making (Earnest et al., 2004). A more recent qualitative study of a PHR without secure messaging reported similar themes including, "communication with providers and the health system, enhanced knowledge of their [participants] health and improved self-care, and … greater participation in the quality of their care such as follow up" (Woods et al., 2013, Abstract Results section). The secure messaging component of our PHR seems to have augmented participant experiences and satisfaction by giving an additional conduit for communication and collaboration with providers. In another focus group study of a PHR, Zarcadoolas et al. (2013) report a similar set of themes including "empowerment," patient–provider communication, and proactivity. Their participants noted that the ability to make appointments, order medication, and receive test results were crucial to their overall experience in the PHR, all elements noted by our participants as well (Zarcadoolas et al., 2013).

Limitations

Our study has several primary limitations. It is limited to a specific PHR at a single institution. It is possible that not all of the responses generalize to different PHR systems. However, given the confluence of themes identified in the focus groups, extant qualitative studies, and other emerging data (Earnest et al., 2004; Tang & Lansky, 2005; Winkelman et al., 2005; Woods et al., 2013; Zarcadoolas et al., 2013), there seems to be thematic consistency across PHR systems. Additionally, qualitative research focuses on presenting insights unique to a specific study sample and is not meant as a methodology for producing data that are generalizable (Kuzel, 1992).

Another potential limitation is that our focus group participants were drawn from a group of patients who had already agreed to be part of a randomized controlled trial. Therefore, their responses may not represent the responses of a broader population. Furthermore, since the applications that our focus group participants were using contained both the passive and active elements of the PHR investigated in our parent study, the focus group findings cannot be isolated to effects produced solely by the active version. For example, patient-driven communication could theoretically occur in any PHR with secure messaging capabilities, although it is certainly possible that the active nature of the PHR engaged patients more in this communication. This study is not designed to separate out these effects.

Our participant demographic characteristics further limit the applicability of our findings. Our participants were largely white, female, and well educated (Table 1). Hence, our findings do not shed light on all barriers to participant satisfaction and adoption. For example, there are reported barriers to PHR user satisfaction and use in vulnerable populations (Zarcadoolas et al., 2013) that our study was not designed to address.

In addition, several studies have noted that low health literacy and numeracy may be major impediments to the effective use of PHRs by patients and may limit the quality and probity of patient reports about their experiences while using them (Koh et al., 2013; Taha, Czaja, Sharit, & Morrow, 2013; Zarcadoolas et al., 2013). Our focus group study was not designed to assess health literacy at baseline or after the intervention. Instead, our approach was designed to assess whether patients felt that the PHR was improving their engagement and ability to keep in contact with providers. Such reports can tell us a great deal about patient experience and satisfaction, two potential drivers for expanding patient uptake of PHRs. Moreover, participant "beliefs" about their role in their health are viewed as critical to developing patient activation (Greene & Hibbard, 2012; Hibbard et al., 2004). As has been noted by previous researchers (Rief et al., 2012; Rubinelli et al., 2009), activation in one's care is crucial to developing health literacy. Hence, our focus group participants are reporting on experiences that may bear on their development of health literacy in the long run.

Despite these limitations, qualitative studies like this one offer needed insights into what patients want and expect from PHRs, something that can contribute to designing patient-centered applications of PHRs and to generating future questions for research.

Conclusions

In our study, participants reported that an active PHR with personalized alerts, far from simply providing health information, allowed them to develop knowledge and self-management skills while promoting enhanced and informed communication with their providers. These findings indicate that active PHRs can indeed address the gap between being merely informed and becoming activated and engaged (Hibbard et al., 2004; Roter et al., 2001; Rubinelli et al., 2009; Von Korff et al., 1997; Wagner et al., 2001). Our patient-driven communication and proactivity themes indicate that patients using this PHR felt more informed, more capable when requesting information and making decisions in partnership with their physicians, and more in control of their health-related activities. In the case of these participants, access to information and reminders became a starting point for improved patient communication with providers as stakeholders knowledgeable about their own medical care. Thus, they were able to seek out even more information in order to better meet their health needs. All of these benefits may lead to more efficient, productive interactions during the clinical encounter and promote shared decision-making.

Our participants' experiences of and satisfaction with HealthTrak indicate the potential active PHRs with personalized alerts have to empower patients to take a more proactive role in their healthcare. This enhanced self-management can be an important first step toward improved health outcomes (Lorig et al., 1999; Von Korff et al., 1997). Health systems in the process of developing their own active PHR system can draw on our findings as they develop systems to empower patients with chronic conditions turning them into proactive communicators and partners with their healthcare providers.

Future Trajectories for Research

Future studies should assess the degree to which active elements of PHRs (e.g., personalized alerts) that reach out to patients rather than waiting for them to make contact or seek out information on their own might contribute to resolving the health literacy and numeracy gap (Koh et al., 2013; Taha et al., 2013; Zarcadoolas et al., 2013). Work in this area could include observing clinical encounters (either in-person or audiotaped) to compare patients who received information actively in advance of the encounter versus those that did not. In addition, future studies should continue to assess barriers to adoption (Archer et al., 2011; Goldzweig et al., 2013) and the potential factors limiting the effectiveness of online information delivery, information exchange, and active communication between providers and their patients. While our participants did not express any particular issues with the online environment, the fact remains that the technological revolution in medicine carries potential advantages and disadvantages (Shortliffe, 2005; Topol, 2012) that will need to be managed through patient-centered and provider-friendly designs.

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