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A Personal Health Network for Chemotherapy Care Coordination: Evaluation of Usability Among Patients

Katherine K. KIM[a,b,1], Janice F. BELL[a], Richard BOLD[b], Andra DAVIS[c], Victoria NGO[a], Sarah C. REED[a], Jill G. JOSEPH[a,b]
[a]*Betty Irene Moore School of Nursing,* [b]*Comprehensive Cancer Center, University of California Davis, United States,* [c]*College of Nursing, Washington State University*

Abstract. Cancer is a top concern globally. Cancer care suffers from lack of coordination, silos of information, and high cost. Interest is emerging in person-centered technology to assist with coordination to address these challenges. This study evaluates the usability of the "personal health network" (PHN), a novel solution leveraging social networking and mobile technologies, among individuals undergoing chemotherapy and receiving care coordination. Early results from interviews of 12 participants in a randomized pragmatic trial suggest that they feel more connected to the healthcare team using the PHN, find value in access to the patient education library, and are better equipped to organize the many activities that occur during chemotherapy. Improvements are needed in navigation, connectivity, and integration with electronic health records. Findings contribute to improvements in the PHN and informs a roadmap for potentially greater impact in technology-enabled cancer care coordination.

Keywords. Care coordination, oncology, chemotherapy, person-centered, mobile technology, social network

1. Introduction

Care coordination is a critical need across the world to address fragmented and efficient care of individuals with complex care needs such as cancer.[1,2] Cancer patients can benefit from active engagement with their healthcare teams and active participation in improved care coordination.[3,4] Some have argued that this type of complex coordination is made possible and improved with technology.[5,6] Yet, there are few examples or evaluations of information technology (IT)-enabled care coordination beyond telephone follow-up.[7]

The "personal health network" (PHN) was developed to address this gap. The PHN is a personalized social network built around a patient for collaboration with clinicians, care team members, carers, and others designated by a patient, to enable patient-centered health and healthcare activities across a relevant community.[8] It was designed based on published frameworks for care coordination and the expertise of an interprofessional clinical and research team, and applied to a use case of patient

[1] Katherine Kim, University of California Davis, Betty Irene Moore School of Nursing, 2450 48th Street, Suite 2600, Sacramento, CA 95817; email: kathykim@ucdavis.edu

initiating chemotherapy with PHN members including family members, oncologists, primary care physicians, nurse care coordinators, dietary, social work, and community services such as transportation and meal programs. The development of the PHN is reported in detail elsewhere.[8] The objective of this study was to assess the initial usability of the PHN among patients.

2. Methods

The PHN was implemented in a small (n=60) two-arm, randomized, pragmatic trial with the control group receiving standard nurse care coordination, and the intervention group receiving nurse care coordination and the PHN. Participants were adult, English-speaking patients of the University of California Davis, Comprehensive Cancer Center, with a primary diagnosis of cancer (any site), initiating chemotherapy, with an expected survival period of six months or longer. Participants were followed for six months even if chemotherapy was completed in less than six months. Participants received an 8.4 inch, Samsung Galaxy tablet with Wifi and 4G data plan and an individual orientation to the tablet and the PHN on enrollment. Technical assistance was offered via a help button in the PHN application and telephone helpline.

Interviews were conducted based on think-aloud methodology.[9] Interviews of the intervention group were conducted by one of two trained interviewers using an interview guide approximately three to four weeks after starting the trial in order to assess initial usability of the PHN. Participants were asked to show how they used each major function in the application with their own tablet and PHN account. The functions included: login, view members of the PHN, send/view a secure text message, start a video chat, use patient education library, complete symptom assessment survey, access plan of care, add or check appointments in calendar. The interviewer made notes on points at which the participant hesitated, seemed unsure how to proceed, or expressed frustration with the PHN so that she could prompt the participant to think aloud about the experience at those points. Interviewers also asked questions: How do you typically use this feature, what is easy or challenging, what would make this easier to use or more useful, has use of the PHN changed anything you do in your daily life? Interviews were recorded and transcribed verbatim. Transcripts were coded inductively by one investigator following principles of grounded theory.[10,11] Findings were used to develop version 2 of the PHN. The study was approved by UC Davis IRB.

3. Results

23 participants were enrolled in the RCT at the time of this qualitative study (78% recruitment rate). The mean age was 60 (range 46 to 81). They were 74% were female, 91% white. They had on average a college degree and $70 – $79k annual income. The control group (n = 8) was slightly younger (mean age 59 vs. 64) and lower income ($60 – 69k vs. $70 - 79k). Interviews were completed on 12 of 15 intervention group participants and lasted 30-45 minutes each. Table 1 lists the commonly mentioned impacts of the PHN on daily life and challenges to use/areas of improvement for the application. Version 2 of the PHN is shown in Figure 1.

Table 1. Themes

Impacts on daily life	**Representative Quotes**
Connectedness to healthcare team	*"…then it [messaging] kind of feels like you're an email friend of mine rather than you're a medical provider…And it makes it feel, our connection feels more personal…like, hey, I can build a relationship with these women and see how that goes. And that's just going to be better for me in the long run with my whole care."*
Coordination of activities	*"It helps keep me engagement in what's going on. It kind of gives me something to do. If I think about every day I just have to check in and see if there's anything, any messages that I've gotten. I've used it to keep notes when I have something going on so when I go to my doctor's appointment I can remember to talk to my doctor about it, which came in very useful because I had an appointment on Monday and I think I had five things that I had already written down."*
Positive aspects of PHN	
Ease of communication	*"…if I had my email I'd have to sort through all my emails…what's nice about this is that it's controlled, it's contained. I have like five people on there so it's really easy to see whom I'm giving my record. Yeah, so it's faster to access things that way rather than having to scroll through. And it's really easy to use" "I guess you know I'm saying like feedback on this one, like for me coming in and let us say it's not—I have additional questions to this, maybe I can forward it to my care team." "I don't think there was anything really challenging about it. I just go along and press the buttons and figure out what I need to do."*
Access to patient education	*"I guess it's easy in term of because it's all in category, then you know if I'm looking for certain things. Like for example, this is the one that I was reading a lot, the transportation and travel, and then the common concerns." "It gives you a place to go. I mean you don't have to bother the staff or contact the med center directly. This will be a good beginning and if there's something on here that you know doesn't answer your questions then you could very often just call."* *"Perhaps there was a few things there about some of the issues I talked to her about. She listened to me and offered to send over documents to help me…So it's not just a document, it's actually a link to like guided imagery, like audio things that you can like listen to. So, I do like this feature a lot."*
Attention to symptoms	*"And then using it to let people know if I'm having any health issues. Like I think when I have the heartburn, I let [care coordinator] know that I had pretty bad heartburn and then she was able to send me some suggestions." "You know like if they are doing a survey about my pain, about my emotional state, is it useful to share it with my medical oncologist or my surgical oncologist or something, or my primary doctor." "So it reminded me to pay more attention to things on a daily basis andlie, oh year, that's right, I am having these little tingles on my tongue. Oh, that is part of sensory changes. So it kind of educated me like, I'm not going crazy. Like, oh yeah, the medication can."*
Family/caregiver access	*"And then [spouse] is on it but he hasn't gone on and played with it. I just let him get on it…If he is concerned about it and I'm say no, I'm fine, it's fine. Then he can always check in with [care coordinator] and say, she's saying this is fine but I don't know. And I think that would give him some peace of mind. Because I don't want to be sick. I don't want to seem sick."*
Suggested improvements in PHN	
Similar functions in EHR	*"The other thing is that since a lot of appointments are on MyChart [EHR] and some are on this and it would be nice to have them all in in one place." "I think the biggest challenge is whether some of these responded or not…because I don't know if they're on vacation or you know something like that…because usually I do get a response whether it's from the doctor or nurse [in MyChart EHR]""It's much more focused or targeted because …I know this is going straight to [care coordinator]...With MyChart I know I'm going to send it to the doctor, but then there is going to be an intermediary that's going to come into the picture."*
Confusing navigation	*"Well yeah, and then it would be a lot easier. And I still say that the tabs for me going to this and find those buttons, why isn't it topic A and the three buttons there and topic B and the two buttons there and everything written out in some menu or something so there's no confusion."* *"No, here we go. Doggone it, I don't know, I think it's one of these. Nope, not that one. It's behind door number two."*
Connectivity/ Tablet	*"So the one issue that I have has is that my home internet is very slow…" "It's been a little rough. Yes, because I've had trouble getting connections."* *"And it kept saying, oh SIM card, activate SIM card. The SIM card needs to be installed, you know and I thought, isn't this a SIM card I pulled off? Isn't the SIM card a tiny card about*

	that big with a corner cut off?"
Appointments	*"Because I could have sworn I put one in but I was also having a little bit of problems, tech problems. And so I don't know whether it actually went in…I'd like it if I pulled up a calendar and it showed the whole month and be able to click on the date of the month."*

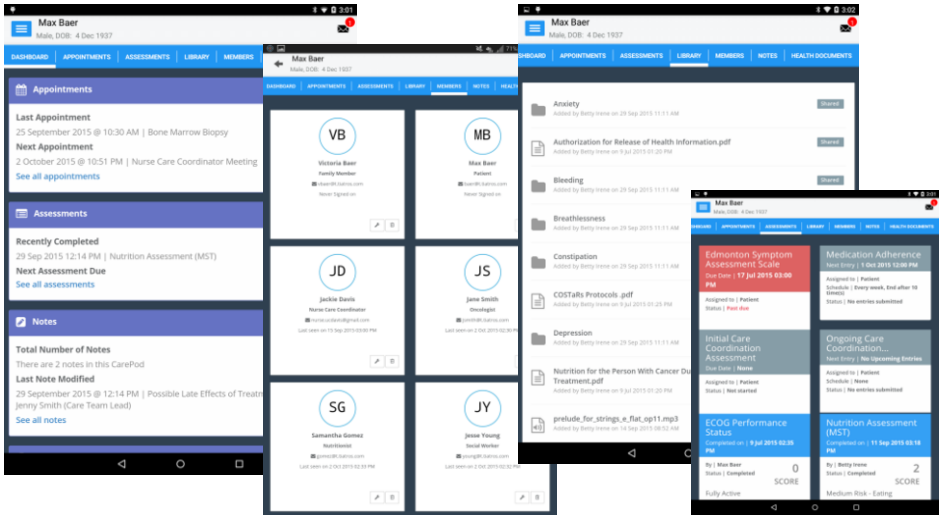

Figure 1. The Personal Health Network Mobile Application v2.0: Patient Dashboard (Overall Care Plan), Members, Library, Symptom Assessments and Patient-reported Outcomes

4. Discussion

Refinements to the user interface focused on the major challenges and usability issues identified by participants: simplifying the navigation, offering a dashboard as an alternative organization for information, and creating utilities for synchronizing appointments with Google and Outlook. Two of the key challenges identified will require additional investigation. First, the PHN is a rich application requiring substantial bandwidth for adequate performance. Connectivity is an ongoing challenge both on the medical center's wireless network, and in the home environments even using 4G. Strategies for optimizing performance must be investigated. Second, interoperability of the PHN with the EHR, particularly with respect to appointments, is critical for adoption. Synchronizing clinical and care coordination appointments and activities so that an individual and the healthcare team can have a comprehensive view of her schedule is a prerequisite for effective coordination. Interoperability in consumer and workplace scheduling systems is a well-documented user preference for which Internet standards have been promulgated since the 1990s.[12] Yet, these standards have not been adopted by EHRs for healthcare, perhaps due to privacy concerns.

Participants indicated the PHN supported communication with the healthcare team as well as engagement of family members in care particularly with symptom management. Enabling one-on-one and group communication among the healthcare team members, individuals, and family and caregivers offered a feeling of

connectedness that was important to participants. These findings align with previous work that suggests well-designed IT can preserve trust and sense of relationship.[5]

This study had several limitations. First, data was not collected on prior use of tablets or mobile applications limiting interpretation of potential usability challenges due to lack of experience. Second, since the study is in progress data on actual use of the technology was not available to allow for triangulation of interview findings with objective use of technology.

Early evaluation of the usability of the PHN has allowed for refinements in the mobile application to be implemented and rolled out to the same participants. Summative evaluation will be conducted to understand whether we have improved usability as well as gauge effectiveness of the. As one of the first examples of a technology-enabled care coordination intervention in oncology, this study contributes an early view into the possibilities for healthcare improvement that a person-centered model such as this may enable.

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