Exploration of the Personal Health Record as a Tool for Spinal Cord Injury Health Self-Management and Coordination of Care

Manon Maitland Schladen, MSE, PMP, EdS, PhD,^{1,2} Inger H. Ljungberg, MPH,¹
J. Austin Underwood, BS,³ and Suzanne L. Groah, MD, MSPH^{4,5}

¹MedStar Health Research Institute, Hyattsville, MD; ²Georgetown University Department of Rehabilitation Medicine, Washington, DC; ³Georgetown University School of Medicine, Washington, DC; ⁴Paralysis and Recovery Program, MedStar National Rehabilitation Hospital, Washington, DC; ⁵Rehabilitation Medicine, Georgetown University Hospital, Washington, DC

Background: A personal health record (PHR) is a collection of electronic health data drawn from multiple sources but managed by the patient. The PHR is a strategy that enables patients to be proactive in the coordination of their care. **Objective:** The purpose of this clinical improvement study was to discover what worked, what did not work, and what could be improved in the initial implementation of MyPHR, a PHR tailored to patients with spinal cord injury (SCI), to make it a useful tool for care coordination and health self-management. **Methods:** Five individuals with chronic (>1 year) SCI carried out trial use of MyPHR. Twelve hours of interactions, including screen navigation and think-aloud reflection, were recorded and analyzed using formative research, a qualitative method and type of case study research. **Results:** Two key themes emerged to guide the implementation of PHR technology: selectivity in the identification of information for the patient to track, and continual support and communication with the clinical team. **Conclusion:** Given the volume of electronic data available to patients with SCI, the data identified to import, manage, and keep current in a PHR have to be thoughtfully selected to make sure the patient is convinced of the worth of this data record and is willing to invest the time and effort it will take to maintain it. A PHR should be implemented with a deliberate focus on its function as a tool that patients and providers use together to expand communication as they work toward their common goal of optimizing health after SCI. **Key words:** care coordination, case study, formative research, health information technology, personal health records, self-management, spinal cord injury, use cases

With the signing into law of the Health Information Technology and Clinical Health (HITECH) Act in 2009,¹ the aggregation and coordination of health data became a national priority. While progress has been made, coordination of information across multiple health care providers remains a problem for people living with complex health management needs^{2,3} such as those experienced by people with spinal cord injury (SCI). The personal health record (PHR) is a strategy that helps patients be proactive in the coordination of their own care. A PHR, as defined in national, health information technology (HIT) policy, is an “electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and

controlled by the individual.”^{4(p6)} Patient control distinguishes the PHR from other forms of health information exchange.

According to a national consumer survey, people with chronic health conditions, particularly those with multiple health conditions, perceive PHRs as particularly relevant to managing their health.⁵ Utilization modeling grounded in the Health Information National Trends Survey data from 2008, 2011, and 2013 suggests that as many as 75% of all patients in the United States will be using a PHR by 2020.⁶ A study based on SCI Model Systems data found that people with SCI were spending more than 60% of their time online focused on health information and concluded that Internet use among people with SCI was sufficiently broad-based to support leveraging it as a long-term treatment modality.⁷

Corresponding author: Dr. Manon Maitland Schladen, Research Division, MedStar National Rehabilitation Hospital, 102 Irving Street NW, Washington, DC 20010; phone: 202-302-1931; fax: 443-703-7014; e-mail: manon.schladen@medstar.net

Top Spinal Cord Inj Rehabil 2017;23(3):218–225
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www.scijournal.com

doi: 10.1310/sci2303-218

MyPHR: Tool for SCI Care Coordination and Self-Management

MyPHR is an online PHR tailored to the specific health management needs of people with SCI (**Figure 1**). It was developed to support a comprehensive clinical program, the SCI Patient-Centered Specialty Practice (SCI-PCSP). The design of the SCI-PCSP was based on an SCI specialty practice variant of the Patient-Centered Medical Home, a model of care that brings health promotion, disease prevention, health maintenance, counseling, patient education, and diagnosis, as well as treatment of acute and chronic illnesses, under the same roof.⁸

MyPHR was built on a federally certified HIT platform, InstantPHR®, to support both care coordination and self-management in the SCI-PCSP. MyPHR makes it possible for patients to augment their medical records with health status data that they have gathered on their own, for instance, by journaling their urinary symptoms or importing their exercise data from the activity trackers they wear. MyPHR was also designed to facilitate communication between patients and providers through health information applications (apps), such as shared health action plans linked to automated, out-of-range alerting and secure messaging targeted to the patient's e-mail and mobile device. See **Table 1** for the types of health

Figure 1. MyPHR home page.

Table 1. Types of health information managed through MyPHR

Types of information	Description
Provider-maintained information	Information imported from health providers and services: physicians, therapists, pharmacy, lab, radiology. Facilitated by information exchange standards adopted in the context of Center for Medicare & Medicaid Services (CMS) and Office of the National Coordinator for Health Information Technology (ONC) EHR certification criteria and Meaningful Use/ Medicare Access and CHIP Reauthorization Act of 2015.
Health device information	Information imported from patient devices: home blood pressure monitors, exercise trackers. Data available through apps participating with Microsoft Healthvault.
Information based on self-observation	Health information journaled by the patient: urinary symptoms log, skin breakdown and healing log (with images).
Enhanced communications	Action plans to monitor and manage health goals, created by either care providers or patients, linked to patient educational materials, for example, videos demonstrating upper body strengthening. Secure messaging with prompts to patients' e-mail or mobile devices.

Note: EHR = electronic health record.

information patients have the potential to manage through MyPHR.

The SCI-centric design criteria for MyPHR originated in the findings of an exploratory study⁹ we conducted during 2010-2011 to identify use cases¹⁰ for PHRs in SCI self-management. The key themes that emerged from that study were (a) the importance of having a portable, up-to-date, and easily accessed health record to share across providers (particularly in emergency situations such as during episodes autonomic dysreflexia when an individual's ability to self-advocate is compromised) and (2) the importance of regular, programmatic support of persons with SCI in the task of selecting, making sense of, and using their health information in self-management.

These tentative, SCI-focused themes have been supported by various findings of Patient-Centered Medical Home/Specialty Practice Model implementation research as follows. The use of HIT to support clinical workflow, as well as for messaging and tracking patients, has been identified as a characteristic of high-performing patient-centered practices.¹¹ Further, the importance of intensive care coordination and self-management support, ideally delivered by a care manager who does not have another role competing for his/her attention on the care team, has been underscored.¹¹⁻¹⁶ Consequently, we identified these 2 practices among our key SCI-PCSP practices: (a) an HIT tool, MyPHR, tailored to SCI to manage health information and facilitate communication among patients, caregivers, and

health care providers and (b) a care coordinator whose primary responsibility is to proactively reach out to patients to identify gaps in knowledge, communication, and action and help them address needs before they become health crises. The purpose of this article is to share the experience and reflections of a cohort of 5 patients with chronic (>1 year) SCI as they worked through a guided exploration of MyPHR. Care coordinators were not included in this initial study.

Methods

This project focused on clinical process improvement in support of our SCI-PCSP. As such, it was designated exempt by the MedStar Health Institutional Review Board.

We used formative research,¹⁷ a form of case study research, to discover what worked, what did not work, and what could be improved in the initial implementation of MyPHR to make it a useful and usable tool for SCI health self-management for patients with SCI. We invited 5, community-dwelling patients with chronic (>1 year) SCI to participate in structured examination and pilot use of MyPHR. Participants (see descriptions, **Table 2**) created their secure MyPHRs. Subsequently, we asked them to "think-aloud," a common, IT usability testing technique¹⁸ with a history of use in PHR testing,¹⁹ while we recorded their comments as they explored MyPHR guided by a facilitator (M.M.S. or I.H.L.). We followed a semi-structured test plan over the course of up to 3, one-hour sessions with participants.

Table 2. Participant characteristics

No.	Sex	Injury	Age, years	Race/Ethnicity	Employment	IT/HIT use	No. of testing sessions
1	F	Para	33	Mixed race	Health analyst, community activist, para-athlete	Internet, computer, smartphone, Fitbit®, insurer EHR portal	3
2	M	Para	49	Caucasian	Body-builder/trainer	Internet, computer, smartphone, Fitbit®	3
3	MM	Para	34	Caucasian	Federal lawyer	Internet, computer, smartphone, Fitbit®, multiple provider portals	4 ^a
4	MM	Tetra	57	Caucasian	Philanthropy executive	Internet, computer, smartphone, speech recognition, mechanical AT	1
5	MM	Para	31	Caucasian/ East Indian	Peer-mentor/wellness coach	Internet, computer, smartphone	1

Note: AT = assistive technology; EHR = electronic health record; IT/HIT = information technology/health information technology; Para = paraplegia; Tetra = tetraplegia.

^aThis patient participated in 3 MyPHR testing sessions and provided reflections on preliminary analysis of testing in the context of clinical use of MyPHR in the SCI Patient-Centered Specialty Practice after it opened its doors.

Each session was conducted either face-to-face or online. Replicating a technique leveraged in other PHR development work,²⁰ we recorded participants' computer screens, along with their think-aloud reactions, to create enduring, observational videos of their interactions. Participants were given homework between sessions: They were given tasks to populate their MyPHRs with their personal health data and to edit and amplify that data where needed.

The MyPHR test plan was progressively elaborated as we worked with participants. This approach is in keeping with the principle of emergence in qualitative inquiry,²¹ to verify and further explore the experience of each participant against that of subsequent participants. No new information emerged after the 10th interaction of participants with MyPHR. Sessions 11 and 12, conducted with the last 2 participants, served to confirm saturation. Twelve hours of audio (discourse) and video (screen capture of MyPHR navigation) were recorded. Recordings were memoed, and the memos were analyzed for cross-cutting themes by the principal author. One participant became the first patient to use MyPHR in receiving care in the SCI-PCSP. He participated in an additional interview to review the initial findings from MyPHR testing and to reflect on his experience using the tool to interact with his care team. A summary of initial findings about what worked and what could be improved in MyPHR

was given to all participants for member checking, and their amplifications were incorporated in the final analysis.

Results

What worked: Wealth of data available to personalize health care after SCI

Participants were successful in capturing a wide variety of health information in their MyPHRs. These data came from provider and insurer portals, a national chain pharmacy, and an activity tracker (Fitbit®). Structured data (eg, measures such as weight, blood pressure, blood glucose, and lipid profile, shared in standardized, xml format that can be used by health applications for trending and alerting) were available, though not uniformly across all portals. All participants were successful in importing medications as structured data. Two participants who patronized a national chain pharmacy used the pharmacy's app to bring their prescriptions into MyPHR when structured data were not available through their provider portals.

The functions of MyPHR that facilitated communication with the care team were also appreciated. The participant who became the first patient to use MyPHR in receiving care endorsed the positive impact of MyPHR's text-based prompts that were sent to patients' e-mail or phones to help them carry out action items and to

advise them that they had a secure message from care providers. “I need to go get an MRI, and I get an e-mail! ... [With this approach,] you don’t have to worry about cluttering the mind of somebody who’s overwhelmed with the circumstances or just not fluent in this type of activity [managing health data].”

What didn’t work: Not enough “bang for the buck”

The magnitude of effort to manage their health information versus the utility of that information was the predominant theme that emerged from participants’ interactions with MyPHR. All data imported required verification and, as needed, manual editing in MyPHR. Prescription data, which was highly valued, proved most sensitive to inaccuracies due to changes negotiated between provider and patient but not communicated to the pharmacy.

Two participants imported structured data from primary care providers (PCPs) who used the same patient portal, but implemented it differently. One practice configured its portal to allow bulk export of a patient’s entire medical record, whereas the other practice required each visit’s data to be exported separately. The participant whose provider had the more restrictive policy did not see value in investing effort in capturing each of his provider visits to his MyPHR. “At a point, you get so much data that you miss the essential qualities of what you need.”

Similarly, the participant who was able to import his *entire* provider electronic health record did not see this as being useful to him personally, due to the excellent communication and relationship of reciprocity that existed between him and his PCP. “They’re [his PCP] close,” he explained. “If I have a question, I’ll just go see them.”

The participant with the restrictive provider reflected further on his experience and expectation for the use of electronic health data: “I remember back, 13, 14 years ago when I just started, you got a stack of paper. My mother carried around a bag that had all of my MRIs, all of my doctors’ notes, all of my EOBs [explanation of benefits] from the insurance company ... SCI is a *great* community to start with [managing personal health data]. In any major life-changing community, you have *all*

of these things that you have to do...[However] unless I’m a super engaged patient, I AM an engaged patient, I’m not going to be logging in all that often. It’s burdensome – I barely log in to check my *bank* account as much as I should, much less my doctor.”

One participant discovered that her entire, longitudinal SCI care history, across all of her providers and services, was available as structured data from her insurer’s portal. She found, however, that the portal’s encoding confounded dates of service and dates of payment in the export file, which required extensive editing in MyPHR to sequence health events accurately.

In the case of this participant’s prescription records, medications prescribed did not equate to medications taken. The participant was prescribed antispasticity medication that required on-going adjustment. The pharmacy dosage of one tablet per day needed to be edited to one and one half tablets per day. The participant was able to figure out how to do this in MyPHR with relative ease. However, the changes in a personal health record are one-way; the pharmacy does not receive information back. When the medication was renewed, the new prescription came into MyPHR with the old dosage information and a purchase date instead of the actual start date. The patient was required to edit this information again to ensure it was correct when she shared it with her many providers. The patient reasoned that she could have asked the prescribing physician to write and transmit a new prescription to the pharmacy with the correct dosage. The patient perceived both approaches as excessively burdensome.

Focus for improvement: Engaging, communicating, and supporting the patient

Reaching out to patients to support their self-management versus the more passive approach implemented in some HIT designs was seen as the area where PHRs could have the greatest impact for optimizing health in a complex, chronic condition such as SCI. One participant shared his perspective: “I have three different doctor portals that I have to log into, so I have to set a reminder in my phone to remind myself to log in to check to make sure – I know in my mind that I have to set

up a primary care appointment, that I'm probably past due, but I have to log in to check that I was supposed to do it – and they never called. It's also just discouraging to the patient who doesn't have a lot of excitement about doing this, or the time. You want to encourage patient engagement as much as possible – those [experiences] are roadblocks to making that happen. ... The *structure* has to change."

Participants endorsed the patient-centered design of MyPHR that incorporated a human being, the SCI care coordinator, in the loop to monitor activity and mediate information. One individual opined, "There needs to be a position somewhere between a nurse and an admin that comes in like, 'Hey, these are the reasons why, between now and your next appointment, you should probably get an MRI.' I already knew it; it's something I *hate* doing, and it's also time-consuming. So it's like, I need to schedule that. It's a good reminder. I know why I need to do these things [but I tend to put them off]."

The participant further reflected relative to the potential of an SCI care coordinator to mediate information between patients and health care providers: "The changing nature of health care is that doctors have less and less time, but [for] patients, there're more and more requirements... trying to find somebody who can fit into that void that we previously didn't have to fill is somewhat important. ... It's almost a patient advocate [that's needed] ... somebody who is a central point of contact, [and] doesn't need to consume all of the doctor's time."

Mediation of information in the reversed direction, health care provider to patient, was also seen as an important role of the SCI care coordinator in patient mentoring and empowerment. One participant offered, "That type of person could then [engage] the patient and say, 'Hey, by the way, these are the reasons why the doctor wants you to do X, Y, and Z.' And especially in the spinal cord world, someone who is fluent in the types of issues that are prominent [is essential]."

Discussion

All participants displayed high levels of self-efficacy, health literacy, and comfort with online technologies. As other research has shown, these characteristics may have reduced, but did not remove, difficulties implementing a PHR as part of health maintenance planning.²² Even though all participants recognized and appreciated the potential health management benefit of having electronic and centralized health records, that vision was not compelling enough to move them past the perceived burden of importing, organizing, and acting on the vast amount of health information available to them. This finding tracks an acceptance model²³ developed by Tavares and Oliveira for electronic health record portals. Tavares and Oliveira's model identifies having a chronic condition as a predictor of interest, but the most significant predictor is expectation of performance followed by expectation of the effort using the technology will require. To realize the potential of the aggregated health data in MyPHR, the SCI-PCSP will need to thoughtfully determine which items of information are the most relevant to each patient and continually demonstrate the importance of creating and working with those sets of data to manage health.

Participants strongly advocated for using MyPHR as a tool to enhance communication between patients and clinicians and engage patients around their health information to facilitate self-management, not as a way to distance patients by automating and, in the process, depersonalizing interactions. This perspective accords with patient portal research,²⁴ which suggests that if patients see a technology as a barrier interposed between themselves and their care providers rather than a tool that increases contact and improves communication, it is less likely to be used.

The literature supports enhanced communication, in the form of secure messaging, as a highly valued adjunct of a PHR not only from the patient but also from the clinician point of view.²⁵ Though a care coordinator was not specifically identified as functioning within the operational plan of PHR implementation, the importance of educating patients on the what, how, and why of PHR was highlighted.

Limitations

This study is preliminary and findings are based on a small cohort of highly activated patients. It is possible that individuals with less SCI experience and lower technical skills would approach using their MyPHRs differently and different criteria for implementation use would emerge.

Conclusion

Until such time as the vision of a truly unified national health information system becomes reality, managing SCI means coordinating and making sense of multiple streams, and a large volume, of health data. Traditionally, patients have played a passive role in their care. PHR technology provides many opportunities for increased patient engagement and empowerment, but more research is needed to understand how best to use PHRs in providing care. Based on the experience of our first cohort of patients interacting with MyPHR,

we identified 2 fundamental principles guiding PHR implementation to support patients. First, if a PHR is to be useful in helping patients promote health, it is important to work with patients individually to identify the information that has the greatest relevance to their current health concerns and goals and, further, to support them in the process of getting that information into their PHRs and then using it in self-management. Our patients testing MyPHR were unequivocal in their endorsement of the need for a responsive human being behind the technology to help them act on care plans developed in conjunction with their providers. Second, therefore, an individual whose primary responsibility is to engage patients in the life-long process of managing their SCI, a task driven by information and communication, will be an indispensable member of the SCI-PCSP team. A follow-on study of the use of PHR technology from the care provider/coordinator perspective is needed.

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