Research Article

Potential of personal health record portals in the care of individuals with spinal cord injuries and disorders: Provider perspectives

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Context/Objective: Although personal health record (PHR) portals are designed for patients, healthcare providers are a key influence in how patients use their features and realize benefits from them. A few studies have examined provider attitudes toward PHR portals, but none have focused on those who care for individuals with spinal cord injuries and disorders (SCI/D). We characterize SCI/D provider perspectives of PHR portals, including perceived advantages and disadvantages of PHR portal use in SCI/D care.

Design: Cross-sectional; semi-structured interviews.

Setting: Spinal Cord Injury (SCI) Centers in the Veterans Health Administration.

Participants: Twenty-six SCI/D healthcare providers.

Interventions: None.

Outcome Measures: Perceived advantages and disadvantages of PHR portals.

Results: The complex situations of individuals with SCI/D shaped provider perspectives of PHR portals and their potential role in practice. Perceived advantages of PHR portal use in SCI/D care included the ability to coordinate information and care, monitor and respond to outpatient requests, support patient self-management activities, and provide reliable health information to patients. Perceived disadvantages of PHR portal use in SCI/D care included concerns about the quality of patient-generated health data, other potential liabilities for providers and workload burden, and the ability of individuals with SCI/D to understand clinical information accessed through a portal.

Conclusion: Our study highlights advantages and disadvantages that should be considered when promoting engagement of SCI/D healthcare providers in use of PHR portals, and portal features that may have the most utility in SCI/D care.

Keywords: Patient portals, Personal health records, Provider attitudes, Spinal cord injury

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Introduction

Recent years have seen a proliferation of technologies addressing patients' health and self-management efforts. Personal health records (PHRs) are secure, Internet-based resources comprised of health

information that is owned by individuals, can originate from different sources, and is used to make health decisions.¹ Many PHRs are “tethered” to healthcare systems and offer different kinds of features^{2,3} including patient self-entered information, pharmacy and laboratory data, portions of a patient’s electronic health record (EHR) maintained by the healthcare system, tools that support online healthcare system transactions (e.g. refilling prescriptions), and electronic communication with providers. The terms “patient portal” or “PHR portal” describe the Internet-based location where such features are accessed. Table 1 presents common PHR portal features, organized into functional categories,⁴ with corresponding descriptions of each feature. The Veterans Health Administration (VHA) PHR portal, My HealtheVet (Fig. 1) includes self-entered information from patients, extracts from the VHA EHR, self-management tools, health education materials, and other features like secure messaging and prescription refills intended to engage patients in their care.⁶ As of August 2016, VHA’s My HealtheVet had over 3.7 million users with access to basic portal features and of those users, over 2.2 million VHA patients had fully-upgraded user accounts with access to all portal

features such as access to information from their medical record and secure messaging.

Across health care settings, PHR portal use is increasing, driven in part by the 2009 United States (U.S.) Health Information Technology for Economic and Clinical Health (HITECH) Act which called for the creation of Meaningful Use incentives to offer financial support to providers and health systems adopting EHR technologies.⁷ Coupled with these trends, questions have arisen about which patients may benefit most from portal use. Studies have reported associations between PHR portal use and mitigation of distress, enhanced clinic visits, and better clinical outcomes including medication adherence, low-density lipoprotein levels, glycemic control, and other quality measures of diabetes management.^{8–10} Similarly, others have reported associations between PHR portal use and HIV-disease measures including viral suppression and engagement in care.^{11,12} Consequently, some argue that chronic health conditions requiring self-management are may be the most responsive to PHR portal use.¹³

SCI/D represents a lifelong condition that necessitates self-management to reduce complications and achieve a

Table 1 Typical features of phr portals organized by functional category.

Functional Category	Representative PHR Portal Features	Description of Feature
Transactions Features that enable patients to interact with and make requests of a health care system	Make and view appointments View and refill prescriptions	Make appointments online and view upcoming appointments Request prescription refills and view records of prescriptions
Communication Features that enable mass or interpersonal communication	Asynchronous electronic communication (e.g. secure messaging)	Exchange secure, electronic messages between patients and healthcare providers
Storage and Access to Personal Health Information Features that enable patients to self-enter and track details about their health, and to access other information from their EHR maintained by the healthcare system	Patient information Track and visualize information Access EHR extracts	Maintain contact/emergency information, insurance details, information about allergies, immunizations, over-the-counter medications, caregivers and providers, a personal or family health history, etc. Track personal health details like diet and exercise habits, blood pressure, blood sugar levels, weight, etc. and view them graphically to facilitate understanding View select information from the medical record, including clinical progress notes
Health Education Features that provide reliable information on a variety of health topics	View lab results Online health information libraries Community	View results of recently conducted laboratory tests Collections of evidence-based health information in different formats for patients to search and access Information about news and events related to a health care provider/system
Behavior Support Features that cue, remind, and promote desirable health behaviors	Health assessments, reminders, self-screening tools	Complete assessments, screening tools, and view customized reminders for aspects of care

*Features listed are examples of those available in VHA’s PHR portal and other portals; for a clinical vignette that illustrates use of such features in the context of SCI/D, see reference.⁵

Figure 1. Screenshot of the VHA My HealtheVet PHR portal homepage.

high quality of life.^{14–17} Individuals with SCI/D exhibit high levels of health information seeking,^{18–20} including frequent use of health professionals as information sources and internet use for health maintenance.^{18,20,21} A cross-sectional analysis found that adoption of VHA's PHR portal among Veterans varied significantly by condition, and that Veterans with SCI/D were among the highest adopters.²²

Although PHR portals are intended for patients, there is growing recognition that healthcare providers are key determinants of how patients adopt and use portal features.^{5,23–25} Provider endorsement can influence patient opinion of a PHR portal and its relevance to their own health, affecting patient adoption and subsequent use. Provider engagement with use of the PHR portal is also necessary to maximize the potential benefit of specific portal features. Furthermore, offering patients capabilities like managing clinical appointments online, viewing lab and test results, refilling prescriptions, and exchanging asynchronous, secure messages with their providers has fundamental implications for how services are accessed, provider daily clinical work, and even the provider-patient relationship. Some studies have examined provider attitudes toward PHR portals and barriers

to their use in practice;^{26–29} but none have focused on SCI/D healthcare providers. We sought to characterize SCI/D provider perspectives of PHR portals, including perceived advantages and disadvantages of PHR portal use in SCI/D care.

Methods

Data were collected as part of an implementation study to facilitate adoption of the VHA's PHR portal in the VHA Spinal Cord Injury (SCI) System of Care from 2010 to 2011. The study involved various stakeholder groups, including SCI/D healthcare providers, SCI/D clinical leadership, and individuals with SCI/D. In this paper, we report on the in-person, semi-structured interviews that were conducted with SCI/D healthcare providers. Study activities were approved by VHA Institutional Review Boards (IRB).

Recruitment

A convenience sample of providers were recruited from two VHA SCI Centers located in the Midwestern U.S. VHA SCI centers provide acute rehabilitation in addition to inpatient and outpatient services. In an effort to reach a range of different providers, we

attended staff meetings at the two SCI Centers and asked those who were interested in participating to share their contact information. We recruited providers representing different clinical roles (e.g. physician, nurse, therapist) to understand perceptions of PHR portals related to various aspects of SCI/D care. As data collection proceeded, providers were asked to recommend colleagues appropriate to interview, a technique known as snowball sampling.³⁰ The study team had IRB approval for recruitment of 30 total providers, a sample size that we assumed to be sufficient to reach saturation, the point at which little to no new information is being uncovered.^{31,32}

Data collection

Two health services researchers trained in qualitative research, and semi-structured interviewing techniques (JNH, TPH), conducted the interviews which were audio-recorded and held in private offices at the SCI/D Centers. An informational letter was given to providers and verbal consent was secured before the start of each interview. Providers first completed a brief questionnaire to document their demographic and professional characteristics. The interview followed, typically lasting 30–45 minutes. The semi-structured interview guide was focused on SCI/D provider perceptions of PHR portals and the advantages and disadvantages associated with their use in SCI/D care. Because the interviews were part of an implementation study, interview questions were informed by the Promoting Action on Research Implementation in Health Services (PARIHS) framework,³³ which emphasizes the importance of evidence, context, and facilitation in efforts to incorporate change in clinical practice settings.

As highlighted in Table 2, the interview guide was comprised of open-ended questions and probes specific to the SCI/D care context to ensure focused responses, and was reviewed by study team clinicians and piloted prior to data collection. As our objective was to understand provider perspectives of PHR portals in general, we also provided descriptions of features that are commonly available across PHR portals, including VHA's portal (Table 1), to support interview discussions.

Data processing and analysis

Audio recordings of three initial interviews were reviewed to assess their consistency with the interview guide and study objectives. Audio recordings were transcribed by a research assistant using transcription software (Olympus AS2400) and NVivo (Version 8.0) was used for coding and analysis. Analysis proceeded through thematic content analysis, and the constant comparative method, which involves identifying themes from data and organizing them into categories.³⁴ The principal investigator (TPH), and another study team member (JNH), began coding with a list of basic categories derived from interview guide topics. Within these categories, they identified emergent subcodes. To ensure rigor, the two team members each independently reviewed five transcripts and then convened to compare subcodes which they defined in a codebook. The two team members then began the process of coding all interviews independently, using the codebook. The categories and subcodes became saturated after coding about 12–14 transcripts. The two team members worked closely during this process, meeting weekly to compare interpretations, resolve coding discrepancies, and merge and refine codes as needed. Background

Table 2 Interview topics and sample questions.

Topics	Questions and Corresponding Probes
Clinical setting	<ul style="list-style-type: none"> • Please describe the service/clinic/team that you are a part of. • What is a typical day of work like for you? • Tell me about the individuals with SCI/D that you see for care. <ul style="list-style-type: none"> ◦ Social, financial, and living situations ◦ Types of health conditions
Understanding of PHR portals and features	<ul style="list-style-type: none"> • What do you know about PHR portals? • What role do you see for PHR portals in your work with individuals with SCI/D? • Do you ever talk about PHR portals with your patients? What do you know about their use of PHR portals?
Advantages of PHR portals	<ul style="list-style-type: none"> • What potential advantages do you think PHR portals offer to individuals with SCI/D? To the clinical teams who care for them? <ul style="list-style-type: none"> ◦ What features are potentially the most useful for individuals with SCI/D? For their clinical team members?
Disadvantages of PHR portals	<ul style="list-style-type: none"> • What potential disadvantages do you think PHR portals pose for individuals with SCI/D? For the clinical teams who care for them? <ul style="list-style-type: none"> ◦ What features are potentially the most problematic for individuals with SCI/D? For their clinical team members?

Table 3 Sample description.

Provider Characteristics	n (%)
Sex	
Female	19 (73.1%)
Male	7 (26.9%)
Average age	47.6 years
Average years in VHA	11.62 years
Average years at current VHA SCI Center	10.62 years
Clinical team member role*	
Nurse	8 (30.8%)
Therapist	5 (19.2%)
Physician	4 (15.4%)
Psychologist	3 (11.5%)
Social worker	3 (11.5%)
Dietitian	2 (7.7%)
Workload distribution averages	
Direct patient care	52.9%
Administrative tasks	44.6%
Other (e.g. patient education, research)	21.7%
Have you ever visited VHA's PHR portal, My HealtheVet?	
Yes	18 (69%)
No	8 (31%)

*Indicates missing value (n=1)

questionnaire data were analyzed using descriptive statistics.

Results

Sample characteristics

As shown in Table 3, the 26 providers who completed an interview had a range of clinical roles within the SCI Centers and primarily treated patients with SCI/D-related care needs. The majority (69%) reported that they had visited VHA's PHR portal at least once.

The influence of patient complexity

Providers described caring for individuals with SCI/D as extremely complex. They discussed the prevention and management of co-morbidities associated with SCI/D, and the frequent contact with the healthcare system that individuals with SCI/D often require. Providers also commented on the aging of their patients and their evolving needs. Finally, they described patient socioeconomic status, particularly the challenges of living on a fixed income with a severe disability. This complexity directly shaped provider perspectives on PHR portals and their potential role in SCI/D care.

Below, we present the primary themes we identified, organized according to perceived advantages and disadvantages for SCI/D care.

Advantages of PHR portals in SCI/D care

Nearly 81% (n=21) of the SCI/D providers perceived advantages associated with use of PHR portals in

SCI/D care. Primary themes identified as advantages included coordinating clinical information and care, monitoring and responding to ongoing needs between visits, supporting patient self-management activities, and providing information to patients to facilitate adjustment to life following SCI/D.

Coordinating clinical information and care

Providers raised the issue of fragmentation across care settings, explaining that many individuals with SCI/D use different healthcare systems, and attributed this pattern to specialty care needs, urgent situations, and limited numbers of community-based providers with SCI/D expertise. A recurring theme was the potential of PHR portals to support access to information about the management of patients who receive care in different settings and using that information to supplement the EHR. One physician explained, "*Personal health records are really very valuable from a provider point of view. People move around...Tracking flu shots, summaries, medications, so you know what you're dealing with when you see that person is very valuable.*" Other examples included the potential for PHR portals to reduce communication gaps and to support coordination of the frequent appointments of individuals with SCI/D. Additional quotes are provided in Table 4.

Monitoring and responding to ongoing needs between visits

Providers mentioned the need for more complete understanding of the status of outpatients with SCI/D in between face-to-face appointments. Patient-generated health data, data collected or created, entered by, and shared by a patient through a PHR portal, were seen as one way to obtain those status updates. One social worker commented on the value of patient-generated data to understand health trends: "*If you could go in there and see historic health trends, because sometimes you are trying to do these histories with patients, and they are able to report certain things but they don't remember that well. You would be relying on the patient to be diligent and put stuff in there, but I think if a patient was doing that, it would be an outstanding resource.*"

Providers described how reporting of patient-generated data through a PHR portal might reduce unnecessary clinic visits, and also improve their effectiveness in responding to patient needs using asynchronous communication features such as secure messaging. Additional quotes are provided in Table 4.

Supporting patient self-management activities

The potential of PHR portals to support self-management activities was discussed by many providers. They

Table 4 Advantages of PHR portals in SCI/D care.

Sub Theme	Providers, Mentions*	Example Quotes
Coordinating clinical information and care	7 providers, 9 mentions	<p><i>"Individuals with SCI/D, as they get older, as they have more appointments, [instead of] me giving you a piece of paper and somebody else giving you a piece of paper, and it [being] up to you to keep these pieces of paper together, it's all in one place and we can access it [through a PHR portal]."</i>(Physician)</p> <p><i>"Some of our patients go to multiple sites ... if that [PHR portal] could help facilitate communication between these providers and the patient, I think that would be very helpful – the communication aspect to cut down on errors in communication between multiple providers."</i>(Physical Therapist)</p>
Monitoring and responding to ongoing needs between visits	7 providers, 14 mentions	<p><i>"It would be nice if the SCI patient could interact with a physician and type a note like 'my wound change dressing kits expired as of this month, can you renew them for me' versus having to make a phone call to the secretary, and wait for the doctor to call back."</i>(Nurse)</p> <p><i>"A person who has to monitor their blood pressure and their pulse rate, instead of having them come in, if it was able to be downloaded onto the system, I could just look at it and call them on the phone. It would save the patient from having to come in. So it will save time; it will save money."</i>(Registered Nurse)</p>
Supporting patient self-management activities	10 providers, 18 mentions	<p><i>"I think if we incorporate this into active rehabilitation and occupational therapy ... this would make a difference. The idea that you can enter your blood pressure, weight, and so forth could make an impact."</i>(Physician)</p> <p><i>"If a patient has a history of UTIs [urinary tract infections], common for patients with spinal cord injuries, if a patient is able to track their behaviors, maybe they can get better control of what causes them to have a UTI, what they can do to avoid that..."</i>(Social Worker)</p>
Providing information to facilitate adjustment to life following SCI/D	10 providers, 13 mentions	<p><i>"...Traveling as a wheelchair-bound person, asking questions like 'how do you travel in airplanes, how do you arrange it' and 'how do you find hotels to make sure they are really handicapped accessible' ... that sort of thing [might be helpful to include in a PHR portal]."</i>(Physician)</p> <p><i>"A lot of them, the computer is their world. I told you about their travel limitations. So yes, this could bring the world to them more easily."</i>(Kinesiotherapist)</p>

*The number of times this specific subtheme was referred to by study participants.

saw an important role for the tracking features that portals offer for pursuing personal goals, and for supporting behavior change among patients. A physical therapist described how journaling in a PHR portal could support weight management efforts: *"A food and activity journal would be very helpful because we are trying to get an SCI MOVE! [weight management] program up and running ... That would be huge to see for behavior change."* Other examples included PHR portal use to track rehabilitation progress and understand the causes of complications and ways to avoid them. Of note, providers commented on the potential of tracking information in a PHR portal to increase self-management. As a physician commented, *"It also makes it clear to the patient beyond words that, ultimately, they are responsible for themselves."*

Lastly, many individuals with SCI/D manage complex medication schedules. Providers felt that the medication management features offered by PHR portals may help their patients be more organized and adherent. An occupational therapist remarked that, *"I can see how getting the patient to use it will make their life easier. I have a*

lot [patients] here on so many medications...If they could view it on the screen ... know what they're taking, when they're running out ... why they are taking it, it might help them stay on top of their medication issues better." Additional quotes are provided in [Table 4](#).

Providing information to facilitate adjustment to life following SCI/D

Providers also viewed PHR portals as a channel to provide information intended to facilitate adjustment to life following SCI/D. They described the printed materials that they currently offer to newly injured individuals and how these materials could also be offered electronically through a PHR portal. Another commonly suggested topic area was SCI/D medical equipment and devices. As one physician commented, *"There's a lot of trouble-shooting on wheelchairs. Simple diagrams would help them troubleshoot minor problems."* Additional suggested topics focused on other aspects of life with SCI/D, such as planning travel when a wheelchair is involved, and *"providing*

patients access to the world.” Additional quotes are provided in Table 4.

Disadvantages of PHR portals in SCI/D care

Nearly 58% (n=15) of the SCI/D providers perceived disadvantages associated with use of PHR portals in SCI/D care. Primary themes identified as disadvantages included the integrity of the information accessible through a PHR portal, liability concerns and workload burden, and the quality and complexity of information accessible to patients from the EHR.

Integrity of the information accessible through a PHR portal

PHR portals support access to different kinds of information for providers and patients. For providers, this includes patient-generated health data; for patients, information from the EHR. Providers expressed concerns about the integrity of both kinds of information. Some questioned the accuracy of information that individuals with SCI/D enter into a PHR portal. In addition to concerns regarding the ability of patients to gather or record their data reliably, providers described the influence that a patient’s medical and emotional states may have on reported data. A physician commented, “Sick patients can have their own anxieties and so that affects, colors their interpretation of things...They are likely to put information in there [a PHR portal] that is not helpful and will create problems.”

Providers were concerned about individuals with SCI/D misinterpreting information accessed from the EHR and how that concern may impact their own clinical documentation practice. Speaking about SCI/D and co-occurring mental health issues, a nurse remarked, “You will stop being frank in the record if now people... are going to see these charts. They’ll look at everything all the time and they’ll be after you for every little thing that is off...” Additional quotes are provided in Table 5.

Liability concerns and workload burden

Providers worried about the new responsibilities that might emerge in their work if their patients engaged in PHR portal use. Some expressed concerns over potential liability for reviewing portal information. Others felt that given the complex health situations of their patients, the kinds of asynchronous electronic communication supported by many PHR portals may introduce unique risks for individuals with SCI/D. As one physician noted, “Somebody can send a message...and the problem can get really bad if not handled properly. Our patients tend to go from one extreme to another very quickly, especially in spinal cord injury, because they have very fragile bodies and fragile systems; their physiology and pathology is so unique.” Other providers voiced intersecting concerns around the implications of PHR portal use on time demands and already heavy workloads. Additional quotes are provided in Table 5.

Table 5 Disadvantages of PHR portals in SCI/D care.

Sub Theme	Providers, Mentions*	Example Quotes
Integrity of the information accessible through a PHR portal	4 providers, 8 mentions	<i>"I think that from the providers' standpoint, if the [patient] enters it, and if I know that it is factual information that I can rely on, it's going to make me use it more."</i> (Nurse Practitioner) <i>"Progress notes might become less useful [clinically] because they are written with a different audience [the patient] in mind."</i> (Physician)
Liability concerns and workload burden	7 providers, 9 mentions	<i>"There's a liability. There are only so many pots I can watch at one time. I can stay on top of my phone, I can stay on top of my pager, but then if I have to start checking [the PHR portal] and logging into that to check emails, forget it ... and heaven forbid I missed one that was critical and a patient goes and hurts [them]self."</i> (Psychologist) <i>"Providers maybe won't take the time to contact other providers to clarify things if they have something [from the PHR portal] in front of them already."</i> (Nurse)
Quality and complexity of information accessible to patients from the EHR	11 providers, 22 mentions	<i>"Understanding the intricacies of how and why things are being done...even an educated person would be very confused as to what's going on, what's happening."</i> (Physician) <i>"If a [patient] goes to read and interpret, it might be different from what they think they heard from their physician, or it very well may be different. Their case of depression may be atypical, and they don't fully understand what atypical means. I think it's good for the providers to know what is being put out there...to ensure it makes sense to the [patient]."</i> (Physician)

*The number of times this specific subtheme was referred to by study participants.

Quality and complexity of information accessible to patients from the EHR

Providers recognized the role of PHR portals in supporting access to clinical information that was previously challenging for patients to obtain, but described how the quality and complexity of information from the EHR could pose problems for patients. Some concerns focused on the completeness of EHR information. Other concerns were related to patient abilities to understand EHR information, including medical terminology, and the importance for providers to be aware of the kinds of EHR information accessible to patients so that they can facilitate understanding when necessary. Supporting quotes can be found in [Table 5](#).

Discussion

The providers in this study saw a variety of advantages to PHR portal use in SCI/D care. These advantages included coordinating clinical information and care, monitoring and responding to ongoing needs between visits, supporting patient self-management activities, and providing information to patients to facilitate adjustment to life following SCI/D.

Our findings regarding coordination, are similar to other reports.^{29,35–38} In a study of family physicians, coordinating information across clinical settings was a perceived benefit of PHR portals.²⁹ Other studies have suggested that providers believe that access to PHR portal information can enhance their capacity for patient monitoring^{36,39}; however, use of PHR portals for this purpose has been less widely studied. The extent to which SCI/D providers viewed PHR portals as a means to respond to outpatient needs is another benefit reported by others,^{2,40} including some studies focused on chronic illness.^{36,37} The prominence of this theme in our data may reflect unique aspects of SCI/D care, namely, frequent contact with the healthcare system.⁴¹

The theme of supporting self-management activities is similar to previous work showing that PHR portals support various patient tasks.^{35,42–44} Studies of patients with diabetes indicate that self-management was enhanced by PHR portal use, especially tracking blood sugar levels.^{36,39,45} This speaks to the potential of PHR portal tracking features as discussed by providers in this study. Our findings also highlight the role PHR portals can play to deliver informational resources to patients, and are similar to studies describing portals as sources for health information generally,⁴⁶ and for specific conditions.^{35,45} Similar to earlier research, our analysis suggests the importance of portals to address topics broadly related to the experience of living with

SCI/D.^{18–20} Based on our data, this may include, but may not be limited to, tips on traveling with a disability, managing one's medical equipment, and maintaining an active lifestyle.

Providers also reported a variety of disadvantages to PHR portal use in SCI/D care. These included concerns over the integrity of the information accessible through a PHR portal, liability concerns and workload burden, and the quality and complexity of information accessible to patients from the EHR. These themes are consistent with studies outside SCI/D in which providers expressed concern over the accuracy, timeliness, completeness, and clarity of information available to patients and providers through PHR portals.^{36,42,44,47} The concerns of SCI/D providers regarding access to EHR information were similar to those voiced by some providers participating in initiatives to engage patients in reading clinical progress notes online.^{48,49} Other studies, however, including some conducted in VHA, show that patients derive benefit from online access to clinical notes.^{25,50} Concerns over potential liabilities associated with PHR portal use have been described in studies outside SCI/D.^{29,43,44,51–53} The various PHR portal policies that healthcare systems implement (e.g. asynchronous electronic communication which must be addressed within specified time intervals) are a means to address such concerns.

Lastly, SCI/D providers perceived the potential for negative impacts from the EHR information that is accessible to patients. Concerns from providers included the potential that patients might encounter incomplete EHR information or struggle to make sense of other information. Other studies suggest that patients may struggle to understand medical terms and may feel overwhelmed by the information available through PHR portals.^{43,54} The difficulty that patients may experience trying to interpret clinical content, and any negative outcomes associated with accessing that content, speaks to the liability concerns documented here and elsewhere.^{44,54}

Implications for SCI/D care

The findings from our interviews with SCI/D healthcare providers align closely with previous studies of provider attitudes toward PHR portals and barriers to their use in other care contexts. The potential for improved patient monitoring, however, is a unique theme from our analysis in the SCI/D context that warrants further attention. Below we posit the following implications for SCI/D care.

First, the themes that we identified suggest that certain PHR portal features may have the greatest

potential to improve SCI/D care. These include features that support access to and sharing of clinical information across care settings, remote monitoring through patient-generated health data, asynchronous electronic communication, tracking patient behaviors and goals through patient-generated data, supporting self-management activities, and offering access to health education resources. Use of such features could translate to measurable gains in access to services, and a shift to more continuous as opposed to episodic care for individuals with SCI/D. Moreover, if patients and providers collaborate to identify when and how specific portal features may be used to best meet the needs of a particular patient along the trajectory of their care, both utilization of portal features and resulting benefits may be optimized. Realizing such improvements may require training to raise awareness of key PHR portal features among providers and patients, and to build skills so that these features are used effectively.

Second, perceived advantages revealed in our analysis suggest targets for measuring the benefits of PHR portal use in SCI/D care. These targets include care coordination, information sharing, and patient-provider communication, which may in turn enhance other outcomes. Such targets are not unique to SCI/D and have been described as part of existing evaluation frameworks for PHR portal features.⁵⁵

Third, the perceived disadvantages suggest barriers that should be addressed if PHR portals are to be more widely used in SCI/D care. In many cases, meaningful use incentives and rapid health care technology deployment have created expectations for healthcare providers to adopt PHR portals. Still, concerns about data quality, liability, and negative impacts from incomplete or complex information are significant, and are unlikely to resolve without intervention. Additional exposure, training to guide effective use, and opportunities for SCI/D providers to contribute to PHR portal design and evaluation can help mitigate perceived disadvantages.^{51,56,57} Likewise, organizational policies and effective communication strategies can help to ensure that patients and providers have a common understanding, including roles and responsibilities for managing and reviewing data, use of asynchronous communication tools, and resources available to clarify complex medical terms.

Limitations

Our study has limitations. First, as part of a larger implementation study as noted above, we recruited SCI/D providers through two VHA SCI Centers, which limits generalizability. Second, recruiting

providers at team meetings may have introduced sampling bias. Third, PHR portals continue to evolve, as do policies guiding their use. As such, perceptions of their advantages, disadvantages, and potential role in SCI/D care may be changing. Future work should continue to evaluate changes in perceptions over time. Integrating healthcare provider perspectives with those of other key stakeholders, including clinical leadership and individuals with SCI/D, will be necessary to identify effective strategies for enhancing the implementation of PHR portals in SCI/D care.

Conclusion

Similar to other chronic health conditions, the chronic nature of SCI/D, requiring complex clinical and self-management activities, suggests that it may be a condition which could be positively impacted by enhanced PHR portal use.¹³ To our knowledge, this is the first study to characterize the perspectives of SCI/D healthcare providers related to PHR portals, including advantages and disadvantages of portal use in SCI/D care. Maximizing the potential benefits of PHR portals in SCI/D care will require leveraging engagement among individuals with SCI/D; however, it will also require the healthcare providers who care for them to meaningfully engage with the technology. Our study highlights key factors that should be addressed to realize this engagement, and the aspects of PHR portals that may have the most utility in SCI/D care.

Disclaimer statements

Contributors None.

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