Feasibility Report: Use of Personal Health Records in Spinal Cord Injury Health Information Self-Management

Background and Significance

Chronic Illness, Disability and Health Information Management

Managing chronic illness to drive improvement in health status poses a major hurdle worldwide. According to the World Health Organization (WHO), noncommunicable diseases, principally cardiovascular disease, diabetes, cancer, and obesity, account for approximately 60% of the deaths worldwide and make up almost half (47%) of the total global disease burden (http://www.who.int/dietphysicalactivity/faq/en/index.html). In the United States, 7 out of 10 deaths each year are the result of chronic disease (http://www.cdc.gov/nchs/data/nvsr/nvsr56/nvsr56_10.pdf) and almost one half of all American adults have at least one chronic illness (Wu & Green, 2000).

Chronic health conditions as sequelae to physical disability are common (Hwang et al., 2009) and spinal cord injury provides an exemplar case. Spinal cord injury (SCI) is defined as damage to the spine that results in loss of mobility (paralysis) and/or sensation (National Spinal Cord Injury Association, 2010). Persons with SCI experience permanent physical disability and subsequent onset of multiple chronic medical conditions. Most prevalent among these conditions are chronic infections (urological, skin, and respiratory), followed closely by musculoskeletal, gastrointestinal, and cardiometabolic disorders (Cardenas, Hoffman, Kirshblum, & McKinley, 2004; Chiodo et al., 2007; Finnie, Buchholz, Martin Ginis, & SHAPE SCI Research Group, 2008; Groah, Lichy, Libin, & Ljungberg, 2010; Groah et al., 2011; Jaglal et al., 2009; Krause, Saunders, DeVivo, Reed, & Johnson, 2010). These s*e*condary medical conditions create a burden on health and function that is related to but *distinct* from the loss of sensory and motor function that people with SCI experience immediately following injury.

Successful health self-management after SCI requires individuals to coordinate a wide variety of interventions, both curative and preventative, prescribed by an equally wide variety of medical specialists. Individuals with multiple chronic conditions, such as those that characterize SCI, benefit from systematic health surveillance and coordination of care (Bates & Bitton, 2010; Coleman, Austin, Brach, & Wagner, 2009; Hwang et al., 2009). In the United States, however, persons with severe physical disabilities (such as those seen in SCI) are less likely than the general population to receive health maintenance services (Kroll, Jones, Kehn, & Neri, 2006) or to have a consistent relationship with a single primary care provider (Hwang et al., 2009). Reasons offered for the breakdown in receipt of care coordination by people with SCI include lack of insurance reimbursement, lack of reliable, wheelchair-accessible transportation, inaccessible medical offices, and patients' perception that medical generalists often lack understanding of how the health needs of persons with SCI diverge from those of the general population (Special Interest Group on SCI Model System Innovation, 2010).

Quality health care depends on the availability of the right information, to the right people, at the right time, to enable them to make the best possible health-related decisions (American Health Information Management Association, 2007; Care Quality Commission, 2009; U.S. Department of Health & Human Services, Agency for Healthcare Research and Quality, 2005). Lack of complete and accurate information to guide health care decision-making has been associated with decreased patient safety and poorer health outcomes as well as increased health resource utilization (Bourgeois, Olson, & Mandl, 2010). For persons with chronic medical conditions, health status surveillance and coordination

of care, both information-intensive activities, have been shown to produce positive health outcomes (Bates & Bitton, 2010; Coleman, Austin, Brach, & Wagner, 2009; Hwang et al., 2009).

eHealth, the use of electronic information and communication technologies to enhance the quality and safety of health care, has emerged as a top priority worldwide. The WHO acknowledges eHealth as a cost-effective and secure use of information and communications technologies to support health and health-related fields and includes health-care services, health surveillance, health literature and health education, knowledge and research among areas of anticipated impact (http://www.who.int/topics/ehealth/en/). In the United States, the Health Information Technology and Clinical Health (HITECH) Act, part of the American Recovery and Reinvestment Act of 2009, established transition to eHealth systems as a national priority.

The HITECH Act mandated by law an "Office of the National Coordinator (ONC) for Health Information Technology (HIT")" within the U.S. Department of Health and Human Services (Redhead, 2009). The ONC oversees a national program of incentives designed to encourage the development of an eHealth infrastructure in the U.S. to promote coordination of care and better health outcomes (Office of the National Coordinator for Health Information Technology, 2010). The programs the ONC has created, however, are still in their infancy, and assessment necessarily waits on development. Operational decisions, which are in turn rooted in ethical considerations, impede adoption of eHealth in the United States. Particularly with respect to a national EHR, questions of what data will be shared and with whom remain to be resolved (Cushman, Froomkin, Cava, Abril, & Goodman, 2010). Among the difficult issues are: How to promote integrity of data while at the same time protecting patient privacy; when to restrict patients' access to their own information when access might not be in their therapeutic best interest; and how to preserve the integrity and credibility of data if patients can amend their own records on providers' systems (Cushman, et al., 2010; Etzioni, 2010; Halamka, Mandl, & Tang, 2008).

Personal Health Records

Consumer health informatics is an emerging field that offers the ability to enhance the quality and safety of care by leveraging information and communication technologies to enable the patient to be at the center of his/her care. A patient-centric approach to health information management side-steps many of the difficult issues plaguing provider-to-provider information sharing. Accordingly, the ONC has included a consumer-focused technology, the personal health record (PHR) among its evolving HIT infrastructure portfolio. A PHR is a standards-based, interoperable, electronic record of an individual's health-related information that is *controlled by the individual* (National Alliance for Health Information Technology [NAHIT], 2008). It puts the three, principal functions of e-Health at the service of the patient. PHR technology allows consumers (1) to store, retrieval, and share their personal health information with providers and other trusted entities; (2) to make self-management decisions based on their stored information, often with the help of data visualization applications; and (3) to receive care recommendations from providers remotely and asynchronously (Mandl & Kohane, 2008).

The purpose of the PHR is to serve as a life-long resource for an individual's composite health information drawn from a wide variety of sources (NAHIT, 2008). The most salient sources of PHR health information, according to NAHIT, are records imported from those maintained by health care and service providers, individuals' personal health data from medical devices, information manually generated by individuals for self-management or to alert care providers, and information from insurance providers. Over the past several years, interoperable, standards-based PHR products (e.g. Google Health, Microsoft HealthVault), have become freely available to consumers and allow them, in

theory, to begin managing all the previously-listed types of health information. (Executive Office of the President, President's Council of Advisors on Science and Technology, 2010, p. 33).

The PHR has been classified as a health *self*-management intervention (Solomon, 2010) because of the values of patient-centeredness and consumer-empowerment that underlie it. Health care frameworks that are characterized by a strong focus on health self-management, notably the Chronic Care Model (Coleman et al., 2009) and Medical Home Model (Bates & Bitton, 2010), increasingly include PHRs in their paradigms for patient engagement. A survey conducted and published by Lake Research Partners [LRP] in 2010 demonstrated that people with chronic health conditions, particularly those with multiple health conditions, perceived PHRs as particularly relevant to managing their health. LRP's results corroborated earlier research (Lafky, 2008) that had also found significant interest in PHRs among persons with chronic conditions.

Pilot Study of the Usefulness of PHRs in SCI Health Promotion

In 2010, the consumer and professional advisory panel of the Rehabilitation Research and Training Center (RRTC) on Secondary Conditions in the Rehablitation of Individuals with Spinal Cord Injury recommended investigating ways to help persons with SCI bridge the information gap between themselves and their health care providers to promote better health management and outcomes. Consequently, in the spring of 2011, the RRTC began a study exploring how persons with SCI might use PHR technology. A recent guide to SCI self-management, *Healthmechanics: Tools for self-management of spinal cord injury and disease* (Meade, 2009), provided a template for deciding what types of information are important to people with SCI in maintaining their health. Ehealth2go, the Medstar Health-sponsored PHR, served as the initial input portal. Eheath2go serves as a customizable user interface to Microsoft Health Vault.Microsoft Health Vault is a standards-compliant PHR platform that functions as a data repository. Various user interfaces can store and retrieve data from Health Vault. It supports information standards that make it potentially interoperable with providers' electronic medical records (EMRs). National programs coordinated by the ONC encourage providers to adopt standards' compliant EMRs through preferential funding.

Preliminary Outcomes

To date, we have explored PHR needs, development and use extensively with one participant. We have seen the PHR in use for self-management, routine information exchange with health providers and in the emergency department (ED). A case study of this participant is part of an article submitted to the Journal of Health Information Management for a spring 2012 issue focused on interoperability, i.e. sharing health information across consumer and provider management systems. A second participant has begun to work with us to set up her PHR and two further participants have expressed interest in the study. One was provided information on how to set up a PHR but had to be disqualified from the study as she did not actually have an SCI.

The most significant finding from this participant interaction was the non-utility of the PHR for day-to-day self-management. Persons with chronic conditions like diabetes benefit from doing finger sticks, tracking their blood glucose and dietary intake. Persons with SCI benefit from doing their bowel program and   skin inspection but tracking that information is unnecessary self-management overhead. It is not as granular as the values tracked by persons with diabetes; they can simply remember what happens and trending is almost intuitive. On the other hand, the PHR proved very useful for tracking medications that were numerous and continually being adjusted for this participant with SCI. It is also useful for communicating information gathered from individual providers to ED staff.

Synopsis of Experience So Far: Facilitators, Barriers and Future Directions

Friendliness of User Interface

ehealth2go, in its current implementation (tailored to the needs of the MedStar Health diabetes clinic) is focused on consumer-provider collaboration in the tracking of trends in an individuals' diabetes status such as blood glucose, A1C and blood pressure, is not particularly useful for persons with SCI unless they are actively managing diabetes. Currently, the technology partner (Get Real Consulting) is working to make a generic patient portal available with a customizable dashboard. This would benefit persons with SCI as they could "front" information that was actually relevant to their individual circumstances. Ehealth2go, as currently implemented, does not provide an advantage over simply entering information directly into HealthVault, which serves as the cross-platform data repository. Notably, patients must actually set up a HealthVault account before they can link to their data via eHealth2go.

It was difficult for a person with tetraplegia to enter his/her own information into HealthVault. Even working with a computer- and assistive technology-savvy participant, it took several hours to set up an account and input rudimentary information. For example, the security mechanism that assures the persons setting up an account is actually a person and not a bot, was virtually impossible for the participant to pass through. It is noteworthy that the user interface to HealthVault has changed since the product was evaluated with the participant with tetraplegia. It appears to be more user friendly, better use of menus highlighting information, so reexamination is warranted.

Physical disability aside, the capabilities of a PHR are not intuitive and the complexities of the U.S. Health care environment are daunting. The HealthVault tutorial focuses on aspects of health maintenance that are important to people with mobility disabilities (for example, tracking diet, blood pressure, and exercise) but not of prime concern. It requires special insight to realize, for example, that prescription information from different pharmacies can be consolidated in a PHR. If a patient is to get off to a good start with a PHR, facilitation, education and training should be provided. These activities lie somewhere between patient navigation and assistive technology prescription and training.

Readiness of Commercial Providers to Share Information

Capturing health information in a PHR is only one of several options. Increasingly providers, for example CVS and QUEST Diagnostics, allow customers to view their health records and share them is a variety of ways. Our participant pulled his CVS records into ehealth2go where he could share them with specific providers by giving them viewing access to his PHR. He could also download the CVS app for his Droid and share his prescriptions with ER staff by simply handing them the device. Further, the CVS interface (online and on mobile device) is more intuitive, attractive and user-friendly than the corresponding presentation of information in an aggregated PHR.

The participant's reaction on seeing the CVS service was to make an effort to make sure he ALWAYS filled his prescriptions with that provider! For individual providers, offering internet access to information may provide a competitive advantage. Coordinating prescription information across pharmacies is a different problem from coordinating information across health care providers (e.g. physicians) however. It is possible to have all one's medications delivered by CVS. There is no such one-stop-shopping option for medical specialties. This reality may be reflected in the participant's inability to get any sort of electronic file from his various providers (primary care, urology, plastic

surgery) to upload to his PHR. All of that information has to be entered manually, so the participant entered it as a synopsis. This leaves him the burden of manual update, which means the information is likely to age and become untrustworthy.

Readiness of Providers to Accept Electronic Information from Patients

None of the participant's providers were able (willing wasn't even a question) to accept his information electronically during office visits. No one was willing to log on to his PHR and review or download his information when he informed them of the capability. The participant took printed copies of his information to providers which intake staff accepted with a simple, "thank you." There was no apparent realization of time savings as otherwise someone would have had to assist him in filling out forms. Printing, further, was burdensome for the participant, required assistance, and consumed material resources.

Prior to his ER visit, we worked with the participant to transfer his health information to a secure USB key. Since these systems are not available free-of-charge, cost was an important consideration in selecting a device for trial. Consequently, due to expense, the system chosen did not interoperate with HealthVault but had a proprietary interface that transferred information entered online to the USB key. The appearance of the key was reminiscent of a medic alert tag. The participant attached it to the lanyard he uses to manage his phone.

When he subsequently visited the ED, intake staff did receive and use the information he delivered via the USB key. "How neat is this!" was the response the participant reported. Increasingly, however, we anticipate that medical staff will not be able to access "foreign" USB keys on hospital computers for security reasons.

Smartphone access may be an increasingly more efficient way of communicating health information. We created a prototype smartphone-based PHR for the second participant and tested it in the course of a training (simulation) exercise for new (PGY-2) residents at NRH. Testing in this manner allowed us to gauge provider response when surprised with information delivered via a smartphone app without having to wait for an actual medical situation to occur.

The participant feigned distress and handed her iPHONE to the resident taking her history. All six residents in the simulation exercise easily navigated the smartphone-based record and found the "clue" to solving the problem that was key to the exercise. (Notably, they did not all APPLY that knowledge to correctly diagnose the patient's problem!). On debrief, we discovered that residents were very comfortable with smartphone technology but had questions about the ethics of viewing a patient's information in this manner. Several related that they had previously had patients offer them personal health information on their smartphones in real clinical situations.

It is possible that individual providers, particularly more recent graduates and those working in higher stakes environments such as the ED, may be able to make good use of personal health information delivered directly on handhelds. Clearly, there is no process in place for using this information as demonstrated by the inability of the medical office bureaucracy to incorporate it. The cost of accommodating personal health data offered by patient has, in fact, been a subject of controversy (Steward, Hofler, Thaldorf, & Milov, 2010).

Future Directions

A PHR is likely to be useful to a person with SCI to the degree that he/she is comfortable with technology, has access to technology, and is motivated to self-manage. It is a stop-gap solution to the problem of "siloed" health information that is the status quo in the U.S. today. National programs are in place to address this problem; the question is how to divide resources between working to make the system itself more efficient and working to help patients overcome the shortcomings of the system that they, in reality, are forced to work within.

Technology is rapidly evolving and along with it, the applications that take advantage of it. Coordination of data so that complete information on an individual is available when needed does not imply a single means of delivery. The model of a PHR where an individual and his/her providers share a common record securely online does not seem workable for persons with SCI. It may work for diabetes because all an individual's most crucial data is coordinated through the diabetes provider. The individual works in collaboration with the provider to increase richness of data (e.g. more frequent BG and BP measures) and thereby improve decision-making around titration of medication and other interventions.

The specialty providers seen by a person with SCI do not focus on SCI per se but the associated chronic condition. They are related by SCI, but SCI is not a condition that occurs with sufficient frequency to generate coordination among specialties such as urology and plastic surgery. So the onus of coordination is thrown back on the individual with SCI, in the absence of centralized SCI services – the occurrence of which is rare. In the current provider environment, electronic sharing of records with patients (as well as with other providers) is a work in progress. Therefore, focusing on the most accessible and important data to manage may provide the most realizable benefit to persons with SCI. Identifying this information and developing a strategy to capture it and make it accessible to providers, particularly in emergencies, needs to be facilitated, "coached," and tailored to each individual's personal circumstances.

In the immediate future, health information applications offered via smartphone apps seem to hold great promise, but availability is not universal. For example, HealthVault is available now on Windows 7 handheld devices. Apps for the iPHONE and Droid are in the works, but not yet on the market. Further, smartphones are relatively expensive and persons with SCI generally are less affluent than the population at large. Given that we are still fighting for adequate wheelchair provision under Medicaid, it is not likely that the program will provide beneficiaries with smartphones in the near future. That said, as the technology becomes further diffused in society, more people will have devices analogous to smartphones as a matter of course. Ten years ago, one would not expect to see an underserved person with SCI with a cell phone. Today, it is common. Since this is the trend, exploring PHR apps on smartphones is likely profitable.

The new generation of medical providers has grown up with technology and uses it as a matter of course. They are comfortable with technology, but unsure of how to use it appropriately in traditional interactions with patients such as history-taking. Adding this topic to clinician education to prepare them to interact appropriately with patients who come bearing information, whether personal or from sources they have found online, might go a long way to enhancing provider/patient communication and quality of care.

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