Youtube How-to-Videos (HtV)
A Well-being Literacy Tool for Promoting Community Integration in Persons with Disability

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Abstract: Social media's power to connect and educate those with chronic conditions opens new avenues for improving patient self-management. Recent studies have reported increased condition knowledge, patient satisfaction, and compliance with treatment following social media involvement. A 5-year, consumer-focused training project conducted at the Rehabilitation Research and Training Center on Spinal Cord Injury aims to promote self-management skills in persons with SCI in areas of skin care, cardiometabolic risk reduction, and obesity prevention. The training framework incorporates a YouTube-based, shared video social network that connects participants with community-based resources necessary to achieve independence, stability, and community integration. It is anticipated that findings from the project will increase well-being literacy in individuals with SCI and enable them to self-manage health to function more independently in their daily lives and integrating back into the community.

1 INTRODUCTION: HISTORY OF SOCIAL MEDIA IN HEALTH CARE

Social media has accumulated a powerful history of promoting and illustrating various aspects of medical self-management (Agenda, 2013). In recent years, social media has blossomed to include sites such as Facebook (2004), Twitter (2006), and Tumblr (2007) (Shontell, 2012). A Pew Research Report from August 2013 states that 72% of online adults utilize social networking (Brenner, 2013). The popularity of such sites has driven national organizations, including the American Diabetes Association and the Veterans Health Administration, to advertise links to Facebook and Twitter on their homepages to connect and educate online visitors (American Diabetes Association, 2013; Veterans Health Administration, 2013).

In 2012, Goldstein, et al. of the National Kidney Disease Education Program (NKDEP) reported successful use of social media to promote education and health literacy in chronic kidney disease patients. Over the course of one year, NKDEP's Facebook page, *Make the Kidney Connection*, garnered 3500 "likes," while NKDEP's Twitter handle gained 375 followers. Facebook was found to be one of the top 15 referrers to the NKDEP education webpage in 2012, thus exemplifying successful social media promotion of healthcare education (Goldstein et al., 2013).

Similarly a 2013 study by Van der Ejik et al., analyzed the use of Online Health Communities (OHCs) in patient education and connections with clinicians. The research presented case examples in the Netherlands of a nationwide online Parkinson community available to all interested in Parkinson Disease and the ParkinsonNet community, a closed professional network of both Parkinson patients and providers. Over a 12-month period, 54% of both Parkinson community members and ParkinsonNet users posted comments or new content. Implementation of OHCs and Personal Health

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Communities (PHCs: composed of a patient, health care providers, and caregivers) in clinics were associated with four improvements in care: improved sharing of knowledge and skill for health care providers, smoother collaboration throughout medical networks, well-supported patient self-management, and the success of patient-focused care. Such improvements could increase patient empowerment and support more successful clinical outcomes (Van der Ejik, 2013). OHCs, such as ParkinsonNet or online SCI communities, have significant potential to improve patient self-management.

2 HEALTH, WELL-BEING LITERACY, AND COMMUNITY INTEGRATION

Health literacy as a foundation for individual and societal well-being literacy has the potential greatly increase the effectiveness of medical treatments. A 2006 report by Kutner et al. analyzed the health literacy of American adults in 2003. The researchers presented 19,000 American adults with 28 activities to measure literacy in "clinical, prevention, and navigation of the health care system" based on literacy scales: a prose literacy scale, a document literacy scale, and a quantitative scale. Participants' literacy was rated "Below Basic," "Basic," "Intermediate," or "Proficient." Of the responders, 53% were scored as "Intermediate" in their health literacy while 12% were rated "Proficient." A significant proportion scored "Basic" (22%) or "Below Basic" (14%) in health literacy. A large percentage of all respondents, regardless of health literacy score, accessed the Internet to obtain health information. Twenty-percent of those with "Below Basic" scores, 42% with "Basic" scores, 67% with "Intermediate" scores, and 85% of respondents with "Proficient" score reported using the Internet to access information about health (Kutner, 2006). Given this information, the use of the Internet, and social media in particular, to increase the health literacy of American adults is a very viable option and one that is furthered by the presented in this publication concerning the work of the Well-being Literacy via Multimedia Education and Psychosocial Research Program.

The Well-being Literacy via Multimedia Education and Psychosocial Research Program (WeLL) is "centered on promoting everyday life skills using evidence-based approaches in health and psychosocial sciences" (Libin, 2013). The purpose of the WeLL program is to apply psychosocial research to improve health literacy through new technology, media, social networks, and artificial intelligence. The term *HtV* (How-To-Videos) was proposed in the course of developing multimedia health education for persons with the Spinal Cord Injury (SCI) as a social network platform for building the self-management skills for persons with Spinal Cord Injury (SCI) (Schladen, Libin, Ljungberg, Tsai, & Groah, 2011) HtV serve as the basis for a social network platform for building the self-management skills in Persons with Diabilities (PWD) relevant to coping with daily challenges.

2.1 YouTube and SCI

With the inception of free video sharing on-line via the YouTube network in 2005, opportunities for self-education increased enormously. YouTube is a popular on-line video community where viewers discover, watch, and share videos that they have created. The online network provides an international forum for people to connect and share knowledge and information. In September 2013, YouTube reported over 1 billion unique visitors per month (Statistics. *YouTube*, 2013). According to a 2013 Pew Research Study, 31% of American adults uploaded videos online as compared to 14% in 2009. Similarly, 78% of American adults watch or download videos today as compared to 69% of internet users in 2009 ((Purcell et al., 2013). Such a popular and growing forum provides an opportunity to present videos to empower persons with SCI and other disabilities.

The Rehabilitation Research and Training Center (RRTC) on Spinal Cord Injury developed "How-to" videos (HtVs), short videos demonstrating SCI life skills, and made them freely available on YouTube (http://www.youtube.com) as part of a consumer-focused training program. HtVs are offered on YouTube as an empowering tool for self-management of physical tasks to increase independence after SCI or other disabling conditions. The following study investigates the utilization of How-to-Videos by patients, therapists, and communities.

2.2 Purpose of On-line Education Media for People with SCI

The innovation of an online video social network like YouTube supports disability self-management in SCI in two fundamental ways. Video social

media engage persons with SCI in the development of highly context-specific enacted knowledge that aggregates over time to form an accessible record, a "library" of disability-specific self-management skills. Freely available social media can also function as an ad hoc consumer-oriented program that works with and for persons with SCI as they self-advocate with health care professionals, researchers, or community advocates. Disability self-management can be broadly defined as the ability to successfully cope with consequences of chronic health conditions (Bodenheimer et al., 2010; Libin, 2008). As persons gain experiences in living with disability their mastery of self-management grows. Studies have shown that people who have long experience of living with disability demonstrate higher levels of self-management skills in their daily lives. For instance, mobility and higher physical activity are associated with effective self-management in persons with chronic SCI but not in newly injured individuals (Libin et al., 2010).

In our approach, the use of interactive technology is conceptualized as a self-management tool (Libin, 2006; Libin, 2001; Libin, 2006) for persons with life-long disabilities such as SCI. It builds upon foundations laid by SCI peer mentoring and the patient navigation models (Ljungberg et al., 2010). Peer mentors are individuals with SCI who provide emotional support and education to persons with newly acquired SCI. They use widely accepted techniques such as peer-to-peer focused communication based on sharing one's own everyday experiences. Patient navigators are broadly defined as individuals who are from the patient's community and have accumulated specialized knowledge regarding specific health conditions. An analysis of SCI-specific education videos posted to YouTube follows.

2.2.1 Research Methodology

SCI therapists and consumers with chronic SCI, together with the RRTC team, developed a set of HtVs for the purpose of educating the online SCI community, including newly injured individuals, about the skills and techniques necessary to effectively perform a variety of everyday tasks (Schladen et al, 2011). A series of studies was conducted exploring qualitative and quantitative aspects of SCI-specific education videos generally available on YouTube, as well as those specifically developed by the RRTC team (HtVs). Studies focused on 3 aspects of the SCI-focused educational videos: (A) content analysis of SCI-specific educational videos posted on YouTube, (B) therapists' evaluation of SCI HtVs, and (C) analysis of viewers' responses to SCI HtVs published on YouTube.

Figure 1: Screenshot of "How-To: video "How to Cook in a Wheelchair."

The screenshot shown in **Figure 1** illustrates the way the HtV is presented on YouTube. It shows an SCI-Navigator, a person with the C5-6 (level of severity) SCI, demonstrating how she cooks from a wheelchair.

2.2.2 Phase a. Content Analysis of YouTube Videos Focused on SCI

A search query on YouTube using the YouTube Analytic engine and the key words "'How-To' videos," "SCI," "self-management," and "patient education" returned about 10,900 video entries (as of November 13, 2013). A previous selective analysis of the first 1,000 search results in 2010 suggested that the first 100 entries were representative of the content of SCI-specific videos posted on YouTube between 2006 and 2010. These 100 video titles, content confirmed by reference to the video's abstract, were analyzed with regard to the cross-cutting topics and were further combined in categories.

Data analysis focused on how SCI inquiries were addressed by both the individuals who uploaded videos and their viewers by defining categories that adequately described the spectrum of SCI-related videos. The search-generated data were analyzed to describe the frequency of the identified topics. A list of topics was analyzed through sorting qualitative descriptive data (Chwalisz et al, 1996). Each category was then further divided into several subcategories specific to the single problem domain. Categories of SCI-related on-line education videos emerged as follows based on the frequency of their appearance on the Web (see Figure 2):

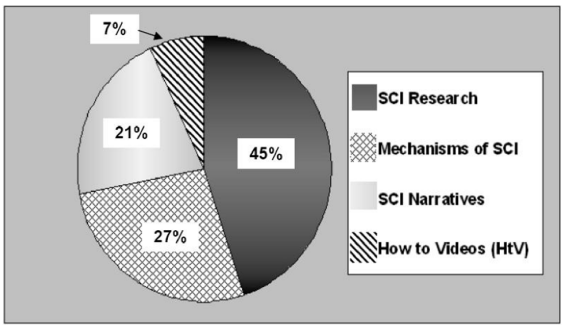

Figure 2: SCI-related multimedia health literacy videos.

A1. SCI research, inclusive of both recovery (including the ongoing debate concerning stem cells, cell-based therapies), and health/wellness research on quality of life, nutrition, and accessibility barriers.
A2.Mechanisms of SCI, including understanding levels of SCI and associated levels of functioning
A3. SCI narraitves, including personal stories of SCI survivors, sharing family experiences of coping with SCI
A4. HTVs, with the most frequent topic being exercise videos (athletic, swimming, adaptive tennis, and skiing) (see Phase C).

SCI research health literacy videos were the most viewed videos in the analyzed sample (45%). Videos on how to understand the link between the severity of injury and everyday functioning were the second (27%) most reported. The third most common category (21%) included videos on personal stories, or narratives describing day-to-day challenges for persons with SCI and sharing experiences of living with disability. The least frequent category included instrumental or HtVs that provided various types of guidance on daily task performance. As was evident from their comments requesting additional videos showing variations in demonstration, YouTube viewers found content more accessible when they were able to view a peer enacting the task they wished to accomplish.

2.2.3 Phase B: Therapists' Evaluation of SCI HtVs

Patient-oriented multimedia products, such as SCI HtVs, are created in the wider context of clinical, research, and training practice. For this purpose, 10 HtVs were developed by an occupational therapist (OT) in collaboration with a senior peer mentor/educator to model adaptive skills that could be most effectively and clearly demonstrated by an individual who actually uses a wheelchair. Videos depicted techniques a person with SCI might use to increase independence in driving (transferring to and from a car), floor transfers (from wheelchair to floor and back to wheelchair), use of public transportation (up and down the escalator and riding the metro), and daily activities such as putting on boots from a wheelchair and cooking from a wheelchair.

Thirty-one physical therapists (PTs) and OTs experienced in working with patients with SCI viewed HtVs on car transfer/driving, floor transfers, and riding an escalator. Therapists evaluated the videos and ranked them on a 3-point Likert scale (where 3 was high and 1 was low) in terms of (a) utility of the skills they demonstrated, (b) helpfulness in fostering self-efficacy, and (c) usefulness in demonstrating skills that otherwise could not be demonstrated. Thus, each participating therapist viewed the videos and ranked them with regard to 1 of the 3 concepts, for example, how a particular video may promote a feeling of self-efficacy or how a specific video could be useful in the everyday routine of a person with SCI.

Data analysis using Kendall's W test demonstrated that the floor transfer video was associated with the concept of fostering self-efficacy (M=2.30, P=0.37) and showed a similar trend with the perception of utility of skills (M = 2.42, P = .057), while the escalator video was associated with adaptation to the environment, though non-significantly (M = 2.23, P = .33). Analysis of open-ended questions demonstrated that clinicians considered the videos to be an important addition to patient self-management education.

2.2.4 Phase C. Community Response to SCI HtVs

Initially the study evaluated viewers' responses to 10 SCI HtVs on YouTube using the YouTube statistic utility, Analytics. Since this initial analysis in 2010, the Healthy Tomorrow YouTube channel developed as part of our project and use as a platform for posting HtV, has grown to include 47 videos. Topics treated in these videos included "How to Do Pressure Reliefs in a Wheelchair and "How to Cook in a Wheelchair," themes highly germane to the ultimate knowledge translation objectives of the RRTC, as well as more eclectic, general interest topics such as "How to Take off Boots" and "How to Transfer from Wheelchair to Bed and Bed Mobility." More recently, the Healthy Tomorrow Channel has introduced HtVs for weight-lifting and other gym activities.

The new data were analysed to show the community response to HtVs during the 30-day period, October 13 through November 11, 2013.

Views ranged from nearly 1,400 to just under 100, demonstrating that all SCI life skills may not all be of uniform interest. The video demonstrating the more basic life skill of transferring from wheelchair to bed and bed mobility was by far the most engaging of any of the HtVs. It captured nearly 400 more views than the next most popular video, one that showed how to transfer from wheelchair to floor.

In fact, since its publication in September 2009, the wheelchair-to-bed transfer and bed mobility video has demonstrated a constant rate of daily access as reported for November 10, 2013, which was 55 views. More investigation is needed, but the relative popularity of a very basic life skill (transferring from wheelchair to bed) versus an unusual and "edgy" life skill (going down the escalator in a wheelchair) suggests that most HtV viewers are persons with SCI, persons with other mobility disabilities, or family and friends. We hypothesize that a person without a disability who accesses HtVs out of curiosity would be more drawn to dramatic and unusual skills demonstrations, such as riding an escalator in a wheelchair. Comments posted and subscription requests further suggest that most of the viewers of HtVs were persons with SCI, family, or friends. Most HtVs focused on SCI life skills were "discovered" on YouTube by referral from related videos. In October and November 2013, seventy-four percent of the persons who engaged the wheelchair-to-bed HtV found it through a related YouTube referral.

This number is significant when we realize that referral from other videos is not the only way persons connect with one another in the YouTube community. We associated key words
with this popular video: "wheelchair," "SCI," "bed mobility," "transfer," "peer mentor," "spinal cord injury," "NRH," and "disability awareness." Only a small minority (11.6%) of viewers arrived at the wheelchair-to-bed video by searching one of these key words inside of YouTube. An even smaller number (0.5%) found the HtV from the Google search engine outside of YouTube. Rather it was YouTube's own "interest engine" that connected interested people with our demonstration of wheelchair-to-bed transfer. YouTube utilities "observe" users' patterns of interest and viewing and suggest other community resources. Most viewers, therefore connected with the wheelchair-to-bed HtV without explicitly knowing that they wanted to. Long-term viewing patterns were sinusoidal, suggesting that viewers alerted one another to the videos' existence. Viewing accelerated and then dropped; subsequently, the pattern repeated. HtVs dealing with the RRTC themes of diet and skin management skills (ie, the videos on how to cook from a wheelchair and how to do pressure reliefs in a wheelchair) appear to have about the same number of referrals from related videos as does the most popular wheelchair-to-bed transfer video. In fact, every referral to the RRTC-themed videos, without exception, was made from our popular wheelchair-to-bed HtV. The power of referral in connecting people with SCI with information that they may not initially find engaging is a topic for continued investigation.

Among the data returned by the YouTube web statistics utility, Analytics, was the geographic location of view requests. In the lifetime statistics of the channel, viewers were located largely in the United States (31.4%), but a significant number of views originated in Europe, especially in Germany (11.5%), and in South America and Asia. The appeal of HtVs, narrated in English, to persons who likely are not native speakers suggests the utility of video demonstration of skills.

According to a survey conducted by the Pew Internet & American Life Project, 91% of Americans own a handheld device (cell phone, smart phone), Of individuals who own mobile devices, 40% have used it to access social networking on-line (Duggan, 2013; Brenner, 2013). As use of the mobile Web grows, persons with disabilities are likely to be a percentage of those users. During October and November of 2013, YouTube documented a median value of 16.1% of HtV views as originating from mobile phones, while 11.0% originated from tablets. This is a four-fold percentage increase in mobile device viewing since 2010. One video theme, however, represented by "How to do One Arm Cable Bicep Row/Curl with a Cable Machine" garnered a remarkable 30% of its views from persons believed to be using mobile devices. This unusual rate of mobile access coupled with the mobile theme of the HtV suggests persons who accessed this video from their handhelds may have been looking for real-time support in solving problems they were encountering while exercising at the gym. Alternatively, they may have specifically invoked the HtV from a mobile device to use it as a reference while practicing the skills it demonstrated at the gym.

2.2.5 Discussion: Persons with Disability Interests in Social Media

Each of the 3 phases of study described in this article create a tentative profile of SCI interests as

they present across the social media site, YouTube. A dichotomy of cure versus care can be used to describe the results of the content analysis. SCI research educational videos were the most common videos in the analyzed sample (45%). Videos on how to understand the link between the severity of injury and everyday functioning were the second (27%) most reported. The third category (21%) included videos on personal stories, or narratives, describing day-to-day challenges for persons with SCI and sharing experiences of living with disability. Finally, the least frequent category included instrumental videos, or HtVs, that provided various types of guidance on daily task performance. You-Tube viewers found content more accessible when they were able to view a peer enacting the same task they wished to accomplish, as demonstrated by a preponderance of comments asking for additional videos showing variations in demonstration.

Findings from Phase B of the research on clinician's perceptions of how HtVs might benefit persons with SCI by addressing such specific areas of self-management as "developing a sense of self-efficacy" or "mastering the SCI-specific skills" support a patient-centered paradigm of care; with reduced length of stay in inpatient rehabilitation, mobility and function videos can play an important role to increase independence in individuals with SCI.

Further, data from Phase B regarding associations between specific features of HtV and self-management for disability concepts are validated by the analysis of the view volume in Phase 3 of the study. The most stable Web-driven behavioral patterns were those that can be described as a combination of the video content, such as mastery of SCI-specific skills necessary to effectively function in everyday situations, and a high frequency of viewing volume.

3 CONCLUSIONS: PEER-TO-PEER KNOWLEDGE MOBILIZATION AS COMMUNITY INTEGRATION

A peer-to-peer knowledge mobilization approach promotes self-management of health and community integration after an individual has been impacted by a traumatic event. A library or repository of multimedia health literacy on-line HtVs available free of charge through support groups, rehabilitation programs, and on-line forums will provide a variety of models for individuals with an SCI for learning new ways to carry out activities of daily living. The HtV paradigm in multimedia-based education for health care needs to advance a new methodology based on a more individualized, disability-specific approach while employing videos as learning tools.

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