YouTube as an On-line Disability Self-Management Tool in Persons With Spinal Cord Injury

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On-line knowledge sharing of disability self-management offers a learning advantage in that it can be individualized to on-line community members’ needs. It also promotes accessibility by removing the geographic, transportation, financial, time, and distance barriers that often accompany face-to-face, patient-oriented education. A 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 the 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. The purpose of this article is to describe a preliminary analysis of SCI-specific educational videos posted to the YouTube Web site. It is anticipated that findings from the project will enable individuals with SCI to self-manage health and function more independently in their daily lives. Key words: how-to videos, patient-oriented education, peer-to-peer knowledge translation, self-management skills, spinal cord injury, YouTube network

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The Rehabilitation Research and Training Center (RRTC) on Spinal Cord Injury developed "How-to" videos (HtVs), short videos demonstrating spinal cord injury (SCI) life skills, and made them freely available on YouTube (http://www.youtube.com) as part of a consumer-focused training program. YouTube is a popular on-line video community where viewers discover, watch, and share videos that they have created. YouTube provides an international forum for people to connect and share knowledge and information. 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 history of on-line videos in promoting and illustrating various aspects of self-management of medical conditions is a short but very powerful one. It is not known who was the first individual to post a health care–related educational video on the Web, but the first known appearance can be traced to 1999, long before the YouTube video-sharing network was originated in 2005.\(^1\) This patient-oriented educational video on self-management of diabetes immediately became a popular on-line vehicle for experience sharing in communities with special needs associated with a chronic illness. It yielded 9,165 views in the year following production.

With the inception of free video sharing on-line via the YouTube network in 2005, opportunities for self-education increased enormously. In May 2010, it was reported that YouTube was hosting more than 2 billion videos per day.\(^2\) Such a popular forum provides an opportunity to present videos to empower persons with SCI and other disabilities. Individuals whose health care needs have historically been underserved are gaining increasingly broad access to Internet resources,\(^3,4\) which suggests that on-line videos will reach this population.

**Purpose of On-line Educational Media for People With SCI**

The innovation of an on-line video social network like YouTube supports disability self-management in SCI in 2 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.\(^5,6\) As a person gains experiences in living with disability, their mastery of self-management grows.\(^2\) Studies have shown that people who have a 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.\(^7\)

In our approach, the use of interactive technology is conceptualized as a self-management tool\(^8–10\) for persons with life-long disabilities such as SCI. It builds upon foundations laid by the SCI peer mentoring and the patient navigation models.\(^7,11\) 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. This article provides a preliminary analysis of SCI-specific educational videos posted to YouTube.

Methodological Framework

SCI therapists and consumers with chronic SCI, together with the RRTC team, developed a set of HtVs for the purpose of educating the on-line SCI community, including newly injured individuals, about the skills and techniques necessary to effectively perform a variety of everyday tasks.12 A series of pilot studies was conducted exploring qualitative and quantitative aspects of SCI-specific educational 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: (1) content analysis of SCI-specific educational videos posted on YouTube, (2) therapists’ evaluation of SCI HtVs, and (3) analysis of viewers’ responses to SCI HtVs published on YouTube.

Figure 1. Screenshot of “How-To” video “How to Apply Makeup.”
The screenshot shown in Figure 1 illustrates the way the HtV is presented on YouTube. It shows an SCI-Navigator, a person with the C6-7 SCI, demonstrating how she applies make-up.

Pilot Study 1. Content analysis of YouTube videos focused on SCI

A search query on YouTube using the Google analytic engine and the key words “‘How-To’ videos,” “SCI,” “self-management,” and “patient education” returned 6,561 video entries (as of August 1, 2010). A selective analysis of the first 1,000 search results suggested that the first 100 entries were representative of the content of SCI-specific videos posted on YouTube between 2006 and the date of the search. 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. Each category was then further divided into several subcategories specific to the single problem domain. Categories of SCI-related on-line educational videos emerged as follows based on the frequency of their appearance on the Web (see Figure 2):

![Figure 2. SCI-related on-line educational videos.](image-url)
1. **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

2. **Mechanisms of SCI**, including understanding of levels of SCI and associated levels of functioning

3. **SCI narratives**, including personal stories of SCI survivors, sharing family experiences of coping with SCI

4. **HtVs**, with the most frequent topic being exercise videos (athletic, swimming, adaptive tennis, and skiing) (see Pilot Study 3)

SCI research educational 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.

**Pilot Study 2. 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 (see Table 1 for more details).

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 ($M = 2.30, P = .037$) 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 con-
sidered the videos to be an important addition to patient self-management education.

Pilot Study 3. Community response to SCI HtVs

As part of the pilot study of the 10 SCI HtVs on YouTube, we evaluated viewers’ responses using the YouTube-native Web statistic utility, Insight. 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 put on fashion boots when you have an SCI and how to transfer from wheelchair to floor.

Table 1 shows the community response to HtVs during the 4-week period, July 15 through August 14, 2010. Views ranged from nearly 3,000 to just over 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 more than twice the views of the next most popular video, one that showed how to transfer from wheelchair to floor.

In fact, since its publication in 2009, the wheelchair-to-bed transfer and bed mobility video has demonstrated a constant rate of access in the range reported for July to August 2010, which was 2,849 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

Table 1. On-line community response to RRTC “How-to” videos during a 4-week period

<table>
<thead>
<tr>
<th>“How-to” video title</th>
<th>Views/month (July 15 to Aug. 14, 2010)</th>
<th>Referred from related YouTube videos (%)</th>
<th>Probable mobile access (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to Transfer from Wheelchair to Bed and Bed Mobility</td>
<td>2,849</td>
<td>73.0</td>
<td>4.1</td>
</tr>
<tr>
<td>How to Transfer from Wheelchair to Floor</td>
<td>1,099</td>
<td>66.1</td>
<td>3.5</td>
</tr>
<tr>
<td>How to Transfer from a Wheelchair to a Car</td>
<td>521</td>
<td>57.9</td>
<td>6.2</td>
</tr>
<tr>
<td>How to Put on the Boots</td>
<td>520</td>
<td>63.5</td>
<td>4.6</td>
</tr>
<tr>
<td>How to Do Pressure Reliefs in a Wheelchair</td>
<td>275</td>
<td>80.0</td>
<td>5.2</td>
</tr>
<tr>
<td>How to Cook from a Wheelchair</td>
<td>268</td>
<td>70.8</td>
<td>3.4</td>
</tr>
<tr>
<td>How to Drive a Car and Do a Transfer from a Car to a Wheelchair</td>
<td>191</td>
<td>34.3</td>
<td>20.0</td>
</tr>
<tr>
<td>How to Go Up in the Escalator</td>
<td>147</td>
<td>66.0</td>
<td>4.0</td>
</tr>
<tr>
<td>How to Apply Makeup</td>
<td>142</td>
<td>57.1</td>
<td>1.6</td>
</tr>
<tr>
<td>How to Travel in a Metro train and Go Down the Escalator with a Wheelchair</td>
<td>102</td>
<td>65.2</td>
<td>4.3</td>
</tr>
</tbody>
</table>

Note: RRTC = Rehabilitation Research and Training Center.
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. Seventy-three percent of the persons who engaged the wheelchair-to-bed HtV found it through referral from the video of another person concerned with wheelchair-to-bed mobility. 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 (7.4%) of viewers arrived at the wheelchair-to-bed video by searching one of these key words inside of YouTube. An even smaller number (1.5%) 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, Insight, was the geographic location of view requests. Viewers were located largely in the United States, but a significant number of views originated in Europe, especially in Germany, and in South America. 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 of the 85% of individuals who own a handheld device (cell phone, smart phone), 39% have used it to access information on-line. As use of the mobile Web grows, persons with disabilities are likely to be a percentage of those users. During July and August of 2010, YouTube documented a median value of 4.2% of HtV views as originating from mobile devices. One video, however, “How to Drive a Car and Do a Transfer from a Car to a Wheelchair,” garnered a remarkable 20% 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 in transferring from their cars to wheelchairs.
Alternatively, they may have specifically invoked the HtV from a mobile device to use it as a reference while practicing the skills it demonstrated in their cars.

Discussion

The 3 case studies 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. YouTube 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 Pilot Study 2 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 Pilot Study 2 regarding associations between specific features of HtV and self-management for disability concepts are validated by the analysis of the view volume in Pilot Study 3. 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.

Conclusions

A peer-to-peer knowledge mobilization approach promotes self-management of health and social function after an individual has been impacted by a traumatic event. A library or repository of 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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