

# Use of on-demand video to provide patient education on spinal cord injury

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**Background/objective:** Persons with chronic spinal cord injury (SCI) have a high lifetime need for ongoing patient education to reduce the risk of serious and costly medical conditions. We have addressed this need through monthly in-person public education programs called SCI Forums. More recently, we began videotaping these programs for streaming on our website to reach a geographically diverse audience of patients, caregivers, and providers.

**Design/methods:** We compared information from the in-person forums to that of the same forums shown streaming on our website during a 1-year period.

**Results:** Both the in-person and Internet versions of the forums received high overall ratings from individuals who completed evaluation forms. Eighty-eight percent of online evaluators and 96% of in-person evaluators reported that they gained new information from the forum; 52 and 64% said they changed their attitude, and 61 and 68% said they would probably change their behavior or take some kind of action based on information they learned. Ninety-one percent of online evaluators reported that video is better than text for presenting this kind of information.

**Conclusion:** Online video is an accessible, effective, and well-accepted way to present ongoing SCI education and can reach a wider geographical audience than in-person presentations.

**Keywords:** Patient education, Spinal cord injuries, Media, Print, Digital, Video, Internet, Secondary complications, Prevention, Self-care, Quality of life

## Introduction

Persons with chronic spinal cord injury (SCI) have a high lifetime risk for serious, debilitating, and costly medical conditions such as pressure ulcers, urinary tract infections, pain, spasticity, and respiratory complications.<sup>1,2</sup> Many of these conditions can be prevented or minimized through informed self-care practices. While inpatient rehabilitation is devoted to teaching patients and family members how to stay healthy and avoid secondary conditions after SCI, as length of stay has decreased, many patients are discharged before they have absorbed the information and mastered these critical skills.<sup>3</sup> Little time is available to address education on community integration, participation, and adjustment to disability. Furthermore, patients and families are often overwhelmed by the psychological and physical consequences of the injury and therefore, not 'ready' to receive and retain all the information that they will eventually need.<sup>3,4</sup>

Many rehabilitation centers have tried to reach beyond formal rehabilitation programs by giving patients educational pamphlets and self-care manuals (e.g. Yes, You Can!<sup>5</sup>). Recognizing the limitations of print media, some specialty centers have provided more up-to-date information on living with SCI via community-based educational programs. These efforts can facilitate long-term adjustment to SCI by providing access to timely information about health as well as non-medical topics such as employment, transportation, recreation, and housing.<sup>6</sup> However, these presentations are limited to persons who live nearby and can attend. Ironically, the people who may most need such information may be least able to attend such meetings.

The Internet has emerged as an important way for people with disabilities to overcome barriers and access health information at the time they need it. This is especially true for people who have a rare medical condition like SCI and live far away from experts in their condition. It is not surprising, therefore, that Internet use has been associated with better health-related quality of life in persons with SCI.<sup>7</sup> The

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Internet has the potential to provide user-friendly health information to people living with disabilities as well as those with limited access to other sources of information.<sup>8</sup> Moreover, video media has been shown in several randomized trials to enhance understanding and retention of health information compared to written or in-person instruction only.<sup>9–11</sup> Therefore, advances in digital media and the Internet have made it possible to deliver more current, interesting, and useful information to people with SCI.

Our SCI center, the Northwest Regional Spinal Cord Injury System (NWRSCIS), has faced the same challenges and has responded in ways that we seek to describe and evaluate in this paper. We produce an in-person lecture and discussion series called the SCI Forum and videotape it for on-demand viewing from our website. We obtain feedback about the quality and effectiveness of the forums using a short evaluation form. Here we report on these evaluations and compare the responses of in-person attendees to those of online viewers.

## Methods

In 1987, SCI consumers and staff began a community-based consumer education series called the SCI Forum, at the University of Washington (UW). The SCI Forum was designed to help consumers and professionals stay up to date on topics related to SCI, and learn from people living with SCI. It became a regular educational and social event for consumers and professionals, drawing audiences of 15–50. However, attendance was limited to those who were able to arrange transportation and whose health allowed them to attend. Since our regional center serves people with SCI in four states – Washington, Idaho, Montana, and Alaska – only a tiny fraction of our patient population could attend these presentations.

In 2005, we began receiving requests to post recordings of SCI Forums online. According to the 2006 Annual Statistical Report for the Model Spinal Cord Injury Care Systems, 67.6% of individuals with SCI in our Model System had access to a computer and 65.6% used email or the Internet.<sup>12</sup> A 2008 study reported that 69.2% of persons with SCI in the national SCI Model System used computers and 94.2% of these access the Internet.<sup>13</sup>

With funding from the Department of Education's National Institute of Disability and Rehabilitation Research (NIDRR) SCI Model System program we began professionally videotaping selected SCI Forums in 2006 and posting them on our website. Videography is done by an outside production company to ensure

professional quality video and sound. Mini-digital video tapes are encoded into Windows Media Video for editing. Our staff edits the videos and inserts any presentation slides where needed. The finished video is sent to a transcription and closed-captioning service. Our webmaster creates a new page for this video and includes an accompanying written report if applicable. Finally, an announcement is sent to more than 700 email subscribers.

SCI Forum videos are typically posted online within 3–6 months from the original forum date. Topics cover a range of SCI-related issues (see Table 1), including medical concerns, recreation, employment, finding personal care assistants, and sexuality. Topics are chosen based on input from our Consumer Advisory Board, from topic suggestions written on past forum evaluations, and from email and phone requests for information that staff regularly receive. Presenters are either specialists in the subject (often UW staff or faculty) or panels of community members with SCI who have experiential knowledge of the topic.

## Outcome measures

We use consumer evaluations to describe the influence of and satisfaction with the SCI Forum presentations viewed in person or via the Internet. The evaluations were developed based on NIDRR recommendations to disseminate information to consumers that would lead to new knowledge, a change in attitude, and/or change in behavior. The evaluations conducted in person and online share four questions: (1) I learned new information from this forum/video, (2) I changed my attitude about something as a result of this forum/video, (3) information presented at this forum/in this video will benefit me or my family member, friend, or patients, (4) I will probably change my behavior or take some kind of action (for example, discuss something with my health care provider or start doing something differently) as a result of this forum/video.

In addition, we report selected comments from online viewers to describe some of the strengths of this approach and to guide future innovation in the area of online dissemination. Finally, information on people visiting our website was gathered from Google Analytics,<sup>14</sup> an analytic tool that generates statistics on website visitors.

Data are presented for the videos that were available to watch between 1 April 2009 and 31 March 2010 for which we have data from all three sources. The videos available are from forums taking place between 2006 and 2009. A total of 422 evaluations from individuals who attended those forums that have been uploaded as

**Table 1 Videos and frequency of web hits April 1, 2009 to March 31 2010**

Video title	Date posted	Total hits	Average hits per month
Repairing the spinal cord from within: regeneration potential of the adult spinal cord	8/17/06	39	3.3
Advances in treatment of urological conditions in the SCI patient	6/29/07	94	7.8
Review of human trials of SCI and X-irradiation as well as tempol, a nitroxide antioxidant, improves locomotor function in an animal model	8/1/07	6	.5
Worst case scenarios: be prepared!	10/15/07	38	3.2
Universal fitness: fitness after SCI	11/1/07	200	16.7
Home modification	12/19/07	192	16
Using hypnosis for spinal cord injury pain management	2/6/08	221	18.4
Autonomic dysreflexia	3/28/08	287	23.9
Navigating the system: social security disability insurance (SSDI) and supplemental security income (SSI)	6/19/08	17	1.4
Osteoporosis in SCI	8/19/08	39	3.3
Getting your life back after SCI: finding meaning through volunteering, school, and work	10/17/08	39	3.3
Personal caregivers	12/5/08	97	8.1
Conversations about ... living with spinal cord injury	2/23/09	361	30.1
Stem cells and regeneration of the spinal cord: practical barriers and new cell technologies	8/3/09	527	65.9
Sexability	10/29/09	190	31.7
Conversations ... artists with spinal cord injury	12/16/09	11	3.7
Aging with a spinal cord injury	1/21/10	114	38
Management of urinary problems caused by SCI	3/9/10	38	38

video were tabulated. The evaluations from the 66 individuals who chose to complete a brief survey after watching online is a small sample of the total who watched these videos and is also limited to a 1-year period, due to Google Analytics' start date for recording usage activity on the individual videos.

## Results

Table 1 provides the list of forum video titles that were evaluated. There were 2510 hits on the video pages over the 1 year tracked compared to 422 people who attended those forums in person over the 3 years during which the forums took place. Although many of these videos were first posted in 2006–2008, they continue to be of interest to viewers in 2009–2010.

The majority of online viewers and in-person attendees were people with SCI, our primary target population. The proportion of online versus in-person viewers who have SCI is similar (42.4 and 45.3%, respectively). Both the online videos and in-person forum presentations draw large proportions of health care providers (21.2 and 23.5%, respectively), and students (24.2 and 10.9%, respectively). The higher ratio of family/friends of persons with SCI among the in-person forum attendees (20.4 versus 12.1%) may reflect the need for some people with SCI to have caregiver assistance to attend.

The geographic distribution of the web visitors within the US is roughly proportional to the population density of the regions listed<sup>15</sup> with the exception of over-representation of visitors from Idaho and Washington,

especially Western Washington. The majority of individuals who viewed or provided feedback on videos come from outside of our catchment area, with a sizeable proportion watching from outside of the country (see Table 2).

Table 3 provides average ratings of both the online and in-person versions of the forum presentations. Responses suggest that ratings of the forums are statistically the same whether individuals watch it live or on video with the majority of people expressing agreement or strong agreement with each statement. For example, 88 and 96% agreed or strongly agreed that they learned new information from the online video and in-person forum presentations, respectively, 52 and 64% reported that they changed their attitude, and 61 and 68% reported they will probably change their behavior or take some kind of action as a result of the video or in-person forum. For those watching online, additional questions about their experience indicate that viewing online is easy, useful, understandable, and convenient.

**Table 2 Location of web visitors**

Region	% Of those rating videos	% Of those watching videos
Western Washington	13.6	7.3
Eastern Washington	4.5	0.7
Idaho	3.0	0.4
Montana	0	0.2
Alaska	0	0.2
Other state	65.2	66.6
Outside USA	13.6	25.0

**Table 3** Ratings of videos/forums

Question	Average rating for in-person forums Mean (SD) <i>n</i> = 422	Average rating online Mean (SD) <i>n</i> = 66
I learned new information from this forum	4.47 (0.68)	4.35 (0.77)
I changed my attitude about something as a result of this video (or forum)	3.73 (1.03)	3.62 (1.09)
Information presented at this forum/in this video will benefit me (or my family member, friend, or patients)	4.25 (0.86)	4.21 (0.82)
I will probably change my behavior or take some kind of action (for example, discuss something with my health care provider or start doing something differently) as a result of this video or forum	3.86 (0.99)	3.79 (1.07)
The information in the video was useful to me	n/a	4.41 (0.80)
The video was easy to watch on my computer	n/a	4.38 (0.70)
I could understand the information presented	n/a	4.47 (0.71)
Video is a better way to present this information than a written report or article	n/a	4.55 (0.66)

\*All ratings on 1–5 scale, with 1 = strongly disagree to; 5 = strongly agree.

Note: All mean comparisons between in-person and online ratings were not statistically significant suggesting no difference between ratings.

The vast majority of online viewers (91%) reported that video media is a better means of presenting the information compared to written reports.

Finally, viewer's comments (Table 4) highlight the importance of providing information that is available on demand, of using video as a more interesting learning format than text, of including presentations by people with SCI as firsthand sources of lifestyle advice for their peers and of using the Internet to overcome geographic and other barriers to information access.

## Discussion

We found that posting digital videos of our community-based educational forums is an effective way of delivering up-to-date, just-in-time educational content to our geographically dispersed consumer population as well as those far beyond our target population. Almost six-times more people in a single year accessed the videos via the Internet (2510 hits on the video links) than attended our SCI Forum presentations in person (*n* = 422) over 3 years. Even videos posted several years ago still attract a substantial number of viewers based on web hit data. Another advantage of this format is that it allows expert speakers with limited availability, such as medical specialists or community-based rehabilitation professionals, to educate a much larger audience with a single presentation.

A large proportion of forum attendees reported that they learned new information, the information was useful, and the SCI Forum presentation contributed to changes in their attitudes and behavior. Feedback from those viewing the SCI Forum presentations online represents only a small fraction of those who clicked on these videos, but their responses show that

the value and impact of the online version are as positive as the in-person version. Moreover, 91% agreed or strongly agreed that presenting the information in video format is better than presenting the same information in written form. Finally, SCI is a relatively uncommon disability and unless a person with SCI lives in a large urban setting with access to specialized services, he or she can feel isolated and cut off from the health information needed to stay healthy. Viewers have commented that listening to others with SCI via our videos is not only educational, but also motivating and comforting. An unexpected finding was that these forum videos are meeting a need for health professionals around the country and the world who are looking for high-quality SCI information for their patients and for training staff and students.

A number of limitations of this study merit comment. We do not have information on the number or characteristics of individuals who did not provide feedback on the in-person SCI Forum presentations. However, we believe that survey data were obtained from the vast majority of attendees based on staff observation. The representativeness of the online surveys is uncertain. We obtained completed surveys from only about 2.6% of those who watched all or part of a video. It is possible that survey respondents are biased toward people who valued this form of media and as a result, overestimate the magnitude of the benefits that would be experienced by the population as a whole. While our survey questions ask respondents to indicate whether their attitudes or behavior changed as a result of viewing the forum presentation, we are not able to confirm the validity of their self-report. This is a limitation of almost all self-report research. This paper focuses on a single year of online data.

**Table 4 Comments from online viewers on how information is used**

Individual with SCI	<ul style="list-style-type: none"> <li>• It gave me a better understanding of how hypnosis interacts with chronic pain, what to expect and what to look for in a therapist. I have more confidence in trying something new. <i>Hypnosis for SCI pain</i> (other state in the US)</li> <li>• I know about autonomic dysreflexia but this video explained everything clearly. <i>Autonomic dysreflexia</i> (other state in the US)</li> <li>• I would like to use the video in training sessions with new care givers. <i>Autonomic dysreflexia</i> (outside US)</li> <li>• Shows new ways to cope and I'm not the only one going through these problems. <i>Conversations...living with SCI</i> (Idaho)</li> <li>• I live too far away to attend in person to learn information, however, with videos such as this I can keep informed about vital and new information concerning my SCI. <i>Treatment of urologic conditions</i> (Western Washington State)</li> <li>• Helps me to ask more informed questions of my physician. <i>Review of human trials of SCI</i> (Western Washington State)</li> <li>• Provided immediate information at the moment I was interested. Video versus written transcript is more entertaining and helped drive home material through visual expression and emotion. Loved actually seeing real life people provide examples. Learned about respiratory fitness. Can go back to review. <i>Fitness</i> (other state in US)</li> </ul>
Health care professional	<ul style="list-style-type: none"> <li>• I can now direct my patients to resources and provide them with up-to-date information. Your videos are fabulous and I am beginning to use them and information gleaned from them in my therapies. <i>Hypnosis for SCI pain</i> (other state in US)</li> <li>• I use hypnosis with US active duty soldiers and veterans. We have virtual reality equipment that we use to treat PTSD. As a result of watching this video I will incorporate VTR hypnosis to the treatment offered to them. Thanks! <i>Hypnosis for SCI pain</i> (other state in the US)</li> <li>• I am an educator for an acute rehab hospital. Currently we have a self-learning package for autonomic dysreflexia that is mostly written info and boring. This would be wonderful to use with the new nurses especially. <i>Autonomic dysreflexia</i> (other state in US)</li> <li>• Excellent educational tool. Written in an 'easy to understand language' and very concise, clear format! <i>Autonomic dysreflexia</i> (other state in US)</li> <li>• My new specialty includes assessing lifetime needs of persons with spinal cord injuries. This provides me with outstanding, credible, information for persons with spinal cord injuries. <i>Osteoporosis</i> (Western Washington state)</li> </ul>
Others (family, friend, students)	<ul style="list-style-type: none"> <li>• It is much easier to listen to a person speaking about technical information than to read about it. I'm much more likely to listen to the whole presentation than to read the whole article. <i>Treatment of urologic conditions</i> (other state in US)</li> <li>• I feel better prepared to respond (to autonomic dysreflexia). <i>Autonomic dysreflexia</i> (Western Washington)</li> <li>• I'm doing a neurology rotation, and also preparing some tutorials for first year medical students on stem cells and it was a great refresher for me! <i>Stem cells and regeneration of the spinal cord</i> (outside US)</li> <li>• We can read about the injury from medical documentation but, to listen to SCI patients is priceless. <i>Conversations...living with SCI</i> (other state in the US)</li> <li>• My son has had surgery for kidney stones and nearly a dozen urinary tract infections in less than two years. We attended this presentation. It was very helpful and also helpful to be able to review it online to catch the details. <i>Treatment of urologic conditions</i> (Western Washington state)</li> </ul>

Online video is an effective way of delivering patient education to our target population and may be a useful model for other individuals with rare disorders who could benefit from presentations by experts who are in limited supply as well as from hearing the experiences of others who share the disorder. Archiving our forums online and collecting data on viewing activity can help us improve the forum program in the future. As we collect more Google Analytics data over time, we will have a better idea about what is viewed at high frequency and how to direct our choice of future topics.

## Conclusion

In the current model of SCI rehabilitation, people with SCI are exposed to an overwhelming amount of information during shortening inpatient rehabilitation stays. This is a time when physical and psychological stresses as well as uncertainty about prognosis may limit one's readiness and ability to learn and make major lifestyle changes. After discharge and more direct experience living with SCI, the perceived need for practical information on health and wellness continues and may even increase. Therefore, model rehabilitation centers need to develop approaches by which high-quality, accessible,

and effective health and wellness information can be delivered to people living with SCI. We have shown that an online video approach to post-acute SCI education seems especially promising because it is informative, understandable, and associated with self-reported attitude and behavior change. More importantly, video media delivered via the Internet can overcome geographic, temporal, and built-environment barriers to critical health information. People are able to access this information when they are ready to receive it, and the use of both professional and peer presenters may enhance the credibility and uptake of information presented. These features are especially important to SCI survivors who reside in vast, largely rural regions like ours. However, we have learned that these resources can benefit people with SCI, their family members, professionals, and trainees throughout the United States and the world.

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