

Research article

# Online support for individuals with spinal cord injuries: An ethnographic investigation

Alisa A. O'Riley<sup>1</sup>, Jon Rose<sup>2</sup>, Brinda Dalal<sup>3</sup>

<sup>1</sup>University of Rochester School of Medicine and Dentistry, New York, USA, <sup>2</sup>Veteran Affairs Palo Alto Health Care System, California, USA, <sup>3</sup>Dhoopa Ventures LLC, California, USA

**Background:** Although social support is an important protective factor for individuals with spinal cord injuries (SCIs), individuals often encounter significant barriers to obtaining support after experiencing a SCI. It has been suggested that the Internet may serve to help individuals with disabilities overcome common barriers in obtaining support, yet research examining the efficacy of Internet-based support for individuals with SCI has been mixed.

**Objective:** To develop a more nuanced understanding of how individuals with SCI can or might use the Internet for support.

**Design:** Using an ethnographic approach, we conducted semi-structured interviews with nine individuals with SCI to explore perceived needs and barriers to information-seeking and online support.

**Setting:** Participants were recruited from Veterans Administration medical center outpatient and inpatient units providing specialty care to individuals with SCIs and from a community SCI Center of Excellence.

**Results:** Individuals with SCI gain emotional, problem-focused, and reciprocal support from online sources.

**Conclusions:** Online resources can provide important opportunities for social support for individuals with SCI.

**Keywords:** Spinal cord injuries, Tetraplegia, Paraplegia, Disability, Social support, Internet use, Problem-focused support, Emotion-focused support, Veterans, Online support, Rehabilitation

## Introduction

Research suggests that social support may buffer individuals against negative outcomes associated with stressful life events.<sup>1</sup> A change in health status and functional ability, such as the experience of a spinal cord injury (SCI), constitutes a major life stressor, and research suggests that social support may provide an invaluable buffer after a SCI.<sup>2</sup> Studies have demonstrated that having quality social support has been associated with better well-being and life satisfaction<sup>3</sup> and less depression and hopelessness<sup>2,4,5</sup> in individuals with SCI. Conversely, poor social support has been associated with increased depression<sup>5</sup> and suicidal ideation.<sup>6</sup>

Some research has suggested, however, that only specific types of social support are predictive of better outcomes among individuals with SCI. For example, Post *et al.*<sup>7</sup> found that emotional social support, or support meant to help people change negative emotions associated with stressful situations (e.g. listening as

individuals with SCIs discussed their distress), provided by family and friends was associated with life satisfaction, but problem-focused support, or support meant to help people change stressful situations (e.g. helping individuals with SCIs solve specific problems or acquire specific information), was not associated with positive or negative outcomes. In addition, a review recently found that peer-to-peer support groups for health-related concerns<sup>8</sup> did not significantly impact depressive symptoms. Thus, the relation between social support and outcomes associated with health and function-related stressors may be mediated by the source of social support.

Although research has suggested that social support is important after a SCI, there is evidence that individuals with SCI face unique barriers to obtaining social support. For example, many individuals with SCI have restricted mobility, and research has demonstrated that problems with mobility put individuals at significant risk for poor social support.<sup>9</sup> Other evidence has shown that it can be difficult for individuals with disabilities to form social connections with the able-bodied,

Correspondence to: Alisa A O'Riley, University of Rochester Medical Center, 300 Crittenden Blvd, Box Psych, Rochester, NY 14607, USA.  
Email: Alisa\_oriley@urmc.rochester.edu

because able-bodied people often have biases, prejudices, and fears about individuals with disabilities.<sup>10</sup>

Some studies have suggested that the Internet may be an essential resource for helping individuals with disabilities overcome barriers to attaining social support.<sup>11</sup> However, research on the Internet's utility as a source of support for individuals with SCIs has yielded mixed results. Research has consistently demonstrated that, when given the opportunity, individuals with SCI use the Internet frequently for various activities, including: sending and receiving email, collecting health information, and entertainment.<sup>12</sup> Most research has shown that the Internet provides individuals with disabilities (and particularly individuals with SCI<sup>11,15</sup>), an important resource for social support.<sup>10,13,14</sup> However, some research has demonstrated that Internet use in the general population is associated with more social isolation,<sup>16</sup> and compulsive Internet use is associated with both depressive symptoms and loneliness.<sup>17-19</sup> In a 2008 study, Miller<sup>20</sup> examined self-reported Internet usage in 137 individuals with different levels of SCI and an average of 10.6 years since injury. Miller found that using the Internet for online gaming and for disability-related information seeking (a form

of problem-focused support) was negatively associated with well-being. Researchers have proposed several hypotheses to explain how Internet use might result in negative consequences. For example, Miller<sup>20</sup> hypothesized that seeking disability-related information may increase stress. Likewise, excessive Internet use for gaming and other activities may result in individuals failing to attend to face-to-face interactions with people in their lives, which may lead to loneliness even if Internet activities involve other people online.<sup>19,20</sup> Finally, some researchers have hypothesized that online relationships may have less depth than other relationships.<sup>16</sup>

Given the mixed results of past research, we need to better understand the Internet's potential as a source of support for individuals with SCI. The ethnographic grounded research method is particularly useful when engaging in exploratory research and when seeking to clarify conflicting results.<sup>21</sup> Thus, in this study, we used grounded theory qualitative methods (i.e. methods in which themes and hypotheses are generated from data rather than specified *a priori*) to identify and categorize themes and concepts related to Internet-based emotional and problem-focused social support for individuals with SCI.

**Table 1 Characteristics of participants interviewed**

Characteristics	N (%)
Sex	
Male	8 (88.88)
Female	1 (11.11)
Age	
18-40 years	1 (11.11)
40-59 years	4 (44.44)
60+ years	4 (44.44)
Injury level	
C4-C6	3 (33.33)
T1-T9	4 (44.44)
T10-L1	1 (11.11)
Unknown	1 (11.11)
Time since injury	
1-2 years	3 (33.33)
8-12 years	3 (33.33)
20+ years	3 (33.33)
Occupation	
Social services	3 (33.33)
Software engineer	1 (11.11)
Self-employed	2 (22.22)
Retired/volunteer	3 (33.33)
Self-reported health problems*	
Wounds	2 (22.22)
Pressure ulcers	2 (22.22)
Sepsis	2 (22.22)
Urinary tract infections	3 (33.33)
Blood pressure problems	2 (22.22)
Diabetes	1 (11.11)
Cancer	1 (11.11)
Hepatitis C	1 (11.11)

\*Most participants reported multiple concerns.

## Method

### Participants

In Table 1, we present characteristics of our study participants. Level and cause of individuals' SCI was heterogeneous. All participants interviewed required a wheelchair for mobility. Time elapsed since participants' SCI ranged from 1 to 33 years. Four participants interviewed were Veterans and all of these individuals utilized Veterans' Affairs (VA) health care. In Table 1, we also present information about participants' self-reported health problems. Two participants were temporarily hospitalized for wound care at the time of the interview. All other participants resided in the community. All participants had completed extensive inpatient rehabilitation following their injuries, and all participants received regular medical care at clinics or units that specialized in treating patients with SCI.

### Procedure

The Institutional Review Board at Stanford University and the Research Administration of the Veterans Affairs Palo Alto Health Care System approved this study. All participants completed informed consent and signed forms prior to participation. Given the exploratory nature of this ethnographic study, we conducted semi-structured interviews with eight men and

one woman with SCI. We developed the semi-structured interview specifically for this study. The authors conducted the interviews, which included multiple choice and open-ended questions across topics ranging from people's use of technology and sources of emotional support to their daily routines and activities. We tape-recorded all interviews with participants' consent. We conducted interviews in a variety of venues chosen at the convenience of participants, including: a participant's workplace (one interview), an inpatient unit for SCI in a VA hospital (two interviews), a VA outpatient clinic for SCI (five interviews), and via telephone (two interviews).

During the interviews, we first provided participants with a brief description of the study's purpose with specific instructions to provide as much information about topics covered in the interview as they deemed necessary. Next, we asked participants a series of open-ended questions covering the following topics: demographics, military experience, experience with the VA, details about their SCI, details of Internet usage (frequency, types of Internet activities), satisfaction with Internet usage, challenges with Internet usage, resources they would like to have available on the Internet, health information, how they gained knowledge about health-related topics, how they communicated with family and friends, and details about the types of social support they utilized. (Copies of the full interview are available from the authors upon request.) As generally recommended when using qualitative methods,<sup>21</sup> in addition to using the semi-structured interview guide, we asked follow-up questions and additional questions when necessary for clarification. This enabled participants to reflect on their lives, experiences, and the challenges they faced in more depth. Interviews ranged in length from 45 minutes to 3 hours. After we completed the interviews, practicum students, who were blinded to the study's purpose, fully transcribed all tape recordings. Additional volunteers checked transcripts for accuracy.

### *Data analysis*

Grounded theory enables social science researchers to systematically investigate the confluence of behaviors, preferences, and perceptions of research participants, from the participants' points of view.<sup>21</sup> We used grounded theory methods to identify crosscutting themes around people's needs, based in part on specific examples of their practices and how, when, and why they used technology. These data enabled us to comprehend unanticipated responses to open-ended interview questions. These analytic techniques were especially useful

to gain insights into the diverse types of information that research participants sought online and to comprehend people's subjective experiences as they used the Internet to connect with others or find information relevant to their symptoms and needs.

Two authors (A.O. and J.R.) first read completely through all the transcripts in order to become familiar with the data and the major concepts present. Next, A.O. and J.R. independently categorized information from the transcripts into concepts, which were compared to a cluster analysis of emerging themes elicited from field notes and summaries by another author (B.D.). A.O. and J.R. then met and reached a consensus about the concepts identified from the transcripts and developed a coding system for the concepts. A.O. then reread all the transcripts and coded each transcript using the coding system developed. Finally, all authors used the information from the coded concepts to develop a framework of synthesized themes from the data. A.O. then went back through the transcripts to identify exemplary quotations.

## **Results**

### *Internet usage*

All participants reported using the Internet frequently and engaging in several activities, including: work-related activities, receiving and sending personal email, reading the news, researching topics related to their SCI (i.e. health issues and information about adaptive equipment), shopping, accessing information about transportation for leisure activities, accessing advice about finance and jobs, and paying bills. Two participants reported that they used the Internet to keep up with breakthroughs in SCI research, especially to track stem cell research development.

Three participants also utilized the Internet for social coordination (e.g. as a way to meet new people and arrange social activities with friends and family members). These participants wished to connect with other individuals with SCI who they could meet socially and identify individuals who had experienced similar health problems as themselves (e.g. surgery for wounds, urinary tract infections, blood pressure problems). Two participants frequently used a website specifically designed for individuals with SCIs (<http://www.sci-peers.org/about.php>), and two participants were members of a Facebook<sup>®</sup> page devoted to individuals with SCI. These participants reported that, in addition to using these sites to communicate online with friends, they developed new social relationships with people they met through these social networking sites.

Five participants used assistive devices designed to facilitate computer use. Three individuals used hand braces for typing, and two participants with C4–C6 level injuries used voice recognition software; both reported significant problems with the software used, that created barriers to their ability to access the Internet. Two participants noted they did not have regular Internet access while hospitalized for several months. They reported that this (temporary) barrier to their ability to access the Internet was associated with increased isolation and decreased knowledge about their health.

Finally, we asked participants if they had concerns about online privacy risks associated with using Internet sites for the purpose of seeking social support for their SCI. None of the participants believed that confidentiality was a significant problem; they thought that individuals should be depended upon to use common sense about disclosing information on the Internet. Their contention was that, as long as they are adults, individuals with SCI should be allowed to choose how much information to post on websites. As one participant remarked, 'You should have the choice of controlling your own privacy'.

#### *Using the Internet for problem-focused support*

All participants considered the Internet to be an important source of problem-focused support (other sources of problem-focused support included medical professionals, peers, and family members). Six participants reported that they did not always trust the accuracy of information they received from the Internet; however, this was not always seen as a bad thing. For example, when asked about why the Internet is a helpful source of information, one participant stated that the Internet provides 'a range of information. It's not just coming from one source. There are many people that tap into it so, again, the opinions vary. It's very open-minded. You can find anything'.

Six participants noted that SCI peer-to-peer chat rooms are a particularly invaluable source of problem-focused support. When asked about why peers provide an important source of problem-focused support, one older man with paraplegia gave the following example:

How am I going to fly in an airplane (which is what I did for the company I worked for), and how am I going to go to my favorite sporting event now? How am I going to go to my favorite restaurant now; how am I going to go to a movie theater now? Those are questions that had I gone

to my doctors or nurses they probably could have given me some insight but my peers laid the thing out [for] each one of those issues. This is what you do when you get to the airport. This is what you do when you get to the door of the airplane. This is what you do when you get in the airplane.

#### *Using the Internet for emotional support*

Six participants reported that they relied heavily on emotional support from peers (i.e. other individuals with SCI) in order to cope with challenges related to their injuries. These participants reported that the Internet has helped to facilitate the emotional support they received. Participants reported that support is always accessible on the Internet any time of day. Three participants who used peer support noted that the breadth of opinions on the Internet enhanced the emotional support they received from discussion forums and chat rooms. One participant with a T1–T9 SCI noted that he actually preferred receiving emotional support from peers on the Internet (as opposed to in-person support groups):

I used to tell myself, you know, I'm not going to feel good about myself if I'm around other people in wheelchairs. I'm gonna feel more paralyzed...I would rather chat on here [online] with people in wheelchairs, than be in a room like Alcoholics Anonymous, sitting there with a bunch of other guys in wheelchairs telling war stories...I guess it's kind of cowardly maybe but... I guess I'm more apt to follow some advice... if I'm reading it...I don't feel as handicapped [online], I guess. But [if] I'm sitting around a bunch of people in wheelchairs: that makes me just feel even more handicapped, so it's easier for me to get online.

Looking back, participants noted that emotional support from peers (both in-person and online) was particularly important immediately following their injuries. For example, all participants who used peer support spoke positively about support they received (both in-person and online) while they were undergoing rehabilitation directly following their SCI.

In addition to discussing the emotional support they have received from peers both online and in person, five participants spoke about how much they valued giving support to their peers. Two participants were actively involved in building and maintaining a website designed to provide a forum for peer support for individuals with SCI. These two individuals were

injured 8–12 years prior to our interviews and stated that providing peer support to other individuals with SCI ‘keep[s] them going’. One participant stated that his mission in volunteering to work on this website was ‘to show everyone that we pretty much can do everything that everyone else does just with maybe some modifications’. All participants who were engaged in providing peer support reported that giving support to peers gives their life meaning.

It is important to note, however, that some participants had negative experiences with peer support. Two participants reported that they avoided interacting with peers, especially on Internet forums. One individual, who acquired tetraplegia more than 20 years prior to our interview, reported that he found peer support groups to be ‘depressing’. ‘Quite honestly,’ he stated, ‘I don’t like to hear people complain about not walking and have to go through all this stuff. I mean, this is your life and deal with it, quite honestly. It’s the only life you have, so make the best of it’. The other individual, who acquired a non-specific SCI 1–2 years prior to our interviews, reported that, in his experience, peer support groups got ‘bogged down in negativity’.

Three participants reported that their friends and loved ones need more Internet resources for emotional support. As one participant, who had been injured 8–12 years prior to our interview, put it, ‘Family members and loved ones often get left out of the equation. They’re suffering just as much if not more than we are but they’re afraid to admit it’. There was a general consensus among participants that more resources for caregivers of individuals with SCI were needed.

#### *Additional Internet resources for individuals with SCI*

The final theme that emerged centered on the need for some additional resources for individuals with SCI on the Internet. Six participants expressed the need for websites that allow individuals with SCI to connect with peers with similar interests. In addition, six participants stated that they would like to see more information available about traveling for people with SCI. One participant, who was injured 1–2 years prior to our interview, reported that he would have liked to see a peer-led website that provides reviews of the accessibility of airlines, restaurants, and hotels; because, he often found that information about such venues online was inaccurate. In subsequent interviews, we asked participants about the potential utility of this idea, and all participants concurred that this was a much needed online resource.

## **Discussion**

This qualitative examination suggests that individuals with SCI gain both emotional and problem-focused support from Internet-based resources. Additionally, participants reported that providing support to peers via Internet-based resources increased their sense of meaning and purpose in life, suggesting that individuals with SCI engage in reciprocal social support on the Internet. While participants identified some challenges associated with using Internet-based resources (i.e. problems with voice recognition software and difficulties accessing the Internet while hospitalized) and some concerns about the utility of such resources, overall, Internet-based resources were perceived as largely positive.

In addition to the positive sources of Internet support identified by participants, several gaps in Internet resources were identified. In particular, participants reported that more resources are needed for caregivers of individuals with SCI. Participants also suggested that Internet resources could be better utilized to address challenges associated with traveling for individuals with disabilities.

The results of this investigation largely support prior research suggesting that the Internet is a resource that may assist individuals with SCI in overcoming barriers to social support that people with disabilities often experience.<sup>10</sup> Although two participants expressed concerns about negativity on Internet discussion boards, none of the participants reported experiencing loneliness, depression, or stress because of their Internet use, as has been reported in some prior research.<sup>16–19</sup> Indeed, most participants reported that having access to the Internet reduced their isolation. This discrepancy from findings in other research may be due to the fact that participants in this study used the Internet to connect with friends, family, and peers, rather than for activities like gaming. Additionally, although some previous research has not found strong support for the efficacy of live peer-to-peer support groups for people with health problems,<sup>8</sup> participants repeatedly reported that they found the peer support available on the Internet to be invaluable. This finding may provide evidence for the notion that Internet-based peer-to-peer support may be more helpful than live peer-to-peer support groups, at least for people with SCI.<sup>13,14</sup>

#### *Limitations*

As is the case with any small qualitative study, it is possible that our findings would not generalize to other individuals with SCI. The participants in our study were high-functioning in terms of social support, emotional

well-being, financial stability, access to medical care, and feeling as if they had a purpose in life. It is possible that individuals with SCI who are experiencing significant distress may not endorse the utility of the Internet for emotional and problem-focused support. Future research should focus on examining whether the Internet provides support to individuals with SCIs who are having more difficulties coping with their disabilities. It is important to note that we did not interview any of the participants immediately following their injuries (even the individuals who had been injured less than 2 years prior to this study had already completed rehabilitation). Thus, the themes we identified in this research may not reflect the experience and needs of individuals first learning to cope with SCI. Additional research is needed examining how newly injured individuals may benefit from Internet-based social support.

### *Future research*

Based on the interviews we conducted, it appears that the Internet may be one avenue of helping individuals with SCI increase social support, particularly support received from peers. In addition to addressing some of the limitations we outlined above, future studies might focus on developing, implementing, and testing interventions that utilize online resources to increase problem-focused, emotional, and reciprocal social support in patients with SCI.

Although previous studies have failed to demonstrate the utility of problem-focused social support in terms of increasing psychological well-being,<sup>7</sup> participants emphasized the importance of this form of support, especially immediately following their injuries. According to participants, the Internet may be a particularly useful mechanism to deliver the kinds of problem-focused support they reported needing (e.g. assistance with travel). Future work should seek to capitalize on the opportunities the Internet provides for problem-focused support by examining ways in which individuals with SCI can be encouraged to utilize such venues. For example, research might seek to follow-up on our participant's notion about the utility of a travel information website for people with SCI. In addition to developing such a website, research might seek to evaluate its usefulness, popularity, and accuracy.

Future research might also investigate our finding that individuals with SCI were concerned about their inability to access the Internet during hospitalization in order to conduct research on their health problems and the treatments they were receiving. For example, research may examine why individuals with SCI desire Internet resources to obtain health information in

situations where they presumably have regular interaction with health professionals (e.g. are they seeking to verify information provided, seeking additional information, or asking questions about their current situation). Understanding this finding might help us to develop interventions that use the Internet to increase health knowledge and facilitate improved communication between patients and health care providers.<sup>22</sup>

Participants reported that they received support from peers on forums such as Internet chat rooms, which suggests that utilizing Internet-based peer support for individuals with SCI in rehabilitation units and clinics may augment our ability to increase the social support individuals with SCI receive in a cost-effective and simple way. Future research might focus on facilitating the use of Internet resources for peer support for individuals with SCI and developing and testing interventions that leverage online sources of peer support (e.g. using Telepresence tools, open learning platforms, and opportunities for virtual, shared online activities, including mentoring, social TV, gaming, and psychosocial support).

### **Conclusions**

This qualitative investigation serves to deepen and inform our understanding of how the Internet can be an integral source of support to individuals with SCI. It provides evidence for the potential utility of Internet-based sources of emotional, problem-focused, and reciprocal support for individuals with SCI and sheds some light on additional Internet resources that may be needed to help people with SCI cope with their disabilities.

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