

# Identifying and Understanding the Health Information Experiences and Preferences of Individuals With TBI, SCI, and Burn Injuries

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## Abstract

**Introduction:** Traumatic brain injury, spinal cord injury, and burn injury can cause lifelong disability and changes in quality of life. In order to meet the challenges of postinjury life, various types of health information are needed. We sought to identify preferred sources of health information and services for persons with these injuries and discover how accessibility could be improved. **Methods:** Thirty-three persons with injury participated in semistructured interviews. Responses to interview questions were coded using NVivo. **Results:** Participants' difficulties accessing health information varied by injury type and individually. The majority of respondents found information via the Internet and advocated its use when asked to describe their ideal health information system. Nearly all participants supported the development of a comprehensive care website. When searching for health information, participants sought doctor and support group networks, long-term health outcomes, and treatments specific to their injury. **Conclusion:** To optimize the quality of health information resources, Internet-based health-care platforms should add or highlight access points to connect patients to medical professionals and support networks while aggregating specialized, injury-specific research and treatment information.

## Keywords

brain injuries, spinal cord injuries, knowledge translation, health services accessibility, qualitative research, rehabilitation

## Introduction

Traumatic brain injury (TBI), spinal cord injury (SCI), and burn injury (burn) are serious conditions affecting millions of Americans each year (1-3). The symptoms vary, but all 3 types of injuries can impact physical and cognitive well-being. Rehabilitation has been shown to improve physical, social, and cognitive functioning of persons with TBI, SCI, and burn injuries (4-7).

In order to meet the challenges of postinjury life, persons with an injury need access to health information. Health information needs are complex and vary over time with the changing needs of the individual (8). Those with chronic injury conditions have a high risk for medical complications and other health conditions throughout their lives (9). Despite the ability to access information through a variety of sources, previous studies have shown many individuals with injuries such as SCI continue to have unmet information needs (9,10).

We sought to identify the preferred sources of health information for individuals with TBI, SCI, and burn injuries and explore how those individuals thought access could be improved. These injuries are highly prevalent and severe in nature (1-3). Due to their severity, all 3 injuries can require long-term care and rehabilitation; thus, the need for health information among persons with these injuries is pronounced. Medical professionals and the Internet are 2 of the

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most common sources of health information for persons with injuries such as SCI (9-11). Likewise, experiential knowledge shared from others with similar injuries is highly valued (8). Medical professionals are often seen as the most trusted source of health information, while the Internet is the most common and preferred format for information (11,12).

We explored how participants felt the health-care system and the accessibility of health information and services could be improved. Access to a computer-based personal health support system has been found to positively impact access to health-care information and patient quality of life (13). When communicating with medical professionals, shared decision-making can provide positive patient outcomes such as satisfaction and improvements in functional status (14). Self-reported descriptions of experiences and preferences may help determine ways to anticipate the needs of persons with injury and improve care while increasing the applicability and accessibility of health information resources. Such data would also help clarify the areas that need improved health information access and research for TBI, SCI, and burn injuries.

Previous studies exploring the health information needs of persons with injury have examined either a single injury type or populations with a broad range of conditions; this study uniquely compares and contrasts the needs and experiences of persons with common types of injuries: TBI, SCI, and burn. This study aimed to collect a broad range of information, examining not only qualitative health information needs and experiences but also collecting activities of daily living (ADLs), instrumental activities of daily living (iADL), and quality of life data. Additionally, it sought to assess the obstacles faced by persons with these injuries when accessing services and information through the US health-care system.

## Methods

### Participants

A total of 33 persons with injury were interviewed: 13 with TBI, 8 with SCI, and 12 with burn. Participants gave an oral consent prior to their participation in the phone interviews as approved through the institutional review boards of the American Institutes for Research and George Mason University.

Participants were recruited through a number of different outreach methods. First, National Institute on Disability, Independent Living, and Rehabilitation Research-funded SCI, TBI, and Burn Model Systems grantees were contacted to recruit participants. Participants were also solicited through advertisements placed in printed materials, websites, social media sites, and through recruitment messages sent to e-mails provided by consumer advocacy groups.

### Data Collection

Semistructured interviews were conducted with individuals having TBI, SCI, and burn injuries. The first part of the

interview discussed the participant's injury and care background as well as ADL and iADL. Activities of daily living were calculated using the Barthel Index of Activities of Daily Living, and iADL was determined using the Lawton Instrumental Activities of Daily Living scale (15,16). The World Health Organization Quality of Life Instrument-abbreviated version (WHOQOL-BREF) was used to assess each participant's quality of life (17).

The final open-ended part of the interview examined each individual's medical, rehabilitation, and continuing care experience, specifically focusing on an information needs assessment.

Interviews were conducted and recorded over the phone and ranged from 20 to 128 minutes with the average phone call lasting 40 minutes. The questions were read to study participants. To assess ADL, iADL, and quality of life, the interviewer read a list of answers from which participants selected the one they felt was most appropriate. The last section consisted of open-ended questions. Scripted prompts were utilized in the open-ended portion to ensure that participants' answers were comprehensive.

### Data Analysis

**Qualitative data coding.** Prior to analyzing participants' responses, the research team created a bank of answers and themes. This bank was developed based on the responses of a random sample of interviews that included all injury types (TBI, SCI, and burn injury). After the answer bank had been reviewed and refined, 2 researchers coded interviews to determine interrater reliability. NVivo's coding comparison query showed a 98.99% agreement ( $\kappa$  coefficient = .7464). Percentage agreement is the percentage of the source's content where the 2 users agree on the code used to record a response. Since audio files were coded, the unit of measurement is seconds of duration.

Interviews were coded to record participants' direct answers to each question as well as to identify themes in the responses that may have fallen outside the scope of a direct answer to a question. In some cases, a participant would respond to a question in a way that fell beyond the scope of the developed answer bank. In those cases, a new answer or theme code was added to the answer bank and the remaining research team members were notified of the change. In total, 10 new codes were added and 18 codes were modified during the coding process.

**Qualitative data analysis.** Qualitative data from participants' open-ended responses were coded using NVivo for Mac. Five of the interviews were unusable and were excluded from coding. The Nvivo tree map feature was used to both visually represent and quantify how frequently each code was assigned across all interviews. The coding responses were quantified for all interviews, as well as for each injury type (TBI, SCI, burn) individually. Interview data were

**Table 1.** Study Participant Characteristics.<sup>a</sup>

	Total (N = 33)	Burn (n = 12)	SCI (n = 8)	TBI (n = 13)
Age	43.5 ± 10.8	38.0 ± 8.0	48.3 ± 12.3	45.7 ± 10.7
Gender: female	48.5%	41.7%	25.0%	69.2%
Ethnicity				
Caucasian	48.5%	33.3%	62.5%	53.8%
African American	33.3%	33.3%	25.0%	38.5%
Hispanic	27.3%	33.3%	12.5%	30.8%
Other	15.2%	25.0%	12.5%	7.7%
Multiethnic	3.0%	8.3%	0.0%	0.0%
Education				
High school graduate or less	21.2%	16.7%	25.0%	23.1%
Vocational school/some college	36.4%	50.0%	25.0%	30.8%
College graduate	36.4%	33.3%	50.0%	30.8%
Graduate school	6.1%	0.0%	0.0%	15.4%
Marital Status				
Single	42.4%	41.7%	37.5%	46.2%
Married	45.5%	50.0%	50.0%	38.5%
Divorced/separated	12.1%	8.3%	12.5%	15.4%
WHO-QOL(0-100 scale)				
Physical health	53.6 ± 15.1	54.3 ± 13.0	63.4 ± 15.5 <sup>b</sup>	46.8 ± 14.0 <sup>c</sup>
Psychological health	64.6 ± 13.3	66.6 ± 14.6	69.6 ± 8.4	59.7 ± 13.7
Social relationships	56.3 ± 26.2	65.2 ± 28.2	61.8 ± 19.0	44.7 ± 25.3
Environment	67.7 ± 21.4	69.6 ± 23.9	81.5 ± 15.1 <sup>b</sup>	57.4 ± 17.9 <sup>c</sup>
Self-reported overall health status				
Poor	3.0%	8.3%	0.0%	0.0%
Fair	27.3%	16.7%	0% <sup>b</sup>	53.8% <sup>c</sup>
Good	39.4%	58.3%	25.0%	30.8%
Very good	27.3%	16.7%	62.5% <sup>b</sup>	15.4%
Excellent	3.0%	0.0%	12.5%	0.0%
Length of time of receiving care, years	4.5 ± 7.4	2.0 ± 2.9	7.4 ± 12.6	5.0 ± 5.9
Hours per week receiving care	20.1 ± 27.2	16.5 ± 20.9	28.8 ± 35.6	17.9 ± 27.5
ADL <sup>d</sup>	16.4 ± 3.8	17.5 ± 2.8 <sup>b</sup>	12.5 ± 3.5 <sup>c</sup>	17.9 ± 3.2 <sup>b</sup>
iADL <sup>e</sup>	33.0 ± 6.5	12.0 ± 7.0	8.0 ± 6.6	13.0 ± 6.0
Health insurance				
Medicare	36.4%	8.3% <sup>b</sup>	62.5%	46.2%
Medicaid	24.2%	33.3%	12.5%	23.1%
Private insurance	45.5%	41.7%	50.0%	46.2%
No insurance	21.2%	33.3%	25.0%	7.7%

Abbreviations: ADLs, Activities of Daily Living; iADL, instrumental Activities of Daily Living; WHO-QOL, The World Health Organization Quality of Life Scale.

<sup>a</sup>Superscript letters (b and c) indicate statistically significant differences between injury groups.

<sup>b</sup>The value is significantly different from unmarked values.

<sup>c</sup>A statistically significant difference from both b and unmarked values.

<sup>d</sup>Barthel Activities of Daily Living Index (18).

<sup>e</sup>Lawton Instrumental Activities of Daily Living Scale (19).

highlighted based upon overall participant response trends as well as any standout patterns for each injury type.

**Quantitative data analysis.** Descriptive statistics (means and standard deviations) were computed for collected quantitative data (ie, age, ADL, iADL; Table 1). Analyses of Variance with post hoc testing were conducted to determine whether there were statistically significant differences among the 3 injury groups. Percentages and frequencies were calculated for categorical data (ie, gender, ethnicity). The  $\chi^2$  tests were then performed to determine whether there were statistically significant differences between the injury

groups. All of the quantitative analyses were conducted using SPSS version 22 statistical software package.

## Results

Study participants responded to open-ended questions focusing on personal challenges faced since their injury and how their health had consequently been impacted. In addition, study participants discussed health information sources used to understand their injury and challenges they faced in finding resources. In doing so, respondents provided valuable insights into their existing support networks and perceived gaps in injury care information.

**Table 2.** Patient Information Source Preferences and Obstacles to Accessing Information.

	N = 33
Information sources	
Internet sources	
Medical sites	22
Discussion board sites	5
Support group sites	6
Government sites	8
Search engine	21
Medical sources	11
Support groups	6
Obstacles to access	
Lack of Internet access	1
Finding credible sources	2
Understandability	2
Time constraints	1
Cultural appropriateness	1

### Population Demographics

The study population's mean age was  $43.5 \pm 10.8$  years. Of note, 72.7% of participants did not have a caregiver; however, of those who did, 75.9% of caregivers were either a member of the participant's family or significant other. The study population's ethnic, socioeconomic, and injury type can be found in Table 1.

### Information Sources

Almost all participants (91.7%) searched for and found information on participants related to treatment, rehabilitation, and coping via the Internet (Table 2). In fact, use of the Internet was indicated in twice as many responses than the second highest choice, medical sources such as doctors and nurses (45.8%). Of the 91.7% using the Internet as an information source, 88.0% stated they had used medical websites such as WebMD and Mayo Clinic. The following interviewee cites advantages such as convenience and having up-to-date information.

And in this day and age, the internet is probably the best model of ... getting and accessing that information. Because, even if you built it into a module, a program that had modules, the information is so ever changing ... or where you find that information is so ever changing every day that it would be soon outdated. (Interview 2201: SCI)

However, not every type of online resource was embraced; the majority of the study population did not use some platforms we hypothesized to be highly utilized. Online discussion boards were the most commonly unused platform, with 70.8% of respondents stating they did not use them. Additionally, 59.1% of respondents stated they did not use online support groups, and 61.5% indicated they did not use government websites.

**Table 3.** Information Format Preferences for an Ideal Health-Care System.

	Total (N = 33)	TBI (n = 13)	SCI (n = 8)	Burn (n = 12)
Internet	17	4	5	8
Printed materials	7	0	3	4
In-person communication	5	4	0	2

Abbreviations: TBI, traumatic brain injury; SCI, spinal cord injury.

### Obstacles to Accessing Health Information

Study participants reported few obstacles to accessing health information (Table 2). Only 3.8% reported that lack of "Internet access" interfered with their ability to access information. Some of the most common causes of interference were "finding credible sources" (15.4%), "understandability/language" (12.0%), "available time" (7.1%), and "cultural appropriateness" (7.1%). One study participant discussed how the Internet mitigated the obstacles they would otherwise face when accessing information:

... I was looking for medical related issues and I went to the library, I don't know how current, how much or how current they would have at the library. And then of course access to the library is time consuming. You've got to get the van parked; you've got to get your chair in and out, that kind of a thing. So the internet is like a godsend. (Interview 2201: SCI)

### Preferred Care System

The final interview question asked participants to describe their ideal health-care system without having to consider practical limitations such as cost. In doing so, respondents offered a variety of improvements to health information systems, which they felt would be beneficial to others with similar perspectives and experiences.

**Information format.** When asked how they would like for information to be made available to them, participants most commonly preferred the Internet (41.5%). This was the most common answer for all injury groups, although within the TBI group, an equal number of participants wanted information to be shared in person (Table 3). One study participant discussed a structured system of services likely needed based on the level of severity and time since the injury event occurred.

I would like to see some type of color-coded ranking system depending upon your level of severity, at the time of your injury. Then, from there, it would gauge what type of services you're most in need of at that point. From financial, to physical, to emotional, whatever. Then, from that ladder if you will, there is a clearinghouse you would go to, something universal ... like a referral list or network. (Interview 3209: TBI)

An overwhelming majority (92.3%), including 100% of the TBI and SCI respondents, stated they would use a “comprehensive care website” (encompassing information on injury, treatment, recovery, support network), if it was available.

**Desired information.** When asked what types of information this ideal system should provide, 2 categories clearly emerged. The most common preference was for the new system to act as a comprehensive, consolidated information source (62.5%). Participants requested particular types of information be available in an ideal health information system. Twenty percent of respondents discussed access to advanced research, such as health studies or the latest advances in technology, and tools designed to offer self-care education as part of the ideal system. One participant describes limitations in access to advanced information:

It’s been understandable, but sometimes it’s been too basic, and I would like more thorough information or more in-depth information. And sometimes, this might be more applicable to an earlier question, you know you get into the websites and it’s like different studies that have been done, and the author who conducted the study, but all you can get maybe is a summary of it. You can’t access the rest of the information because you don’t have the authority to or they’re not giving you access to that information. You have to go to a medical library, which we don’t have access to. (Interview 2201: SCI)

Participants wanted material on support networks (31.3%) from an ideal health-care system. Similarly, the 2 most common types of services participants cited an ideal health-care system should provide were support groups (22.2%) and access to medical professionals (22.2%). Participants mentioned support groups not only in the context of social and emotional support but also as a means of sharing information. Several wanted a more relatable group:

I think a young adult support would be beneficial . . . You see a lot of support groups and there is usually an older demographic. Something more on a level playing field would *have been more comfortable and I think that would have been more beneficial for me.* (Interview 1212: Burn)

More than half of the participants wanting “access to medical and support professionals” had burn injuries (56.3%). Participants with traumatic brain injury differed, desiring classes on their “condition, treatment, and life” (20.0%) more than “access to medical and support professionals” (12.0%). Participants did not want information and services for themselves alone; 17.8% of respondents referenced providing training for caregivers as a desired system feature.

Many desired information specific to their injury (46.4%). Individuals in the burn group expressed a need to see more diagrams and pictures as a method to identify

severity and to search injuries based on where they occurred on the body. One SCI respondent described her need for gender-specific information.

My biggest difficulty is getting information related to women and spinal cord injury. And it’s not a lot out there right now, particularly as it relates to pregnancy and sexuality. (Interview 2208: SCI)

**Desired services.** Study participants detailed a number of additional services their ideal health-care system would provide. Psychological and physical therapies were 2 of the most common services discussed (21.4% and 17.9%, respectively).

Getting back to work helped me to overcome some obstacles that only if I had gone back to work I would be able to overcome. Even with physical therapy, I wouldn’t be able to. So I would say, physical therapy in the beginning, and going back to work afterwards. (Interview 2209: SCI)

In participants’ descriptions of an ideal treatment world, quality physical therapy was often synonymous with improved health status because quality centers were seen as places where comprehensive care and information were provided. Specific centers of care, such as The Miami Project and Kernan Hospital (now University of Maryland Rehabilitation & Orthopaedic Institute), were mentioned by respondents as examples of how an ideal form of care would look, including the best way to learn comprehensive information about SCI, TBI, or burn.

I would say that [Kernan Hospital] have a magnificent staff that is attuned to head injuries and brain injuries; and they are very knowledgeable and very, very understanding of the type of injury and what’s available to treat it. (Interview 3204: TBI)

The ability to physically reach care centers and professionals was even more essential in some cases. Transportation systems were mentioned as an important component to access information at support groups or care facilities. Of note, 24.1% of respondents mentioned transportation services had not been available. Participants with burn discussed a desire for transportation services to be provided by health-care entities in an ideal setting twice as often as participants in either the TBI or the SCI group.

Interviewer: So when you were first injured, did they provide you with transportation services?

Participant: No. But I did, needed that. (Interview 3209: TBI)

## Discussion

This study provides in-depth understanding into the issues affecting the pursuit of health information for persons with TBI, SCI, and burn injuries. The interviews examined

participant health status, their views on the applicability and usefulness of accessible postinjury care and rehabilitation materials, obstacles faced when seeking information, and desired programs, services, and knowledge.

The source of health information is a critical component to those seeking it. Interviews explored the types of websites persons with injury used when seeking health information. Our findings emphasize the utility of the Internet. Still, many participants also referenced health information experiences with a doctor. Thus, combining the strengths of each type of experience should be a priority when developing a comprehensive website. Although previous studies found web-based peer support groups can improve mental health symptoms such as depression, our study population generally favored health-related websites over web-based support group sites and discussion boards (20,21).

Despite the relative unpopularity of support group websites in our study sample, support networks emerged as a critical service for study participants. Contact information for support groups and doctor networks improves the accessibility of resources for information-seeking persons. This form of desired information is therefore vital to a patient-centered health-care website. Studies have shown online communication assisted with problem-solving and coping strategies for people with chronic illnesses (22). A mixed-methods inquiry into informal friend and family networks for persons with SCI revealed that different networks served different roles related to advice, knowledge, advocacy, preventing secondary illness, managing secondary illness, and finances (23). Health-care systems should therefore apply a patient-centered perspective to sharing network information.

Many study participants sought advanced research related to technological advancements, updated self-care tools, or medical research. Our study sample thus identifies an emergent information need, advanced research, which goes beyond general injury information, in a format where participants seek more technical information individually, as opposed to within a peer network. Persons with injury face information barriers when attempting to access advanced research to find high-quality medical information (24). In another qualitative study of persons with multiple sclerosis, researchers found that patients searched for health information related to medicines, expert therapies, and latest developments in the medical field (25).

Injury-specific health information was important to study participants in the context of a comprehensive care site. Persons with TBI, SCI, and burn have ongoing health needs related to quality of life (10). Injured persons often rely on support networks to prevent and manage secondary health conditions (23). Serious injuries can require home modifications and health equipment, supplies, and devices; all of which have been reported as a barrier to reintegration for injured persons (18).

Participants listed services that were important for an ideal health system, including many types of rehabilitation that can improve the quality of life. Previous studies have

identified transportation as a health service need for populations with SCI and neurological disorders (18,19). Our study expanded upon those findings by examining the transportation needs of persons with TBI and burn injury, as well as individuals with SCI, and identifying it as a critical resource for accessing non-Internet health information, services, and care.

Health literacy, especially online health literacy, has been reported as a major barrier in finding information (12,26). High health and computer literacy skills have been linked to accessing higher quality information (22), but lack of e-health literacy skills has been identified as an intrinsic barrier for persons with chronic conditions (24). Our study population expressed less skepticism of online sources than what had been reported in previous studies, perhaps due to higher e-health literacy; however, the small sample size or the relatively high percentage of native English speakers may have also been a factor. Study participants discussed using more than 1 source, and some compared information from previous research. In order to match the recommendations put forth by participants, referrals and links to resources from medical professionals to online health information should be incorporated into an ideal health information website.

### **Strengths and Limitations**

The semistructured interviews allowed each participant to provide an in-depth perspective of health information issues related to their injury. Common experiences emerged, denoting the transferability of responses. However, the total US population that has experienced TBI, SCI, or burn is too large for this sample size and data to statistically represent them, making generalizability a limitation. However, since this is a qualitative study, generalizability was not the goal of the investigation.

Study participants were recruited using the Internet (as well as other sources), which may have biased our sample in terms of preferences for Internet resources. Different numbers of persons with injury were interviewed for each injury group. For this reason, each injury type was not equally represented in the statements dealing with overall responses. Interrater reliability measures, percentage agreement and  $\kappa$  coefficient, indicated both coders applied codes consistently. However, internal rate of return was not 100%, therefore, minor discrepancies in code placement may be assumed.

### **Conclusion**

In-depth interviews conducted in this study reveal how persons with TBI, SCI, and burn injuries get health information. Participants revealed preferred sources of information, namely, the Internet and medical professionals. Ideal health information preferences emphasized sources of information and format. Study participants favored a comprehensive care website and sought support network resources, information on long-term care and outcomes, and materials specific to their injury. Service preferences included quality rehabilitation,

support groups, and transportation. An ideal health information system should also incorporate information referrals from health professionals. Generalizability may be improved in future studies by recruiting participants from randomly selected rehabilitation facilities across the country.

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