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Unique Needs, Barriers, and Discrimination Experienced by Spinal Cord Injury Patients in Dental Facilities

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Read, approved, and signed by:

Amy Peak	5/5/21 Date
Chad Knoderer	Date 5/5/21 Date
	Date
Director, Honors Program	Date
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Unique Needs, Barriers, and Discrimination Experienced by Spinal Cord Injury Patients in Dental Facilities

A Thesis

Presented to the Department of History

College of Liberal Arts and Sciences

and

The Honors Program

of

Butler University

In Partial Fulfillment

of the Requirements for Graduation Honors

Lindsey Brooke Schuler

May 6, 2021

Abstract

Objective:

The primary objectives of this study are to determine SCI patients' barriers to dental care, perceptions regarding dental professionals understanding of their unique needs, and feelings of SCI- related discrimination.

Methods:

An online survey was conducted through SCI social media support pages. A modified version of the Discrimination in Medical Settings Scale (DMSS) was utilized to capture perceived discrimination in dental facilities.

Results:

The majority of participants (53%) experienced at least one barrier in dental care. If patients experienced a barrier, they reported lower oral health ratings (p=0.031) and were less likely to have been to the dentist within the last year (p=0.011). Over 70% of patients believed their dentist did not understand the unique complications of SCI and over 40% felt their dentist was unaware of how common SCI medications impacted oral health. These correlated with greater instances of reporting oral health as fair/poor/very poor. Approximately 19% of participants experienced dental discrimination. Those who rated their oral health as fair/poor/very poor were 3.4 times more likely to experience dental discrimination.

Conclusions:

Dental care and outcomes in patients with SCI could be improved by decreasing accessibility barriers and educating dental health professionals about medical/dental complications unique to those with SCI, including autonomic dysreflexia, spasticity, and oral adverse effects of commonly used medications. Approximately one in five patients with SCI experience discrimination in the dental setting (DMSS score > 21). Quality of care and dental outcomes could be further improved by mindfully addressing implicit and explicit biases against disabled individuals.

Introduction

Spinal cord injury (SCI) is a traumatic injury leading to a loss of function, mobility, and/or feeling. Almost 300,000 individuals in the United States currently live with a SCI with an annual incidence of approximately 10,000 newly acquired injuries.¹ In addition to mobility and sensation loss, SCI patients may experience secondary complications such as muscle spasms, chronic pain, and the inability to regulate blood pressure.¹ The neuronal complications of spinal cord injuries have profound effects on the entire body, potentially creating challenges in performing activities of daily living (ADL) and inherently affecting all aspects of health, including oral health.

Individuals with disabilities have poorer oral health and greater difficulty accessing dental services compared to disability-free persons. The disabled population may be at a greater risk for oral diseases, such as tooth decay and dental caries.² Complications, such as dependence on others for daily care, side effects from medications, and overall lack of access to dental office may increase this risk in the SCI population.³

Dental fear and physical inaccessibility are the greatest discrepancies encountered by SCI patients compared to their able-bodied peers. Dental fear stems from nonwheelchair accessible dental office environments, lack of trust for dental professionals, and anxiety of additional unique SCI complications, such as autonomic dysreflexia (AD).² Though rare, autonomic dysreflexia, an acute hypertensive condition, has the capability to be life-threatening. AD can be triggered by pain, potentially including discomfort from dental procedures.³ Further, it was found adults with SCI were 4.5 times more likely not to visit the dentist in the past year if they reported physical barriers such as office inaccessibility or inability to transfer from the wheelchair to dental chair.⁴

In 1990, the Americans with Disabilities Act (ADA) mandated all public facilities to be physically accessible to all people. ADA standards focus on accessible entrances and access to goods and services. Entrances must have a level entryway and a minimum clearing distance of 32 inches when the door is open to 90-degrees.⁵ Wheelchair users should have adequate space in waiting rooms, and the receptionist window should be between 28-34 inches above the ground.⁶ Within exam rooms, 30x 48 inches of clear space is needed next to the examination table so the individual can approach and transfer.⁵ To increase accessibility, though not required by the ADA, offices should have adequate space on both sides of the examination table to account for individuals who may only be able to transfer from one side. Additionally, an adjustable exam table that lowers to wheelchair seat height (about 17-19 inches from the ground) aids in transferring.⁵ Even if facilities are ADA compliant, accessibility challenges may still arise if staff are unfamiliar with the adaptive equipment and/or the unique needs of patients with disabilities.⁷

Further education and training are desirable when working with patients with special needs.⁸ Sullivan and colleagues state that only 53% of dentists practicing in the United States have been provided with any special needs training during dental school. Of those who received training, less than five hours of didactic education and even less experiential training was provided.² Casamassimo and colleagues found that dentists who had not been educated or exposed to patients with special needs were less likely to treat

those patients. In contrast, dentists with hands on experience with this patient population were less likely to consider level of disability as an obstacle of care.⁹

Lack of education can lead to implicit and explicit bias, prejudice, and potentially discrimination.¹⁰ Societal discrimination has been associated with negative health outcomes.^{11,12,13} Few studies have examined the effects of perceived discrimination on health outcomes, with nearly none addressing oral health within the SCI community. One study looked at the effects of how perceived discrimination within SCI patients was associated with clinically relevant outcomes, such as pain and depression. Hogaboom and colleagues found there was a greater risk of negative health outcomes with higher levels of perceived discrimination. Those that were less educated, of lower income, or black were more likely to perceive discrimination. Their study suggests that eliminating attitudinal barriers in health care may help alleviate the potential cycle of worsening health perpetuated by bias.¹⁴

The primary objectives of this study are to determine SCI patients' barriers to dental care, perceptions regarding dental professionals understanding of their unique needs, and feelings of SCI- related discrimination (as measured by a modified version of the Discrimination in Medical Settings Scale.) Secondary objectives are to a) ascertain any associations between dental office accessibility or SCI- related barriers and overall oral health, b) determine if there is association between perceived discrimination and overall oral health, and c) gather data related to ADA compliance and accessibility in dental facilities.

Materials and Methods

Participants were recruited through spinal cord injury support group social media pages: SCI Survivors, Spinal Cord Injury USA Group, Spinal Cord Injury Support Group, Spinal Cord Injury Rehabilitation & Recovery, and Spinal Cord Injury Walkers. To be included in the study, participants needed to be at least 18 years old, live in the United States, have personally sustained a SCI, and must have visited the dentist since the onset of their SCI.

Participants completed a 26-question online survey which, on average, took six minutes to complete. Data was collected during October and November 2020. The survey inquired about socio-demographics, SCI-related information, oral health maintenance, barriers to receiving dental care, degree of dental professionals' understanding of SCI patients' unique needs, perception of potential discrimination- as measured by a modified version of the Discrimination in Medical Settings scale, dental office accessibility, and overall quality of dental healthcare. The full survey is available in **Appendix A.** The study was approved by the Institutional Review Board at Butler University.

The Discrimination in Medical Settings Scale (DMSS) is a seven-question assessment using a 5-point Likert scale. The DMSS scale was modified slightly in order to optimally address the primary objectives by comparing participants' perception of their treatment by dental professionals before and after their SCI. (For example, "Compared to before your injury, how often do you feel your dental professionals treat you with less courtesy?"). Question 23 in Appendix A utilizes the DMSS. Scores range from 7-35, with higher scores representing greater perceived discrimination. Likert scales were also used to collect participants' perceptions of their own oral health, the quality of care they received, and their dental professionals' understanding of the unique needs of SCI.

Statistical analysis:

Descriptive statistics were used to characterize respondent demographics. For data analysis, Discrimination in Medical Settings Scale scores of 7-21 were categorized as having rarely or never felt discrimination and scores of 21-35 were grouped as having experienced discrimination. When analyzing oral health and quality of care, ratings of fair, poor, and very poor were combined as a negative response. Ratings of good to very good were combined as a positive response. Similarly, questions regarding dentists' understanding of unique SCI needs grouped the ratings of never, rarely, or sometimes as a negative response and ratings of most of the time to always as a positive response. Groupwise comparisons were made using independent samples *t*-tests, Chi-squared analyses, and Mann-Whitney tests for non-parametric continuous data. P-values of less than 0.05 were considered to be statistically significant. Statistical analyses were conducted using Statistical Package for Social Sciences version 26 (SPSS, Inc., Chicago).

Results:

Demographic and Baseline Information

A total of 110 respondents completed the survey. Five responses were excluded because they had not been to the dentist since the onset of their SCI, 6 were excluded due to not personally having a SCI, and an additional 8 were excluded because they lived outside of the United States. Thus, a total of 91 participants were included in this study. Study sample demographics are presented in **Table 1**. The majority of participants were 40-59 years of age, with an even dispersion of males and females. SCI distribution is shown in **Table 2**. Most participants acquired a cervical SCI greater than 3 years ago and use a manual or electric wheelchair to ambulate indoors. Oral health scores indicated 75% of subjects viewed their oral health as good/very good and 91% rated their overall quality of care received from their dental professional as good/very good. There was no significant difference found between the level of SCI and the perceived oral health rating (p=0.717) or quality of care (p=0.260).

Barriers to Receiving Dental Care and Degree of Accessibility





Self-identified barriers to dental care are displayed in **Figure 1.** The majority of participants (53%) reported at least one barrier in receiving dental care. The most commonly identified barriers were cost, inadequate space to safely transfer, exam room inaccessibility, and dental fear. Participants who experienced dental care barriers reported lower perceived oral health ratings (p=0.031). Of the participants who experienced at least one barrier, 18% had not been to the dentist in the past year compared to only 4% of their counterparts (p=0.011). When patients had not been to the dentist within the last year, they were ~4.5 times more likely to rate their quality of care

as fair/poor/very poor (odds ratio (OR)=4.467, 95% confidence interval (CI): 1.002-19.913, p=0.58). They were also 6 times more likely to rank their self-perceived oral health as fair/poor/very poor (OR= 6.009, 95% CI: 2.046-17.653, p=.001). Approximately 95% of patients who experienced physical barriers utilized a wheelchair indoors.

ADA compliance and accessibility components are reported in **Table 3**. With regard to ADA compliance, the vast majority of participants indicated a level entry way (85%), adequate waiting room space (86%), and appropriate door width (92%). However, only 57% of participants reported adequate space to safely transfer into the dental chair. Sixty percent reported the ability of the dental chair to raise and lower to assist in transfers, 42% of the participants were able to receive dental care in their wheelchair, and just 12% of the participants expressed that their dental facility had an automatic push button to operate doors.

Perceived level of dentist understanding of unique needs

Over 70% of the participants believed that their dental care provider did not understand the unique complications of SCI, such as autonomic dysreflexia and spasticity. Participants who felt like their dental provider did not understand their unique needs were more 1.6 times likely to report their oral health as fair/poor/very poor (OR= 1.619, 95% CI: 1.343-1.952, p=0.000128). All participants who reported that their dentist did not spend adequate time treating them perceived their dentist to be unaware of unique SCI complications (p=0.032).

The majority of patients (85%) felt their providers worked to accommodate their needs. When participants felt their dentist worked to accommodate their needs, they were

9.3 times more likely to rate their oral health as good/very good (OR= 9.351, 95% CI: 3.014-29.014, p=.00009) and 1.5 times more likely to perceive their provider as aware of SCI complications (OR= 1.5, 95% CI: 1.3-1.832, p=.001). No significant difference was shown between level of SCI and awareness of unique SCI complications (P=0.666).

Approximately 43% of participants felt their dental provider was unaware of how medications commonly used in individuals with SCI may impact oral health. Those that felt their dentist was unaware of medication-induced adverse oral health effects were 4.5 times more likely to report their oral health as fair/poor/very poor (OR=4.472, 95% CI: 1.612- 012.407, p=0.004).

Perceived discrimination and oral health effects

The median (IQR) DMSS score was 9 (7-29) and 81% of the sample reported rarely feeling discrimination in the dental setting (defined by a DMSS score < 21). Those who never or rarely reported feeling dental discrimination were 5.3 times more likely to rate their quality of care as good/very good; this accounted for about 95% of this population (OR=5.308, 95%CI:1.176-23.961, p=0.039). Participants were also 3.4 times more likely to rate their oral health as good/very good if they did not experience discrimination (OR=3.437, 95% CI: 1.134-10.416, p=0.033).

Approximately 19% of participants experienced discrimination in the dental setting (defined by a DMSS score > 21). Those that experienced discrimination had significant negative impacts on their health and dental experiences. **Figure 2** shows the distribution of the 7 questions that comprised the DMSS and the frequencies at which participants reported sometimes, most of the time, or always, representing higher DMSS scores. These scores were combined and correlated to the perceived levels of dental

discrimination. The symbols above **Figure 2** represent characteristics that had statistically significant correlations of rating quality of care (\diamond) and oral health (\blacklozenge) as fair/poor/very poor. Overall, participants who self- reported their oral health as fair/poor/very poor were 3.4 times more likely to experience discrimination in dental offices compared to those who rated their oral health as good/very good (OR= 3.437, 95% CI: 1.134-10.416, p=0.033).





Dental discrimination was 4.7 times more likely to be perceived by individuals who were not independent in maintaining their oral health (OR=4.7, 95% CI: 1.55-14.480, p=0.011). There was no significant difference between the level of SCI or wheelchair use and perceived discrimination.

Discussion

Barriers to receiving dental care and degree of accessibility

Prior literature found physical barriers, dental fear, and cost to be the three main obstacles the SCI population faces when receiving dental care.⁴ The present study

supports these results with the greatest portion of respondents addressing cost as a barrier, followed by physical barriers (exam room inaccessibility, waiting room inaccessibility, and space to safely transfer), and then dental fear. Physical barriers are the unique challenge SCI patients face compared to their able-bodied peers. When patients experienced barriers, they were significantly less likely to have visited the dentist in the past year and more likely to have dental fear and to self-report their oral health as fair/poor/very poor. Sullivan and colleagues suggest that increased fear may be correlated with the lack of routine dental care among the SCI population or an unpleasant past dental experience.²

There also is the potential misconception among the SCI population that oral health is not a priority.² One participant said, "I am 42 years old as a complete T 4/5 SCI. I have not been to a dentist for at least 15 years because of pressure wounds and transportation and sitting difficulties. Dental work has just been way down on the list of priorities." This testimony demonstrates the need for healthcare professionals to communicate the importance of oral health to SCI patients while also addressing the accessibility needs to provide the best care possible for all patients.

Perceived level of dentist understanding of unique needs

The present study expands upon prior literature and looks into potential factors that underly perceived barriers. In doing so, this study analyzed how SCI patients perceive their dental professionals to understand the unique needs of their injury. It was found that 70% of patients did not feel as if their dental provider was aware of unique complications related to their injury, including autonomic dysreflexia, spasticity, and chronic pain. When asked, "What is one thing you wish your dental professional knew about your health since your SCI?" one participant mentioned the fear of autonomic dysreflexia (AD). This is a hypertensive condition commonly found in SCI at or above thoracic level 5/6. AD symptoms commonly include pounding headache, acute anxiety, shivering, blurred vision, flushing and sweating. In severe cases, cerebral and spinal subarachnoid hemorrhage, seizures, and pulmonary edema may occur.¹⁵ This patient-perceived lack of dental understanding supports the work done by Sullivan and colleagues who found that 90% of dental professionals reported no knowledge of autonomic dysrefelxia.¹⁶

Following trauma to the spinal cord, neuroplasticity is essential to regain neurological function. Neuroplasticity can lead to the development of neuropathic pain and spasticity.¹⁷ Spasticity is characterized by increased muscle tone, hyperreflexia, and painful muscle spasms in response to stimulation. Of individuals living with a SCI, 70% experience spasticity and 50-60% have neurologic pain.¹⁷ One participant stated, "[My dentist] wants me to get multiple teeth pulled at once and doesn't understand I can't handle too much extra pain on top of what I always have from my SCI." It is necessary for dental providers to understand these common SCI conditions in order to provide the best care.

Additionally, over 40% of participants did not feel as if their dental provider was aware of how their medications impact their oral health. Studies report that nearly half (43-49%) of individuals with SCI take medication to control muscle spasms.¹⁸ A common side effect of such medications is xerostomia, or dry mouth, which is associated with the increased development of plaque and dental caries. With less saliva, food is more likely to stay in teeth longer.³ Several participants commented on this aspect by saying, "My mouth and teeth are greatly affected by my SCI and medications." Another patient expressed, "My medicine and subsequent health issues really relate so much to my oral health. If my oral health isn't good, it can relate to my other health issues." Due to these complications, it is important for this vulnerable SCI population to have professional dental cleaning every 6 months to prevent oral disease.² However, as previously stated, SCI patients are less likely to attend these routine visits if there is perceived dental fear or barriers for care.² Through increased awareness of adverse effects of common medications used in the SCI population, dental professionals will be able to better address their unique needs.

Perceived discrimination and oral health effects

Based on DMSS scores, the present study found that just under 20% of SCI patients experience discrimination in the dental setting. When patients were subjected to these experiences, they were more likely to have rated their oral health and quality of care as fair/poor/very poor. Negative experiences impact the oral health of SCI patients.

Bias involves automatic assumptions about particular patient groups. While implicit bias is an unconscious preference, it can unintentionally lead to inequality and disparities in patient care. Implicit bias has the tendency to effect vulnerable populations and can potentially impact disease diagnosis, management of care, and patient outcomes.¹⁹ The results of the present study are in accordance with two other studies which found that physician bias was associated with less positive interactions and lower patient satisfaction scores.²⁰

In the current study, the vast majority of participants utilized a wheelchair indoors. Galli and colleagues found that while people claim to not make assumptions about people with disabilities, implicit psychophysiological measures indicated a sense of discomfort in the presence of disabled individuals.²¹ In the present study, nearly 20% of all patients, not only those who experienced discrimination, were treated with less courtesy and about 12% with less respect sometimes, most of the time, or always after their acquired SCI. Spinal cord injury patients have the unique lens of experiencing life as both an able body and disabled person, essentially serving as their own control. These patients are witnessing differences in their dental provider before and after their SCI.

VanPuymbrouch and colleagues found that the majority of healthcare providers have low explicit prejudice and high implicit prejudice.²² This is supporting evidence that no health care provider intentionally discriminates against his/her patients. While it may not be intentional, nearly 1 in 5 patients are experiencing these feeling during their care. In other words, providers may not consciously perceive disabled patients in a different manner, but subconsciously they may have conditioning that lead to prejudgment and potentially discrimination.²²

It has been found that people adjust their perceptions of groups according to personal experiences with members of that group. Galli and colleagues showed that longterm exposure of health professionals to wheelchair users may decrease implicit biases toward wheelchair users.²¹ Interestingly, their study also indicated that participants who passively listened to a lecture on SCI patients did not reduce their bias.²¹ This study aligns with a previous study which found that only 53% of dentists receive disability training in dental school and, of that, less than 5 hours of didactic training.⁶ In that study, those who received training were less likely to have viewed the disability as a barrier to care.⁹ Therefore, positive exposure and clinical training are important to increase awareness and help break these barriers to provide the best care for all patients.

Study Limitations

Data was collected via a voluntary survey using convenience sampling, thus response/non-response biases could have been present. The survey was distributed through SCI support groups on social media. Therefore, participants were limited to those with internet or cellular data access and members of those SCI support groups. The sample size was relatively small (n=91) and ninety five percent of participants were white. While we certainly desired to have a larger and more diverse participant population, having predominately white participants did minimize the potential for racial discrimination to confound DMSS scores obtained in this study.

Relevance, and Recommendations

This study addresses topics for which there is a significant gap in current medical literature. There are very few studies exploring the dental care received in by patients in the United States with SCI, and even fewer that examine perceived SCI-related discrimination in the dental care setting. Most of the existing literature are from studies conducted more than a decade ago or initiated outside the United States. This current study shows that while the majority of patients with SCI rate their oral health and the dental care they receive as good/very good, there is substantial room for improvement in regard to accessibility, provider knowledge of unique needs of those with SCI, and addressing the potential for bias and discrimination toward those with SCI. Therefore, we make the following recommendations.

Regarding accessibility:

- Ensure at least one exam room has sufficient open space on both sides of the exam chair for 360-degree wheelchair movement and safe transfers; as well as an exam chair that raises and lowers to wheelchair height.
- Install automatic push button door openers, especially on external doors
- Ensure an area within the check-in or out space is wheelchair-height.

Regarding SCI patient's unique needs

- Increase dental provider knowledge of autonomic dysreflexia and spasticity and how those conditions may impact the optimal provision of care.
- Increase dental provider knowledge of common medications used to treat complications of SCI and spasticity, and the potential adverse effects those medications may have on oral health
- Train all employees the proper technique to assist patients in safe transfers from wheelchairs to exam chairs
- Consider longer appointment times for individuals with SCI

Regarding implicit bias and awareness of potential prejudice and discrimination

• Consider having all employees complete a self-assessment of implicit bias such as those available for free at

https://implicit.harvard.edu/implicit/takeatest.html

 Increase awareness of aspects of prejudice, discrimination or discomfort commonly felt by SCI patients (treated with less courtesy & respect, emotions dismissed, etc.) and purposefully provide care in a way that is likely to prevent/address these concerns.

Conclusions

The most common barriers to receiving optimal dental care that SCI patients experience are cost, inadequate space to safely transfer, exam room inaccessibility, and dental fear. Patients experiencing at least one of these barriers were more likely to report dental health as fair/poor/very poor. SCI patients who feel their dental care providers do not understand their unique needs are significantly more likely to rate their oral health as fair/poor/very poor, and those that felt their dental health professionals were unaware of medication-induced adverse oral health effects were 4.5 times more likely to have poor oral health. Approximately 1 in 5 SCI patients indicated they have felt discrimination in the dental health setting, as defined by a DMSS score above 21.

Gender	
Male	49.5%
Female	50.5%
Race	
White	94.5%
Other	5.5%
Age	
18-39	23%
40-59	55%
60+	22%
Dental Insurance	
Yes	68.1%
No	30.8%
Current Mobility Status Indoors (Select	
all)	
Electric Wheelchair/Scooter	46.2%
Manual Wheelchair	46.2%
Non-Wheelchair Assistive device	14.3%
(Walker, Crutches, Cane, AFO)	
Hybrid of Wheelchair and Assistive	2.2%
Devices	
Independent	6.6%
Time Since Last Dental Visit for Any	
Reason	
Less than 6 months	57.1%
6 Months to 1 Year	20.9%
1-2 Years	18.7%
More than 2 Years	3.3%

 Table 1: Demographics

Table 2: SCI Variable

Degree of Injury	
Tetraplegia Complete	22%
Tetraplegia Incomplete	26.4%
Paraplegia Complete	18.7%
Paraplegia Incomplete	33%
Level of Injury	
Cervical (C1-C8)	53.8%
Thoracic (T1-T12)	38.5%

Lumbar (L1-L5)	7.7%
Time Since SCI	
Less than 1 Year	5.5%
1-3 Years	14.3%
Longer than 3 Years	80.2%

Table 3: Accessibility

ADA Compliance	
Level Entry Way or Ramp	84.6%
Adequate Waiting Room Space	85.7%
Appropriate Door Width	92.3%
Receptionist Window Height	60.4%
Adequate Space to Transfer	57.1%
ADA Accessible	
Ability to Raise and Lower Dental	60.4%
Chair	
Ability to Receive Care in Wheelchair	41.8%
Automatic Push Button	12.1%

Appendix A: SCI Dental Research

Q1

My name is Lindsey Schuler, and I am a senior Health Sciences major conducting research for my honors thesis. The purpose of this study is to identify perceived discrimination in dental offices and how that affects oral health for spinal cord injury patients. In order to qualify you must have sustained a spinal cord injury, be 18+ years of age, live in the United States, and have seen a dental professional since your spinal cord injury. Your participation will involve completing an online survey based on your dental experiences since the onset of your injury. The survey includes demographic questions, as well as questions specifically about your dental interactions and accessibility. Survey completion is approximately 5 minutes. Your participation in this research is completely voluntary, and you are free to withdraw your consent to participate at any time. All responses will be kept confidential. There are no foreseeable risks from participating in this study, but has the potential to help create systemic changes in dental education. If you have any questions about the research, please contact me (lbschule@butler.edu) or my thesis advisor, Amy Peak (apeak@butler.edu).

By selecting "I agree," you are consenting that you understand and agree to the terms described above.

- \circ I agree (1)
- \circ I disagree (2)

Skip To: End of Survey If My name is Lindsey Schuler, and I am a senior Health Sciences major conducting research for my ho... != I agree

Q2 I personally have sustained a spinal cord injury (SCI)

- \circ Yes (1)
- No (2)

Skip To: End of Survey If I personally have sustained a spinal cord injury (SCI) != Yes

Q3 I am 18+ years of age

- \circ Yes (1)
- No (2)

Skip To: End of Survey If I am 18+ years of age != Yes

Q4 I currently live in the United States

- \circ Yes (1)
- No (2)

Skip To: End of Survey If I currently live in the United States != Yes

Q5 I have been to the dentist since the onset of my SCI

- \circ Yes (1)
- No (2)

Skip To: Q7 If I have been to the dentist since the onset of my SCI = Yes

Q6 Why have you not been to the dentist since your injury? (Check all that apply)

- \circ It has been less than 6 months (1)
- Accessibility limition (2)
- Medical complications (3)
- \circ Dental fear (4)
- Recent onset of SCI (5)
- Other (6)

Skip To: End of Survey If Condition: Why have you not been to th... Is Greater Than or Equal to 1. Skip To: End of Survey.

Q7 Age

- o¹⁸⁻²⁹ (1)
- o 30-39 (2)
- o 40-49 (3)
- o 50-59 (4)
- o 60-64 (5)
- o 65+ (6)

Q8 Gender

- Male (1)
- \circ Female (2)
- \circ Other (3)

Q9 Race

- \circ White (1)
- Black or African American (2)
- American Indian or Alaska Native (3)
- o Asian (4)
- Native Hawaiian or Pacific Islander (5)
- \circ Other (6)

Q10 Education

- \circ Less than high school degree (1)
- \circ High school degree or equivalent (2)
- Some college but no degree (3)
- Associates degree (4)
- Bachelor's degree (5)
- \circ Graduate degree (6)
- \circ Prefer not to answer (7)

Q11 Degree of Injury

- Tetraplegia Complete (1)
- Tetraplegia Incomplete (2)
- Paraplegia Complete (3)
- Paraplegia Incomplete (4)

Q12 Level of SCI

- \circ Cervical (C1-C8) (1)
- \circ Thoracic (T1-T12) (2)
- \circ Lumbar (L1-L5) (3)
- \circ Sacral (S1-S5) (4)

Q13 Time Since SCI

- \circ Less than 1 year (1)
- 1-3 Years (2)
- Longer than 3 years (3)

Q14 Current Mobility Status Indoors (Check all that apply)

- Electric wheelchair/ scooter (1)
- Manual wheelchair (2)
- o Non-wheelchair assistive device (Walker, Crutches, Cane, AFO, etc.) (3)
- \circ Hybrid of wheelchair and assistive devices (4)
- Independent/ do not use a wheelchair (5)
- Other (6)_____

Q15 Do you have dental insurance?

- Yes (1)
- No (2)

Q16 How do you maintain your oral health (i.e brush and floss your teeth)?

- o Independently (1)
- Independently with assistive devices (2)
- With the help of a caregiver (3)
- Other (4)_____

Q17 How often do you brush your teeth?

- \circ Less than twice a day (1)
- At least twice a day (2)

Q19 How long has it been since you have last seen the dentist for any reason?

- \circ Less than 6 months (1)
- \circ 6 months to a year (2)
- o 1-2 years (3)
- More than 2 years (4)

Q20 How would you rate your oral health?

- \circ 5- Very Good (1)
- 4- Good (2)
- 3- Fair (3)
- 2- Poor (4)
- \circ 1- Very Poor (5)

Q21 Are any of the following barriers preventing you from receiving dental care? (Check all that apply)

- \circ Cost (1)
- Dental Fear (2)
- \circ Transportation (3)
- Waiting room inaccessibility (4)
- Exam room inaccessibility (5)
- Transferring into dental chair (6)
- \circ Other (please explain) (7)

	1- Never (1)	2- Rarely (2)	3- Sometimes (3)	4- Most of the time (4)	5- Always (5)
I feel my dentist works to accommodate my needs (1)	0	0	0	0	0
I feel my dentist is confident in handling my wheelchair (2)	O	0	O	O	0
I feel my dentist knows how my medications interact with my oral health (3)	0	0	Ο	0	o
I feel my dentist is aware of complications unique to SCI patients (i.e. autonomic dysreflexia and spasticity) (4)	O	Ο	Ο	O	ο

Q22 How do you perceive your dentist's understanding of your unique needs?

	1- Never (1)	2- Rarely (2)	3- Sometimes (3)	4- Most of the time (4)	5- Always (5)
Treat you with less courtesy (1)	0	0	0	0	0
Treat you with less respect (2)	0	0	0	0	0
Act as if they think you are not as smart (3)	0	0	0	0	0
Did not spend adequate time treating you (4)	0	0	0	Ο	Ο
Act as if they are better than you (5)	0	0	0	o	0
Dismiss your emotions (6)	0	0	0	0	0
Are afraid of you or your SCI (7)	0	0	0	0	0

Q23 Compared to before your injury, how often do you feel your dental professionals_____

	1- Never (1)	2- Rarely (2)	3- Sometimes (3)	4- Most of the time (4)	5- Always (5)
I feel my dentist treats me differently. (1)	0	0	0	0	0
I feel my dentist encourages me (2)	o	0	0	0	0
I feel my dentist pities me (3)	0	0	0	0	0
I feel like my dentist does not believe I am self sufficient (4)	0	0	0	0	0
I feel like an inconvenience to my dentist (5)	0	0	0	0	0
I feel my dentist is invested in my holistic care (6)	0	0	0	0	0

Q24 Since my spinal cord injury

	Yes (1)	No (2)	N/A (3)
Is there a ramp or even level entry into dental office? (1)	0	0	0
Is there an automatic push button to open doors? (2)	0	0	Ο
Is the receptionist window at an appropriate height for a wheelchair? (3)	0	0	Ο
Is there adequate space in the waiting room for a wheelchair? (4)	0	0	0
Are doorways wide enough to accommodate a wheelchair? (5)	0	0	0
Is there adequate space to safely transfer from a wheelchair to the dental chair? (6)	0	0	Ο
Does the dental chair raise and lower to assist in transferring? (7)	0	0	0
Is there adequate space to receive dental care while staying in a wheelchair? (8)	0	0	0

Q25 Addressing accessibility of your dental office

Q26 How would you rate the overall quality of care received from your dentist?

- \circ 5- Very Good (1)
- 4- Good (2)
- 3- Fair (3)
- 2- Poor (4)
- \circ 1- Very Poor (5)

Q27 (Optional) What is one thing you wish your dental profession knew about your health since your SCI?

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