

ORIGINAL ARTICLE

Health Care Utilization and Barriers Experienced by Individuals With Spinal Cord Injury



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Abstract

Objectives: To identify from whom individuals with spinal cord injury (SCI) seek health care, the percentage who receive preventative care screenings, and the frequency and types of barriers they encounter when accessing primary and specialty care services; and to examine how sociodemographic factors affect access to care and receipt of preventative screenings.

Design: Cross-sectional, observational study using an Internet-based survey.

Setting: Internet based.

Participants: Adults (N=108) with SCI who use a wheelchair as their primary means of mobility in the community.

Interventions: Not applicable.

Main Outcome Measures: Health care utilization during the past year, barriers encountered when accessing health care facilities, and receipt of routine care and preventative screenings.

Results: All but 1 participant had visited a primary care provider within the past 12 months, and 85% had had ≥ 1 visit to specialty care providers. Accessibility barriers were encountered during both primary care (91.1%) and specialty care (80.2%) visits; most barriers were clustered in the examination room. The most prevalent barriers were inaccessible examination tables (primary care=76.9%; specialty care=51.4%) and lack of transfer aids (primary care=69.4%; specialty care=60.8%). Most participants had not been weighed during their visit (89%) and had remained seated in their wheelchair during their examinations (85.2%). Over one third of individuals aged ≥ 50 years had not received a screening colonoscopy, 60% of women aged ≥ 50 years had not had a mammogram within the past year, 39.58% of women had not received a Papanicolaou smear within the previous 3 years, and only 45.37% of respondents had ever received bone density testing.

Conclusions: Individuals with SCI face remediable obstacles to care and receive fewer preventative care screenings than their nondisabled counterparts. We recommend that clinics conduct Americans with Disabilities Act self-assessments, ensure that their clinical staff are properly trained in assisting individuals with mobility disabilities, and take a proactive approach in discussing preventative care screenings with their patients who have SCI.

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A number of previous studies describe the struggles people with disabilities face when attempting to engage knowledgeable physicians,¹ locate physically accessible medical offices,²⁻⁵ and fully

participate in disease prevention efforts.^{6,7} However, disability is a broad term with >47 definitions across federally funded programs⁸ and often includes conditions as dissimilar as psychiatric disease and knee osteoarthritis. Therefore, findings from these studies are often nonspecific and not applicable to certain patient populations.

Few studies have specifically addressed the challenges people with spinal cord injury (SCI) face when seeking health care. Donnelly et al⁹ reported that 27% of people with SCI could not

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use all the equipment in their family physicians' offices, Lavelle et al¹⁰ found a significant discrepancy in receipt of recommended cancer screenings between women with SCI and able-bodied veterans, and other studies have documented the paucity of primary care for individuals with SCI. In the Donnelly study, only 76% of respondents with SCI reported having a family physician, and others have found that between 60% and 96% of people with SCI consider a physiatrist to be their primary care physician (PCP),^{11,12} despite physiatrists' reluctance to fill that role.¹³

This cross-sectional observational study used an Internet-based survey to identify from whom individuals with SCI seek health care, the percentage who receive preventative care screenings, the frequency and type of physical barriers they encounter when accessing primary and specialty care services, and whether sociodemographic factors affect their access to and receipt of care. We conclude with recommendations for improving access to quality health care and future research.

Methods

The study was conducted in accordance with the University of Louisville Institutional Review Board (no. 13.0058). The self-selected study population was based on eligibility criteria limiting participation to individuals ≥ 18 years of age who reported using a wheelchair as their primary means of mobility outside the home. Included in the survey were questions asking respondents to identify the primary underlying diagnosis that resulted in use of a wheelchair. The results presented herein are for the subgroup of respondents who self-identified as having an SCI ≥ 1 year prior to participation in the survey.

Subject recruitment

Electronic brochures announcing the survey were distributed to several national disability groups and Americans with Disabilities Act (ADA) coordinators in all 50 states. Survey announcements directed potential respondents to a website listing inclusion criteria and a statement that participation was voluntary and anonymous. Although participants could ask a proxy to complete the survey on their behalf, access to the Internet was required. Subjects were not compensated for participating.

Survey development

Survey questions addressed health care utilization during the past year, demographic and socioeconomic data, difficulties encountered when accessing health care facilities, and participants' satisfaction with and thoroughness of care. The survey was pilot tested using a convenience sample of wheelchair users and reviewed by experts in the fields of health care delivery and accessibility for individuals with mobility impairments. The pilot survey was refined based on this feedback. The final survey is included in [appendix 1](#).

Participants were asked how many primary, specialty, and emergency care visits they had during the preceding year. Demographic and socioeconomic data included sex, age, marital status, years since and level of injury, type of wheelchair used,

living status, household income, education level, and primary health insurance. Information was gathered regarding the population of the participants' city or town of residence and the distance they traveled to their most frequently visited health care facility.

Questions on health care facility accessibility addressed requirements from the ADA Standards for Accessible Design¹⁴ and the ADA technical guideline, Access To Medical Care For Individuals With Mobility Disabilities.¹⁵ Participants were asked to select items from a multiple choice list identifying ways in which health facilities and/or office equipment were less than fully accessible to them. Response items were subcategorized to address barriers associated with facilities (3 items: accessible parking, wheelchair ramp, exterior door), clinic spaces (3 items: interior doorways, hallways, restroom), and examination rooms (4 items: space to accommodate wheelchair, accessible exam table, transfer aids, staff assistance). Participants could indicate additional barriers encountered under another accessibility issue response option, and if they indicated that they had been referred to a testing center or other outpatient facility, this series of questions was repeated to assess that space.

Questions addressing receipt of routine care and preventative screenings were based on established guidelines¹⁶⁻¹⁹ and best clinical practices for individuals with SCI. Age-specific queries addressed recommended guidelines for screening colonoscopy, Papanicolaou (Pap) smear, and mammography; all participants were asked if they had received a pneumococcal vaccine, bone density testing, and an annual influenza vaccine and dental care. Those who had received a primary care examination within the past year were asked whether or not an accessible weight scale had been available for use, whether or not they had remained in street clothing during their examination, and whether or not they had been examined while seated in their wheelchair. Finally, participants were asked how satisfied they were with their last primary care examination and how well they felt their PCP understood medical concerns specific to their disability.

Statistical analysis

Descriptive statistics were used to describe participant demographics and socioeconomic data, accessibility barriers, and the percentage of participants who received preventative care screenings. A chi-square test was used to investigate relationships between demographic and socioeconomic factors, number of primary care visits, receipt of preventative care screenings, and participant satisfaction variables. A Fisher exact test was used when < 5 observations were reported. Statistical analysis was conducted using SPSS version 21.^a

Results

Demographic and socioeconomic data

One hundred and eight wheelchair users with SCI participated in the survey. Most subjects were men (55.6% vs 44.4% women; average age, 48 \pm 14y) ([table 1](#)), and most (73.1%) lived with a spouse/partner or other family member.

A slight majority lived with paraplegia (52.8% vs 43.5% tetraplegia), more subjects reported having a complete than incomplete SCI (61.1% and 38%, respectively) (see [table 1](#)), and 86% reported having an SCI for ≥ 6 years, with a mean duration of 18 \pm 13 years.

List of abbreviations:

ADA	Americans with Disabilities Act
Pap	Papanicolaou
PCP	primary care physician
SCI	spinal cord injury

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