



Research Paper

Healthcare utilization and associated barriers experienced by wheelchair users: A pilot study



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ABSTRACT

Background: More than twenty-five years after passage of the ADA, little remains known about the experiences of wheelchair users when attempting to access health care and how accessibility may influence health care utilization.

Objective/Hypothesis: To describe health care utilization among wheelchair users and characterize barriers encountered when attempting to obtain access to health care.

Methods: An internet-based survey of wheelchair users was conducted. Measures included demographics, condition, socioeconomic status, health care utilization and receipt of preventive services within the past year, physical barriers encountered at outpatient facilities, and satisfaction with care.

Results: Four hundred thirty-two wheelchair users responded to the survey. Nearly all respondents (97.2%) had a primary care appointment within the past year and most reported 3–5 visits to both primary and specialty care providers. Most encountered physical barriers when accessing care (73.8% primary, 68.5% specialty). Participants received most preventive interventions at rates similar to national averages with the exception of Pap tests. Most participants remained clothed for their primary care evaluation (76.1%), and were examined seated in their wheelchair (69.7%). More than half of participants (54.1%) felt they received incomplete care, and 57% believed their physician had no more than a moderate understanding of their disability-specific medical concerns.

Conclusions: Wheelchair users face persistent barriers to care, may receive less than thorough physical evaluations, receive fewer screenings for cervical cancer, and largely believe they receive incomplete care.

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Despite passage of the Americans with Disabilities Act (ADA) over 25 years ago, evidence persists indicating individuals with disabilities are not afforded full and equal access to health care services and facilities.^{1–7} The ADA mandates the provision of accommodations to insure individuals with disabilities can access and receive care that is equal in quality to that provided by patients without disabilities.⁸ Accommodations may be architectural, equipment, or service-based to ensure patients receive equivalent care, such as a thorough physical exam, weight measurement and

preventive screenings (e.g. colonoscopy, pelvic exam and Pap smear, mammogram).

While several studies have examined the types of health care services individuals with disabilities obtain, none has specifically investigated utilization of, and access to care by individuals who use a wheelchair as their primary means of mobility. Approximately 3.3 million Americans, or 1.5% of this country's adult population, use wheelchairs or motorized scooters as their primary means of mobility.^{9,10} Medical conditions commonly leading to wheelchair use include arthritis, back or spine disorders, stroke, diabetes, and cardiovascular and pulmonary disease.¹¹ The majority of wheelchair users tend to be less affluent, less well educated, and more likely to rate their health as “fair” or “poor” than the general population.⁹ Eighty-five percent of wheelchair users consider themselves to have a disability,¹¹ yet despite their financial and

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medical vulnerabilities, little is known about their specific experiences when attempting to access health care.

When queried, health care providers indicate their facilities are accessible to people with disabilities, despite contrary evidence. Bachman et al. (2007) surveyed 265 Massachusetts outpatient primary and specialty care providers on attitudes and perceptions of being able to care for patients with disabilities. Sixty-six percent of providers reported no difficulty caring for patients with disabilities, even though 20% reported not having accessible restrooms and/or examination rooms, and 40–50% said they lacked staff capable of helping wheelchair users transfer from their wheelchair to an examination table, dress or undress, and use the restroom.¹² Graham and Mann (2008) surveyed 68 primary care practices in South Carolina and found that more than 50% did not have examination tables accessible to wheelchair users, and more than 90% did not have fully accessible restrooms.¹³

More recently, Frost et al. (2015) conducted site assessments and surveys among a convenience sample of primary and specialty care providers in Louisville, KY¹⁴. Site assessments revealed 83% did not have fully accessible restrooms, 64% did not have an accessible weight scale, and 80% of primary care and 63% of specialty care providers were not equipped with a height adjustable examination table. Although the ADA does not specifically address weight scales and adjustable height examination tables, both items are important for providing equivalent care. At the time of assessment, 70% of surveyed clinical managers reported wheelchair users were examined while remaining seated in their wheelchair. However, follow-up telephone validation revealed 87% of providers examined patients while seated in their wheelchair. These findings reinforce earlier studies and those of others evidencing misperceptions of accessibility among health care providers related to facility,^{4,15–17} clinic and equipment accommodations.^{4,15,17,18} Although these studies were limited to specific geographic regions, in aggregate, these findings paint a worrisome picture of health care accessibility.

Reports of challenges people with disabilities face when attempting to access medical facilities^{13–15,17,19,20} echo these findings. Among individuals with spinal cord injury (SCI), 27% of participants ($n = 63$) surveyed by Craig Hospital (Engelwood, CO) reported they were unable to use equipment in their primary care office. In a study conducted by Stillman et al. (2014), nearly 90% of participants with SCI ($n = 108$) in an internet survey reported encountering a physical barrier when seeking primary care, and all had physical examinations performed while fully clothed and sitting in their wheelchair.²¹ Veltman et al. (2001) reported that 38% of individuals with physical disabilities had difficulty accessing medical equipment.¹⁹

Inaccessible medical facilities and equipment force individuals with disabilities to accept less than thorough care. Studies have shown that individuals living with severe disability are less likely than those with less severe or no disability to receive an influenza vaccine²² or be screened for colorectal cancer^{7,22} or dyslipidemia.²³ Women with more severe disability are less likely to be screened for breast and cervical cancers.^{7,23,24} Facility, clinic and medical equipment barriers that prevent or delay patients from obtaining health care are widespread and can lead to deteriorating physical health and economic, social and psychological consequences.^{6,25}

The purpose of this pilot study was to describe health care utilization among the subset of individuals with mobility impairment who use a wheelchair as their primary means of mobility, and to characterize barriers these patients encounter when seeking primary and specialty care services and preventive care screenings. We also sought to identify participant health condition, demographics and socioeconomic factors associated with utilization, barriers to access and receipt of preventive care.

Materials and methods

This was a cross-sectional observational study employing an internet-based survey taken by adult wheelchair users.

Study population and subject recruitment

Participation in this study was limited to people 18 years of age or older who had access to the internet and who used a wheelchair as their primary means of mobility in the community for more than 1 year. Subject recruitment was conducted online. Electronic brochures announcing the survey were distributed to ADA coordinators and Centers for Independent Living in all 50 states, as well as to national disability organizations. Survey announcements directed potential respondents to a website listing inclusion criteria and a statement that participation was voluntary and anonymous. This study was conducted in accordance with the University of Louisville Institutional Review Board (#13.0058).

Survey

The survey and details regarding its development were previously published.²¹ The survey comprised 35 questions; time needed to complete the survey was between 10 and 15 min, and participants were not compensated for completing the survey. Questions addressed demographic and socioeconomic status, primary health condition requiring use of a wheelchair, primary means of mobility, health care utilization during the past year, difficulties encountered when accessing health care facilities and clinics, and receipt of routine care and preventive screenings.

Questions related to health care facility accessibility were focused on requirements from the ADA Standards for Accessible Design¹⁵ and the ADA technical guideline, *Access To Medical Care For Individuals With Mobility Disabilities*¹⁶ issued by the US Department of Justice (DOJ) and Department of Health and Human Services (DHHS). Questions were categorized to address barriers associated with facilities (accessible parking, wheelchair ramp, exterior door), clinic spaces (interior doorways, hallways, restrooms), and examination rooms (space to accommodate wheelchairs, accessible exam tables, transfer aids, staff assistance). Participants could indicate additional barriers they encountered using a free text comment box, and those referred to testing centers or other outpatient offices were asked to complete this same series of questions for those facilities.

Questions addressing receipt of routine care and preventive screenings were based on established guidelines^{27–31} and best clinical practices for wheelchair users. Age-specific queries addressed recommended guidelines for screening colonoscopy, Papanicolaou (Pap) smear, and mammography. Participants were also asked if they received an annual influenza vaccine and dental care. Those who had received a primary care examination within the past year were asked whether they were weighed using an accessible weight scale, whether they remained in street clothing during their examination, and whether they were examined while seated in their wheelchair. Finally, participants were asked how satisfied they were with their last primary care examination and how well their primary care physician understood medical concerns specific to their disability.

Statistical analysis

Descriptive statistics were used to describe participant demographic and socioeconomic status, and to characterize barriers to accessibility and the percentage of respondents who received preventive care interventions and screenings. A chi-square (X^2) test was used to investigate relationships between demographic and

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