



Original Article

Identification of targets for improving access to care in persons with long term physical disabilities



Jennifer L. Wong, PhD, Kevin N. Alschuler, PhD, Tracy M. Mroz, PhD, OTR/L, Kimberly P. Hreha, EdD, OTR/L, Ivan R. Molton, PhD*

University of Washington, Rehabilitation Medicine, United States

ARTICLE INFO

Article history:
Received 5 June 2018
Received in revised form
23 December 2018
Accepted 6 January 2019

Keywords:
Long-term physical disability
Health care
Access
Utilization
Barriers

ABSTRACT

Background: People with long-term physical disability (LTPD) continue to experience difficulties in accessing health care despite the focus of highlighting disparities in the last two decades.
Objectives: To describe health care utilization, accommodations and barriers experienced while accessing health care, and reasons why individuals delay or skip health care among people with LTPD.
Methods: The current study was a part of a larger longitudinal survey administered to individuals with physical disability associated with one of four long-term conditions (MS; SCI; PPS; MD). Measures included demographics, health care utilization, barriers to health care, and reasons for delaying or skipping medical care from the sixth wave of data from 2015 to 2016.
Results: Roughly 90% of all participants ($N = 1159$) saw at least one medical provider within 12 months. The most encountered barrier participants reported experiencing within that time was an office that did not have a safe transfer device to move them to an exam table (69%). Participants' physical function, quality of life, status of living with a spouse, diagnostic condition, and sex (male) were significantly associated with endorsing a barrier in accessing health care. The inability to afford out of pocket expenses was the highest reported reason for delaying health care.
Conclusions: People with LTPD access a variety of health care, including rehabilitation services, and continue to experience barriers when doing so. While understanding barriers individuals experience when accessing health care is important, it is equally important to document the type of care they delay or skip due to barriers.

© 2019 Elsevier Inc. All rights reserved.

There is continued interest in health care differences and disparities among individuals with a disability, leading to calls for investigations of key components of care.¹ Despite the identification of a number of health care disparities over the past two decades, people with disability continue to experience difficulties in accessing health care. One possible reason for the ongoing gap in addressing health care disparities may be the complex nature of health status and health care utilization.² Another plausible reason may be the interconnected relationship between health care utilization and barriers.³ While a national agenda was created and policies have been updated in an effort to close the quality gap for persons with disabilities, the continued gap suggests an updated

description of health care utilization, experienced barriers to health care, and reasons why individuals with LTPD delay or skip care seems warranted.

How individuals with disabilities utilize health care is not a novel exploration. Economic explorations have included estimates of state-level health care expenditures associated with noninstitutionalized adults with disabilities.⁴ Past literature has fallen within one of two story lines. In terms of utilization, some individuals with physical disabilities rely on certain types of health care and health support services (e.g., home health services) more regularly than those without disabilities. This increased utilization may reflect an effort to monitor their physical condition over time, address secondary conditions, and/or to prevent costly and debilitating medical complications.^{5,6} In contrast, people with disabilities are often less likely to engage in certain types of health care services in comparison to those without disabilities. This prior research has focused on disparities in preventative health care

* Corresponding author. University of Washington, Rehabilitation Medicine, 1959 NE Pacific St., Box 356490, Seattle, WA, 98195, United States.

E-mail addresses: jlwong2@uw.edu (J.L. Wong), imolton@uw.edu (I.R. Molton).

underutilization between people with and without disability.^{7–9} While preventative health care is an important place to identify inequity in utilization, accounting for ways people with LTPD use rehabilitation services (e.g., physical therapy; occupational therapy; speech therapy) to maintain or improve their health is vital to understanding utilization.

It is well established that individuals living with disability experience a disproportionate number of accessibility concerns.^{2,6,10,11} Health care facilities have been described as architecturally inaccessible or difficult to access because of the physical layout or location of the property.^{3,12} Lack of accessible examination tables or inaccessible weight scales have been repeatedly encountered by individuals with disabilities and identified as physical barriers related to lower quality of care.^{3,10} Beyond the physical health care environment, transportation has been recorded as a common barrier for those with a disability.¹⁰ There are also barriers rooted in emotion, perception, and stigma, such as individuals with disabilities describing feeling invisible by providers or incompetent.^{2,5,10} This growing body of research suggests that both the built environments and individuals' perceptions of barriers to health care should be considered together when exploring utilization. Further, individual characteristics should be explored to determine whether there are associations between physical and mental differences with reporting a barrier.

While individuals and built environment characteristics are vital to accessibility and subsequent utilization of health care services, systemic factors have also been explored. These have included assessments of public programs, health insurance, policy and legislation. Health expenditures associated with disabilities have been estimated at \$400 billion annually, with approximately 70% of the cost covered through public programs.¹² Although public programs are seen as a social "safety net," many individuals with disabilities continue to lack insurance coverage therefore experiencing financial barriers to accessing care.¹³ Regardless of health insurance status, working-age adults with a disability were roughly 2.5 times more likely to endorse delaying or forgoing medical care in the past year due to cost than those without a disability.¹⁴ Among working-age adults who were insured continuously for the last year, 15.5% of those with a disability reported delaying or forgoing medical care needs in contrast to 5.8% of those without a disability.¹⁴ While these findings give insight into systematic barriers to health care services, they are limited to those who have had continuous insurance coverage and are of working age.

People with conditions related to LTPD are living longer than ever before. This suggests that preemptive maintenance and monitoring of their condition may influence their health care utilization. It is also important to look at conditions within LTPD that represent unique symptom trajectory (e.g., multiple sclerosis, muscular dystrophy, post-polio syndrome, and spinal cord injury). Beyond screenings and basic preventative care, people with LTPD may require ongoing services including chronic care management for primary and secondary conditions and rehabilitation services to maximize functional outcomes. The purpose of the present study was to better understand the health care experiences across multiple services, types of barriers, conditions with varying trajectories, and discuss the related policy implications. In the achievement of this understanding, we aimed to describe: (1) individuals' health care utilization with specific interest to expand assessment of their utilization from screening and preventative services to include community-based rehabilitation; (2) accommodations and barriers individuals experience when accessing health care and explore characteristics associated with reporting a health care barrier; and (3) reasons individuals with disabilities may delay or skip medical care due to commonly reported barriers.

Methods

Participants

Participants ($N = 1159$) were enrolled in an ongoing U.S. longitudinal study examining secondary health conditions and aging in individuals with a condition related to physical disability (i.e., multiple sclerosis [MS], muscular dystrophy [MD], post-polio syndrome [PPS], or spinal cord injury [SCI]). Several other articles have been published using data from these surveys, although none using our study aims or hypotheses.^{41,42,43} For the purposes of this paper we will refer to this participant group as people with LTPD. The inclusion criteria for the larger ongoing study required participants to be at least 18 years of age; able to read and write in English; self-report one of four conditions listed previously; and give their consent for participation. Survey data for these participants have been collected at seven time points for the ongoing longitudinal study; the current analyses use data focused at only the sixth time point from 2015 to 2016 when adapted health care questions of interest were included in the questionnaire.

Procedures

All procedures were reviewed and approved by the Institutional Review Board at the University of Washington. We recruited participants using several strategies (e.g., disability specific registry newsletters). Eligible and interested participants were mailed surveys with a postage paid return envelope. Of those sent a survey, recruitment strategies included: 11% word of mouth; 21% ongoing study; 19% department participant pool; 28% web or print advertisement recruitments; 18% disability specific registries; 3% other source. To contact participants who did not return their surveys, reminder letters and phone calls were conducted. For the sixth wave of data used in the current study, 1573 surveys were mailed to potential participants, 26% were from the ongoing study and 35% from web or print advertisement recruitments. Of the total mailed surveys, 1457 were returned, 9 were excluded for either being returned too late or indicating a MS misdiagnosis and 107 surveys were never returned. Participants received a \$25 honorarium for each returned survey.

Measures

Demographics

The demographic information collected included self-reported birth date, sex, marital status, race/ethnicity, education level, disability condition, health insurance coverage, zip code, and income. Age was calculated from the participants' reported birth date and duration of condition was calculated from the reported year of diagnosis both with respect to the date of the participants' survey. Duration was recorded from the date of the participants' reported diagnosis (i.e., MS; MD; SCI); for those who reported PPS, duration was calculated from the date of their PPS diagnosis. Insurance was categorized as: (a) government assisted (e.g., Medicare); (b) private insurance (e.g., employer provided); and (c) uninsured. Residency (i.e., urban, rural, isolated rural) was determined based on the zip code of participants according to rural indicators from Centers for Medicare and Medicaid Services.¹⁵

Health care related measures

Health care utilization Health care utilization was collected using a developed item which asked participants whether they saw or talked with any of the 11 different providers listed (e.g., medical doctor that specializes in your condition, physical therapist, mental health professional) within the past 12 months. Participants were

asked to respond with either: (a) yes; (b) no; or (c) don't know to each of the 11 providers.

Health care accommodations and barriers. Participants were asked to indicate whether they encountered necessary accommodations related to their physical environment (e.g., a doctor's office that has an adjustable exam table) and social environment (e.g., a doctor's office with providers and staff who respect me and accept my decisions and preferences) when accessing health care within the last 12 months (see Table 2). Response options were: (a) I needed it and I couldn't get it; (b) I needed it and I got it; and (c) I did not need this accommodation. Those who indicated that they needed an accommodation and were unable to receive it were considered as experiencing a health care related barrier compared to their counterparts who did not experience a health care barrier.

Barriers to seeing rehabilitation specialists. Barriers to seeing rehabilitation specialists (i.e., physical therapist, speech therapist, and occupational therapists) were also assessed. Participants were

asked whether they needed and were unable to see these therapists due to three barriers: (1) health insurance would not cover it; (2) there were no therapists located near them; and (3) lack of accessible transportation to get them to and from their therapy appointments. Response options were: (a) yes; (b) no; and (c) don't know. Participants were able to indicate whether they did not need to see each rehabilitation specialist presented.

Delaying and skipping health care. To further explore participants' barriers in health care utilization, participants were asked if they delayed getting care due to five common reasons within the past 12 months. One such reason is described in this item, "I couldn't afford the out-of-pocket expenses." Response options were: (1) yes; (2) no; and (3) don't know. Lastly, participants were asked if there was a time that they needed five different medical services (e.g., "to see a health care specialist") but didn't receive them due to cost. Response options were: (1) yes; (2) no; and (3) don't know.

Table 1
Characteristics of respondents.

| Variable | Total (1,159) | MD (170) | MS (313) | PPS (384) | SCI (229) |
|---|---------------|-----------------|-----------------|----------------|-----------------|
| Age [65.10/65.56 ^b (10.79)] | 1080 | [59.92 (10.17)] | [63.56 (8.82)] | [72.57 (7.71)] | [58.58 (10.55)] |
| Duration of Disability [25.34 (9.88)] | 1056 | [28.08 (10.29)] | [25.58 (8.34)] | [21.36 (8.96)] | [29.41 (10.55)] |
| Sex | 1157 | — | — | — | — |
| Women | 765 | 111 | 258 | 276 | 147 |
| Men | 392 | 59 | 55 | 108 | 82 |
| Education level | 1079 | — | — | — | — |
| Less than HS/HS Graduate/Technical School | 216 | 47 | 57 | 59 | 58 |
| Some College | 263 | 35 | 81 | 73 | 52 |
| College Graduate | 309 | 45 | 97 | 107 | 63 |
| Professional/Graduate School | 318 | 43 | 77 | 145 | 56 |
| Ethnicity/Race ^a | — | — | — | — | — |
| White (non-Hispanic/Chicano) | 1087 | 164 | 292 | 352 | 199 |
| African American | 39 | 1 | 12 | 5 | 15 |
| Asian | 10 | 1 | 0 | 3 | 2 |
| Hispanic/Chicano | 20 | 2 | 2 | 8 | 4 |
| Native American/American Indian/Alaska Native | 24 | 1 | 5 | 8 | 7 |
| Another race not listed | 13 | 1 | 2 | 7 | 2 |
| Annual household income [\$69,553.78/\$50,000 ^b (\$92,314.96)] | 899 | — | — | — | — |
| < \$25,000 | 228 | 28 | 59 | 82 | 63 |
| > \$25,000–55,000 | 256 | 37 | 74 | 93 | 55 |
| > \$55,000–85,000 | 192 | 27 | 53 | 80 | 36 |
| > \$86,000 | 222 | 41 | 67 | 71 | 46 |
| Marital Status | 1156 | — | — | — | — |
| Married | 652 | 116 | 191 | 212 | 106 |
| Divorced/separated | 220 | 24 | 70 | 58 | 61 |
| Living with a significant other | 45 | 8 | 10 | 13 | 11 |
| Never married | 122 | 15 | 17 | 32 | 43 |
| Widowed | 117 | 7 | 25 | 68 | 8 |
| Insurance type | 932 | — | — | — | — |
| Government ^c | 679 | 81 | 187 | 297 | 124 |
| Private | 245 | 67 | 86 | 46 | 49 |
| Uninsured | 8 | 1 | 0 | 2 | 5 |
| Residence type | 1159 | — | — | — | — |
| Urban | 930 | 134 | 266 | 309 | 169 |
| Rural | 160 | 29 | 28 | 55 | 42 |
| Isolated Rural | 69 | 7 | 19 | 20 | 18 |
| Health | — | — | — | — | — |
| Physical Function [35.12 (9.86)] | 1076 | [33.44 (9.94)] | [39.14 (10.92)] | [34.91 (7.08)] | [31.44 (10.34)] |
| Quality of Life [52.46 (8.73)] | 1073 | [51.01 (8.61)] | [52.81 (9.09)] | [53.29 (7.97)] | [51.57 (9.35)] |
| Anxiety [50.79 (8.86)] | 1077 | [51.63 (8.75)] | [50.14 (9.24)] | [51.31 (8.58)] | [50.35 (8.96)] |
| Depression [51.47 (9.16)] | 1079 | [52.97 (9.37)] | [50.89 (9.25)] | [51.20 (8.64)] | [51.84 (9.74)] |

Note. N = 1159; [Mean (Standard Deviation)].

^a Participants were able to check all that applied; 26 participants indicated they were more than one race/ethnicity listed.

^b Median.

^c Government included: Medicare; Medicaid; State Subsidized Insurance (e.g., Washington Apple); Indian Health Insurance Coverage; and Tri-Care, CHAMPUS, CHAPUS-CA, or any other military health care plan.

Table 2

The percentages of individuals who needed a health care related accommodation.

| Accommodation | N | | |
|---|------------------------|--------------------------|--------------------------------|
| | Needed it ^b | Received it ^c | Didn't Receive it ^d |
| A doctor's office that has a safe transfer device to move me to the exam table ^a | 266 | 82 (31%) | 184 (69%) |
| A doctor's office that is capable of weighing me in my own wheelchair ^a | 295 | 98 (33%) | 197 (67%) |
| A doctor's office that has an adjustable exam table ^a | 462 | 261 (56%) | 201 (44%) |
| A doctor's office with providers and staff who respect me and accept my decisions and preferences | 837 | 679 (81%) | 158 (19%) |
| A doctor's office with adequate disability parking | 887 | 739 (83%) | 148 (17%) |
| Accessible transportation to get me to and from my doctor's appointments ^a | 472 | 412 (87%) | 60 (13%) |
| A doctor's office with providers and staff who are knowledgeable about my condition | 878 | 806 (92%) | 72 (8%) |
| A doctor's office with providers and staff who respect me and accept my decisions and preferences | 970 | 899 (93%) | 71 (7%) |
| A doctor's office with an accessible entrance ^a | 851 | 793 (93%) | 58 (7%) |
| A doctor's office with a restroom that is accessible to me ^a | 666 | 621 (93%) | 45 (7%) |
| A doctor's office with providers and staff who helped me get around the office | 533 | 500 (94%) | 33 (6%) |

Notes.

^a Accommodations that are required by the ADA via the 2010 ADA Standards for Accessible Design³¹ and the ADA Access to Medical Care for Individuals with Mobility Disabilities³³.

^b "Needed it" is the total count of individuals who indicated they needed a health care related accommodation.

^c "Received it" includes individuals who indicated they needed the health care accommodation and received the accommodation.

^d "Didn't receive it" includes individuals who indicated they needed the health care accommodation and did not receive it.

Measures of health

Physical functioning and general health. Disability severity was measured using adapted items from the Patient-Reported Outcomes Measurement Information System (PROMIS) Physical Functioning subscale.¹⁶ This subscale measures individuals' ability to perform physical functioning of activities of daily living. Items were adapted to create a mixed mobility aid user short form measure which asked participants to rate how well they are able to complete physical tasks. An example item is, "Are you able to wash and dry your body?" Participants responded to eight to 12 items depending on their mobility using a five-point Likert-type scale from (1) unable to do to (5) without any difficulty. For each participant, a total score was created by summing each response and then converting each raw score to a t-score. Lower scores indicated lower physical functioning. The PROMIS Physical Functioning subscale has been demonstrated as a valid and reliable among individuals with a variety of chronic health conditions.¹⁷

To evaluate participants' general health, a singular item from the 36-item bank from the Medical Outcomes Study¹⁸ was used. Specifically, the item asked participants to evaluate their health by completing this sentence, "In general, would you say your quality of life is ..." using a five-point response scale ranging from (1) poor to (5) excellent. This item has been found to be both valid and reliable in measuring the general health of individuals.¹⁹ Despite people with physical disabilities reporting higher rates of secondary conditions and mobility limitations compared to those without physical disabilities^{20,21}; previous studies have also found that those with physical disabilities report good general health (e.g., adults with Cerebral Palsy²²).

Quality of life. The Older People's Quality of Life Questionnaire – Brief has been found to be a highly reliable and valid, short measure of quality of life in older age.²³ This questionnaire asked participants their level of agreement with 13 statements such as, "My family, friends, or neighbors would help me if needed." Higher scores indicated a higher quality of life. One of the items was adapted for readability for U.S. residents.

Mental health: depression and anxiety. The PROMIS depression profile was used to determine individuals' depression within the last seven days.¹⁶ Respondents were presented with six items including, "In the past seven days I felt hopeless ..." and responded to items on a five point Likert-type scale. The response options ranged from (1) never to (5) always. For each participant, a total score was created by summing each response and then converting each raw score to a t-score. Higher t-scores indicated increased

depressive thoughts. Similarly, the PROMIS anxiety profile was also administered to measure participants' anxiety within the last seven days. Four items were presented such as, "In the past seven days my worries overwhelmed me ..." and used the same five-point Likert-type response scale from (1) never to (5) always. A total score was created for each participant by summing each response and then converting each raw score to a t-score. Higher scores indicated more reported anxious symptoms.

Data handling and analytics

All participants who consented and met the inclusion criteria for the current study were included in the following analyses, regardless of their level of survey participation. To ensure accuracy in survey responses, a double-coded entry process was used. Descriptive statistics were used to describe participant demographic characteristics, socioeconomic status, medical providers seen or spoken with, and reasons for delaying or skipping health care. Health care utilization, accommodations needed, barriers to seeing a rehabilitation specialist, reasons for delaying medical care, and the proportion of participants skipping medical care due to cost over the past 12 months were calculated as means, standard deviations, and rank orders. To determine the effects of participants' demographic characteristics, physical health, and mental health on whether they reported experiencing at least one health care barrier multiple logistic regression was conducted. All statistical analyses were conducted using Stata version 15.

Results

Participant demographics

Participants ($N = 1159$) were included in the current analytic sample if they reported a condition of MS, MD, SCI for at least 15 years or reported PPS. Collectively, participants were between the ages of 29.37 and 100.17, predominately female (66.13%), Caucasian (91.59%), and college educated (57.91%). See Table 1 for a breakdown of participants' demographic information.

Health care utilization within the last 12 months

On average, participants reported seeing or speaking to 2.82 ($SD = 1.85$) different medical providers over the past 12 months. Roughly 10% of participants indicated not visiting with nor talking

to any providers within the last 12 months; 16.45% reported visiting or speaking with one provider; 19.14% reported two; 20.35% reported three; 15.80% reported four; 7.81% reported visiting or talking to five or more different providers. Participants most commonly indicated that they had interactions with a general doctor, a medical doctor who specializes in their condition, and neurologists while infrequently indicating neuropsychologists, speech therapists, and respiratory therapists.

Health care access within the last 12 months

Three-hundred and seventy-one (32%) participants endorsed that they needed at least one health care accommodation and did not receive it ($M = 0.92$, $SD = 1.70$). The most endorsed accommodations that participants needed and did not receive were: (1) a doctor's office that had a safe transfer device to move them to the exam table (69%); (2) a doctor's office that was capable of weighing the participants in their wheelchair (67%); and (3) a doctor's office without an adjustable exam table (44%; see Table 2). In contrast, participants indicated a number of accommodations were needed and received, including being treated with respect by their providers and office staff, having their decisions and preferences accepted, being viewed by their physician as more than their condition, and encountering an accessible entrance at their provider's office.

Results of a multiple logistic regression examining characteristics associated with reporting a health care barrier are presented in Table 3. Results indicated females were more likely to report experiencing a barrier in comparison to men. Those living with their significant other were 67.52% less likely to report experiencing a barrier than those living alone. Likewise, participants who reported higher physical function and quality of life scores were less

likely to report experiencing a barrier. Lastly, participants' condition was significantly associated with experiencing a health care related barrier; compared to people with MD, people with SCI were 89.72% more likely to report experiencing a health care related barrier.

Barriers to seeing a rehabilitation specialist

Five hundred and eighty-eight (48.14%) participants reported visiting at least one rehabilitation specialist. Across all three rehabilitation specialists, 45.86% of barriers reported were due to health insurance; 27.82% were categorized due to no therapist near them; and the last 26.32% were because the participant lacked accessible transportation. Responses are described in Fig. 1.

Reasons for delaying medical care

While the majority of participants did not report delaying care, 220 (18.98%) participants reported delaying care due to one or more of the five listed reasons (see Fig. 2). The inability to afford the out-of-pocket expenses was the highest reported reason for delaying care, while not having health insurance coverage was the least reported reason.

Skipping medical care due to cost

Two-hundred and thirty-two (20.02%) participants reported skipping one of five types of medical care and/or equipment due to cost (see Fig. 3). Participants indicated they skipped purchasing assistive device equipment, follow-up health care, and seeing a health care specialist most often due to cost.

Table 3
Regression coefficients predicting whether a participant experienced a health care barrier.

| | OR | p | 95% CI |
|--|-------|------|-------------|
| Age | .99 | .117 | .97–1.00 |
| Male | .44 | .000 | .30–.63 |
| Cohabiting ^a | .70 | .031 | .51–.97 |
| Education | – | – | – |
| Less than HS/HS Graduate/Technical School (ref.) | – | .473 | – |
| Some College | 1.06 | – | –.65–1.72 |
| College Graduate | .93 | – | .59–1.48 |
| Professional/Graduate School | 1.27 | – | .81–2.01 |
| White ^b | .84 | .613 | .423–1.65 |
| Diagnosis | – | – | – |
| – MD (ref.) | – | .016 | – |
| – MS | 1.01 | – | .60–1.70 |
| – PPS | 1.67 | – | .99–2.82 |
| – SCI | 1.91 | – | 1.11–3.28 |
| Resident Type | – | – | – |
| – Urban (ref.) | – | .297 | – |
| – Rural | .77 | – | .48–1.22 |
| – Isolated Rural | .64 | – | .31–1.32 |
| Global Health | 1.17 | .192 | .92–1.49 |
| Insurance Type | – | – | – |
| – Government (ref.) | – | .531 | – |
| – Private | 2.44 | – | .40–14.73 |
| – Uninsured | 2.66 | – | .45–15.84 |
| Physical Function | .92 | .000 | .90–.94 |
| Quality of Life | .96 | .002 | .93–.98 |
| Anxiety | 1.00 | .844 | .98–1.03 |
| Depression | 1.02 | .198 | .99–1.05 |
| Constant | 28.28 | .038 | 1.20–665.99 |

Note. Observations $N = 913$.

^a Cohabiting = those who indicated they were married or living with a significant other compared to all others.

^b White = White compared to those who did not identify as White.

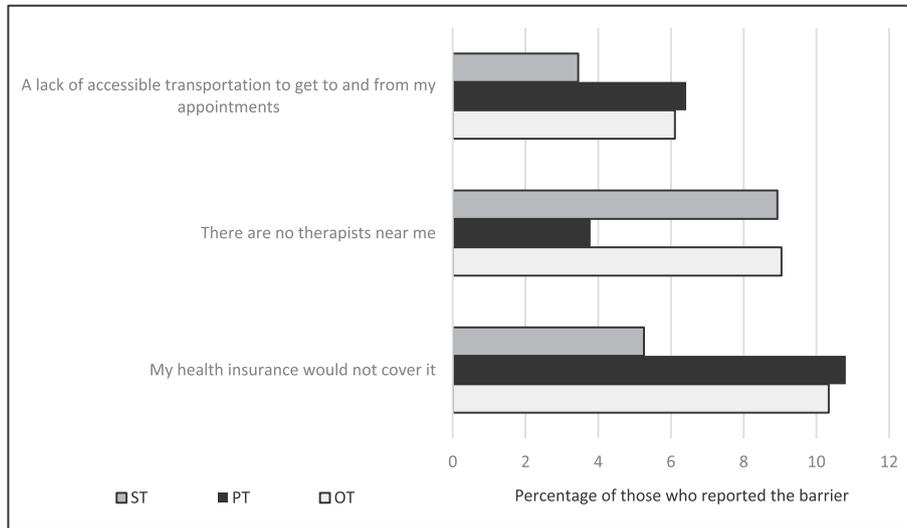


Fig. 1. The percentage of individuals who indicated the following barriers to seeing rehabilitation specialists.

Discussion

This study aimed to fill gaps in the literature regarding health care utilization and perceived barriers in health care specifically among people with LTPD. Novel findings from the current study are: (1) nearly 75% of all participants reported visiting or talking to one or more types of medical providers within a 12 month period; (2) lower physical functioning, lower quality of life, living alone, and being female were significant associated with report of experiencing a health care related barrier; (3) nearly half of the barriers associated with seeing a rehabilitation specialist reported were due to health insurance; (4) the inability to afford out of pocket expenses was the most endorsed reason for delaying medical care across participants; and (5) participants reported skipping purchasing assistive device equipment more often than other medical expenditures. Overall, our findings are consistent with prior research with other populations regarding experiencing ongoing unmet health care needs,^{24,25} forgoing physician visits due to cost,^{14,26} insurance concerns,^{13,27–29} and physical barriers.^{3,10,12,30} An important contrast to past research that highlighted emotion, perception or stigma related barriers,^{2,5,10} is our finding that individuals felt treated with respect by providers and office staff. These results suggest a multifactorial solution is needed when addressing how to minimize barriers to health care and

highlighting improvement in care.

As a first step to exploring barriers and skipped or delayed care of individuals aging with a LTPD, we provided an updated description of health care utilization beyond preventative care. Medical doctors who specialize in the participant’s condition and neurologists were the top providers that participants reported seeing or speaking with during the 12 month period, while rehabilitation providers (e.g., speech, respiratory therapists) were among the ones least frequented. While unable to distinguish whether rehabilitation services were not needed or skipped due to cost, these findings seem to align with previous research and suggest some participants may be prioritizing providers and thus forgoing care.^{14,26}

The physical environment in which individuals receive their health care also matters. The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities including the requirement that health care providers grant full and equal access to their services and facilities (i.e., Title II and Title III³¹; standards for accessible design^{32,33}). However, our participants indicated three physical office features as the top endorsed barriers, a finding consistent with past findings.³⁴ Previous research has found an inverse relationship between practice administrators’ knowledge of the ADA and the number of barriers reported in clinics.³⁵ While a less encouraging body of research found health

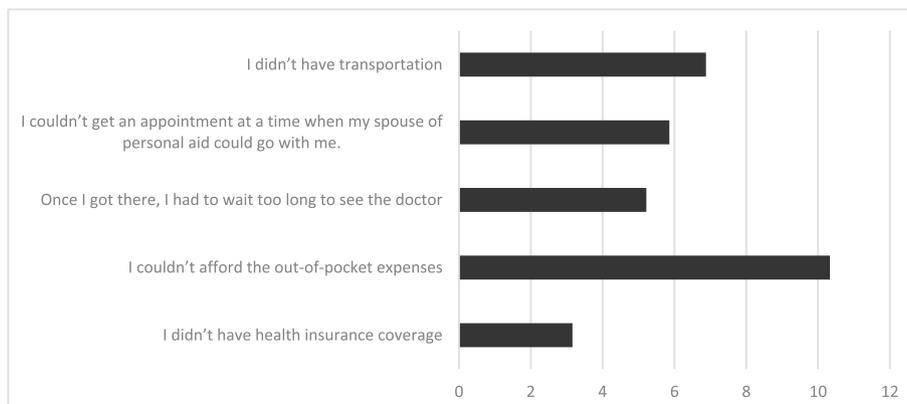


Fig. 2. The percentage of individuals who indicated the following reasons for why they delayed medical care.

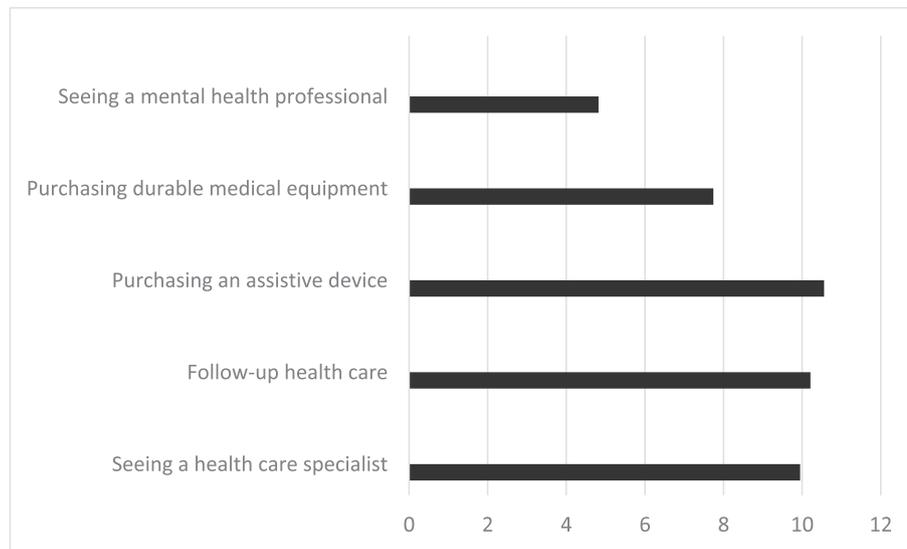


Fig. 3. The percentage of individuals who skipped these activities or equipment due to cost.

care providers describe their facilities are accessible to people with disabilities despite contrary survey findings of environmental inaccessibility.³⁶ Moreover, prior assessments of health care sites demonstrate poor ADA compliance.³⁴ Our findings agree with the lack of ADA compliance in some facilities. The social environment should also be considered when assessing barriers to care. Policy and services aimed toward social support (e.g., Medicare Case Management) may serve as a substitution for cohabitation. The increase of health care accessibility for those aging with a disability ultimately increases access for a variety of patients including the general aging population.

The current study found that individuals with LTPD reported the inability to afford out-of-pocket expenses as the most endorsed reason for delaying care. This finding is similar to past investigations that found that younger adults with a disability were more likely to endorse delaying seeking medical care due to cost than those without a disability regardless of health insurance enrollment.¹⁴ Similarly, prior research found the median estimated prevalence of an unmet health care need because of cost over the prior 12 months among a community sample of adults was 15.3%.³⁷ Additionally, participants in the current study reported skipping purchasing an assistive device as the most endorsed reason for forgoing care. Health care policy is constantly evolving. For example, financial barriers to accessing rehabilitation services for Medicare beneficiaries have been reduced somewhat due to recent legislation eliminating annual caps on outpatient rehabilitation services³⁸ and the *Jimmo v. Sebelius* settlement agreement³⁹ which clarifies skilled nursing and rehabilitation services to maintain, prevent, or slow decline of function are covered services; however, even though these changes help ensure Medicare coverage for long-term outpatient rehabilitation services, cost-sharing for visits may still hinder access to these services for individuals. In addition, understanding what health care needs individuals with disabilities prioritize over others (e.g., medication over assistive devices, primary care visits over rehabilitation) and the consequences of delayed and foregone care would further contribute to development of programming and policy to maximize individual outcomes while minimizing societal costs. Ultimately, medical care and medical equipment is especially vital for maintaining health in individuals with disabilities and health policy should consider ways that these individuals are compromising their health and wellbeing due to inability to afford recommended treatment.

Study limitations

This study has several limitations that should be considered when interpreting these results. First, our study sample was primarily older, non-Hispanic white, women, and college educated. While these characteristics might be representative of the population of those living with a long-term physical disability of these four conditions,^{42,44} we recognize our results may not generalize to other populations. This limitation may also serve as a source of strength given the research questions. These demographic characteristics suggest that this sample is in many ways privileged and still report experiencing barriers and delaying and/or forgoing health care. Second, the limited diversity in our sample should be considered when examining the results of our regression analysis. Another limitation was the use of a mail survey for data collection, which may have limited those who continued to participate in the larger longitudinal study. This may have introduced additional selection bias in the current study (e.g., individuals who had more health care needs and were unable to participate in the survey due to a hospitalization or sickness). Fourth, many of the primary measures are the first of their kind and may have limited validity and reliability. The research group created these measures similar to those in the National Health Interview Survey⁴⁰ that aims to track health status and health care access. Validation of these measures will support the use of these measures in future longitudinal research. Lastly, government assisted health insurance varies in coverage parameters and therefore was unable to be assessed here due to our sample size; future research should include an examination of beneficiaries' experiences by insurance type.

Conclusions

More than twenty-five years after the passage of the ADA, people with disabilities continue to experience health care utilization barriers. While previous research has examined disparities in access to care, difference of care, and barriers to care, inequity is still widely prevalent in people with disabilities. Our research aimed to contribute to this growing literature by describing the types of providers individuals with LTPD visit or talk with, health care barriers they encounter, and care they delay or skip due to barriers. The findings from the current study suggest many

implications for health care policy for adults with LTPD. While identifying ways that screening and preventative services can be more equitable across status of ability is a social justice concern, it is also important to identify ways to diminish barriers related to rehabilitation and maintenance. Safe and appropriate access to health care would significantly decrease the number of barriers reported by this population. Further, timely access to health care services and durable medical equipment may have serious impact on the health status and maintenance of individuals with LTPD. For 28 years the ADA has called for equitable treatment of people with disabilities, future health policy and standards of care should aim to decrease the many health care related barriers that people with disability far too often encounter.

Conflicts of interest

No commercial party having a direct financial interest in the results of the research supporting this article has of will confer a benefit on the authors or on any organization with which the authors are associated.

Disclosures

The contents of this paper were developed under a grant from National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90RT5023-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this paper do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

Prior Presentation

Preliminary results were presented at the National Association of Rehabilitation Research and Training Centers' annual meeting in Arlington, VA.

References

- Turk MA, McDermott S. How to address continued health care differences and disparities among people with disability. *Disability and Health Journal*. 2017;10(2):163–164.
- Stillman MD, Bertocci G, Smalley C, Williams S, Frost KL. Healthcare utilization and associated barriers experienced by wheelchair users: a pilot study. *Disability and health journal*. 2017;10(4):502–508.
- Prevention CfDca. *Environmental Barriers to Health Care Among Persons with Disabilities—Los Angeles County, California, 2002–2003*. *MMWR Morbidity and Mortality Weekly Report*. vol. 55. 2006:1300 (48).
- Anderson WL, Armour BS, Finkelstein EA, Wiener JM. Estimates of state-level health-care expenditures associated with disability. *Publ Health Rep*. 2010;125(1):44–51.
- Neri MT, Kroll T. Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disabil Rehabil*. 2003;25(2):85–96.
- Kroll T, Jones GC, Kehn M, Neri MT. Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: a qualitative inquiry. *Health Soc Care Community*. 2006;14(4):284–293.
- Armour BS, Swanson M, Waldman HB, Perlman SP. A profile of state-level differences in the oral health of people with and without disabilities, in the US, in 2004. *Publ Health Rep*. 2008;123(1):67–75.
- Iezzoni LI, McCarthy EP, Davis RB, Siebens H. Mobility impairments and use of screening and preventive services. *Am J Public Health*. 2000;90(6):955.
- Smith DL. Disparities in health care access for women with disabilities in the United States from the 2006 National Health Interview Survey. *Disability and Health Journal*. 2008;1(2):79–88.
- de Vries McClintock HF, Barg FK, Katz SP, et al. Health care experiences and perceptions among people with and without disabilities. *Disability and health journal*. 2016;9(1):74–82.
- Glennie RA, Batke J, Fallah N, et al. Rural and urban living in persons with spinal cord injury and comparing environmental barriers, their health, and quality-of-life outcomes. *J Neurotrauma*. 2017;34(20):2877–2882.
- Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health*. 2015;105(S2):S198–S206.
- Iezzoni LI, Frakt AB, Pizer SD. Uninsured persons with disability confront substantial barriers to health care services. *Disabil Health J*. 2011;4(4):238–244.
- Prevention CfDca. Quick-Stats: delayed or forgone medical care because of cost concerns among adults aged 18–64 years, by disability and health insurance coverage status—national Health Interview Survey, United States, 2009. *MMWR Morb Mortal Wkly Rep*. 2010;59(44):1456.
- Services CFMM. *2016 End of Year Zip Code File*. 2016.
- Cella D, Riley W, Stone A, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *J Clin Epidemiol*. 2010;63(11):1179–1194.
- Cook KF, Jensen SE, Schalet BD, et al. PROMIS measures of pain, fatigue, negative affect, physical function, and social function demonstrated clinical validity across a range of chronic conditions. *J Clin Epidemiol*. 2016;73:89–102.
- Ware JE, Kosinski M. Interpreting SF&-36 summary health measures: a response. *Qual Life Res*. 2001;10(5):405–413.
- Ware JE, Kosinski M, Bayliss MS, McHorney CA, Rogers WH, Raczek A. Comparison of methods for the scoring and statistical analysis of SF-36 health profile and summary measures: summary of results from the Medical Outcomes Study. *Med Care*. 1995;33(4 Suppl):AS264–279.
- Groah SL, Charlifue S, Tate D, et al. Spinal cord injury and aging: challenges and recommendations for future research. *Am J Phys Med Rehabil*. 2012;91(1):80–93.
- Reichard A, Stolze H, Fox MH. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and health journal*. 2011;4(2):59–67.
- Benner JL, Hilberink SR, Veenis T, Stam HJ, van der Slot WM, Roebroek ME. Long-term deterioration of perceived health and functioning in adults with cerebral palsy. *Arch Phys Med Rehabil*. 2017;98(11):2196–2205. e2191.
- Bowling A, Hankins M, Windle G, Bilotta C, Grant R. A short measure of quality of life in older age: the performance of the brief Older People's Quality of Life questionnaire (OPQOL-brief). *Arch Gerontol Geriatr*. 2013;56(1):181–187.
- Mahmoudi E, Meade MA. Disparities in access to health care among adults with physical disabilities: analysis of a representative national sample for a ten-year period. *Disabil Health J*. 2015;8(2):182–190.
- Osborn R, Doty MM, Moulds D, Sarnak DO, Shah A. Older Americans were sicker and faced more financial barriers to health care than counterparts in other countries. *Health Aff*. 2017;36(12):2123–2132.
- Lee JC, Heinemann AW. Forgoing physician visits because of cost: a source of health disparities for elderly people with disabilities? *Arch Phys Med Rehabil*. 2010;91(9):1319–1326.
- Wei W, Findley PA, Sambamoorthi U. Disability and receipt of clinical preventive services among women. *Wom Health Issues*. 2006;16(6):286–296.
- Chevarley FM, Thierry JM, Gill CJ, Ryerson AB, Nosek MA. Health, preventive health care, and health care access among women with disabilities in the 1994–1995 National Health Interview Survey, Supplement on Disability. *Wom Health Issues*. 2006;16(6):297–312.
- Iezzoni LI, Ngo L, Kinkel RP. *Social Security Disability Application Experiences of People with Multiple Sclerosis in the United States*; 2012. <http://dxdoiorg/107224/1537-2073-94131>.
- Sanchez J, Byfield G, Brown TT, LaFavor K, Murphy D, Laud P. Perceived accessibility versus actual physical accessibility of healthcare facilities. *Rehabil Nurs*. 2000;25(1):6–9.
- States U. Americans with disabilities Act of 1990. Public law No. 101-336. *US Statut Large*. 1990;104:327–378.
- United States Department of Justice. *2010 ADA Standards for Accessible Design*. Washington, D.C.: Dept. of Justice; 2010. http://purl.fdlp.gov/GPO/gpo22806http://www.ada.gov/regs2010/2010ADAStandards/2010ADAStandards_prt.pdfAlexanderStreethhttp://www.aspresolver.com/aspresolver.asp?DISAhttp://utils.louislibraries.org/cgi-bin/lz0050.x?sitecode=LAVW?http://purl.fdlp.gov/GPO/gpo22806http://proxying.lib.ncsu.edu/index.php?url=http://www.aspresolver.com/aspresolver.asp?DISA.
- United States. Department of justice. Disability rights section., United States. Department of health and human services. Office for civil rights. Access to medical care for individuals with mobility disabilities. In: *Washington, D.C.: U.S. Dept. Of Justics, Civil Rights Division, Disability Rights Section*. U.S. Dept. of Health and Human Services, Office for Civil Rights; 2010. http://purl.fdlp.gov/GPO/gpo22953http://www.ada.gov/medcare_mobility_ta/medcare_ta.pdfhttp://utils.louislibraries.org/cgi-bin/lz0050.x?sitecode=LAVW?http://purl.fdlp.gov/GPO/gpo22953.
- Frost KL, Bertocci G, Stillman MD, et al. Accessibility of outpatient healthcare providers for wheelchair users: pilot study. *J Rehabil Res Dev*. 2015;52(6):653–662.
- Pharr J, Chino M. Predicting barriers to primary care for patients with disabilities: a mixed methods study of practice administrators. *Disability and health journal*. 2013;6(2):116–123.
- Bachman SS, Vedrani M, Drainoni ML, Tobias C, Andrew J. Variations in provider capacity to offer accessible health care for people with disabilities. *J Soc Work Disabil Rehabil*. 2007;6(3):47–63.
- Okoro CA, Zhao G, Fox JB, Eke PI, Greenlund KJ, Town M. Surveillance for health care access and health services use, adults aged 18–64 Years - behavioral risk factor surveillance System, United States, 2014. *MMWR Surveill Summ*. 2017;66(7):1–42.
- Rep.. In: Larson JB, ed. *115-123 HRN. H.R.1892 - Bipartisan Budget Act of 2018*.

2018. Washington, D.C
39. Services CfMaM. *Jimmo v. Sebelius Settlement Agreement Fact Sheet*; 2012. <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/SNFPPS/Downloads/Jimmo-FactSheet.pdf>. Accessed May 1, 2018.
 40. Schiller JS, Lucas JW, Peregoy JA. Summary health statistics for u.s. Adults: national health interview survey, 2011. *Vital Health Stat.* 2012;10(256):1–218.
 41. Silverman AM, Molton IR, Alschuler KN, Ehde DM, Jensen MP. Resilience predicts functional outcomes in people aging with disability: a longitudinal investigation. *Arch Phys Med Rehabil.* 2015;96(7):1262–1268.
 42. Terrill AL, Molton IR, Ehde DM, Amtmann D, Bombardier CH, Smith AE, Jensen MP. Resilience, age, and perceived symptoms in persons with long-term physical disabilities. *J Health Psychol.* 2016;21(5):640–649.
 43. Jensen MP, Smith AE, Alschuler KN, Gillanders DT, Amtmann D, Molton IR. The role of pain acceptance on function in individuals with disabilities: a longitudinal study. *Pain.* 2016;157(1):247–254.
 44. Smith AE, Molton IR, Jensen MP. Self-reported incidence and age of onset of chronic comorbid medical conditions in adults aging with long-term physical disability. *Disabil Health J.* 2016;9(3):533–538.