Understanding Barriers to Rehabilitative Care in Neurodegenerative Diagnostic Groups

Articles (complete references for each study included below evidence table)	**Research question:** In the United States, do people with multiple sclerosis, amyotrophic lateral sclerosis, and/or Parkinson's disease, experience differences in access to physical therapy rehabilitation care due to specific demographic characteristics? **Common abbreviations:** **ADL** - activities of daily living; **ALS** - amyotrophic lateral sclerosis; **CP** - cerebral palsy; **CVD** - cerebrovascular disease; **DMA** - disease-modifying agent; **EDSS** - Expanded Disability Status Scale; **EMR** - electronic medical record; **MCS** - mental component summary; **MS** - multiple sclerosis; **OT** - occupational therapist; **PCS** - physical component summary; **PD** - Parkinson's disease; **PT** - physical therapist; **Pw** - people or person with (eg. PwMS or PwALS); **SCI** - spinal cord injury; **SES** - socioeconomic status; **SLP** - speech language pathologist; **SSDI** - Social Security Disability Insurance; **SSI** - Supplemental Security Income.			
Title **Author** **Year** **Purpose**	**Design (n=)** **Inclusion & Exclusion Criteria**	**Outcome Measures & Timeframes** **Interventions**	**Results & Conclusions**	**Comments & Limitations**
Rural-urban analyses of health-related quality of life among people with multiple sclerosis. Buchanan et al. (2008) *To identify factors associated with health-related quality of life (HRQOL) as well as any rural-urban differences in HRQOL among people with multiple sclerosis (MS) using the SF-8 Health Survey.*	Cross-sectional study (1,518) that surveyed the HRQOL of individuals with MS using the SF-8 Health survey among individuals with MS residing in all 50 states. **Inclusion Criteria:** NMSS member diagnosed with 1 of the 4 types of MS **Exclusion Criteria:** None reported.	**Outcome Measures:** The primary outcome measures for this study were to evaluate MS characteristics, HRQOL, health services, and socio-demographic characteristics for individuals with MS. This was mainly done using the SF-8 and responses from the MS survey.	**Results & Conclusions:** Buchanan et al. concluded that **PwMS who resided in rural areas had a significantly lower HRQOL** as demonstrated by the SF-8 scores relating to the PCS and MCS. Lower HRQOL scores demonstrate the need for additional healthcare services. As for MS characteristics, a depression diagnosis, worsening MS symptoms, mobility limitations, and lack of assistance were all associated with a lower HRQOL. They suggest that the more disabled a person with MS is, the more the individual's MCS is affected over their PCS. **Participants who received specialty MS care had higher HRQOL scores**, which is expected as MS clinics may offer	**Comments & Limitations:** The response rate for this study was only 31% which makes it difficult to generalize to the MS population. The voluntary participation of this study makes it more difficult to the general MS population. This study found that demographic and MS characteristics lacked the ability to demonstrate the variability of the mental dimensions of HRQOL when compared to the physical dimensions. This cross-sectional, level 4 study rates on the lower end of the level of evidence scale with increased risk of bias. The potential bias is from self-report, as there is no confirmation validity of the participants' responses. The authors also failed to include clear inclusion criteria and gather

			interdisciplinary, comprehensive care, resulting in improved outcomes. There are significant differences in urban-rural specialty care. Rural physicians tend to be general practitioners, lacking specialty care for individuals who need it. This, in addition to lack of transportation, increases the difficulty of receiving interdisciplinary care. **Four in 10 participants residing in remote rural areas reported driving themselves approximately 100 miles to an MS clinic, while 6 in 10 of their urban counterparts drove themselves an average of 26 miles.** "The challenge is to increase the access that PwMS living in rural areas have to MS-focused care and disease management provided by an interdisciplinary team, including mental health services." (pg.8).	confirmation of the MS diagnosis, requiring additional investigation to find the answers.
Quality of life in people with multiple sclerosis: data from the Sonya Slifka Longitudinal Multiple Sclerosis Study Wu et al. (2007) *The aim of this study was to assess the HRQOL in a large sample of individuals*	A longitudinal study (2,109) that consisted of interviewing individuals (mostly recruited from the NMSS) with MS about the HRQOL using the SF-12. Data for this study was used from the Slifka Study which enrolled participants every 6 months beginning in 2000 from all regions of the US and represented all	**Outcome Measures:** The SF-12 was used to measure HRQOL for these participants. The SF-12 was chosen in part by the fact that it is part of the Multiple Sclerosis Quality of Life Index (MS-QLI) which has been well studied and proven to have good psychometric properties. Additionally, this study also used information gathered by the Slifka Study. The Slifka Study used the	**Results & Conclusions:** Upon applying sampling weights, Wu et al. estimates the sample used in this study represents about 180,000 PwMS. About 75% of participants were limited in their ability to navigate stairs, work, perform activities, and attain their goals. As expected, their PCS scores were significantly lower than the	**Comments & Limitations:** This longitudinal study researched many variables (demographic variables, disease characteristics, access to healthcare, ADL's/IADL's, and symptoms) and their relation to HRQOL. The data from the Slifka study shows that individuals with MS score lower on the SF-12 than the general US population as well as other individuals with

with MS and determine how it related to mental and physical health.	varieties of MS illness. The interview was completed via computer-assisted telephone interviews (CATI). **Inclusion Criteria:** No clear inclusion or exclusion criteria were given. **Exclusion Criteria:** Participants were excluded mainly due to missing data. 47 individuals that were excluded were more likely to have another form of MS (not RRMS), longer duration of illness, more severe disability, and unemployed.	Medical Expenditure Panel Survey (MEPS) to obtain information about access to care, ADL's, and instrumental ADL's (IADLs). They also used the US Census for race and ethnicity, the Current Population Survey (CPS) for labor force participation, and the EDSS to determine the disability scale for MS.	general population. Participants reported significantly lower physical health when compared to other chronic disease populations. **Male gender, older age, widowed or separated, lower education, and residing in rural areas were all associated with lower physical health. In addition, participants that are unemployed and have lower family incomes, had lower physical health** most likely due to increased MS duration and relapses, greater disability, additional symptoms, and required more help with ADL's. Most importantly, **the data showed that these participants "typically did not have a usual MS care provider** and highlighted the significant contributions to poorer physical health made by older age, secondary progressive MS, more relapses, greater disability, specific symptoms (problems walking, pain or unpleasant sensations, fatigue, spasticity or stiffness, bowel problems, cognitive or memory problems, and vision problems), and difficulty with specific ADLs and IADLs (toileting, shopping, and housework)." MCS scores from these participants were also worse than	chronic illnesses. The data from Wu et al. shows that there is a correlation between MS type, severity of MS, access to care, living situation, income, employment status, education level, urban-rural residence, and race/ethnicity to PCS and MCS scores. This shows that there are barriers to care for individuals with MS and that finding solutions to these barriers could result in improved QOL.

			the general population, but better than those with MS and depression. Wu et al. suggests that the SF-12 underestimates the mental health of individuals with MS. Even though these participants scored better than those who were depressed, their scores were still lower than the general population and other comparable chronic illnesses, making it clear that **PwMS should be properly screened, evaluated, and treated for mental health disorders.** Wu et al. suggests that other confounding factors may influence MCS scores due to the negative loading of the 4 physical scales when calculating the MCS score and that individuals with MS "adjust their expectations that produced a positive view of general health status that could also result in a downward adjustment of expectations regarding the factors in the MCS, accomplishments, performance, socializing, and mood."	
Racial disparities in neurologic health care access and utilization in the United States. Saadi et al. (2017) *The aim of this study was to evaluate*	Cross-sectional study (16,936) using data from the Medical Expenditure Panel Survey (MEPS) in order to examine neurologic diagnoses, services usage, and demographics of	**Outcome measures:** Outpatient neurologist visits (annually); expenses incurred with these visits; inpatient and emergency department admissions; outpatient visits to PTs, OTs, and physiatrists; self-report of neurologic condition; race; ethnicity; age; annual household	**Results & Conclusions:** Overall, the authors report that **factors promoting access to or use of outpatient neurologists were older age, female sex, being white, having higher levels of education and income, being privately insured or**	**Comments & Limitations:** It is interesting to observe that the **data presented in this study demonstrate lower rates of neurologist visits among black participants and equal rates of outpatient PT and OT visits compared to white participants.**

differences based on race/ethnicity in accessing neurologic health care among people with self-reported neurologic disease or impairment, including PD, MS, headache, cerebrovascular disease, and epilepsy.	participants. **Inclusion Criteria**: participants included in MEPS database; 5 neurologic conditions (PD, MS, headache, CVD, epilepsy). **Exclusion Criteria:** None reported.	income; education; health insurance; self-report health status. **Timeframe:** Single point in time. **Interventions:** Participant questionnaires conducted via computer-assisted personal interviews.	**having Medicare coverage, and living in the Northeast region.** Results from this study demonstrate that non-Hispanic white and black participants visited outpatient PTs in equal numbers, and were similar to the Hispanic population of any race. The authors conclude that while race and ethnicity do seem to play a large role in a person's access to a neurologist, the causes of observed differences are likely multifactorial.	This finding is somewhat at odds with the Minden et al. (2008) study that reported lower rates of utilization of a PT in PwMS. While this study demonstrates racial and ethnic disparities in access to neurologist care, its design does not allow it to do more than speculate on causality. Like the Minden et al. (2008) study, this one is limited in its inability to distinguish among participant race beyond white, black, and other, and ethnicity as Hispanic or not Hispanic.
Determinants of utilization of physical rehabilitation services for persons with chronic and disabling conditions: an exploratory study. Elrod & DeJong (2008) *The aim of this study was to determine how variable demographic factors affect access to physical, occupation, and speech therapy in people with conditions such as MS, CP, and SCI.*	Secondary analysis of cross-sectional convenience sample (502) of adults with MS, CP, and SCI. **Inclusion Criteria:** Registered with mailing list of national MS, CP, or SCI association or recruited through community referrals; diagnosis of MS, CP, or SCI. **Exclusion Criteria:** Under 18 years old; uninsured at time of completing questionnaire.	**Outcome Measures:** Self-reported need for or receipt of physical rehabilitation services (PT, OT, SLP) in the preceding 3 months; health insurance plan; age; sex; race; education level; job status; marital status; household income including SSDI or SSI; health status; and limitations in ADL completion. **Timeframe:** The same survey was conducted one time annually in 1999, 2000, and 2001. **Interventions:** Twenty-page, 80-question pen-and-paper questionnaire.	**Results & Conclusions:** The primary question asked of respondents was whether they needed physical rehabilitation and, if so, if they had been able to access it in any form. **Forty percent of respondents reported requiring physical rehabilitation, but more than half of that group said they did not receive any services. Nearly all (99 percent) of this subset of respondents reported needing physical therapy services.** Compared to those respondents who both needed and received rehabilitation care, those who did not receive any were more likely	**Comments & Limitations:** That people reporting the worst health status were also least likely to receive the rehabilitation care they expressed needing is indicative of a failure of health care at some point in the system. The greatest limitation of this study as it pertains to the research question we have put forth lies in the fact that the authors disregard any respondents without insurance. This was done, they state, in order to better compare types of insurance with rehabilitation service usage. It is the opinion of this author that lack of insurance is, in itself, a category worth

			to be older, have Medicare health coverage, have lower incomes, and report the poorest health status. **While lower income was generally associated with reduced access to rehabilitation services, respondents who received Medicaid assistance were, in fact, more likely than any other group (based on health care coverage) to receive services.** Two major caveats to this study that the authors discuss are that, compared to national averages, the respondents tended to be white and with greater levels of education. As such, the study was not able to make comparisons between groups of different races and ethnicities, and broad generalizations specific to education are likewise not possible. While the study has limitations the authors suggest that, ultimately, it demonstrates that there likely exist multifactorial disparities in access to physical rehabilitation services and no one factor seemed to have the greatest amount of influence.	exploring as it relates to a person's use of or ability to access different health care services. There are many inherent limitations to studies such as this one that rely on self-report surveys and convenience samples. The sample does not necessarily represent the population at large, and in this case, the authors report getting rid of 10 percent (51 of 502) responses due to incomplete data, but do not provide any of those partial responses. Another limitation of this study as it relates to the research question presented for this evidence table is the age of the survey results. The article was published in 2008, yet deals with data from the turn of the century. Thus, two decades have elapsed since the original surveys were completed.

Access to and utilization of neurologists by people with multiple sclerosis. Minden et al. (2008) *The aim of this study was to identify factors that influence a person with MS's access to and utilization of a neurologist, and it examined how this could influence the individual's course of treatment.*	Cross-sectional study (2,156) using telephone interviews. **Inclusion Criteria:** 18 years old or older; diagnosis of MS; English speaking. **Exclusion Criteria:** None reported.	**Outcome Measures:** Data were analyzed based on: Self-report of visit with neurologist; visit with other providers or specialists; demographic information such as age, sex, race, ethnicity, MS diagnosis, income, geographic location; health insurance status. **Timeframe:** Single time point interview. **Interventions:** Computer-assisted telephone interview.	**Results & Conclusions:** The authors report that **PwMS who see a neurologist were more likely to receive DMAs and outpatient rehabilitation services** (OT, PT, and/or urology). Participants in the study were *less* likely to see a neurologist if they had no health coverage or low income, were from a rural area, were African American, had been diagnosed more than 15 years, had ambulatory difficulty, but did not use an assistive device, or if they required power mobility or were confined to bed. Participants who had reported a recent relapse (<1 year) were *more* likely to see a neurologist. The authors state that these data suggest that **PwMS are more likely to receive specialist neurology care early on in their disease, but not necessarily when they have greater levels of disability.** Participants were more likely to have **greater levels of disability and longer lengths of illness if they had lower income levels, and African Americans tended, too, to have greater disability.** The authors further state that	**Comments & Limitations:** As it relates to the research question presented for this evidence table, this study indirectly supports the idea that those of lower SES, greater disability, African Americans, and without health insurance are less likely to be seen by a PT. As it pertains to race, the study only identified participants as Caucasian, African American, or other, without distinguishing between other groups, limiting the utility of the data in comparing any groups other than Caucasians and African Americans. Ethnicity was classified as either Hispanic or not Hispanic for any race. The authors report the main limitations of the study characterized by self-report measures, outreach via mail and telephone interviews, the lack of a true control or comparison group, and a focus on a single point in time that does not allow for longitudinal comparisons or studying cause and effect.

			these results should not be misconstrued as making a judgement on quality of care vis-à-vis utilization of neurologists versus other types of providers. They conclude that PwMS would be best served by a combination of specialist and generalist care.	
Treatment Disparities in Parkinson's Disease Dahodwala et al. 2010 *The aims of this study are to examine the management of PD after an initial diagnosis among a group of middle-aged adults with equal health insurance and to determine whether there are racial differences in prescribed treatment.*	Data were abstracted from Pennsylvania Medicaid. Patient information included date of birth, sex, self-identified race and ethnicity, and zip code. 307 newly diagnosed PD cases were identified. **Inclusion Criteria:** To be considered a new PD case, patients must have fulfilled these criteria: (1) be Medicaid enrolled, (2) have at least one Medicaid-reimbursed claim associated with a principal diagnosis of PD (ICD-9 332.0), (3) have no claim associated with a diagnosis of PD (ICD-9 332.0) or parkinsonism (ICD-9 332.1) in the 12 months before the index claim, and (4) not have received medication indicated for PD in those 12 months.	**Outcome Measures:** Treatment was categorized between initial diagnosis and the 6 months after as follows: (1) medication for PD, (2) physical therapy, (3) second visit for PD. All therapies were covered by Medicaid insurance. Age, sex, race, county, reason for Medicaid eligibility, and specialty of treating physician for index claim were abstracted from the claims data. Age was categorized into two groups: ≤55 and >55 years. A location of care variable was created based on the urbanization spectrum for counties from the National Center for Health Statistics' urban-rural classification scheme. **Timeframe:** January 1, 1999 to December 31st, 2003.	**Results & Conclusions:** The authors report that 34% were prescribed PD medication or physical therapy, and 40% had a second visit for PD after initial diagnosis. In unadjusted analysis, African American patients were less likely to receive any medication treatment or physical therapy than white patients (12% vs 38%). They were also less likely to receive just medication therapy (12% vs 33%). There was no significant difference in the number of second visits for PD in the 6 months after initial diagnosis. **In adjusted analysis, African American race and older age remained significantly associated with any medication treatment or physical therapy.** These factors were also significantly associated with use of medication treatment only. Individuals who received care in an urban area had almost half the odds of medication treatment than those who lived in rural areas. African American	**Comments & Limitations:** As it pertains to this evidence table, although both antiparkinsonian medications and physical therapy are effective treatments for PD, only about a third of newly diagnosed PD patients were started on therapy. African American patients were significantly less likely to receive treatment for PD than white patients. These differences remained after controlling for other demographic and clinical factors, including age, sex, geography, initial visit with a neurologist, and reason for Medicaid eligibility. The use of administrative data does not allow for examination of potential clinical factors that could influence treatment decisions such as disease stage. White patients may be more likely than African American patients to approach Medicaid for care at later stages of illness when other health care options are

	Exclusion Criteria: Because of concerns about misclassification, all individuals with at least one claim for conditions that are common causes of secondary parkinsonism: stroke, schizophrenia, and bipolar disorder were excluded from the cohort.		patients were significantly more likely to receive care in an urban setting than white patients (93% vs 46%).	exhausted, which would select for sicker white patients. Second, the diagnosis of PD has not been validated in the Medicaid claims. This study also excluded those individuals who were at increased risk for secondary parkinsonism based on a history of stroke, bipolar disorder, or schizophrenia. If misclassification differed between African Americans and white patients, it might confound observed differences.A third limitation relates to the generalizability of the results. The sample was relatively young, poor, and disabled. The high level of disability would favor symptomatic treatment among both African American and white patients; however, multiple comorbid conditions that require treatment may discourage clinicians from adding therapies with potential cross-interactions.
Effects of Demographic Factors on Survival Time after a Diagnosis of Amyotrophic Lateral Sclerosis Jordan et al. 2015 *The Agency for Toxic Substances and Disease Registry established surveillance*	Cross-sectional research study (493) **Inclusion Criteria:** Cases were reported by neurologists for all PwALS who were New Jersey residents, under the physician's care at some point between January 1, 2009 and December 31, 2011, and who met the El	Vital status was calculated, as of December 31, 2013, of the 493 incident cases was determined through a search of N.J. death records. Decedents were classified based on the causes assigned for death in their death certificates–that is, whether ALS was a cause for death–by a review of all contributing and underlying causes of death. Survival time of a patient was calculated from the month and year of	**Results & Conclusions:** As of December 31, 2013, 64.1% of incident cases were known to be deceased. This proportion was higher among those diagnosed in 2009 (68.4%) compared with those diagnosed in 2010 (65.5%) and 2011 (58.5%). For 93.7% of those known to be deceased, ALS was specified as the cause of death on the death certificate. Respiratory failure, aspiration,	**Comments & Limitations:** While it is known that older age is a strong predictor of shorter survival, and there is some indication of differences based on sex, race, and ethnicity, but these differences were not statistically significantly different when accounting for age. There were apparent differences in the median survival time

projects to determine the incidence, prevalence, and demographic characteristics of persons with Amyotrophic Lateral Sclerosis (ALS) in defined geographic areas. There is a need to characterize and account for the survival and prognostic factors among a population- based cohort of ALS cases in the United States.	Escorial criteria. There were 764 prevalent cases in this period, of which 493 cases were included. **Exclusion Criteria:** All death certificates that explicitly listed a motor neuron disease other than ALS were excluded from follow-up activities. To calculate the average annual incidence for 2009, 2010 and 2011, all cases with a date of diagnosis before 2009 were excluded. To calculate the prevalence as of December 31, 2011, all cases with a known date of death in 2009, 2010 and 2011 were excluded.	diagnosis to the month and year of death, regardless of the cause of death. **Timeframe:** Jan 1st 2009- Dec 31st 2011	pneumonia, other neuromuscular disorders, sepsis, acute cardiac events, malnutrition, and chronic obstructive pulmonary disorder were among the causes of death listed for the 20 cases that did not list ALS as one of the causes of death. The remaining analyses, 37 cases were excluded on the basis of race being 'Other' or 'Unknown' or Hispanic ethnicity being 'Unknown'. Among the remaining 456 incident cases diagnosed during 2009–2011, the median survival time from the time of diagnosis to the time of death was 21 months. The median survival time varied significantly by age group from a high of 38 months for the age group <55 years, to a low of 11 months for those 75 years of age or older. The median survival time was shorter among females compared with that of males, among whites compared with that of blacks and Asians, and among non Hispanics compared with that of Hispanics.	based on race and ethnicity. Differences by race and ethnicity remained but were not statistically significant; however, these comparisons were based on small case counts among blacks, Asians and Hispanics. Little is known about differences in survival time among different races in the United States. Since diagnoses of incident cases were between January 1, 2009 and December 31, 2011, the follow-up time to date has been insufficient to define longer-term survival. Incident cases had a minimum of 24 months and a maximum of 60 months of follow-up time.It is possible that some cases originally reported by neurologists relocated to other states, became residents of those states, and died there. It is also possible that some N.J. resident cases could have died in another state and their death certificates have not yet been reported to N.J.
Sex Disparities in Health and Health Care Utilization after Parkinson Diagnosis: Rethinking PD Associated Disability Fullard et al. 2018	Retrospective Cohort Study (133,000) **Inclusion Criteria:** Medicare beneficiaries with an incident PD diagnosis in the year 2002 were	**Outcome Measures:** They compared the prevalence and cumulative incidence of common medical conditions, trends in survival and health care utilization between men and women with PD.	**Results & Conclusions:** Women and men with PD differed in their comorbid disease burden throughout the observation period. At baseline, women with PD had	**Comments & Limitations:** It is interesting to see that female patients with PD had a higher incidence rate of depression. I am not surprised to see that they had higher rates of hip fracture, osteoporosis, and

The goal of this study was to examine sex differences and trends in comorbid disease and health care utilization in individuals with newly diagnosed Parkinson disease (PD).	identified using the Centers for Medicare & Medicaid Services (CMS) Carrier file. The Carrier files were searched to identify beneficiaries with claims containing ICD-9 codes for "Parkinson disease" or "Paralysis agitans." Participants were required to have at least 2 years of Medicare eligibility prior to a new claim of PD. **Exclusion Criteria:** Beneficiaries that had a diagnostic claim for "Secondary/Drug induced Parkinsonism." or "Atypical Parkinson Syndromes," "those with PD who were younger than the age of standard Medicare eligibility (65 years) because these individuals likely have different clinical courses and health care needs."	The primary study outcomes were comorbid disease diagnosis and health service use. They examined survival through 2008 as a secondary outcome. They determined the frequency of a diagnosis of atrial fibrillation, acute myocardial infarction, depression, dementia, cataract, chronic obstructive pulmonary disease, congestive heart failure, diabetes, glaucoma, hip fracture, ischemic heart disease, osteoporosis, rheumatoid arthritis/osteoarthritis, stroke, breast cancer, uterine cancer, lung cancer, and prostate cancer. Diagnosis dates were used to examine the timing of comorbid disease relative to PD diagnosis. Health service use was calculated annually and reported as the proportion (crude prevalence) of the PD population in receipt of a given service. **Timeframe:** Trends in health service utilization from 2002–2008 were stratified by sex.	a lower prevalence of atrial fibrillation, acute myocardial infarction, chronic obstructive pulmonary disease, diabetes, colorectal cancer, ischemic heart disease, chronic kidney disease, stroke/transient ischemic attack, and lung cancer. Women had higher baseline prevalence of cataracts, depression, dementia, glaucoma, hip fracture, osteoporosis, rheumatoid arthritis/osteoarthritis, and congestive heart failure. **After adjusting for age and race, the incidence ratios for depression, hip fracture, osteoporosis, and rheumatoid/osteoarthritis remained elevated for women compared to men.** **In contrast, almost all other conditions studied were more common in men**, including atrial fibrillation, acute myocardial infarction, colorectal cancer, and chronic obstructive pulmonary disease were more common in men. The incidence ratios for dementia, diabetes, and glaucoma were very close to 1, suggesting a nearly equal age and race adjusted incidence of these diseases between men and	rheumatoid/osteoarthritis than men due to the general higher prevalence of these in women. In spite of greater survival, women with PD used home health and skilled nursing facility care more often, and had less outpatient physician contact than men throughout the study period. Women in this cohort on average were older than men at the time of diagnosis, a finding which may be explained by a later disease onset, delay in diagnosis, or longer life expectancy. Limitations of this study include the possibility of selection bias and misclassification of outcome or exposure variables, as it is retrospective in design. Other limitations are associated with Medicare and administrative datasets such as coding errors, inability to currently adjust for disease severity, and case mix bias. Unknown and unobservable factors may contribute to health care utilization and diagnoses. Additionally, this study includes patients 65 years or older, so the results may not be generalizable to younger PD patients.

			women after PD diagnosis. **Women had fewer physician office visits than men at the time of diagnosis and at every followup**. Furthermore, the decline in physician care was greater in women compared to men. Previous data on gender disparities in specialty care for PD demonstrated that women were less likely than men to have neurologists involved in their care, which may explain a portion of these observed differences. **After adjusting for age at diagnosis, race, and comorbid diseases which affect both sexes, women were almost 25% less likely to die during the observation period.**	
A spatial analysis of amyotrophic lateral sclerosis (ALS) cases in the United States and their proximity to multidisciplinary ALS clinics, 2013 Horton et al. 2018 *The purpose of this study was to assess the relative geographic location and prevalence of ALS cases in the United States and their*	Cross-sectional study (15,633) using data from the National ALS Registry. **Inclusion criteria:** All cases of ALS identified in the registry. **Exclusion criteria:** None reported.	**Outcome measures:** Patient demographics (age, sex, race, geographic location); multidisciplinary clinic location. **Timeframe:** 2013	**Results & Conclusions:** The findings of this study demonstrate that **nearly half of PwALS live more than 50 miles away from a multidisciplinary ALS clinic and a quarter live more than 100 miles from one.** Comparing racial groups, the researchers found that **white and younger PwALS were more likely to live farther from a multidisciplinary clinic**. The cases of ALS identified by	**Comments & Limitations:** The results from this study showed that a plurality, more than a third, of ALS cases in the United States are in the South, where there is the smallest proportion of specialty clinics relative to population. While the authors are explicit in saying that specialty ALS clinics do not necessarily result in improved care, that assumption nevertheless exists. Further research still needs to be

relationship to multidisciplinary ALS clinics.			this study were geographically diverse, but did tend to be focused around larger cities and metropolitan areas. The authors suggest that this could be a limitation if there were missed cases in more rural areas that simply are not included in the National ALS Registry.	undertaken to ask whether the current models provide the best care to everyone who needs it. This study did not look into the utilization of ALS clinics. While the results demonstrate that black and other racial groups tended to live in closer proximity to clinics, the researchers do not attempt to determine whether that leads to a greater use of such clinics by those populations compared to whites. Likewise, they do not categorize usage of the clinics based on geographic proximity, only supposing that living closer to a clinic will result in a greater rate of utilization.
Same-day physical therapy consults in an outpatient neuromuscular disease physician clinic. Pucillo et al. (2016) *The aim of this study was to assess whether referral to a same-day PT visit had a positive impact on patient outcomes in those with neuromuscular diseases.*	Cross-sectional study (134) using patient satisfaction surveys and demographic data from the patient's EMR. **Inclusion criteria:** Attendance at outpatient physician visit with subsequent referral for same-day PT consult at Neuromuscular Division of Medicine at the Clinical Neuroscience Center (University of Utah); neuromuscular disease diagnosis.	**Outcome Measures:** 8-question patient satisfaction survey; Press-Ganey Provider satisfaction survey; downstream billing and revenue information; patient demographic information (age, sex, residential zip code; neuromuscular disease diagnosis). **Timeframe:** Single time point per patient during 12-month period of January 2015 to January 2016. **Interventions:** All subjects included in trial were seen by a physician. If the physician deemed PT service to be warranted	**Results & Conclusions:** The study population's median age was 60 years old, and included 76 male and 58 female participants. **Overall, the subjects were positively impacted by the same-day referral to a PT**, though only 61 of 134 subjects completed the survey after their physical therapy appointment, limiting the conclusions the authors could draw. **More than 75 percent of respondents reported never before having received physical therapy services**	**Comments & Limitations:** While there are significant limitations to this study and the conclusions that could be applied to a patient population with MS, ALS, or PD, it does offer a novel solution to enhancing access to physical therapy care that can be rather difficult to find anywhere else. It would be important to study this type of service more specifically among PwMS, ALS, and PD in order to draw more relevant conclusions, however, it is reasonable to expect that this type of service delivery could help

	Exclusion criteria: Concurrent use of PT services prior to same-day visit or already scheduled return visit.	for the subject, they were offered same-day appointment with a PT for a standard initial evaluation. There was no control group.	**specifically for their neuromuscular disease diagnosis.** The results also demonstrated that the process of setting up same-day consults with a PT following a physician appointment was easy and well liked by the physicians themselves. However, the downstream financial viability was not sustainable as set up by the study protocol.	to fill a niche for people who have experienced more difficulty accessing rehabilitation services for one reason or another. A significant limitation of this study as it relates to our research question lies in the fact that the diagnosis categories used by the authors do not include MS, ALS, or PD. Instead, these three diseases would fall under the more general categories of motor neuron disease (n=8) and movement disorders (n=6).

References

1. Buchanan RJ, Zhu L, Schiffer R, Radin D, James W. **Rural-urban analyses of health-related quality of life among people with multiple sclerosis.** *J Rural Health*. 2008;24(3):244-252. doi:10.1111/j.1748-0361.2008.00165.x
2. Wu N, Minden SL, Hoaglin DC, Hadden L, Frankel D. **Quality of life in people with multiple sclerosis: data from the Sonya Slifka Longitudinal Multiple Sclerosis Study**. *J Health Hum Serv Adm*. 2007;30(3):233-267.
3. Saadi A, Himmelstein DU, Woolhandler S, Mejia NI. **Racial disparities in neurologic health care access and utilization in the United States**. *Neurology*. 2017;88(24):2268-2275. doi:10.1212/WNL.0000000000004025
4. Elrod CS, DeJong G. **Determinants of utilization of physical rehabilitation services for persons with chronic and disabling conditions: an exploratory study.** *Arch Phys Med Rehabil*. 2008;89(1):114-120. doi:10.1016/j.apmr.2007.08.122
5. Minden SL, Hoaglin DC, Hadden L, Frankel D, Robbins T, Perloff J. **Access to and utilization of neurologists by people with multiple sclerosis.** *Neurology*. 2008;70(13 Pt 2):1141-1149. doi:10.1212/01.wnl.0000306411.46934.ef
6. Dahodwala N, Xie M, Noll E, Siderowf A, Mandell DS. **Treatment disparities in Parkinson's disease.** *Ann Neurol*. 2009;66(2):142-145. doi:10.1002/ana.21774
7. Jordan H, Fagliano J, Rechtman L, Lefkowitz D, Kaye W. **Effects of demographic factors on survival time after a diagnosis of amyotrophic lateral sclerosis**. *Neuroepidemiology*. 2015;44(2):114-120. doi:10.1159/000380855
8. Fullard ME, Thibault DP, Todaro V, et al. **Sex disparities in health and health care utilization after Parkinson diagnosis: Rethinking PD associated disability**. *Parkinsonism Relat Disord*. 2018;48:45-50. doi:10.1016/j.parkreldis.2017.12.012
9. Horton DK, Graham S, Punjani R, et al. **A spatial analysis of amyotrophic lateral sclerosis (ALS) cases in the United States and their proximity to multidisciplinary ALS clinics, 2013**. *Amyotroph Lateral Scler Frontotemporal Degener*. 2018;19(1-2):126-133. doi:10.1080/21678421.2017.1406953
10. Pucillo EM, Christensen-Mayer N, Poole SD, Whitten DM, Freeman D, Bohe BR, Swensen BR, Smith AG, Johnson NE. **Same-day physical therapy consults in an outpatient neuromuscular disease physician clinic.** J Multidiscip Healthc. 2016;9:493-497. doi:10.2147/JMDH.S113045