

Understanding Barriers to Rehabilitative Care

in Neurodegenerative Diagnostic Groups

PHYT 854 Capstone – Spring 2021

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Objectives

- Provide an overview of the survey and research project: *Understanding Barriers to Rehabilitative Care*.
- Summarize recent literature related to access to health care among people with neurological diagnoses.
- Summarize what we know about any issues faced by people with multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), and Parkinson's disease (PD) in accessing and receiving physical therapy (PT).
- Discuss the findings and conclusions of our study.
- Analyze how the study could have been conducted differently and propose questions that remain to be answered.

Background information

- Informed by national events during the summer of 2020.
- Two surveys were created for:
 - People with multiple sclerosis, amyotrophic lateral sclerosis, and Parkinson's disease
 - Physical therapists in North Carolina
- Both surveys asked similar demographic information with separate questions specific to each group related to access to PT care.
- Participants recruited from a variety of locations and groups:
 - Support groups for people with MS, ALS, and PD
 - Multidisciplinary clinics
 - Physical therapy clinics
 - The Neuro STEP UP Volunteer Leadership Team
 - Facebook groups

Background 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?

Racial disparities in neurologic health care access and utilization in the United States.

Saadi A et al. (2017)

- Participants with MS, PD, cerebral palsy (CP), headache, epilepsy, cerebrovascular disease
- Factors promoting access to outpatient neurologist care:
 - Older age
 - Female
 - White
 - Higher income
 - Medicare or private insurance
 - Higher level of education
 - Living in northeast United States

Determinants of utilization of physical rehabilitation services for persons with chronic and disabling conditions: an exploratory study.

Elrod & DeJong (2008)

- Participants with MS, CP, and spinal cord injury (SCI).
- More than 20% stated they required, but did not receive rehabilitation care – mostly PT.
- More likely to be older, lower income, have Medicare coverage.
- More likely to report negative health status.

Same-day physical therapy consults in an outpatient neuromuscular disease physician clinic.

Pucillo et al. (2016)

- Subjects with variety of neuromuscular diseases all seen by physician were referred to same-day physical therapy when needed (determined by physician).
- Mean satisfaction for same-day PT consults was 97.4%.
- 3 out of 4 subjects had never seen a PT before for their diagnosis.
- Model of care shown to be effective and well-liked by patients and providers.
- Long-term financial sustainability was not viable.

Introduction to the current study

Purpose: To understand accessibility to rehabilitation care from the patient and clinician perspective.

People with MS, ALS, PD

- **General background**
- Household information
- Satisfaction with physical therapy
- **Access/barriers to rehab care**
- **Impact of COVID-19**

Physical Therapists

- **General background**
- Experience as a clinician
- Experience with MS, ALS, PD
- **Access/barriers to rehab care**
- **Impact of COVID-19**

Methods of the current study

- Survey questions written and compiled end of summer 2020.
- IRB approval from UNC Office of Human Research Ethics October 2020.
- Two surveys created for paper and online responses.

People with MS, ALS, PD

- 30 questions
- Recruitment: in person, email, flyers, support groups, clinics, Facebook groups

Physical Therapists

- 19 questions
- Recruitment: in person, email, flyers, clinics, Facebook groups, Neuro STEP UP VLT

Inclusion Criteria

People with MS, ALS, PD

- ≥ 18 years old
- Diagnosis of MS, ALS, or PD
- Currently living in North Carolina

Physical Therapists

- Licensed in North Carolina
- Practicing in North Carolina
- ≥ 6 months clinical experience

Results from the current study

- 32 total respondents (n=16 per survey)
 - Multiple Sclerosis (n=7)
 - Amyotrophic Lateral Sclerosis (n=5)
 - Parkinson's Disease (n=4)
- Low racial/ethnic diversity in both studies
- No teletherapy utilized over the course of COVID-19 pandemic
 - Yet, 31% (n=5) reported discontinuing PT care due to pandemic
- **Limitations identified warrant further discussion more than results of the study.**

Results from the MS, ALS, PD survey

General findings of note

- Female (n=10)
- White (n=12)
- Black (n=3)
- Asian (n=1)
- Hispanic/Latinx (n=0)
- 25% (n=4) had never received PT for dx

Respondents with ALS vs. MS and PD

- Younger (18-65+ vs. 55+)
- More racially diverse
- Lower annual income (<\$30k vs. >\$40k+)
- Lower education
- More recently diagnosed (< 5 years vs. > 10 years)
- All paper surveys vs. online computer format

Biggest barriers to accessing PT care:

- Lack of transportation
- Cost/insurance/co-pay
- Distance to clinic/hospital
- Difficulty due to diagnosis
- Lack of available time

Results from the PT survey

Demographic characteristics

- Female (n=13)
- White (n=13)
- Asian (n=2)
- Native Hawaiian or Pacific Islander (n=1)
- Hispanic/Latinx/Spanish (n=1)

Biggest barriers to *providing* quality care:

- Lack of specialized equipment
- Lack of time in clinic
- Need for advanced knowledge
- Cultural differences

Biggest barriers to *accessing* PT care:

- Lack of transportation
- Cost/insurance/co-pay
- Distance to clinic/hospital
- Difficulty due to diagnosis
- Lack of available time

Discussion and conclusions of the current study

- Sought to assess barriers to physical therapy care.
- Even those with greater resources identified many barriers to care:
 - Transportation, finances, geographic location, time
- People with higher income and levels of education reported shorter distance to care.
- Face-to-face participant recruitment may result in greater diversity.

- What manageable barriers prevented our study from reaching more people and a more diverse study population?
 - Reliance on online and flyer recruitment.
 - Limited individual and face-to-face recruitment.
 - Little outreach beyond the relative affluence of the Triangle.

Strengths of the current study

- Offers preliminary evidence of barriers to physical therapy care.
- Provides jumping-off point for future research or projects.
- Good diversity of MS, ALS, and PD diagnoses.
- Recruitment of both patients and clinicians.
- Recruitment via more than one channel.

What could we have done differently?

- COVID-19 pandemic restricted participation and recruitment.

However, to address shortcomings we could have:

- Worked more closely with individual clinics/hospital systems.
- Spent more time at multidisciplinary clinics.
- Sought out more support groups.

What questions remain?

- For what reasons did we not receive responses from a racially, ethnically, educationally, or financially diverse pool of participants?
- Does the diversity of the respondents accurately reflect the diversity of the people reached?
- Was there skepticism of this questionnaire?
- Does diversity of PTs affect diversity of the patient population in general?
- For those who discontinued care due to the pandemic, was teletherapy an option?

Presentation feedback

Questions and discussion

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References

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