

Longitudinal Study of People Aging with Long-Term Physical Disabilities

Diversity of Disability Pathways for Middle-Aged Adults

Implications for Services and Supports

We analyzed data from our longitudinal cohort study of 474 people aged 45–65 with long-term physical disabilities to explore diverse pathways of disability for middle-aged adults.

Specifically, we looked at the pathway variables of **age of disability onset** and self-reported **primary cause of disability** and how they relate to the lived experience of disability for participants.

Age of Onset

- Early: 0–31
- Adult: 32–44
- Midlife: 45–60



Primary Cause

- Neurological
 - Cerebral palsy, multiple sclerosis, polio, spinal cord injury, stroke
- Musculoskeletal
 - Amputation, arthritis, hip/knee replacement
- Other single cause
 - Cardiovascular, endocrine, immunological disorders; sensory impairment
- Two or more causes

To see how these diverse aging-with-disability pathways shape the lived experience of people aging with long-term physical disabilities, we examined how they relate to:

Social context factors

- Gender
- Race
- Education level
- Marital status

Overall health status

- Physical health
- Mental health

Personal service use

- Need for services
- Use of services

Barriers to participation

- Transportation
- Lack of information
- Lack of access to health-care services
- Need someone else's help
- Prejudice

Three Objectives:

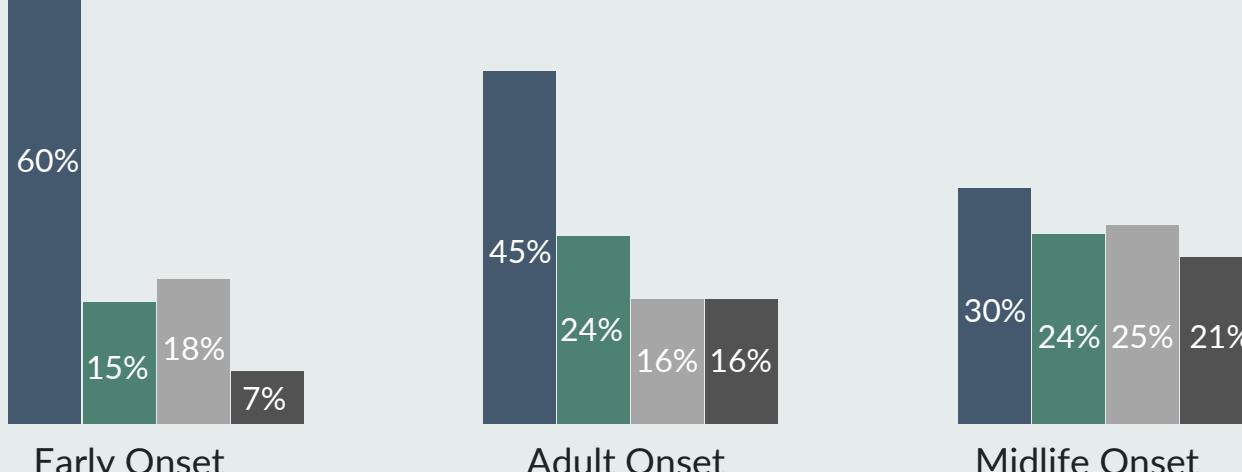
1. Expand our understanding of how age of onset shapes self-reported causes of disability
2. Document the relationship between diverse aging-with-disability pathways and the social context of the lived experience of disability
3. Explore relationships between diverse pathways of disability and health status, service use, and barriers to participation

Findings

Objective 1: Exploring Age of Onset and Primary Cause of Disability

First, we looked at how the two pathway variables relate to each other. Neurological conditions were the most common cause of disability in all three age-of-onset categories, particularly high in the early-onset group. The number of people reporting musculoskeletal causes and two or more causes of disability increased as age of onset increased.

Primary Cause of Disability by Age of Onset



Objective 2: Exploring Diverse Pathways and Social Contexts

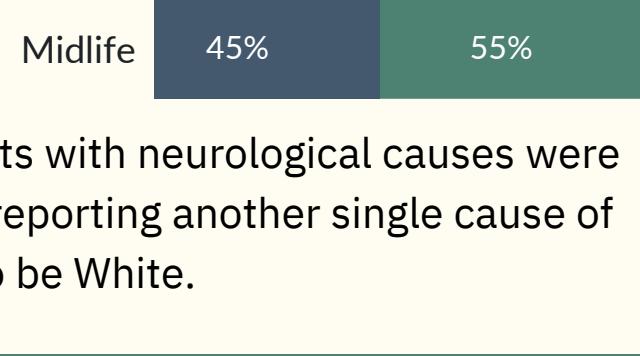
Race

Race was associated with age of onset and primary cause of disability.

70% of participants reporting early-onset disabilities were White. The percentage of non-White participants increased as age of onset increased.

Race and Age of Onset

■ Non-White ■ White



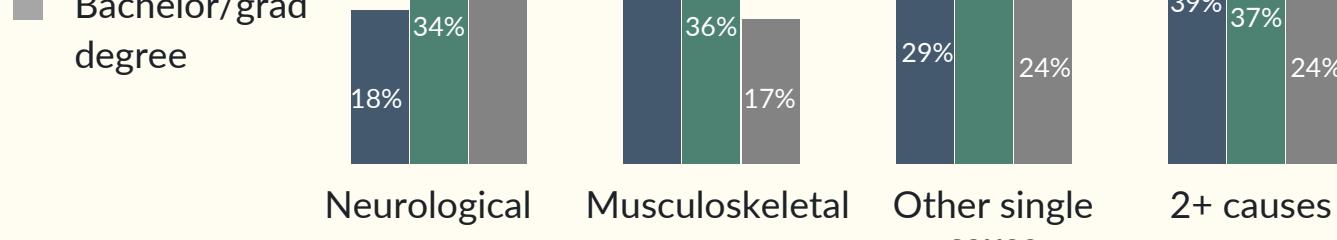
For cause of disability, participants with neurological causes were around 70% White. Participants reporting another single cause of disability were also more likely to be White.

Education

Education was also associated with both age of onset and primary cause of disability.

Education levels decreased as age of onset increased, with early-onset participants having the highest frequency of college and/or graduate-level education.

Looking at primary cause of disability, participants with neurological conditions had the highest levels of education.



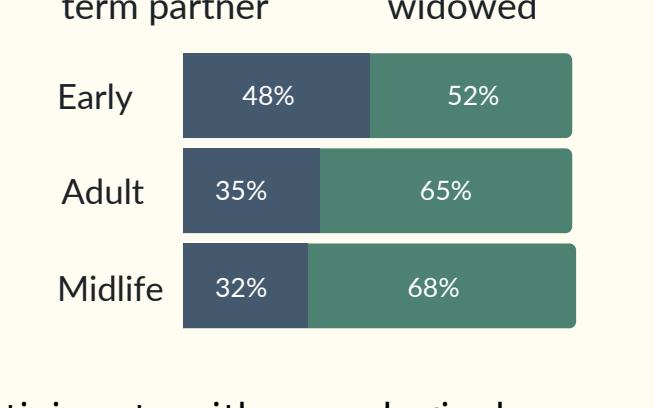
Marital Status

Marital status was also associated with both age of onset and primary cause of disability.

Participants with early-onset disabilities were more likely to be married than participants with adult- or midlife-onset disabilities.

The number of single, divorced and/or widowed participants increased with age of onset.

Marital Status and Age of Onset



For primary cause of disability, participants with neurological conditions were the most likely to be married, and participants with musculoskeletal conditions were the least likely.

Gender

Gender was the only social context factor that did not have a significant association with age of onset or primary cause of disability.

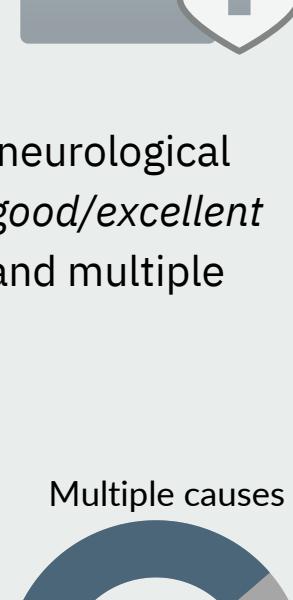
Objective 3: Exploring Relationships Between Diverse Pathways and Health Status, Services, and Barriers to Participation

Health Status

Self-Rated Physical Health

The majority of all respondents reported their physical health as poor or fair.

Participants with early-onset disabilities were the age-of-onset group most likely to report their physical health as good or very good/excellent.



Regarding primary cause of disability, people with neurological conditions were most likely to report good or very good/excellent physical health. People with another single cause and multiple causes reported the worst health.

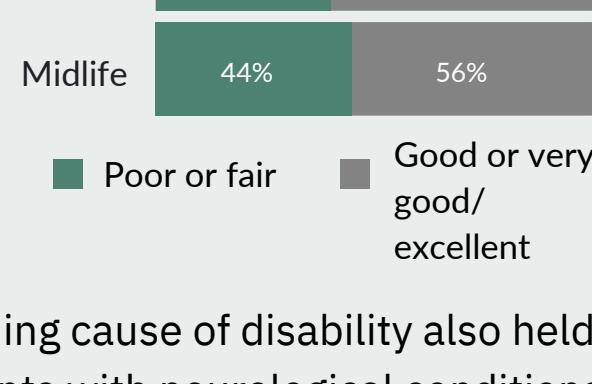
Physical Health and Cause of Disability



Overall, ratings for mental health were higher than those of physical health.

Participants with early-onset disabilities had a higher percentage of good or very good/excellent ratings than the other onset groups.

Mental Health and Age of Onset



The pattern we have seen regarding cause of disability also held true for mental health: respondents with neurological conditions were the most likely to rate their mental health as good or very good/excellent. Participants with multiple causes of disability were most likely to rate their mental health as poor.

Services

We asked participants about both their use of community services and their need for community services.

Use of Services

The majority of participants in **all subgroups** for both pathway variables said that they use personal services.



Need for Services

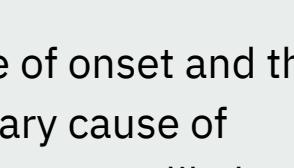
When we looked at what participants said about their need for more services, we found a similar pattern seen with previous variables:

- Participants with early-onset disabilities were less likely to report needing more services than the later-onset groups.
- Participants with neurological causes of disability were the least likely to report needing more services.

Barriers to Participation

Transportation

For every pathway variable category, the majority of participants said transportation was a barrier to participation. There were no significant correlations between specific pathway variables and transportation.

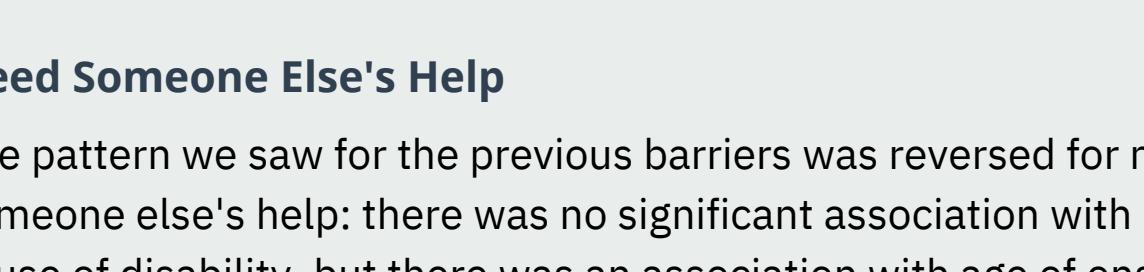


Lack of Access to Health-Care Services

There was no significant association between age of onset and this variable, but we did find an association with primary cause of disability: people with neurological conditions were more likely to cite lack of access to health services as a barrier than people with other causes of disability.

Lack of Information

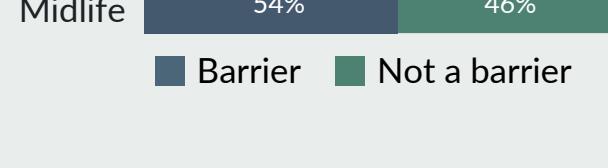
Again, we found no association between lack of information and age of onset, but we did find that participants with neurological conditions were least likely to report lack of information as a barrier.



Need Someone Else's Help

The pattern we saw for the previous barriers was reversed for need someone else's help: there was no significant association with cause of disability, but there was an association with age of onset. Participants with adult-onset disabilities were the most likely group to report lack of someone else's help as a barrier.

Prejudice



The majority of participants in all subgroups for both pathway variables reported prejudice as a barrier to participation, with the early-onset category being the highest overall.

Summary

Regardless of age of onset or primary cause of disability, the majority of participants told us that:

- Physical health is disproportionately rated as *poor* or *fair*
- Mental health is disproportionately rated as *good* or *very good/excellent*
- Participants currently routinely use personal services
- Transportation and prejudice are significant barriers to participation

But within this overall pattern, there were important differences by both age of onset and primary cause of disability.



Age of Onset

Early-onset more likely to:

- Have one cause of disability, primarily neurological
- Be White
- Have a higher education level
- Be married
- Report *good* or *very good/excellent* physical and mental health
- Report prejudice as a barrier to participation

Midlife-onset more likely to:

- Have 2+ causes or "other" single cause
- Be non-White
- Have a lower education level
- Be single/divorced/widowed
- Report *poor* or *fair* physical and mental health
- Report needing more health-care services

Primary Cause of Disability

Neurological more likely to:

- Be White
- Have a higher education level
- Be married
- Report *good* or *very good/excellent* physical and mental health



All other causes more likely to:

- Be non-White
- Have a lower education level
- Be single/divorced/widowed
- Report *poor* or *fair* physical and mental health
- Report needing more health-care services
- Report lack of health-care services as a barrier
- Report lack of information as a barrier

Implications for Service Providers

Individuals with early-onset physical disabilities, primarily with neurological causes, may benefit from an early diagnosis, contributing to better access to:

- Health-care and rehabilitation services
- Disability services and advocacy information
- Support from family and teachers
- Educational opportunities

Individuals with midlife-onset physical disabilities and higher frequencies of musculoskeletal, other single, and multiple causes of disability may be at greater disadvantage in accessing the services, resources, information, and formal and informal supports they need.