Community Participation and Environmental Influences Among People with Multiple Sclerosis: Challenges and Solutions from a Community-Engaged Perspective

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Abstract

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Multiple sclerosis (MS) is the most common non-traumatic neurodegenerative disease among young adults. It is affecting nearly one million adults in the US and two million adults worldwide. Participation in meaningful and important activities as desired is highly valued by people with MS (PwMS) and is an important clinical outcome indicating quality of life and well-being. However, research has shown that PwMS experience significant declines in participation after their diagnosis, and they report fewer barriers to participating in activities at home but more barriers outside the home. Although numerous conceptual frameworks and empirical studies with other diagnostic groups highlight the role of environments in affecting participation, specific environmental impacts on community participation of PwMS have not been thoroughly explored. Using mixed-methods design and community-engaged research approaches, this dissertation broadly aims to understand community participation experiences among PwMS and how physical, societal, and attitudinal environments affect these experiences. In addition, the dissertation also focuses on advocacy for system-level improvements for enhancing community participation. The dissertation includes three phases: (1) a secondary analysis of quantitative data

on person factors, environment, and community participation of people with MS, (2) focus group discussions with individuals with MS, and (3) a community engagement meeting with the broader MS community.

In this dissertation, Chapter 1 presents a literature review on the conceptualization of participation and environmental influences, as well as empirical evidence relevant to multiple sclerosis, community participation measurement, and environmental impact, revealing research gaps and justifying the content and design of this dissertation. Chapters 2-4 are the three main articles that jointly achieve the overarching purpose of this dissertation with various specific aims. Chapter 5 is a conclusion chapter summarizing the study findings and implications.

The first article (Chapter 2), "*Is Doing More Always Better? A Mixed Methods Study Examining Relationship Between Subjective and Objective Dimensions of Community Participation among Individuals with Multiple Sclerosis*," utilized results from the first and second phases of this project to examine the relationship between subjective perspective of participation and objective community mobility performance both quantitatively and qualitatively. Results show that subjective and objective dimensions of community participation are positively related, but the association is generally weak, indicating that better perceptions of participation outcomes do not require high quantities of community engagement, such as frequency, distance, and duration of community outings. The study also found that personal factors (e.g., symptoms, preference, lifestyle, resilience) and environmental factors influence subjective and objective aspects of participation differently, which supported the distinction between the two dimensions. These findings emphasized the need for rehabilitation professionals to measure both subjective and objective dimensions of participation and identify contributors to the divergence in order to fully understand individual community participation experiences and to inform interventions.

The second article (Chapter 3), "*Environmental Influences on Community Participation among People with Multiple Sclerosis: A Mixed Methods Study*," has three specific aims: (1) To quantitatively assess the impact of environmental factors (EFs) on community participation among people with MS; (2) To quantitatively explore the effect modification of EFs on the relationship between symptom severity and community participation; (3) To qualitatively understand participant perspectives on environmental influences and identify needs for system-level changes to facilitate community participation. This study also used results from the first two phases of the dissertation project to address these three aims. Quantitative results showed that EFs (e.g., perceived social support, financial resources, neighborhood safety, and use of wheeled aid) were significantly associated with both subjective and objective participation measures, however, only perceived financial resources demonstrated a moderate association with subjective participation, and other associations were weak. EFs independently explained a portion of the variation in satisfaction with participation and radius of gyration, but not in other participation outcomes. Statistical analyses revealed that compared to environmental factors, person factors had stronger impacts on community participation among PwMS and did not support the role of EFs in moderating the association between symptoms and participation. Focus group participants, however, highlighted the enabling role of environmental supports that facilitated their community participation while living with functional limitations. They also described barriers in physical, societal, and attitudinal environments and advocated for system-level improvements in four areas: accessibility in the built environment, information access, MS specialty care, and public attitudes toward people with disabilities.

The final article (Chapter 4), "*Identifying Collective Efforts to Support Community Participation: A Community Engagement Meeting with the Multiple Sclerosis Community*" described the practice of community-engaged approaches throughout the dissertation research process and reported findings from the final phase—an online MS community engagement meeting. The paper focuses on introducing the roles of community partners, their involvement in various research stages, and strategies researchers use to support their engagement. The findings from the final phase are action-oriented recommendations generated by community engagement meeting attendees for achieving system-level changes in four areas identified in the second article (i.e., improving accessibility in the built environment, information access, MS specialty care, and public attitudes towards people with disabilities).

Together, these articles provide valuable insights for clinicians and researchers on measuring community participation among PwMS to enhance understanding of their experiences and the importance of understanding what environmental factors support or hinder community participation experience of PwMS and how. The studies also offer potential solutions for clinicians, organizations, and policymakers to support community participation of PwMS through increasing environmental support. Last but not least, the dissertation highlights the meaningfulness of community-engaged research centering the community's voices and needs and provides an example for engaging the MS community and other disability communities in research process.

This research was conducted with the approval of the Human Subjects Division

of the University of Washington with exempt status

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Plain Language Summary

Why is it important to study community participation and understand environmental influences on community participation among people with multiple sclerosis?

Community participation, defined as doing activities outside of the home, is highly valued by individuals living with multiple sclerosis (MS). Being able to go out and do meaningful things in the community as desired is an important component of their quality of life and well-being. Research shows that after diagnosis, many people with MS experience a decline in their ability to take part in community activities outside their homes. Community participation challenges could be related to the chronic symptoms and functional limitations associated with the disease; however, people with MS have shared that the barriers they experience outside the home are mostly extrinsic factors. For example, a person with MS who uses a wheelchair and cannot drive may find participating in activities outside the home challenging because taking public transportation is not convenient. Many studies have been done to understand how MS-related symptoms, such as mobility difficulty, fatigue, and pain, affect community participation. However, it is not fully explored how external factors in people's surrounding physical and social environments affect their participation experience. Understanding community participation experiences and how the external environment affects the experiences is critical to inform interventions to promote community participation among people with MS.

What was the focus of this study?

The aim of this study was to explore the experiences of community participation among people with MS. It focused on how physical, societal, and attitudinal environments impact their satisfaction and ability to participate in activities in the community. The research team also aimed to identify what needs to be changed in society and offer ideas for clinicians, researchers, organizations, and policymakers to better support people with MS to participate in community activities with satisfaction.

How was the research done?

The study included multiple phases and centered perspectives of people living with MS and those without MS but having a connection with MS, such as clinicians and MS researchers, throughout the process. A community advisory board was formed with two individuals with MS and one caregiver who also has a leadership role in the National MS Society. The advisory board helped plan and carry out research activities. We first conducted statistical analyses on previously collected data to better understand how community participation should be measured and also to learn about the association between environmental factors and participation. These data were collected from 101 people with MS who participated in an earlier research study. We then had four online focus groups with 24 people with MS to discuss how external factors affect their ability and satisfaction during their participation outside of the home and how they navigate the environmental barriers. We asked them what changes in society they would like to see to better support people with MS to go out and do things in the community as they wish. Finally, we hosted an online community engagement meeting with 21 attendees who are individuals with MS, caregivers, MS community organization personnel, clinicians, and researchers to brainstorm what can be done to increase societal and political support for community participation.

What are the key findings and takeaways?

From the statistical analyses, we found that environmental factors are significant in influencing community participation, even though severe symptoms may play a bigger role in interfering with participation. However, focus group participants shared that various environmental barriers make it difficult for them to do what they want to do and need to do in the community. These barriers include but are not limited to inaccessible public spaces and public transportation, weather, locations, difficulty in obtaining resources, employment challenges, and other people’s negative attitudes. Those who live with long-term functional limitations emphasized that environmental support is of great help enabling them to go out more and do more meaningful things outside the home. Participants in this study advocated for and brainstormed solutions for improvements in the accessibility of the built environment, access to useful information, MS specialty care, and public attitudes toward people with disabilities. This project provides useful information for healthcare professionals, MS community organizations, and policymakers on how to measure and support community participation among people with MS. Additionally, the project demonstrates the value of engaging individuals with lived experiences in research projects.

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Many people say that PhD is hard, and some people have no idea what PhD is like. Indeed, PhD, just like everything else in life, is an experience you must go through yourself to truly understand what is like. My PhD was meaningful and perhaps less hard because I knew I was not alone. Thank you to other PhD peers in our program for the company and support. Our cohort started during the pandemic, I learned a lot from each other's resilience, and I am always inspired by the work that everyone is doing. Particular thanks to those who were willing to listen and chat with me as well as share your insights that were helpful for getting me through various life aspects. I am extremely grateful that when I just moved to Seattle, I met a group of close friends, Mary, Maleen, and Maochuan, who are also PhD students. They were with me witnessing the highs and lows in my professional and personal life in these past years and always showed their understanding and support for me. Thank you for spending time with me and exploring the Pacific Northwest together. To my other friends whom I have met over the past few years, your companionship has made my PhD years more enjoyable. As an international student navigating a foreign country alone, friends have been an important component of my mental health. Thank you all for adding fun to my life during this time.

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Table of Contents

Chapter 1. Background and Overview of the Dissertation

The overarching objective of this dissertation is to understand the construct of community participation and examine environmental influences on community participation experiences of people with multiple sclerosis (PwMS) using mixed methods design and community-engaged research approaches. This chapter will first provide a review of the conceptualization of participation, revealing the importance of understanding how participation should be measured comprehensively and the need for using empirical data to reinforce the conceptual argument for the distinction between subjective and objective aspects of participation. In addition, conceptual frameworks describing environmental impact on disability will be detailed highlighting the need for investigating environmental influences and person-environment interaction on participation. Next, a literature review of previous MS studies was conducted to describe participation experiences of PwMS. The review revealed that PwMS face fewer barriers at home but more barriers during their participation in out-of-home activities. However, the environmental impact specifically on community participation is underexplored in the current MS literature. Following this, methods for rigorously measuring community participation will be explored, which is essential to understand prior to investigating the factors that influence community participation outcomes among PwMS. After examining the empirical studies focusing on environmental influences on participation among PwMS and the values of community-engaged research, the related research gaps in the current MS literature will be outlined, highlighting the importance of the study. Lastly, an overview of the aims and design of the dissertation and an introduction to the subsequent chapters will be provided.

Background

Conceptualization of Participation

Participation is an important outcome in rehabilitation research and practice. Since the World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF) in 2001, an increasing number of studies have considered participation a clinical outcome measure to indicate intervention effectiveness, well-being, and quality of life among people with disabilities (Hammel et al., 2008). While the ICF has served as an important conceptual framework for the development of many participation instruments since its publication (Magasi & Post, 2010), there are considerable critiques around the conceptualization of participation in the ICF. These critiques are essential to inform a full understanding of participation as a construct and participation measurement, as well as to guide empirical researchers in selecting proper instruments to measure participation in a rigorous way.

The ICF defines participation as "involvement in a life situation (WHO, 2001)." Rehabilitation scholars have raised concerns about this ambiguous definition of participation and the overemphasis on performance. Through the lens of the ICF, participation measurement primarily focuses on how independently the person is completing the activity or how much accomplishment the person achieves. Rehabilitation scholars have stressed that participation is a complex concept and can be defined differently by individuals due to its inherent individualized nature. Imrie (2004) disagreed with the ICF's attempt to universalize its classification for all people, critiquing its ignorance of the particularism variant within universalism, and emphasizing that overlooking individual differences may be unhelpful for developing just disability policies. Dijkers (2010) added that the ICF's definition of participation provides limited specificity on to what extent of involvement should be considered adequate participation. Participants in Hammel et al. (2008) seemed to answer this question by voicing that adequate participation can be defined differently by individuals depending on their participation goals, and even if people with the same participation goal can achieve it in diverse ways based on their abilities, surrounding environments, and wills.

While acknowledging that participation performance is a valuable dimension when learning about the individual's participation experience, experts have argued that the subjective perception of participation should not be overlooked (Dijkers, 2010; Whiteneck & Dijkers, 2009). **They described that participation includes two dimensions, and each dimension consists of various aspects: (1) Objective participation performance** is externally observable by other people, and it includes aspects like frequency, variety, and length of activities, as well as use of resources, observed difficulty, company, and location. **(2) Subjective perspectives of participation**, on the other hand, are only known by the individual, including aspects such as perceived difficulty, importance, meaning, satisfaction, and self-efficacy in doing the activities. Experts have argued that better objective participation performance (e.g., doing more, more often, or more independently) does not equate to better subjective experiences and, hence, does not necessarily indicate better participation outcomes (Dijkers, 2010; Whiteneck & Dijkers, 2009). For example, a person working part-time could be more satisfied with their participation than someone who works full-time because they have a lower participation goal, perceive their job as more meaningful, or encounter fewer barriers at the workplace than the other person.

Notably, the argument for the distinction between subjective and objective dimensions of participation has been primarily established conceptually, and limited empirical research evidence is available to fully reveal the degree of similarity and difference between these two dimensions. To our knowledge, only one study has explored the relationship between self-reported subjective participation measures (i.e., importance and satisfaction with participation), self-reported objective participation measures (e.g., frequency of participation and variety of activities), and objectively measured (GPS-based) objective community mobility patterns (e.g., number of non-home destinations, time spent outside the home, travel distance, and activity space) among adults with mental health disorders (Brusilovskiy et al., 2020). The study found no significant correlation between self-reported frequency of participation and self-reported satisfaction with participation, with a low correlation coefficient ($r = 0.04$, $p > 0.05$). Furthermore, none of the community mobility variables observed were significantly linked to self-reported satisfaction with or the importance of participation, suggesting that higher levels of community mobility do not equate to better perceived participation outcomes. While this study supported the distinction between subjective and objective aspects of participation, it did not include a qualitative design to provide contextual explanations from participant perspectives.

Additionally, participation is also challenging to conceptualize because of its dependence on the type of activities and the context in which the activities occur, as well as the individual's social roles (e.g., child, parent, friend, spouse, neighbor, student, employee) and perceived responsibilities within those roles (Whiteneck & Dijkers, 2009). Many researchers tried to further define the ICF's classification of participation and have proposed alternative classifications for the construct of participation. For example, Eyssen et al. (2011) conceptualized participation as encompassing social functioning, family, home, financial, work/education participation, and general participation. Chang and Coster (2014) argued that participation consists of work and education, household, and community participation components. In contrast, Magasi et al. (2009) divided participation into social participation, productivity and economic participation, and leisure or recreational participation, without recognizing home participation as an independent component. Chang et al. (2013) described that community participation should be distinguished from home or domestic participation, emphasizing that activities in the community context outside of the home demand more from the individual and require greater external support. This perspective is also supported by Hammel et al. (2015), where people with disabilities reported encountering significantly greater barriers to activities outside the home than inside it. These varying perspectives highlight the complexity and multifaceted nature of participation as a construct.

Conceptualizing Environmental Influences on Participation

The important role of the environment in influencing participation outcomes has been highlighted in previous literature. As Mallinson and Hammel described (2010, p. 30), full participation occurs "*at the intersection of what the person can do, wants to do, has the opportunity or affordances to do, and is not prevented from doing by the world in which the person lives and seeks to participate*." While acknowledging that internal factors, such as the individual's personality, will, and functioning, also influence participation outcomes, the environmental impact, in particular, is inseparable when discussing contributors to participation, yet is often overlooked. Environmental factors (EFs) are external factors embedded in the surrounding contexts where people live and conduct their lives that can hinder or facilitate their behaviors (Noreau & Boschen, 2010; WHO, 2001). These factors can be largely categorized into physical, social and societal environment, and attitudinal environment. **Physical environment** includes natural environments (e.g., climate, air quality) and built environments that are made of human-made objects used for any purposes, such as buildings for private or public use, roads, transportation, and assistive technology (i.e., products and technologies owned by individuals for the purpose of improving independent living such as mobility aid devices). **Social and societal**

environment refers to emotional, material, or informational social support, community services and resources, policies and regulations, and socioeconomic status. **Attitudinal environment** is formed by other individuals' attitudes towards the person, including attitudes from family members, friends, and colleagues; and organizational and systematic attitudes such as workplace culture, regional cultures, and religious cultures (WHO, 2001; Brandt & Pope, 1997).

Another way to categorize EFs is based on how closely or remotely the environment relates to the individual. **Micro-level environment** is the immediate environment they have direct contact with where they live, work, study, or play, including the places and people within these settings. **Meso-level environment** refers to the community they live in that has indirect influences on them, and the **macro-level environment** is the socioeconomic and political contexts in the state, country, or the globe (Hammel et al., 2015; Whiteneck & Dijkers, 2009). Numerous conceptual frameworks and systematic reviews have described the relationship between environmental factors and participation in general populations. Here, we will briefly review three representative theoretical frameworks illustrating environmental influences and how the environment interacts with internal factors of the person (e.g., function) to affect participation and other health aspects. While the Social Determinants of Health Framework highlights that macro-level environment is the root cause of health inequity experienced by communities disadvantaged by socioeconomic status, race, gender, ability, and so forth, the Social Model of Disability describes that environmental barriers are disabling for people with impairments to participate in desired activities, and the Institute of Medicine Model of Disability illustrates how the person's internal factors and environments interact to determine the amount of disability or the extent of participation restrictions.

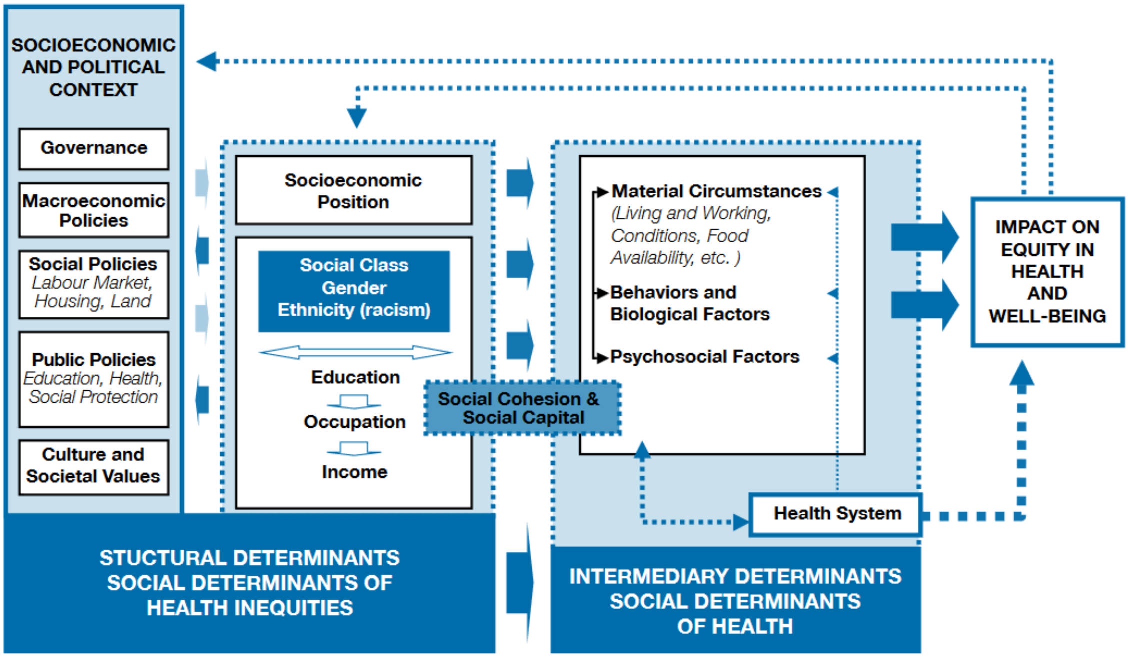
The WHO Social Determinants of Health Framework

The US spends more on health care than other countries in the world; however, health outcomes in the US ranked almost the bottom among the countries in the Organization for Economic Cooperation and Development OECD (Schroeder, 2007). This result suggests that biomedical factors are not the only determinants of health, and health problems cannot be addressed by medical care alone. Since the early 20th century, there has been growing recognition of social determinants of health (Braveman et al., 2011). Social determinants of health (SDH) refer to a set of social factors in the environment where people live that affect individual and population health and that significantly contribute to health inequities (Centers for Disease Control and Prevention, 2021).

In 2010, WHO published a conceptual framework to guide actions for promoting population health and advancing health equity (See Figure 1.1). Health equity is defined as "the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically (WHO, 2010, p. 12)." The WHO SDH framework identifies structural determinants, including the socioeconomic and political environment, as the root cause of health inequities. These upstream factors lead to social stratification, resulting in hierarchical socioeconomic positions based on gender, race, ethnicity, education, occupation, and income. Socioeconomic positions also influence social cohesion and social capital.

Upstream structural factors affect health through direct effects of a set of downstream intermediary determinants, including material circumstances, behaviors and biological factors, psychosocial factors, and the health system. Higher socioeconomic positions enable individuals to purchase products, utilize resources, adopt healthy lifestyles, and access quality health systems, reducing the risk of physical and mental illnesses. Therefore, through intermediary determinants, lower socioeconomic positions cause disadvantaged communities, including disability communities, to experience higher risks of exposure and increased vulnerability to disabling health conditions and worse health outcomes. In turn, illnesses negatively impact the socioeconomic positions of the disadvantaged, for example, through job loss or increased barriers to participation. Moreover, population health problems can also impact the entire upstream structure (i.e., socioeconomic and political context) in certain circumstances, such as a disease pandemic with high prevalence and mortality rates.

Figure 1.1 The WHO SDH conceptual framework diagram.



Social Model of Disability

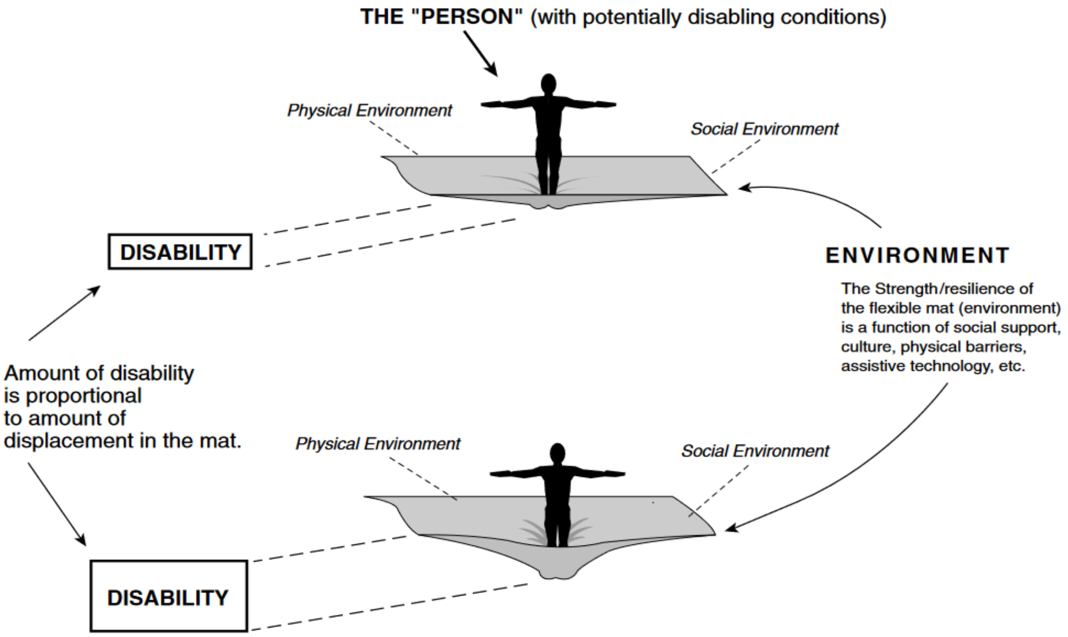
While the traditional medical model of disability suggests that the person’s impairments are the root cause of any disadvantages they experience in society and therefore these disadvantages can only be addressed by medical treatment or cure, the social model of disability

(Oliver, 1996) emphasizes that people with functional impairments are in fact disabled by the injustices in their surrounding physical, social and societal, and attitudinal environments. The social model of disability distinguishes the concept of disability from impairment, stating that disability is the “disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (Oliver, 1996, p. 22). In addition, the social model of disability also highlights the attitudinal barriers experienced by people with functional limitations who are expected to meet the expectations of the non-disabled world to achieve a standard level of quality of life and productivity. These attitudes can further disable individuals by making it difficult for them to feel good about themselves. While the social model of disability has successfully drawn attention to environmental influences on participation among people with impairments and motivated the disability rights movement that resulted in increasing societal and political support for disability communities, disability studies scholars have pointed out that this model neglects the negative impact of chronic impairments as a component of disability (Goering, 2015).

The 1997 Institute of Medicine Model of Disability

Different from the Social Model of Disability that considers environments as the sole cause of disability, the 1997 Institute of Medicine (IOM) model of disability (Brandt & Popo, 1997) acknowledges the equal contribution of the individual's biological, lifestyle, and behavioral factors, as well as the environment to determining the presence or absence of functional limitations. More importantly, the 1997 IOM Model conceptualizes the key role of person-environment interaction in determining the amount of disability (Figure 1.2).

Figure 1.2 Concept of person-environment interaction from the 1997 IOM Model of Disability



In this model, disability is a relational concept affected by the interaction between the person with functional limitations and the amount of support their surrounding environment provides. In Figure 1.2, physical and social environments form a flexible three-dimensional mat, and the strength of the mat represents the amount of environmental support. The displacement in the mat represents the amount of disability resulting from the person-environment interaction. When the same person with functional limitations stands on two mats with different strengths, standing on the weaker mat (the bottom one in Figure 1.2)—meaning they receive less support from the environment—would result in greater disability. In other words, environmental support can reduce the negative impact of functional limitations, and people with more severe functional limitations would need increased environmental support. People with functional limitations would not experience disadvantages in participation when there is sufficient environmental support.

Importance of Improving Community Participation of People with Multiple Sclerosis

Multiple Sclerosis (MS) is the most common inflammatory and neurodegenerative disease affecting approximately 2.2 million adults worldwide and one million adults in the U.S., and the prevalence has been rising over the years (Wallin, Culpepper, Campbell, et al., 2019; Wallin, Culpepper, Nichols, et al., 2019). MS-related symptoms include mobility impairments, visual issues, fatigue, pain, cognitive problems, bowel and bladder dysfunction, sexual dysfunction, sensory issues, and secondary psychological disorders such as depression and anxiety (Parker et al., 2021). The cause of MS remains unclear; however, several well-defined risk factors include low vitamin D level or ultraviolet B (UVB) light exposure, Epstein–Barr virus (EBV) infection, obesity, and smoking (Dobson & Giovannoni, 2019). The initial onset of MS occurs typically in young adulthood with relapsing-remitting symptoms. One to two decades after the initial onset, many people with MS (PwMS) transition to secondary progressive MS where their symptoms will continue to worsen. For a minority of patients, their diagnosis is Primary Progressive MS, meaning their MS is unremitting but progressive from the beginning (Wallin, Culpepper, Nichols, et al., 2019; Dobson & Giovannoni, 2019). Although there is no cure for MS, the drastically increasing effort to advance disease-modifying therapies has resulted in some level of success in extending the remission term and slowing down MS progression, which is hopeful for many PwMS (Dobson & Giovannoni, 2019). Despite the promising advancement in biomedical treatments and multidisciplinary rehabilitation interventions for PwMS, MS indeed remains life-changing for PwMS. For those who experience a relapsing-remitting phase, MS brings great uncertainty to their life, and for those who have primary progressive MS, MS seems to represent a daunting future of increasing helplessness and hopelessness (Simmons, 2010). Even though the MS journey is not identical in every person, Simmons' (2010) review also stressed that most PwMS as well as their partners and families experienced decreased quality of life and mental health oftentimes not directly because of illnesses, but because of the increased difficulty in maintaining participation in meaningful community activities, such as work, that offers a sense of self-worth.

Participation is highly valued by PwMS and is significantly associated with their well-being and quality of life (Faraclas et al., 2022; Karhula et al., 2013; Mikula et al., 2017). However, PwMS face critical challenges in participating in what they want to do and need to do in post-MS life. Goverover et al. (2020) found that PwMS reported a lower perceived amount of participation in various activities, such as domestic, leisure, and social activities, compared to people without MS. A longitudinal study showed that PwMS across different severities demonstrated declines in participation frequency over 10 years after their diagnosis (Conradsson et al., 2021). Moreover, previous research highlighted that compared to home participation, people with MS encounter more barriers in community contexts outside the home such as at workplaces and public places, where they are directly involved but have less control (Hamed, 2012; Khan & Pallant, 2007; Prodinger et al., 2010). Therefore, it is important to fully understand their experiences and contributing factors to declined and dissatisfactory participation, especially in the community contexts outside of the home where they experience more barriers. While recognizing that participation has been defined in various ways in previous research, community participation is defined as *involvement in activities occurring outside of the home* throughout this dissertation

Measuring Community Participation in a Rigorous Way

According to the conceptualization of participation reviewed in the above section, the first key recommendation applicable to community participation measurement and followed by this dissertation is **measuring both subjective aspects and objective aspects of participation in order to understand a full participation experience.** Systematic reviews of participation-focused empirical studies found that most studies used stand-alone assessments to measure participation, but many assessments only focus on either the subjective dimension or objective dimension of participation (Eyssen et al., 2011) or one aspect (e.g., frequency or intensity) within a participation dimension (Chang et al., 2013). Moreover, more participation measures inquired about participation performance or accomplishment, and fewer were centered around satisfaction with participation (Eyssen et al., 2011). Therefore, it is important to consider selecting multiple instruments to capture both subjective and objective dimensions and various aspects within each dimension in empirical participation research. To our knowledge, no studies have reviewed community participation measures specifically with the MS population; however, we found that despite the recommendation for measuring both dimensions occurring over two decades ago, many MS studies published after the 2010s attempting to measure participation used instruments measuring either only objective dimension (Bertoni et al., 2018; Cameron et al., 2014; Cattaneo et al., 2017; Conradsson et al., 2021; Hughes et al., 2015; Johansson et al., 2020; Kierkegaard et al., 2012) or only subjective dimension (Amtmann et al., 2019; Battalio et al., 2019; Blikman et al., 2017; Heine et al., 2017; Judd et al., 2022; Kwiatkowski et al., 2014; Ryan et al., 2019; Salter et al., 2019; van den Akker et al., 2016), rarely both.

Two reviews provided valuable insights into how to measure community participation in a rigorous way (Chan et al., 2021; Figueiredo et al. 2022). They stated that most community participation measures used in empirical studies are self-report outcome measures, such as surveys developed by the research team or existing standardized scales. Some of them measure subjective aspects of participation and some of them inquire about objective aspects. While subjective aspects of participation can only be measured using self-report methods due to the subjective nature, using self-report methods to capture objective participation performance may affect data quality. Chan et al. (2021) and Figueiredo et al. (2022) recommend using real-time objective measures, such as Global Positioning System (GPS) technology, for the objective dimension of community participation (i.e., community mobility performance). The GPS technology has advantages in minimizing reliance on the respondent's memory recall and active completion of lengthy questionnaires while capturing large amounts of quantifiable data (e.g., frequency of out-of-home trips, trip distance, duration, destination, activity space). To ensure the breadth of participation construct measured, Chan et al. (2021) and Figueiredo et al. (2022) recommend a complementary use of real-time self-reported measures, such as a travel diary, to record the subjective perspectives of community participation (e.g., purpose, and importance of trips). Although using GPS to measure community mobility has been validated across many health conditions and countries (Figueiredo et al., 2022), only one pilot study with a small sample size of people with MS has collected GPS data and travel diary data to document the number, type, and duration of outdoor activities and travel modes (Neven et al., 2013). Nevertheless, their study did not include participants' subjective perspectives of participation. Measuring both community mobility and subjective community participation experience rigorously will help researchers better understand complex participation experiences as well as the relationship between the two dimensions of community participation among people with MS.

Existing Evidence of Environmental Influences on Community Participation in PwMS

Systematic reviews of studies with people who have other neurological conditions, such as stroke (Nicholson et al., 2013), spinal cord injury (Kashif et al., 2019), and traumatic brain injury (de Kloet et al., 2015), emphasized the effects of external factors on participation, which supported the WHO SDH, social model of disability, and the 1997 IOM model of disability developed decades ago. Nevertheless, MS research has primarily focused on documenting the significant impact of functional impairments and secondary conditions on participation, particularly fatigue (Salter et al., 2019), limited mobility (Edwards et al., 2022), and depression (Pokryszko-Dragan et al., 2020). In contrast, only a limited number of studies have examined the influences of EFs on participation outcomes among PwMS. Within the limited literature available, many participation-focused MS studies adopted either quantitative or qualitative design and investigated a specific type of participation (e.g., communicative participation, work participation, social participation) using different measurement instruments, which could lead to variable findings regarding environmental influence on participation. Among quantitative studies, Plow et al. (2015) found that cognitive problems explained the most variance in community participation, measured by the Community Participation Indicator (Heinemann et al., 2013), with self-reported environmental barriers being the second most significant factor among PwMS. Baylor et al. (2010) focusing on communicative participation of PwMS revealed that social support is significantly associated with self-reported communicative participation; however, this correlation is weaker compared to the relationship between communicative participation and symptoms such as fatigue, depression, and cognitive problems. Lehmann et al. (2020) found that aspects of workplace environments, such as job resources and job demands, demonstrated a more prominent role in job retention compared to other person factors (e.g., age, health-related quality of life, MS duration, and symptom severity). In qualitative research, PwMS have reported that their participation restrictions are mainly due to external factors, including limited accessibility in the built environment, inadequate access to services and accommodations, and judgmental attitudes (Fong et al., 2006; Learmonth et al., 2015; Lee et al., 2019). These qualitative studies also emphasized the use of individual management strategies, such as home modifications, advance planning, self-regulation, and meditation, to manage MS-related symptoms and enhance participation. A mixed methods study by Dyck and Jongbloed (2000) found that person factors explained only 20% of the variance in work participation among women with MS, while the qualitative findings revealed the significant impact of extrinsic factors such as job flexibility and family support on employment.

Despite these insights into the role of extrinsic factors in participation outcomes, the environmental impact on community participation is yet to be fully understood. More research is needed to examine environmental influences specifically on out-of-home community participation, given that the same EFs may have different effects in different participation contexts. According to the observed discrepancy between the relevant quantitative and qualitative MS literature, it is also important to adopt mixed methods designs (Creswell & Plano Clark, 2018) capturing both quantitative and qualitative data to comprehensively reveal environmental influences on community participation among PwMS. The independent effects of EFs on community participation outcomes after accounting for personal factors, and their potential moderating role on the relationship between person factors and community participation, remain underexplored. Additionally, beyond identifying individual strategies to overcome barriers, there is a need to focus on system-level changes that can support community participation for PwMS.

Values of Conducting Community-engaged Research with the MS Community

Patient-centered care that emphasizes individual needs and preferences has long been a core component of rehabilitation practice and has proved to facilitate intervention efficacies and adherence (Danzl et al., 2012; Whiteneck & Dijkers, 2009). Additionally, there is growing recognition among researchers in rehabilitation, disability studies, and other health-related fields of the importance of involving individuals who are researched or will be affected by the research findings in the research process. People with disabilities shared concerns that researcher-driven projects may be less relevant to their lived experience and have historically perpetuated ableist attitudes and practices (Kitchin, 2000). Furthermore, disability and rehabilitation research projects conducted without genuine engagement of people with disabilities can negatively impact knowledge translation and service adoption and enlarge the research-practice gap.

Community-engaged Research (CEnR) is an approach to conducting research where community members who have shared needs, values, and interests are involved in some or all research stages (i.e., research problem identification, study design, data collection, analysis and interpretation, dissemination). CEnR is not a research methodology requiring particular study designs; rather it reflects the attitude and philosophical beliefs of the researchers—especially those who are not part of the community—who value the community's knowledge and contributions (Wallerstein et al., 2017). The significance of CEnR has been increasingly recognized in health-related fields, including public health, psychology, and nursing, since its introduction a few decades ago, and a variety of terms are used interchangeably, such as community participatory research, participatory action research, and action research. Despite the different ways of framing the participatory component and the varying histories behind each term, the shared goal of CEnR approaches is to inform and achieve positive, transformative, and sustainable changes in the community through collaborative efforts between researchers and community members (Collins et al., 2018).

Establishing a community advisory board (CAB) is a common approach to building and maintaining structured academic-community partnerships in CEnR projects (Clifasefi et al., 2020; Ehde et al., 2013). A CAB is comprised of represented community members who can advise on the research process. They can be service recipients, service providers, representatives of community organizations, caregivers, and policymakers. CAB members are invited to work with the researchers and share decision-making power during any or all of the research stages, including identifying research problems, designing and implementing research activities, analyzing data, and disseminating research findings. A CAB plays a key role in voicing the community's needs and interests and ensuring the research projects' relevance and meaningfulness to the community.

There has been a call for conducting more empirical studies adopting a CEnR approach due to its values in overcoming common challenges in rehabilitation research, such as: (1) the existence of research-practice gaps due to the irrelevance of research products to the needs of disability communities and limited access to research evidence for nonacademic decision makers, (2) challenges in participant recruitment, high attrition rate, low satisfaction, and (3) difficulty in sustaining academic-community collaboration (Camden et al., 2015; Ehde et al., 2013). Although the practice of community engagement has been growing in rehabilitation and disability research, there is a noticeable scarcity of CEnR projects specifically involving the MS community. The International MS in the 21st Century Steering Group and other MS experts called for more participatory research and encouraged information and knowledge exchange with the MS community (Rieckmann et al., 2018; Roberts et al., 2022). Current MS literature mostly presents community engagement in the early research stages, where people with MS were involved in co-identifying research topics and refining research questions (Kuspinar et al., 2020; Lee et al., 2019; Silveira et al., 2021). Few studies involved community members in data interpretation and dissemination (Koch & Kralik, 2001; Lacerda et al., 2019). No CEnR projects were found to seek a better understanding of community participation experiences among PwMS and how environments affect these experiences. Given the progressive nature of MS and its onset during young adulthood—often a time when individuals hold significant social roles (e.g., employee, student, parent) associated with high community participation needs—PwMS may face unique challenges in community participation. Therefore, it is important for researchers to center their voices and needs in order to learn about what external changes would be more beneficial for supporting their community participation.

Summary of Research Gaps Addressed by The Dissertation

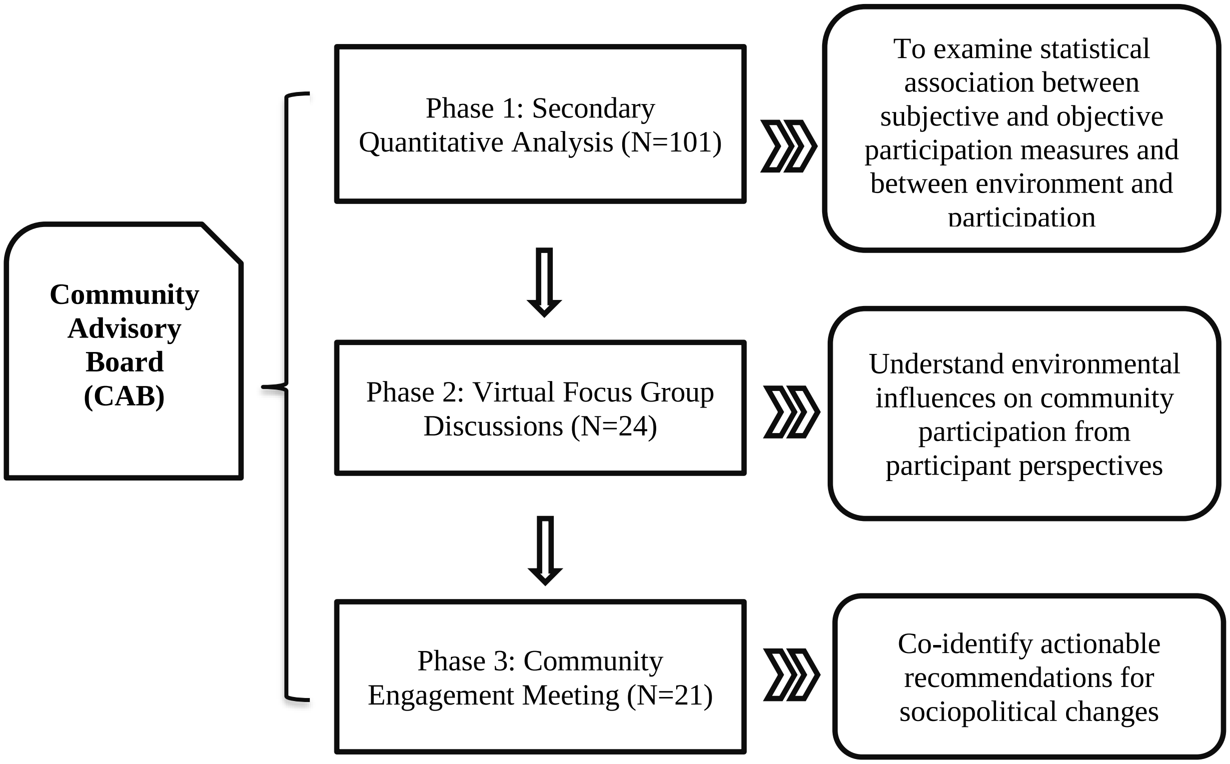
With the literature review presented above, the identified underexplored research needs informing the objectives and design of the dissertation project are: (1) understanding the relationship between subjective and objective aspects of community participation using empirical data collected from PwMS; (2) investigating environmental influences on both subjective and objective aspects of community participation after adjusting for effects of person factors as well as the interaction between person factor and EFs in affecting community participation; (3) using mixed methods design to collect both quantitative and qualitative data to fully address the first two needs; (4) exploring the need for system-level environmental support for PwMS; and finally, (5) using community-engaged research approach to involve MS community members throughout the project to ensure the relevance of this project to the community's interests and facilitate knowledge translation.

Overview of the Dissertation

The dissertation adopted a mixed-methods explanatory sequential design and community-engaged research approaches to (1) examine the relationship between subjective perspectives of participation and objective community mobility patterns among people with MS, (2) investigate environmental influences on community participation experiences of people with MS, and (3) identify individual strategies and collective efforts needed to support community participation for people with MS. The project consisted of three study phases, and Figure 1.3 presents the study procedure and the purpose and sample size for each phase. The first phase was a quantitative secondary analysis of GPS-measured and self-reported data collected from 101 people with MS who participated in a previous intervention study (Molton, NCT03653390, 2019, January 31 – 2022, November 14). The data included self-reported subjective and GPS-based objective participation measures, person factor data (i.e., demographics, physical function, fatigue, and depression), and environment data (i.e., perceived social support, perceived financial resources, perceived neighborhood safety, mobility aid use status). The second phase commenced upon the completion of secondary data analysis and consisted of online focus group discussions that were conducted with 24 individuals who have MS to explore their perspectives on contributors to satisfaction with participation as well as environmental impacts on community participation. The final phase was an MS community engagement meeting with 21 attendees who are members of the MS community to first disseminate preliminary findings of the first two phases as a background introduction and to discuss action-oriented recommendations for system-level changes. A Community Advisory Board (CAB) was established with two individuals living with MS and one individual who is in a leadership role in the National MS Society as well as a family member of someone with MS. The CAB was involved in the planning, data collection, interpretation, and dissemination throughout the project. A detailed description of their roles in the MS community and their involvement in the project is included in Chapter 4.

The rest of the dissertation is organized into three linked articles with various specific aims but will cover the findings of the entire project. Using data results from the first two phases, the first article (Chapter 2), "*Is Doing More Always Better? A Mixed Methods Study Examining the Relationship between Subjective and Objective Dimensions of Community Participation among Individuals with Multiple Sclerosis*" is a mixed methods paper revealing the relationship between subjective and objective community participation measures using empirical quantitative and qualitative data from people with MS. The second article (Chapter 3), "*Environmental Influences on Community Participation among People with Multiple Sclerosis: A Mixed Methods Study*" also utilized data results from the first two phases; however, answered the following research questions: (1) How do physical, societal, and attitudinal environments influence community participation experiences among people with MS? (2) How might environmental factors moderate the relationship between symptom severity and participation? (3) What are the priorities for increasing environmental support? The final article (Chapter 4), "*Identifying Collective Efforts to Support Community Participation: A Community Engagement Meeting with the Multiple Sclerosis Community*" describes the process of community engagement in the dissertation project and showcases strategies used to engage the MS community members in research. The article also reported findings from the third phase, which are MS community-informed action-oriented recommendations for sociopolitical changes that can optimize community participation experience for people with MS. The final chapter (Chapter 5) summarizes the findings of all studies and discusses implications and future research directions.

Figure 1.3 Flow of study



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Chapter 2. *Is Doing More Always Better?* A Mixed Methods Study Examining the Relationship Between Subjective and Objective Dimensions of Community Participation among Individuals with Multiple Sclerosis

Abstract

Previous research has highlighted the complexity and individuality of participation, emphasizing the necessity to measure both subjective (e.g., satisfaction) and objective (e.g., engagement quantity) dimensions of participation to fully understand the experience. However, empirical evidence distinguishing these dimensions remains limited. While subjective aspects are best captured through self-reports, real-time objective measures like the Global Positioning System (GPS) technology are recommended for objective participation. Despite these recommendations, current practices in measuring participation among people with multiple sclerosis (MS) often lack adherence. Given the critical challenges faced by those with MS during community participation outside the home, it is essential to measure their participation rigorously to comprehend real-world experiences. This study used a mixed methods design to examine the relationship between subjective and objective dimensions of community participation among people with MS in the US and explore factors explaining the relationship. Correlation analyses of GPS-measured and self-reported participation measures, person factors, and environment data from 101 individuals with MS found a significant, positive, but weak association between objective and subjective participation measures. As one exception, trip duration was moderately associated with subjective measures. The same person factors and environmental factors demonstrated varying magnitudes of association with subjective compared to objective participation measures. Focus group findings supported the quantitative results, indicating that while more community outings might lead to higher satisfaction, satisfaction does not require frequent or lengthy outings. Individual participation goals, functional declines, resilience, and environmental barriers may be the reasons explaining the weak relationship between subjective and objective participation measures. This study provides empirical evidence supporting the importance of measuring both subjective and objective participation outcomes. It suggests that attention must be paid to the divergence between these dimensions to help practitioners better address the specific needs of people with MS, ultimately enhancing their community participation.

Keywords: Community participation, participation, measurement, global positioning system, multiple sclerosis

Introduction

Participation is defined as “individuals’ involvement in life situations” in the International Classification of Functioning, Disability and Health (ICF, World Health Organization, WHO, 2001, p. 10). Rehabilitation scholars have raised concerns about the oversimplified definition of participation in the ICF, emphasizing that participation is a multifaceted concept that is complex and individualized in nature (Imrie, 2004). One of the critiques agreed upon by rehabilitation scholars is that the ICF overemphasizes participation performance which focuses on the quantity of activities and independence (i.e., objective dimension of participation) but overlooks individual participation goals and how the person perceives their engagement in activities (i.e., subjective dimension of participation, Dijkers, 2010; Wade & Halligan, 2003). The overemphasis on participation performance assumes that doing more activities and completing activities more independently is better, however, it penalizes people with disabilities who often establish different ways of participating in life which may look like they do less than others without disabilities (Hammel et al., 2008).

Experts argued that improved objective participation (e.g., increased frequency, greater independence) does not always result in better subjective perception, and thus does not necessarily indicate better participation outcomes (Dijkers, 2010; Whiteneck & Dijkers, 2009). For instance, someone who socializes infrequently but with close friends might report higher satisfaction compared to a person who frequently attends large social gatherings but feels disconnected by the interactions. Therefore, it is argued that due to the divergence, both subjective and objective aspects of participation need to be measured in order to fully understand participation. As discussed in a systematic review (van de Velde et al., 2018), the importance of including measurements for subjective aspects of participation has been well-supported by existing qualitative literature. However, empirical studies directly examining the relationship between subjective and objective dimensions of participation are generally lacking. Several empirical studies have investigated relationship between subjective and objective aspects of participation and supported a divergence between the two dimensions with various findings. For example, Johnston et al. (2005) explored the relationship between the self-reported frequency of participation in various home and community activities and individuals' satisfaction with these activities among people with traumatic brain injury. They found that the associations were generally weak and non-significant, although significant and moderate correlations are seen in some activities. Yorkston et al. (2008) assessed the association of symptoms (e.g. mobility difficulty, pain, depression, fatigue) with self-reported subjective participation (i.e., perceived importance and self-efficacy) as well as self-reported objective participation (i.e., frequency) in 28 daily activities among people with multiple sclerosis. They found that symptoms were more strongly associated with self-efficacy, less associated with self-reported frequency, and not significantly associated with perceived importance. These findings revealed that subjective and objective aspects of participation are influenced by symptom factors differently, indicating the distinction between the two dimensions. Brusilovskiy et al. (2020) also examined the association between subjective and objective aspects of participation outside the home among adults with mental health disorders and reported weak and non-significant correlations between self-reported subjective (i.e., importance and satisfaction with participation) and objective (i.e., self-reported frequency of participation and GPS-based community mobility performance) community participation measures. Nevertheless, although these studies provided quantitative support for the distinction between subjective and objective participation, they did not include a qualitative design to explain the weak and non-significant associations from participants’ perspectives or comprehensively explore contributing factors to the relation between subjective and objective dimensions to reveal a more precise relationship between the two dimensions.

Participation is challenging to operationalize and measure also due to its dependence on the purpose of the activity, context, and the individual's social roles and perceived responsibilities to fulfilling those roles. Researchers have attempted to standardize the classification of participation for measurement purposes. For example, Eyssen et al. (2011) argued that participation encompasses social functioning, family, home, finance, work/education, and general activities, while Chang and Coster (2014) defined participation as consisting of work and education, household, and community participation. Magasi et al. (2009) categorized participation into productivity and economic activities, social interactions and relationships, and leisure pursuits, without recognizing home participation as a distinct component. Chang et al. (2013) distinguished community participation from home participation, emphasizing that activities in the community are more complex and have higher demands for the individual. This was also supported in a study by Hammel et al. (2015) where participants with disabilities reported facing significantly more barriers outside the home, requiring more external support to participate in activities in the community. Therefore, understanding the participation experiences of people with disabilities in the community contexts is crucial. While acknowledging that participation has been defined in various ways in previous research, in this study, community participation is conceptualized as *activity involvement in activities occurring outside of the home*.

Community participation is an important rehabilitation and health outcome among people with chronic conditions and therefore is important to measure in a comprehensive way to reveal the full picture of participation experience (Chang et al., 2013; Whiteneck & Dijkers, 2009). The subjective dimension of community participation has been commonly measured as perceived difficulty, satisfaction, importance, and autonomy. The objective dimension of community participation can be reflected by company, variety of activity, and community mobility patterns such as travel frequency, distance, and duration, and activity space outside the home (Dijkers, 2010; Figueiredo et al., 2022). Previous studies have mostly used self-report measures to assess both the subjective (e.g., satisfaction) and objective (e.g., frequency of activities in a given time period) dimensions of participation. Chan et al. (2021) and Figueiredo et al. (2022) discussed that while subjective participation aspects can only be measured using self-report methods due to the subjective nature, using self-report surveys to measure objective aspects may limit the data quality. They further described that real-time observation methods, such as the global positioning systems (GPS) technology, have been recommended as a reliable and valid tool to capture objective community participation (e.g., community mobility patterns) given its advantages of minimizing recall bias and respondent burden while collecting a vast amount of data.

People living with multiple sclerosis (MS), the most common inflammatory neurodegenerative disease among young adults, experience participation restrictions reflected by declined frequency of activity participation after the diagnosis (Conradsson et al., 2021). People with MS also voiced that their dissatisfaction with and the critical challenges faced during participation outside the home are mainly due to extrinsic factors, such as an inaccessible built environment, lack of social support, and negative attitudes from others (Learmonth et al., 2015; Prodinger et al., 2010). Participation-focused studies in the MS literature have mainly documented the impact of person factors on participation, as shown by reviews synthesizing the effects of age, disease duration, mobility limitations, fatigue, and depression (Boeschoten et al., 2017; Chaudhuri & Behan, 2004; Edwards et al., 2022; Marrie et al., 2015). Several empirical studies have also explored the influence of environmental factors, such as social support and use of mobility devices, on participation experiences of the MS population (Learmonth et al., 2015; Lehmann et al., 2020; Plow et al., 2015). These studies conveyed that both person factors and environmental factors (EFs) environmental factors can impact participation outcomes among people with MS. However, it is less known whether they affect subjective and objective dimensions of participation similarly or differently.

It is worth noting that despite the emphasis on the distinction between subjective and objective dimensions of participation and the argument for the importance of measuring both dimensions arose over two decades ago, most participation-focused MS studies published after the 2010s adopted only a single instrument measuring either only the objective dimension (Bertoni et al., 2018; Cameron et al., 2014; Cattaneo et al., 2017; Hughes et al., 2015; Conradsson et al., 2021; Johansson et al., 2020; Kierkegaard et al., 2012) or the subjective dimension of participation (Amtmann et al., 2019; Battalio et al., 2019; Blikman et al., 2017; Heine et al., 2017; Judd et al., 2022; Kwiatkowski et al., 2014; Ryan et al., 2019; Salter et al., 2019; van den Akker et al., 2016), but rarely both (Plow et al., 2015 who used Community Participation Indicator by Heinemann et al., 2013 measuring self-reported frequency, importance, and enfranchisement of participation). Notably, among these cited participation-focused MS studies, a variety of instruments were used to measure only the objective or objective dimension. For example, instruments used to measure objective dimension of participation included Community Integration Questionnaire focusing on the frequency and assist level during participation (Hirsh et al., 2011) as well as Frenchay Activities Index focusing on the frequency of activity participation (Holbrook & Skilbeck, 1983). Assessments for subjective dimension of participation included PROMIS Ability to Participate in Social Roles and Activities and PROMIS Satisfaction with Participation in Social Roles (Hahn et al., 2010).

Furthermore, although using GPS to measure community mobility has been validated across many health conditions and countries (Figueiredo et al., 2022), only one pilot study with a small sample size of people with MS has collected GPS data to document the number, type, and duration of outdoor activities and travel modes (Neven et al., 2013). Nevertheless, Neven et al. (2013) did not investigate participants' subjective perspectives of participation. It is important to establish evidence using rigorous data to reveal whether subjective and objective dimensions of participation are closely related or differ drastically as well as to explore whether they are similarly or differently influenced by person factors and EFs in order to better understand participation experience among PwMS and inform effective interventions.

This mixed methods study aimed to examine the relationship between subjective aspects of community participation, measured by self-reported instruments, and objective aspects of community participation performance, described with GPS data and real-time travel log data collected from a sample of individuals with MS. In addition, we examined the association of person factors and EFs with both subjective and objective aspects of community participation. We hypothesized that subjective and objective aspects of community participation are positively related but the strength of association is weak. We also anticipated that person factors and environmental factors have different strengths of association but similar directions with subjective participation measures compared to objective measures. These hypotheses were further explored using qualitative data.

Methods

Research Design

This study used a mixed-methods design collecting both quantitative and qualitative data to answer research questions (Creswell & Plano Clark, 2018). This design not only allowed us to detect the strength and direction of the relationship between subjective and objective dimensions of community participation but also offered contextual explanations of the relationship. This study was approved by the University of Washington Human Subjects Division with an exempt status.

Quantitative Phase

Parent Study and Data Source

Quantitative data for this study were derived from a longitudinal clinical trial that compares the effectiveness of Enhance®Wellness to a generic well-being education program and treatment as usual groups among adults living with long-term physical disabilities (Molton, NCT03653390, 2019, January 31 – 2022, November 14). Enhance®Wellness is an evidence-based program that helps improve the general well-being of individuals with chronic conditions (Hughes et al., 2011). The parent study (n = 516) included adults aged 45-64 who had at least one chronic condition such as amputation, muscular atrophy, spinal cord injury, stroke, or MS, who could communicate in English and with no significant cognitive impairments as indicated by the Six-item Screener (Callahan et al., 2002). Only baseline data collected from participants with an MS diagnosis were included in the quantitative phase of this project. Baseline data was collected between April 2019 and September 2021. At baseline, all participants completed a survey inquiring about their current well-being. A random subset of baseline participants with MS (n = 122) was invited to a GPS sub-trial where participants were asked to carry a GPS device (QStartz BT Q1000XT GPS logger) for seven consecutive days to record their real-time community mobility patterns. Eighty-three percent (n=101) of participants with MS returned valid GPS data (have at least two days of GPS tracking data as defined by the original study).

Therefore, baseline survey and GPS data from a total of 101 participants with MS were included in the quantitative phase of this study.

Participation Measures

The subjective dimension of participation included two aspects: **Perceived ability to participate** in meaningful activities, measured by PROMIS Ability to Participate in Social Roles and Activities short form (PROMIS-AP), as well as **satisfaction with participation**, measured by PROMIS Satisfaction with Social Roles and Activities short form (PROMIS-SRA). Both PROMIS-AP and PROMIS-SRA include 8 items using a 5-point scale (Hahn et al., 2010). T-scores were derived based on the sum of the raw scores. A PROMIS-AP T-score greater than 45 falls within normal limits compared to the general US population, while a PROMIS-SRA T-score between 40-60 represents the average level in the general U.S. population (HealthMeasures, 2023). Higher T-scores indicate better perceived ability or higher satisfaction.

The objective dimension of participation is indicated by community mobility performance measured by GPS technology and includes four aspects: **Daily trip frequency** (number of times a person goes out per day), **daily trip distance** (cumulative distance of trips per day, reported in kilometers or km), **daily trip duration** (cumulative hours of trips per day), **and radius of gyration** during the entire tracking period (reported in meter or m). In the context of community mobility, radius of gyration measures how far a person typically moves from the central point (i.e., their home) to all the locations they visited outside the home during the tracking period (Gonzalez et al., 2008). Radius of gyration is a metric representing one's activity space; therefore, it is a spatial concept distinct from daily trip distance that focuses on the linear length of a typical single trip. A trip is defined by the original study as a journey that starts and ends at an individual's home, including any intermediate stops. Trips outside the home were identified using point-level GPS data, with movements beyond 200 meters from the home considered as outside trips.

Person Factor and Environmental Factor Variables

Person factors include demographic information and MS-related symptoms measured by the baseline survey. **Demographics** included age, disease duration (years living with MS), gender, race and ethnicity, educational background, annual household income, marital status, employment status, and comorbidity status. Only age and disability duration were included in inferential analyses because they are known influencing factors in participation outcomes among PwMS (Allataifeh et al., 2020; Goverover et al., 2020). **MS-related symptoms** consisted of physical function, fatigue, and depression. They were measured by the 11-item PROMIS Physical Function Short Form (PROMIS-PF, Rose et al., 2014), 4-item PROMIS Fatigue Short Form (Cook et al., 2012), and PROMIS Depression 6-item Short Form (Pikonis et al., 2011), respectively. A PROMIS-PF T-score greater than 45 falls within normal limits compared to the general U.S. population. For the PROMIS Fatigue and Depression scales, a T-score lower than 55 indicates within normal limits, while scores of 55-60, 60-70, and above 70 represent mild, moderate, and severe fatigue or depression, respectively, compared to the general U.S. population (HealthMeasures, 2023). Higher T-scores of the three measures indicate higher physical function, more severe fatigue, and more severe depression, respectively.

Environmental factors (EFs) included **perceived social support**, **perceived financial resources, perceived neighborhood safety, and mobility aid use status** captured by the baseline survey. Perceived social support, financial resources, and neighborhood safety were measured by three items from the Older People Quality of Life short form (QPQoL): *"My family, friends or neighbors would help me if needed", "I have enough money to pay for household* *bills," and "I feel safe where I live."* The OPQoL is a reliable and valid measure assessing respondents' overall perceptions of quality of life with a 5-point rating scale for each item with a higher rating indicating stronger agreement with the statement (Bowling et al., 2013). Participants were asked about their **mobility aid use status** by responding to the question, "How often do you use each of the following: crutches, cane(s), walker, medical shoes, manual wheelchair, power wheelchair, scooter, brace, hiking poles," with options of never, sometimes, or always. Their answers were then categorized into three groups: (a) using any mobility aids (0 = No, 1 = Yes), (b) using walking aids only (e.g., cane, walker, brace) (0 = No, 1 = Yes), and (c) using wheeled aids (e.g., manual wheelchair, power wheelchair, scooter), which also includes using a combination of wheeled and walking aids (0 = No, 1 = Yes).

Quantitative Data Analysis

A descriptive analysis was used to report participant characteristics, including descriptive community participation measures. Pairwise correlations were calculated to investigate associations between subjective (i.e., perceived ability to participate, satisfaction with participation) and objective (i.e., trip frequency, trip distance, trip duration, radius of gyration) participation measures as well as to examine the association of person factors (i.e., age, disease duration, physical function, fatigue severity, depression severity) and EFs (i.e., perceived social support, financial resources, neighborhood safety) with both the subjective and objective aspects of participation. Distributions of continuous variables were examined on continuous variables prior to correlation analyses. The correlation measure reported differed based on the distribution of the data. The correlation measure reported differed based on the distribution of the data. **Pearson Correlation (r)** was utilized for normally distributed continuous variables, **Spearman's Rho (ρ)** was utilized for continuous variables with non-normal distributions, **Point-**

Biserial (rpb) was used for correlations between dichotomous and normally distributed continuous variables, while **Rank Point-Biserial (rank-rpb)** was used for correlations between dichotomous and non-normally distributed continuous variables. Correlation results with an associated p-value below 0.05 are considered statistically significant. Correlation coefficients of 0.3 or below were considered weak, those above 0.3 but below 0.7 were considered moderate, and coefficients of 0.7 or higher were considered strong (Akoglu, 2018). A p-value below 0.05 is considered statistically significant. Quantitative analyses were conducted with IBM SPSS Statistics (Version 27).

Qualitative Phase

Online Focus Group Recruitment

Convenience and purposive sampling were utilized to recruit participants for online focus groups in January 2024. Participants in the qualitative phase were not the same individuals who participated in the quantitative phase. A screening survey, collecting details on demographics, mobility aid usage, and interest in participation, was disseminated to the University of Washington MS Rehabilitation and Wellness Center national registry, the National MS Society website, and their registries for three states (WA, IL, NY), representing the West, Midwest, and Northeast regions. Participants for the focus groups were selected from the pool of people who responded to this screening survey. To be eligible, participants needed to be adults with MS who had access to Zoom, could communicate functionally in English, and agreed to join the focus groups. Participants were also selected to represent diversity in gender, race, MS duration, location, employment status, and mobility aid use status.

Data Collection

Four online focus groups were conducted via Zoom videoconferencing. Participants were grouped based on their mobility aid use status, which was considered relevant for additional research questions reported elsewhere (Chapter 3). A discussion guide was developed and reviewed by academic advisors with expertise in focus group studies and community advisors with lived experiences to facilitate conversation. Community advisors were two individuals with MS and one family member of someone with MS. At least one community advisor co-facilitated focus group discussions with the lead researcher. While focus groups also discussed other topics, such as the effects of internal and external factors on their experiences in participating in out-of-home activities, only data relevant to their perspectives of satisfaction with community participation were included in this paper. As an example, focus group participants were asked, "Are you satisfied with your current level of community participation, why or why not?" Focus groups were recorded on Zoom and transcribed verbatim for analysis.

Data Analysis

A full in-depth analysis was completed for another study (See Qualitative Data Analysis Section in Chapter 3). For the purpose of the analysis in this paper, only a subset of participant perspectives specific to the question regarding the relationship between satisfaction with participation and the quantity of out-of-home participation was coded. Directed content analysis (Hsieh & Shannon, 2005) with deductive coding technique was used. Two coders participated in the independent coding, coding review, and theme development process with multiple discussion meetings held to reach an agreement. Member checking was conducted by emailing focus group participants a summary of results and a request for feedback. Qualitative findings and quantitative findings were interpreted together to answer overarching research questions in a comprehensive manner.

Results

Participant Characteristics and Descriptive Results

Among the 101 participants in the quantitative phase, the average age was 55.5 years old, ranging from 45-64 years, and the average MS duration was 19.5 years, ranging from 1-45 years. Most participants were White (86%) and female (80%), and over half reported an annual household income higher than US $50,000 (68%), had a college degree or higher (68%), and were married (62%). Only 34% of the participants were employed. Among the 67 participants using a mobility device, 33% used walking aids only and 33% used a wheeled aid or a mixture of wheeled aids and walking aids. The results of impairment and EF assessments indicated that our participants had lower physical function (T-score = 40.8), greater fatigue severity (T-score = 59.9), and depression severity within normal limits (T-score = 51.8) compared to the national average populations in the US (T-score = 50.0, HealthMeasures, 2023). They perceived high levels of social support, financial resources, and neighborhood safety (mean scores > 4).

When it comes to community participation characteristics, participants' perceived ability to participate ($\text{T-score}_{\text{PROMIS-AP}} = 42.1$) and satisfaction with participation ($\text{T-score}_{\text{PROMIS-SRA}} = 43.2$) were both within the average levels of the general US populations (HealthMeasures, 2023). The 101 participants wore a GPS device for an average of 7.7 consecutive days, with a range between two and 19 days. Most participants (90.1%) were tracked for 7 days or more with the most common tracking lengths being either 7 days (47.5%) or 8 days (23.8%). The GPS data indicated that, on average, participants made one trip per day, with a daily cumulative trip distance of 30 km and a cumulative trip duration of 3 hours. Additionally, the GPS data showed that the average radius of gyration over the entire tracking period was 14,849 meters, with significant variability among participants (SD = 32,019).

Twenty-four people with MS participated in four online focus groups, with each group having six participants and lasting for about 90 minutes. On average, participants aged 50 years, ranging from 33-66, and lived with MS for 16 years, ranging from 1-33 years. Participants were located in 10 different states. The majority of participants were female (63%), non-Hispanic White (75%), unemployed or retired (54%), and identified as disabled (71%). Half (n = 12) of them reported using mobility aids during community outings. Eight participants took part in member checking, providing comments that validated the results and emphasized the importance of certain content. Table 1 presents the characteristics of individual focus group participants.

Table 1. Characteristics of Individual Focus Group Participant

ID	Age	MS Duration (year)	Gender	Race	Employment	Region	Use of Mobility Aid
P1	55	29	Female	NH White	Retired	Midwest	None
P2	63	25	Male	NH White	Employed, part-time	Northwest	None
P3	59	18	Female	NH White	Retired	South	None
P4	39	5	Female	African American	Employed, full-time	Northwest	None
P5	36	5	Female	African American	Employed, full-time	West	None
P6	40	3	Male	NH White	Unemployed	Northwest	None
P7	42	6	Female	African American	Employed, full-time	Midwest	None
P8	35	12.5	Male	NH White	Other	West	None
P9	47	7.5	Female	mixed race	Employed, full-time	Northwest	None
P10	51	24	Male	NH White	Employed, full-time	Midwest	None
P11	33	10	Female	NH White	Employed, full-time	West	None
P12	37	1	Nonbinary	NH White	Unemployed	West	None
P13	57	27	Female	NH White	Retired	Midwest	rollator
P14	58	24	Male	NH White	Unemployed	Northwest	power wheelchair and scooter
P15	42	11	Female	NH White	Unemployed	Midwest	manual wheelchair and scooter
P16	44	14	Male	NH White	Employed, full-time	Northwest	cane
P17	66	33	Female	NH White	Retired	Midwest	power wheelchair and scooter
P18	62	22	Female	NH White	Retired	West	walker
P19	66	28	Female	NH White	Retired	West	power wheelchair
P20	58	8	Male	African American	Employed, part-time	Northwest	power wheelchair
P21	65	10	Female	NH White	Retired	Northwest	cane, walker, medical shoes, manual wheelchair
P22	61	28	Female	African American	Unemployed	South	cane, walker, medical shoes, manual wheelchair
P23	44	5	Female	NH White	Employed, part-time	Midwest	cane, walker, manual wheelchair
P24	47	12	Male	NH White	Unemployed	Midwest	power wheelchair

Note. NH = Non-Hispanic

Quantitative Results

Age, disease duration, MS-related symptom variables, and subjective participation variables were normally distributed. Objective participation measures were nonnormally distributed continuous variables. Table 2 shows correlations between subjective and objective participation measures. First, associations within subjective participation measures and within objective participation measures were positive and moderate to high. A high correlation was found between perceived ability to participate and satisfaction with participation ($r = 0.78$, $p < 0.001$). Among the four objective participation outcomes, strong correlations were found between three pairs—trip duration and trip frequency, trip duration and trip distance, and radius of gyration and trip distance ($\rho_{range} = 0.78 – 0.88$, $p < 0.001$). Trip distance and trip frequency, trip frequency and radius of gyration, and radius of gyration and trip duration were moderately correlated ($\rho_{range} = 0.43 – 0.69$, $p < 0.001$). Second, most of the associations between subjective and objective participation measures were significant and positive but weak, with one exception. Only trip duration showed significant, positive, and moderate association with both perceived ability to participate ($\rho = 0.33$, $p < 0.01$) and satisfaction with participation ($\rho = 0.32$, $p < 0.01$). Trip distance had a significant, positive, but weak association with both perceived ability to participate ($\rho = 0.27$, $p < 0.01$) and satisfaction with participation ($\rho = 0.29$, $p < 0.01$). Trip frequency was significantly and positively associated with satisfaction with participation only but the magnitude was weak ($\rho = 0.25$, $p < 0.05$). Radius of gyration demonstrated non-significant, positive, and weak association with both subjective participation measures.

Table 2. Correlations between Subjective and Objective Participation

Measure	1.	2.	3.	4.	5.	6.
1. Perceived Ability to Participate	--					
2. Satisfaction with Participation	.78 ***	--				
3. Trip Frequency	.19	.25 *	--			
4. Trip Distance	.27 **	.29 **	.69 ***	--		
5. Trip Duration	.33 **	.32 **	.78 ***	.88 ***	--	
6. Radius of Gyration	.18	.19	.43 ***	.82 ***	.59 ***	--

Note. *N*=101. ** p < .05, ** p < .01, *** p < .001.*

Table 3 presents the association of person factors and EFs with both subjective and objective participation measures. When significant, the associations between the same person factor or EF and both subjective and objective participation measures were in the same direction. For example, depression severity was significantly and negatively associated with both subjective (i.e., perceived ability to participate and satisfaction with participation) and objective participation measures (i.e., trip distance). Among person factors, physical function, fatigue, and depression showed significant and moderate associations with subjective participation measures (r_{range} = 0.37 - -0.57, p < 0.001). Among EFs, perceived financial resources showed moderate correlations with both subjective participation measures (r_{range}=0.38 - 0.48, p < 0.001), and use of any mobility aids showed a moderate correlation with satisfaction with participation (rbp = -0.31, p < 0.01). However, only physical function was significantly and moderately associated with three out of four objective participation measures (i.e., trip frequency, trip distance, and trip duration, r_{range} = 0.33 – 0.37, p < 0.05). The use of any mobility aids had moderate correlations with two of the objective measures (i.e., trip distance and trip duration, rank-rbp_{range}= -0.30 - -0.33, p < 0.01). All other correlations were weak and non-significant.

Table 3. Correlations between Independent Variables and Participation Outcome Variables

Measure	1. Perceived Ability to Participate	2. Satisfaction with Participation	3. Trip Frequency	4. Trip Distance	5. Trip Duration	6. Radius of Gyration
Person Factors						
Age	-.10	-.11	-.02	.03	-.01	.00
Disease Duration	.02	-.03	.09	.02	.07	-.06
Physical Function	.37***	.41***	.34**	.33**	.37***	.21*
Fatigue Severity	-.57***	-.41***	-.09	-.01	-.01	.02
Depression Severity	-.38***	-.45***	-.16	-.23*	-.14	-.16
Environmental Factors						
Perceived Social Support	.24**	.29***	.14	.16*	.10	.10
Perceived Financial Resources	.38***	.48***	.13	.19*	.16*	.15
Perceived Neighborhood Safety	.22**	.22**	.12	.20*	.12	.20*
Using Any Mobility Aids	-.28**	-.31**	-.16	-.33**	-.30**	-.28*
Using Walking Aid Only	-.06	-.04	.06	-.11	-.11	-.12
Using Wheeled Aid	-.22*	-.28**	-.22*	-.22*	-.19	-.15

Note. N=101. * p < .05, ** p < .01, *** p < .001. Using wheeled aid includes both the exclusive use of wheeled aids and the combined use of wheeled aids and walking aids.

Qualitative Findings

Two themes emerged from focus groups to further describe the relationship between the frequency of community outings and satisfaction with community engagement from participant perspectives. In theme 1, some focus group participants shared that being able to go out and participate in activities outside the home as desired is an important component of satisfaction and that the reduced frequency of community outings after being diagnosed with MS made them feel dissatisfied. Among these participants, they implied that person factors (i.e., functional declines) and environmental factors (e.g., COVID-19, employment challenges) contributed to both reduced frequency and reduced satisfaction. Theme 2 presents that some focus group participants highlighted that satisfaction does not require frequent outings, and going out frequently does not always mean that they are satisfied. There appeared to be somewhat more resonance among group members for Theme 2. Participants discussed that people can feel satisfied regardless of the frequency of outings because some people willingly choose not to go out frequently or have accepted the new life with a lower frequency of community outings and developed strategies to engage in community proactively. Therefore, the perception of participation is primarily influenced by the person's preference, lifestyle, and resilience, rather than the frequency of outings. A few participants also implied that they go out frequently because they needed to and wanted to. However, a high frequency of participation did not always lead to satisfaction because of the environmental barriers in the community.

Overall, qualitative findings revealed that although some participants considered going out more frequently as a factor leading to higher satisfaction, many disagreed that satisfaction requires frequent, lengthy, or extended community outings. These findings indicated that frequency of participation and satisfaction with participation are positively related but their association is weak, which supported the quantitative findings showing significant, positive, but weak to moderate association between subjective and objective participation measures. Focus group participants also expressed additional perspectives explaining the various magnitude of influence of person and environmental factors on subjective perception of participation compared to objective participation measures. Details of each theme are described below.

Theme 1: Doing More May Be Better: For some people who are experiencing major limitations of community participation due to functional declines, COVID-19, or employment loss, going out more would make them more satisfied.

Some voiced that the frequency of their community outings has a direct impact on their satisfaction because going out and doing things in the community brings them positive moods and a sense of self-worth. For example, P4 described how community participation served as a distraction for her to look away from her limitations by saying, “I feel like sometimes when we sit inside our minds take us to places that we don't necessarily want to go. When I'm out, I don't think about, ‘Oh my God, I have MS,’ and so it's like when I'm out and about, it goes away.” In turn, when they do not go out as frequently, they would feel less satisfied and desire to go out more, as P21 expressed, “I do like to knit and crochet (at home), so I do that for an occupation, but I really miss people. I've always been a people person and I'm just not out around people anymore.” In particular, participants who reported dissatisfaction implied that the frequency of community participation does matter because their dissatisfaction is related to a substantial reduction in their ability and frequency of participation. Participants further discussed that the contributing factors to major reductions in the frequency of participation included MS-related functional declines, loss of employment, and COVID-19.

Eight participants shared that they lost their jobs after they had MS because of progressive functional declines and employers’ failure to provide accommodations. They expressed that going to work used to be an important component of their community participation, and loss of employment led to financial stress, which negatively impacted not only their ability to participate in meaningful activities but also their satisfaction with fulfilling social roles.

> I am not satisfied. I'm 42. I have two kids, They're very active. A year ago, I had to stop working because I was a case manager, and was doing home visits, and things like that, and I just can't really walk well anymore. I have to use a walker, and I can't even walk long with the walker. A big part of me, when I stopped working, is now gone. I felt myself as being able to participate in the working environments, and now that I'm just kind of stuck at home all the time, I feel like I've lost a little bit of myself. And I've had friends at work. So, I feel like I've lost that too. And I feel it's like I know that I should get over it, and suck it up, and be like, "This is my new life." But on the other hand, I'm like, "I'm only 42. I should be able to go out and coach softball or enjoy sitting out in the sun at my son's baseball games or be able to go to the grocery store. P15

Participants agreed that the COVID-19 pandemic drastically reduced their opportunities to engage in activities outside the home, for example, by altering in-person interaction to remote socialization or by closing the accessible gym that was the only place to exercise outside the home for some people. Some participants stated that even in the current post-COVID era, they continue to feel isolated because of their immunosuppressed status while people around them without MS may be gradually recovering to their previous level of participation.

> I was diagnosed in 2016 with MS, so I had it for a while. If you had asked me before COVID, I would've said I'm pretty satisfied. If I was a 10 out of 10 before I was diagnosed with MS, I was maybe a 9 out of 10 before COVID, and now I feel like I'm a 2 out of 10… I'll do anything. Like I'll go out and I do a lot, but I'm not taking my mask off to eat or drink indoors because I take a B cell depleter and I have zero protection to COVID. So I can do things where if there's a meeting with a hundred people or something, and there's a lecture, and then there's snacks and drinks and stuff after, I would've gone to the whole thing before and now maybe I'm going to sort of the lecture, but I'm skipping the snacks, and drinks, and chatting after... And I definitely am not satisfied with that. I feel like I'm missing.
> P9

Theme 2: Doing More is Not Always Better: For people who willingly choose not to go out frequently and those who have developed resilience, satisfaction does not require a high quantity of community engagement. For those who experience environmental barriers in the community, more community outings do not always lead to satisfaction.

Consistent with the absence of a strong positive relationship observed in the correlation analysis between objective and subjective participation measures, some focus group participants emphasized that satisfaction does not always require a high quantity of participation. These are participants who acknowledged their low frequency of community outings but reported satisfaction with their current level of community engagement. They implied that satisfaction is inherently subjective and dependent on whether their participation goals are achieved. Notably, not everyone perceives having frequent, lengthy, and extended community outings as a participation goal. They further indicated that how the person perceives their participation varies by their preference, lifestyle, and resilience.

Some participants shared that they did not sense a major decrease in satisfaction after the diagnosis of MS even if their MS-related impairments led to some level of limitation to out-of-home participation. The reasons are related to their preference, previous lifestyle, and technological support for in-home social participation. A few participants shared that they prefer to stay at home more, as one participant commented, “In my opinion, it depends on if you're an introvert or an extrovert because in my case I'm an introvert, so I'm happy sitting, I'm satisfied sitting at home and reading or do my Bible studies (P3).” Another participant added that he feels his participation goal is met without frequent outings not only because he spent most time at home pre-MS but also because he had adequate support from technology and services for remote participation.

> And I'll say the one silver lining of that is I've always kind of been a homebody even before all this stuff [MS and COVID-19]. So things like video games, Zoom, has been wonderful just being able to connect with people that way and virtually and things like that has meant a lot to me. And services like Instacart and things that can deliver groceries, all of that stuff has been really helpful. (P12)

Several participants acknowledged that their frequency of outings had reduced after the MS diagnosis and they felt dissatisfied at the beginning; however, they currently feel satisfied with their levels of engagement. These individuals typically have lived with MS for many years and have built resilience and developed acceptance and adaptation to new lifestyles. As P18 commented, “It's taken work [effort] to get to be in the places of satisfaction.” With optimistic attitudes and self-efficacy in managing barriers, they now focus more on what they are still able to do and appreciate the social support they have from their immediate network. They remain proactive in looking for resources and opportunities to stay active in the community even though they experienced increased challenges associated with their MS-related functional limitations. For example, when going out is not possible because of fatigue or extreme weather, participants would choose to engage more in activities at home that they found enjoyable. In addition, some participants also implied the perspective that it is less of how much you go out but more of how well you feel supported and understood that helps you reach satisfaction.

One interesting scenario described by a few participants was that if they need to, want to, or have to, they will go out frequently regardless, but it does not mean that they are satisfied with their engagement in the community. This usually resulted from external barriers, particularly in the social and built environments. One participant who is employed and goes out to work regularly shared that even though she goes out frequently, she is dissatisfied because of the lack of opportunities for socialization or building a network with peers with MS in her geographical community. Another participant who is a disability activist and self-motivated to achieve a high quantity of community engagement voiced that he was not completely satisfied with his experience primarily because the built environment was not accessible for people like him who use mobility devices.

> My level of community participation is really high because when I got diagnosed in 2016, I spent a week in the hospital, and then they sent me home. So I didn't understand the disease, I didn't understand the healthcare industry…Being an African American from the inner city, we don't go to the hospital…So my community participation came out of anger. I mean not necessarily anger, but I wanted to make a difference because I know that there was no voice out there for

> African American males who were diagnosed with MS. And I knew I could make a difference because of the disparities that I experienced seeking diagnosis. So I really wanted to make a difference. So I got involved with the [name of an institution]. I'll go anywhere, do anything, I'll speak to anybody. But the barriers that I experienced, getting places, going into offices, having space available to accommodate me in a wheelchair, these are social barriers that I experienced…So that to me is satisfying that I can get out into the community and reach folks and bring a level of awareness that wasn't necessarily there. But it is unsatisfying that when I go to these places, I'm not as comfortable, nor is it as accessible. P20

Discussion

This study sought a better understanding of the relationship between subjective and objective aspects of community participation using quantitative and qualitative data with a sample of individuals with MS. Study findings supported the divergence between subjective and objective dimensions of participation in various ways. First, quantitative findings revealed that associations between subjective and objective participation measures were significant and positive but generally weak, except for trip duration, which demonstrated a significant, positive, and moderate association with subjective participation measures. In addition, across the person factors and environmental factors included in the quantitative analyses, most of the variables showed generally stronger correlations with subjective participation measures, compared to objective measures. Only physical function and use of mobility aid demonstrated moderate associations with some of the subjective and objective participation measures. Focus group findings provided contextual explanations for the quantitative findings. While some participants agreed that going out more can lead to higher satisfaction, and functional declines and environmental barriers negatively impacted their frequency of outings, other participants highlighted that frequent community outings are not a necessity for satisfaction. Satisfaction is inherently subjective and individualized and is achieved when participation goals are met. In other words, if the person’s participation goal or lifestyle does not involve a high quantity of community engagement, their satisfaction would less likely be influenced by the quantity of participation. Focus group participants also implied that functional declines and environmental factors had less impact on the frequency of outings but more influence on satisfaction. Together, the findings of this study supported our hypothesis that subjective and objective dimensions of participation are positively related but are distinct in nature.

Trip duration, as an objective aspect of community participation, was found to have a stronger association with subjective participation measures, compared to other objective participation measures (i.e., trip frequency, trip distance, and radius of gyration). This finding contrasts with Brusilovskiy et al. (2020) where no significant associations were found between any GPS-measured community mobility variables (e.g., total time spent outside of home and total distance traveled) and self-reported importance and satisfaction with participation among a sample of people with mental health conditions. Although our study could not provide a firm explanation of this result, focus group participants indicated that being able to spend more time outside the home could improve their subjective feelings. In the study by Brusilovsliy et al. (2020), it was reported that more time spent outside the home was significantly moderately associated with a higher number of unique destinations. It is possible that longer cumulative daily trip duration reflects the ability to complete more meaningful community activities, which can lead to a greater perceived ability to participate and higher satisfaction. More attention may be paid to supporting people with MS to spend more time outside the home in order to facilitate their perception of participation outcomes.

The study established empirical evidence supporting the divergence between subjective and objective dimensions of participation and the conceptual argument for the importance for rehabilitation professionals to measure both dimensions to capture a full picture of community participation experiences (Dijkers, 2010; Whiteneck & Dijkers, 2009). Previous studies have emphasized that community participation can be defined differently by the individual and an individual can have different appraisals of various community activities; therefore, an individual's perceptions of participation (e.g., satisfaction) should be prioritized when measuring participation (Johnston et al., 2005). Our study offered contexts to present why measuring only one dimension, either subjective or objective participation, may fail to capture real-world problems by describing the underlying reasons for the divergence between subjective and objective dimensions of participation. As reported in qualitative findings, a person reporting a high level of satisfaction may still experience major barriers to going out more in the community. While the person may feel satisfied because of their optimistic mindset or resilience, they might still benefit from interventions focusing on building their ability and skills to navigate environmental barriers and supports to improve their community participation experience. On the other hand, someone can go out and participate in a lot of activities in the community but may not feel satisfied because of the environmental barriers in the community. If only looking at their objective participation outcomes, we would fail to identify their need for more environmental support. Therefore, it is important to measure both dimensions of participation and to seek reasons for the potential divergence between subjective and objective participation measures to inform the focus of potential interventions that can best support individuals.

This study provides clinical implications for intervention development aiming to promote community participation for people with MS. Although quantitative findings revealed that person factors and environmental factors showed weak to moderate correlations with objective aspects of participation, quantitative and qualitative findings in general jointly indicated that functional impairments and environmental barriers can influence both subjective and objective community participation outcomes. Focus group participants further illustrated how functional declines, employment challenges, and COVID-19 resulted in reduced frequency of outings, and hence reduced satisfaction. While statistical results showed that symptom severity and environmental barriers can negatively impact the subjective perception of participation, focus group participants indicated that resilience facilitated their satisfaction despite experiencing functional declines and environmental barriers. This finding is consistent with literature reporting that resilience can moderate the relationship between symptoms and perceived ability to participate in social roles and activities (Lee et al., 2023), and that resilience can predict social functioning among people with MS (Alsheikh & Alqudah, 2023). Therefore, people with MS who live with irreversible long-term functional impairments may benefit from intervention to enhance their resilience and self-efficacy in navigating environmental barriers to achieve satisfactory participation outcomes. As discussed in Lee et al. (2023), despite the limited evidence for resilience interventions specific to the MS population, evidence-based interventions oriented by cognitive behavioral therapy, mindfulness, and acceptance and commitment therapy have shown promising effects in improving resilience and physical and mental health for people with MS.

Several limitations may affect the generalizability of the study findings. First, the study had a relatively small sample with a single diagnostic group; therefore, the findings of this study may not be generalizable to populations with other chronic conditions. The number of correlations tested may also be a limitation of quantitative analyses as it may lead to false positives. In addition, the statistical analyses were limited by the variables available in the parent study’s dataset, which is a common limitation in secondary data analysis (Cheng & Phillips, 2014). Our analyses did not include other known person factors (e.g., resilience, self-efficacy, cognition, and pain) and EFs (e.g., transportation access, Bezyak et al., 2019) that may have significant impacts on participation, as well as other aspects of the community mobility performance (e.g., number of destinations, travel mode, companion). We noted that all person factors and EFs included in the quantitative analyses were measured using self-report methods, which may have resulted in stronger correlations with subjective participation measures; however, the quantitative findings were supported by qualitative data. Another limitation is noted in the GPS data used in the quantitative phase. The parent study selected a 7-day tracking period, following Figueiredo et al. (2022), who suggested that this duration may be adequate to capture typical community mobility patterns. Figueiredo et al. (2022) also reported that existing GPS studies adopted tracking durations ranging from five hours to 30 days, and therefore, no standards for tracking duration have been established. The parent study defined participants returning at least two days of tracking data to be acceptable. In our study, despite most participants in the quantitative phase being tracked for at least 7 days, the number of tracking days in the sample ranged from 2 – 19 days. People with longer tracking periods likely had greater community mobility values.

Furthermore, a few discrepancies between the quantitative and qualitative data should be noted when interpreting findings First, the quantitative data were collected from April 2019 to September 2020 which includes time of the COVID-19 pandemic. It is possible that the pandemic has affected the frequency and perception of community participation among participants of the quantitative phase. Some focus group participants reflected on how the pandemic has negatively impacted their decisions in going out which is consistent with previous research that has reported that COVID-19 exacerbated people with disabilities' disparities in accessing community services and engaging in community activities (Kersey, Lane, et al., 2024). Future studies may investigate the impact of the pandemic on changes in community participation among PwMS. Lastly, although this study focused on participation outside the home; the measures used for the subjective dimension of participation (PROMIS-AP and PROMIS-SRA) included activities (e.g., leisure activities, family activities, work including work at home) that could happen both at home and outside the home. Future studies examining the relationship between subjective and objective dimensions of participation may include a broader range of important person factors, EFs, and participation aspects and follow Chan et al. (2022) recommendations for using a combination of GPS and ecological momentary assessments to collect objectively measured objective aspects of community participation, self-reported subjective aspects of community participation, as well as objectively measured environmental factors in real-time.

Conclusion

This study, conducted with individuals with multiple sclerosis, offers empirical research evidence supporting that participation includes two related but distinct dimensions—objective performance that is observable and subjective perception that is only known by the person. This study also attempted to explain the complex relationship between the subjective and objective dimensions of participation using both quantitative and qualitative data. Rehabilitation professionals and researchers should measure both dimensions to better understand participation experiences with appropriate methods: using self-reported methods to measure subjective aspects of participation and real-time objective methods for objective aspects of participation. Measuring participation rigorously is a key step to identifying the real-world participation challenges and needs for support among people with MS and other chronic health conditions.

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Chapter 3. Environmental Influences on Community Participation among People with Multiple Sclerosis: A Mixed Methods Study

Abstract

Objectives: To examine the influence of environmental factors and interactive effects between person factors and environmental factors on community participation among people with multiple sclerosis (PwMS). Additionally, to identify individual strategies used to navigate environments and needs for environmental improvements to promote community participation of PwMS.

Methods: A mixed methods explanatory sequential design was used including a secondary data analysis of GPS-measured and self-reported data from 101 PwMS, followed by focus groups with 24 PwMS. Correlation and multiple linear regression analyses assessed the associations of environmental factors with subjective perspectives of participation and community mobility performance and the effect modification of environment on the association between symptom and participation. Online focus group discussions using a semi-structured interview guide were conducted to understand how the environment affects community participation experiences and the needs for enhancing environmental support. Content analysis was used for qualitative data.

Results: Among environmental factors, financial resources independently affected subjective participation, and neighborhood safety influenced trip distance and radius of gyration after accounting for person factors (i.e., age, disease duration, physical function, fatigue, and depression). Environmental factors explained an additional 13% variation in satisfaction with participation and 12% in radius of gyration after accounting for person factors. Overall, symptom severity showed greater impacts on community participation outcomes. Although no statistical results supported the environment moderating the association between symptoms and participation, focus group participants with functional limitations indicated that environmental support enabled their participation. Mobility aid users reported more challenges with the built environment, while non-users were more concerned with the attitudinal environment. Participants noted acceptance and adaptation as useful strategies but called for improvements in the built environment, information access, MS specialty care, and public attitudes.

Conclusion: This study highlighted the important role of environments in out-of-home participation and described barriers in physical, societal, and attitudinal environments faced by people with MS. The need for increased system-level support is emphasized.

Keywords: Environment, multiple sclerosis, community participation, person-environment interaction, mixed methods

Introduction

Multiple Sclerosis (MS) is a common inflammatory and neurodegenerative disease affecting approximately 2.2 million adults worldwide and one million adults in the US (Wallin, Culpepper, Campbell, et al., 2019; Wallin, Culpepper, Nichols, et al., 2019). MS-related symptoms include visible symptoms such as mobility limitations, and invisible symptoms, such as impaired vision, fatigue, pain, cognitive problems, bowel and bladder dysfunction, sexual dysfunction, sensory issues, and psychological disorders (Parker et al., 2021). The initial diagnosis of MS typically occurs in young adulthood around the age of 30 with periodic symptoms (i.e., relapsing-remitting MS). One to two decades after the initial onset, many people with MS (PwMS) transition to a progressive phase (i.e., secondary progressive MS), in which symptoms will continue to worsen. Some PwMS may also experience non-relapsing progressive symptoms when they are first diagnosed (i.e., primary progressive, Dobson & Giovannoni, 2019)

Although experiences living with MS can vary by individual, PwMS in general face critical challenges in meeting their goals and needs of participating in important and meaningful activities after the MS diagnosis (Conradsson et al., 2021; Goverover et al., 2020). Previous studies have shown that PwMS encounter fewer barriers at home but more barriers in community contexts outside the home, such as workplaces and public spaces, where they are directly involved but have less control (Hamed, 2012; Khan & Pallant, 2007; Prodinger et al., 2010). Due to the inherent complexity of activities that occur outside the home and the additional barriers in the community, participation in community activities likely places higher demands on the individual and requires greater external support (Chang et al., 2013; Hammel et al., 2015). This study specifically examines community participation as a distinct construct from home participation, focusing on participation in community activities occurring outside the home.

Community participation is an important rehabilitation outcome. It includes subjective aspects that are known only to the individual, such as the importance of and satisfaction with participation, as well as objective aspects reflecting the quantity of engagement such as activity frequency, travel distance, duration, and activity variety that are observable by others (Chan et al., 2021; Chang et al., 2013). Community participation has been primarily measured by self-report measures, which have been proven to be reliable, valid, and suitable to measure the subjective aspects of participation. However, for objective aspects of community participation, real-time objective methods of measurement have been recommended to improve data accuracy (Chan et al., 2021; Figueiredo et al., 2022). Figueiredo et al. (2022) scoping review concluded that global positioning systems (GPS) technology is a promising tool for measuring community mobility performance (e.g., trip frequency, distance, duration, activity space) that reflects objective community participation outcomes in real-time. They also suggested that a tracking period of seven consecutive days is sufficient to capture typical community mobility patterns. While research using GPS to measure community participation among people with various health conditions is expanding (Figueiredo et al., 2022), only one pilot study with a small sample size has used GPS data to describe community mobility patterns of PwMS (Neven et al., 2013). The study focused on documenting community mobility patterns (e.g., number of daily activities, travel modes, trip distance, activity type) of PwMS and found that participants with moderate to severe MS showed significant restriction in community outings compared to healthy controls. However, they did not explore participants' perceptions of the amount of community mobility, which has been considered a critical outcome of community participation (Chang et al., 2013). Literature has emphasized the importance of measuring both the objective and subjective aspects of participation (Dijkers, 2010). Therefore, collecting both community mobility performance and subjective community participation experience rigorously is crucial to best understanding individuals' participation experiences before examining factors influencing community participation.

Systematic reviews examining participation among people with other chronic neurological conditions (e.g., stroke, spinal cord injury) have shown that factors contributing to participation are multifaceted (Kashif et al., 2019; Nicholson et al., 2013). These factors include not only person factors (e.g., age, disease duration, impairments, psychological factors) but also external barriers in the environment. The person-environment interaction and its influence on participation have been highlighted in theoretical frameworks, such as the Institute of Medicine (1997) Model of disability (IOM, Brant & Pope, 1997) and Lawton's Environmental Press Theory (1985). These frameworks suggest that the association between person factors and participation outcomes can be modified by environmental factors (EFs). For example, an individual with mobility limitations will likely face increased participation restrictions due to EFs such as negative attitudes or physical barriers in the community; at the same time, EFs such as a wheelchair or positive social support may moderate these restrictions and facilitate the person's participation.

The significant impact of person factors, such as age, disease duration, mobility limitations, and other MS-related symptoms (e.g., fatigue, pain, depression), on participation have been well-supported in a large body of existing MS systematic reviews and empirical studies (Boeschoten et al., 2017; Cattaneo et al., 2017; Chaudhuri & Behan, 2004; Edwards et al., 2022; Jawahar et al., 2014; Stein et al., 2023). For example, Allataifeh et al. (2020) reported that age, gender, mobility function, cognition, and fatigue can explain 37-49% of the variation in the self-reported amount of participation among PwMS. Battalio et al. (2019) found that functional impairments, chronic medical comorbidities, mood, and pain explained 52% of the variation in self-reported satisfaction with participation of people with long-term physical disability, including PwMS. In addition, Khan and Amatya (2017) conducted a systematic review of systematic reviews and reported that contemporary MS rehabilitation interventions focus on improving physical and cognitive function to facilitate participation in PwMS. A significant paucity of participation-focused interventions addressing external factors, such as a training program equipping PwMS with skills and resources to facilitate work participation, was noted in another systematic review (Nastasi & Harris, 2021). One reason may be that limited research evidence is available to support the significant impacts of EFs on participation outcomes among PwMS, and within the limited literature, often the impact was inconsistently reported and with a specific focus on aspects of participation such as work or social participation.

Within the limited MS literature focusing on participation and environmental influence on participation, many studies adopted either quantitative or qualitative design to investigate the impacts of environmental factors on a specific domain of participation, such as communicative participation and work participation. These studies also measured participation in different ways, which may have led to inconsistent findings. In quantitative literature, Plow et al. (2015) found that cognitive issues were the most significant factor influencing community participation, as measured by the Community Participation Indicator (Heinemann et al., 2013), with environmental barriers reported by individuals with MS being the second most significant factor. Baylor et al. (2010) who explored communicative participation in individuals with MS found that while social support significantly impacted self-reported communicative participation, its effect was weaker than that of symptoms such as fatigue, depression, and cognitive problems. Lehmann et al. (2020) reported that workplace factors such as job resources and demands played a more crucial role in job retention than personal factors like age, health-related quality of life, MS duration, and symptom severity. One mixed methods study by Dyck and Jongbloed (2000) reported that person factors only accounted for 20% of the variance in work participation among women with MS while its qualitative findings revealed the critical influences of EFs (e.g., job flexibility, family support). Similarly, in other qualitative studies, PwMS voiced that their work or social participation restrictions are largely due to extrinsic barriers, such as limited accessibility in the built environment, lack of access to services and accommodations, and judgmental attitudinal environment (Fong et al., 2006, p. 200; Learmonth et al., 2015; Lee et al., 2019). Despite these insights into the importance of environmental factors in affecting participation outcomes, the environmental impact on community participation remains poorly understood. Further research is needed to explore the quantitative relationship of person-environment interactions and the qualitative perspectives to understand environmental influences on community participation specifically. Furthermore, although the existing participation-focused qualitative studies have described the use of management strategies (e.g., using assistive technology, advance planning, self-regulation, and meditation) at the individual level as ways to mitigate the impact of MS-related symptoms on participation, there is a limited focus on the needs for system-level support in addressing environmental factors. As previously described, community participation is often affected by system-level barriers (e.g., workplace policy, access to resources), in which individuals have limited control, therefore, it is necessary to seek a better understanding of which system-level environmental factors are most relevant and crucial for supporting participation and what improvements are desired to enhance community participation from the perspectives of PwMS.

The objectives of this study were to 1) quantitatively examine the associations between EFs and community participation outcomes, including subjective perspectives of participation and community mobility performance among PwMS, 2) quantitatively explore the moderator role of EFs in the association between person factors and community participation outcomes, and 3) qualitatively understand participant perspectives about environmental influences on their community participation experience and identify individual strategies and needs for system-level environmental improvements that can support community participation among PwMS.

Materials and Methods

Study Design

This study used a mixed methods explanatory sequential design that begins with a quantitative phase followed by a qualitative phase (Creswell & Plano Clark, 2018). This sequence allows researchers to use quantitative findings to design specific questions in the qualitative phase to provide a more in-depth explanation of quantitative results and collect complementary data, and therefore, to better understand the phenomena and answer the research questions more comprehensively (Ivankova et al., 2006). The first phase of this study was a quantitative secondary analysis of GPS-measured and self-reported data assessing the relationship between person factors, EFs, and community participation outcomes. In the second phase, online focus groups with PwMS explored their perspectives on the impact of environments on their participation experience outside the home, helpful strategies they used to overcome barriers, and sociopolitical changes needed to promote community participation. This study was approved with an exempt status by the University of Washington Human Subjects Division (IRB ID: STUDY0018560).

Quantitative Phase

The Parent Study and Data Source

Quantitative data were extracted from a longitudinal three-arm intervention study (Molton, NCT03653390, 2019, January 31 – 2022, November 14) investigating the effectiveness of Enhance®Wellness, an evidence-based program that aims to improve well-being for people living with chronic conditions through working one-on-one with personal health and wellness coach (Hughes et al., 2011). Inclusion criteria for the parent study were adults (1) aged 45-64, (2) living with at least one chronic neurological or musculoskeletal condition, such as stroke, spinal cord injury, muscular atrophy, amputation, and MS, and with disease onset before 40 years old; (3) able to communicate functionally in English; and (4) without significant cognitive impairments as defined by the Six-item Screener (Callahan et al., 2002). While the parent study (n = 561) had multiple time points of data collection, only baseline data from participants diagnosed with MS were used in the quantitative phase of this project. Baseline data was collected between April 2019 and September 2021. At baseline, all participants completed a survey about their current well-being. A random subset of baseline participants with MS was invited to join a GPS sub-trial to document their community mobility performance. Consequently, baseline survey and GPS data from 101 participants with MS were included in the quantitative phase of this study.

Independent Variables: Person Factors and Environmental Factors

Person factors included **demographic information** and **MS-related symptoms** measured by the baseline survey. **Demographics** included age, years living with MS (disease duration), gender, race and ethnicity, educational background, annual household income, marital status, employment status, and comorbidity. While all variables were included in descriptive analyses, only age and disease duration were included in inferential analyses because age and disease duration are known influencing factors in participation outcomes among PwMS (Allataifeh et al., 2020; Goverover et al., 2020). Three **MS-related symptom variables** were included. (1) **Physical function** was measured by PROMIS Physical Function Short Form (PROMIS-PF, Rose et al., 2014) which asks participants to report perceived difficulties in self-care activities and mobility with a 5-point scale (1 = Unable to do, 2 = With much difficulty, 3 = With some difficulty, 4 = With a little difficulty, and 5 = Without any difficulty). (2) **Fatigue severity** was assessed by PROMIS Fatigue Short Form (Cook et al., 2012) which includes four items asking participants to rate the frequency of their fatigue during the past 7 days on a 5-point scale (1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always). (3) **Depression severity** evaluated by PROMIS Depression 6-item short form (Pilkonis et al., 2011) asked respondents to rate the frequency of their depressive moods over the past 7 days (1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always). PROMIS scales use a T-score matrix from 1-100 to indicate a level of health. A PROMIS-PF T-score above 45 is considered within normal limits when compared to the general U.S. population. For the PROMIS Fatigue and Depression scales, a T-score below 55 is within normal limits, while scores of 55-60, 60-70, and over 70 indicate mild, moderate, and severe fatigue or depression, respectively, compared to the general U.S. population. Higher T-scores on these three measures reflect greater physical function, more severe fatigue, and more severe depression, respectively (HealthMeasures, 2023).

Environmental factors (EFs) involved perceptions of surrounding environments (i.e., perceived social support, perceived financial resources, and perceived neighborhood safety) and use of mobility aids. The Older People Quality of Life short form (OPQoL, Bowling et al., 2013) is a reliable and valid measure assessing respondents' overall perceptions of quality of life with a

5-point scale (1 = Strongly disagree, 2 = Disagree, 3= Neither agree or disagree, 4 = Agree, 5 = Strongly agree). **Perceived social support** was captured by responses to the related item in the QPQoL, "*My family, friends or neighbors would help me if needed*." **Perceived financial resources** were inquired by the OPQoL item, "*I have enough money to pay for household bills*." **Perceived neighborhood safety** was measured by an item in the OPQoL, "*I feel safe where I live*." **Mobility aid use status** was inquired by asking participants to respond to the question in the baseline survey, “How often do you use each of the following: crutches, cane(s), walker, medical shoes, manual wheelchair, power wheelchair, scooter, brace, hiking poles” with never, sometimes, or always. Their responses were recoded into three categories: (a) using any mobility aids (0 = No, 1 = Yes), (b) using walking aids (e.g., cane, walker, brace) only (0 = No, 1 = Yes), and (c) using wheeled aids (e.g., manual wheelchair, power wheelchair, scooter), which includes using a mixture of wheeled and walking aids (0 = No, 1 = Yes).

Outcome Variables: Community Participation Measures

Subjective perspectives of participation include **perceived ability to participate** and **satisfaction with participation**, measured by PROMIS Ability to Participate in Social Roles and Activities (PROMIS-AP) and PROMIS Satisfaction with Social Roles and Activities short forms (PROMIS-SRA, Hahn et al., 2010), respectively. In each 8-item questionnaire, participants reported their level of agreement using a 5-point scale on statements about their perceived difficulty with participating (e.g., "I have trouble doing all of my regular leisure activities with others") and about their satisfaction with participation (e.g., "I am satisfied with my ability to do things for my family"). A PROMIS-AP T-score above 45 is within normal limits relative to the general U.S. population, while a PROMIS-SRA T-score between 40-60 reflects the average level in the general U.S. population. Higher T-scores on these scales indicate better perceived ability and greater satisfaction (HealthMeasures, 2023).

Community mobility performance was captured by GPS and travel log data. Participants were asked to wear a portable GPS device (QStartz BT Q1000XT GPS logger) for seven consecutive days. Simultaneously, they were asked to fill out a pen-and-paper daily travel log to document the purpose of activity (i.e., activity type) throughout the day. A total of 122 participants were sent with the GPS device and travel log, and 101 returned with valid data (have at least two days of tracking data as defined by the criteria of the parent study), resulting in an 83% completion rate. The combination of GPS and travel log data provided information on where, how often, how long, how far, and why the person engaged in community activities outside of the home. Community mobility variables included in the analysis were GPS-based **daily trip frequency**, cumulative **daily trip distance** (reported in kilometers), cumulative **daily trip duration** (reported in hours), and **radius of gyration** during the entire tracking period (reported in meters or m). Radius of gyration in the context of community mobility measures how far a person typically moves from the central point (i.e., home location in this study) of all their visited locations outside the home during the entire tracking period (González et al., 2008). It is a matrix reflecting one’s activity space, which is a spatial concept distinct from daily trip distance that focuses on the linear length of a single trip. **Time spent outside the home by activity type** captured jointly by GPS and travel log was only included in the descriptive analysis.[1] A trip was defined as a journey beginning and ending at the individual’s home, excluding intermediate stops. Trips outside the home were identified using point-level GPS where points beyond 200 meters of the home were considered a movement outside the home.

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[1] Travel log and GPS data were reconciled in the parent study without further reference to the travel log for this analysis.

Data Analysis

All quantitative analyses were conducted using IBM SPSS Statistics (Version 27). Descriptive analysis was used to calculate the percentages, means, and standard deviations. Pair-wise correlations were calculated on all included outcome variables and independent variables to measure their direct association with each other. Normality of continuous variables was assessed using visual inspection of histograms and by examining skewness values, with values between -1 and 1 considered indicative of a normal distribution. Based on these assessments, parametric or nonparametric correlation tests were applied as appropriate. **Pearson Correlation (r)** was used between normally distributed continuous variables. **Spearman's Rho (ρ)** was used between continuous variables with mixed distributions. **Kendall's Tau (τ)** was used between ordinal variables and continuous variables with mixed distributions. For correlations between dichotomous and normally distributed continuous variables, and correlations between dichotomous and nonnormally distributed continuous variables, we performed **Point-Biserial (rpb)** and **Rank Point-Biserial (rank-rpb)**, respectively. Correlation coefficients equal to or less than 0.3 were interpreted as weak correlations, those greater than 0.3 and less than 0.7 as moderate, and those equal to or greater than 0.7 as strong correlations (Akoglu, 2018).

To examine the independent association of EFs (i.e., perceived financial resources, perceived social support, and perceived neighborhood safety) with community participation outcomes (i.e., perceived ability to participate, satisfaction with participation, trip frequency, trip distance, trip duration, and radius of gyration), multiple linear regression with a stepwise entry manner was used. There was no evidence of multicollinearity among the variables included in the regression analyses. The assumption of normality in linear regression— the residuals, or differences between observed and predicted values, are normally distributed— was tested prior to the conduction of regression analyses. The examination was completed through visual observations of how close the distribution was to a bell curve in histograms and how aligned the distribution of standardized residual points was with the diagonal line in cumulative probability plots of residuals (P-P plots, Matsanny et al., 2016; Knief and Forstmeier, 2021). Violation of normality was found on trip distance, trip duration, and radius of gyration. Therefore, a natural log transformation method was used on these three variables (See Supplement 1 for Figures S1-S3 for demonstration of normality violation and improvement in normality with natural log transformation presented by histograms and P-P plots). While a significant improvement of normality was seen with the log transformation on both trip distance and trip duration, which was determined as a tolerable situation, we did not see the same magnitude of improvement for radius of gyration. Experimentally, we removed outlier cases that reported very high values to compare normality improvement in radius of gyration. We removed four outlier cases in the first round but did not see a notable improvement and continued to remove eight outliers until we noted the improvement (See Supplement 1 Figure S3.1 for P-P plots). However, after removing eight cases, the observed degree of deviation of residual points from the diagonal line is similar to what we see with the log transformation method (Supplement 1 Figure S3). Considering that reducing sample size would have an impact on power for analysis and potentially introduce bias, we decided to proceed with log transformation to trip distance, trip duration, and radius of gyration.

Using linear regression analyses to measure the effects of EFs on participation outcomes after accounting for person factors, (age, disease duration, physical function, fatigue, depression)— were entered in Block 1, EF variables (i.e., perceived social support, perceived financial resources, and perceived neighborhood safety) were then entered into Block 2. We also observed whether the addition of EF variables resulted in an additional explanation of variance in the outcome variable indicated by ΔR^2. Separate regression models were established with six community participation outcome variables (i.e., perceived ability to participate, satisfaction with participation, trip frequency, trip distance, trip duration, and radius of gyration).

To explore the moderation effect of EF on the association between person factors and each of the six community participation outcomes, multiple linear regression models were used. Specifically, we examined (1) whether the use of mobility aid modified the association between physical function and community participation; (2) whether social support modified the association between fatigue severity and community participation; and (3) whether social support modified the association between depression severity and community participation. A total of eighteen models were established for three pairs with each of the six participation outcome variables. Each model consisted of a participation outcome, main effects for the EF and person factor of interest, and their interaction while adjusting for age and disease duration. A significant interaction term indicates the presence of effect modification. Taking the first pair as an example, the regression model contained age, disease duration, physical function, use of walking aid only, use of wheeled aid, and interactive terms between physical function and both use of walking aid only and use of wheeled aid. A significant interaction term indicates that the association between physical function and the outcomes differs with the use (or lack thereof) of a mobility aid. For all aforementioned analyses, associated p-values <0.05 (two-tailed tests) indicate statistically significant results due to the exploratory nature of the analyses.

Qualitative Phase

Online Focus Group Recruitment

Upon the completion of the quantitative phase, primarily convenience and purposive sampling methods were used to recruit participants for online focus groups. Focus group participants are different people from participants in the quantitative phase. A screening survey was distributed through the University of Washington MS Rehabilitation and Wellness Center national registry and the National MS Society website and their registry for three states (WA, IL, NY) representing the West, Midwest, and North-East regions. The survey gathered information on demographics, mobility aid use, and interest in study participation. Focus group participants were chosen from those who completed the survey. Eligibility criteria included being an adult with MS, having access to Zoom, the ability to communicate effectively in English, and a willingness to participate in the focus groups. A group of selected participants were invited to ensure diverse backgrounds of gender, race, MS duration, location, employment status, and a mixture of mobility aid users and nonusers.

Focus Group Data Collection

Online focus group discussions were held via Zoom. Based on previous literature suggesting that participation experiences and perspectives differ significantly between PwMS who use mobility aids during community participation and those who do not (Learmonth et al., 2015), participants were grouped into two groups of mobility aid users and two groups of non-user groups. For comparison and description purposes, participants who use mobility aids are referred to as “mobility aid users,” and participants who do not use mobility aids are referred to as “nonusers” or “those who live with invisible MS” in this manuscript. Focus group discussions were facilitated using a discussion guide. The development of the discussion guide was informed by quantitative findings and reviewed by three academic advisors who are rehabilitation researchers with expertise in qualitative research methods as well as three community advisory board (CAB) members who have lived experience with MS either as an individual living with MS or a caregiver. The discussion guide was used to prompt conversations about how external and internal factors affect participation outside the home and what strategies participants have used to navigate the environment (See Table 1 for sample questions). An additional question inquiring about the experience of using mobility devices in the community was asked to focus groups with mobility aid users. To orient focus group participants to the anticipated discussion, the definition of community participation in this project and a list of example external and internal factors were shared with participants one day before the focus group. Each focus group was co-facilitated by the lead researcher and one or two CAB members. All online focus group discussions were recorded, and audio recordings were transcribed verbatim.

Table 1. Example Focus Group Questions

1. Share 1 or 2 environmental/external factors that make it most difficult for you to do things outside the home while living with MS. Give us some examples.
2. How do you manage those most difficult situations/significant barriers in order to go out and do things as wished? What would have better supported you? What changes would you like to see or advocate for?
3. How do internal factors impact your community participation? Do you have experiences where internal and external factors interact to affect your participation? How has this changed since you've had MS?
4. [For mobility aid users only] Some people see that using mobility aid devices in the community is a support, while others say that it's a barrier, what has been your experience? For those who use more than one kind of device, how does your experience differ by device?

Qualitative and Integrated Data Analysis

With ATLAS.ti 23 for Windows, transcripts were analyzed using content analysis (Elo & Kyngäs, 2008; Vaismoradi et al., 2013) and a technique combining deductive and inductive coding (Fereday & Muir-Cochrane, 2006). Pre-specified code groups and codes were established by the lead researcher based on the research questions, literature review, and a global impression of the discussions from initial reviews of the transcripts. Inductive coding pertained throughout the coding process to develop data-driven codes. Two coders participated in the coding and theme development process guided by (Vaismoradi et al., 2016). An initial codebook was developed after two coders independently coded one transcript of a mobility user group and one of a nonuser group and discussed discrepancies to reach a consensus. The codebook revision and finalization continued with two coders coding the rest of the transcripts, and a reviewer who was familiar with all transcripts participated in group meetings to support the consensus-building process. Memos were written throughout the coding process to record coders' interpretation and impression of each transcript, as well as to reflect on the differences in perspectives between mobility aid users and nonusers. Upon completion of coding, a code report generated by ATLAS.ti included final code names, definitions, and related quotations. The initial themes were developed with the guidance of memos and the code report, as well as the frequency of code use. Themes and subthemes were revised based on the consensus achieved through meetings with the coders and reviewer. To enhance the credibility of the findings, member checking was then conducted by emailing focus group participants a two-page summary of results and requesting feedback. Eight participants participated in member checking and shared comments validating the results and highlighted the importance of some content, which informed the reporting of qualitative data.

As a key component of mixed-methods research, integrated analysis features a comparison between quantitative findings and qualitative findings (Creswell & Plano Clark, 2018). In explanatory sequential design, the integrated analysis uses qualitative findings to further explain specific quantitative results complementarily to reveal similarities or discrepancies. During the integrated analysis, attention was given to how qualitative findings may explain the significant statistical relationships between variables of interest or lack thereof, and how qualitative findings may contribute added or different insights compared to quantitative findings.

Results

Characteristics of Participants in the Quantitative Phase

Table 2 presents the characteristics of the 101 participants with MS included in the quantitative phase. On average, these participants were 55.5 years old and had lived with MS for 19.5 years. Participants came from 29 different states in the US. The majority of participants were female (80%), non-Hispanic White (86%), married (62%), had a college degree or higher (68%), and used a mobility aid device at least some of the time (66%). Among 67 mobility aid users, 33 of them used walking aids exclusively, and 34 used either wheeled aids only or used both walking aids and wheeled aids. Half of the participants reported an annual household income higher than US$50,000, and approximately 34% of the participants were employed. Participants perceived their social support, wealth, and neighborhood safety at high levels (mean scores > 4). Compared to the average US population, participants reported lower physical function (T-score = 40.8), higher fatigue severity (T-score = 59.9), and depression severity within normal limits (T-score = 51.8). Regarding community participation outcomes, the average T-score of PROMIS-AP and PROMIS-SRA were 42.1 and 43.2, respectively, which are within the average levels of US populations (HealthMeasures, 2023). Participants were tracked by the GPS device for an average of 7.7 consecutive days, ranging from two to 19 days, in which the majority of our participants (71.3%) were tracked for 7 or 8 days, and 90.1% of participants were tracked for 7 days or more. The GPS data revealed that on average, participants' daily trip frequency was one time, daily cumulative trip distance was 30km, and daily cumulative trip duration was 3 hours. In addition, GPS data show that the average radius of gyration during the entire tracking period was 14,849m, with a large variability in participants (SD = 32,019). Figure 1 presents the amount of time spent on different types of out-of-home activities per day. Participants spent the most time outside the home working (2.2 hours/day, SD = 1.91), followed by socializing in person (1.1 hours/day, SD = 1.1), spending time on social media (1 hour/day, SD = 0.84), and commuting (0.9 hours/day, SD = 0.66).

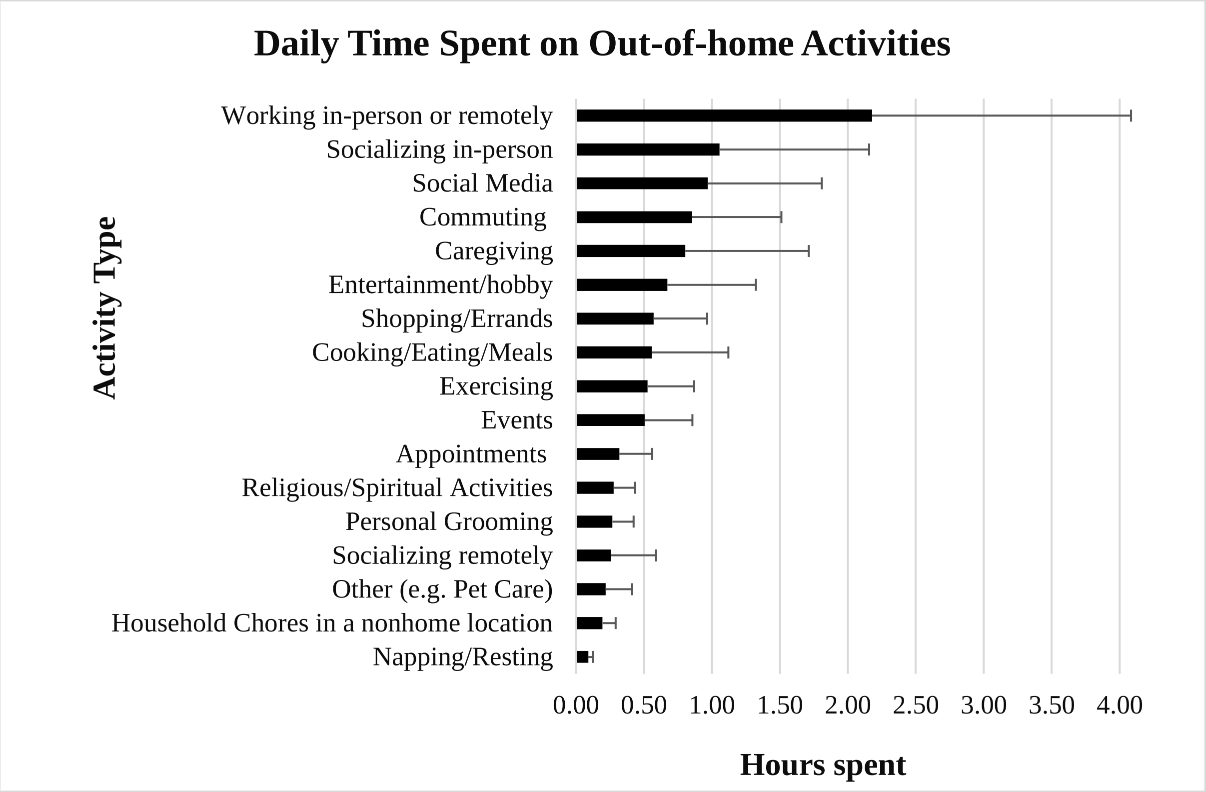
Table 2. Descriptive Statistics for Participants in the Quantitative Phase (N=101)

Measure	*M or N*	*(SD) or (%)*
Age	55.54	*(5.39)*
(Range)	(45-64)	
Disease Duration	19.45	*(8.35)*
(Range)	(1-45)	
Gender		
Female	81	*(80.20%)*
Male	18	*(17.82%)*
Declined to Answer	2	*(1.98%)*
Race and Ethnicity		
NH White	87	*(86.14%)*
NH Mixed-race	6	*(5.94%)*
NH African American	4	*(3.96%)*
Hispanic	4	*(3.96%)*
Educational background		
High School Graduate	3	*(2.97%)*
Some College	28	*(27.72%)*
College Graduate	35	*(34.65%)*
Graduate school	34	*(33.66%)*
Declined to Answer	1	*(0.99%)*
Annual Household Income		
Less than $15,000	5	*(4.95%)*
$15,000 to $24,999	14	*(13.86%)*
$25,000 to $49,999	12	*(11.88%)*
$50,000 to $75,000	13	*(12.87%)*
More than $75,000	38	*(37.62%)*
Declined to Answer	18	*(17.82%)*

Missing	1	*(0.99%)*
Marital Status		
Married	63	*(62.38%)*
Divorced	13	*(12.87%)*
Single	11	*(10.89%)*
Partnered	4	*(3.96%)*
Separated	4	*(3.96%)*
Widowed	4	*(3.96%)*
Declined to Answer	2	*(1.98%)*
Employment Status		*(0.00%)*
Employed Full-time	22	*(21.78%)*
Employed Part-time	13	*(12.87%)*
Unemployed	3	*(2.97%)*
Unemployed due to disability	37	*(36.63%)*
Retired	7	*(6.93%)*
Homemaker	6	*(5.94%)*
On sick or other leave	2	*(1.98%)*
Other	6	*(5.94%)*
Declined to Answer	5	*(4.95%)*
*Diagnosis in addition to MS**	13	*(12.87%)*
Impairments		
Physical Function	40.84	*(11.12)*
Fatigue Severity	59.94	*(8.24)*
Depression Severity	51.84	*(9.14)*
Environmental Factors		
Perceived Social Support	4.47	*(0.76)*
Perceived Financial Resources	4.07	*(0.93)*
Perceived Neighborhood Safety	4.50	*(0.70)*
Use a Mobility Aid	67	*(66.34%)*
Use Walking Aids Only	33	*(32.67%)*
Use Wheeled Aids	34	*(33.66%)*
Use Mixed Mobility Aids	26	*(25.74%)*
Outcome Descriptives		
Perceived Ability to Participate	42.12	*(6.06)*
Satisfaction with Participation	43.15	*(7.75)*
Travel Frequency	0.93	*(0.65)*
Travel Distance	30.05	*(35.33)*
Travel Duration	3.00	*(3.07)*
Radius of Gyration	14849.16	*(32019.01)*

Note. NH = Non-Hispanic. M = Mean, SD = standard deviation. * Examples of diagnoses in addition to MS include spinal cord injury, neuropathy, fibromyalgia, arthritis, and depression

Figure 1. Daily Time Spent on Different Types of Activity Outside the Home



Focus Group Participant Characteristics

A total of 24 people from nine different states participated in four focus group discussions, and eight participants contributed to member checking. Each focus group lasted for about 90 minutes and had six participants and one to three facilitators. Two focus groups were with PwMS who use mobility aids (P1-P12) and the other two groups were with PwMS who do not use mobility aids (P13-P24). The average age and disease duration of the participants were 50.3 and 16.0 years, respectively. Similar to the participant sample in the quantitative phase, the majority of focus group participants were female (63%) and non-Hispanic White (75%). Most participants (96%) resided in an urban area. Descriptively, there were observed differences between mobility aid user groups and nonuser groups in age, disease duration, employment status, and disability identity (Table 3). Table 4 presents characteristics of each of the 24 focus group participants.

Table 3. Descriptive Statistics for Focus Group Participants

	All (N=24)		Mobility Aid Users (N=12)		Nonusers (N=12)	
Measure	*M or N*	*(SD) or (%)*	*M or N*	*(SD) or (%)*	*M or N*	*(SD) or (%)*
Age	*50.29*	*(10.98)*	55.83	*(9.12)*	44.75	*(10.08)*
Disease Duration (year)	*16.02*	*(11.24)*	18.27	*(9.23)*	12.1	*(9.25)*
Gender						
Female	15	*(62.50%)*	8	*(66.67%)*	7	*(58.33%)*
Male	8	*(33.33%)*	4	*(33.33%)*	5	*(41.67%)*
Genderqueer/Nonbinary	1	*(4.17%)*	0	*(0.00%)*	1	*(8.33%)*
Race and Ethnicity						
NH White	18	*(75.00%)*	10	*(83.33%)*	8	*(66.67%)*
NH African American	5	*(20.83%)*	2	*(16.67%)*	3	*(25.00%)*
NH Mixed-race	1	*(4.17%)*	0	*(0.00%)*	1	*(8.33%)*
Employment Status						
Employed Full-time	7	*(29.17%)*	1	*(8.33%)*	6	*(50.00%)*
Employed Part-time	3	*(12.50%)*	2	*(16.67%)*	1	*(8.33%)*
Unemployed	6	*(25.00%)*	4	*(33.33%)*	2	*(16.67%)*
Retired	7	*(29.17%)*	5	*(41.67%)*	2	*(16.67%)*
Other	1	*(4.17%)*	0	*(0.00%)*	1	*(8.33%)*
Use a Mobility Aid	12	*(50.00%)*				
Use Walking Aids Only	3	*(12.50%)*				
Use Wheeled Aids	9	*(37.50%)*				
Use Mixed Mobility Aids	4	*(16.67%)*				

Note. NH = Non-Hispanic.

Table 4. Characteristics of Individual Focus Group Participant

ID	Age	MS Duration (year)	Gender	Race	Employment	Region	Use of Mobility Aid
P1	55	29	Female	NH White	Retired	Midwest	None
P2	63	25	Male	NH White	Employed, part-time	Northwest	None
P3	59	18	Female	NH White	Retired	South	None
P4	39	5	Female	African American	Employed, full-time	Northwest	None
P5	36	5	Female	African American	Employed, full-time	West	None
P6	40	3	Male	NH White	Unemployed	Northwest	None
P7	42	6	Female	African American	Employed, full-time	Midwest	None
P8	35	12.5	Male	NH White	Other	West	None
P9	47	7.5	Female	mixed race	Employed, full-time	Northwest	None
P10	51	24	Male	NH White	Employed, full-time	Midwest	None
P11	33	10	Female	NH White	Employed, full-time	West	None
P12	37	1	Nonbinary	NH White	Unemployed	West	None
P13	57	27	Female	NH White	Retired	Midwest	rollator
P14	58	24	Male	NH White	Unemployed	Northwest	power wheelchair and scooter
P15	42	11	Female	NH White	Unemployed	Midwest	manual wheelchair and scooter
P16	44	14	Male	NH White	Employed, full-time	Northwest	cane
P17	66	33	Female	NH White	Retired	Midwest	power wheelchair and scooter
P18	62	22	Female	NH White	Retired	West	walker
P19	66	28	Female	NH White	Retired	West	power wheelchair
P20	58	8	Male	African American	Employed, part-time	Northwest	power wheelchair
P21	65	10	Female	NH White	Retired	Northwest	cane, walker, medical shoes, manual wheelchair
P22	61	28	Female	African American	Unemployed	South	cane, walker, medical shoes, manual wheelchair
P23	44	5	Female	NH White	Employed, part-time	Midwest	cane, walker, manual wheelchair
P24	47	12	Male	NH White	Unemployed	Midwest	power wheelchair

Note. NH = Non-Hispanic

Quantitative Findings

Person factors and subjective participation variables were normally-distributed continuous variables. Among EFs, perceived social support, perceived financial resources, and perceived neighborhood safety were ordinal variables. Objective participation measures were nonnormally distributed. To assess the adequacy of the sample size, we performed a post hoc power analysis for each of the 24 established regression models. The results indicated that all six regression models examining the EF influence on participation outcomes achieved a power above 83%, which is deemed acceptable for two-tailed tests (Serdar et al., 2021). However, 10 out of the 18 regression models assessing the effect modification of EFs exhibited a power level lower than 80%, ranging from 15% - 74%. See **Supplement 2** for the power analysis results. This variability in power is reflective of the different effect sizes and numbers of independent variables included in the models.

Table 5 presents the correlation results between person factors and EFs and participation variables. Specifically, age and disease duration were not significantly correlated with any outcomes, whereas physical function showed weak to moderate significant association with all outcomes (r or ρ ranging from 0.21 - 0.41). Both fatigue and depression were moderately associated with subjective perspectives of participation (r_{range} = -0.41 - -0.57), and depression also demonstrated a significant but weak association with GPS-measured trip distance (ρ = -0.23). Among EFs, perceived social support, financial resources, and neighborhood safety showed weak to moderate significant correlations with perceived ability to participate (τ_{range} = 0.22 - 0.38), satisfaction with participation (τ_{range} = 0.22 - 0.48), and trip distance (τ_{range} = 0.16 - 0.20). Increased perceived financial resources was also related to increased trip duration (τ = 0.16), and a safer neighborhood environment was associated with a larger radius of gyration (τ =

0.20). In addition, use of mobility aids was significantly negatively associated with all participation measures except trip frequency (rpb or rank-rpb ranging from -0.28 to -0.33). Interestingly, use of wheeled aids was significantly associated with lower perceived ability to participate (rpb = -0.22), lower satisfaction with participation (rpb = -0.28), reduced trip frequency (rank-rpb = -0.22), and reduced trip distance (rank-rpb = -0.22); however, use of walking aid only did not have significant association with any participation measures.

Table 5. Correlations between Independent Variables and Participation Outcome Variables

Measure	Perceived Ability to Participate	Satisfaction with Participation	Trip Frequency	Trip Distance	Trip Duration	Radius of Gyration
Person Factors:						
Age	-0.10	-0.11	-0.02	0.03	-0.01	0.00
Disease Duration	0.02	-0.03	0.09	0.02	0.07	-0.06
Physical Function	0.37*	0.41*	0.34*	0.33*	0.37*	0.21*
Fatigue Severity	-0.57*	-0.41*	-0.09	-0.01	-0.01	0.02
Depression Severity	-0.38*	-0.45*	-0.16	-0.23*	-0.14	-0.16
Environmental Factors:						
Perceived Social Support	0.24*	0.29*	0.14	0.16*	0.10	0.10
Perceived Financial Resources	0.38*	0.48*	0.13	0.19*	0.16*	0.15
Perceived Neighborhood Safety	0.22*	0.22*	0.12	0.20*	0.12	0.20*
Using Walking Aid Only	-0.06	-0.04	0.06	-0.11	-0.11	-0.12
Using Wheeled Aid	-0.22*	-0.28*	-0.22*	-0.22*	-0.19	-0.15

Note. N=101. * p < .05. Using wheeled aid includes both the exclusive use of wheeled aids and the combined use of wheeled aids and walking aids.

Multiple linear regression results are reported in Table 6 showing independent effects of independent variables on participation outcomes. In general, person factors (Block 1) as a group were significantly associated with all participation outcomes except radius of gyration (range of $R^2 = 0.13 – 0.48$). EFs as a whole group (Block 2) had additional significant effects on satisfaction with participation ($\Delta R^2 = 0.13$, $p = 0.001$) and radius of gyration ($\Delta R^2 = 0.12$, $p = 0.035$) after accounting for person factors. Among individual person factors, age, disease duration, and depression severity did not show significant independent effects on any participation outcomes. After adjusting for other variables in the model, physical function was significantly associated with perceived ability to participate ($p = 0.04$), trip frequency ($p = 0.027$), and trip duration ($p = 0.044$). Fatigue severity was negatively associated with perceived ability to participate ($p < 0.001$) and satisfaction with participation ($p = 0.005$). Among individual EFs in the regression models, perceived financial resources had significant positive independent effects on perceived ability to participate ($p = 0.011$) and satisfaction with participation ($p < 0.001$) after accounting for person factors in the model, while perceived neighborhood safety was independently positively associated with trip distance ($p = 0.036$) and radius of gyration ($p = 0.002$).

Table 6. Regression Results

Measures	**Model 1: Person Factors**			**Model 2: + Environmental Factors**		
	b	**sr^2**	**R^2**	**b**	**sr^2**	**ΔR^2**
Outcome: Perceived Ability to Participate						
Intercept	67.63*			53.21*		
Block 1: Person Factors			0.48*			
Age	-0.12	<0.01		-0.07	<0.01	
Disease Duration	0.03	<0.01		0.02	<0.01	
Physical Function	0.18*	0.10		0.12*	0.02	

Fatigue Severity	-0.40*	0.22		-0.37*	0.19	
Depression Severity	-0.06	<0.01		0.02	<0.01	
Block 2: Environmental Factors						0.06
Perceived Social Support				0.25	<0.01	
Perceived Financial Resources				1.62*	0.03	
Perceived Neighborhood Safety				0.33	<0.01	
Using Walking Aid Only				-0.81	<0.01	
Using Wheeled Aid				-1.37	<0.01	
Outcome: Satisfaction with Participation						
Intercept	66.64*			42.37*		
Block 1: Person Factors			0.41*			
Age	-0.09	<0.01		0.00	<0.01	
Disease Duration	0.01	<0.01		0.00	<0.01	
Physical Function	0.25*	0.11		0.14	0.02	
Fatigue Severity	-0.27*	0.06		-0.23*	0.04	
Depression Severity	-0.24*	0.06		-0.10	<0.01	
Block 2: Environmental Factors						0.13*
Perceived Social Support				0.98	<0.01	
Perceived Financial Resources				3.22*	0.08	
Perceived Neighborhood Safety				-0.65	<0.01	
Using Walking Aid Only				-0.85	<0.01	
Using Wheeled Aid				-2.20	<0.01	
Outcome: Trip Frequency						
Intercept	0.50			0.06		
Block 1: Person Factors			0.15*			
Age	0.00	<0.01		0.00	<0.01	
Disease Duration	0.01	0.01		0.01	0.01	
Physical Function	0.02*	0.10		0.02*	0.05	
Fatigue Severity	0.00	<0.01		0.00	0.04	
Depression Severity	-0.01	<0.01		-0.01	<0.01	
Block 2: Environmental Factors						0.01
Perceived Social Support				0.04	<0.01	
Perceived Financial Resources				-0.01	<0.01	
Perceived Neighborhood Safety				0.04	<0.01	
Using Walking Aid Only				0.01	<0.01	

Using Wheeled Aid				-0.05	<0.01	
Outcome: Trip Distance						
Intercept	0.28			-2.61		
Block 1: Person Factors			0.13*			
Age	0.03	0.01		0.05	0.03	
Disease Duration	0.00	<0.01		-0.01	<0.01	
Physical Function	0.03*	0.08		0.01	<0.01	
Fatigue Severity	0.02	<0.01		0.02	0.01	
Depression Severity	-0.03*	0.04		-0.01	<0.01	
Block 2: Environmental Factors						0.09
Perceived Social Support				-0.05	<0.01	
Perceived Financial Resources				0.13	<0.01	
Perceived Neighborhood Safety				0.50*	0.04	
Using Walking Aid Only				-0.50	0.02	
Using Wheeled Aid				-0.81	0.03	
Outcome: Trip Duration						
Intercept	0.11			-0.74		
Block 1: Person Factors			0.15*			
Age	0.01	<0.01		0.01	<0.01	
Disease Duration	0.01	0.01		0.01	<0.01	
Physical Function	0.02*	0.12		0.02*	0.04	
Fatigue Severity	0.00	<0.01		0.00	<0.01	
Depression Severity	-0.01	<0.01		0.00	<0.01	
Block 2: Environmental Factors						0.03
Perceived Social Support				0.06	<0.01	
Perceived Financial Resources				0.01	<0.01	
Perceived Neighborhood Safety				0.08	<0.01	
Using Walking Aid Only				-0.26	0.02	
Using Wheeled Aid				-0.21	<0.01	
Outcome: Radius of Gyration						
Intercept	5.85			1.34		
Block 1: Person Factors			0.06			
Age	0.02	<0.01		0.04	<0.01	
Disease Duration	0.01	<0.01		0.00	<0.01	
Physical Function	0.04	0.02		0.00	<0.01	
Fatigue Severity	0.03	<0.01		0.03	<0.01	

Depression Severity	-0.05	0.03		-0.02	<0.01	
Block 2: Environmental Factors						0.12*
Perceived Social Support				-0.56	0.01	
Perceived Financial Resources				0.09	<0.01	
Perceived Neighborhood Safety				1.52*	0.09	
Using Walking Aid Only				-0.95	0.02	
Using Wheeled Aid				-1.53	0.03	

Note. *N*=101. Block 1 F-change test df = 5, 95; Block 2 df = 5, 90. * $p < 0.05$. Using wheeled aid includes both the exclusive use of wheeled aids and the combined use of wheeled aids and walking aids.

No statistically significant results were found to support the effect modification of environmental factors in moderating the association between person factors and community participation outcomes (Tables 7-9). Figures S4-S21 in Supplement 3 were plotted to provide visual illustrations of how the use of mobility aids and social support might make a difference in the association of physical function, fatigue, and depression with community participation outcomes, despite the absence of statistical significance ($p > 0.05$).

Table 7. Moderation of the Use of Mobility Aids on the Association between Physical Function and Community Participation

Measures	**Model 1: Demographics, Physical Function, and Mobility Aids**			**Model 2: + Effect Modification**		
	b	**sr^2**	**R^2**	**b**	**sr^2**	**ΔR^2**
Outcome: Perceived Ability to Participate						
Intercept	34.37*			28.78*		
Block 1			0.16*			
Age	-0.01	0.01		0.01	<0.01	
Disease Duration	0.07	<0.01		0.06	<0.01	
Physical Functions	0.20*	0.06		0.29	0.03	

Using Walking Aid Only	-1.52	<0.01		1.04	<0.01	
Using Wheeled Aid	-0.76	<0.01		5.92	<0.01	
Block 2						0.01
UsingWalkingAidOnly X PF				-0.05	<0.01	
UsingWheeledAid X PF				-0.16	<0.01	
Outcome: Satisfaction with Participation						
Intercept	31.88*			41.74*		
Block 1			0.18*			
Age	0.03	<0.01		0.01	<0.01	
Disease Duration	0.04	<0.01		0.05	<0.01	
Physical Functions	0.25	0.07		0.07	<0.01	
Using Walking Aid Only	-2.09	0.01		-16.99	0.02	
Using Wheeled Aid	-1.90	<0.01		-10.13	<0.01	
Block 2						0.01
UsingWalkingAidOnly X PF				0.32	0.01	
UsingWheeledAid X PF				0.16	<0.01	
Outcome: Trip Frequency						
Block 1			0.14*			
Intercept	0.01			-1.28		
Age	0.00	<0.01		0.00	<0.01	
Disease Duration	0.01	0.02		0.01	<0.01	
Physical Functions	0.02*	0.06		0.04*	0.05	
Using Walking Aid Only	0.00	<0.01		1.06	<0.01	
Using Wheeled Aid	-0.01	<0.01		1.36	0.02	
Block 2						0.02
UsingWalkingAidOnly X PF				-0.02	<0.01	
UsingWheeledAid X PF				-0.03	0.02	
Outcome: Trip Distance						
Block 1			0.12*			
Intercept	-0.21			-0.23		
Age	0.04	0.02		0.04	0.02	
Disease Duration	0.00	<0.01		0.00	<0.01	
Physical Functions	0.03	0.02		0.03	<0.01	
Using Walking Aid Only	-0.49	0.02		-0.24	<0.01	
Using Wheeled Aid	-0.55	0.02		-0.35	<0.01	
Block 2						0.00
UsingWalkingAidOnly X PF				-0.01	<0.01	

UsingWheeledAid X PF				0.00	<0.01	
Outcome: Trip Duration						
Block 1			0.16*			
Intercept	-3.73			-0.29		
Age	0.01	<0.01		0.01	<0.01	
Disease Duration	0.01	0.01		0.01	0.01	
Physical Functions	0.02*	0.05		0.02	<0.01	
Using Walking Aid Only	-0.26	0.02		-0.44	<0.01	
Using Wheeled Aid	-0.15	<0.01		-0.21	<0.01	
Block 2						0.00
UsingWalkingAidOnly X PF				0.00	<0.01	
UsingWheeledAid X PF				0.00	<0.01	
Outcome: Radius of Gyration						
Block 1			0.05			
Intercept	5.63			5.81		
Age	0.03	<0.01		0.04	<0.01	
Disease Duration	0.01	<0.01		0.01	<0.01	
Physical Function	0.03	<0.01		0.02	<0.01	
Using Walking Aid Only	-0.84	0.02		-2.98	<0.01	
Using Wheeled Aid	-0.82	<0.01		-0.34	<0.01	
Block 2						0.01
UsingWalkingAidOnly X PF				0.05	<0.01	
UsingWheeledAid X PF				-0.02	<0.01	

Note. N=101. Block 1 F-change test df = 5, 95; Block 2 df = 2, 93. Using wheeled aid includes both the exclusive use of wheeled aids and the combined use of wheeled aids and walking aids. UsingWalkingAidOnly X PF = Interaction between using walking aids only and physical functions; UsingWheeledAid X PF = Interaction between using wheeled aids and physical function. * $p < 0.05$.

Table 8. Moderation of Social Support on the Association between Fatigue Severity and Community Participation

Measures	**Model 1: Demographics, Social Support, and Fatigue Severity**			**Model 2: + Effect Modification**		
	b	**sr^2**	**R^2**	**b**	**sr^2**	**ΔR^2**

Outcome: Perceived Ability to Participate						
Intercept	71.72*			83.17*		
Block 1			0.39*			
Age	-0.20	0.02		-0.20*	0.03	
Disease Duration	0.02	<0.01		0.02	<0.01	
Fatigue Severity	-0.41*	0.28		-0.59	0.02	
Social Support	1.31	0.02		-1.17	<0.01	
Block 2						0.00
Social Support X Fatigue				0.04	<0.01	
Outcome: Satisfaction with Participation						
Intercept	60.93*			41.78*		
Block 1			0.27*			
Age	-0.17	0.01		-0.17	0.01	
Disease Duration	-0.02	<0.01		-0.03	<0.01	
Fatigue Severity	-0.35*	0.12		-0.05	<0.01	
Social Support	2.86*	0.07		7.00	<0.01	
Block 2						0.00
Social Support X Fatigue				-0.07	<0.01	
Outcome: Trip Frequency						
Intercept	1.31			3.59		
Block 1			0.03			
Age	-0.01	0.01		-0.02	0.01	
Disease Duration	0.01	0.01		0.01	0.01	
Fatigue Severity	0.00	<0.01		-0.04	<0.01	
Social Support	0.10	0.01		-0.40	<0.01	
Block 2						0.01
Social Support X Fatigue				0.01	<0.01	
Outcome: Trip Distance						
Intercept	-0.37			0.33		
Block 1			0.05			
Age	0.02	<0.01		0.02	<0.01	
Disease Duration	0.00	<0.01		0.00	<0.01	
Fatigue Severity	0.01	<0.01		-0.01	<0.01	
Social Support	0.37*	0.04		0.22	<0.01	
Block 2						0
Social Support X Fatigue				0.00	<0.01	

Outcome: Trip Duration						
Intercept	0.86			2.52		
Block 1			0.04			
Age	0.00	<0.01		0.00	<0.01	
Disease Duration	0.01	<0.01		0.01	<0.01	
Fatigue Severity	-0.01	<0.01		-0.03	<0.01	
Social Support	0.13	0.02		-0.22	<0.01	
Block 2						0
Social Support X Fatigue				0.01	<0.01	
Outcome: Radius of Gyration						
Intercept	4.47			6.60		
Block 1			0.02			
Age	0.01	<0.01		0.01	<0.01	
Disease Duration	0.01	<0.01		0.01	<0.01	
Fatigue Severity	0.01	<0.01		-0.02	<0.01	
Social Support	0.47	0.02		0.01	<0.01	
Block 2						0
Social Support X Fatigue				0.01	<0.01	

*Note. N=101. Block 1 F-change test df = 5, 95; Block 2 df = 2, 93. UsingWalkingAidOnly X PF = Interaction between using walking aids only and physical functions; UsingWheeledAid X PF = Interaction between using wheeled aids and physical function. * p < 0.05.*

Table 9. Moderation of Social Support on the Association between Depression Severity and Community Participation

Measures	**Model 1: Demographics, Social Support, and Depression Severity**			**Model 2: + Effect Modification**		
	b	**sr^2**	**R^2**	**b**	**sr^2**	**ΔR^2**
Outcome: Perceived Ability to Participate						
Intercept	54.26*			73.68*		
Block 1			0.19*			
Age	-0.15	0.01		-0.15	0.01	
Disease Duration	0.05	<0.01		0.06	<0.01	
Depression Severity	-0.21*	0.08		-0.53	0.02	

Social Support	1.33	0.02		-2.80	<0.01	
Block 2						0.01
Social Support X Depression				0.07	<0.01	
Outcome: Satisfaction with Participation						
Intercept	59.42*			64.37*		
Block 1			0.26*			
Age	-0.17	0.01		-0.17	0.01	
Disease Duration	0.01	<0.01		0.01	<0.01	
Depression Severity	-0.32*	0.11		-0.40	<0.01	
Social Support	2.08*	0.03		1.03	<0.01	
Block 2						0.00
Social Support X Depression				0.02	<0.01	
Outcome: Trip Frequency						
Intercept	1.86			3.69		
Block 1			0.04			
Age	-0.02	0.01		-0.02	0.01	
Disease Duration	0.01	0.01		0.01	0.01	
Depression Severity	-0.01	0.01		-0.04	<0.01	
Social Support	0.05	<0.01		-0.33	<0.01	
Block 2						0.01
Social Support X Depression				0.01	<0.01	
Outcome: Trip Distance						
Intercept	2.16			7.88		
Block 1			0.06			
Age	0.02	<0.01		0.01	<0.01	
Disease Duration	0.00	<0.01		0.00	<0.01	
Depression Severity	-0.02	0.02		-0.12	0.02	
Social Support	0.24	0.01		-0.98	<0.01	
Block 2						0
Social Support X Depression				0.02	0.01	
Outcome: Trip Duration						
Intercept	1.21			2.18		
Block 1			0.04			
Age	-0.01	<0.01		-0.01	<0.01	
Disease Duration	0.01	<0.01		0.01	<0.01	

Depression Severity	-0.01	<0.01		-0.03	<0.01	
Social Support	0.10	<0.01		-0.11	<0.01	
Block 2						0
Social Support X Depression				0.00	<0.01	
Outcome: Radius of Gyration						
Intercept	8.90*			18.98		
Block 1			0.03			
Age	0.00	<0.01		0.00	<0.01	
Disease Duration	0.01	<0.01		0.01	<0.01	
Depression Severity	-0.04	0.01		-0.21	0.01	
Social Support	0.23	<0.01		-1.91	<0.01	
Block 2						0.01
Social Support X Depression				0.04	<0.01	

*Note. N=101. Block 1 F-change test df = 5, 95; Block 2 df = 2, 93. UsingWalkingAidOnly X PF = Interaction between using walking aids only and physical functions; UsingWheeledAid X PF = Interaction between using wheeled aids and physical function. * $p < 0.05$.*

Qualitative Findings

A total of three themes and eight subthemes emerged from focus groups. To compare and contrast the findings from quantitative and qualitative data, the results from the quantitative analysis were integrated with the insights from the qualitative data. In line with the quantitative findings, the first theme further illustrated the significant impact of EFs on some aspects of community participation from the perspectives of participants who use or do not use mobility devices. Unlike the results from the quantitative analysis, the second theme illustrated the potential moderator role of environmental support in buffering the negative impact of functional impairments to improve community participation outcomes. Finally, the last theme describes strategies employed by participants to navigate environmental barriers and highlights advocacy priorities for addressing sociopolitical environmental barriers, which were not captured in quantitative data.

Theme 1: Barriers in Physical, Societal, and Attitudinal Environments Bring Additional Challenges, and the Magnitude of These Influences Differs Between Mobility Aid Users and Nonusers

Consistent with the significant association between person factors and community participation outcomes found in the quantitative data, focus group participants provided further insights into how internal factors impacted their satisfaction with and frequency of participation in activities occurring outside the home. These factors included MS-related symptoms (e.g., fatigue and heat intolerance), personal factors (e.g., personality, motivations, social roles), and psychological factors (e.g., internalized stigma around disability, fear of becoming an "easy target" in an unsafe neighborhood). In addition, qualitative findings supported the significant association between EFs and both frequency and satisfaction with community participation and provided contextual details regarding what barriers in physical, societal, and attitudinal environments influenced community participation experiences and how. Participants also implied that the magnitude of environmental influences varied based on their mobility aid use status.

Subtheme 1.1: Barriers in Natural and Built Environments

Participants discussed the impact of natural (e.g., weather, geographical characteristics) and built environments (e.g., transportation systems, buildings) on community participation. Some participants voiced that opportunities for engaging in social activities outside the home varied based on the characteristics of one's geographical location and surrounding community. For example, P23 who lived in “a village of 350 people” commented, “There's nothing around. There's probably more cows in the area than there are people, but you don't have interactions with community. Besides going to work, I am home by myself and so it's not very satisfying, it's not very inclusive.”

While acknowledging that weather can influence everyone's ability to participate in activities outside the home, most focus group participants indicated that extreme weather conditions—such as very cold, hot, or humid weather—are particularly demotivating due to extreme temperature or humidity intolerance, which is common among individuals with MS. Snow and ice, particularly, had a greater impact for mobility aid users due to unsafe and unclear sidewalks, as one shared, “Wheelchairs don't do well in the snow or ice. It's difficult. And what'll happen is if you're on a sidewalk, the snowplows will push the snow onto the sidewalks (P24).”

Participants indicated that in addition to snow and ice on the sidewalks, barriers in the built environment created challenges during community trips, especially for those who use mobility devices. Mobility aid users shared that the unavailability of public transportation, uneven surfaces on the street, and inaccessible buildings and public spaces made it difficult for them to engage in out-of-home activities as desired.

> For me, transportation is one, being in an inner city, then accessibility is hard for me to get in and out of places. Sidewalks, I think there should be a policy or something mandated to have all entries and sidewalks more wheelchair accessible because the doors that you go in now are very thin. (P20)

Furthermore, participants provided insights on the significant independent association of perceived neighborhood safety with greater trip distance and radius of gyration. From participant perspectives, neighborhood safety encompassed two aspects: one related to security and crime, and the other to the streets and sidewalks that are accessible and free from tripping hazards. Both internal fear of being a target of criminal activities and the risk of injury from falling on unsafe sidewalks had negative impacts on their community participation outcomes.

Subtheme 1.2: Barriers Related to Resources, Systems, and Policies

Participants identified COVID-19, employment challenges, and difficulty in obtaining useful information as major barriers in the societal environment. All participants discussed how the COVID-19 pandemic had negatively impacted their social lives and reduced their frequency of going outside the home significantly. While they acknowledged that COVID-19 impacted everyone’s life including those without MS, having MS as an underlying condition and receiving immunosuppressive treatment exacerbated their fear of contracting COVID-19. Between different groups of participants, those who live with invisible MS shared stronger feelings of isolation and frustration not only because they couldn't engage in certain activities due to infection risk, but also because others often did not understand their reasons for limiting in-person interactions.

> It's really isolating… It's not even a mindset or whatever. If I just ate in crowded bars all the time, I would get COVID all the time. I just don't have the protection and I can't change that. So I will occasionally just decide whether an event is worth the risk, but I don't have the same level of freedom and that's just really isolating because separate from that, I don't have that many limitations, so having one that's sort of a big one that you sort of don't have to have it's really frustrating. (P9)

> I was immunosuppressed as well and not something that I really enjoyed, especially when they [friends] kind of diminished the fact that, "Hey guys, I'm immunosuppressed. I appreciate it if you don't do these things and bring it back to

> me." But they're like, "Hey, we're on vacation. We're doing this. You knew what was happening." I'm like, "I guess you're right. But come on guys, be a little kind.” (P8)

Work was an essential component of community participation for most participants; yet, many of them shared struggles in either maintaining employment or seeking new employment after they were diagnosed with MS. Several participants had to resign from their previous physically-taxing jobs as their MS progressed. Based on participants’ experiences, employment challenges were oftentimes related to employers' failure to provide requested accommodations.

> They terminated me because they wouldn't give me reasonable accommodation. And I'm like, "My doctor didn't want me to work a 12-hour shift. He wanted me to work a 10-hour shift." And you're like, "Oh, well we can't help you with that one." (P4)

Participants explained that loss of employment oftentimes led to financial instability, and financial stress limited their ability to participate in more community activities. This finding is consistent with the significant independent effect of perceived financial resources on subjective participation measures. In addition, several participants highlighted that living with MS is expensive due to the need for long-term healthcare services and the additional costs associated with accommodating their fatigue (e.g., taking a cab instead of walking, hiring help with house chores), and therefore, they reported needing to “budget a lot harder and cut a lot of things [activity participation] out (P9).”

Difficulty in obtaining information and resources was discussed across groups, pointing to the gap between availability and accessibility. One participant commented, “There are so many things that are out there that's able to help, but the difficulty is finding the information

(P22)." Participants implied that these access barriers created unnecessary challenges to community participation, adding to the existing disease burden and emotional distress they experienced. For most participants using mobility aids, getting the devices they needed, though requiring effort, did not involve many obstacles; however, when P19 shared that she recently got an elevated power wheelchair, P20 reflected on his past experience that demonstrated the availability-accessibility gap.

> That [trying to get an elevated power wheelchair] was a barrier for me. I remember when I first got diagnosed with MS, I tried to get that elevator chair and they did everything they could possibly do for me not to get that seat. I don't understand why they make something for people for convenience, especially those that have a disability, but make it so hard for you to get it, especially if you're a minority. (P20)

Subtheme 1.3: Barriers in the Attitudinal Environment

Participants expressed that the attitudinal environment formed by the attitudes of others, including acquaintances and strangers, can also influence their motivation and satisfaction with community participation as those affect their psychological well-being. A few participants across groups implied that ableist attitudes exist in the general public. They have encountered or witnessed negative attitudes from strangers who showed little caring for people with disabilities. For example, a participant shared that she once received a note with hateful words on her car that was parked at an accessible spot in a school. Participants discussed that negative experiences and witnessing ableism in the past and currently have led to the gradual formation of internalized stigma.

> I think for me it was, I saw the treatment of my mom. She was in a wheelchair. I have three memories of her walking, ever. And she got the stigma of, "Oh, she can't do this, she can't do that, and we're going to look at her funny and we're going to ask other people about it and talk about her behind her back." And that's a stigma that I have from childhood. And that's all I ever knew was that's what she had and that's how people looked at her with the wheelchair, and they didn't question and they were judging… And now my husband has the excitement of me in a wheelchair, and my dad's like, "Oh, you married her. She's your problem now." And after dad dealt with mom for so many years, you are stuck in this mental space of, "Is it on me? Is it my perception of reality? What is it?" (P23)

The attitudinal environment was discussed more as a major concern among participants with invisible MS, and particularly, the discussions around MS disclosure only came up in the groups with nonusers. They stressed that whether to disclose their diagnosis is a personal choice, but they implied that if they chose to reject disclosure, it was oftentimes due to fear of stigma. Specifically, they expressed a strong opinion that they would decline to disclose MS at workplaces unless necessary, including during the job application process, due to negative past experiences with discrimination and the fear of stigma affecting perceptions of their capability.

> I had a somewhat obnoxious diagnostic path where doctor didn't believe me, and when they finally diagnosed me, he was pretty flippant and they just kind of thrust a brochure at me about MS. And in my memory, emblazoned on this brochure was basically, 'be careful who you tell, people may be prejudiced against you.' And I'm sure it didn't actually come across that way entirely, but that's the impression that I walked away with. And so immediately my sense of community

> shrank drastically… I felt extremely isolated all of a sudden and that I was no longer in control of my own destiny, that people would judge me and predefine and assume what I was capable of with the diagnosis if I shared it… for better or worse, I guess we do live in a society where people, especially in employment opportunities, can be prejudged based on what they bring to the table in terms of physical and mental ability. (P11)

Theme 2: Environmental Support May Help Mitigate the Negative Impact of Impairments on Community Participation

This theme describes participant perspectives about external supports promoting their out-of-home participation despite the co-existing negative impact of MS-related impairments. Environmental supports mentioned by participants included services and resources available for both the general disability community and the MS population, social support from peers who have MS, friends or family, and the use of mobility aids. While quantitative findings showed that the use of wheeled aid was significantly associated with worse community participation, focus group findings told a different story, stating that using mobility aids enabled community participation. In addition, focus group findings illustrated how social support and the use of mobility aids, especially wheeled aids, are great support and might mitigate the negative impact of MS-related symptoms on community participation. Although not significant, quantitative findings seemed to be in agreement with qualitative findings. For example, Figure S4 and Figure S7 in Supplement 3 show a trend that as physical functions decrease, use of wheeled aid seemed to result in a smaller reduction in perceived ability to participate and trip frequency, compared to no use of mobility aid, and use of wheeled aid resulted in the smallest reduction. Higher levels of social support seemed to prevent more dramatic drops in perceived ability to participate, trip frequency, trip duration, and radius of gyration associated with increased fatigue severity (See Figures S10, S12, S14, S15 in Supplement 3).

Subtheme 2.1: Having Access to Resources and Opportunities

Participants shared that having access to community-based resources and opportunities to participate as a members of the community facilitated their community engagement. A couple of participants shared that they are involved in collaborative projects with regional universities as disability advocates or advisory board members. This participation not only made them feel like they were contributing but also motivated them to engage in activities outside the home. Some mobility aid users shared that they lost their ability to drive a standard vehicle after their mobility impairments had progressed, and having access to vehicle modifications and adaptive driving training enabled them to be mobile in the community again. In addition, participants conveyed that disability services, such as priority boarding at airports, accessible gyms, and accessible public transportation, established a supportive environment for people living with functional limitations to engage more in out-of-home activities as wished.

> I went six years without any problems…when it got to the point where I couldn't work, and I couldn't drive, I was by myself a lot. Transitioning into what was next took some effort... The para-transit shuttle, which picked me up where I lived, took me wherever I was going. Because of that, I started to get involved with things again and I got involved in things for people with disabilities, started going to an MS support group. (P18)

Subtheme 2.2: Social Support from Colleagues, Family, Friends, and Peers with MS

Aligned with the quantitative results that revealed that social support was a significant factor associated with both satisfaction with participation and perceived ability to participate, focus group participants highlighted the important role of their social support. Many participants shared that there was a lack of understanding from people who have a more remote relationship with them, and they sensed that their social network had shrunk after they had MS. Yet, they were grateful for their lasting support network formed with close friends, colleagues, and family members. For example, a former clinician shared that he felt supported by understanding colleagues when he had to take days off during his relapsing period. Another participant whose work environment may be less supportive stated that her support network formed with close friends is small but strong, “So for the first two years after I was diagnosed, my sense of community participation shrank way down. But after coming to terms with what it meant for me to be living with MS, I started to share with a couple of close friends and people were so supportive, and kind, and loving, and we've established a history of doing the walk/run MS and also bike MS in [location name]. This will be our seventh year doing it (P11).” In addition to personal networks, many participants also acknowledged the increased availability of community resources specific to the MS population over the past years. For example, some participants described that the Bike MS and Walk MS events as well as the gifted cooling vest included in a care package from the National MS Society facilitated their participation in out-of-home activities and socialization. Many participants have also shared that they consider MS support groups as social support where they found a sense of community and learned coping strategies from peers.

> Having that community and building that relationship with other people that are understanding, and having empathy, and understand what you're going through is so beneficial that you're able to share that and help you get through the day. (P22)

Subtheme 2.3: Use of Mobility Aids

All participants who use mobility aids voiced that using these assistive devices enabled them to travel to places that they wanted to visit; otherwise, their participation would have been much more restricted due to mobility impairments. However, they acknowledged that the use of mobility aids was associated with fear of stigma, especially at the beginning stage when they just recognized their need for aids. As P15 stated, “I went through that [the fear of stigma phase]. I was so embarrassed to use it,” many participants shared a perspective that the stigma takes time to overcome. They described that mobility devices seemed to be a symbol of “disabled” and “incapable;” however, once they have moved past the stigma phase, use of mobility aids is perceived as a great support. Those who use different types of devices expressed that the devices help meet their real-time needs depending on travel distance and energy level.

> I have a walker, I have a wheelchair, I have canes. It just depends on how my fatigue level is that day….It's (using mobility aid devices) helping me stay involved, it's helping me to still get out there and participate and just making myself happy. And that's the whole point is making myself happy and making myself stay involved. (P22)

Theme 3: Acceptance and Adaptations are Helpful Individual Strategies, but More Needs to Be Done at the Societal Level

This theme provides further understanding of how people navigate environmental barriers which was not captured in the quantitative data. The theme highlights additional insights into the strategies used by participants during community participation and their advocacy for societal improvements. Participants shared that accepting the fact that they live with MS and adapting their thinking and behaviors were helpful when facing challenges, but they highlighted that reaching satisfaction was a process. They indicated that existing obstacles in the environment require PwMS to put in extra effort to achieve their goals. Although participants acknowledged the importance of individual efforts, they emphasized the need for greater collective efforts in society to better support PwMS to optimize their community participation experience.

Subtheme 3.1: Acceptance, Optimistic Thinking, and Adaptation as Individual Strategies

Most participants who have lived with MS for many years shared that they developed acceptance of MS and their functional limitations, and therefore, they are able to think positively when encountering barriers. They implied that developing acceptance and a positive mindset was not easy but necessary, as P17 stated, “That was very hard to learn at first, to accept, and ask for that help. But now I know that it's the only way I can do things is I need that help." Participants who have developed acceptance proudly agreed that MS “doesn't necessarily define me, but it is a part of me (P12)." Optimistic thinking is viewed as an empowering tool by participants to conquer life challenges by focusing on positivity to reduce mental distress, as P14 shared with others, “Don't concentrate on what you can't do. Concentrate on what you can do, concentrate on your strengths.” P22 summarized the importance of acceptance and optimistic thinking very well by stating, “I think in order to get us through a lot of the things that we're doing with MS, is mindset.”

Another common strategy used across participants with MS was proactively assessing needs and adapting behaviors based on the environment when changing the environment is not possible. Participants have learned about their limitations and what would work to maintain a higher level of community engagement, as one put, “I've lived with MS for so long, and I'm in the power wheelchair, I know what it's going to take to accomplish something (P17).” This ability is not simply innate but rather a result of proactivity, which empowered them to make constant efforts and take action to successfully overcome challenges in the environment. For example, in winter times when the streets were covered by snow, some participants living in an assisted living setting shared that they prioritized and found joy in participating in social activities occurring at the facility. A participant who loves jogging outdoors would shift to more tolerable activities in the summer, such as biking, due to their heat intolerance. Recognizing the fluctuating nature of MS, some participants shared that they have learned to be flexible in planning and pacing activities based on the energy level of the day and the priority of tasks. Lastly, participants described that actively seeking information and resources, such as putting effort into finding an accessible restaurant, planning an accessible route, and asking for help when needed, is part of their proactive adaptation.

Subtheme 3.2: Advocacy for Enhancing Environmental Supports

Although participants implied that they were able to achieve some level of success in optimizing community engagement through extensive individual efforts, they agreed that increasing environmental support is necessary. Across focus groups, participants identified four priorities for increasing system-level support for community participation of PwMS: improving accessibility in the built environment, access to information, MS specialty care, and public attitudes toward disability. Drawing from the major barriers experienced by mobility aid users, participants advocated for **policy enforcement to improve accessibility in the built environment**. Participants noted the existing Americans with Disabilities Act (ADA) law mandates an accessible built environment, but the problem is around the lack of enforcement.

> Most of the world isn't ADA accessible. So, being active, there's lots of barriers to getting in and out of places. Even when they say they're ADA accessible, they're full of shit. (P18)
>
> A lot of this issue in my opinion boils down to your local municipalities or your local towns and villages, cities. No one enforces ADA issues, okay? Like the sidewalks being without snow and ice and things... You get the handout or the annual update that says, "You homeowners have to do your sidewalks, you have to shovel your sidewalks and things like that." But no one, no one enforces it. So that's where we're stuck. (P21)

Reflecting on the challenging journey of trying to find helpful information during their early MS stage, participants emphasized the need for **improving the ease of access to useful information and resources**, **especially for those who are newly diagnosed**. As presented in Subtheme 1.2, helpful resources and programs supporting PwMS are not lacking, however, finding the helpful information they need, especially when they just got diagnosed can be challenging. As one reflected, when people just received their diagnosis, “they're in shell shock. It's so devastating at the time. You don't know what's going to happen next (P21).” However, that is the time when they need to be aware of the external support. Therefore, increasing the awareness of existing resources is key. One participant suggested, “coming up with some type of toolkit to get all this information in one spot to be able to give to people so they'll have access to it (P22).” Others agreed that this would be a great program if neurologists, who are typically the first contact of MS patients, could share useful information and connect them to resources once they get the diagnosis.

Participants also desired **improvements in MS specialty care**. This advocacy highlighted the need for not only expanding coverage of and access to MS specialty clinics nationwide, but also increasing the number of healthcare providers with expertise in MS. A few participants pointed out the lack of resources supporting the MS population in their regions, and one expressed hope that the newly built hospital would bring more MS specialty care to the region. Several participants shared stories about their dissatisfactory interactions with healthcare providers, describing experiences related to delayed diagnosis, not being trusted, having to switch practices, and receiving "bad advice (P18)" from providers. These experiences added psychological burdens and affected their motivation for community involvement.

Participants called for changes in public attitudes toward people with disabilities. Based on their negative experiences with misunderstanding and discrimination, they emphasized the need for **everyone to be more caring, understanding, and empathetic, especially toward those with invisible disabilities.** Many mobility aid users expressed that despite the internal fear of being discriminated against, most people they met seemed respectful, and some acted even nicer after they noticed their mobility devices. However, those with invisible MS shared a different perspective, as one put it, "As a society, we have a hard time putting empathy into those things that we cannot see (P1)." They stressed that improving the attitudinal environment of the general public is particularly important for people with invisible disabilities. Participants suggested that the improvements should begin with educating younger generations in school and at home.

Discussion

The study aimed to explore how physical, societal, and attitudinal environments influence community participation outcomes among PwMS, and to understand the systemic support needed to enhance their community participation from participant perspectives. The quantitative findings highlighted the important role of EFs in influencing both subjective and objective aspects of community participation. Regression analyses found that EFs generally have a greater impact on satisfaction with participation and radius of gyration that reflects activity space among PwMS, compared to other community participation outcomes. Different EFs demonstrated varying magnitudes of influence on different aspects of community participation. Perceived financial resources and perceived neighborhood safety demonstrated greater effects on some subjective or community participation outcomes, while other EFs showed a generally weak association with community participation.

Among the EFs analyzed statistically, perceived financial resources demonstrated the strongest association with subjective participation perspectives, even when accounting for personal factors. Perceived neighborhood safety showed a positive independent association with trip distance and radius of gyration. These findings are consistent with Hall et al. (2022) revealing a significant association between lower income and lower satisfaction with social participation, and Desai et al. (2023) scoping review that reported the influence of neighborhood safety on the ability to reach destinations of interest among people with physical disabilities. Nevertheless, the associations between EFs and community participation measures were generally weak, with EFs explaining a relatively small amount of variance in community participation outcomes compared to person factors. These findings align with previous MS studies, which revealed a generally stronger association between symptoms and participation than with external factors (Plow et al., 2015; Baylor et al., 2010).

These results might indicate that the impact of symptom severity was greater than that of EFs among participants in the quantitative phase. The weak association might also be due to the limitation of secondary data analysis, in which only a few environmental factor variables were available. Other known significant environmental factors, such as access to public transportation and the objective built environment, as reported in previous literature (Desai et al., 2023; Bezyak et al., 2020) and highlighted by the focus group participants were not included in the analysis. Noreau and Boschen (2010) also noted that the lack of significant statistical findings on environmental impacts does not equate to an absence of environmental influence on participation in the real world. In reality, the impact of environmental influences on community participation is often underestimated by empirical statistics due to the difficulty in quantifying contextual nuances. In our quantitative sample, it is possible that some people who faced more participation restrictions also perceived higher levels of environmental support due to optimistic mindsets, resulting in limited quantitative support for a relationship between higher levels of environmental support and better community participation outcomes (Reinhardt & Post, 2010). This perception was also reflected in the focus group discussions. In this study, qualitative focus group data complemented the quantitative analysis by providing contextual insights on the importance of environmental factors in hindering or facilitating community participation among PwMS.

Qualitative findings not only supported the significance of environmental influences but also identified several major environmental barriers to community participation. These barriers included unfavorable geographical characteristics, weather, inaccessibility of the built environment, COVID-19, employment challenges, difficulty obtaining useful information, and internalized and external ableist attitudes. These environmental barriers were also reported to be interfering with participation by populations with other disabilities (Hammel et al., 2015). Even though qualitative data were collected in 2024, after the peak of COVID-19 restrictions, many focus group participants stressed the ongoing negative impact of the pandemic on community participation. Participants noted that a lack of understanding from others about their fear of COVID-19 and their intentional reduction in activity engagement was a barrier in the attitudinal environment. In addition, they expressed continued feelings of isolation and hesitation to engage in certain activities with increased risks of infection, reflecting the persistent effects of COVID-19 in the current post-pandemic era. These findings are consistent with Morris-Bankole and Ho (2021) who reported that the COVID-19 pandemic posed substantial challenges for many PwMS primarily due to their immunosuppressed status from disease-modifying treatments. Similarly, people with brain injury also have voiced that COVID-19 has exacerbated ongoing challenges to social participation (Kersey, McArthur, et al., 2024). As revealed by a population-level survey, people with various types of disabilities experienced enlarged disparities in accessing community services and engaging in community activities compared to non-disabled people during the COVID-19 pandemic (Kersey, Lane, et al., 2024). Future studies should explore the potential long-term impact of COVID-19 on community participation among PwMS. Interestingly, PwMS who use mobility devices reported more barriers in the built environment outside the home, whereas those with invisible MS shared internalized stigma around MS disclosure and more concerns about the attitudinal environment. The invisibility of MS often leads to others' lack of understanding or disbelief in their struggles, resulting in a feeling of isolation (Parker et al., 2021).

The study provided valuable insights into the role of mobility aid use. The correlation analyses showed negative associations between both subjective and objective participation measures and the use of mobility, which agrees with Best and Miller (2011) who reported the use of wheelchairs as a risk factor for reduced participation. However, focus group participants implied that these quantitative findings may not be sufficient to draw a conclusion that using mobility aids is a barrier to participation. The absence of statistical evidence supporting the positive role of using a mobility aid may be due to the moderator role of physical impairments in the association between the use of mobility aid and participation. It is likely that in our sample, the association between physical impairments and use of mobility aids as well as the association between physical impairments and worse community participation outcomes are strong, resulting in a negative association between mobility aid use and participation. In addition, literature has also revealed that people who use mobility devices are more likely to perceive worse health outcomes and rely on external assistance (Meng et al., 2019; Best & Miller, 2011). Nevertheless, as discussed by Widehammar et al. (2019), mobility devices are designed to support people with mobility impairments to engage in activities outside the home more actively; however, various factors, such as an inaccessible environment, lack of training on the use of the device, lack of social and societal support, and unfavorable weather, could turn the use of mobility devices from support into a barrier. Therefore, the supportive role and the moderation effect of mobility aid use may not be statistically confirmed unless all confounding factors that lead individuals to perceive mobility aids as a barrier are controlled. Findings from the focus groups revealed that using mobility devices can be viewed as a barrier for some people when they feel embarrassed about using them or when the physical surroundings are not accessible. However, many mobility aid users agreed that despite those influencing factors, using mobility devices has in fact enabled them to participate in more frequent and lengthy community activities outside the home, which led to higher satisfaction.

The study identified priorities for increasing external support in society to promote community participation of PwMS. While MS rehabilitation primarily focuses on addressing person factors, such as physical function, fatigue, and cognitive problems, to improve activity participation (Edwards et al., 2022; Khan et al., 2017), focus group participants noted that PwMS make substantial effort at the individual level to overcome environmental barriers. They also conveyed that while individual effort is crucial, it is insufficient on its own to reach success because, despite individual efforts, environmental barriers persist and are difficult to overcome without system-level effort in reducing them. Many rehabilitation researchers have stressed the necessity of addressing environmental barriers to promote community participation among people with disabilities. In practice, enhancing environmental supports may be more achievable than finding a cure for many chronic diseases, as Whiteneck and Dijkers (2009, p. S24) wrote, "modern medicine can still not eliminate many activity limitations, but at least in theory, with the right assistive devices, personal assistance, social support, policies, and environment, people with disability can fully participate in society." Although advocacy topics in this study were raised by PwMS and some were MS-specific, the areas align with existing advocacy for promoting accessibility and participation within the larger disability community, including improving accessibility in the architectural environment (Newman & SCI Photovoice Participants, 2010), public transportation (Bezyak et al., 2019), and access to healthcare services (Rotoli et al., 2022). The study highlighted the ongoing need for advocacy efforts and systematic actions to support community participation experiences of PwMS through addressing system-level barriers.

Several limitations of this study should be noted. First, the number of tests conducted in the quantitative phase may lead to an increased probability of false positives. Second, although the study is the first study in the MS literature using GPS data with a substantial sample size, the sample size was still relatively small and may lead to insufficient power for some analyses in the quantitative phase, particularly those examining the effect modification of EFs. We expected that findings might be different with a larger sample size supporting sufficient power. Third, limitations on the GPS data should be noted when interpreting findings. The parent study selected a 7-day tracking period, following Figueiredo et al. (2022), who suggested that a 7-day tracking period may offer a balance between collecting a sufficient amount of representative community participation data and maintaining participants' compliance with wearing the GPS device. Figueiredo et al., (2022) also noted that no standards for tracking duration have been established and that existing GPS studies vary widely in tracking durations, ranging from five hours to 30 days. The parent study of our quantitative phase considered participants returning at least two days of GPS tracking data acceptable. In this study, despite most participants in the quantitative phase being tracked for at least 7 days, the number of tracking days in the sample ranged from 2 – 19 days. It is likely that people with longer tracking periods had greater community mobility values.

Furthermore, as mentioned above, only a limited number of environmental factors were included in quantitative analyses due to the nature of a secondary analysis. All EFs included in the quantitative analyses were measured using self-report methods. Different results may be expected if EFs were measured objectively using GPS and Geographic Information System technology, as suggested by Chan et al. (2021) and Magasi et al. (2015). Some discrepancies between the quantitative and qualitative data should be considered when interpreting the findings. For example, the participants in the quantitative phase were aged 45-65, while the focus group participants were aged 33-66. Different age groups may have had varied experiences and perspectives on community participation. Additionally, while the baseline quantitative data were collected between April 2019 and September 2020, the focus groups were conducted in early 2024. The COVID-19 pandemic may have influenced community participation outcomes among participants in the quantitative phase. Future studies could explore the pandemic's impact on changes in community participation among PwMS. Future studies may investigate the impact of the pandemic on changes in community participation among PwMS. Finally, while this study focused on participation outside the home, the measures used for the subjective dimension of participation (PROMIS-AP and PROMIS-SRA) included activities that could occur both at home and outside the home (e.g., leisure activities, family activities, work including work at home. Despite these limitations, this mixed methods study contributes meaningful research evidence to community participation and MS research as well as advocacy efforts for addressing systematic environmental barriers. Future studies examining environmental influences on community participation should aim to have a large enough sample size with sufficient statistical power and include a broader range of important environmental factors.

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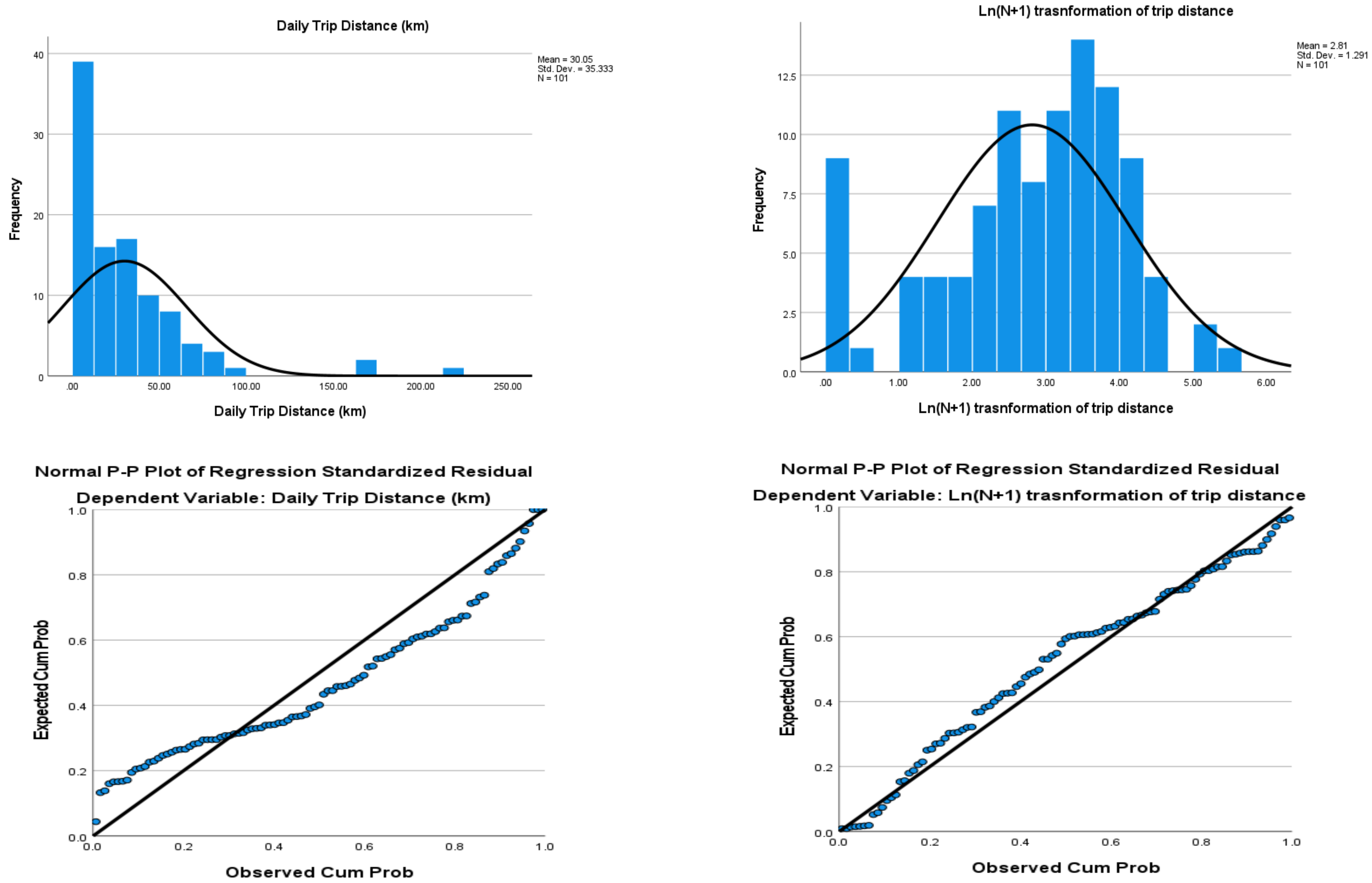
Supplement 1. Normality Testing for Regression Analyses

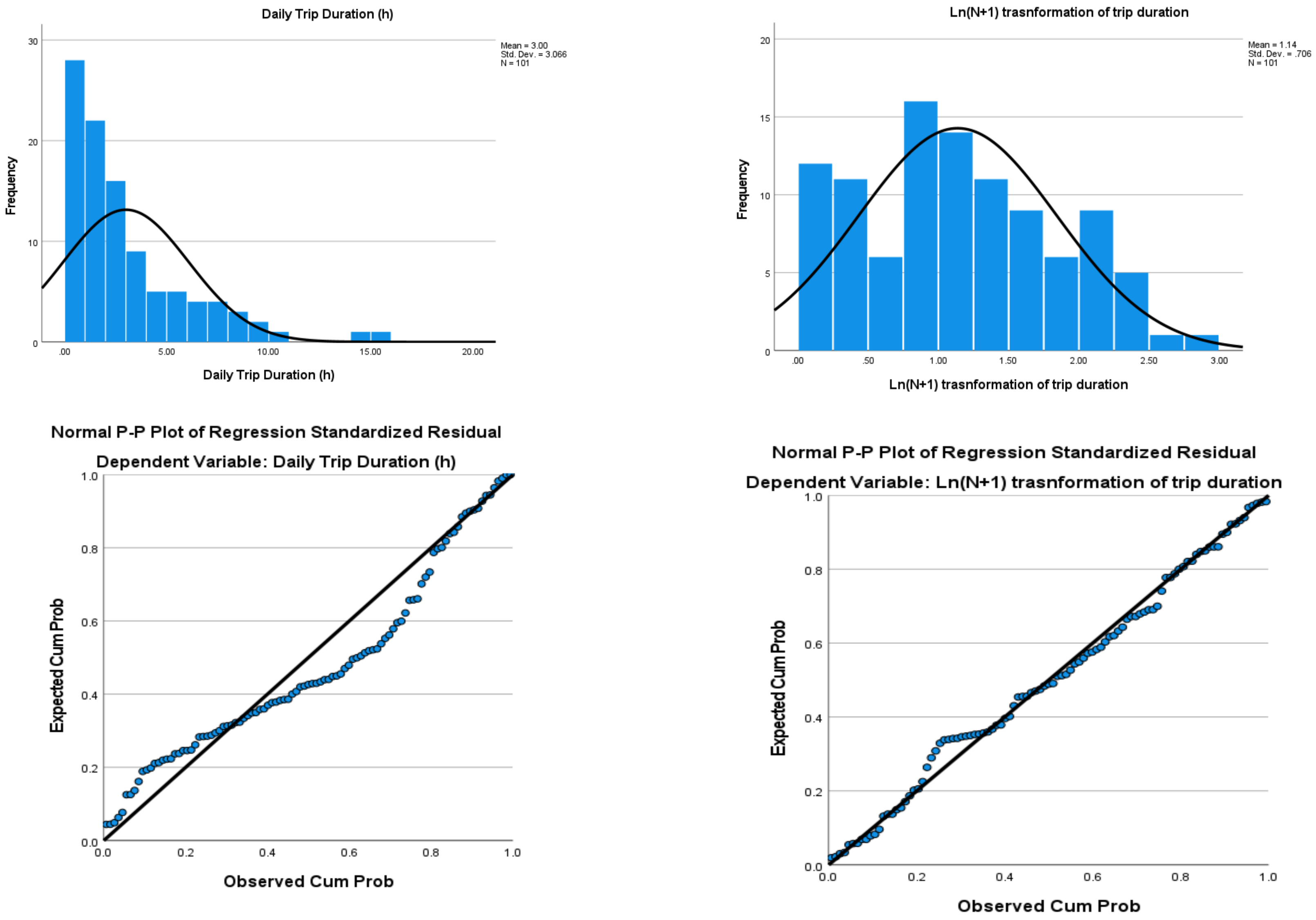
Figure S1. Examination of Daily Trip Distance Distribution and Normality Assumption for Linear Regression Analysis



Note. N=101. Histograms of the natural log-transformed daily trip distance showed improved normality. P-P plot of Regression Standardized Residuals for the natural log-transformed daily trip distance showed better alignment with the normality assumption.

Figure S2

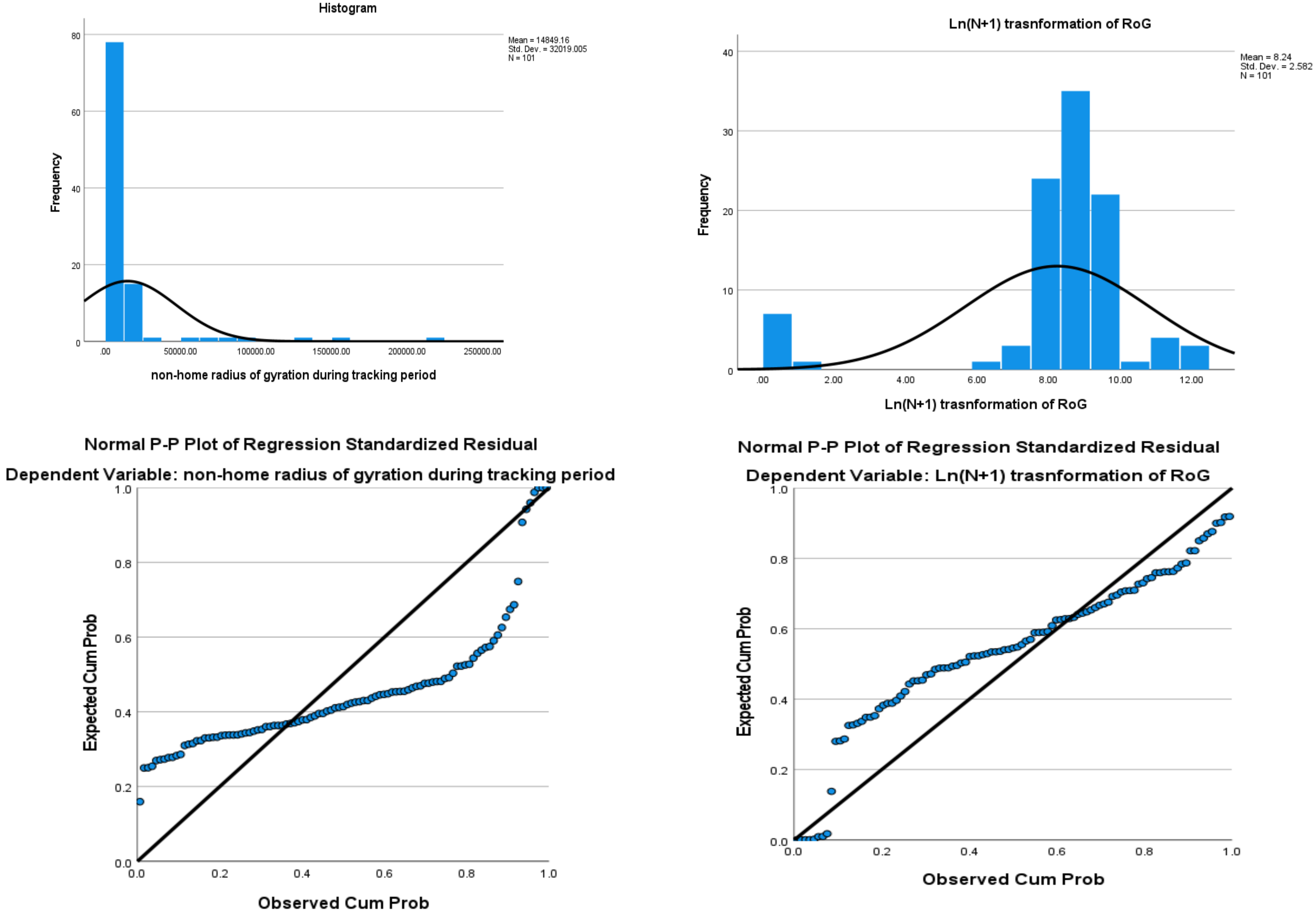
Examination of Daily Trip Duration Distribution and Normality Assumption for Linear Regression Analysis



Note. N=101. Histograms of the natural log-transformed daily trip duration showed improved normality. P-P plot of Regression Standardized Residuals for the natural log-transformed daily duration distance showed better alignment with the normality assumption.

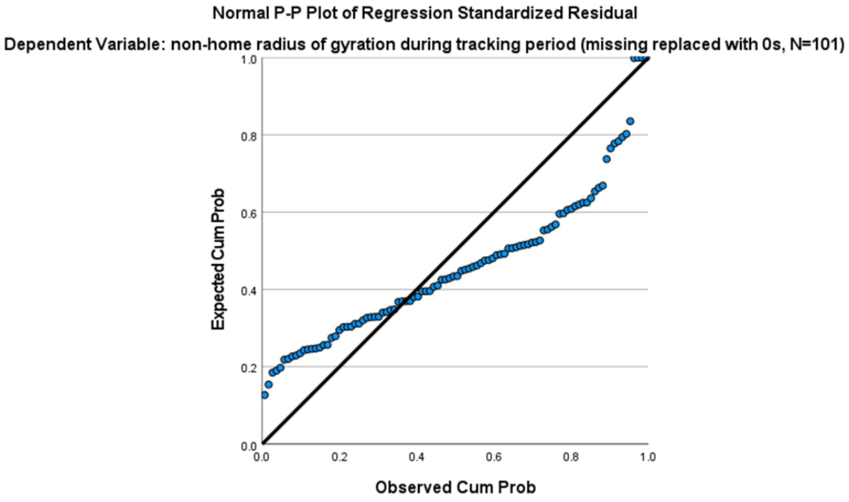
Figure S3

Examination of Radius of Gyration Distribution and Normality Assumption for Linear Regression Analysis

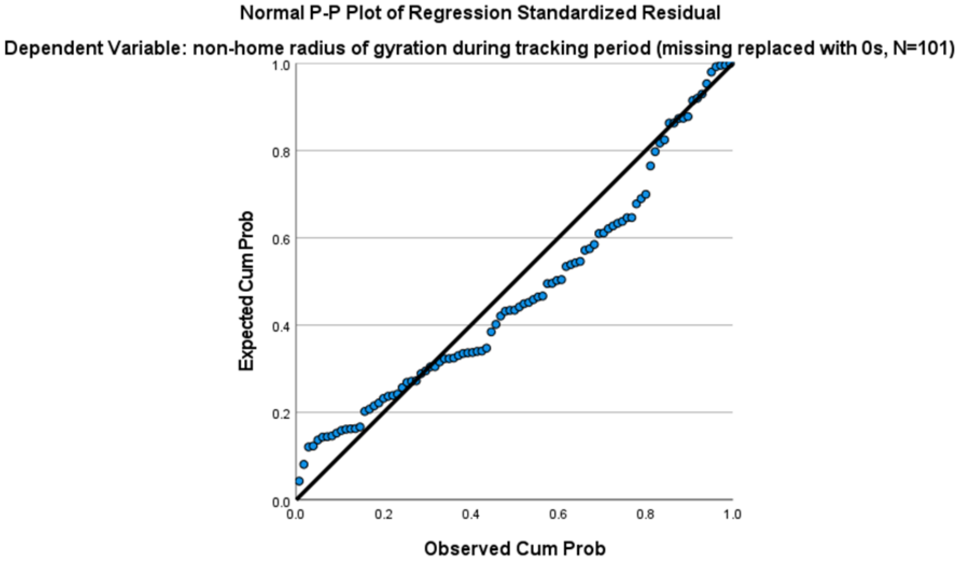


Note. N=101. Histograms of the natural log-transformed radius of gyration showed improved normality. P-P plot of Regression Standardized Residuals for the natural log-transformed radius of gyration showed better alignment with the normality assumption.

Figure S3.1



P-P Plot after removing 4 outliers



P-P Plot after removing 8 outliers

Supplement 2: Post hoc Power Analysis Results

Table S1. Post Hoc Power Analysis Results

Model	R^2total	Effect size	Power
Outcome: Perceived Ability to Participate	0.54	1.17	100%
Independent Variables:			
Age			
Disease Duration			
Physical Function			
Fatigue Severity			
Depression Severity			
Perceived Social Support			
Perceived Financial Resources			
Perceived Neighborhood Safety			
Using Walking Aid Only			
Using Wheeled Aid			
Outcome: Satisfaction with Participation	0.54	1.17	100%
Independent Variables			
Age			
Disease Duration			
Physical Function			
Fatigue Severity			
Depression Severity			
Perceived Social Support			
Perceived Financial Resources			
Perceived Neighborhood Safety			
Using Walking Aid Only			
Using Wheeled Aid			
Outcome: Trip Frequency	0.16	0.19	83%
Independent Variables			
Age			
Disease Duration			
Physical Function			
Fatigue Severity			
Depression Severity			
Perceived Social Support			
Perceived Financial Resources			

Perceived Neighborhood Safety Using Walking Aid Only Using Wheeled Aid			
Outcome: Trip Distance *Independent Variables:* Age Disease Duration Physical Function Fatigue Severity Depression Severity Perceived Social Support Perceived Financial Resources Perceived Neighborhood Safety Using Walking Aid Only Using Wheeled Aid	0.22	0.28	96%
Outcome: Trip Duration *Independent Variables:* Age Disease Duration Physical Function Fatigue Severity Depression Severity Perceived Social Support Perceived Financial Resources Perceived Neighborhood Safety Using Walking Aid Only Using Wheeled Aid	0.18	0.22	89%
Outcome: Radius of Gyration *Independent Variables:* Age Disease Duration Physical Function Fatigue Severity Depression Severity Perceived Social Support Perceived Financial Resources Perceived Neighborhood Safety	0.18	0.22	89%

Using Walking Aid Only			
Using Wheeled Aid			
Outcome: Perceived Ability to Participate			
Independent Variables:			
Age			
Disease Duration			
Physical Functions	0.17	0.21	92%
Using Walking Aid Only			
Using Wheeled Aid			
UsingWalkingAidOnly X PF			
UsingWheeledAid X PF			
Outcome: Satisfaction with Participation			
Independent Variables:			
Age			
Disease Duration			
Physical Functions	0.19	0.24	95%
Using Walking Aid Only			
Using Wheeled Aid			
UsingWalkingAidOnly X PF			
UsingWheeledAid X PF			
Outcome: Trip Frequency			
Independent Variables:			
Age			
Disease Duration			
Physical Functions	0.16	0.19	89%
Using Walking Aid Only			
Using Wheeled Aid			
UsingWalkingAidOnly X PF			
UsingWheeledAid X PF			
Outcome: Trip Distance			
Independent Variables:			
Age			
Disease Duration	0.12	0.14	**74%**
Physical Functions			
Using Walking Aid Only			
Using Wheeled Aid			

UsingWalkingAidOnly X PF			
UsingWheeledAid X PF			
Outcome: Trip Duration	0.16	0.18	89%
Independent Variables:			
Age			
Disease Duration			
Physical Functions			
Using Walking Aid Only			
Using Wheeled Aid			
UsingWalkingAidOnly X PF			
UsingWheeledAid X PF			
Outcome: Radius of Gyration	0.06	0.06	**37%**
Independent Variables:			
Age			
Disease Duration			
Physical Functions			
Using Walking Aid Only			
Using Wheeled Aid			
UsingWalkingAidOnly X PF			
UsingWheeledAid X PF			
Outcome: Perceived Ability to Participate	0.39	0.64	100%
Independent Variables:			
Age			
Disease Duration			
Fatigue Severity			
Social Support			
Social Support X Fatigue			
Outcome: Satisfaction with Participation	0.27	0.43	99%
Independent Variables:			
Age			
Disease Duration			
Fatigue Severity			
Social Support			
Social Support X Fatigue			
Outcome: Trip Frequency	0.04	0.04	**29%**

Independent Variables:			
Age			
Disease Duration			
Fatigue Severity			
Social Support			
Social Support X Fatigue			
Outcome: Trip Distance			
Independent Variables:			
Age			
Disease Duration	0.05	0.05	**36%**
Fatigue Severity			
Social Support			
Social Support X Fatigue			
Outcome: Trip Duration			
Independent Variables:			
Age			
Disease Duration	0.04	0.04	**29%**
Fatigue Severity			
Social Support			
Social Support X Fatigue			
Outcome: Radius of Gyration			
Independent Variables:			
Age			
Disease Duration	0.02	0.02	**15%**
Fatigue Severity			
Social Support			
Social Support X Fatigue			
Outcome: Perceived Ability to Participate			
Independent Variables:			
Age			
Disease Duration	0.2	0.25	98%
Fatigue Severity			
Social Support			
Social Support X Depression			
Outcome: Satisfaction with Participation	0.26	0.35	99%

Independent Variables:			
Age			
Disease Duration			
Fatigue Severity			
Social Support			
Social Support X Depression			
Outcome: Trip Frequency			
Independent Variables:			
Age			
Disease Duration	0.05	0.05	**36%**
Fatigue Severity			
Social Support			
Social Support X Depression			
Outcome: Trip Distance			
Independent Variables:			
Age			
Disease Duration	0.06	0.06	**44%**
Fatigue Severity			
Social Support			
Social Support X Depression			
Outcome: Trip Duration			
Independent Variables:			
Age			
Disease Duration	0.04	0.04	**29%**
Fatigue Severity			
Social Support			
Social Support X Depression			
Outcome: Radius of Gyration			
Independent Variables:			
Age			
Disease Duration	0.04	0.04	**29%**
Fatigue Severity			
Social Support			
Social Support X Depression			

Note. N=101. UsingWalkingAidOnly X PF = Interaction between using walking aids only and physical functions; UsingWheeledAid X PF = Interaction between using wheeled aids and physical function; Social Support X Fatigue = Interaction between perceived social support and fatigue severity; Social Support X Depression = Interaction between perceived social support and depression severity. Power below 80% are bolded.

Supplement 3: Plots of Interactive Effects Between EFs and Symptom on Participation Outcomes

Figure S4. Interaction between Use of Mobility Aid and Physical Function on Perceived Ability to Participate

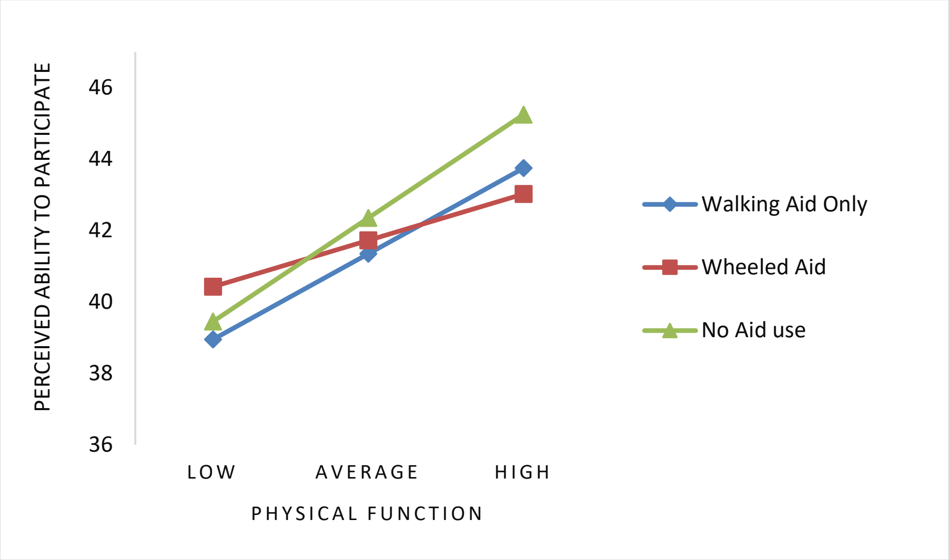


Figure S5. Interaction between Use of Mobility Aid and Physical Function on Satisfaction with Participation

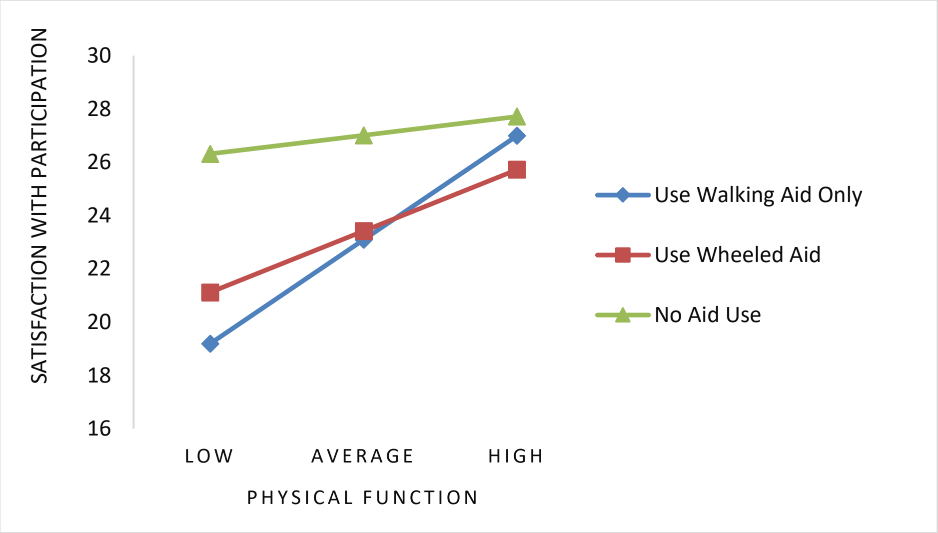


Figure S6. Interaction between Use of Mobility Aid and Physical Function on Trip Frequency

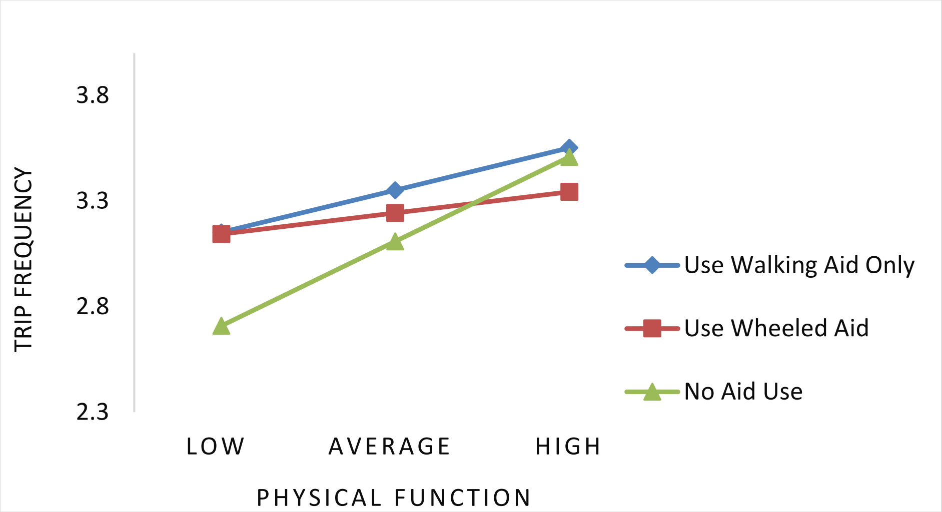


Figure S7. Interaction between Use of Mobility Aid and Physical Function on Trip Distance

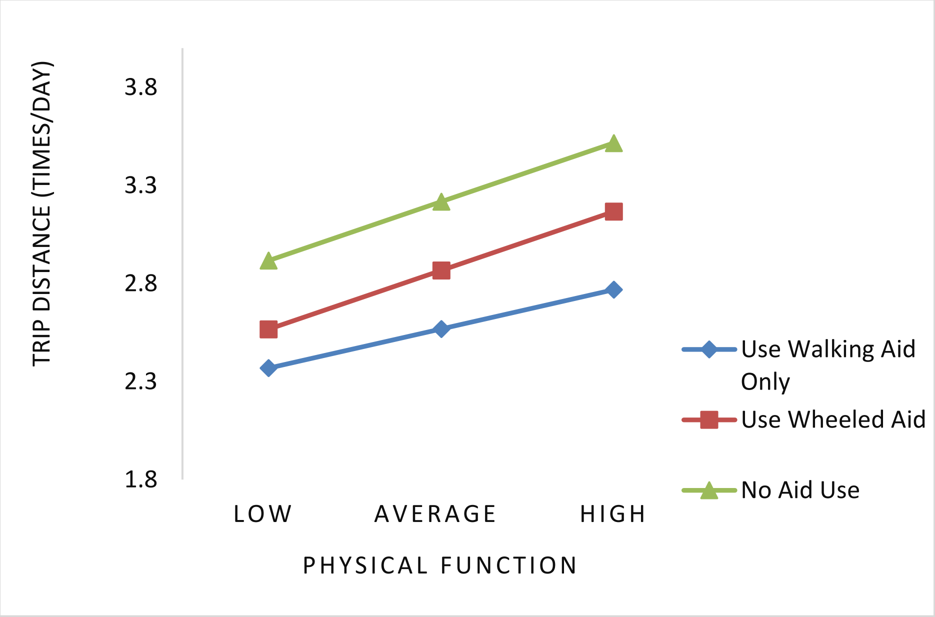


Figure S8. Interaction between Use of Mobility Aid and Physical Function on Trip Duration

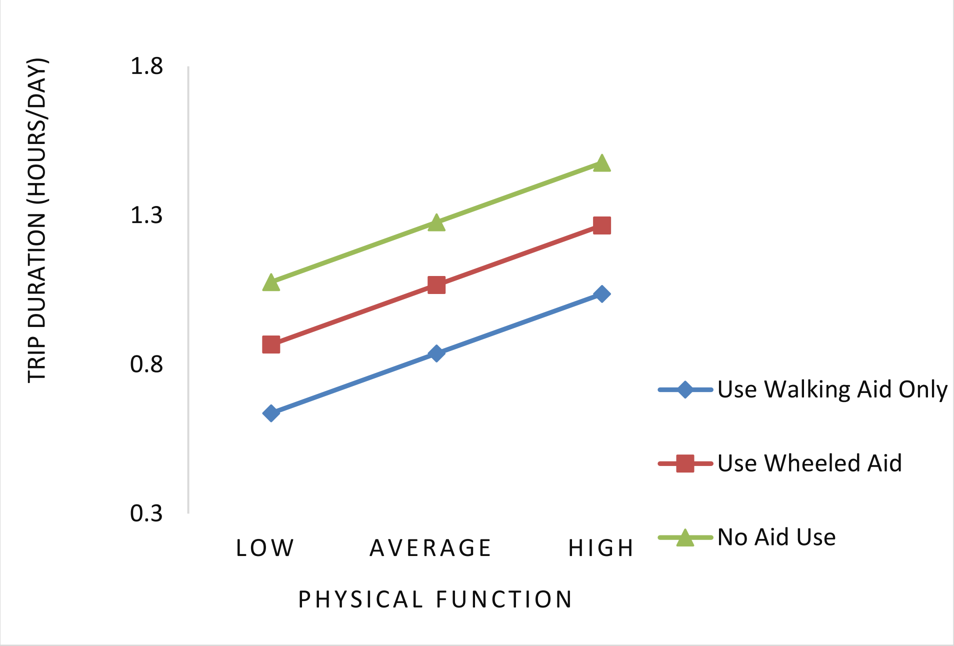


Figure S9. Interaction between Use of Mobility Aid and Physical Function on Radius of Gyration

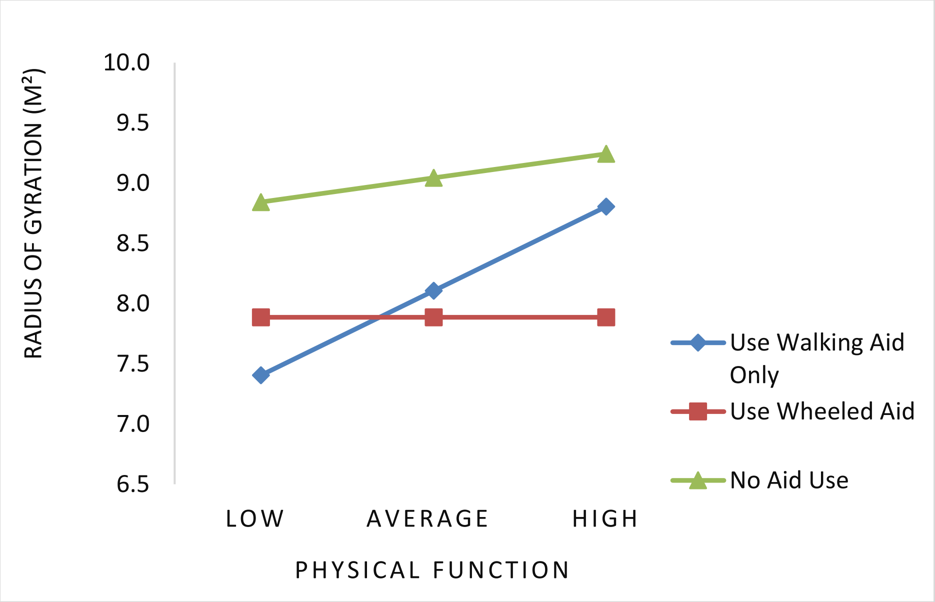


Figure S10. Interaction between Social Support and Fatigue Severity on Perceived Ability to Participate

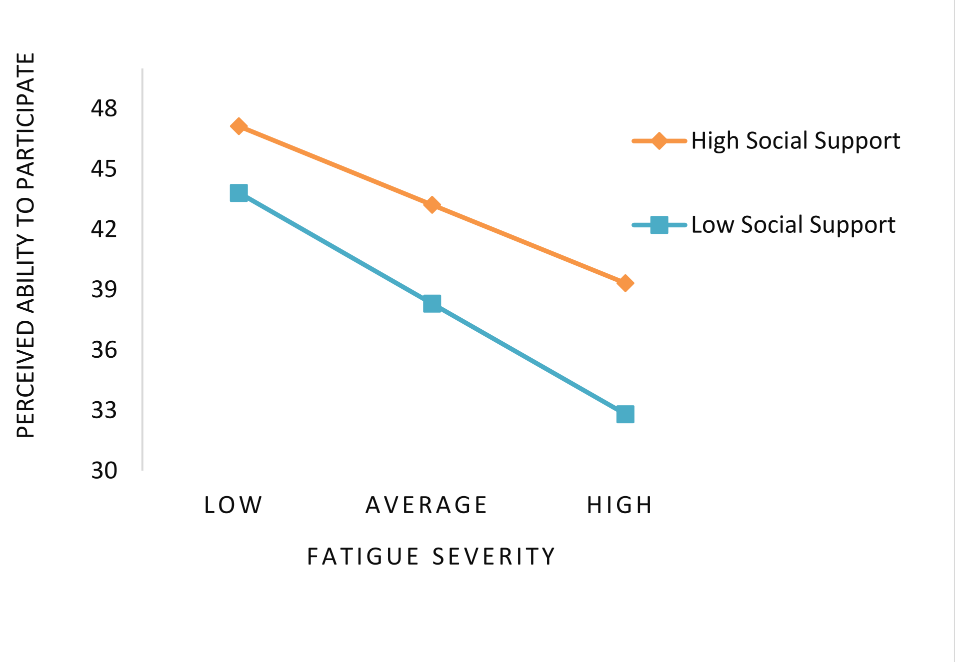


Figure S11. Interaction between Social Support and Fatigue Severity on Satisfaction with Participation

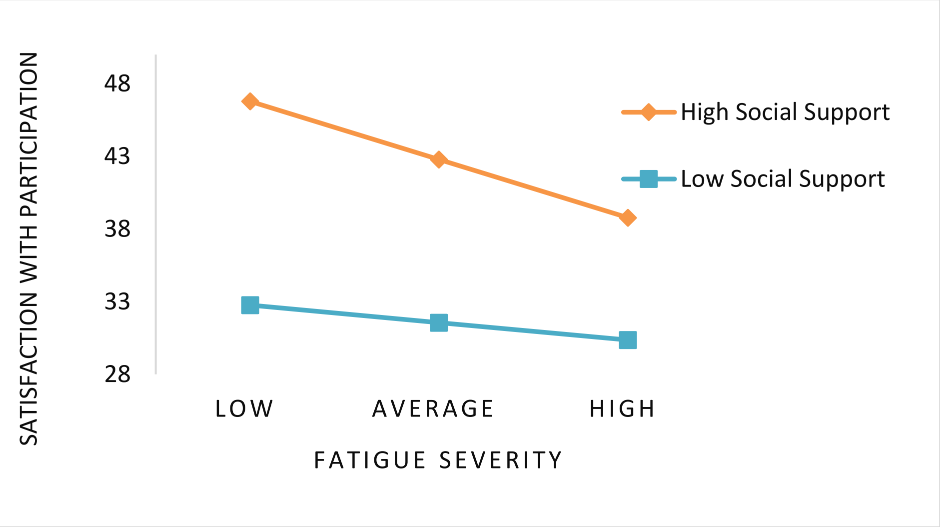


Figure S12. Interaction between Social Support and Fatigue Severity on Trip Frequency

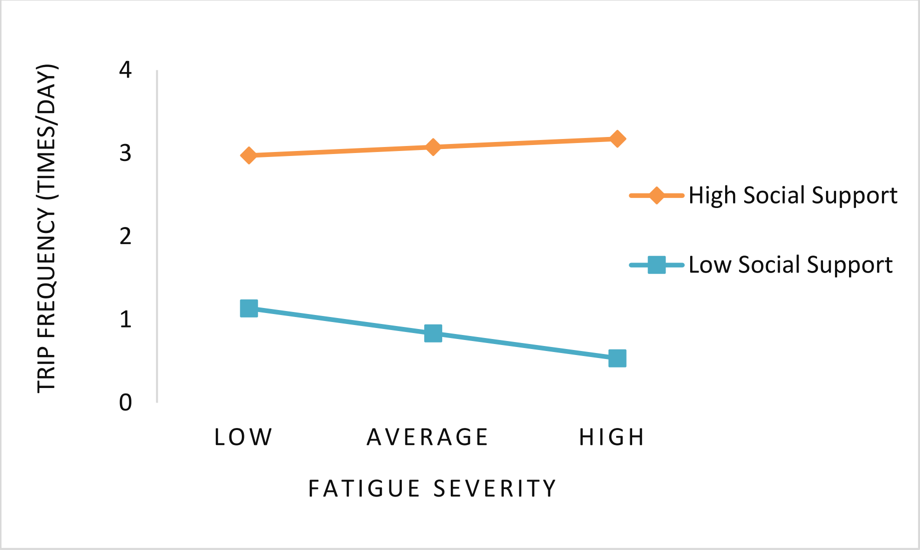


Figure S13. Interaction between Social Support and Fatigue Severity on Trip Distance

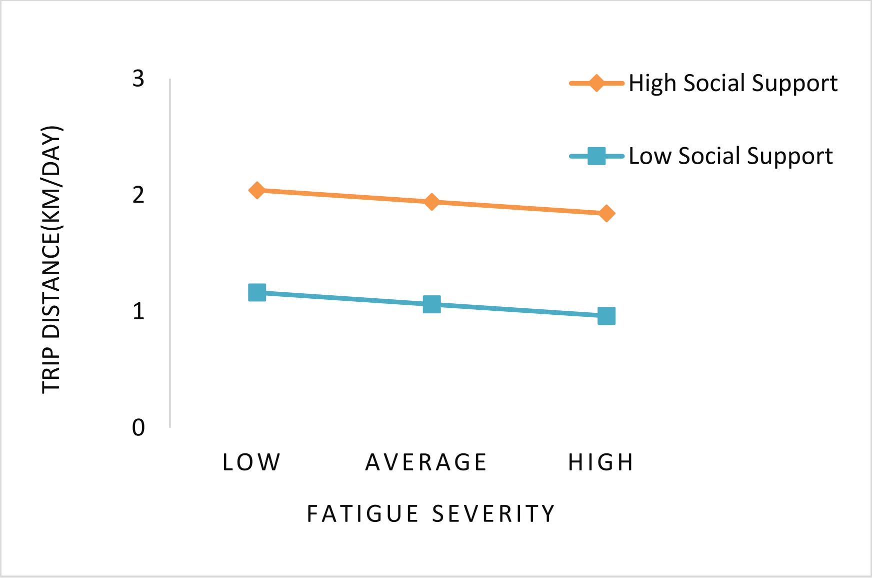


Figure S14. Interaction between Social Support and Fatigue Severity on Trip Duration

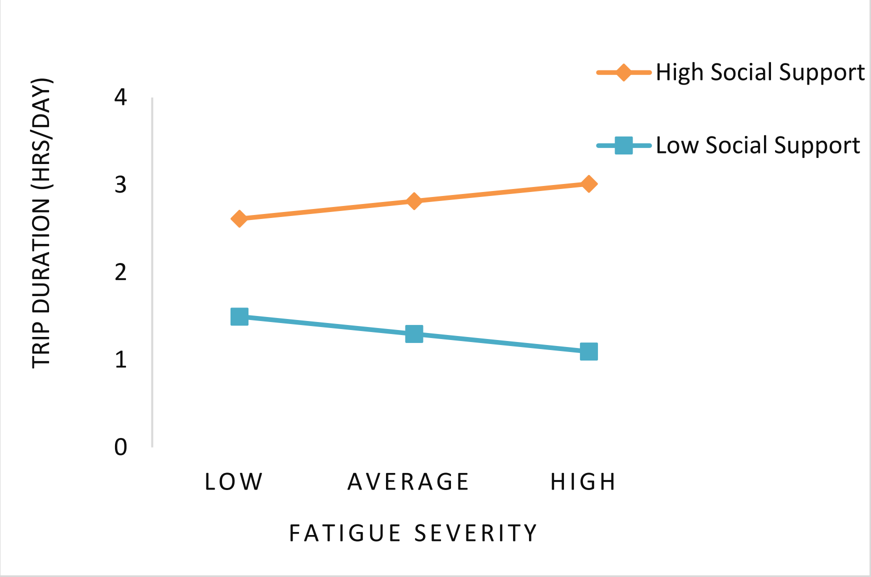


Figure S15. Interaction between Social Support and Fatigue Severity on Radius of Gyration

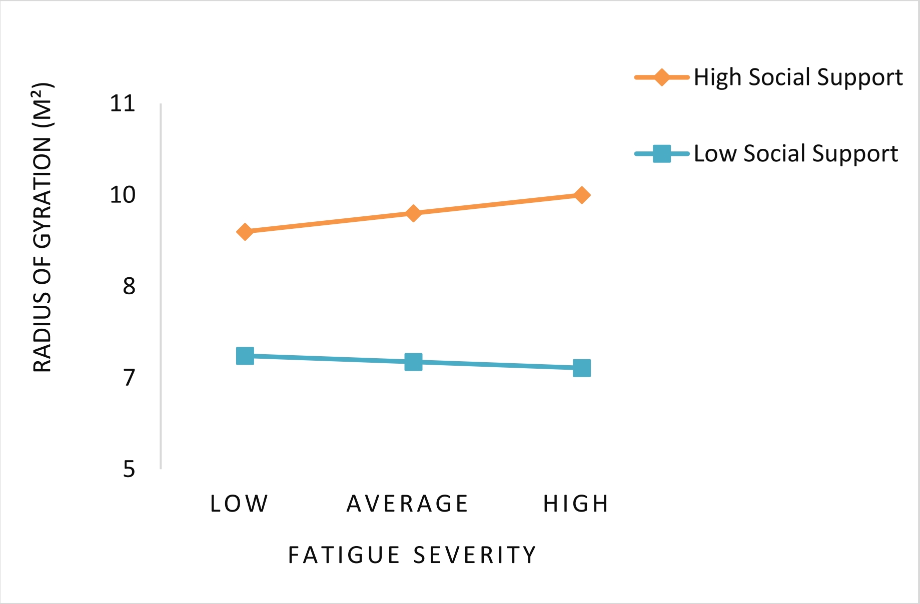


Figure S16. Interaction between Social Support and Depression Severity on Perceived Ability to Participate

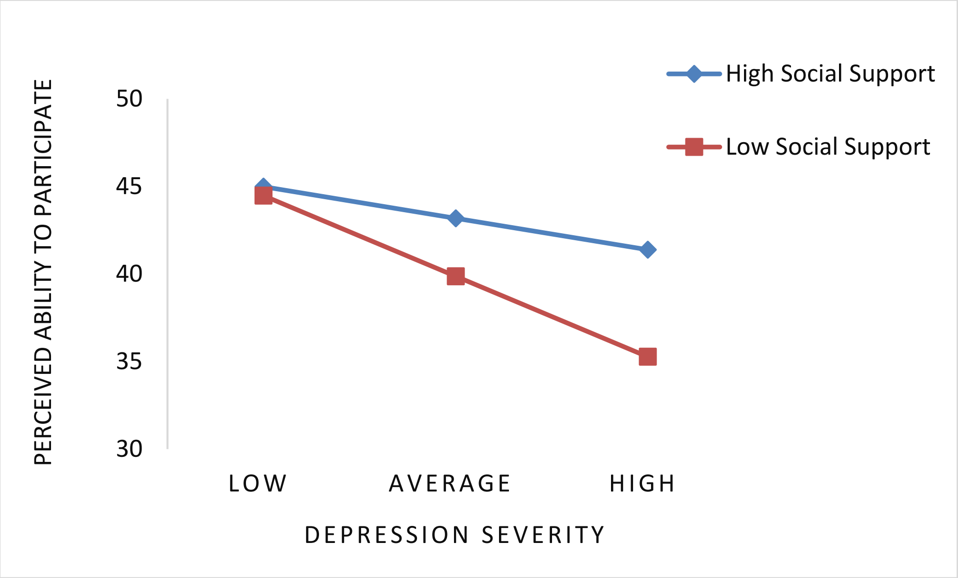


Figure S17. Interaction between Social Support and Depression Severity on Satisfaction with Participation

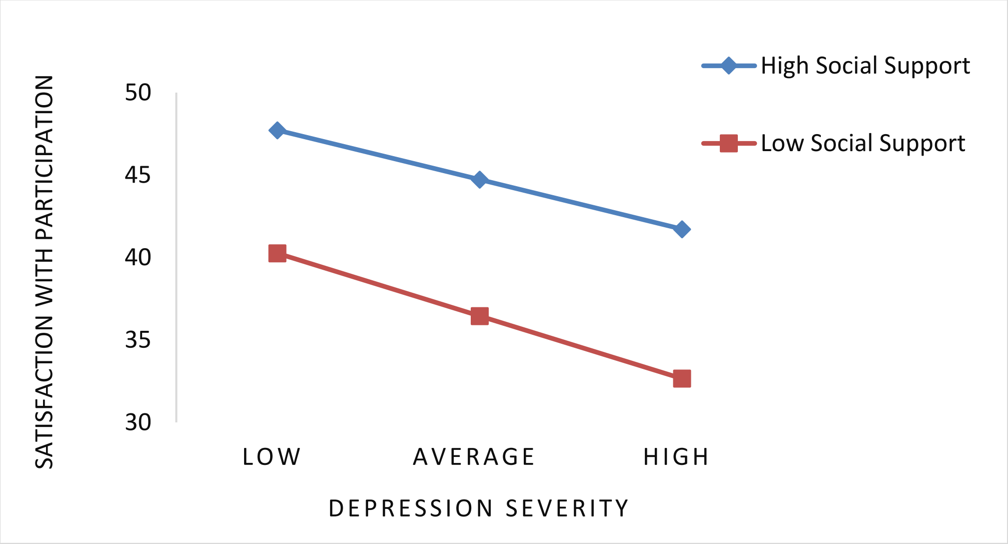


Figure S18. Interaction between Social Support and Depression Severity on Trip Frequency

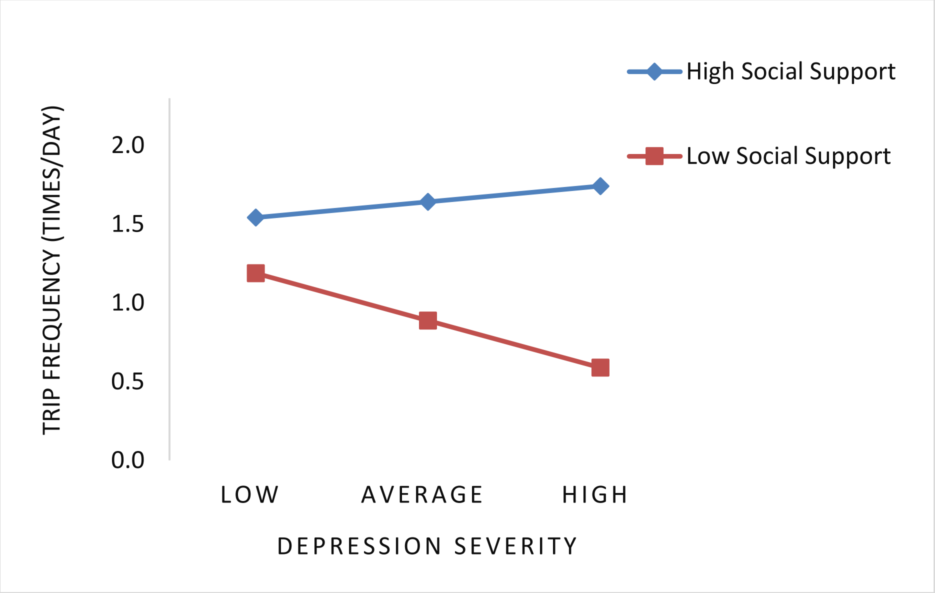


Figure S19. Interaction between Social Support and Depression Severity on Trip Distance

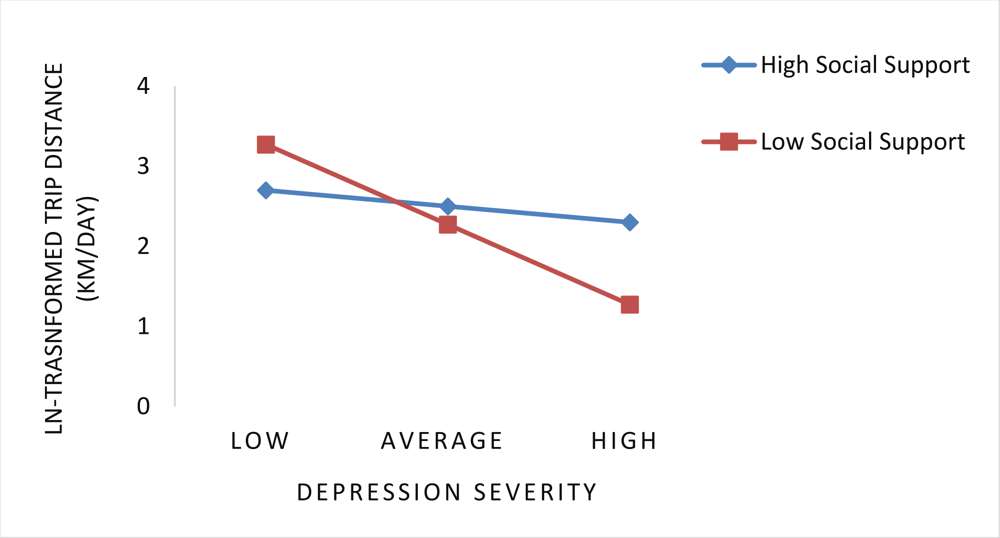


Figure S20. Interaction between Social Support and Depression Severity on Trip Duration

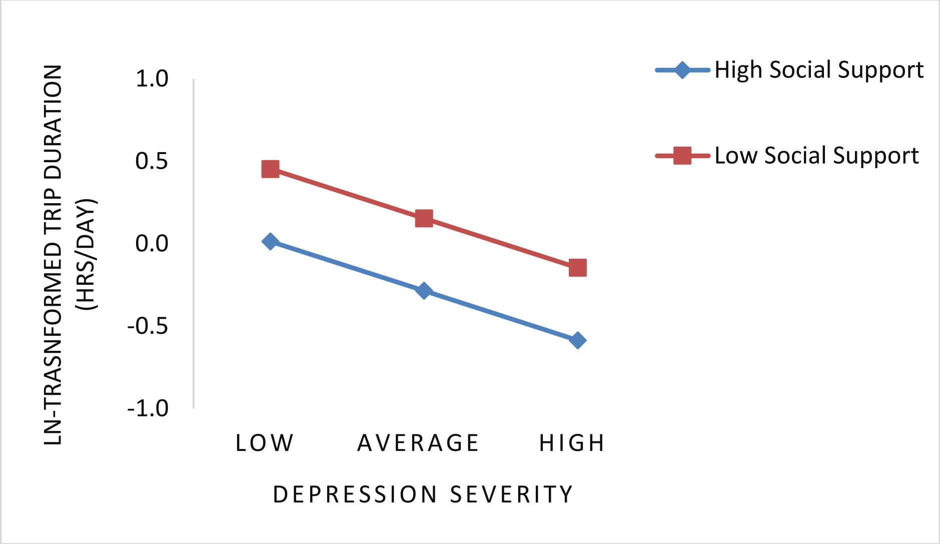
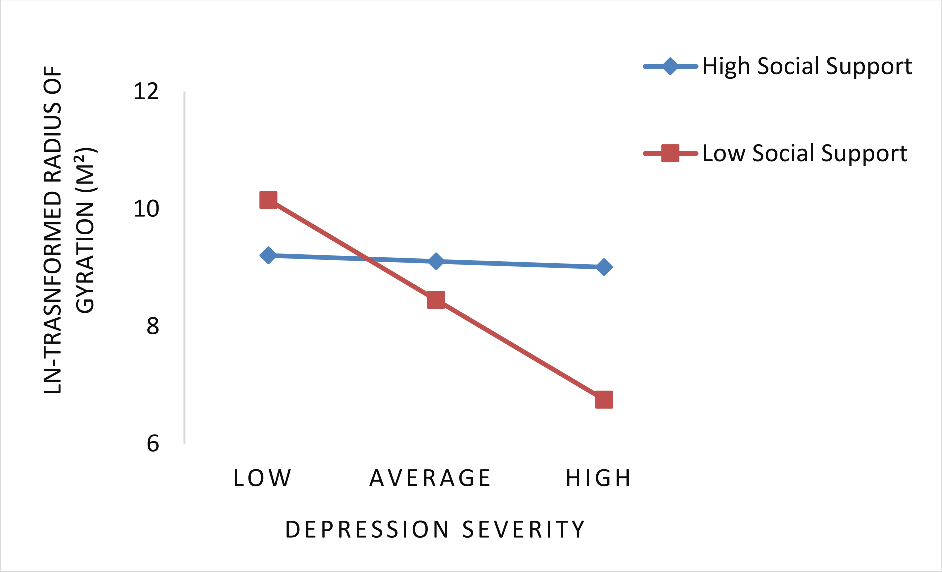


Figure S21. Interaction between Social Support and Depression Severity on Radius of Gyration



Chapter 4. Identifying Collective Efforts to Support Community Participation: A Community Engagement Meeting with The Multiple Sclerosis Community

Abstract

Community-engaged research is a research approach emphasizing collaboration and partnership with community members to ensure research relevance to the community's needs and acceleration of knowledge translation. While this approach has been increasingly employed in health-related research with people with disabilities, there has been a paucity of community-engaged research within MS literature. The goal of this study was to identify collective efforts needed to support the community participation experiences of people with MS. This study is part of a larger multi-phased community-engaged project that aimed to understand community participation experiences among people with MS. This chapter first introduces the community engagement components integrated throughout the larger study, then focuses on reporting the methods, procedure, and findings of the community engagement meeting where preliminary findings of the larger study were disseminated and recommendations for collective efforts were developed. In the community engagement meeting, action-oriented recommendations were discussed on topics of bridging the information gap, advancing MS specialty care, collaborating with other disability groups to promote accessibility in the built environment, and promoting an anti-ableist environment. This study provides useful information for clinicians, researchers, and policymakers interested in promoting community participation of people with MS. The study also highlights the importance of centering community voices in research and may serve as a reference for future community-engaged projects with other disability communities.

Introduction

Community-engaged research (CEnR) involves collaboration between academic researchers and community members who have shared interests, experiences, and needs in research projects that aim to address issues affecting the community's well-being. CEnR is not a methodology that requires particular study designs. Instead, it is an orientation to respecting and valuing the community's wisdom and knowledge ownership and fostering academic-community partnerships to ensure the research's relevance to the community's needs (Wallerstein, 2020). Community engagement is a continuum consisting of five levels of community involvement. From the lowest to the highest level, the five levels are *outreach, consult, involve, collaborate,* and *shared leadership.* The higher the level, the more power the community has in the decision-making process (Clinical and Translational Science Awards Consortium, CTSA , 2011). Community partners can be engaged in some or all research stages, including conceptualizing research problems, study design, data collection, analysis, interpretation, and dissemination, with various levels of engagement. The level of engagement can also shift over time or based on the research stage within the project.

CEnR arose in response to the historical underrepresentation of marginalized populations in research and the domination of researcher-driven "evidence-based" research that is sometimes unacceptable or untranslatable to those who would benefit from research findings (Wallerstein et al., 2017). CEnR addresses concerns from disability communities and disability studies scholars that researcher-driven disability and health-related research often fails to meet the actual needs of people with disabilities and perpetuates ableism in healthcare practice and society (Kitchin, 2000; Ortiz et al., 2020). A core disability studies perspective and the international disability rights movement motto, "Nothing about us without us," affirms the necessity of community engagement in disability research (Bhattarai et al., 2020). The common key principles of CEnR approaches are to clearly understand the community’s needs while recognizing diversity within the community and to build a trustworthy community-academic partnership where community partners have shared power to participate in the decision-making process (CTSA, 2011; Collins et al., 2018). CEnR has been rapidly growing in public health, psychology, nursing, and other health-related fields over the last three decades. The practice of community engagement in health-related research has been shown to be effective in addressing health disparities and improving health outcomes among marginalized communities (Ortiz et al., 2020).

One community that may benefit from CEnR is the multiple sclerosis (MS) community. Nearly one million adults in the US and 2.2 million adults worldwide are living with MS, a neurodegenerative disease without a cure (Wallin, Culpepper, Campbell, et al., 2019; Wallin, Culpepper, Nichols, et al., 2019). Having equal access and opportunities to participate in domestic, work, social, and civic activities is a human right; however, literature shows that people with various severities of MS face increased restrictions in participating in community activities outside the home to fulfill their social roles (e.g., employee, student, friend, parent) after diagnosis (Conradsson et al., 2021; Hamed, 2012; Prodinger et al., 2010). While living with progressive MS-related symptoms (e.g., mobility impairments, chronic fatigue, pain, vision problems, and cognitive issues) may make it challenging to participate in activities, people with MS (PwMS) have reported that they experience substantial external barriers in the community, such as inaccessible public spaces, lack of accommodations, and microaggressions at workplaces (Learmonth et al., 2015; Lee et al., 2019). Numerous conceptual frameworks, such as the Social Model of Disability (Oliver, 1996) and the World Health Organization Social Determinants of Health framework (2011), and systematic reviews of empirical studies with other diagnostic groups (e.g., spinal cord injury, Kashif et al., 2019; stroke, Nicholson et al., 2013) have emphasized the disabling effects of sociopolitical barriers; however, the MS community's calls for increased societal support to promote community participation remains underexplored.

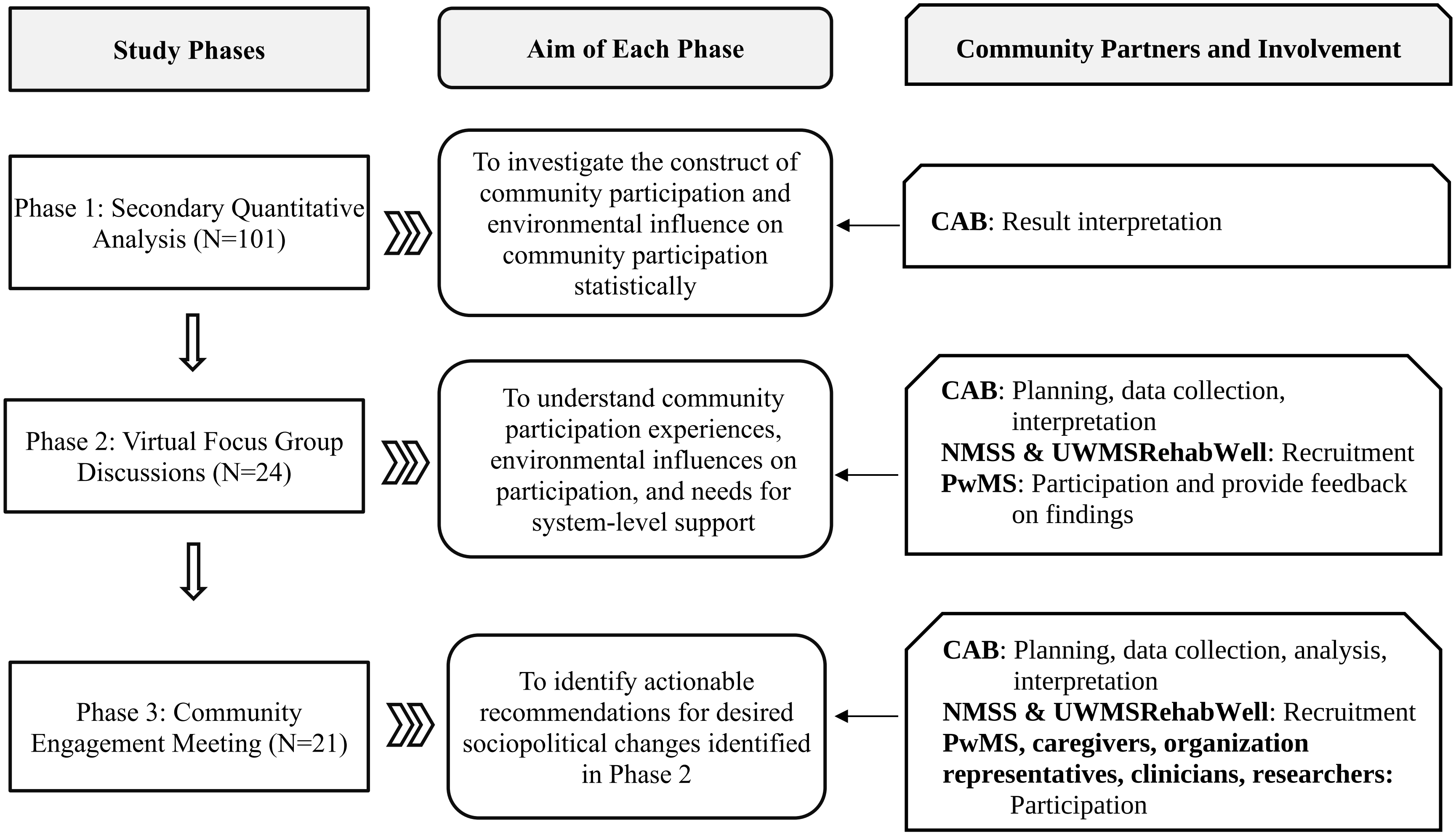
Simmons (2010) discussed that people living with MS and their families experience life-changing impacts, such as employment loss and declining mental health, after the diagnosis. Oftentimes these impacts do not come from the disease itself, but the disadvantaged status due to social exclusion and lack of social and societal support. The community participation experiences of PwMS are shaped by those around them, including family, friends, colleagues, employers, and healthcare providers. Therefore, supporting community participation of PwMS requires community efforts. Environmental influences on community participation are inherently individualized and subjective. Adopting a CEnR approach that honors community members' lived experiences and expertise is beneficial for exploring the environmental impact on community participation and identifying actions that need to be taken at the system level to support community participation of PwMS. Community-based resources for individuals with MS, caregivers, and MS researchers are growing with the National MS Society (NMSS) being the most well-known nonprofit organization providing community-based support programs, funding MS research, and initiating advocacy efforts. However, despite the increasing recognition and application of CEnR in rehabilitation research (Camden et al., 2015) and the call for engaging the MS community members in clinical practice (Rieckmann et al., 2018), there is a paucity of CEnR projects that partner with the MS community. While limited, current literature on CEnR projects involving PwMS demonstrates various levels of community engagement: some community-engaged MS studies only involve community members in the reviewing and revision process of agenda setting and design of the project (Kuspinar et al., 2020; Silveira et al., 2021), and others invite community partners to collaborate on most research stages, including co-designing intervention, data interpretation and dissemination (Donisi et al., 2021; Koch & Kralik, 2001). However, to our knowledge, no research studies have focused on collaborating with the MS community to identify collective efforts needed to optimize community participation experiences of PwMS.

This article focuses on describing the process and results of an online MS community engagement meeting intended to generate action-oriented recommendations for system-level changes that will better support community participation of PwMS. The MS community engagement meeting was the last phase of a larger three-phase CEnR project with the MS community. In order to provide a better understanding of the context of the community engagement meeting, the article first describes an overview of the previous phases and how they informed the conduction of the final phase. Then CEnR components of the project, including the roles of the community partners and strategies used to engage them, are described

Context of the Community Engagement Meeting

The Community Engagement Meeting is situated in a larger project with a focus on collaborating with the MS community to understand community participation experiences and the influences of physical, societal, and attitudinal environments on community participation of PwMS. The larger project included three phases with different specific purposes while the findings of each phase informed the next phase (See Figure 1 for study phases). In phase 1, a secondary analysis of a dataset with 101 PwMS was conducted to quantitatively investigate the construct of community participation and its association with environmental factors. In phase 2, 24 individuals living with MS participated in four online focus groups to share their experiences and perspectives about community participation and how environmental factors play a role in affecting their community participation. Participants also discussed changes they would like to see at the system level to promote community participation. Details of the methods and results of the first two phases are described elsewhere. Findings from the first two phases highlighted the significant impact of environmental factors, such as neighborhood safety, social support, financial resources, accessibility in the built environment, and access to information, on community participation experiences among PwMS. In addition, the findings also revealed four priority areas in which PwMS desired to see improvements: (1) **accessibility in the built environment**, especially the public transportation system, (2) **ease of access** to useful information and resources, especially for people who are newly diagnosed, (3) **MS specialty care**, (4) the **general public's attitude**s towards people with disabilities, especially invisible disabilities. These findings informed the focus of the agenda for the final phase, an online community engagement meeting with a larger MS community designed to generate actionable recommendations addressing the four priority areas. Further details of the meeting will be described in the Methods section.

Figure 1. Study Flow Diagram



Note. CAB: Community advisory board; NMSS: National Multiple Sclerosis Society; UWMSRehabWell: University of Washington Multiple Sclerosis Rehabilitation and Wellness Research Center; PwMS: People with multiple sclerosis

Reflexivity Statement

The lead researcher is a doctoral student with a background in occupational therapy and clinical practice experience with people with disabilities. She does not identify as disabled or as someone living with MS, positioning her as an outsider of the MS community. However, her experiences living with other minority identities (e.g., women, an international student studying and living in the US) had deepened her understanding of social determinants of health and how the systemic barriers in the real world prevent marginalized populations from achieving quality of life and satisfactory participation. She acknowledges the historical privileges associated with being a researcher, which prompts her to internally practice cultural humility throughout the project. In this project, she directly interacted with all involved community members throughout the project while receiving guidance from other outsider academic researchers who are experts in Rehabilitation Science and MS care. All academic researchers are affiliated with the same research-focused university in the US.

Community Partners and Their Involvement in the Project

Community Advisory Board

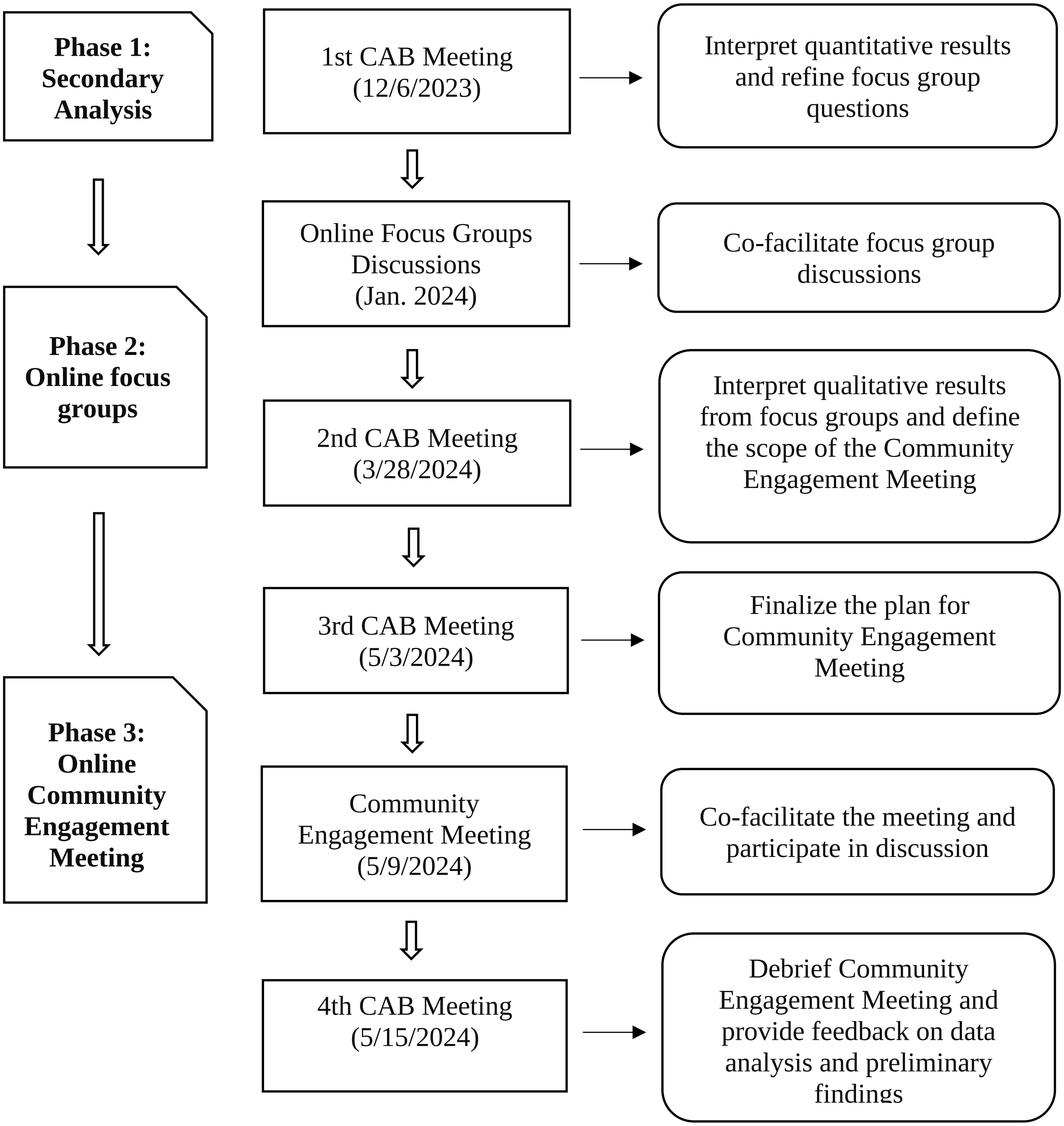
A community advisory board (CAB) was formed with three individuals who are insiders of the MS community to be involved throughout the larger CEnR project. Establishing a CAB is a common approach for building a structured academic-community partnership in CEnR projects (Clifasefi et al., 2020; Ehde et al., 2013). By participating in a shared decision-making process, a CAB can play a key role in voicing the community's needs and interests and ensuring the research projects' relevance and meaningfulness to the community.

The three Community Advisory Board (CAB) members, J.S., M.S., and E.L., were recruited through various ways to ensure diverse representation, experiences, and expertise. J.S.

is a family member of someone living with MS and has a leadership role in the National MS Society (NMSS). She also has a research background in a non-health-related field. She was connected with the lead researcher during an academic event and joined the CAB with NMSS's support. M.S., nominated by J.S., has lived with progressive MS for many years and uses a mixture of wheeled aids and walking aids during community participation. He has been an active advocate for the MS community. However, this was his first time engaging in academic research. The last member, E.L., was introduced by the University of Washington Multiple Sclerosis Rehabilitation and Wellness Research Center (UWMSRehabWell). E.L. has over 20 years of experience living with MS and uses walking aids for long-distance travel. She has an educational background in research and has participated in academic research. She is passionate about mentoring people who are newly diagnosed with MS as a peer. The CAB was officially established prior to Phase 1 after letters of agreement were sent to all members.

Among all community partners, the CAB demonstrated the highest level of participation in the project, providing advice and insights from insider perspectives throughout the planning, data collection, analysis, and interpretation stages of the project (See Figure 2). Although the initial protocol was informed by existing literature and developed by the lead researcher prior to the formation of the CAB, the CAB engaged in the revision and refinement of details in all phases. In the first CAB meeting after the completion of the quantitative analyses in Phase 1, the CAB members helped interpret the quantitative results based on their knowledge and experiences, and they supported the planning for Phase 2—focus groups. During this process, the CAB suggested grouping the focus group participants based on their mobility aid use status, acknowledging that mobility aid users have distinct perspectives and experiences in navigating the environment. In Phase 2, the CAB members supported data collection by co-leading the discussions. Following the qualitative analysis, the CAB helped interpret qualitative findings based on their expertise and impressions from co-facilitating focus groups, which helped establish the storyline for the research report. During the second and third CAB meetings, the CAB members helped plan the community engagement meeting. For example, they suggested specific ways to assign discussion questions to different audience groups, which was then implemented in Phase 3. Finally, the CAB co-hosted the community engagement meeting and participated in discussions with other attendees. Afterward, a debriefing meeting was held to discuss the findings from the community engagement meeting and plan for the dissemination activities.

Figure 2. CAB's Contribution to Planning, Data Collection, and Interpretation



Other MS Community Members Involved in the Project

In addition to the CAB members, other members of the MS community were involved in the project. The community members included MS organizations, individuals with MS, caregivers, MS activists, MS community organization representatives, MS clinicians, and researchers. They participated in the project with various levels of engagement, ranging from supporting recruitment to active participation in the second and third phases (See Figure 1 for their involvement by phase). For example, the NMSS and the UWMSRehabWell provided recruitment support while individuals with MS were represented as participants in all phases.

Strategies to Engage Community Partners Throughout the Activities

Various strategies were implemented to increase accessibility and inclusion, as well as to facilitate community engagement throughout the project. **Active listening and cultural humility** were practiced by the researcher during the interaction with the CAB and other community members. Throughout the research activities, community members were constantly reminded that they are the experts on the research topic and therefore their perspectives are highly valuable. **Flexible scheduling** options were offered to accommodate the diverse availability of the CAB members and focus group participants. When scheduling the community engagement meeting, we intentionally selected times that would accommodate the schedules of participants' various roles (e.g., clinician, researcher) and accounted for time differences across the nation to ensure broad participation. **Regular reminders** were sent to keep participants informed about the upcoming meetings. To support preparedness and effective contribution, **meeting materials and discussion points were shared** in advance of the meeting. We utilized **plain language** in all materials and researcher's presentations to ensure that information was easily understood by all community partners regardless of their level of experience with research. To improve accessibility during the meeting, all sessions were held on the **Zoom videoconferencing platform**, allowing people located in different regions to participate in this project. **Auto-generated captioning** was enabled, and participants were encouraged to **take breaks** as needed. In addition, participants were allowed to **contribute nonverbally** through the Zoom chat function and a web-based interactive platform.

Several strategies were used to **build a sense of community** during focus groups and the community engagement meeting. First, we intentionally adopted the **focus group design** instead of other methods (e.g., individual interviews), considering that participants may benefit from learning about others' MS journey and useful strategies. In order to create a safe environment, the CAB members served as peer facilitators, and at the beginning of every group meeting, facilitators **acknowledged the shared and different characteristics** among attendees and introduced the **community agreement** which requested everyone to be respectful and welcoming of different perspectives. These strategies resulted in participants actively exchanging useful resources with each other during the meeting, and many participants and CAB members expressed a willingness to stay connected with each other. Participants were also **invited to provide feedback** on the focus group findings for the researcher. Lastly, CAB members, focus group, and community engagement meeting participants were offered compensation for their participation, recognizing the value of their expertise and ensuring equitable participation (Gill, 1999). Differential compensation was provided based on time and contribution to the study.

Methods of the Community Engagement Meeting

The purpose of the MS community engagement meeting was to invite the broader MS community to co-identify collective efforts needed to increase system-level support to improve accessibility of built environment, access to useful information, MS specialty care, and the public's attitudes to help optimize community participation experiences of PwMS.

Recruitment and Attendees

Anyone available and interested in participating in the community engagement meeting regardless of their direct connection with MS was welcome to attend the meeting. Meeting invites were distributed through (1) invitation emails to focus group participants, (2) networks of UW faculty and the UWMSRehabWell, (3) an announcement on the NMSS website, (4) physical flyers in campus buildings at the University of Washington, (5) flyers at the Walk MS event in Seattle, WA, and (6) social media. People interested in attending were asked to complete a registration form. During the one-month recruitment period, 36 potential participants registered, and 21 of them attended the meeting in addition to the co-facilitators. Attendees were located in 10 different states and represented various roles in the MS community, including nine individuals living with MS, two family caregivers, two MS community organization representatives, four activists, five MS care providers, five MS researchers, and two students. Some of the participants attended the meeting in multiple capacities, such as being both an individual living with MS and an advocate.

Procedure

The two-hour community engagement meeting was held on Zoom. The first part of the meeting included an introduction of the research team and a 25-minute research presentation by the lead researcher introducing the context of the project, including findings from the first two phases. The second part of the meeting consisted of a 15-minute breakout group discussion, a 15-minute report back, and a 30-minute large group discussion. Participants were first assigned to three breakout groups based on their roles in the MS community: (1) individuals with MS and

MS activists, (2) organization representatives and caregivers, and (3) MS professionals including, clinicians, researchers, and students. Each breakout group, facilitated by at least one research team member, including the CAB members, discussed actions that individuals, institutions, and society could take to address two of the four priority areas (i.e., improving accessibility of built environment, access to information, MS specialty care, and public attitudes toward disability). A reporter from each breakout room then shared the recommendations with the larger group. After the report-back, the larger group discussion focused on identifying potential collaboration opportunities between different parties (e.g., clinicians and patients, organizations and legislators) within the MS community to address the four priority areas. Recommendations for future research directions were also briefly discussed.

The report-back and large group discussions were recorded via Zoom. To facilitate accessibility and participation, self-paced nonverbal contributions via Zoom chat and a real-time interactive whiteboard (Padlet.com) were enabled throughout the meeting. The audience had access to the Padlet whiteboard until three days after the meeting, allowing continued offline contributions. The audience was also asked to complete a post-event survey with open-ended questions to share their feedback and takeaways from participating in the community engagement meeting.

Rapid Data Analysis

A rapid analysis of the audio recording and text from Zoom chat and Padlet whiteboard was completed following the guidelines by Neal et al. (2015). The focus of coding was recommendations made by the audience for increasing environmental support and future research needs. A coding form was created in Microsoft Excel deductively including seven codes: 1) improve accessibility in the built environment, 2) improve accessibility in public transportation, 3) improve ease of access to useful information, 4) improve MS care, 5) improve people's attitudes, 6) collaboration, and 7) future research directions. The length of the audio recording was 45 minutes, and the time segment was 3 minutes (i.e., the 45-minute recording was divided into 15 3-minute segments). While listening to the audio recording, the researcher noted the occurrence codes in each time segment and saved short exemplary quotations. The researcher then repeated this procedure when reading the text from the saved Zoom chat and Padlet whiteboard. The following report on findings was organized by priorities. Priority was indicated by the frequency of the mentioned codes and the researcher's interpretation of intonation, plus the impression of researchers and CAB who facilitated the meeting. If one person spoke to the same code multiple times, we only counted it once but noted nuances if any.

Outcomes of the Community Engagement Meeting

The community engagement meeting resulted in three key outcomes. First, a list of action-oriented recommendations for system-level improvements was generated. These recommendations focused on bridging the information gap, advancing MS specialty care, promoting accessibility in the built environment in solidarity with other disability communities, fostering anti-ableist attitudes among the general public, and addressing community-informed future research needs. Second, the community members highly valued the opportunity to attend the meeting and add their voices to the recommendations. . Third, the recommendations were disseminated to the community and a policy maker to facilitate community-engaged knowledge translation.

Actionable Recommendations for Systemic Changes Supporting Community Participation

During the community engagement meeting, participants made actionable recommendations for system-level changes in the four priority areas to support community participation among PwMS. These areas were (1) Bridging the information gap; (2) Advancing MS specialty care; (3) Standing in solidarity with other disability communities to promote accessibility in the built environment; and (4) Promoting anti-ableist attitudes among the general public. Each of these four areas included various recommendations for MS community organizations, MS care providers, and policymakers.

Bridging the Information Gap

According to the findings from the previous phases, a gap between the availability and awareness of existing resources for the MS population was recognized. Participants of the meeting discussed potential solutions for bridging the information gap. **A pamphlet provided to new MS patients by healthcare providers** was agreed by all attendees as a great idea. Participants suggested that healthcare providers, especially neurologists and ophthalmologists who are usually the first professional contact for people newly diagnosed with MS, should take the lead on orienting patients to information not only about disease-modifying treatments and drug trials but also community-based resources, such as support groups and other programs offered by MS community organizations. Some participants highlighted the importance of using accessible design and plain language in all educational materials. In addition, participants emphasized the necessity for including educational materials about the Americans with Disability Act (ADA) laws, disability rights, and disability advocacy because a large MS population is living with or developing cognitive and physical difficulties, but very few are knowledgeable of how to protect their rights.

MS community organizations need to expand their outreach to PwMS and providers according to participants in the meeting. While agreeing that the NMSS is the most well-known resource hub for the MS community with the longest history, participants suggested that the NMSS needs to increase collaboration with other MS community organizations and advocacy groups, as well as to expand outreach to PwMS and providers to bridge the gap between resource availability and awareness. A participant shared the positive impact of the NMSS on their MS journey because of their critical work in funding research and providing educational programs. However, he mentioned feeling “lucky” to have been referred to NMSS by his neurologist in the beginning, implying that not all newly diagnosed patients receive the same support. Another attendee spoke about her feeling of isolation as a young person living with progressive MS, noting the difficulty in finding peers with similar experiences in local resources. The NMSS representatives shared information about programs such as *New to MS* and *MSFriends* that would be helpful for her.

Establishing a peer support program in clinical settings was suggested by clinician attendees. They noted that clinicians often lack time to fully understand patient experiences and needs. Integrating a peer support program into clinical settings more regularly, where new MS patients can connect with experienced peers as mentors, would help expose new patients to useful information and resources at the beginning of their MS journey.

Advancing MS Specialty Care

Continuing MS training for specialists and general practitioners on the latest diagnostic methods and treatments was recommended as an important solution to advance MS specialty care. Attendees echoed a finding from another manuscript (Chapter 3) that many PwMS experienced delayed diagnosis that subsequently delayed their interventions, and others had unsatisfactory experiences interacting with their providers. For example, an attendee shared, “When I was first diagnosed, I changed practices because they told me that their patients would tell them about the newest medication, and I was not okay with that.” Representatives from the

NMSS shared that the NMSS offers a program, *Partners in MS Care*, to train healthcare providers (e.g., physicians, physical therapists, psychologists) to become MS experts. However, the NMSS needs to expand outreach to more clinicians to raise their awareness of this program.

In addition, participants shared that one of the biggest challenges is early detection and early intervention, and the delays in this process are partly due to barriers to accessing an MRI, an effective diagnostic tool for establishing MS diagnosis, and medical care. Participants voiced that **legislative effort is needed to improve access to MRI and MS specialty care** by adjusting medical costs for low-income households.

Self-management skills and **self-advocacy** were highlighted as ways to support PwMS to continue their own care and management of their chronic conditions. Participants voiced that the use of integrated care addressing the chronic effects of MS, such as lifestyles, diet, physical activities, and mental health, should be included in regular MS care practice. Self-advocacy was highlighted as an important skill to help facilitate satisfactory interactions with MS care providers. Participants stressed that it is important for individuals with MS to be proactive in advocating for their own needs. As a participant put it, “We are all advocates for ourselves. Nobody understands our bodies better than we do. So your neurologist is just another tool to use to have someone to speak to about the things you're dealing with, and your neurologists will then not only help you with drugs but help you find a good therapist or get into a social group.”

Standing in Solidarity with Other Disability Communities to Promote Accessibility in the Built Environment

Although this project focused on the MS community, participants recognized the importance of collaborating with other disability communities to improve accessibility in the built environment and public transportation. As a participant stated, “It’s important for us not just to think about MS, but to think about disabilities as a whole.” Given the shared critical challenges faced by PwMS and other people with disabilities in accessing accessible housing, employment, and public transportation, our participants discussed that **collective legislative efforts are needed to promote architectural universal design, affordable and accessible housing, disability rights protection—especially at workplaces—and accessibility of public transportation.** Specifically, they recommended incorporating sensory rooms in workplaces, schools, and public spaces to accommodate sensory and other access needs. Regarding public transportation, participants highlighted several issues. They noted the limited coverage of public transit and poor connection between transit options, which prevent distant travel for people who do not own or drive a vehicle. They also commented that the current accessible public transportation services are burdensome for riders with disabilities. For example, in addition to the limited coverage, there is a lack of real-time communication between the rider and driver, resulting in extended wait times and unclear pickup locations. Thus, they recommended expanding accessible transit coverage, increasing door-to-door transit programs, providing anti-ableist training for service providers, and improving communication systems between riders and drivers.

Promoting Anti-ableist Attitudes among the General Public

Participants recommended a few strategies to “fight ableism” in society, including **incorporating disability awareness and ADA education into K-12 curricula** to foster younger generations’ empathy and understanding of disabilities, particularly invisible disabilities. These curricula could include “MS experience” or “disability experience” events, where people without disabilities experience a day living with MS or other conditions with appropriate items or devices. However, holistic narratives of individuals with lived experiences should be included to avoid perpetuating sympathy and implicit bias. In addition, they called for **increased and nuanced media representation of people with MS and other disabilities**, showcasing their capabilities and accomplishments rather than misery, to challenge stereotypes and prejudgments about what people with disabilities can or cannot do.

Community-informed Future Research Needs

Participants discussed future research directions based on their observations and experiences. They suggested future MS research to focus on (1) assessing health disparities in PwMS who are multiply-marginalized by gender, race and ethnicity, and socioeconomic status; (2) facilitating early MS detection and public awareness of MS; (3) identifying effective components of community-based support programs for the MS population; (4) investigating associations between loneliness and social participation in the MS population and interventions addressing the discrepancy; and (5) understanding and meeting accommodation needs across disability communities.

Participants' Perceived Meaningfulness of Their Engagement in the Meeting

Participants who completed the post-event survey (n=11) considered their participation in the community engagement meeting meaningful, despite most wishing for more time for discussions. Respondents expressed their appreciation for the opportunity of participating in a meeting with other MS community members to "identify shortfalls that exist and brainstorm solutions," They also commented that the project is important and needed as it represented community members' voices. One shared,

> It was meaningful for me to participate because I feel like I have a lot of experiences to offer and my thoughts and experiences were valued by the research

> team. My main takeaways is that much work needs to be done, but this project is a good start to organizing thoughts & mobilizing a plan of attack.

Another wrote,

> I really enjoyed connecting with other PwMS., researchers and representatives from the MS Society. They heard first-hand about issues that need improvement from MSer's side of view. [These are] Real things to address… it's always nice to get together with a group of people living with MS voicing the needs of our community. When [we] are together in numbers that is allowing our voice to be heard louder. The louder we are heard the faster changes can be made.

Others expressed their excitement "to see continued research with MS in areas other than straight drug and treatment." and their desire to be informed about the findings of this study and the opportunity to participate in future research studies.

Advocacy Efforts for Systemic Changes

To disseminate the recommendations generated from this project with decision-makers who have more power to facilitate system-level changes, the lead researcher and two CAB members made efforts to meet with a State Representative who is interested in promoting disability rights and has previously established a connection with the NMSS. A summary of the study and recommendations requiring legislative efforts were shared and discussed during the meeting. The importance of legislative efforts and the impact of policy change on people's lives were shared by the CAB members. The Representative supported the importance of the recommendations and specific solutions as they were in line with the legislative agenda.

Discussion

The purpose of the community engagement meeting was to identify community-informed actionable recommendations for supporting community participation of PwMS. The study serves as a novel example of inviting members with diverse roles within the MS community to collaboratively identify collective efforts. In doing so, the study operationalizes two key concepts in the field of disability studies—interdependence and collective access (Mingus, 2017). Interdependence challenges the notion of independence as the standard of success, recognizing that everyone needs assistance from others at times. Building on this concept, collective access emphasizes that creating accessible environments is not solely the responsibility of individuals directly impacted by chronic functional limitations and needed improved access; instead, it is a shared responsibility of the entire community. As a result of the meeting, the list of specific recommendations has a focus on calling the broader MS community, including clinicians, community organizations, and legislators to collaboratively make efforts to support community participation of PwMS, rather than expecting PwMS to navigate the environmental barriers on their own.

Unlike researcher-driven studies, the discussion topics of the community engagement meeting were informed by the MS community, and the recommended action items were drawn from lived experiences and direct interests of community members in prioritizing the community's well-being (Collins et al., 2018). The majority of existing research-driven MS rehabilitation research has focused on restoring impaired functions and finding a cure (Dobson & Giovannoni, 2019; Khan & Amatya, 2017). While the medical focus is important, the participants implied that before the cure is found, more attention needs to be drawn to the systemic barriers that PwMS are experiencing and seeking solutions for increased system-level support for community participation. This advocacy perspective is in agreement with Simmons (2010) who reviewed the life issues faced by PwMS using both a biopsychosocial model of disability and social model of disability and suggested that participation restrictions cannot be fully addressed without sociopolitical efforts. Future MS research should focus more on advocacy needs and addressing sociopolitical factors affecting the well-being of the MS community.

The findings of this study contributed to existing disability advocacy and health-related research. Participants noted that people with other health conditions and disabilities experience similar systemic barriers as PwMS do in the community, leading to a recommendation to collaborate with other disability advocacy groups. In fact, the prioritized advocacy areas that emerged from the MS community in this study are applicable across disability communities, reinforcing calls for improved accessibility in built environment, public transportation, and access to healthcare in existing disability advocacy research (Bezyak et al., 2020; Newman & SCI Photovoice Participants, 2010; Rotoli et al., 2022). This study further contributed actionable recommendations. In addition, by inquiring about the participants' views on future research needs, the study adds to the growing body of literature in health-related fields that prioritizes the opinions of those who are researched to inform future research direction (Lacerda et al., 2019).

Community-engaged dissemination is a meaningful component of the CEnR that most researcher-driven studies fail to include. This method can accelerate knowledge translation and bridge the research-practice gap by disseminating study findings to non-academic audiences who may be affected by the research and who may have more power to translate findings into practice (Castello et al., 2022). As discussed in Kitchin (2000), participants of disability research desire to be informed about the research outcomes, and the participants of this study also expressed a similar wish. This study practiced community-engaged dissemination in a few ways. During the community engagement meeting, a research presentation disseminating findings of the previous phases was delivered using lay language to the audience who may not have access to scientific research reports. The project did not stop at collecting and analyzing data from the community engagement meeting, rather, we extended our efforts by sharing study findings with a policymaker who has been working on promoting disability rights with legislative efforts. Future plans for disseminating the information gained from the study and using it for advocacy include an information-sharing meeting with the NMSS Advocacy team. We also plan to provide open access to academic manuscripts to honor the knowledge ownership of the community members.

CEnR experts have emphasized the importance of establishing and sustaining an equitable community-academic partnership, and achieving this goal essentially requires researchers to be respectful, open-minded, and committed to co-learning (Camden et al., 2015; Mayan & Daum, 2016; Ward et al., 2018). Building on successful examples of previous CEnR projects (Collins et al., 2021; Koch & Kralik, 2001; Lacerda et al., 2019) and recommendations for promoting accessibility, inclusion, and equitable participation in research with marginalized communities (Gill, 1999), we implemented various strategies to facilitate engagement of the MS community. These strategies included active listening and cultural humility, allowing self-paced contribution, using plain language, sharing access to research materials, and offering compensation. These efforts likely contributed to participants' perceived meaningfulness of their engagement. As reflected in the feedback survey responses, participants of the meeting felt that their voices were represented in the project and that the opportunity to engage in MS research like this is valuable. This outcome aligns with prior participatory research that also included a component evaluating the engagement process where community members shared a sense of validation through sharing their stories and perspectives with peers (Koch & Kralik, 2001).

We acknowledge that community partners were not involved in the conceptualization and initial design of the larger CEnR project, which may be seen as a limitation to achieving the highest level of community engagement. However, prior literature has discussed the spectrum of community engagement and stated that the level of engagement is dependent on research questions and available resources (Brown, 2022). In reality, it is rare for CEnR to achieve the highest level of community engagement in all research stages where community members demonstrate fully egalitarian collaboration. During the implementation of this CEnR project, we recognized challenges commonly discussed by CEnR practitioners, such as demands for time and funding, building trust, power sharing, and genuine inclusion (Horowitz et al., 2009; Magasi et al., 2021). While the research agenda was primarily driven by the researcher in this study, the CAB, which included members with research backgrounds, participated in decision-making processes at each phase, and genuine efforts were made to establish an equitable partnership with respect and commitment to co-learning. Due to limited time and funding, only one community engagement meeting was held with one group of representative community members. Consequently, the recommendations from this meeting, while likely beneficial to the MS community at large, may reflect the perspectives of this particular group, and certain topics of interest to other MS community members might not have been discussed. Future studies may consider hosting a series of community engagement meetings to recruit more community members and capture nuanced perspectives.

Despite the limitations, this project demonstrated meaningful outcomes by centering community voices and informed collective actions that could be taken by the larger MS community to support community participation of PwMS. The methodologies, strategies, and findings of this study may serve as a reference for future community-engaged projects with the MS and the broader disability communities.

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Chapter 5. Conclusion

Summary of Findings

The research questions of the three studies in this dissertation were guided by existing literature, including both conceptual works and empirical studies. The identified research gap supported the need for utilizing community-engaged-research (CEnR) approaches and mixed methods design to better measure and understand community participation experiences of people with multiple sclerosis (PwMS), investigate environmental influences on community participation, and explore solutions informed by community perspectives.

Chapter 2 explored the relationship between subjective and objective dimensions of community participation using quantitative and qualitative data collected from PwMS. According to the previous conceptual opinions, we hypothesized that subjective aspects of participation, such as satisfaction, would be positively but weakly related to objective community participation measures, such as frequency and distance of out-of-home trips. The quantitative findings supported our hypothesis and indicated that although a high quantity of some community participation measures is positively associated with better subjective perception of participation, the association is generally weak. Qualitative findings also indicated that a high quantity of participation is not mandatory to have satisfaction with community participation. In addition, qualitative findings contributed possible explanations of this weak association between subjective and objective dimensions of participation, implying that personal factors such as personality, lifestyle, and optimistic thinking could lead to high satisfaction regardless of the quantity of community participation.

Chapter 3 is a mixed methods study examining the influences of physical, societal, and attitudinal environments on the subjective and objective aspects of community participation among PwMS. The study also sought to understand how individuals navigate the environment outside the home and their advocacy for environmental support. Quantitative results highlighted that environmental factors have a greater impact on satisfaction with participation and activity space among PwMS, and revealed that different environmental factors have various magnitudes of influence on different participation aspects. For example, perceived financial resources has a stronger relationship with subjective perspectives of participation, while neighborhood safety has more effects on trip distance and activity space. Focus group participants also supported the perspective that environmental barriers interfere with their ability and satisfaction with community participation outside the home. Notably, PwMS using mobility devices reported more barriers in the built environment, whereas those living with invisible MS shared more concerns about others' attitudes. Participants emphasized the necessity of increasing environmental support, specifically in four areas: accessibility of built environment, access to information, MS specialty care, and public attitudes toward disability.

Chapter 4 focuses on reporting the methods and findings of the final phase—the online MS community engagement meeting, which was built on the findings of the first two studies to co-identify actions that individuals, organizations, and policymakers could take to increase system-level support. This article also describes the community engagement component of the entire dissertation project by introducing the overarching purpose, roles of community partners involved in the project, and strategies used to support community engagement. The findings of the study are a list of action-oriented recommendations made by the attendees for improving the four areas reported in Chapter 3.

Implications and Future Research Directions

This was the first community-engaged research project with the MS community focusing on understanding community participation experiences, investigating environmental influences on community participation, and identifying collective efforts in society needed to support community participation for PwMS. The study findings indicate that improving community participation of PwMS requires collective actions. This dissertation offers several implications for rehabilitation professionals, MS community organizations, researchers, and policymakers. The first study revealed the necessity of using multiple measures to assess both subjective and objective aspects of community participation due to their differences. Only when measuring both dimensions, can professionals develop a full understanding of the individual's community participation experiences and specific needs for support, which can inform effective interventions improving participation outcomes.

The second study conveyed that environmental influences as a significant component of community participation cannot be left unaddressed. As indicated by the participants, environmental barriers are persistent while research funding and resources are focused on advancing disease-modifying therapy and finding a cure for MS. PwMS need more system-level support for navigating the environment to achieve full community participation. More organizational and legislative efforts are desired to increase support for socioeconomic status, bridge the information gap, improve the accessibility of the built environment, advance MS specialty care, and promote anti-ableist public attitudes in society.

Considering the limitations related to discrepancies between the instruments used to measure subjective participation (PROMIS scales) and objective participation (GPS), as well as the fact that the environmental factors in the quantitative phase were assessed with only three variables derived from a single self-reported quality of life measure, future research should continue exploring the relationship between subjective and objective dimensions of participation using real-time measures. As recommended by Chan et al. (2021) and Magasi et al. (2015), a combination use of Global Positioning System (GPS), Geographic Information System (GIS), and ecological momentary assessment offers substantial advantages for capturing accurate data. GPS and GIS can objectively measure community mobility performance (e.g., trip frequency, distance, and duration) and environmental characteristics (e.g., neighborhood walkability, availability of resources in the community), while an immediate use of ecological momentary assessment can capture subjective perspectives, such as purpose, satisfaction, perceived difficulty, and how environments influence these perceptions specific to the trip. This approach may reveal a more precise relationship between subjective and objective dimensions of community participation and environmental influences on community participation outside the home.

Reflecting on the findings of this dissertation, several research topics may be interesting to further investigate. First, drawing from the perceived impact of COVID-19 among focus group participants, it would be interesting for future studies to investigate the potential long-term impact of COVID-19 on community participation experiences among PwMS using data collected before and after COVID-19 in regions that had stricter restrictions during COVID-19. The study findings revealed that while perceived ability to participate and satisfaction with participation are highly correlated, environmental factors have more impact on satisfaction with participation compared to perceived ability to participate. Future studies may investigate the underlying reasons. Lastly, our qualitative findings implied that resilience may be a moderator for the association between subjective and objective aspects of community participation among PwMS, it would be worth examining the role of resilience quantitatively.

This dissertation also demonstrated the value of community-engaged research that centers the needs and voices of the MS community and shares the process, implements strategies to facilitate community engagement, and extends efforts to disseminate findings to non-academic audiences. The engagement of and partnership with the MS community throughout the research process helped identify priorities and needs for system-level support that directly emerged from community perspectives, ensuring the relevance of findings to the community's interests. Community engagement strategies and approaches were implemented to support accessibility and facilitate active participation, which has contributed to participants' perceived meaningfulness of engaging in this collaborative project. The methodologies and findings of this project may serve as a reference for researchers who plan to conduct community-engaged disability research with the disability community and make efforts to accelerate knowledge translation to practice.

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