

Perceived Vulnerability to Disability-Related Victimization in People With Multiple Sclerosis: Community Survey on Risk and Protective Factors

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ABSTRACT

BACKGROUND: The perception that one is at increased risk of interpersonal victimization or violence can deleteriously affect community participation and quality of life. Race, sex, and disability status, often associated with use of an assistive mobility device (AD), are known correlates of perceived risk of victimization; however, almost no research has explored how these variables intersect for individuals with multiple sclerosis (MS), and none have sought to identify potential risk and protective factors.

METHODS: Data for the present study come from a single time point derived from a 10-year longitudinal survey of 446 individuals with MS. Lifetime trauma exposure, personal resilience and self-efficacy, control over participation, and perceived risk of interpersonal victimization due to disability were all assessed via self-report. Statistical analyses included analysis of covariance with participants stratified by race/ethnicity, sex, and AD use.

RESULTS: After controlling for lifetime trauma exposure and severity of physical impairment, the use of an AD was significantly associated with greater perceived risk of victimization due to disability. Further, people with MS from racial and ethnic minority groups who used ADs had the highest perceived risk relative to all other groups. Higher levels of perceived risk were associated with a lower sense of control over community participation, lower resilience, and lower disease management self-efficacy.

CONCLUSIONS: Visible indicators of disability may contribute to perceptions of vulnerability, especially among people with MS who are racially and ethnically marginalized. Clinicians should be aware of how perceived vulnerability may impact a sense of control over community participation, particularly when educating patients on AD use.

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Living with a cognitive or physical disability can affect a person's sense of personal safety, contributing to an increased fear of interpersonal victimization (eg, physical/sexual assault, theft, etc).^{1,2} Increased perception of crime can follow in the wake of personal victimization, witnessing a crime, or even hearing about a crime in the community.^{3,4} Fear of victimization may also be related to age and sex, with some previous research suggesting that women, older adults, and young adults fear interpersonal victimization at higher rates than men and middle-aged adults.^{5,6} While men are generally more likely to be the target of crimes than women, women with disability are more likely to be targeted than men with disability.^{7,8} Fear of victimization can lead to restrictions in community participation, as individuals may (for example) avoid strangers, restrict social activities, or avoid activities at night. These behaviors can lead to social isolation and poorer quality of life.⁶

In addition to personal demographic factors, visual indicators of disability, such as the use of an assistive mobility device (AD), may also contribute to a sense of vulnerability. One qualitative study of people with disabilities in Ireland noted that using an AD can be a double-edged sword,⁷ such that while utilization of ADs can increase one's feelings of safety in some situations, in other instances, ADs may draw attention to one's disability and may make them a target for interpersonal crime.

The current literature on disability and perceived risk of victimization has several conceptual and methodological problems. First, most studies do not differentiate between a *general* fear of crime vs a *specific* perception of increased risk due to one's disability. Second, some research suggests that being a woman or belonging to a racial or ethnic minority group influences a person's fear of victimization,^{5,6,8,9} but very few studies take an intersectional approach, examining how gender and race interact to influence perceived risk of victimization.¹⁰ Third, few studies have examined perceived risk of victimization in a sample of adults with a chronic and progressive health condition, such as multiple sclerosis (MS).

Finally, research has yet to investigate risk or protective factors linked to perceived risk, nor has it adequately addressed potential confounding variables, such as lifetime trauma exposure, when examining perceptions of vulnerability.

These factors are paramount in MS, where a progressive loss of neurologic function and increased use of ADs is common. This analysis examines fear of interpersonal victimization due to disability among a large sample of adults with MS. We examine how race, age, sex, and use of a visible AD for mobility relate to fear of interpersonal victimization. We identify potential protective factors and examine how perceived vulnerability is related to community participation outcomes.

METHODS

Participants

This study used data from a national, longitudinal survey funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. This survey tracked mental and physical health in 1855 individuals with spinal cord injury, MS, muscular dystrophy, or postpolio syndrome and included 7 assessment time points from 2010 to 2018. Final surveys were completed and returned by 446 participants with MS (91.6% of 487 originally sent). Data for the present analysis were limited to this final time point, where measures relevant to trauma and perceived vulnerability were collected. All surveys for this time point were mailed between October 2016 and May 2017.

Study Procedures

Participants were recruited from a research participant registry at the University of Washington (UW), advertisements in MS organization newsletters and websites, word of mouth, and the UW MS clinic. Inclusion criteria included self-report of physician-confirmed MS diagnosis, 18 years of age or older, and English language literacy. Participants completed consent documents and returned them with completed surveys. Each returned survey was examined by research staff for completeness; if missing data were identified, staff attempted to contact the participant and obtain the missing data via letters and phone calls. Participants were reimbursed \$25 for completing each survey. All study procedures were approved by UW's Human Subjects Division.

Measures

Demographic variables, including age, race/ethnicity, years since diagnosis, education and income level, zip code, and sex, were included for descriptive purposes. Due to the relatively small number of respondents belonging to a racial minority, compared to White, this measure was collapsed into binary categories, White and racial minority. Individuals who identified as belonging to the racial or ethnic groups of Black, Asian/Pacific Islander, Hispanic/Chicano, Native American/Alaska Native, or other were categorized as racial minority. We chose the terminology *identifying as a racial minority* per the Centers for Disease Control and Prevention's recommendations of preferred language.¹¹ Lifetime traumatic exposure was measured

using the Life Events Checklist (LEC5) from the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition. The LEC5 is a 17-item measure based on the original Life Events Checklist developed by the National Center for PTSD and was initially designed to assist a clinician in diagnosing posttraumatic stress disorder (PTSD).⁴ The LEC5 asks respondents about lifetime (ie, childhood, adolescent and/or adult) exposure to stressful or traumatic events, including natural disasters, serious transportation accidents, physical and sexual assault, and combat exposure.⁶ Respondents are asked to indicate 1 of 3 levels of exposure to each event (*happened to me, witnessed it, or learned about it*). The LEC5 demonstrates convergent validity with other measures that assess trauma exposure and is associated with PTSD severity.⁴ A total count of personally affecting events (ie, events that *happened to me*) is commonly used in PTSD research and demonstrates adequate reliability¹² and temporal stability.¹³

No validated measure of perceived risk of victimization due to disability could be identified for this study; therefore, this study created a 3-item scale based on the original wording of 3 LEC5 interpersonal victimization items. Participants were asked, "Because of your disability, how much more at risk do you feel for: (1) Physical assault (for example, being attacked, hit, slapped, kicked or beaten up); (2) being the victim of robbery or theft; and (3) sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)?" Responses on a 5-point scale were *no greater risk, a little more risk, somewhat more risk, quite a bit more risk, and much more risk*. A total score was created by summing these 3 items, such that the total possible score ranged from 3 to 15. Cronbach α for this measure was 0.93, suggesting a strong internal consistency. For clarity, this in-house measure is referred to as the Perceived Risk of Victimization due to Disability (PRoV-D) scale.

Severity of physical disability or impairment was measured using the Patient-Reported Outcomes Measurement Information System (PROMIS) Physical Function With Mobility Aid (version 1) short form. This 11-item measure assesses the ability to engage in activities of daily living (eg, bathing, eating, and toileting) and physical ability (eg, ability to reach an overhead object, open a heavy door, and stand upright briefly without support). Response choices are on a 5-item scale, ranging from *without any difficulty to unable to do*. This measure demonstrates strong psychometric properties in samples of people with medical conditions, including MS.¹⁴ The total score collected from the PROMIS Physical Function Scale was later normalized to a *t* score based on a large national comparison sample for analysis.

Choice and control over participation was assessed using the 13-item Control Over Participation Subscale, taken from the Enfranchisement Scale.¹⁵ The Control Over Participation subscale reflects the extent to which one perceives a degree of control over and choice in participation and contains items such as, "I am able to go out and have fun," "I have control over how I spend my time," and "I participate in activities that I choose." Response choices range across a 5-point scale from

almost never to all the time. Raw scores were transformed to a normalized *t* score for analysis. Psychometric properties, including internal consistency and sensitivity to change in people with disabilities, have been previously described.^{15,16}

Use of an AD for mobility was measured by a single item asking participants, “Do you use any equipment or devices to help you move around?” If answered in the affirmative, participants were asked to name the specific AD and frequency of use. This question was dichotomized as yes/no for the present analysis.

Disease-management self-efficacy was measured using the University of Washington Self-Efficacy Scale. This 6-item scale asks participants to describe their confidence in managing their health condition. Two of the items are “How confident are you that you can keep your health condition or disability from interfering with your ability to interact socially?” and “How confident are you that you can figure out effective solutions to issues that come up related to your health condition or disability?” Items are scored on a 5-point scale ranging from *not at all to completely*, with the total score converted to a *t* score metric. This scale has demonstrated strong psychometric properties in people with disabilities.¹⁷

Resilience was measured using a custom short form derived from the 28-item University of Washington Resilience Scale (UW RS).¹⁷ This short-form UW RS was developed and validated in people with disabilities, including MS, and conceptualizes resilience as the capacity to bounce back from and/or maintain function in the face of adversity. The UW RS and sample short forms demonstrate strong psychometric properties in both the general population and in people with chronic health conditions. UW RS was derived via a formal process utilizing item response theory, allowing for the creation of custom short forms by selecting different items and different numbers of items from the bank.^{18,19} In the present study, participants were offered 10 statements from the item bank with responses scored from 1, not at all, to 5, very much. The statements included, “I maintain a positive outlook even in bad circumstances” and “When something stressful happens, I keep going.” Total scores were transformed to a *t* score metric for analysis.¹⁸

Aims and Analytic Plan

This study had 4 overall aims: (1) describe the overall rates of lifetime trauma exposure and of the perceived risk of victimization due to disability in this sample of people with MS; (2) evaluate the differences in perceptions of perceived risk among subgroups of people with MS, stratifying the sample by race/ethnicity, by use of a visible AD, and by sex; (3) describe the potential protective factors associated with lower perceived risk; (4) characterize the potentially negative impact of perceived risk on control over participation.

We initially hypothesized that women with MS who used visible ADs and who were in a racial or ethnic minority group would report the highest level of risk for being a target of crime due to their disability. We further hypothesized that this heightened perception of risk would be negatively associated with control over participation. Finally, we hypothesized that personal protective factors like resilience and self-efficacy

TABLE 1. Participant Demographics (N = 446)

Years since diagnosis	Mean = 22.0 (SD 9.3) Range = 6-57
Age	Mean = 62.0 (SD 9.8) Range = 28-86

Characteristic	n (%)
Multiple sclerosis type (patient reported)	
Relapsing-remitting	269 (60.9%)
Secondary progressive	96 (21.7%)
Primary progressive	29 (6.6%)
Progressive relapsing	13 (2.9%)
Don't know	35 (7.9%)
Sex	
Male	77 (17.4%)
Female	365 (82.6%)
Marital status	
Married or living with someone	284 (64.3%)
Separated or divorced	97 (22%)
Never married	24 (5.4%)
Widow/widower	37 (8.4%)
Education	
Less than high school	3 (0.7%)
High school/GED	39 (7.0%)
Vocational/technical school	31 (7.0%)
Some college	112 (25.3%)
College graduate	148 (33.5%)
Graduate school	109 (24.7%)
Race	
Black	29 (6.6%)
Asian/Pacific Islander	3 (0.7%)
White	406 (91.9%)
Hispanic/Chicano	9 (2%)
Native American/Alaska Native	9 (2%)
Other	4 (0.9%)
Assistive device use	
Uses equipment or devices to move around	267 (60.4%)
Uses orthosis or prosthesis	41 (9.3%)
Uses walking aid, such as cane, walker, or crutches	202 (45.7%)
Uses wheeled mobility (scooter, wheelchair)	151 (34.2%)

GED, general education diploma.

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would be associated with less perceived risk of victimization due to disability.

To evaluate these hypotheses, we utilized approaches within the general linear model, including linear regression and analysis of covariance (ANCOVA), adjusting for control variables. Race (White vs racial minority), AD use (yes vs no), and sex (men vs women) were dichotomized for analyses. In all analyses, we controlled for lifetime personal trauma exposure and severity of physical impairment, as these would be expected to influence the perceived risk of the likelihood of victimization.

RESULTS

Participant Characteristics

After removing cases with missing values for the study variables, the final sample consisted of 442 participants. **TABLE 1** presents the demographic and diagnostic variables of the cohort. Participants were predominantly White (91.9%), and mostly women (82.6%), and had relatively high education levels (58.2% completed college, and 24.7% completed postcollegiate education). Participants ranged in age from 28 to 86 years (M age = 62, SD = 9.8). They reported an average of 22.0 (SD = 9.3) years since being diagnosed with MS. More than 60% of participants used ADs. **TABLE 2** presents the means and standard deviations for key study variables.

Aim 1

Rates of lifetime exposure to traumatic events are shown in **TABLE S1**. On average, participants reported a personal lifetime history of 1.7 traumatic events (SD = 2.1). They also reported witnessing 1.5 (SD = 0.9) events and learning about an additional 3.1 (SD = 3.7) events as happening to a close family member or friend. The most frequently reported events that happened to me were transportation or car accidents (29.4%) and natural disasters (24.4%). A minority of participants reported a personal history of interpersonal violence marked by either unwanted/uncomfortable sexual experience (14.7%), physical assault (12.2%), sexual assault (10.4%), or assault with a weapon (4.8%).

The mean score on the PRoV-D measure was 5.5 (SD = 3.2) and ranged from 3 to 15. Combining the 3 domains in this measure, 31.4% of participants endorsed that disability made them feel at least somewhat more at risk for victimization in at least 1 domain. In comparison, nearly half (45.7%) indicated their disability put them at no greater risk for victimization in any domain.

Aim 2

To evaluate aim 2, we conducted an ANCOVA, controlling for traumatic exposure (in terms of the total number of personally affecting events on the LEC5) and for disability severity (using the PROMIS Physical Function measure). Categorical predictors were sex (male vs female), use of an AD (Y/N), and race (White vs racial minority). The main effect and interaction terms were computed.

The primary outcome (PRoV-D total score) was positively skewed (skewness = 1.0, kurtosis = 1.2), and examination of the quantile–quantile plot for residuals for this outcome also

suggested nonnormality. To address this problem, a log¹⁰ transformation was utilized, which resulted in more favorable characteristics (skewness = .38, kurtosis = -.30). All further analyses were conducted on this transformed variable.

The overall ANCOVA model was significant (F [1,9] = 14.94, P < .001). As expected, both personal trauma exposure (F = 5.0, P = .03) and severity of disability (F = 29.2, P < .001) were significantly associated with higher PRoV-D scores. A main effect existed for the use of an AD (F = 10.72, P = .001) but not for sex (P > .20) or race (White vs racial minority; P > .20). There was a significant interaction between AD use and race (F = 3.8, P = .05).

Post hoc analysis revealed that, after controlling for the severity of disability and personal trauma history, people who were from racial or ethnic minority groups and used an AD (n = 32) had the highest PRoV-D scores (M = 6.9). The interaction also suggested that, for those who did not use an AD, race did not make a significant difference in perceived vulnerability (P = .50), whereas among those who did use an AD, belonging to a racial or ethnic minority group was associated with greater perceived vulnerability (P = .02).

Aim 3

We used linear multiple regression to determine whether positive psychological factors (resilience and self-efficacy) were associated with PRoV-D after controlling for the effects of trauma exposure and disability severity, predicting the PRoV-D outcome while adjusting for covariates. The overall model was significant (F [2436] = 55.5, P < .001) and accounted for 20% of the variance in PRoV-D. After controlling for personal trauma exposure and disability severity, a step including self-efficacy and resilience was significant (F change = 13.63, P < .001) and contributed an additional 5% of variance to the model. As expected, self-efficacy and resilience were negatively associated with PRoV-D, with similar-sized standardized β coefficients (–0.15 and –0.11, respectively, P < .05), suggesting that each separately contributed to the model.

Aim 4

To examine whether PRoV-D was related to participants' sense of control over community participation, we used a multiple linear regression model controlling for personal trauma exposure and disability severity. PRoV-D total score was used in the final step to predict the Control Over Participation outcome. The overall model was significant (F [2433] = 49.5, P < .001) and accounted for 22% of the variance in the Control Over Participation score. After the inclusion of control variables, PRoV-D was negatively associated with Control Over Participation (F change = 22.1, P < .001; β = –0.22) and contributed an additional 4% of variance to the model (P < .001).

DISCUSSION

This study is unique in its examination of perceptions of the risk of interpersonal victimization due to disability among people with MS. As hypothesized, personal trauma history and severity of physical disability significantly correlated with the perceived risk of victimization due to disability. However, even

TABLE 2. Key Study Variables (N = 446)

		Men	Women	Total
		77 (17.4%)	365 (82.6%)	446 (100%)
PROV-D item				
Perceived risk of physical assault	No greater risk	41 (53.2%)	186 (51%)	227 (51.4%)
	A little more risk	22 (28.6%)	79 (21.6%)	101 (22.9%)
	Somewhat more risk	6 (7.8%)	57 (15.6%)	63 (14.3%)
	Quite a bit more risk	4 (5.2%)	57 (15.6%)	29 (6.6%)
	Much more risk	4 (5.2%)	17 (4.7%)	21 (4.8%)
Perceived risk of robbery or theft	No greater risk	39 (50.6%)	176 (48.2%)	215 (48.6%)
	A little more risk	18 (23.4%)	80 (21.9%)	98 (22.2%)
	Somewhat more risk	8 (10.4%)	62 (17.0%)	70 (15.8%)
	Quite a bit more risk	7 (9.1%)	33 (9.0%)	40 (9.0%)
	Much more risk	5 (6.5%)	13 (3.6%)	18 (4.1%)
Perceived risk of sexual assault	No greater risk	66 (85.7%)	228 (62.5%)	294 (66.5%)
	A little more risk	2 (2.6%)	64 (17.5%)	66 (14.9%)
	Somewhat more risk	4 (5.2%)	38 (10.4%)	42 (9.5%)
	Quite a bit more risk	2 (2.6%)	18 (4.9%)	20 (4.5%)
	Much more risk	2 (2.6%)	16 (4.4%)	18 (4.1%)
		Range	Median	SD
PROMIS Physical Function (t score)		12.2-57.9	40.3	11.2
Control Over Participation		14-65	49.2	10
Disease Management Self-Efficacy (t score)		20-68.9	48	10.3
UW Resilience Scale (t score)		18.6-70.5	51.8	10.7

PROMIS, Patient-Reported Outcomes Measurement Information System; PROV-D, Perceived Risk of Victimization due to Disability; UW, University of Washington.

after controlling for these variables, AD use was significantly associated with greater perceived risk. This result suggests that some people with MS may perceive that the use of a visible AD makes them a target for interpersonal crime. Additionally, participants who identified as a racial or ethnic minority (ie, Black, Asian/Pacific Islander, Hispanic/Chicano, Native American/Alaska Native, or other) and used ADs reported the highest levels of perceived risk. This heightened perception of risk was associated with a lower sense of control over participation, suggesting that a person's sense of personal safety influences

how much they feel that they can participate in activities of their choice. These results are consistent with previous research indicating that increased perceived vulnerability to crime reduces individuals' social engagement and quality of life.³

It is important to note that most participants (71%-82%) reported that they felt either at *no greater risk* or *a little more risk* of interpersonal victimization due to their disability. However, 11.4% to 14% described feeling that they were *at much more risk* for very serious negative events, including theft, assault, and sexual assault, because of their disability. These individuals tended to



PRACTICE POINTS

A significant number of people with multiple sclerosis (MS) fear interpersonal victimization as a result of their disability; this may be especially true for people with MS from racial and ethnic minority groups.

Perceptions of vulnerability to disability-related victimization are associated with less sense of control over community participation, lower resilience, and lower self-efficacy in managing MS symptoms.

The results of this study emphasize the need for clinicians to assess and address these issues to maximize community participation, especially in high-risk demographic groups. ■

have greater levels of physical disability and were more likely to use an AD.

There was no demonstrated effect of participants' sex on perceived risk, which was inconsistent with previous literature showing that being a woman, particularly a woman who identifies as a racial minority, is associated with an increased perception of vulnerability.⁶ One explanation for this difference is that our analyses controlled for lifetime trauma exposure, which was associated with perceived risk and is generally higher in women.^{3,6,8,20} Controlling for this variable may have reduced sex differences in analyses of perceived vulnerability.

When promoting community participation, rehabilitation clinicians may focus on environmental factors (transportation, resources) as well as mobility concerns (eg, ADs, car transfer training). This study emphasizes the importance of also assessing attitudinal factors, such as fear of victimization, when working with individuals with MS. What may present as a lack of adherence to recommendations for AD use may actually represent an unspoken fear for personal safety based on being targeted as disabled, especially for participants from racially and ethnically diverse backgrounds.

The most notable finding is that being from a marginalized group and using an AD was associated with the highest levels of perceived risk of victimization. Historically, MS has

been considered a condition primarily experienced by White women.²¹ Recent research demonstrates more racial/ethnic diversity among adults with MS than previously indicated, with Black women having a higher proportional incidence than other racial groups.²¹ Under-recognition of MS in Black individuals should be viewed within the context of historical marginalization of this population. This history has contributed to group mistrust and skepticism toward the health care system and physicians. This dynamic can negatively influence patient health outcomes and behaviors, including treatment seeking and adherence to treatment plans.

Strengths of the study include using a large, national sample of individuals with MS, including men and women across the adult lifespan. The relative percentage of participants from a racial minority group was low (around 11%), but the 49 racially diverse individuals who participated were enough to allow for meaningful comparisons, a relative rarity in psychosocial MS research. Study weaknesses include a cross-sectional design, reliance on an in-house measure of perceived vulnerability due to disability, and an overrepresentation of White women (74.1%).

CONCLUSIONS

The perceived risk of increased vulnerability to interpersonal violence is an important and understudied factor in MS, and may be related to both participation and use of AD. Future research should continue to increase racial diversity in research, develop validated measures for perceived risk of victimization, address the limitation of dichotomous sex in research, and further evaluate the relationship between MS and lifetime trauma exposure. ■

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TABLE S1. Life Events and Trauma History (N = 446)

Life Events Checklist item	Happened to me	Witnessed it	Learned about it
Natural disaster	108 (24.4%)	20 (4.5%)	100 (22.6%)
Fire or explosion	29 (6.6%)	23 (5.2%)	93 (21%)
Transportation accident	130 (29.4%)	37 (8.4%)	129 (29.2%)
Serious accident at work, home, or recreational activity	42 (9.5%)	26 (5.9%)	89 (20.1%)
Exposure to toxic substance	21 (4.8%)	6 (1.4%)	58 (13.1%)
Physical assault (attacked, hit, beaten up)	54 (12.2%)	15 (3.4%)	86 (19.5%)
Assault with a weapon	21 (4.8%)	5 (1.1%)	80 (18.1%)
Sexual assault	46 (10.4%)	3 (0.7%)	67 (15.2%)
Other unwanted/uncomfortable sexual experience	65 (14.7%)	7 (1.6%)	38 (8.6%)
Combat or exposure to war zone	9 (2.0%)	2 (0.5%)	54 (12.2%)
Captivity (kidnapped, abducted)	4 (0.9%)	3 (0.7%)	41 (9.3%)
Life-threatening illness or injury	82 (18.6%)	91 (20.6%)	106 (24%)
Severe human suffering	22 (5%)	50 (11.3%)	89 (20.1%)
Sudden violent death (homicide, suicide)	0 (0%)	21 (4.8%)	139 (31.4%)
Sudden accidental death	0 (0%)	25 (5.7%)	140 (31.7%)
Serious injury, harm, or death caused to someone else	9 (2%)	10 (2.3%)	12 (2.7%)
Other very stressful event/experience	110 (24.9%)	35 (7.9%)	70 (15.8%)