

## Loneliness in Multiple Sclerosis: Putative Antecedents and Manifestations

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## Manifestations of MS

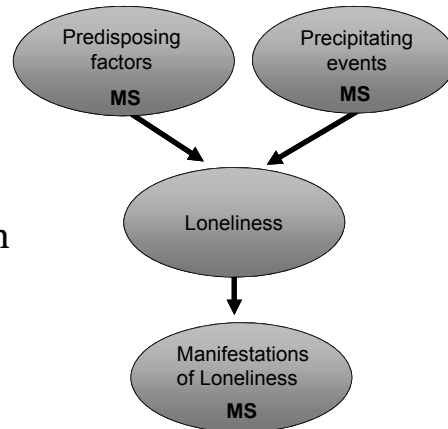
- Loss of walking mobility<sup>1</sup>
- Cognitive dysfunction
- Symptomatic fatigue
- Depression
- Unemployment<sup>2</sup>
- Loss of employment
- Reduced quality of life (QOL)
- Restricted community and social participation

*The impact of MS extends into “work roles, economic status, relationships within the family, and relationships between the family and the larger community”<sup>3</sup>*

<sup>1</sup>Benedict & Zivadinov, 2011, <sup>2</sup>Krupp, n.d.,  
<sup>3</sup>Soderburg, 1992, p. 7

## Social Psychological Theory of Loneliness

- Loneliness is “the unpleasant experience that occurs when a person's network of social relationships is significantly deficient in either quality or quantity”<sup>4</sup>



<sup>4</sup>Peplau & Perlmán, 1979;

## Correlates of Loneliness

- Being a woman<sup>5</sup>
- Low socioeconomic status
- Low education level
- Low competence (e.g. ability to maintain activities of daily living (ADLs))
- Reduced mobility
- Elevated depressive and anxiety symptoms<sup>6</sup>
- Daytime dysfunction (e.g., low energy, fatigue)
- Decreased quality of life (QOL)<sup>7</sup>

<sup>5</sup>Pinquart & Sorensen, 2001, <sup>6</sup>Hawkley & Cacioppo, 2010, <sup>7</sup>Arslantaş, Adana, Abacigil Ergin, Kayar, & Acar, 2015

## Loneliness in MS

- Rokach, 2004
  - Cross-sectional study
  - Examined the qualitative aspects of loneliness in persons with MS
  - Loneliness measure: A 30-item study-generated measure of loneliness with unknown psychometric properties
    - Those with MS had the lowest scores on all domains of loneliness
    - Women with MS expressed higher levels of loneliness than men with MS in all domains.

## Loneliness in MS

- Beal & Stuifbergen, 2007
  - Cross-sectional study
  - Examined the prevalence and correlates of loneliness in women with MS
  - Loneliness measure: a single item from the Center for Epidemiological Studies Depression Scale (CES-D)
  - 50% of the women felt lonely during the past week
  - Loneliness was significantly correlated with
    - social responses of illness ( $r=0.37$ )
    - social support ( $r=-0.37$ )
    - functional limitation ( $r=0.20$ )
    - self-rated health status ( $r=-0.25$ )
    - marital status ( $r=0.20$ ).

## Loneliness Measure

### UCLA Loneliness Scale

INSTRUCTIONS: Indicate how often each of the statements below is descriptive of you.

O indicates "I often feel this way"  
 S indicates "I sometimes feel this way"  
 R indicates "I rarely feel this way"  
 N indicates "I never feel this way"

1	I am unhappy doing so many things alone	O	S	R	N
2	I have nobody to talk to	O	S	R	N
3	I cannot tolerate being so alone	O	S	R	N
4	I lack companionship	O	S	R	N
5	I feel as if nobody really understands me	O	S	R	N
6	I find myself waiting for people to call or write	O	S	R	N
7	There is no one I can turn to	O	S	R	N

## Purpose

- We focused on the extent of loneliness in persons with MS compared with healthy controls, and considered MS as an antecedent of loneliness.
- We examined demographic variables, and features and symptoms of MS as correlates of loneliness.
  - Antecedents: sociodemographic characteristics, disability and functional limitations
  - Consequences or possible manifestations of loneliness: common symptoms of MS including depression, anxiety, fatigue, and QOL

## Participant Inclusion Criteria

### MS

- (1) Age 18-64 years
- (2) Definite diagnosis of MS
- (3) Self-reported Expanded Disability Status Scale (EDSS) score < 8.0
- (4) Relapse free in past 30 days
- (5) Willing and able to visit the University of Illinois at Urbana-Champaign on two testing occasions

### Control

- (1) age 18-64 years
- (2) Willing and able to visit the University of Illinois at Urbana-Champaign on two testing occasions

\*Controls were matched to the MS sample on age, sex, height, and weight.

## Measures

- Loneliness
  - UCLA Loneliness Scale<sup>7</sup>
    - 20 items that are combined as a single measure of one's subjective experience of loneliness, and does not include terms such as "lonely" or "loneliness" to reduce response bias
    - Individual responses are scored (1-4) and then summed into an overall score that ranges between 20 and 80. Higher scores reflect higher degrees of loneliness.

<sup>7</sup>D. Russell, Peplau, & Cutrona, 1980;

## Measures

- Neurological Disability
  - EDSS<sup>8</sup>
- Functional and Disability Limitations
  - Late Life Function and Disability Instrument (LL-FDI)<sup>9</sup>
- Symptoms
  - Hospital Anxiety and Depression Scale (HADS)<sup>10</sup>
  - Modified Fatigue Impact Scale (MFIS)<sup>11</sup>
- Physical and Mental Health Related Quality of Life
  - Multiple Sclerosis Impact Scale (MSIS -29)<sup>12</sup>

<sup>8</sup>Kurtzke, 1983; <sup>9</sup>Mottl, McAuley, & Suh, 2010; <sup>10</sup>Zigmond & Snaith, 1983; <sup>11</sup>Fisk et al., 1994; <sup>12</sup>McGuigan & Hutchinson, 2004

## Procedure

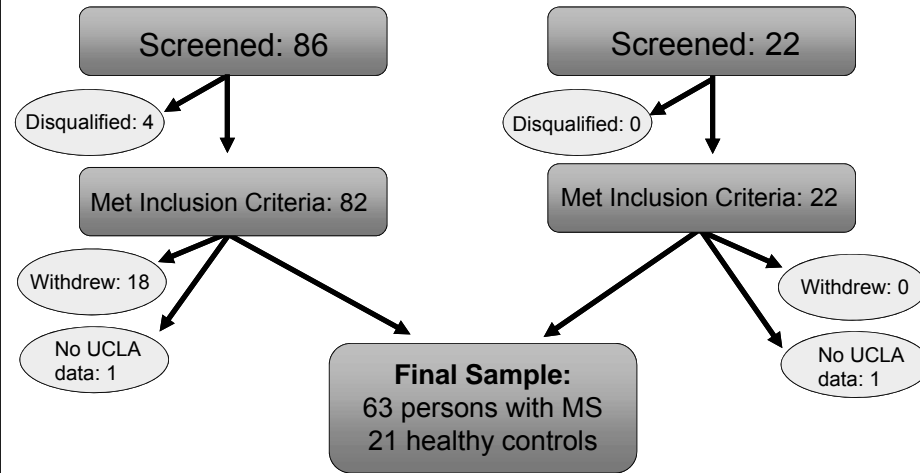
- All participants provided informed consent approved by University IRB
- The data were collected as part of another study examining measures of aerobic and muscular fitness in MS across the disability spectrum<sup>13</sup>
- Participants underwent a neurological evaluation for generation of an EDSS score, and further completed self-report measures (demographics scale, UCLA Loneliness Scale, HADS, MFIS, MSIS-29, and LL-FDI).

<sup>13</sup> Piliutti et al., 2015

# Data Analysis

- Data were analyzed in SPSS v.22.0
- Compared initial differences in demographic variables between MS and control participants using ANOVA, *t*-tests, and chi-square statistics.
- Compared between group differences of the putative antecedents and consequences of MS using *t*-test, effect sizes based on Cohen's *d*, and associations using bivariate Pearson ( $r_p$ ) correlations.
- Stepwise regression analysis to examine which of the antecedents best explained the variance of loneliness scores; we included variables that demonstrated significant associations in the univariate analyses.

# Participants



# Participant Characteristics

**Table 1. Sociodemographic and Clinical Differences between MS and Control groups.**

Characteristic	MS (n=63)	Control (n=21)	p-value
Sex (% female)	71.9%	77.3%	.78
Age, years	52.0 (7.8)	51.1 (10.4)	.68
Race (% Caucasian)	90.6%	77.3%	.22
BMI (kg/m <sup>2</sup> )	27.1 (6.8)	25.7 (6.2)	.40
Marital Status (% married)	63.0%	59.1%	.80
Employed (% employed)	<b>43.8%</b>	<b>90.9%</b>	<b>.00</b>
Education (% some college)	84.4%	90.8%	.44
Annual Household Income (% over \$40,000)	67.2%	95.5%	.16
EDSS, median (IQR)	4.0 (4.0)	--	--
Disease Course (% RRMS or benign)	78.0%	--	--
Disease Duration, years	13.2 (8.8)	--	--
UCLA Score	<b>33.7 (13.1)</b>	<b>27.3 (8.3)</b>	<b>0.04</b>
UCLA Adjusted Score*	33.1(1.6)	29.3 (2.8)	0.27

Note. Values are mean (SD), unless otherwise noted. \*Adjusted mean scores based on ANCOVA controlling for employment status.

**Table 2. Categorical Putative Antecedents of Loneliness in MS**

Characteristics	n (%)	UCLA mean (SD)	t-test	p-value	Cohen's d
<b>Sex</b>					
Female	45 (71.4)	33.2 (13.2)	-0.46	0.65	0.13
Male	18 (28.6)	34.9 (13.2)			
<b>Race</b>					
Caucasian	58 (92.1)	33.3 (13.2)	0.97	0.34	0.45
Other	5 (7.9)	39.2 (11.1)			
<b>Marital Status</b>					
Married	40 (63.5)	30.8 (11.6)	<b>2.48</b>	<b>0.02</b>	<b>0.64</b>
Not Married	23 (36.5)	38.9 (14.2)			
<b>Employment Status</b>					
Employed	28 (44.4)	30.5 (13.0)	1.78	0.08	0.45
Unemployed	35 (55.6)	36.3 (12.8)			
<b>Education</b>					
No college education	9 (14.3)	31.7 (13.0)	-0.51	0.62	0.18
Some college education	54 (85.7)	34.1 (13.2)			
<b>Annual Household Income</b>					
<\$40,000	20 (31.7)	35.8 (11.4)	0.83	0.41	-0.22
>\$40,000	43 (68.3)	32.8 (13.9)			
<b>Type of MS</b>					
RRMS and Benign MS	49 (77.8)	34.0 (13.9)	-0.35	0.73	-0.10
Progressive MS	14 (22.2)	32.7 (10.4)			

**Table 3. Continuous Putative Antecedents and Consequences of Loneliness in MS (N=63)**

Variable	Pearson correlation coefficients	p-value
<b>Antecedents</b>		
Age, years	0.19	0.15
Disease duration, years	0.16	0.23
EDSS	0.11	0.41
BMI	0.16	0.23
LL-FDI, Upper extremity function	<b>-0.28</b>	<b>0.03</b>
LL-FDI, Basic lower extremity function	-0.15	0.26
LL-FDI, Advanced lower extremity function	-0.10	0.43
LL-FDI, Social Disability Frequency	<b>-0.49</b>	<b>0.00</b>
LL-FDI, Personal Disability Frequency	-0.20	0.13
LL-FDI, Social Disability Limitations	<b>-0.38</b>	<b>0.00</b>
LL-FDI, Personal Disability Limitations	<b>-0.29</b>	<b>0.03</b>
<b>Consequences</b>		
HADS, Anxiety	0.24	0.08
HADS, Depression	<b>0.49</b>	<b>0.00</b>
MFIS, Physical fatigue	0.21	0.10
MFIS, Cognitive fatigue	<b>0.34</b>	<b>0.01</b>
MFIS, Psychosocial fatigue	<b>0.30</b>	<b>0.02</b>
MSIS-29, Physical QOL	0.25	0.05
MSIS-29, Psychological QOL	<b>0.44</b>	<b>0.00</b>

## Results

**Table 4. Summary of Hierarchical Regression Analysis for Variables Predicting Loneliness in MS (N=63)**

Variable	B	SE B	$\beta$
<b>Step 1</b>			
LLFDI, Social Disability Frequency	-2.31	0.61	-0.44
<b>Step 2</b>			
LLFDI, Social Disability Frequency	-2.15	0.60	-0.41
Marital Status	-6.38	3.13	-0.23
Note. $R^2 = .20$ for Step 1; change $R^2 = .05$ for Step 2 ( $p$ 's $< .05$ )			

## Preliminary Findings

1. Persons with MS reported worse loneliness than controls, and this difference was seemingly based on employment status
2. Marital status, and functional and disability frequency and limitations represented potential antecedents of loneliness among those with MS
3. Depression, fatigue, and QOL represented manifestations of loneliness among those with MS.

## Strengths & Limitations

- Limitations
  - Homogeneous sample
  - Secondary analysis
- Strengths
  - Novel investigation using validated measure of loneliness
  - Theory-based explanation of loneliness
  - Analysis with a healthy control group

## Conclusion

- Our results suggest that MS and its manifestations represent putative antecedents and consequences of loneliness.
- Additional research using a social psychological framework is needed for continued understanding of the antecedents and manifestations of loneliness in MS.

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Thank you! Questions?