

## ***Disability identity predicts lower anxiety and depression in multiple sclerosis***

The Faculty of Oregon State University has made this article openly available.  
Please share how this access benefits you. Your story matters.

<b>Citation</b>	Bogart, K. R. (2015). Disability Identity Predicts Lower Anxiety and Depression in Multiple Sclerosis. <i>Rehabilitation Psychology</i> , 60(1), 105-109. doi:10.1037/rep0000029
<b>DOI</b>	10.1037/rep0000029
<b>Publisher</b>	American Psychological Association
<b>Version</b>	Accepted Manuscript
<b>Terms of Use</b>	<a href="http://cdss.library.oregonstate.edu/sa-termsfuse">http://cdss.library.oregonstate.edu/sa-termsfuse</a>

Brief Report: Disability Identity Predicts Lower Anxiety and Depression in Multiple Sclerosis

Kathleen R. Bogart, PhD

Reference

Bogart, K. R. (2015). Disability identity predicts lower depression and anxiety in Multiple Sclerosis. *Rehabilitation Psychology*, 60 (1), 105-109. doi:10.1037/rep0000029

Acknowledgements

I thank: Mariah Estill; the patient support groups and foundations for their help with recruitment; Amanda Hemmesch for her comments on an earlier draft of this article.

Kathleen Bogart (corresponding author)  
Oregon State University  
School of Psychological Science  
2950 SW Jefferson Way  
Corvallis, OR 97331, USA  
Kathleen.bogart@oregonstate.edu  
Phone: (541) 737-1357

### Abstract

**Purpose/Objective:** Disability identity involves affirming one's status as a person with a disability and incorporating this group membership into one's identity. It is associated with well-being in populations of people with disabilities, but its relationship with depression and anxiety in multiple sclerosis (MS) has yet to be examined. It was hypothesized that disability identity would predict lower depression and anxiety above and beyond the effects of demographic and disability variables. **Research Method/Design:** 106 participants with MS completed a cross-sectional internet survey measuring disability identity, depression and anxiety, activities of daily living performance (ADL), MS duration, and demographic variables. Inclusion criteria were as follows: self-reported diagnosis of MS, self-reported impairment in walking, age 18 or older, living in the U.S., and English fluency. **Results:** Hierarchical regressions revealed that disability identity was a unique predictor of lower depression and anxiety. Older age and higher ADL performance also predicted lower depression and anxiety. **Conclusions/Implications:** Stronger disability identity predicts lower psychological distress in MS. Clinical implications include supporting patient disability identity by encouraging involvement in disability support and advocacy groups. Future research should examine psychosocial interventions to affirm identity.

**Keywords:** Multiple Sclerosis; disability identity; depression; anxiety; social identity theory

**Brief Report: Disability Identity Predicts Lower Anxiety and Depression in Multiple Sclerosis**

**Impact**

- This study is the first to examine disability identity in Multiple Sclerosis and to examine the relationship between disability identity and anxiety and depression.
- Findings confirm that affirmation of disability identity is associated with lower depression and anxiety in people with Multiple Sclerosis and mobility impairment.
- Clinicians should avoid attempts to “normalize” individuals with chronic disability and instead cultivate disability identity by encouraging involvement in disability support and advocacy groups.

**Introduction**

Negative aspects of disability, such as participation restrictions, are largely socially constructed (World Health Organization, 2001). Thus, disability studies scholars suggest that disability constitutes a marginalized identity, and it should be conceptualized as a minority group (Olkin, 2002). Social Identity Theory (Tajfel & Turner, 1979), a social psychological theory originally conceptualized for ethnic minorities, and recently applied to disability (Bogart, 2014; Dunn & Burcaw, 2013; Fernández, Branscombe, Gómez, & Morales, 2012), suggests that members of minority groups buffer their well-being despite having a stigmatized identity by taking one of two identity pathways. First, they may attempt to “pass,” adopting the values of the majority group, striving to be as normal as possible, and distancing themselves from others with disabilities. Second, they may “affirm” their identity as a person with a disability and align with their minority group, adopting its values and viewing themselves according to its norms. People who affirm their disability identity may seek support and advocacy groups, find meaning

in mentoring and advocating for disability rights, and develop a sense of pride about their group (Dunn & Burcaw, 2013).

Although the protective effects of disability identity have been the subject of theorizing (Dunn & Burcaw, 2013), there has been little quantitative research on this construct. Bogart (2014) found that individuals with congenital mobility disabilities had higher satisfaction with life than those with acquired mobility disabilities. Disability identity and disability self-efficacy mediated this relationship, predicting greater satisfaction with life. Another study of people with a variety of disabilities found that stronger disability identity was associated with higher self-esteem (Nario-Redmond, Noel, & Fern, 2013). In a cross-cultural study, Fernández and colleagues (2012) found a more nuanced pattern, that following the social identity pathway endorsed by support organizations in one's country, whether it was affirmation or denial of disability, was associated with well-being. Because affirming disability identity in progressive or sporadic disabilities such as multiple sclerosis (MS) may be a particularly challenging and dynamic process, which has not been researched quantitatively, this study examined whether disability identity predicts lower levels of depression and anxiety in people with MS.

MS is a chronic inflammatory disease which results in demyelination of the nerve fibers of the central nervous system. Onset is typically in early to middle adulthood. Common symptoms include muscle weakness in the extremities, ataxia, spasticity, significant fatigue, incontinence, vision problems, and speech dysarthria/dysphonia (Jonsson & Ravnborg, 1998). The two most common subtypes are relapsing-remitting and secondary-progressive. Over the course of the disease, the majority of MS cases become progressive (Weinshenker, 1995). Thus, the course of MS is unpredictable, and affected individuals must contend with the high probability that they will become increasingly disabled over time.

Soon after diagnosis, individuals with MS often respond with depression, anxiety, denial, and attempts to conceal their disability (Irvine, Davidson, Hoy, & Lowe-Strong, 2009; Janssens et al., 2003). Qualitative work reveals that diagnosis of MS is often experienced as a loss and reformation of one's identity (Irvine et al., 2009). At first, individuals attempt to "pass" as normal. In a qualitative account (Irvine et al., 2009), a participant noted that her son hid her disabled parking pass so others wouldn't see it. Initially, participants noted avoiding support groups because they did not want to be associated with others with MS. Over the course of several years, however, participants reported reduced psychological distress, increased acceptance of their new identities, and socializing primarily with the MS community (Irvine et al., 2009).

Although disability identity has been found to be associated with higher self-esteem and satisfaction with life (Bogart, 2014; Nario-Redmond et al., 2013), its relationship with depression and anxiety has yet to be examined. MS is associated with increased risk of depression and anxiety compared to the general public, with a reported lifetime prevalence of 36-54% for depression (Beiske et al., 2008; Fruewald, Loeffler-Stastka, Eher, Saletu, & Baumhacki, 2001) and 19-36% for anxiety (Beiske et al., 2008; Korostil & Feinstein, 2007). Thus, if disability identity is found to be protective against anxiety and depression, this study can inform psychosocial treatment of individuals with MS and similar disabilities. It was hypothesized that higher disability identity would be associated with lower depression and anxiety above and beyond the effects of the following demographic variables which have been previously found to be associated with our variables of interest: ADL performance, age, MS duration, gender, and income (Beiske et al., 2008; Bogart, 2014; Janssens et al., 2003)

## **Method**

## **Participants**

Participants were a subsample of a larger internet-based study of people with mobility disabilities.<sup>1</sup> Data from these participants have not been previously published. Internet-based research allows for increased participation among populations that have historically had difficulty accessing research. For this reason, internet-based health research is becoming more common, and samples are becoming more diverse (Whitehead, 2007). Participants were recruited from organizations such as the Multiple Sclerosis Foundation, National Multiple Sclerosis Society and via newsletters, email, discussion board posts, and social media. Inclusion criteria were as follows: self-reported diagnosis of MS, self-reported impairment in walking to any degree, age 18 or older, living in the U.S., and ability to read and write in English. Participants who met these criteria and had completed all measures of interest were selected for this study, resulting in 106 participants. See Table 1 for participant characteristics.

TABLE 1 ABOUT HERE

## **Measures**

The 8-item Disability Personal Identity Scale was used to measure disability identity (Hahn & Belt, 2004). It was designed to assess a sense of positive disability identity and belonging with the disability community. Early evidence suggests the scale has good reliability and validity (Hahn & Belt, 2004). Response options ranged on a 5 point scale from “strongly disagree” to “strongly agree.” Possible scores range from 8-40, with higher numbers indicating stronger disability identity.

The Hospital Anxiety and Depression Scale (HADS), a 14-item scale for use as a brief instrument for detecting depression and anxiety in patient populations, was used (Zigmond & Snaith, 1983). HADS is unlikely to confound with physical symptoms such as pain and fatigue,

---

<sup>1</sup> A different subsample from this dataset was published by Bogart (2014).

and it has been validated for use in the MS population (Honarmand & Feinstein, 2009). Possible scores for the depression subscale and the anxiety subscale range from 0-21, with higher numbers indicating greater anxiety and depression.

Demographic information, including age, gender, duration of MS, and income was also collected. The 13-item Self-Report Functional Measure ADL scale was used to assess how much assistance is needed to complete daily tasks (Hoenig, Branch, McIntyre, Hoff, & Horner, 1999). This is a self-report measure based on the Functional Independence Measure (*Guide for the use of the uniform data set for medical rehabilitation*, 1996), has been validated in the MS population (Hoenig, Hoff, McIntyre, & Branch, 2001). Possible scores range from 13 (total assistance) to 52 (independent). Associated symptoms and use of mobility equipment were also assessed with the Self-Report Functional Measure.

### **Procedures**

The Oregon State University Institutional Review Board provided oversight for this research. Participants gave informed consent and completed all measures on Qualtrics, an online survey presentation system, which took approximately 30 minutes.

### **Data Analysis**

Descriptive statistics were calculated for all measures (see Table 1). The established cutoff of  $\geq 8$  for the two HADS subscales was used to describe likely cases of depression and anxiety. In order to test the hypothesis that disability identity would predict depression and anxiety above and beyond covariates, two separate hierarchical multiple regressions were conducted, one predicting depression and one predicting anxiety (see Table 2). ADL performance, age, MS duration, gender, and income were entered into the first step of each model. Disability identity was added in the second step.

## Results

Approximately half (53%) of participants used wheelchairs as their primary mode of mobility. Participants endorsed a variety of symptoms associated with MS; 73% had sexual or incontinence issues, 43% had vision symptoms, and 24% had speech symptoms. Based on HADS cutoff scores, 37% of participants had likely cases of depression, and 37% had likely cases of anxiety.

### TABLE 2 ABOUT HERE

As predicted, stronger disability identity was significantly associated with less depression when added in the second step, contributing a significant 9% increase in variance predicting depression. The significant predictors of depression in the final model were age, disability identity, and ADL performance. The final model explained 27% of the variance in participants' depression.

In the regression predicting anxiety, as expected, stronger disability identity was associated with significantly lower anxiety and explained a significant 4% increase in variance. The significant predictors of anxiety in the final model were age, disability identity, and ADL. The final model explained 19% of the variance in participants' anxiety.

## Discussion

As hypothesized, stronger disability identity was a unique predictor of lower depression and anxiety in participants with MS. This was the first study to examine the benefits of disability identity among people with MS. Further, it provides the first evidence that disability identity is associated with lower psychological distress. Evidence for the benefits of disability identity are accumulating for a variety of disabilities and for a variety of outcomes: depression and anxiety, self-esteem (Nario-Redmond et al., 2013), and satisfaction with life (Bogart, 2014).

Research has only begun to examine the correlates of disability identity. Affirmation of one's disability identity may involve acceptance of one's disability into the sense of self, social support through the disability community, stigma reduction through disability pride, and meaning-making through disability advocacy (Dunn & Burcaw, 2013). Redefining one's goals and values to fit those of the disability community, rather than the majority group, may be another beneficial aspect of disability identity. For example, one aspect of disability identity may involve valuing interdependence, whereas the majority Western culture values independence and physical competence; this value shift has been suggested to be protective of well-being among people with disabilities (Stensman, 1985).

Age was the strongest predictor of depression and anxiety in this sample, indicating that younger individuals were more likely to experience depression and anxiety. Other research has suggested that younger individuals with acquired disabilities may experience more psychological distress because disability is less expected at their life stage, whereas when people age, disability becomes more common (Beiske et al., 2008; Horgan & MacLachlan, 2004). ADL performance also emerged as a predictor of depression and anxiety. The literature is mixed as to whether depression and anxiety are associated with functional independence, with some studies reporting significant associations (Beiske et al., 2008; Janssens et al., 2003) and some finding none (Figved et al., 2005; Fruewald et al., 2001). It is interesting to consider that disability identity was a stronger predictor of depression than ADL performance, suggesting that the way one's disability is appraised and incorporated into one's identity may be more important than one's functional independence in this case.

Somewhat surprisingly, duration of MS was not associated with depression or anxiety. Depression and anxiety are often a reaction to diagnosis, and they tend to improve as individuals

adjust to their conditions (Janssens et al., 2003). Because participants in our sample had their conditions for an average of 20 years, it is possible that they had already employed coping strategies to reduce psychological distress. Other studies of people with long durations of MS have also failed to find a relationship between duration and depression and anxiety (Beiske et al., 2008).

### **Limitations**

Participants were drawn from a larger internet-based study of mobility disability, so results relied on self-report, and detailed information about participants' disease course was not available. Because the inclusion criteria for the larger study required some degree of difficulty walking, individuals who were younger, had earlier stages of MS, or more mild levels of disability were less likely to be enrolled. Additionally, our sample had similar levels of men and women, but MS occurs more frequently in women (Jonsson & Ravnborg, 1998), thus, women were somewhat underrepresented in the study. MS occurs most commonly in white individuals (Poser, 1994), and the lack of ethnic diversity in our sample reflected this. Future studies should examine the intersection of disability identity and other minority statuses. Results of this study would be best generalized to people with MS who have mobility disability.

### **Clinical Implications**

Well-intentioned rehabilitation practitioners often attempt to “normalize” people with disabilities, implicitly serving to diminish disability identity (Olkin, 2009). Growing evidence of the benefits of disability identity suggests a shift away from this approach towards one that affirms disability identity. A natural first step toward improving disability identity is to encourage involvement in support and advocacy groups. Additionally, a few promising psychotherapeutic approaches may serve to improve disability identity. Disability Affirmative

Therapy emphasizes that living with a disability can be a source of value, meaning, and pride for an individual (Olkin, 2009). It encourages patients to develop a positive disability identity by finding mentors with disabilities and engaging in positive reframing of stigmatized traits.

Additionally, a group-based cognitive behavior therapy program was developed for individuals with MS which focuses on helping individuals to redefine their identities and goals according to their disabilities, and promoting a sense of coherence and self-efficacy (Graziano, Calandri, Borghi, & Bonino, 2014). A randomized controlled trial of this therapeutic approach found that depression and quality of life improved at follow-up. Future research should examine the mediating role of disability identity in the effectiveness of such interventions.

### References

- Beiske, A. G., Svensson, E., Sandanger, I., Czujko, B., Pedersen, E. D., Aarseth, J. H., & Myhr, K. M. (2008). Depression and anxiety amongst multiple sclerosis patients. *European Journal of Neurology*, *15*(3), 239–245. doi:10.1111/j.1468-1331.2007.02041.x.
- Bogart, K. R. (2014). The role of disability self-concept in adaptation to congenital or acquired disability. *Rehabilitation Psychology*, *59*(1), 107–115. doi:10.1037/a0035800
- Dunn, D. S., & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology*, *58*(2), 148–157. doi:10.1037/a0031691
- Fernández, S., Branscombe, N. R., Gómez, Á., & Morales, J. (2012). Influence of the social context on use of surgical-lengthening and group-empowering coping strategies among people with dwarfism. *Rehabilitation Psychology*, *57*(3), 224. doi:10.1037/a0029280
- Figved, N., Klevan, G., Myhr, K. M., Glad, S., Nyland, H., Larsen, J. P., ... Aarsland, D. (2005). Neuropsychiatric symptoms in patients with multiple sclerosis. *Acta Psychiatrica Scandinavica*, *112*(6), 463–468. doi:10.1111/j.1600-0447.2005.00624.x
- Fruewald, S., Loeffler-Stastka, H., Eher, R., Saletu, B., & Baumhacki, U. (2001). Depression and quality of life in multiple sclerosis. *Acta Neurologica Scandinavica*, *104*(5), 257–261. doi:10.1034/j.1600-0404.2001.00022.x
- Graziano, F., Calandri, E., Borghi, M., & Bonino, S. (2014). The effects of a group-based cognitive behavioral therapy on people with multiple sclerosis: a randomized controlled trial. *Clinical Rehabilitation*, *28*(3), 264–274. doi:10.1177/0269215513501525
- Guide for the use of the uniform data set for medical rehabilitation*. (1996). Buffalo, NY: State University of New York at Buffalo.

- Hahn, H. D., & Belt, T. L. (2004). Disability identity and attitudes toward cure in a sample of disabled activists. *Journal of Health and Social Behavior, 45*(4), 453–464.  
doi:10.1177/002214650404500407
- Hoenig, H., Branch, L. G., McIntyre, L., Hoff, J., & Horner, R. D. (1999). The validity in persons with spinal cord injury of a self-reported functional measure derived from the Functional Independence Measure. *Spine, 24*(6), 539–543. doi:10.1097/00007632-199903150-00007
- Hoenig, H., Hoff, J., McIntyre, L., & Branch, L. G. (2001). The self-reported functional measure: Predictive validity for health care utilization in multiple sclerosis and spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 82*(5), 613–618.  
doi:10.1053/apmr.2001.20832
- Honarmand, K., & Feinstein, A. (2009). Validation of the Hospital Anxiety and Depression Scale for use with multiple sclerosis patients. *Multiple Sclerosis, 15*(12), 1518–1524.  
doi:10.1177/1352458509347150
- Horgan, O., & MacLachlan, M. (2004). Psychosocial adjustment to lower-limb amputation: a review. *Disability & Rehabilitation, 26*(14-15), 837–850.  
doi:10.1080/09638280410001708869
- Irvine, H., Davidson, C., Hoy, K., & Lowe-Strong, A. (2009). Psychosocial adjustment to multiple sclerosis: exploration of identity redefinition. *Disability & Rehabilitation, 31*(8), 599–606. doi:10.1080/09638280802243286
- Janssens, A., Doorn, P. A., Boer, J. B., Meche, F. G. A., Passchier, J., & Hintzen, R. Q. (2003). Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and

- distress of patients and partners. *Acta Neurologica Scandinavica*, *108*(6), 389–395.  
doi:10.1034/j.1600-0404.2003.00166.x
- Jonsson, A., & Ravnborg, M. H. (1998). Rehabilitation in multiple sclerosis. *Critical Reviews<sup>TM</sup> in Physical and Rehabilitation Medicine*, *10*(1), 75–100.
- Korostil, M., & Feinstein, A. (2007). Anxiety disorders and their clinical correlates in multiple sclerosis patients. *Multiple Sclerosis*, *13*(1), 67–72. doi:10.1177/1352458506071161
- Nario-Redmond, M. R., Noel, J. G., & Fern, E. (2013). Redefining disability, re-imagining the self: Disability identification predicts self-esteem and strategic responses to stigma. *Self and Identity*, *12*(5), 468–488. doi:10.1080/15298868.2012.681118
- Olkin, R. (2002). Could you hold the door for me? Including disability in diversity. *Cultural Diversity and Ethnic Minority Psychology*, *8*(2), 130–137. doi:10.1037/1099-9809.8.2.130
- Olkin, R. (2009). Disability-Affirmative Therapy. In *The Professional Counselor's Desk Reference* (pp. 355–370). New York, NY: Springer.
- Poser, C. M. (1994). The epidemiology of multiple sclerosis: a general overview. *Annals of Neurology*, *36*(S2), S180–S193.
- Stensman, R. (1985). Severely mobility-disabled people assess the quality of their lives. *Scandinavian Journal of Rehabilitation Medicine*, *17*, 87–99.
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In *The social psychology of intergroup relations* (pp. 33–48). Monterey: Brooks/Cole.
- Weinshenker, B. G. (1995). The natural history of multiple sclerosis. *Neurologic Clinics*, *13*(1), 119–146.

- Whitehead, L. C. (2007). Methodological and ethical issues in Internet-mediated research in the field of health: an integrated review of the literature. *Social Science & Medicine*, 65(4), 782–791. doi:10.1016/j.socscimed.2007.03.005
- World Health Organization. (2001). International Classification of Functioning, Disability and Health. Retrieved from <http://www.who.int/classifications/icf/en/>
- Zigmond, A. S., & Snaith, R. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361–370. doi:10.1111/j.1600-0447.1983.tb09716.x

Table 1

*Participant Characteristics*

Characteristic	Statistic	Range
Female (%)	45	
Black (%)	7	
White (%)	90	
Other or mixed ethnicity (%)	3	
Income (median)	\$45,001-60,000	below 10,000-over 90,000
Age <i>M(SD)</i>	58.30 (8.85)	36-77
MS duration in years <i>M(SD)</i>	20.14 (12.20)	2-54
ADL <i>M(SD)</i>	41.21 (8.49)	13-52
Disability Identity <i>M(SD)</i>	22.65 (4.97)	12-39
Depression <i>M(SD)</i>	6.33 (4.05)	0-20
Anxiety <i>M(SD)</i>	6.19 (4.21)	0-16

*Note.* MS is Multiple Sclerosis and ADL is performance of activities of daily living.

Table 2

*Hierarchical Regressions Predicting Depression and Anxiety*

	Predictor Variable	Outcome Variable			
		Depression		Anxiety	
		b (SE)	$\beta$	b (SE)	$\beta$
Step 1	Duration	0.02	0.05	0.05 (.04)	0.13
	Gender	0.05	0.01	-0.60 (.80)	-0.07
	ADL	-0.14 (.05)	-0.30**	-0.12 (.05)	-0.25*
	Income	-0.42 (.19)	-0.20*	-0.26 (.20)	-0.12
	Age	-0.15 (.05)	-0.33**	-0.18 (.05)	-0.37**
Step 2	Duration	0.01	0.04	0.043 (.04)	0.12
	Gender	0.50	0.06	-0.30 (.80)	-0.03
	ADL	-0.12 (.04)	-0.26**	-0.11 (.05)	-0.22*
	Income	-0.33 (.19)	-0.16	-0.19 (.20)	-0.09
	Age	-0.16 (.05)	-0.34**	-0.18 (.05)	-0.38**
	Disability Identity	-0.25 (.07)	-0.31**	-0.17 (.08)	-0.21*
$\Delta R^2$			0.09**	0.04*	
Total R <sup>2</sup>			0.27**	0.19**	

*Note.* ADL = performance of activities of daily living.

\*\*  $p < .01$ . \*  $p < .05$