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Judgment hurts: The psychological consequences of experiencing stigma in multiple sclerosis

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ABSTRACT

Rationale: People living with MS often report feeling stigmatized, but little research has examined the psychological impact of this, which is important considering the high prevalence of depression in this population. **Objectives:** The aim of this study was to assess, concurrently and prospectively, the association between stigma and depression in people living with MS.

Methods: Data were available from 5369 participants enrolled in the semi-annual survey conducted by the North American Research Committee on Multiple Sclerosis (NARCOMS). Participants reported their MS stigma and depression in the spring 2013 update survey (T1) and their depression again one year later (T2). Demographic and health-related covariates were also assessed.

Results: People experiencing higher levels of stigma reported more depression symptoms and were more likely to meet the threshold for clinical depression at both times, even controlling for covariates. Higher levels of stigma also predicted T2 depression, controlling for T1 depression (and covariates), suggesting a possible causal association. Greater psychosocial reserve, a composite of measures assessing participants' feelings of belonging, social support, and sense of control, attenuated the association between stigma and depression.

Conclusions: Stigma is an important but understudied predictor of depression in people living with MS, but greater psychosocial reserve provides a buffer.

1. Introduction

Multiple sclerosis (MS) is an autoimmune disorder marked by chronic inflammation of the central nervous system (CNS). People diagnosed with MS face a lifetime of progressive disability, including pain, fatigue, muscle weakness, and cognitive dysfunction, as well as incontinence, sexual dysfunction, and depression (Arnett et al., 2008; Frank and Elliott, 2000). MS impacts more than two and half million individuals world-wide; there is no cure for MS (Browne et al., 2014). From the moment people are diagnosed, they are burdened with the knowledge that they have a chronic illness that will, in some ways, influence how others see them and make them a potential target of stigma (Cook et al., 2016). Yet, there is relatively little research about how stigma affects people with MS. Stigma occurs when one is viewed as lower in status and separate from others due to a given characteristic. Stigma undermines health (Link and Phelan, 2006), but its role in the mental health of people living with MS is unclear. Given the high comorbidity of MS and depression, research is needed to examine the potential impact of stigma on mental health in this population (Patten

et al., 2003). The goal of the current study was to clarify the role of stigma in depression symptoms both concurrently and longitudinally among a large national sample of people living with MS.

The lifetime prevalence rate for depression in people living with MS is around 50%, much higher than the 17% lifetime prevalence in the general population (American Psychiatric Association, 2013; Patten and Metz, 1997; Sadovnick et al., 1996). Although many constructs covary with depression in MS (e.g., social support, coping style), much of the variance in depression is left unexplained (Cadden et al., 2017; Mohr et al., 1997). The cause of depression in MS is undoubtedly multi-faceted and includes direct physiological changes in the brain. However, we posit that stigma may account for some of the unexplained variance (Hatzenbuehler et al., 2013).

Stigma has been posited as a social determinant of health (Hatzenbuehler et al., 2013). Members of stigmatized groups disproportionately experience discrimination and loss of status, which can limit access to important resources (e.g., employment, housing, medical care) that affect health (Link and Phelan, 2006). Furthermore, exposure to stigma can lead members of stigmatized groups to experience stress

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and social isolation, and pursue maladaptive coping strategies (e.g., substance abuse), all of which have been linked to poorer physical and mental health outcomes (Hatzenbuehler et al., 2013; Mak et al., 2007). Individuals with chronic health problems, physical disabilities, cognitive disabilities, and depression have all reported feeling stigmatized (De Boer et al., 2008; Pyne et al., 2004; Rao et al., 2009; Susman, 1994; Swaffer, 2014). Given that MS is a chronic health disorder that often comes with both cognitive and mood disruptions in addition to physical disabilities, it makes sense that individuals with MS could feel stigmatized. In one recent study, most individuals with MS reported at least some degree of anticipated stigma (i.e., experiences and/or concerns about biased treatment) and isolation stigma (a sense of being socially isolated due to MS stigma), and anticipated stigma predicted efforts at concealing MS (Cook et al., 2016). Although based on a small convenience sample, this study joins earlier qualitative research in showing that social stigma is a primary concern among individuals living with MS (Rivera-Navarro et al., 2007). Very little research has examined potential outcomes of experiencing stigma in MS. However, in one recent study, individuals who reported feeling stigmatized due to their MS reported a lower overall quality of life, were more likely to incur productivity losses at work, and needed greater informal care (Hategeka et al., 2017). That the majority of individuals living with MS report anticipating or experiencing stigma begets the natural question—what is the psychological consequence of this?

Perceived stigma has been found to predict depression in lung cancer patients (Cataldo et al., 2012), people living with HIV/AIDS (Charles et al., 2012), and individuals suffering from mental-illness (Pyne et al., 2004). To our knowledge, only one study has examined whether stigma predicts depression in people living with MS. In this study, those with the highest levels of stigma were more likely to be depressed (Viner et al., 2014). However, this study was limited by a cross-sectional design and absence of potentially confounding demographic and health-related variables that may co-vary with depression. Therefore, a more rigorous longitudinal examination of stigma's association with depression in MS is needed.

Identifying the role of stigma in depression is important for considering potential intervention strategies. Hatzenbuehler et al. (2013) posited that stigma diminishes individuals' psychological resources and leaves them vulnerable to physical and mental health decline. If so, then individuals living with MS who have more psychological resources, hereafter "psychosocial reserve," may better be able to endure stigma with less risk to physical and mental health. This suggests that psychosocial reserve may moderate any association between stigma and depression. To our knowledge, this has not been investigated empirically. Interventions to bolster psychosocial reserve may be effective if their absence is a contributing factor to depression in people with MS who experience stigma.

To capture the concept of psychosocial reserve, we turned to the literature on fundamental psychological needs. Unlike physical needs (e.g., air, water, food), which are required for survival, psychological needs are thought to be required for thriving, and when thwarted, can lead to deterioration of physical and mental health (Pittman and Zeigler, 2007). We assessed two needs that consistently appear in core needs models (e.g., Fiske, 2004; Maslow, 1943; Murray, 1938; Ryan and Deci, 2000): the need to belong and the need for basic autonomy or control. Relevant to the focus of the current study, research has found that higher levels of belonging can buffer against the deleterious effects of stress on depression (Choenarom et al., 2005), and that social support, a related concept, can buffer against depression in the general population (Lin and Dean, 1984) and among those with MS (Cadden et al., 2017). Previous research has also found beneficial effects of a personal control intervention on people's well-being (Langer and Rodin, 1976). The present study examined whether belonging, perceptions of social support, and perceived autonomy collectively moderated any association between stigma and depression.

Our ultimate goal was to clarify the association between stigma and

depression, both concurrently and longitudinally, with a large national sample of people living with MS. To eliminate potential confounds, we control for relevant demographic and health-related variables and test psychosocial reserve as a moderator of the association between stigma and depression.

2. Methods

Data were collected as part of the semi-annual, volunteer survey of people living with MS, administered by the North American Research Committee on Multiple Sclerosis (NARCOMS) and approved by the Institutional Review Board of the University of Alabama at Birmingham. Participants in the NARCOMS registry initially complete an enrollment form and subsequently are prompted to update their information twice a year. Informed consent was obtained in writing at the enrollment and update surveys. Details on the NARCOMS registry are available elsewhere (Bebo et al., 2017; Marrie et al., 2008b). In the spring 2013 update survey (T1), we included several psychological items assessing stigma and psychosocial reserve (described below). T1 data were linked to participants' enrollment survey, and to their spring 2014 update survey (T2), when disease status and depression were assessed again. We limited eligibility to participants who reported their stigma level at T1 and their depression at T1 and T2. This resulted in a sample of 5413 individuals. Another 44 were excluded because of missing data on covariates (see below) resulting in a final sample of 5369.

The final sample was primarily female (78.4%) and White, non-Hispanic (90.4%) with the rest either Black/African American (2.1%), Hispanic/Latino (0.9%) or another/mixed-race/ethnicity (6.6%). Participants' T1 age ranged from 23 to 93 ($M = 58.27$, $SD = 10.19$). Most had obtained a technical, associate, or bachelor's degree (45.5%), while 31.5% had a high school diploma or less, and 23.0% had completed post-graduate education. Most were unemployed (68.5%). Participants had been diagnosed with MS for 19.82 years on average ($SD = 9.69$), with a range from 1 to 67 years. The majority of participants (55.7%) reported a disease course (i.e., the clinical pattern of symptoms used to describe MS) that was relapsing-remitting (including benign, clinically isolated, and unconfirmed diagnoses). Relapsing-remitting MS generally involves repeated cycles of acute symptom onset followed by resolution of most symptoms within weeks to months. An additional 32.2% reported a progressive disease course (including primary progressive, secondary progressive, and progressive relapsing diagnoses). Progressive MS involves gradual symptoms onset without resolution over time (i.e., progressively worsening disability). The remaining 12.1% were unsure or did not answer. The vast majority had health insurance (97.1%) and were non-smokers (89.1%). Approximately half reported exercising during the past month (58.2%) and nearly the same number (56.1%) reported taking a disease modifying therapy (DMT). Approximately 17.8% reported having a relapse in the past 6 months.

2.1. Measures

Stigma was measured at T1 with 9 self-report items used by Cook et al. (2016) rated on scale from 1 (not at all true) to 5 (very true), with higher scores indicating greater stigma perception. Four items assessed participants' anticipation or experience of MS stigma (Cronbach's $\alpha = 0.78$) (e.g., "People are uncomfortable around someone with MS"). Five items assessed isolation due to MS stigma ($\alpha = 0.86$) (e.g., "Because of my MS, I feel left out of things"). Because these subscales were highly correlated ($r = 0.58$), and analysis of them individually led to a consistent pattern of results, we averaged the subscales to form a composite stigma measure.

Depression was measured at T1 and T2 using the NARCOMS Depression Scale, a validated single-item self-report scale of depression symptoms (Marrie et al., 2008a). Respondents are asked to check a

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