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HOW PSYCHIATRIC REFERRALS INFLUENCE STIGMATIZATION IN PATIENTS WITH MYALGIC ENCEPHALOMYELITIS AND CHRONIC FATIGUE SYNDROME: AN EXAMINATION OF AMERICAN AND BRITISH MODELS

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Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) are controversial chronic illnesses with a myriad of debilitating symptoms. This study aimed to explore physician referrals to psychiatrists or psychologists, perceived stigma, and estrangement for patients with ME and CFS. Findings indicate that patients who have been referred to psychiatrists are likely to perceive illness stigma and feel estranged from others due to their illness. These relationships are moderated by the country of residence, the United States and the United Kingdom. The implications of physician referrals for people with ME and CFS are discussed.

Keywords: *chronic fatigue syndrome, myalgic encephalomyelitis, stigma, estrangement, physician attitudes*

1. Introduction

Individuals with myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) experience a variety of symptoms, including debilitating fatigue, post exertional malaise, cognitive impairments, and autonomic symptoms (Carruthers et al., 2011; Fukuda et al., 1994; Jason, Taylor, Stepanek, & Plioplys, 2001). Regrettably, individuals with ME and CFS consistently report negative experiences with physicians (Åsbring & Närvänen, 2002; Dickson, Knussen, & Flowers, 2007), and poor physician-patient relationships can impede effective treatment (Bieber et al., 2008). Patients report that providers often discount patients' physical complaints and treat them as if the illness is psychological. Previous research has found that in some sample populations, up to 68% of patients with ME/CFS were misdiagnosed with a psychiatric illness despite there being no evidence of a current or previous psychiatric illness (Deale & Wessely, 2000). Frequently, symptoms are attributed to depression instead of ME and

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CFS and patients are referred to psychiatrists or psychologists and prescribed anti-depressant medication (Dickson et al., 2007). Even when patients are confident that their symptoms are not psychological, they often accept psychological prescriptions in order to comply with physician recommendations (Dickson et al., 2007), and this can lead to impairments in self-esteem and dignity (Åsbring & Närvänen, 2002; Werner & Malterud, 2003).

Dismissive physician experiences correlate with estrangement for patients with invisible illnesses (Lennon, Link, Marbach, & Dohrenwend, 1989). Estrangement is defined as an emotional lack of intimacy with others and a social lack of relatedness to the environment, and is a construct with deep ties to loneliness and the social network (Andersson, 1986). Some have conceptualized estrangement as a factor that exists under the umbrella of stigma, as members of stigmatized groups often experience high levels of estrangement (Lennon et al., 1989). An estranged person feels isolated and cannot be one's true self in the presence of others, which leads to role performance and other psychological challenges (Andersson, 1986). Ironically, dismissing physical chronic illness complaints as psychological may actually serve as a risk factor for future psychological challenges via estrangement.

Perceived stigma may explain the link between psychiatric referrals and estrangement. Stigma is often cited as 'situation of the individual who is disqualified from full social acceptance (Goffman, 1963). This implies that the act of attempting to help the individual through psychiatric referral is limiting their social opportunities, and thus their social standing. Some patients with ME and CFS perceive high levels of stigma from family, friends, and the general public (Green, Romei, & Natelson, 1999; Looper & Kirmayer, 2004; Shlaes et al., 1999), which can negatively impact well-being for people with ME and CFS (McManimen, McClellan, Stoothoff, & Jason, 2018; Matthews et al., 2016). Individuals who are estranged lack social support that can protect against internalized stigma and aid the recovery process (Andersson, 1989; Chronister, Chou, & Liao, 2013). One study found that patients with ME and CFS who report depression and suicidal ideation experience higher levels of perceived stigma and estrangement (McManimen et al., 2018). As stigma relates to other indicators of well-being, it may mediate the relationship between physician attitudes and estrangement.

Healthcare practices and attitudes toward psychological treatment, and social stigma are deeply embedded within the context of culture. Culture may serve as a mechanism that influences whether stigmatizing beliefs are internalized and lead to social and psychological challenges (Ikizer, Ramírez-Esparza, & Quinn, 2018). For example, general differences exist between British and American mannerisms, behavior, and values of medical professionalism (Chandratilake, McAleer, & Gibson, 2012; Ineson, Lyons, & Branston, 2006). Specific to ME and CFS, British compared to American patients experience longer periods of onset and significantly more impairment in regards to sore throat, joint pain, impaired memory/concentration, and more often attribute the illness to psychological causes (Zdunek, Jason, Evans, Jantke, & Newton, 2015). These cultural differences likely impact the ways in which health care personnel conceptualize the illness and treat patients.

Previous research has examined the relationship between stigma and health outcomes with other illnesses. In one study of tuberculosis, the relationship between knowledge of tuberculosis, physician-patient communication, and family estrangement was mediated by stigmatization of tuberculosis. (Qiu et al., 2018). Though the study does not examine physician referral to psychiatrists, in the context of ME and CFS, it can be viewed as an inadequate understanding of the illness (Bayliss et al., 2014) and be applied in a similar manner. In the current study, it was hypothesized that psychiatric referral would influence differences in stigma and estrangement.

Furthermore, it was hypothesized that perceived stigma would mediate the relationship between psychiatric referral and estrangement for British and American participants.

2. Method

2.1. Procedure

Convenience sampling was utilized to recruit participants via patient organization websites, patient advocacy newsletters, internet forums, and social media. Participants had self-reported diagnoses of ME or CFS. The study was approved by the DePaul University Institutional Review Board and participants provided written informed consent before completing an online battery of tests on Research Electronic Data Capture (Hutton, Misajon, & Collins, 2013).

2.2. Participants

Data from 182 American (M_{age} = 52.93, *SD* = 11.85) and 135 British (M_{age} = 47.03, *SD* = 13.72) participants with ME and/or CFS were analyzed in the present study. The American sample was 91.21% (n = 166) female, and 8.24% (n = 15) male). One participant endorsed a gender identity of other (0.5%). A majority of Americans (98.90%, n = 180) identified as white and only 3.30% (n = 6) identified themselves as of Latino or Hispanic origin. The British sample was 80.74% (n = 109) female, and 19.26% (n = 26) male. A majority of British participants identified as white (97.78%, n = 132), and 1.48% (n = 2) were of Latino or Hispanic origin. Participants had the option to endorse multiple races and ethnicities; therefore, the race/ethnicity totals are greater than 100 percent.

2.3. Measures

Psychiatric Referral. Psychiatric referral was measured with the following yes/no item: “Have you ever been referred to a psychiatrist or psychologist for your physical symptoms?” While research measuring the construct of psychiatric referral has commonly utilized qualitative approaches, one study used a similar binary item to measure the appropriateness of medical referral, providing some construct validity (Fertig, Roland, King, & Moore, 1993).

Perceived Stigma. Perceived stigma was measured with the psychological attribution subscale of the ME and CFS Stigma Scale (Terman, Awsumb, Cotler, & Jason, under review). This subscale measures the perceived stigma of ME and CFS and consists of 5 items on a 4-point Likert scale (1 = *Strongly Disagree* and 5 = *Strongly Agree*). The items from this measure stated, “1) When people learn that you have been treated for ME or CFS, they begin to search for flaws in your personality; 2) Many people assume that having ME or CFS is a sign of personal weakness; 3) Most people believe that a person with ME or CFS is just as emotionally stable as the average person; 4) Many people assume that a person who suffers from ME or CFS has a deep-seated psychological problem as well; 5) People have a way of associating the occurrence of ME or CFS with psychiatric difficulties”. The factor demonstrated good internal consistency (α = .80).

Estrangement. Estrangement was measured with the estrangement subscale from the ME and CFS Stigma Scale and measures the extent to which patients feel estranged from others due to their illness (Terman et al., under review). This 6-item measure was rated on 4-point Likert scale (1 = *Strongly Disagree* and 4 = *Strongly Agree*) and included the following items, “1) There is a part of me that only other people who have experienced ME or CFS can understand., 2) One problem with having ME or CFS is that people don’t believe that you are really ill., 3) I have sometimes wished that people could see my illness., 4) Having ME or CFS has made me feel very different from other people., 5) Most people have no idea what it is like to have ME or CFS., 6) I often feel totally alone with my illness.” This factor demonstrated acceptable internal consistency (α = .78).

Physician Attitudes. Physician attitudes were measured with the item, “The physician seems to have negative attitudes or beliefs about individuals with ME or CFS.” (Sunnquist, Nicholson, Jason, & Friedman, 2017). Responses were rated on a 5-point Likert scale (1 = *NA* to 5 = *Strongly Agree*).

Specialist Attitudes. Specialist attitudes were measured with the item, “The specialist seems to have negative attitudes or beliefs about individuals with ME or CFS.” (Sunnquist, Nicholson, Jason, & Friedman, 2017). Responses were rated on a 5-point Likert scale (1 = *NA* to 5 = *Strongly Agree*).

Sociodemographics. Participants completed sociodemographic questions regarding age, sex, race, ethnicity, and nationality

2.4. Statistical analyses

Analyses of the variance were conducted to evaluate the effects of physician referrals and country of residence on perceived stigma and estrangement. A moderated mediation models was conducted in SPSS, PROCESS (Hayes, 2017). Multiple regression analyses were conducted to assess each component of the proposed mediation model. Mediation analyses were conducted using the bootstrapping method with bias-corrected confidence estimates (MacKinnon, Lockwood, & Williams, 2004; Preacher & Hayes, 2004). The 95% confidence interval of the indirect effect was obtained with 5000 bootstrap resamples (Preacher & Hayes, 2008).

3. Results

There was a significant difference of age between participants in the United States (*M* = 52.94, *SD* = 11.96) and participants in the United Kingdom (*M* = 47.01, *SD* = 13.77), *t*(311) = 4.06, *p* <.001. Women constituted a greater percentage of the American sample (91.6%) than the British samples (80.6%), χ^2 (2, *N* = 312) = 9.75, *p* < .01. There were no significant differences of participants on disability between United States (46.9%) and the United Kingdom (50.0%) p >.05; no significant differences of marriage rates between participants in the United States (53.4%) and the United Kingdom Overall (47.8%) p >.05; and no significant differences in racial composition between participants in the United States and the United Kingdom.

British participants experienced more negative physician attitudes (*M* = 2.36, *SD* = 1.07) than Americans (*M* = 1.68, *SD* = .82), t(159) = -4.41, *p* < .001, as well as more negative specialist attitudes ($M = 2.04$, SD = 1.03) than Americans ($M = 1.47$, SD = .85). There was a trending relationship between country of residence and psychiatric referral χ^2 (1, $N = 312$) = 1.96, $p = .08$. Participants in the United States (62.4%) were 1.82 times more likely to be referred to psychiatrists than participants in Britain (54.5%).

A 2 x 2 Analysis of the variance (ANOVA) was conducted to evaluate the effects of country of residence and psychiatric referrals on perceived stigma. There was a significant main effect of psychiatric referrals on stigma [$F(1,311) = 16.38$, $p < .001$, $\eta^2 = .05$], but no significant main effect of country [$F(1,311) = 1.31$, $p > .05$] or interaction effect [$F(1,310) = 1.04$, $p > .05$] on perceived stigma. Participants who were referred to a psychiatrist had greater levels of perceived stigma ($M = 2.83$, $SD = .48$) than participants who received no psychiatric referral ($M = 2.61$, $SD = .51$). A second 2 x 2 ANOVA was conducted to evaluate the effects of country of residence and psychiatric referrals on estrangement. There was a significant main effect of psychiatric referrals on estrangement [$F(1,311) = 12.90$, $p < .001$, $\eta^2 = .04$] Those who experienced a psychiatric referral had greater levels of estrangement ($M = 3.58$, $SD = .42$) than those who had not experienced psychiatric referral ($M = 3.39$, $SD = .45$). There was no significant main effect of country of residence [$F(1,311) = 0.19$, $p > .05$] or interaction effect [$F(1,311) = 0.13$, $p > .05$] on estrangement.

Correlations of the major variables were conducted (see Table 1). Perceived stigma was correlated with estrangement for Americans, $r(177) = .29$, $p < .05$, but was significantly stronger in magnitude for British participants, $r(134) = .51$, $p < .001$; $z = -2.28$, p <.05. Additionally Estrangement was not correlated with negative physician attitudes for Americans $r(71) = -.20$, $p > .05$, however estrangement was correlated with negative physician attitudes for British participants $r(90) = .42$, $p < .001$. These correlations were significantly different $z = -4.00$, $p < .001$.

Table 1. Correlations among Variables Between British and American Participants

Variable	M (SD)	1	2	3	4	5	6
1. Psychiatric Referral	54% 62%	-	.29**	.22*	-.01	.02	.04
2. Perceived Stigma	2.77 (.50) 2.72 (.50)	.17*	_-	.51**	.14	.22	.02
3. Estrangement	3.84 (.56) 3.52 (.43)	.19*	.29**	_-	.12	.42**	-.02
4.Specialist Attitudes	2.04 (1.03) 1.47 (.85)	.09	.10	-.13	_-	.40**	-.17
5. Physician Attitudes	2.36 (1.07) 1.68 (.82)	.15	.13	-.20	.50**	_-	-.06
6. Age	47.01 (13.77) 52.94 (11.96)	-.16*	-.07	.02	-.01	-.07	_-

Note. Correlations for British participants (n = 134) are above the line. Correlations for American participants (n = 178) are below the line.
*p<.05, **p<.01

Regression analyses were run to test the moderated mediation model, with country of residence moderating the mediating relationship of stigma between psychiatric referral and estrangement (see Figure 1). Partial mediation was confirmed as the c' path, b = .11, $t(4,306) = 2.20$, $p < .05$, had a reduced effect with regards to the c path, b = .21, $t(4,306) = 2.26$, p < .05. For the a path, psychiatric referral significantly related to the mediator, perceived stigma, b = .22, $t(1,309) = 3.86$, $p < .001$. The b path was also confirmed, as the regression of perceived stigma on estrangement was significant, b = .32, *t*(1,309) = 6.88, *p* < .001. There was a significant effect of the moderator (d), participant country of residence, on the b path relationship. For Americans, the conditional effects on the stigma → estrangement relationship (effect = .23, 95% CI [.11-.35], *t* = 3.82, p<.001) was less than the conditional effects on the stigma → estrangement relationship for British participants (effect = .44, 95% CI [.30-.58], *t* = 6.19, *p* <.001. The moderated mediation index (.05) is significantly different from 0 (95% CI [.01 -.09]) Results indicated that perceived stigma had a greater effect mediating the relationship between psychiatric referral and estrangement for British participants than for American participants.

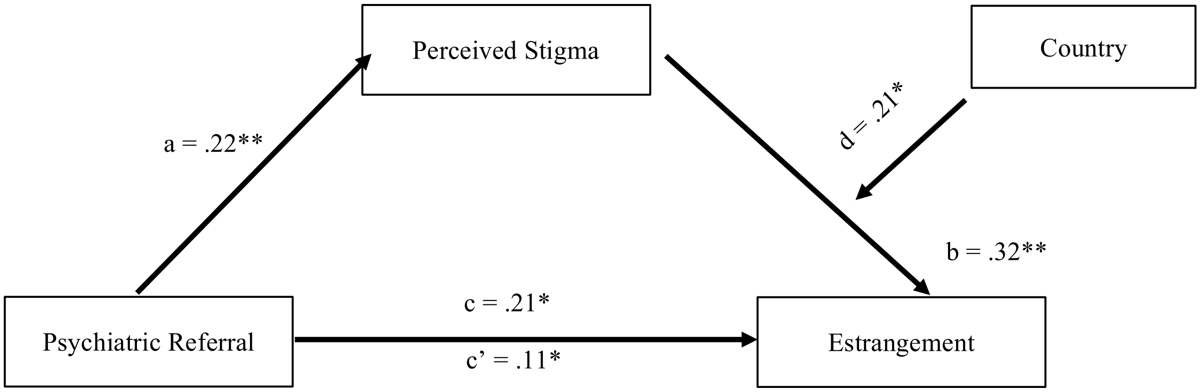

Figure 1. Relationship between psychiatric referral and estrangement, mediated by perceived stigma, moderated by country of residence. *p < .05, **p<.001.

Note*. Conditional effects of Stigma on Estrangement x Country of residence, F(1,306) = 5.10, p<.05. Index of moderated mediation = .05, 95% CI (.01-.10).

4. Discussion

The present findings indicate that patients with ME and CFS who have been referred to psychiatrists are likely to perceive illness stigma and feel estranged from others due to their illness. As previous studies have shown a high propensity of patients with ME and CFS to be misdiagnosed with a psychiatric condition (Deale & Wessely, 2000), these referrals are likely a cause of anxiety and stigma for the patient receiving them. The relationship between psychiatric referral and estrangement was mediated by perceived stigma, yet the impact was stronger for the British sample than the American sample. Despite the different mediation model outcomes due to the moderation effect of country, all three variables correlate with one another for individuals from both countries. These findings corroborate the qualitative accounts that have been reported in previous literature (Åsbring & Närvänen, 2002; Dickson et al., 2007; Jason, Taylor, Plioplys, Stepanek, & Shlaes, 2002), which suggest that physician attitudes related to stigma and estrangement of individuals with ME and CFS.

Findings indicated that patients are at risk for estrangement and high stigma. Stigma can impair help-seeking and predict mental health challenges (Clement et al., 2015; McManimen et al., 2018). Estrangement is also a risk factor for patients because socially isolated individuals may experience loneliness, and loneliness predicts subsequent depression (Cacioppo, Hawkley, & Thisted, 2010; Matthews et al., 2016). Thus, individuals with chronic illness who feel estranged may be at risk for depression (Cacioppo et al., 2010), as well as early mortality (Smith, Jackson, Kobayashi, & Steptoe, 2018).

The differences between the American and British models may, in part, be explained by different illness profiles and cultural differences. British individuals experience more severe symptomology than Americans across several indicators (Zdunek et al., 2015), which may impact their experiences with healthcare providers and peers. It is possible that a patient with more severe symptoms may be treated more negatively by physicians than someone with less severe symptoms, especially if the physician upholds a stigmatizing view of the illness. Another possibility may be due to differences in diagnostic and treatment guidelines between the two countries. In the United Kingdom, the National Institute for Health and Care Excellence (NICE) guidelines for ME and CFS stipulate the cognitive behavioural therapy (CBT) and graded exercise treatment (GET) should be part of the treatment program for patients with ME and CFS (https://www.nice.org.uk/guidance/cg53/chapter/1-Guidance#diagnosis). While this has positive outcomes for patients with depression, patients report that GET often exacerbate symptoms and leaves them feeling more fatigued and more ill than before (Wilshire et al., 2018; Maes & Twisk, 2010). CBT has had more mixed findings, but it has been demonstrated that CBT's effectiveness is directly tied to patient comorbid diagnosis of depression (Sunnquist & Jason, 2018). While these guidelines are in place for U.K. practitioners, the Institute of Medicine in the U.S. does not have specific guidelines for treating ME or CFS. Attitudes toward the illness and treatment likely differ in Britain compared to America due to these nuanced sets of differences, as has been demonstrated with attitudes toward the cause of ME and CFS (Zdunek et al., 2015). These outcomes highlight the importance of co-production in patient healthcare, as stigmatization in patient healthcare can be reduced through the involvement of patients in planning and implementing their treatment and outcome options (Turakhia & Combs, 2017). Community psychologists can use these findings to identify patients who may be at risk for further social and family estrangement due to false positive referrals, and to help administer proper therapies aimed at reintegration into social settings that negate perceived stigma.

While the present study is one of the first to explore physician treatment, stigma, and estrangement for people with ME and CFS cross-culturally, limitations and future directions should be considered. This cross-sectional data cannot be utilized to make longitudinal causal conclusions and should be a point of inclusion in future studies. Additionally, though psychiatric referral was obtained via self-report, we could not ascertain which of these referrals could be deemed inappropriate versus appropriate. Therefore, future studies would be strengthened by conducting clinical interviews with participants to identify which participants would qualify for a psychiatric referral, and which participants would not.

In summation, physician treatment, societal stigma, and the social estrangement of individuals with ME and CFS are interconnected in our two samples of patients. Findings indicate that referral to psychiatric treatment can be damaging when prescribed to someone as a means of dismissing physical complaints. Physicians can utilize a shared decision making treatment model to treat patients with ME and CFS (Bieber et al., 2008). This method involves mutual exchange of information between the doctor and patient, as the doctor holds medical knowledge and the patient holds knowledge about individual health experiences. This model has been effective for those with chronic invisible illnesses and may better allow physicians to aid patients who feel their symptoms are physical and not psychological (Bieber et al., 2008). By remaining sensitive, physicians, friends, and family can aim to improve the lives of those with ME and CFS.

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