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Running title: Stigma & Discrimination in BMS

The social context of Burning Mouth Syndrome: An exploratory pilot study of stigma, discrimination, and pain

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Abstract

The social context of burning mouth syndrome (BMS) has received little attention in the scientific literature. However, social psychological theory and insights from those with lived experiences suggest that people living with BMS experience compounding effects of stigma related to their pain, diagnosis (or lack-there-of), and intersectional identities. Our aim is to provide initial evidence and to motivate new directions for research on BMS. Here, we present the results of an exploratory pilot study (n=16) of women living with BMS in the United States. Participants completed self-report measures of stigma, discrimination, and pain, as well as laboratory assessments of pain through quantitative sensory testing. Results indicate a high prevalence of internalized BMS stigma, experience of BMS-related discrimination from clinicians, and gender stigma consciousness in this population. Moreover, results provide initial evidence that these experiences are related to pain outcomes. The most robust pattern of findings is that internalized BMS stigma was related to greater clinical pain severity, interference, intensity, and unpleasantness. Given the prevalence and pain-relevance of intersectional stigma and discrimination identified in this pilot study, the lived experience and social context should be incorporated in future research on BMS.

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Introduction

Burning mouth syndrome (BMS) is a chronic pain condition characterized by burning orofacial pain. Recent estimates indicate a prevalence of approximately 3% in the general population and 18% among postmenopausal women, though it commonly goes undiagnosed[1]). Lived experiences of BMS often include discrimination in clinical settings and stigma due to intersectional identities as postmenopausal women (e.g., having pain dismissed as "hot-flashes" or anxiety-induced);[2] however, this social context has not been considered in studies of BMS pain.

Prior research in other populations demonstrates that generalized chronic pain injustice and racialized discrimination are associated with enhanced clinical pain, mechanisms of pain facilitation, and inequitable pain management.[3–5] Gendered stereotypes (e.g., women as overly-emotional and unreliable reporters of their own pain experience) impair the quality of pain treatment women receive.[6–8] Stigma refers to convergence of cultural labels, stereotypes, discrimination, and social oppression that leads to unjust distribution of experiences and opportunities, and is increasingly recognized as a social determinant of health disparities.[9] People living with BMS likely experience compounding effects of intersecting stigmas of the pain of women, chronic pain generally, and orofacial pain conditions in addition to processes of stigmatization related to other markers of social status (e.g., racism).[6–8,10,11]

In this pilot study, we had two primary aims: 1) to describe the intensity and frequency of experiences of social and disease-based stigma and discrimination among women with BMS, and 2) to explore the association between these experiences and measures of clinical and laboratory pain. As stigma and discrimination have not previously been examined in the context of BMS, description and exploration – not hypothesis testing – are the focus of this study. However, based

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on insight shared from those with lived experiences with BMS and the established discrimination-pain relationship in other patient populations, we hypothesized enhanced experiences of stigma and discrimination would be associated with enhanced pain.

Method

Data for this study were drawn from a parent study on BMS pain. The detailed recruitment and study procedures, as well as the pain profiles for these participants have been reported elsewhere.[12] In brief, study visits started with self-reported pain questionnaires, followed by two separate laboratory pain testing sessions, and then completion of measures of stigma and discrimination. Due to the circadian pattern of pain in BMS Type I (i.e., tendency to experience more BMS pain later in the day relative to the morning), most pain assessments were conducted twice – in a morning and in an afternoon session. Whether participants started with the morning or afternoon laboratory pain testing session was randomly assigned and counterbalanced across participants. This study was IRB-approved, and all participants provided written informed consent.

Data extraction

All variables representing the constructs of stigma (i.e., internalized stigma, stigma consciousness) and discrimination (i.e., racialized and BMS-related), as well as clinical and laboratory pain, were extracted. Measures of other constructs included in the parent study are outside of the scope of the current aims.[12]

Participants

Eligible potential participants for the parent study were identified at an oral medicine clinic led by co-author TFM.[12] Individuals meeting the criteria for BMS Type I between the years of 2014-2018 were invited to participate. Exclusion criteria included other comorbid orofacial

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conditions, and daily use of medications expected to confound results (i.e., opioids, systemic medications, hormone replacement therapy). Eighteen women with BMS enrolled in the parent study conducted in Baltimore, MD, USA. Two participants did not complete the measures of stigma and discrimination, resulting in an analysis sample of 16 for the present study.

Measures

Self-report measures of stigma and discrimination

Disease-based stigma internalization was assessed using the Internalized Stigma of Chronic Pain scale (ISCPs)[13] comprising 21 items (e.g., *I am embarrassed or ashamed that I have chronic pain*) with response options from 1 (*strongly disagree*) to 4 (*strongly agree*). Participants were instructed to respond to each item with respect to their BMS specifically. Total (α=0.928) and subscale scores (i.e., alienation (α= 0.865), discrimination experience (α= 0.890), social withdrawal (α= 0.907), and resistance (reverse-scored, α= 0.422) are scored as an average. Higher total scores indicate greater internalization of BMS stigma. Separately, to estimate prevalence of internalized BMS stigma, we examined items individually. Participants who did not agree with any item (no single-item responses $\geq$ 3) were considered to not have internalized BMS stigma. We considered a response of 3 or 4 for any item as indicative of some degree of internalized stigma of BMS.

Gender-based stigma consciousness was assessed using the Stigma Consciousness Questionnaire (SCQ).[14] The SCQ has 10 items (e.g., *Stereotypes about women have not affected me personally*, reverse-scored) that participants respond to using a 0 (*strongly disagree*) to 6 (*strongly agree*) scale. However, one item was inadvertently duplicated (*My being female does not influence how people act with me*) and one similarly phrased item consequently omitted (*My being female does not influence how men act with me*). Therefore, after removing the duplicate item, the present

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results reflect the average of 9 items, with acceptable internal reliability (α=0.711). After reverse scoring, a total score was calculated as an average, with higher scores indicating greater degrees of stigma consciousness. To estimate prevalence of gender-based stigma consciousness, we also examined items individually. Agreement with any item (any single-item response ≥ 4) was considered indicative of some degree of gender-based stigma consciousness.

Discrimination in clinical settings was assessed using the discrimination subscale of the short-form Interpersonal Processes of Care survey (IPC-18).[15] Participants responded to each item on a 1 (*never*) to 5 (*always*) scale. The original subscale consists of 2 items specifically assessing racialized discrimination (*How often did doctors pay less attention to you because of your race or ethnicity?*, and *How often did you feel discriminated against by doctors because of your race or ethnicity?*) that demonstrated acceptable internal reliability in this sample (ρ = 0.870). We created two parallel items to assess BMS-specific discrimination (*How often did doctors pay less attention to you because you have burning mouth syndrome?*, and *How often did you feel discriminated against by doctors because you have burning mouth syndrome?*), which were also internally consistent (ρ = 0.806). Therefore, separate total scores were calculated as an average of composite items for racialized discrimination and BMS-specific discrimination, with higher scores indicating more frequent discrimination. Agreement with any item (any single-item responses ≥ 2) was considered indicative of some degree of experience with discrimination from doctors.

Self-report measures of pain

Clinical pain severity was assessed using the Brief Pain Inventory (BPI).[16] Participants reported their current pain ("right now") as well as the worst, least, and average pain over the past week on

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a 0 (*no pain*) to 10 (*pain as bad as you can imagine*) scale. These 4 items were averaged to create the pain severity score (α=0.912), where higher scores indicate more severe pain.

Clinical pain interference was also assessed using the BPI. Participants rated the degree to which their pain interfered with daily functioning and activities using a 0 (*does not interfere*) to 10 (*completely interferes*) scale. Responses to the 7 interference items were averaged to create the pain interference score (α=0.946), with higher scores indicating more pain interference.

Burning pain severity was assessed using face valid questions probing BMS-related "burning pain intensity" and "burning pain unpleasantness" on average in the mornings and afternoons. Participants rated intensity and unpleasantness using a 0 (*none*) to 10 (*as bad as you can imagine*) scale), with higher scores indicating more severe burning pain.

Neuropathic pain component and pain quality was assessed using the Pain DETECT screening questionnaire.[17] Participants indicated the presence of specific pain sensations in their mouths (i.e., burning, tingling, electric shock, numbness, pressure, tactile/thermal allodynia) using a 0 (*never notice*) to 5 (*strongly notice*) scale; pain persistence and attack patterns via selecting the most representative of four graphical representations (scored -1 to 1); and radiating pain (*no*(0)/*yes*(2)). Items were summed to create a total score (α=0.785), with higher scores indicating more neuropathic pain components.

Laboratory assessment of pain

Detailed laboratory testing procedures for this study have been previously reported,[12] and are summarized here.

Sensory detection thresholds were assessed twice (morning, afternoon). Thresholds were determined for warmth (WDT) and cool (CDT) using the PATHWAY model CHEPS (Contact

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Heat-Evoked Potential Stimulator) from Medoc Advanced Medical Systems Ltd. (Ramat Yishai, Israel). Starting from a baseline temperature of 32°C, participants experienced gradually increasing or decreasing temperatures. Participants indicated threshold and simultaneously stopped the stimulus via computer mouse. Each procedure was repeated three times at two body sites (forearm, cheek). Detection thresholds were operationalized as the average °C at which participants first perceived a change in temperature.

Pain thresholds were assessed during the morning and afternoon. Heat pain thresholds (HPT) were determined using the same procedure as sensory detection and were operationalized as the average °C at which participants first experienced pain. Pressure pain thresholds (PPT) were assessed using a Wagner Force Dial tm FDK 10 /FDN Series Push Pull Force Gage pressure algometer applied to bilateral sites at four body locations (muscle bellies of the temporalis and masseter, elbow, thumbnail). Three trials were performed at each site, and PPT was operationalized the pressure (kPa) at which participants first felt pain, reported via hand raise. Averages were taken across the six bilateral trials for each of the four body locations.

Suprathreshold pain was assessed during the morning and afternoon using painful heat delivered to the forearm as above. Participants completed two trials, each including stimuli that started from a baseline (32°C), had a fixed 1.6 second ramp time (and variable ramp rate, accordingly), and sustained (6 second) target temperature stimulation. Participants provided intensity [0 (*no pain*) to 10 (*extremely intense pain*)] and unpleasantness [0 (*not bothersome*) to 10 (*extremely bothersome pain*)] ratings during the 20 second inter-stimulus interval. The two trials differed only in the number and order of stimuli presented. All participants experienced the same series of stimuli. No participants chose to discontinue/stop this procedure. The first trial involved a fixed series of 8

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stimuli in ascending order (35°, 35°, 39°, 41°, 43°, 45°, 47°, 49°C), and the second a series of 19 stimuli ranging from 39-49°C presented in a fixed pseudo-random order.

Averages were calculated across the two trials at each time point to obtain an overall pain intensity score for each participant in the morning and afternoon. For each trial, pain intensity ratings for all stimuli using the same target temperature were first averaged, a total within-trial average across temperatures was calculated, and then within-trial averages combined. This calculation was repeated for morning and afternoon pain unpleasantness.

Pain 6 differentially captures suprathreshold pain as the *stimulus* intensity (°C) corresponding to a subjective pain intensity rating of "6" across suprathreshold testing sessions.

Analyses

All analyses were conducted in IBM SPSS version 27. First, internal reliability was calculated using raw data for all scales and subscales (Spearman-Brown coefficient (ρ) for 2-item scales, Cronbach's coefficient (α) for all other scales).[18] Then, distributions were examined for normality using the Shapiro-Wilk test. Variables with skewed distributions were log transformed to reduce the skew [when minimum values were ≤0, a consistent whole number was added to all observations to support log transformations, in the case of negatively skewed distributions, the reflection procedure was applied before log transformation]. Similar to a previous investigation in a different population,[3] the distribution of scores for the two-item racialized discrimination scale was bimodal. Thus, this variable was dichotomized to represent those who have experienced racialized discrimination from doctors, and those who have not.

Descriptive analyses were conducted to characterize the sample and to determine the prevalence and severity of stigma and discrimination in this sample of women with BMS.

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Association between primary predictors and demographic measures were also probed for potential confounding. Exploratory analyses included probing of simple bivariate associations (point-biserial correlations in the case of dichotomous discrimination variables, Pearson product moment correlations otherwise) to determine relationships between stigma and discrimination with pain. Due to the exploratory nature of this study, all associations are reported in Table 1 without alpha-adjustment. However, only statistically significant associations with primary measures (omnibus scores) are reported in the Results.

Missing data

There are three sources of missing data. One participant did not complete the neuropathic pain questionnaire, one completed only one visit (missing afternoon laboratory pain), and one is missing morning suprathreshold pain (due to response error-related missing values for 45°C and 49°C stimuli).

Results

Sample characteristics

The present analysis sample includes 16 postmenopausal women with BMS, ranging in age from 47-74 years (M=60.56, SD=6.044). One participant identified as Latinx/Hispanic, one as Asian, and all others (87.5%) as White. All participants had at least a high school education (highest level of education: high school diploma (25%), some college (37.5%), a bachelor's degree (25%), a master's degree (6.25%), or doctoral degree (6.25%). The sample represents individuals with diverse BMS histories. At the time of enrollment, participants had been living with BMS between 6 months to 18 years (M=3.6 yrs, SD=4.7), and reported onsets of BMS pain at 41-67.5 years of age (M=56.3 yrs, SD=6.9).

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With the exception of racialized identity – which was associated with racialized discrimination (X^2 (6, N=16)= 32.0, p<.001, such that individuals from racialized groups (n=2) experienced more racialized discrimination in clinical settings, relative to White individuals) – sample characteristics were not associated with primary measures of stigma and discrimination.

Stigma and discrimination prevalence and intercorrelation

Stigma-related and discrimination experiences were common in this sample (Table 1).

Almost all participants had experience with BMS-specific discrimination from doctors (81.3%, M=2.4, SD=.90, with participant experiences ranging from "*1 -never*" to "*4 - usually"*) and some degree of internalized stigma related to their BMS (93.75%; however the mean and range of total scores indicate low agreement with most items M=1.8, SD=.47, range=1 to 2.8). Gender-related stigma-consciousness was also experienced by most participants (87.5%, M=3.4, SD=.95, with responses encompassing almost the full range of the scale: 1.2 to 5.2). And though less common in this sample, 25% (M=1.2, SD=.45, range=1 to 2.5) of participants, and 100% of those with racialized identities (n=2; M=2.3, SD=.35, range=2 to 2.5) also experienced racialized discrimination from their doctors.

Relationship between stigma, discrimination, and pain

Clinical pain

Greater internalization of BMS stigma was associated with enhanced clinical pain severity and interference, and notably also with morning burning pain (intensity and unpleasantness) and afternoon burning pain unpleasantness (Table 1).

Sensory detection thresholds

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Greater internalization of BMS stigma was also associated with higher CDTs on the cheek, but not the forearm in the afternoon. In contrast, greater internalization of BMS stigma was associated with lower WDT on the forearm in the morning, but not cheek. Due to the bimodal distribution of racialized discrimination scores, we probed associations between racialized discrimination in clinical settings and pain by comparing pain measures between those with and without racialized discrimination experiences in clinical settings. Racialized discrimination from doctors was associated with higher WDTs on the cheek in the morning.

Pain thresholds

Greater gender-based stigma consciousness was associated with lower HPTs on the cheek in both morning and afternoon. Racialized discrimination from doctors was associated with lower PPT on the elbow in the afternoon. In contrast, BMS-discrimination from doctors was associated with higher PPT on the face (i.e., masseter am only, temporalis am & pm).

Suprathreshold pain

There were no statistically significant associations with suprathreshold pain intensity, unpleasantness, or Pain 6, even after controlling for age and race.

Discussion

This is the first study to quantitatively examine social-contextual factors in BMS. Results indicate a high prevalence of internalized BMS stigma, experience of BMS-related discrimination, and gender stigma consciousness in this population. Importantly, results suggest that disease-related discrimination from medical providers is part of the lived experience of BMS. Moreover, results provide initial evidence that these experiences are related to pain outcomes. The most robust

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pattern of findings is that internalized BMS stigma was related to greater clinical pain severity, interference, intensity, and unpleasantness.

Results of this study are intended to support future research and should be interpreted cautiously. Limitations include the small sample size, limited scope of measures of social context (future qualitative research may more richly capture these experiences), and limited sample diversity. The current sample is primarily white and highly educated. Racialized discrimination was reported by all non-white participants and should be explored in future representative samples. Finally, inferences are constrained by broader sociocultural context. This study was conducted in the U.S., where BMS is particularly underdiagnosed relative to other countries.[19] Cultural injustice that leads to invalidation of women's pain likely contributes to underdiagnosis and a consequent paucity of research on this not-so-rare condition.[7] Structural injustice and racialized health care disparities are also relevant considerations for future research. Perspectives that may be applied to support future research include the injustice model of pain disparities[5] and consideration of intersectionality[20] (e.g., considering specific experiences of diagnoses that primarily affect people with multiple minoritized identities).

In conclusion, the experience of stigma and discrimination are part of the lived experience of BMS that appear to be compounded in clinical contexts. Adding to prior evidence that women's pain is undermined, that pains that primarily effect women may be specifically stigmatized, and that this stigma contributes to the inferior and inadequate management of the pain of women on average,[7] the present results indicate that this stigma is internalized and may influence the pain experience.

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