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The social context of burning mouth syndrome: an exploratory pilot study of stigma, discrimination, and pain

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Abstract

Background: 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 thereof), and intersectional identities.

Objective: 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.

Methods: Participants completed self-report measures of stigma, discrimination, and pain, as well as laboratory assessments of pain through quantitative sensory testing.

Results: 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.

Conclusion: Given the prevalence and pain-relevance of intersectional stigma and discrimination identified in this pilot study, lived experience and social context should be incorporated into future research on BMS.

Keywords: orofacial pain; pain invalidation; chronic pain stigma; discrimination; Burning Mouth Syndrome; social modulation of pain

Introduction

Burning mouth syndrome (BMS) is a chronic pain condition characterized by burning orofacial pain. The etiology of primary BMS is poorly understood, the diagnosis is complex and involves elimination of secondary causes, and significant individual differences exist in treatment efficacy.[1–3] Recent estimates indicate a prevalence of approximately 3% in the general population and 18% among postmenopausal women, though BMS commonly goes undiagnosed.[4] Lived experiences of BMS often include discrimination in clinical settings and stigma due to intersectional identities as postmenopausal women (eg, having pain dismissed as "hot flashes" or anxiety-induced)[5]; however, this social context has not been considered in studies of BMS pain.

Prior research in other populations has demonstrated that generalized chronic pain injustice and racialized discrimination are associated with enhanced clinical pain, mechanisms of pain facilitation, and inequitable pain management.[6–8] Gendered stereotypes (eg, women as overly emotional and unreliable reporters of their own pain experience) impair the quality of pain treatment women receive.[9–11] *Stigma* refers to convergence of cultural labels, stereotypes, discrimination, and social oppression that leads to unjust distribution of experiences and opportunities, and it is increasingly recognized as a social determinant of health disparities.[12] People living with BMS likely experience compounding effects of intersecting stigmas of the pain of women, age, chronic pain generally, and orofacial pain conditions, in addition to processes of stigmatization related to other markers of social status (eg, racism).[9,10,11,13,14,15,16]

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

Methods

Data for this study were drawn from a parent study on BMS pain. The detailed recruitment and study procedures, as well

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as the pain profiles for these participants, have been reported elsewhere.[2] In brief, study visits started with self-reported pain questionnaires, followed by 2 separate laboratory pain testing sessions, and then ended with completion of measures of stigma and discrimination. Because of the circadian pattern of pain in BMS type I (ie, the tendency to experience more BMS pain later in the day relative to the morning), most pain assessments were conducted twice: in a morning session 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 institutional review board approved, and all participants provided written informed consent.

Data extraction

All variables representing the constructs of stigma (ie, internalized stigma, stigma consciousness) and discrimination (ie, 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 present aims.[2]

Participants

Eligible potential participants for the parent study were identified at an oral medicine clinic led by co-author T.F.M.[2] Individuals between the ages of 40 and 85 years meeting the diagnostic criteria for BMS type I between the years of 2014 and 2018 were invited to participate. Exclusion criteria included other comorbid orofacial conditions and the daily use of medications expected to confound results (ie, opioids, systemic medications, hormone replacement therapy). Eighteen women with BMS enrolled in the parent study conducted in Baltimore, MD, United States. Two participants were not administered the measures of stigma and discrimination (because of time constraints), 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 with the Internalized Stigma of Chronic Pain scale,[17] which consisted of 21 items (eg, "I am embarrassed or ashamed that I have chronic pain"), with response options ranging from 1 (strongly disagree) to 4 (strongly agree). The Internalized Stigma of Chronic Pain scale was originally validated among adults between the ages of 18 and 86 years living with chronic pain. Participants in the present study were instructed to respond to each item with regard to their BMS specifically. Total ($\alpha = 0.928$) and subscale scores (ie, alienation [$\alpha = 0.865$], discrimination experience [$\alpha = 0.890$], social withdrawal [$\alpha = 0.907$], and resistance [reverse-scored, $\alpha = 0.422$]) 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 ≥ 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 with the Stigma Consciousness Questionnaire.[18] The gender-based Stigma Consciousness Questionnaire was originally validated among college-aged women, but it has been modified to examine other stigmatized identities, including older age, and has been used previously in populations with chronic pain.[18–21] The Stigma Consciousness Questionnaire has 10 items (eg, "Stereotypes about women have not affected me personally," reverse-scored) to which participants respond on a scale of 0 (strongly disagree) to 6 (strongly agree). However, one item was inadvertently duplicated ("My being female does not influence how people act with me"), and one similarly phrased item consequently was omitted ("My being female does not influence how men act with me"). Therefore, after removal of the duplicate item, the present results reflect the average of 9 items, with acceptable internal reliability ($\alpha = 0.711$). After reverse scoring, a total score was calculated as an average, with higher scores indicating greater degrees of stigma consciousness. To estimate the 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 with the discrimination subscale of the short-form Interpersonal Processes of Care survey (IPC-18).[22] The IPC-18 was originally validated among Latinx, Black, and White adults between the ages of 21 and 81 years in a primary care setting, and it has been used in other populations with chronic pain.[6,22] Participants responded to each item on a scale of 1 (never) to 5 (always). 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 ($\rho = 0.870$). We created 2 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 ($\rho = 0.806$). 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 response ≥ 2) was considered indicative of some degree of experience with discrimination from doctors.

Self-report measures of pain

Clinical pain severity was assessed with the Brief Pain Inventory.[23] Participants reported their current pain ("right now"), as well as their worst, least, and average pain over the prior week on a scale of 0 (no pain) to 10 (pain as bad as you can imagine). These 4 items were averaged to create the pain severity score ($\alpha = 0.912$), where higher scores indicate more severe pain.

Clinical pain interference was also assessed with the Brief Pain Inventory. Participants rated the degree to which their pain interfered with daily functioning and activities on a scale of 0 (does not interfere) to 10 (completely interferes). Responses to the 7 interference items were averaged to create the pain interference score ($\alpha = 0.946$), with higher scores indicating more pain interference.

Burning pain severity was assessed with 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 on a scale of 0 (none) to 10 (as bad as you can imagine), with higher scores indicating more severe burning pain.

Neuropathic pain component and pain quality were assessed with the Pain DETECT screening questionnaire.[24] Participants indicated the presence of specific pain sensations in their mouths (ie, burning, tingling, electric shock, numbness, pressure, tactile/thermal allodynia) using a 0 (never notice) to 5 (strongly notice) scale; pain persistence and attack patterns by selecting the most representative of 4 graphical representations (scored –1 to 1); and radiating pain (no [0] / yes [2]). Items were summed to create a total score ($\alpha = 0.785$), with higher scores indicating more neuropathic pain components.

Laboratory assessment of pain

Detailed laboratory testing procedures for this study have been previously reported[2] and are summarized here.

Sensory detection thresholds were assessed twice (morning and afternoon). *Warm detection threshold* and *cool detection threshold* were determined using the PATHWAY model CHEPS (Contact 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 the threshold and simultaneously stopped the stimulus via computer mouse. Each procedure was repeated 3 times at 2 body sites (forearm and cheek). Detection thresholds were operationalized as the average degrees Celsius at which participants first perceived a change in temperature.

Pain thresholds were assessed during the morning and afternoon. *Heat pain thresholds* were determined with the same procedure as sensory detection and were operationalized as the average degrees Celsius at which participants first experienced pain. *Pressure pain thresholds* were assessed through the use of a Wagner Force Dial tm FDK 10/FDN Series Push Pull Force Gage pressure algometer applied to bilateral sites at 4 body locations (muscle bellies of the temporalis and masseter, elbow, thumbnail). Three trials were performed at each site, and pressure pain threshold was operationalized as the pressure (in kilopascals) at which participants first felt pain, reported via a hand raise. Averages were taken across the 6 bilateral trials for each of the 4 body locations.

Suprathreshold pain was assessed during the morning and afternoon via painful heat delivered to the forearm, as described previously. Participants completed 2 trials, each including stimuli that started from a baseline (32°C) and 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 interstimulus interval. The 2 trials differed only in the number and order of stimuli presented. All participants experienced the same series of stimuli. No participants chose to discontinue or stop this procedure. The first trial involved a fixed series of 8 stimuli in ascending order (35°, 35°, 39°, 41°, 43°, 45°, 47°, 49°C), and the second consisted of a series of 19 stimuli ranging from 39–49°C presented in a fixed pseudorandom order.

Averages were calculated across the 2 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 were combined. This calculation was repeated for morning and afternoon pain unpleasantness.

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

Analyses

All analyses were conducted in IBM SPSS Statistics for Windows version 27 (IBM Corp., 2020, Armonk, NY, United States). First, internal reliability was calculated from raw data for all scales and subscales (Spearman-Brown coefficient [ρ] for 2-item scales; Cronbach's coefficient [α] for all other scales).[25] Then, distributions were examined for normality with 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,[6] the distribution of scores for the 2-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. Associations 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. Because of 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" section.

Missing data

There are 3 sources of missing data. One participant did not complete the neuropathic pain questionnaire, one completed only one visit (missing afternoon laboratory pain), and one was missing morning suprathreshold pain (because of response error–related missing values for the 45°C and 49°C stimuli).

Results

Sample characteristics

The present analysis sample includes 16 postmenopausal women with BMS, ranging in age from 47 to 74 years (mean = 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

Table 1. Stigma and discrimination prevalence and association with pain in BMS .

	BMS stigma internalization					BMS discrimination	Racialized discrimination	Gender stigma consciousness
	Average	Alienation	Discrimination experience	Social withdrawal	Stigma resistance			
Prevalence (% any)	93.75%	75.00%	18.75%	62.50%	18.75%	81.30%	25.00%	87.50%
Clinical pain								
Severity	.615*	.471	.378	.633**	.550*	–.059	.100	–.085
Interference	.598*	.449	.427	.609*	.463	–.050	.068	–.067
Burning pain intensity								
Morning	.530*	.741**	.006	.004	–.014	.156	–.054	–.118
Afternoon	.427	.294	–.134	–.022	–.019	.021	–.202	–.115
Burning pain unpleasantness								
Morning	.728**	.770**	.104	.003	–.167	.117	.041	.161
Afternoon	.577*	.390	–.083	–.075	–.083	–.065	–.089	.035
Neuropathic pain components	.053	.121	–.139	.053	.180	–.117	–.016	–.276
Sensory detection thresholds								
Warm								
Cheek								
Morning	.077	.092	–.093	.012	.414	.087	.594*	–.406
Afternoon	–.004	–.001	–.015	–.010	.030	–.477	–.060	–.455
Arm								
Morning	–.580*	–.614*	–.460	–.486	–.207	–.222	–.420	–.129
Afternoon	–.425	–.532*	–.399	–.306	.000	–.049	–.104	–.218
Cool								
Cheek								
Morning	–.283	–.302	–.343	–.175	–.022	.304	–.136	–.183
Afternoon	.542*	.561	.378	.502	.239	–.203	–.169	–.056
Arm								
Morning	.128	.167	.261	.097	–.298	–.173	–.019	.066
Afternoon	.036	.012	.182	.075	–.315	–.049	–.082	–.014
Pain thresholds								
Heat								
Cheek								
Morning	–.137	.018	–.263	–.166	–.012	–.088	–.053	–.599*
Afternoon	.114	.237	–.052	.041	.178	–.259	–.015	–.696**
Arm								
Morning	–.203	–.003	–.160	–.312	–.218	–.024	–.034	–.218
Afternoon	.005	.102	.047	–.044	–.175	–.070	–.140	–.439
Pressure								
Thumb								
Morning	.264	.262	.092	.320	.120	.296	–.382	–.101
Afternoon	.336	.459	.023	.339	.152	.289	–.451	–.141
Elbow								
Morning	.297	.229	.191	.394	.039	.299	–.445	.046
Afternoon	.266	.349	.007	.328	.027	.189	–.555*	–.178
Masseter								
Morning	.349	.314	.148	.414	.202	.508*	–.330	.072
Afternoon	–.104	–.261	–.296	.046	.407	.171	–.204	.042
Temporalis								
Morning	.390	.359	.194	.438	.214	.526*	–.309	.104
Afternoon	.388	.386	.101	.417	.296	.556*	–.272	.119
Suprathreshold pain								
Intensity								
Morning	–.030	–.112	.103	–.006	–.103	–.021	.208	.114
Afternoon	–.109	–.163	–.134	–.022	–.019	–.202	.021	–.188
Unpleasantness								
Morning	–.027	–.098	.142	–.001	–.204	.053	.134	.290
Afternoon	–.157	–.208	–.084	–.075	–.202	–.089	–.065	.103
Pain 6	.055	–.012	.305	.074	–.368	–.039	–.055	.037

Abbreviation: BMS = burning mouth syndrome.
* $P < 0.05$.
** $P < 0.01$.
Unless otherwise noted, values represent effect sizes of the simple bivariate associations (point-biserial correlations in the case of dichotomous discrimination variables; Pearson product moment correlations otherwise).
Clinical pain was assessed with the Brief Pain Inventory (Clinical Pain Severity and Interference), Pain DETECT (neuropathic pain components), and face-valid items probing BMS symptoms (burning pain intensity and unpleasantness). Quantitative sensory testing methods were used to assess sensory detection thresholds, pain thresholds, and suprathreshold pain.

[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 and 18 years (mean = 3.6 years, SD = 4.7) and reported onsets of BMS pain at 41–67.5 years of age (mean = 56.3 years, SD = 6.9).

With the exception of racialized identity—which was associated with racialized discrimination (χ^2 [6, $n = 16$] = 32.0, $P < 0.001$, such that individuals from racialized groups [$n = 2$] experienced more racialized discrimination in clinical settings, relative to White individuals)—sample characteristics (ie, age, education, BMS onset, BMS duration) 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%, mean = 2.4, SD = 0.90, 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 [mean = 1.8, SD = 0.47, range = 1–2.8]). Gender-related stigma-consciousness was also experienced by most participants (87.5%, mean = 3.4, SD = 0.95, with responses encompassing almost the full range of the scale: 1.2–5.2). Though less common in this sample, 25% (mean = 1.2, SD = 0.45, range = 1–2.5) of participants and 100% of those with racialized identities ($n = 2$; mean = 2.3, SD = 0.35, range = 2–2.5) also experienced racialized discrimination from their doctors.

Relationship among stigma, discrimination, and pain

Clinical pain

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

Sensory detection thresholds

Greater internalization of BMS stigma was also associated with higher cool detection thresholds on the cheek but not the forearm in the afternoon. In contrast, greater internalization of BMS stigma was associated with lower warm detection thresholds on the forearm but not cheek in the morning. Because of 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 warm detection thresholds on the cheek in the morning.

Pain thresholds

Greater gender-based stigma consciousness was associated with lower heat pain thresholds on the cheek in both morning and afternoon. Racialized discrimination from doctors was associated with lower pressure pain thresholds on the elbow in the afternoon. In contrast, BMS-related discrimination from doctors was associated with higher pressure pain thresholds on the face (ie, masseter morning only; temporalis morning and afternoon).

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 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 capture these experiences more richly), and limited sample diversity. The present sample is primarily White and highly educated. Racialized discrimination was reported by all non-White participants and should be explored in future representative samples. Experiences of ageism, age stigma, and age discrimination were not assessed but are likely common in this population and should be examined in future studies.[15,16,26] Finally, inferences are constrained by broader sociocultural context. This study was conducted in the United States, where BMS is particularly underdiagnosed relative to other countries.[27] 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.[10] 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[8] and consideration of intersectionality[15,28] (eg, considering specific experiences of diagnoses that primarily affect people with multiple minoritized identities).

In conclusion, the experiences 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 affect women are specifically stigmatized, and that this stigma contributes to the inferior and inadequate management of the pain of women on average,[10] the present results indicate that this stigma is internalized and may influence the pain experience.

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Data availability

The raw data that support the findings of this study will be made available upon reasonable request.

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