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Support Group as a Management Modality for Burning Mouth Syndrome: A Randomized Prospective Study

Talia Becker ^{1,*}, Yafit Hamzani ^{2,†}, Gavriel Chaushu ^{2,3,4}, Shlomit Perry ⁴ and Bahaa Haj Yahya ⁵

¹ Department of Oral Medicine, Defense Forces Medical Corps, Tel Hahsomar 5262000, Israel

² Department of Oral and Maxillofacial Surgery, Rabin Medical Center, Beilinson Hospital, Petach Tikva 4941492, Israel; yafitha@clalit.org.il (Y.H.); gavrielce@clalit.org.il (G.C.)

³ Department of Oral and Maxillofacial Surgery, Sackler Faculty of Medicine, The Goldschleger School of Dental Medicine, Tel Aviv University, Tel Aviv 6997801, Israel

⁴ Rabin Medical Center, Beilinson Hospital, Petach Tikva 4941492, Israel; perryshlomit@gmail.com

⁵ Oral and Maxillofacial Private Clinic, Herzliya 4672211, Israel; bahaa.hag@gmail.com

* Correspondence: becktalia@gmail.com

† The first two authors contributed equally to this manuscript.

Abstract: We aimed to investigate the effectiveness of a support group in the management of burning mouth syndrome (BMS). The cohort included 22 adult patients with BMS who attended the oral and maxillofacial department of a tertiary medical center in 2014–2019 and agreed to participate in the study. Eleven patients were assigned to a support group and took part in 90 min sessions held once weekly for 4 weeks (a total of 4 sessions), and the remainder continued their previous individual BMS management routine (control group). All patients completed a life-quality questionnaire before and 3 months after the group sessions. Scores for each group were compared between the two time points with a Wilcoxon signed-rank test. There was a significant decrease in scores for malaise ($p = 0.041$), total pain ($p = 0.046$), and difficulty enjoying food ($p = 0.026$) before and after the group sessions in the study group. No significant changes were found in the control group in any of the parameters examined. A group support can alleviate pain and other clinical symptoms of BMS. Further longer-term prospective studies are needed to corroborate our findings.

Keywords: burning mouth syndrome; support group; life-quality questionnaire



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1. Introduction

Burning mouth syndrome (BMS) is an idiopathic intraoral chronic pain condition without abnormal clinical or laboratory findings. The symptoms described in the scientific literature are nonspecific and include, in addition to burning pain, dysgeusia, dysesthesia, loss of taste, and paraesthesia [1,2]. The disorder has no specific histological features, so biopsy does not contribute to diagnosis.

There is no scientific agreement regarding the classification of BMS. Scala et al. have suggested two main clinical entities: “primary (true) BMS” and “secondary BMS”. The former refers to idiopathic BMS for which oral or systemic causes cannot be identified, and the latter to a variant that results from pathological conditions [3,4]. “Secondary BMS” may potentially arise from systemic abnormalities such as diabetes, nutritional deficiencies, intake of certain drugs, hormonal alterations, and various infections. Moreover, oral burning may accompany local oral abnormalities such as candidiasis, hyposalivation, allergic reactions, mechanical and chemical irritations, and oral parafunctions [3].

BMS has an estimated prevalence of 0.7–7% in the general population. It usually presents in the fifth to seventh decades of life [1,2,5,6] and is seven times more common in females than males [7]. The tongue is the most common site involved, although various oral sites may be affected [8–10].

The pathogenesis of BMS is unclear, and it is assumed to be associated with local, neural, inflammatory, and psychological processes. Some studies have specifically implicated hypersensitivity to dental components [11], central mechanisms involving dopamine receptors [12], primary neuropathic dysfunction [7,13], inflammatory cytokine production [14–16], and psychosocial influences, somatization, and psychiatric morbidity [10,17–19]. Despite the absence of causative organic factors, the precise causative role, if any, of psychological factors has not been elucidated [8,17–25].

Various modalities are used in the management of BMS including pharmacological interventions, behavioral therapy, and psychotherapy. However, there is still no definitive effective gold standard [24]. A previous Cochrane review of therapeutic interventions for BMS found that the existing evidence is of insufficient quality to support or refute the benefit of psychological therapies. The authors emphasized that given the potentially disabling nature of BMS, the need to identify effective modes of treatment was vital [26].

To the best of our knowledge, only two studies have focused on the effect of group support on pain and anxiety in patients with BMS [20,25]. Their results suggested that the intervention led to a reduction in pain intensity and anxiety.

The aim of the present study was to further investigate the effectiveness of a support group in the management of BMS. The evaluation tool was a self-report life-quality questionnaire based on a validated questionnaire by Chaushu et al. [27]. Modifications were made to suit the purpose of the study (see Appendix A).

2. Materials and Methods

A prospective comparative study design was used. The database of a tertiary medical center was searched for adult patients with BMS who visited the oral and maxillofacial department with BMS complaints between January 2014 and December 2019. Of the 365 patients identified, 357 were still alive at the time of recruitment for this study. All were contacted by phone to determine if they were interested in participating in the study. After receiving the details of the procedure, 59 responded positively. From among this group, we selected the patients who met the following inclusion criteria: patients diagnosed with “primary BMS” by an oral medicine specialist experienced with the management of BMS, followed for at least 3 months after diagnosis, and who agreed to sign an informed consent form to attend a support group and complete a life-quality questionnaire. All patients also underwent comprehensive anamnesis and clinical and laboratory evaluations prior to the study, as is customary for BMS patients in the department. Patients with a doubtful diagnosis or whose symptoms potentially arose from systemic or local abnormalities were excluded. The final study cohort consisted of 22 patients. The selection process for the study is shown in Figure 1.

The study protocol was approved by the institutional Helsinki Committee (approval number 0131-19-RMC).

The study cohort was randomly divided into two arms by simple randomization method (by flipping a coin). Eleven patients were allocated to take part in support sessions (study group), and the remainder continued with their previous individual BMS management routine (control group). Cognitive therapy and consultation were introduced as valid options in the management of BMS; however, the control group members were not actively assigned for such supportive care as were the members of the study group.

Support group sessions were held once weekly for four weeks. Each session lasted 90 min. All meetings were conducted by a social worker (S.P.) and an oral medicine specialist (T.B.). In the first meeting, patients received information from the oral medicine specialist about the epidemiology, suspected etiologies, management, and treatments for BMS followed by a discussion of the assumed psychological, behavioral and social aspects of the disorder and the basic principles of pain physiology. The group members then introduced themselves and shared their personal experience with BMS. In the second meeting, the oral medicine specialist answered patients’ questions about the disorder, and the patients discussed assumed triggers of the oral symptoms. The third meeting

was dedicated to a discussion of the different ways in which the members of the group cope with BMS, including physical activity (including yoga, dancing class, Tai Chi, etc.), mindfulness-based meditation, and medication therapy. The social worker and the oral medicine specialist provided information on possible options of management and pain relief methods from the scientific literature, including cognitive therapy. In the fourth meeting, patients discussed their impressions of the group therapy and how, as a result of their participation, they now related to their symptoms.

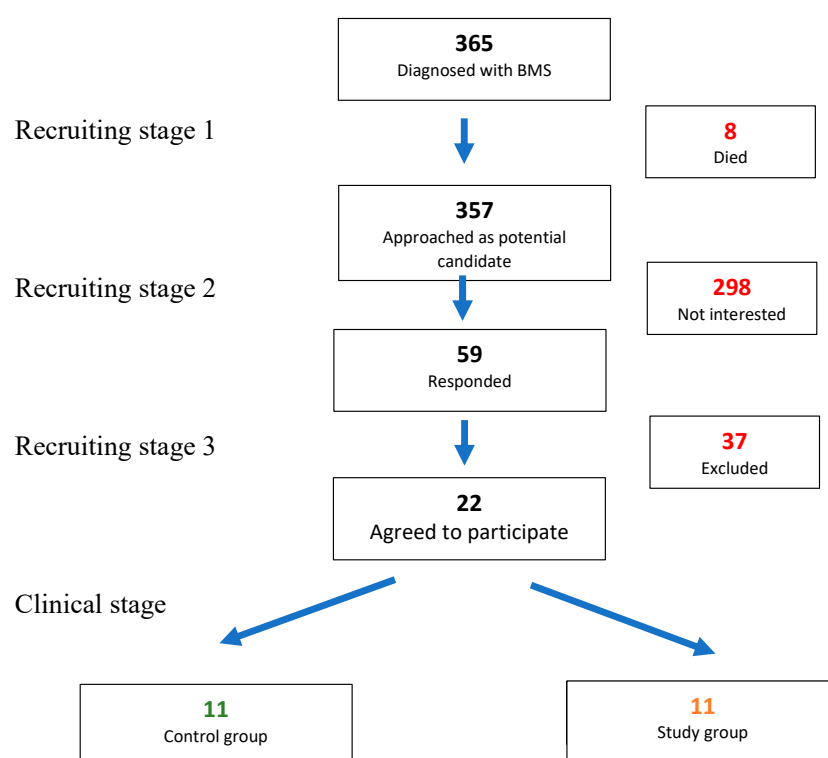


Figure 1. Patient recruitment procedure.

The intensity of symptoms and the degree to which they disrupted the patients' daily life activities were evaluated with an 11-item self-report life-quality questionnaire based on the validated questionnaire by Chaushu et al. [27], with some modifications to suit the purpose of the study (see Appendix A). Pain was ranged between 1 and 10: 1–3 = slight pain, 4–7 = moderate pain, and 8–10 = severe pain. Other evaluated parameters were ranged between 1 and 5, as 1–3 considered acceptable and 4–5 considered poor regarding the patient's subjective assessment of life-quality. The questionnaire was completed by both groups before the sessions and again 3 months after their conclusion. Responses were compared between the two time points for each group.

The statistical analysis was generated using IBM SPSS Statistics software for Windows, version 25. Longitudinal data were compared with the nonparametric test Wilcoxon signed-rank test because of the limited sample size. Nominal and categorical variables were compared using cross tabs (chi-square) tests. Mann–Whitney non-parametric test was used to compare the examined parameters between the two groups. Two-sided p values < 0.05 were considered statistically significant.

3. Results

The study cohort consisted of 17 female (77%) and 5 male patients of mean age 66.86 (SD = 10.25) years. Comparison of the questionnaire responses between the two time points showed that in the patients who attended the support sessions, scores were improved for all 11 parameters evaluated, whereas in the control group, scores were improved for only six parameters (Table 1). The improvement in the study group was statistically

significant (Wilcoxon signed-rank test) for malaise ($p = 0.041$), total pain ($p = 0.046$), and difficulty enjoying food ($p = 0.026$). In the control group, none of the differences were statistically significant.

Table 1. Change in study parameters in patients with BMS who attended a support group (study group) and patients who did not (control group).

Study Parameter	Study Group		<i>p</i> Value *	Control Group		<i>p</i> Value *
	Before Interv.	After Interv.		Before Interv.	After Interv.	
Total pain score	2.36 (1.027)	2 (1)	0.046	1.73 (1.009)	1.6 (0.516)	0.655
Medication use	2 (1.612)	1.55 (0.688)	0.276	1 (0)	1.2 (0.632)	0.317
Swallowing problems	1.64 (1.286)	1.27 (0.647)	0.194	1.55 (1.293)	1.7 (1.160)	0.180
Avoidance of certain foods	2.36 (1.690)	1.64 (1.027)	0.129	2.18 (1.601)	2.5 (1.434)	0.336
Difficulty enjoying food	2.55 (1.809)	1.64 (0.924)	0.026	2.45 (1.440)	1.8 (0.789)	0.131
Difficulty talking	1.64 (0.924)	1.64 (0.924)	0.063	1.64 (1.206)	1.3 (0.949)	0.317
Sleep deprivation	2.09 (1.700)	1.09 (0.302)	0.066	1.55 (1.036)	1.4 (0.843)	0.705
Inability to work	1.36 (1.206)	1 (0)	0.317	1 (0)	1 (0)	1.000
Difficulty performing everyday activities	1.18 (0.405)	1.09 (0.302)	0.317	1 (0)	1 (0)	1.000
Change in taste or odor sensation	2.55 (1.572)	2.09 (1.514)	0.461	2.55 (1.695)	2.4 (0.966)	0.864
Malaise	2.64 (1.502)	1.82 (1.079)	0.041	2.18 (1.537)	2.1 (1.101)	0.854

Note: Parameters were evaluated by questionnaire before onset of group therapy and 3 months after its completion. All values are mean (SD). * Wilcoxon sum-rank test. Values in bold are statistically significant. BMS, burning mouth syndrome; Interv., intervention. *p* value (probability value) ≤ 0.05 was considered statistically significant.

4. Discussion

Burning mouth syndrome is a diagnosis of exclusion. The exact pathophysiology is quite elusive, and so is the etiology. Hence, the management is challenging, and no definitive gold standard has been introduced. The aim of the present study was to evaluate the utility of support group sessions in the management of BMS.

Persistent psychological stress triggers physiological responses in the nervous and immune systems, leading to disruptions in neuroendocrine, neurotransmitter, and neuroanatomical processes. These responses have been elicited under laboratory conditions. The implication of these changes for future health has become an important topic of psychoneuroimmunological research [28]. Studies have shown that cognitive behavioral therapy can lead to normalization of stress-induced neural activity in individuals with a range of anxiety disorders already very early in treatment and relative to a control group [29–32]. According to emerging evidence, the outburst of the COVID-19 pandemic has triggered worsening of anxiety, sleep quality, and pain intensity in BMS patients [33]. It should be mentioned that our study took place shortly before the curfews caused by the COVID-19 eruption in the country.

Ongoing pain can lead to poor sleep quality, mood disturbances, maladaptive behaviors, and ineffective coping strategies, making psychological interventions a logical management modality [34]. Support groups serve an important function in patients affected by a disease, especially a rare disease [35]. Positive effects have been reported in patients with Wilson disease [35], vitiligo [36], lumbar spine fusion [37], and cancer [38–41]. To the best of our knowledge, no opposing evidence has been reported. Support group participants are more often female [41], as demonstrated in our study as well. One of the main benefits of group therapy is the opportunity it provides for social comparison and delivery of targeted education and consistent counselling. Patients report an increase in knowledge, understanding, and confidence in self-managing their pain [42]. In the present study, one of the most prevalent themes discussed by the group members was their unawareness that BMS was a recognized phenomenon. Consequently, they felt exceptional for experiencing BMS symptoms.

The association between traumatic life events and BMS is not well established [20,43]. In the study of Miziara et al. [20], all patients who took part in psychological interviews reported family or personal losses just before the onset of BMS symptoms. This was true

with some of our patients as well. Among the issues discussed in the group sessions were death of a brother or sister (2 patients), a son who became religious and was estranged from the family (1 patient), and cancer in a significant other (2 patients). Although these events may have triggered the patients' symptoms, it should be noted that BMS generally occurs in the fifth to seventh decades of life when the likelihood of loss or illness of an older family member considerably increases. Further studies are needed establish the possible association between BMS and stressful life events.

Several studies have focused on the effect of mental support on pain and anxiety in patients with BMS. Bergdahl et al. [21] reported a significant reduction in pain intensity in patients with BMS who underwent cognitive therapy compared to patients who did not (15 in each group). Using a similar design with a slightly larger cohort, Miziara et al. [20] reported significant improvement of pain symptoms in the study group. Komiya et al. [25] compared the effect of cognitive-behavioral group therapy between patients with BMS and healthy controls (24 in each group). The results suggested that the intervention led to a reduction in pain intensity and anxiety in the patients. By contrast, in the present study, we used a unique evaluation tool based on the validated questionnaire developed by Chaushu et al. [27] (see Appendix A). In addition to pain, we examined the manner in which BMS symptoms interfere with different aspects of everyday life activities such as swallowing, enjoying food, speaking, sleeping, studying or working, and general well-being. An improvement was noted in all tested parameters after the intervention, with statistically significant reductions in pain intensity, difficulty enjoying food, and malaise. Studies have shown that self-efficacy as well as sense of control are important for effective coping with chronic pain [44] and that changing patients' approach to pain from passive to active helps them to better deal with it [45].

The major limitation of this study was the small number of participants. Nevertheless, significant improvement was found in several of the parameters evaluated, which is encouraging. Our findings suggest that group support may serve as an effective modality in the management of BMS. Further investigation is warranted in larger prospective longer-term studies with collaboration among several medical institutions.

5. Conclusions

Our results raise the possibility that along with pain intensity, symptoms such as malaise and difficulty enjoying food are highly influenced by self-efficacy tools such as a support group. A group support can alleviate pain and other clinical symptoms of BMS. Further longer-term prospective studies are needed to corroborate our findings.

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Informed Consent Statement: Written and oral informed consent was provided by the participants.

Data Availability Statement: All data generated or analyzed during this study are included in this published article.

Conflicts of Interest: The authors declare no conflict of interest.

Appendix A. Life-Quality Questionnaire

Dear patient,

In order to improve the quality of care we provide for our patients, we ask you to take a few minutes to complete this survey on the manner in which burning mouth syndrome affects your quality of life.

Please choose the number that corresponds most closely to your experience during the past 24 h.

Rate the worst pain you have felt during the past 24 h on a scale from 1 to 10.

1–3 = slight pain, 4–7 = moderate pain, 8–10 = severe pain

For the following questions, please rate your response on a scale of 1 to 5 as shown.

Have you taken medication to relieve pain today?

1 = not at all, 2 = very little, 3 = some, 4 = quite a lot, 5 = a lot

Has it been difficult to swallow today?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite difficult, 5 = very difficult

Have you found it difficult to eat certain foods today?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite difficult, 5 = very difficult

Have you experienced difficulty in enjoying your food today?

1 = not at all, 2 = very little, 3 = some, 4 = quite a lot, 5 = very much

Has speech been difficult today?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite difficult, 5 = very difficult

Was it difficult to sleep last night?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite difficult, 5 = very difficult

Did you miss school/work today?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite a lot, 5 = very much

Has it been difficult to continue your daily activities today?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite difficult, 5 = very difficult

Have you had a bad taste or bad smell in your mouth today?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite bad, 5 = very bad

Has there been any malaise today?

1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite a lot, 5 = severe

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