Original Article

Effectiveness of the Intervention using Group Empowering Self-management on Patients with Burning Mouth Syndrome

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Background: Burning mouth syndrome (BMS) is characterized by intense chronic burning sensation of the tongue or other regions of the oral mucosa. Patient empowerment is a mechanism to help patients with long-term conditions to better manage their health and achieve better outcomes.

Objective: To evaluate the effective measures of the one-day group-based empowerment activities on patients with primary BMS.

Materials and Methods: The study was based on a self-completed questionnaire as a measure to assess the efficacy of group empowering self-management. The authors distributed questionnaires before and after the one-day group-based empowerment activities, which comprised a 30-minute talk to understand BMS in general, an experience sharing session between BMS patient representatives and dentists and a whole group discussion as interactive dialogue among all BMS patients. Measurement parameters included VAS for burning intensity, knowledge and attitudes, and catastrophizing thoughts. Paired samples t-test was used for statistical analysis to compare each parameter of before and after the one-day group-based empowerment activities.

Results: Twenty-three BMS patients (20 females, 3 males, and age 60.6±10.4 years) participated in one-day group-based empowerment activities. Patients reported 3.3±2.6 years of suffering from BMS. Initial assessments reveal a significant increase of patient understanding to BMS condition, whereas there is a reduction of burning intensity (from 3.9±3.3 to 3.5±2.0). Significant difference in total pain catastrophizing score was observed ($p<0.05$).

Conclusion: Initial assessments suggest that the one-day group-based empowerment activities improve patient understanding and ability to cope with pain. BMS remains a challenge to clinicians and researchers. Patients should be made aware that the symptoms might not totally resolve even after long-term treatment. Patient education and support group play a key role to successful management.

Keywords: Burning mouth syndrome, Empowerment, Self-management, Pain catastrophizing

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Burning mouth syndrome (BMS) is characterized by intense chronic burning sensation of the tongue and oral mucosa that have impacts on mental health, as well as social wellbeing and quality of life. According to the International Headache Society, BMS is described as "an intra-oral burning or dysesthetic sensation, recurring daily for more than 2 h/day for more than 3 months, without clinically evident causative lesions(1)". The International Association for the Study of Pain defines BMS as "burning pain of the tongue and/or other oral mucous membrane in the absence of clinical signs or laboratory findings(2)". It is characterized by an intense burning pain or discomfort on the tongue, lips, hard palate, or the entire oral mucosa may be affected, occasionally associated with dysgeusia or xerostomia, without any identifiable organic cause. The prevalence has been estimated at between 0.1 and 3.9% of the general population(3,4) while in the incidence was 11.4 per 100,000 person-years(5). The condition is most commonly found in perimenopausal or post-menopausal women(5). Scala et al have proposed the terms primary BMS as idiopathic or essential condition where no local or systemic cause for the burning can be identified and secondary BMS when an organic local or systemic cause for the intraoral burning sensation is present(6).

Currently, the etiology of BMS is unknown but several theories of the pathogenesis have been proposed over the years. Patton et al. suggested that in a large percentage of patients, BMS probably involves interactions among local,

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systemic, and psychogenic factors(7). However, the etiology related to trigeminal small fiber neuropathy is now favored(8). Anxiety and depression have also been implicated in the development of BMS, by an unknown mechanism(9). The chronicity and the severity of oral burning sensation severely affect the patients psychologically with high reported rates of anxiety, muscular tension and depression in the BMS patients compared to controls(10). Moreover, cancerphobia, a type of anxiety disorder, was more frequently seen in patients with BMS than in those with other types of orofacial pain(11). The management of burning pain in BMS patients requires multidisciplinary team as many studies have shown a close correlation between symptoms and psychological factors. The intervention using empowering self-management is viewed by policy makers and health care practitioners as a mechanism to help patients with long-term conditions better manage their health and achieve better outcomes. The authors conducted a one-day empowering self-management activity for BMS patients and to assess the effects of a group-based, patient-centered training on their knowledge, attitudes and pain catastrophizing thoughts.

Materials and Methods

The present study was approved by the ethics committee in Human Research of Khon Kaen University (No. HE622220). Twenty-three patients diagnosed with primary BMS participated in the one-day group-based empowerment activities at the Orofacial Pain Clinic, Faculty of Dentistry, Khon Kaen University, Thailand. The inclusion criteria of primary BMS were burning sensation in the clinically normal oral mucosa and absence of local and systemic factors that can lead to burning sensation of the oral mucosa. Local and systemic factors were eliminated by salivary flow rate test, complete blood count, serum iron, vitamin B12, folic acid, thyroid hormones, and blood glucose. The exclusion criteria were the inability to comprehend the questionnaire and inability to complete throughout one-day group-based empowerment activities. In which, the study was based on a self-completed questionnaire as a measure to assess empowerment effectiveness. The authors distributed questionnaires before and after the empowerment activities, which comprised a 30-minute talk to understand BMS in general, an experience sharing session between BMS patient representatives and dentists and a whole group discussion as interactive dialogue among all BMS patients. The questionnaire consisted of four parts. The first part included general parameters (gender, age and duration of symptoms) and the intensity of burning pain. The visual analog scale (VAS) consists of a 10 cm line anchored at each end which labeled as "no burning" and "worse burning ever" was used to assess burning intensity. The second part of the questionnaire consisted of the expectation of patients before attending the empowerment activities, and benefits of participating in the empowerment activities. The attendees can choose more than one of the answers: meeting health care providers who are experts in BMS, improving my knowledge about BMS, improving my pain, helping me feel more in control of my condition, meeting other BMS sufferer, finding out about new treatment, finding way of improving my quality of life. The third part of the questionnaire evaluated their knowledge to the condition and attitudes towards BMS by choosing one of the offered answers: 0 = no knowledge, 1 = lowest, 2 = low, 3 = moderate, 4 = high and 5 = highest. The score, calculated by adding numerical values corresponding to certain answers, was used as a measure for their knowledge and attitudes. A higher score represented good knowledge and positive attitudes toward BMS. The fourth part of the questionnaire assessed pain catastrophizing using the Croatian version of the Pain Catastrophizing Scale(12). The patients expressed the frequency of negative thoughts and feeling that may be associated with burning pain in their mouth, presented in 13 statements, by choosing one of the offered answers: 0 = not at all, 1 = to a slight degree, 2 = to a moderate degree, 3 = to a great degree, and 4 = all the time. The intensity of pain catastrophizing was calculated by adding numerical values corresponding to a certain answer.

Statistical analysis

Descriptive statistics were used to describe the frequency and percentage of demographic characteristics of the patients and duration of burning pain. Measurement parameters included intensity of the symptoms, knowledge and attitudes towards BMS, and pain catastrophizing scale. The Paired samples t-test was used for statistical analysis to compare each parameter of before and after one-day group-based empowerment activities. The data were analyzed using SPSS v19 software. A statistical significance was set at *p*-value less than 0.05.

Results

Twenty-three BMS patients (20 females, 3 males, age 60.6±10.4 years) participated in one-day empowerment activities. Patients reported 3.3±2.6 years (range 0.5 to 8) of duration of pain from BMS as shown in Table 1. The expectations of patients attending the one-day group-based empowerment activities were described as 69.6% "meeting health care providers who are experts in BMS", 65.2% "improving my knowledge about BMS", 60.9% "improving my pain", 47.8% "helping me feel more in control of my condition", 39.1% "meeting other BMS sufferer, 34.8% "finding out about new treatment", and 13% "finding way of improving my quality of life". Following the one-day group-

Table 1. Demographics of attendees of the one-day group-based empowerment activities

	Mean ± SD, n (%)
Age	60.6±10.4 (45 to 76 years)
Gender	
Male	3 (13%)
Female	20 (87%)
Duration of burning pain	39.3±31.1 (6 to 96 months)

based empowerment activities, the benefits of participating were described as 95.7%”improving my knowledge about BMS”, 91.3% “meeting health care providers who are experts in BMS”, 87% “meeting other BMS sufferer, 78.3% “finding out about new treatment”, 73.9% “improving my pain”, 73.9% “helping me feel more in control of my condition” and 43.5% “finding way of improving my quality of life”. Significant reduction in knowledge and attitudes of sufferers attending after the one-day group-based empowerment activities was found ($p<0.05$) as shown in Table 2. No significant difference in reduction in burning pain intensity after the one-day group-based empowerment activities compared with before was observed ($p = 0.294$). The mean reduction in intensity of the symptoms from 3.9±3.3 to 3.5±2.0 after the one-day group-based empowerment activities. Significant difference in total pain catastrophizing score was observed ($p<0.05$). The statement 1, 4, 13 of catastrophizing score were significantly lower after the one-day group-based empowerment activities, however no significant difference in statement 2, 3, 5, 6 to 12 of catastrophizing score between before and after the one-day group-based empowerment activities are shown in Table 3.

Discussion

The present study was conducted to assess the effect of one-day single group session on empowering self-management that focused solely on the reassurance of the elderly BMS patients. The results showed that the implementation of our intervention was effective on the knowledge and attitudes of the BMS participants. Moreover, our results showed that, after participating in a one-day empowerment activity led to a significant decrease in their pain catastrophizing score. Pain catastrophizing scale has a maximum value of 52 points, whereas values above 40 points show clinically significant catastrophizing that require psychological intervention(13). In the present study only 2 patients (8.7%) had values of catastrophizing higher than 40 prior to our intervention focusing on empowerment. The mean score of the pain catastrophizing scale of the BMS patients in our study was 24.3±9.9 which is lower than the catastrophizing score reported in Japanese BMS patients which was 28.19±9.70(14) and 28.4±15 in the Croatian BMS

Table 2. Knowledge and attitudes of BMS sufferers attending the one-day group-based empowerment activities

	Before mean ± SD	After mean ± SD	*p*-value
1) Knowing the disease’s name	1.6±1.6	3.5±1.2	<0.001
2) Being reassured by the absence of severe illness (cancer, contagious illness...)	2.9±1.5	4.0±1.0	0.002
3) Knowing that it is a common disease that is frequently treated in our clinic	1.7±1.5	3.8±1.2	<0.001
4) Understanding the link between pain emergence and difficult or stressful life situations	2.7±1.5	4.1±0.7	0.001
5) Accepting that there are links between the psyche and the body	3.2±1.2	4.3±0.7	0.002
6) Having the opportunity to express one’s feelings	2.7±1.3	3.9±1.0	0.001
7) Having the opportunity to talk about oneself and be heard	2.5±1.5	4.1±0.9	<0.001

Table 3. Burning pain intensity and pain catastrophizing scale before and after the one-day group-based empowerment activities

	Before mean ± SD	After mean ± SD	p-value
Burning pain intensity	3.9±3.3	3.5±2.0	0.294
Pain catastrophizing scale	24.3±9.9	19.9±11.3	0.028*
I worry all the time about whether the pain will end	2.4±1.0	1.8±1.2	0.012*
I feel I can’t go on	1.6±1.3	1.6±1.0	1.000
It’s terrible and I think it’s never going to get any better	1.8±1.0	1.5±1.2	0.166
It’s awful and I feel that it overwhelms me	2.0±1.1	1.2±1.2	0.008*
I feel I can’t stand it anymore	1.4±1.0	1.2±1.1	0.260
I become afraid that the pain will get worse	1.6±1.1	1.4±1.0	0.575
I keep thinking of other painful events	1.5±1.0	1.1±1.1	0.119
I anxiously want the pain to go away	2.7±0.8	2.3±1.3	0.196
I can’t seem to keep it out of my mind	1.7±1.1	1.6±1.4	0.642
I keep thinking about how much it hurts	2.2±1.2	1.9±1.2	0.184
I keep thinking about how badly I want the pain to stop	2.4±1.1	2.1±1.4	0.296
There’s nothing I can do to reduce the intensity of the pain	1.7±1.0	1.5±1.2	0.365
I wonder whether something serious may happen	1.7±1.2	0.9±1.2	0.010*

* Statistically significant difference ($p<0.05$)

patients(15). The lower catastrophizing score found in our study may resulting from the timing of a questionnaire that was given to patients who have already been seen, and managed in our orofacial pain clinic and agreed to participate in the one-day empowerment group activity.

Based on the results of the present study, the pain catastrophizing score was significantly decreased, and the understanding of the condition was much improved after participating in the group-based activity that have focused mainly on the empowering self-management. This result was expected, since the empowering self-management model emphasizes on improved pain coping ability of the participants and the chance to meet and share their experiences with other sufferers. Consistent with the present study, several authors considered the use of the empowering self-management model as efficient in other chronic conditions affecting older persons(16,17).

Group-based self-management needs and goals are met through productive interactions between patients and families and their health care provider team. Productive interactions are more likely to occur when patients actively participate and are invested in their own care and are competent, confident managers of their health and illness. The strength of our study is the use of group-based patient-centered empowering technique in the group of elderly BMS patients. Moreover, the patients who are invited to the one-day empowerment activity were those who were actively engaged in their self-care pain management. The limitation of the present study is the small number of BMS patients participating in the empowering self-management activity and a short-term follow-up of the efficacy of the implementation.

Conclusion

Initial assessments suggest that the one-day group-based empowerment activities improve patient understanding and ability to cope with pain. To date BMS remains a challenge to clinicians and researchers as there is no specific and management for BMS. Patients should be made aware that the symptoms might not totally resolve even after long-term treatment. Patient education and support group play a key role to successful management.

What is already known in this topic?

The self-management skills adopted by chronic pain patients are necessary in order to manage their condition. It is thought that empowerment can promote pain patient wellbeing, decision-making and pain coping ability.

What this study adds?

The group-based training for empowering self-management strategies in patients with BMS is effective by improving their BMS knowledge and reducing pain catastrophizing thoughts.

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Potential conflicts of interest

The authors declare no conflicts of interest.

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ประสิทธิผลของการเสริมพลังอำนาจในการจัดการตนเองในผู้ป่วยโรคกลุ่มอาการแสบร้อนในช่องปาก

วิไลรัตน์ สฤษฎีชัยกุล, ฑีฆายุ พลางกูร จอร์นส, สุพรรณิการ์ เรืองศรี, รัชฎา ฉายจิต

ภูมิหลัง: โรคกลุ่มอาการแสบร้อนในช่องปากมีลักษณะเฉพาะคือ มีอาการปวดแสบปวดร้อนเรื้อรังบริเวณลิ้นหรือเนื้อเยื่ออื่นในช่องปาก การเสริมพลังอำนาจแก่ผู้ป่วยเป็นกลไกหนึ่งที่ช่วยให้ผู้ป่วยที่มีอาการเป็นระยะเวลานานมีการจัดการกับสุขภาพที่ดีขึ้นและให้ผลสำเร็จที่ดีกว่า

วัตถุประสงค์: เพื่อประเมินประสิทธิผลของการวัดกิจกรรมเสริมพลังอำนาจแก่กลุ่มผู้ป่วยกลุ่มอาการแสบร้อนในช่องปากแบบปฐมภูมิ

วัสดุและวิธีการ: เป็นการศึกษาโดยใช้แบบสอบถามให้ผู้ป่วยตอบเพื่อประเมินประสิทธิผลของกิจกรรมเสริมพลังอำนาจในการจัดการตนเองของกลุ่มผู้ป่วย ซึ่งให้แบบสอบถามก่อนและหลังกิจกรรมเสริมพลังอำนาจ โดยประกอบด้วยกิจกรรมบรรยาย 30 นาที เกี่ยวกับความเข้าใจโรคโดยทั่วไป และมีการแลกเปลี่ยนประสบการณ์ระหว่างผู้ป่วยและทันตแพทย์ หลังจากนั้นเป็นการอภิปรายกลุ่มด้วยบทสนทนาเชิงโต้ตอบในกลุ่มผู้ป่วยกลุ่มอาการแสบร้อนในช่องปากทั้งหมด ทำการวัดประเมินด้วยระดับคะแนนความปวด (VAS) ความรู้ และทัศนคติ และความคิดเชิงหายนะเกี่ยวกับโรค โดยใช้สถิติ paired samples t-test เพื่อวิเคราะห์เปรียบเทียบแต่ละการวัดผลของก่อนและหลังกิจกรรมเสริมพลังอำนาจ

ผลการศึกษา: ผู้ป่วย 23 ราย (เพศหญิง 20 ราย เพศชาย 3 ราย อายุเฉลี่ย 60.6±10.4 ปี) มาร่วมงานวันกิจกรรมเสริมพลังอำนาจแก่ผู้ป่วย มีระยะเวลาของอาการปวดจากโรคกลุ่มอาการแสบร้อนในช่องปากเฉลี่ย 3.3±2.6 ปี จากการประเมินผลพบว่ามีความเข้าใจเกี่ยวกับโรคเพิ่มขึ้น ในขณะที่มีอาการปวดแสบร้อนในช่องปากลดลง (จาก 3.9±3.3 ถึง 3.5±2.0) และมีความแตกต่างอย่างมีนัยสำคัญของระดับคะแนนรวมของความคิดเชิงหายนะเกี่ยวกับโรค ($p<0.05$)

สรุป: จากผลการประเมินแสดงให้เห็นว่ากิจกรรมเสริมพลังอำนาจทำให้ผู้ป่วยเข้าใจโรคเพิ่มขึ้นและสามารถอยู่กับอาการปวดนั้นได้ โรคกลุ่มอาการแสบร้อนในช่องปากยังคงเป็นเรื่องท้าทายต่อบุคลากรทางการแพทย์และนักวิจัย ผู้ป่วยควรตระหนักถึงอาการของโรคที่อาจไม่หายหลังจากที่รักษามาเป็นระยะเวลานาน การให้ความรู้กับผู้ป่วยและผู้ดูแลจึงเป็นบทบาทสำคัญในการรักษาโรคนี้ให้ประสบความสำเร็จ