

Visual imagery, a tool to explore the impact of burning mouth syndrome.

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whose language?

Abstract

Aim How photographic images ('Pain Cards') co-created by an artist and chronic pain patients could be used with groups of patients with burning mouth syndrome to facilitate characterisation of their pain and its impact on quality of life.

Method Ten groups of patients with burning mouth syndrome attending a two and a half hour information session in a facial pain unit were presented with 54 Pain Cards put in random order on a table. They were asked to pick one card which described the quality of their pain and one which reflected the impact of the pain on their lives. The total number of patients was 119 (divided into groups of 8-14) over a four-year period.

Results: 114 patients chose a Pain Card, 73 were used to phenotype the pain whereas 127 were used to describe the impact of the pain. The most frequently used Pain Card (13 times) was a pair of lips closed with a clothes peg, whereas most other frequently selected images were black and white. The choice of Pain Card and words used to explain their choice implied a neuropathic type of pain. Themes that are common are those of isolation, loss of confidence, low mood, decrease in activities and socialisation.

Conclusion: The Pain Cards chosen and the main themes support those found in the literature on BMS. The Pain Cards may help pain sufferers gain more empathy and support due to improved understanding by their health care providers.

Keywords : burning mouth syndrome, images, communication, pain

Introduction

Pain and its suffering remains very difficult to express and share with others as there are usually no visible signs and no biomarkers.^{1, 2 3} Our language often fails to get across the characteristics of pain and its emotional impact^{4, 5} and frequently pain is considered to be “normal” i.e something everyone expects to encounter.⁶ This is further compounded when patients are unable to verbally describe their pain due to a variety of reasons such as lack of language, disability or cognitive impairment. There have, therefore been attempts to use images to facilitate this process of helping patients describe their pain. McAuley⁷ developed a toolkit called “Pain pictures a better picture of chronic pain” in conjunction with a pharmaceutical company and Closs et al⁸ used this set of 12 pictograms to determine if they could be used to distinguish neuropathic pain from nociceptive pain. Padfield^{9, 10} on the other hand created photographic images with patients suffering from chronic pain, named Pain Cards, that could then be used by patients in pain consultations as a way to facilitate the expression and communication of their pain.^{11,12} The current study wanted to explore the use of these Pain Cards in a group setting rather than a one to one consultation as has been done previously.^{13,14} In addition this was done with a group of patients with a specific condition, burning mouth syndrome (BMS).

This chronic, rare condition occurring most frequently in post menopausal women¹⁵ has a significant impact on quality of life^{16 17}; and is often associated with anxiety, depression and other mental health problems.¹⁸⁻²¹ Patients feel abandoned, as medical and dental health care professionals do not have the training to offer further

management. Patients are often left with a sense that their condition is psychological in origin and feel labelled as “mad” which can lead to further isolation and distress .

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Throughout the UK there are very few specialist services, which specialise in treatment for or offer individualised treatment approaches to patients with a BMS diagnosis despite recommendations that a multi-disciplinary approach drawing on the biopsychosocial model is essential and the most effective treatment. ²³

The objective of the current study was to see whether the Pain Cards could be used in this group of patients to determine if they could facilitate a broader discussion which could be shared with other sufferers and provide clinicians with increased insight into ways of understanding patients with BMS.

Methods

Patients

Patients diagnosed with BMS by oral physicians in a hospital setting using the ICHC criteria. ²⁴ A management plan was discussed with patients, which included use of medication and an offer to attend an information session if the condition was having an impact on the quality of their lives. Those who were interested in attending were then referred to the information session [by oral physicians or members of the facial pain service . The session was](#) led by the clinical psychology service with the input of the oral physician. Inclusion criteria were male and female patients all above the age of 18 years old. Patients with significant psychological or developmental difficulties were not deemed appropriate for the group setting and where suitable were offered individual assessments and potential treatment with the psychology and

physiotherapy team respectively. In total 114 adult patients participated in the study in ten different groups, 88 women and 26 men. Of the seventy patients whose details were available the mean age was 63 with a range of 33-85 years. The duration of symptoms was mean 45 months with a range of 4-180 months . Fifty-one were married, 20 single, widowed or divorced. There was a range of socio-economic groups represented e.g teachers, clerical, retail assistants.

Setting

A large facial pain unit within a hospital that sees over 700 new patients a year. Each group information session consisted of eight to 14 patients with some patients being accompanied by significant others. Each session lasted two and a half hours and in total 10 sessions were carried out over a period of four years.

Structure

The session was split into three parts; firstly, an interactive talk by a medical/oral clinician (JZ) lasting 45 minutes. During the first part patients had an extensive introduction to the general concept of persistent pain and more specifically BMS including its epidemiology, aetiology and common co-morbidities (JZ). In addition evidenced based treatment approaches were discussed in line with the Cochrane review on BMS.²⁵ Patients were then shown the Pain Cards. All patients were informed of the study and that the anonymised results would be used for a potential publication. All patients attending the teaching hospital sign a consent form agreeing to their data being used for research, verbal consent was implied when patients elected to pick cards and respond. The 54 Pain Cards were put on a table and patients were given roughly 5 minutes to explore the Pain Cards. They were then

invited to choose at least one Pain Card that reflected the characteristics of their condition and at least one Pain Card which reflected the impact of BMS on their lives. Patients were free not to choose a card, or to pick a Pain Card that another patient had already chosen and were asked to describe the meaning they attached to their images and say why they had selected them. Patients were told that they did not need to participate and were therefore free not to choose any of the Pain Cards. The responses were recorded by the medical consultant (JZ), including the Pain Card number chosen and the accompanying comments. This took around 45 minutes, depending on the size of the group. A group discussion lasting around one hour was subsequently led by a clinical psychologist (AF) and completed the session.

The images had been co-created by other patients with pain who worked with an artist ([DP](#)) to decide on the objects to be used and how the material was to be photographed. The methodology is described in other publications ⁹⁻¹². Patients who co-created the images with the visual artist gave their written consent for the images to be used in a variety of settings with appropriate acknowledgment. Ethics approval was obtained from NRES Committee London - Chelsea (REC reference 09/H0801/51). For the patients using the images verbal consent was obtained and generic written consent is obtained from all patients attending the teaching hospital for their data to be used for teaching and research.

Results

In total 114 patients took part in the study out of a total 119 invited to take part. Five patients did not choose a Pain Card either because they felt that none of the cards

resonated with them or they did not understand the instructions. Of the 54 Pain Cards eight were not chosen by any patients during the 10 sessions, Pain Card 43 was chosen 13 times. The most frequently selected Pain Cards (i.e. those chosen more than five times) to describe the character of the pain were: 3, 5, 23, 26, 27 and 43. Sixty three percent of patients chose two Pain Cards but 26 percent chose only one and nine percent chose three as shown in table 1. Six patients reported that they found it difficult to explain why they chose a Pain Card, three patients gave the same reasons as others, as shown in the tables.

Table 1 Number of cards chosen

Although 63% chose two Cards, only 73 Pain Cards were used to phenotype their pain and 127 of the Pain Cards were used for impact. Five cards were used interchangeably in some instances for reflecting both physical characteristics and its psychological impact. Table 2 shows the 24 Pain Cards used to phenotype pain 37 (32%) used it to describe its character but 31 (27%) also used them to describe the associated taste, location, timing and factors affecting pain. A red and rotten apple (Pain Card 26) was used to describe bad taste and inability to eat certain fruits especially citrus fruits. The Pain Cards were used to describe the pins and needles and burning nature of the pain by 42 (36%) of the patients.

Table 2: Pain Cards used to describe the characteristics of BMS

Sixty two percent of Pain Cards were chosen to describe impact of BMS as shown in table 3. Only one Pain Card was chosen for positive feelings . Pain Card 54 as light at the end of the tunnel, 60% used black and white, dark Pain Cards.

Table 3 Pain Cards chosen to describe impact and reasons for the choice

Pain Card 43 figure 1, lower part of the face closed with a clothes peg was one of the Pain Cards most frequently chosen (13 times) for both characteristics of the pain as well as its impact. Nine expressed the need to keep the mouth closed as it could help but four used it to highlight their reluctance to socialise.

Figure 1. Image of pain co-created by Deborah Padfield with Liz Aldous from the series *Face2Face*, 2008-2013 © Deborah Padfield

The second most popular, Pain Card 5 (figure 2) a representation of electrical wires, expressed the burning quality for many but one patient used it to describe how “copper has an unpleasant taste and signifies changes in taste”, a symptom associated with BMS. Pain Card 9 (figure 3), a bag tied to a leg was used by 11 patients to show the restricting effect of the condition, “it is a burden”, but in addition the bag represented the experience of pain being inflicted by some agent outside the body with the hope that it could be removed from the body by [detaching it in some way cutting](#).

Figure 2. Image of pain co-created by Deborah Padfield with Chandrakant Khoda from the series *Face2Face*, 2008-2013 © Deborah Padfield.

Figure 3. Image of pain from the series *perceptions of pain*, 2001-2006 © Deborah Padfield. Reproduced by kind permission of Dewi Lewis.

Pain Card 6, depicting a tight string round a wrist, was used both to express the restriction and tightness in the tongue felt by those with BMS but also of life itself due to the condition. Pain Card 21, a clenched fist, represented one patient’s feeling of being “useless and frustrated” and being unable to enjoy certain things such as food and wine because of the effect the condition has on taste. In contrast, another

patient used Pain Card 21 to explain how the condition affected her mood: “feeling low, angry, tense and at times frozen up”. Pain Card 29, a face with a partial mask, connoted despair and low mood. Pain Cards that included pins were particularly pertinent for patients as they demonstrated the tingling as well as metallic taste often described by patients with BMS and many likened these symptoms to a local anaesthetic wearing off.

Other key themes that the Pain Cards drew out revolved around difficulties within family relationships and breakdown of relationships, poor communication and lack of understanding as illustrated in table 3. A carer chose a picture of a twisted wire (Pain Card 49), reflecting that this represented feelings of being stretched to the limits trying to help and support their partner often feeling hopeless because they “could not work out how to help”. Another carer chose Pain Card 25 a shadow of a face to indicate that they felt as though their partner had become a “stranger in the family”.

One patient chose a Pain Card with a small rag doll sitting on an underground seat and reported that they would have placed the doll in an even larger landscape as they felt nobody understood their problem. For this patient the image represented feeling they had lost their confidence. In addition she suggested a new potential Pain Card: a hamburger burnt on the outside cut in half showing raw meat inside, signifying how her tongue felt.

Discussion

This is the first time that co-created visual images have been used with a group of patients suffering from chronic pain and additionally patients with a diagnosis of BMS. Most but not all patients engaged in the study, often one sentiment expressed

led to agreement from the group which can be explained by Charon's observation that narrative is shared.²⁶ The Pain Cards appeared to facilitate patients sharing their experience. Perhaps this sharing is further enhanced by the ways in which they are physically moved around and through the space they occupy on the table becoming a common shared space.

The specific Pain Cards more often chosen are more abstracted, less personalised, with a theme of splitting being apparent and of feelings of alienation and distance from a previous self or previous sensation. It is not possible to know whether these are therefore more intensified feelings for BMS patients, perhaps reflecting barriers to communication because of its effect on the mouth or whether it is as a result of specifically being asked to select Pain Cards reflecting the emotional impact.

In a previous study using these Pain Cards only one Pain Card of the face was in the most frequently selected group whereas in the current study the selections by the BMS patients included five Pain Cards depicting the face, or part of it, with a further three depicting body parts (two of the hands and one of half a person in black and white and half in colour).²⁷ This of course is not a surprising finding as the symptoms of BMS affect the mouth. In previous studies the dominant effect the Pain Cards had on consultations was to encourage discussion of the affective elements of pain experience.¹¹⁻¹⁴ In previous studies Padfield et al¹² found a preponderance of the Pain Cards being used depicted temperature and cutting, sharp type images. In addition Pain Cards frequently chosen suggested pain as being something done to the body by an outside agent, (external to the person as well as outside the frame of the image – so not visible) over which the subject of the image could be construed as having no control. This sentiment is equally reflected in the BMS patients'

selections, perhaps implying it is one of the core themes and emotional aspects associated with chronic pain conditions of any type. Apart from four Pain Cards none of the other cards selected most frequently in the earlier pain study, which mainly included patients with musculoskeletal pain, were selected frequently by the BMS group and vice versa. This begins to suggest there are particular characteristics of BMS and its impact that distinguish it from other types of chronic pain. Pain Card 45, which depicts medication, and was often chosen by pain patients was not selected more frequently than any others with the BMS patients indicating that medication might not be such a contested issue for this group.

Just as words so pictures can be interpreted in a wide range of ways depending on context. The Pain Cards BMS patients selected to describe the character of the pain were of sharp sensations or of sparks which are words often chosen by BMS patients from neuropathic pain questionnaires.²⁸ The only exception was an image of a rotting apple. However it is not possible to determine if these were diagnostically useful as there was no control group of patients with nociceptive pain [or with other orofacial pain such as temporomandibular disorder](#). Closs et al.⁸ working with a set of 12 pictograms which were drawn in order to differentiate between the quality of different types of pain also showed a lack of consistency when tested with a group of students. They found that one pictogram can be associated with over 200 words and could be interpreted under any of these headings: sensory, location, sensory, affective, temporal, literal and other condition.²⁹ These same themes are to be found in this study with predominance in the affective section, low mood, low self-esteem and isolation.

Patients in the BMS group were told that the Pain Cards had originally been co-created by an artist with chronic pain sufferers. As they were created with pain patients it is likely they have more credibility associated with them than if they had been arbitrarily created. It could be possible to conclude that this had the additional effect of giving the patients in the BMS sessions 'permission' to describe their pain as similarly baffling with equally devastating effects on their lives as the patients who had co-created them. The Pain Cards may thus enable communication by eliciting, exploring and validating not just the pain experience but also emotions such as depression and anxiety. By using the Pain Cards to facilitate discussion around impact especially with regards to mood may enable patients to improve their management of emotions and hence result in improved health outcomes. ³² In making pain visible it was hoped that the Pain Cards also improve trust and 'believability', and so improve communication and rapport between doctor and patient.

One of the limitations of this study is that the sessions were not audio recorded so the exact wording used by the patients was not documented other than via hand written notes, thus losing some of the richness of the dialogue and making it difficult to arrange the Pain Cards thematically. There was no linkage of the psychosocial background of the patients with the choice of images nor of their subsequent outcomes as this was purely an exploratory study. [This was because not all patients were referred to these sessions by the facial pain service. Some of the patients were seen in busy oral medicine clinics who do not ask patients to complete questionnaires so the sociodemographic , pain intensity and quality of life were not recorded.](#) It is difficult to introduce a control group as each information session

brings up different issues. In the future it would be useful to test for the optimum number of Pain Cards, as the high number makes them difficult to use in one to one sessions where the patients have not had a prior chance to review them. This needs to be carefully balanced in order not to remove the very Pain Cards that are needed. As with words it might therefore be difficult to restrict the numbers.³³ We know that the pain experience remains highly personal, is influenced by context and needs to be managed by a multidisciplinary team.³⁴ [It may also be useful to determine if there are gender differences in choice of Pain Cards which potentially could be done once large samples are accumulated.](#)

This study explored the use of the Pain Cards as a way of facilitating conversations around the impact and experience of living with BMS. Generally patients responded well to the use of the Pain Cards and the Pain Cards appeared to resonate strongly with the patients and their experience of living with the condition. Perhaps making these Pain Cards more widely available for health care professionals to use in consultations could provide patients with another way to express their experiences and help them to feel more understood and supported. This could potentially be of special use in settings where there is no access to pain psychologists.

Acknowledgment

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Captions for figures

Figure 1. Image of pain co-created by Deborah Padfield with Liz Aldous from the series *Face2Face*, 2008-2013 © Deborah Padfield

Figure 2. Image of pain co-created by Deborah Padfield with Chandrakant Khoda from the series *Face2Face*, 2008-2013 © Deborah Padfield.

Figure 3. Image of pain from the series *perceptions of pain*, 2001-2006

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Table 1 Number of images chosen

Number of images chosen	Women n=88	Men n=26	total
0	3	2	5
1	18	8	26
2	56	16	72
3	9	0	9
4	2	0	2
Total images used	165	40	205

Table 2: Pain Cards used to describe the characteristics of BMS

Image	Reason for choice	Frequency
5	shock-like, burning, unpredictable, on fire, tingling, metallic taste	9
26	funny, nasty, reduced, bitter taste, hot, citrus makes it worse, eating makes it better	8

43	lip area of pain, uncomfortable, if shuts mouth no symptoms, poor taste, halitosis, eating makes it worse, eating makes it better so worry re weight gain	7
27	pins and needles, prickling	6
23	sharp element, pin pricks, crawling	6
3	shooting, stinging sparks, burning, quick, powerful pain	5
18	burning pain on fire, hot	4
2	location widespread, beyond the mouth, diffuse, no focus present continuously	4
38	burning, needles	3
14	metallic taste	3
6	burnt, radiating, tight tongue, numb	3
1	burning, intense sharp, fire	3
51	salty taste	1
39	red hot knife	1
36	needles	1
32	constant tingling, thick saliva, eating makes it worse	1
30	dry, feels like a stone in the mouth	1

28	pain is all over, better if holds head	1
24	greyness of the image is like the taste	1
21	on fire hot	1
17	tingling and burning	1
15	continuous	1
10	barbed wire, itchiness	1
7	Burning, radiating everywhere	1
TOTAL		73

Table 3 Pain Cards chosen to describe impact and reasons for the choice

Image	Reason for choice	Frequency
9	held back by pain, restricts activities, dragging down, pain pulls away from enjoyable activities, burden, wish to cut the string and be without this heavy bag	11
21	tense, full of pain, frustrated, angry, annoyed, useless, feel down, feel vulnerable	8
29	nothing is abnormal, anxious, cannot go on, despair, nobody knows what going through	7
6	unable to free himself from this tightness, hands tied due to BMS, stopped activates, restricts life, stops going forward	6
28	pain is too much, wants to hide and get away, despair, black hole and does not know how to get out, everything is a big effort.	6
30	if hold head tight things would improve, despair, wants a new head, seems a small problem but goes on and on	6
43	terrified of opening her mouth, doesn't want to socialise, stops communication	6

42	sad, low self esteem, miserable, do not know how to deal with problem, cannot distract, striving to put colour back into the face	5
19	feels wound up, tense, need to unwind, tongue twisted, feels down	4
45	too many drugs, does not work, life dominated by medications	4
49	cannot do things, lost so much as a result of pain, huge impact on life	4
5	feels everything is breaking, things are dislocated, poor quality	3
10	suffering pain everywhere diabetic neuropathy, mesh of nerves not working, irritates and changed personality	3
11	feels unbalanced on one side, lack of colour indicates limited potential, complex problem	3
12	cannot do the things I used, something wrong inside, looks horrible like the tongue	3
14	alarm bells ringing, things were not moving in unison, unable to concentrate, things are all over the place	3
34	brings back negative memories of dentists, anxiety	3

40	loss of pleasure in life, isolating, embarrassed that dribbles	3
41	loss of confidence, fed up, sorry for herself, cannot go out, isolated	3
44	mouth is disintegrating, others do not know how feel, self conscious about loss of teeth	3
50	living in a cloud, all joy has been taken out of life, shadow of themselves, one step away from everybody	3
52	wants a phone to be able to get people to help her, crying on the phone, does not want to speak when in pain	3
53	wants to be contacting other people, no longer sociable, shuts herself off	3
54	gives hope, light at the end of the tunnel, nobody understands, feels in the dark	3
2	miserable, face is vulnerable, cannot do anything	2
3	tense, frustrated, when distracted no pain feels elated	2
15	break in life, frustrating, everything is interrupted, cannot see an end to it.	2
17	constant generalised malaise, loss of pleasure in life	2
35	inability to socialise, two years to get diagnosis and fed up with investigations	2

51	too much pain, nothing helps	2
1	in the dark and not sure where she is going	1
4	represents widespread fibromyalgia	1
13	intricate and represents multiple symptoms	1
18	feel like shadowing a person	1
20	feels all tied up can't speak	1
25	suffocating as if something is covering her face, stopping her functioning, stranger to family	1
31	retreat into a ball to get away from everybody	1
32	pensive, not sure what to do about it	1
33	light feels getting better	1
Total		127

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Figure 1 low res



Figure 2 low res



Figure 3 low res

J Headache

JOPH-2017-197/R1 RESUBMISSION - (2095):

Thank you very much for resubmitting the above manuscript to Journal of Oral & Facial Pain and Headache. It has been reviewed, once again, by external experts in the field as well as by members of the editorial board. All readers found your manuscript much improved but there are still some points of criticism that need to be addressed before your manuscript can be accepted for publication, these are detailed in the reviewers reports.

When you resubmit this paper, please do so online from our home page. You should also specifically address each of the points made by the reviewers. Please highlight all the changes made to the manuscript with the "track changes" function, and upload the PC Word (doc) file with changes tracked. I look forward to receiving the revised article within the next three months, otherwise the article will be considered as withdrawn and subjected to a new review process. Please inform me if you do not wish to resubmit the article.

Thank you, again, for submitting this interesting paper to the Journal of Oral & Facial Pain and Headache.

Sincerely,

Ilana Eli

elilana@post.tau.ac.il

Journal of Oral Facial Pain and Headache

Reviewer 1 report:

After reading auteurs comments. corrections and within the limits of an exploratory study being a primary data collection

I recommend accepting the paper.

I hope it will lead to a more conclusive research.

Reviewer 2 report:

We thank the authors for improvement of the manuscript. However, informations and answers given did not really enrich the study report.

We understand that this study is an exploratory one and that the topic is very interesting and stimulating (sharing experience and open communication), but considering the length of the study (4 years), they could have been more precise for describing the study population and the pain characteristics. [The lack of detail was because not all patients were referred to these sessions by the facial pain service. Some of the patients were seen in busy oral medicine clinics who do not ask patients to complete questionnaires so the sociodemographic , pain intensity and quality of life were not recorded".We have added this in the methods](#)

Major concerns still remain related to the sample study (age still missing for 17 patients, no information concerning intensity or treatment available).

As suggested with the first report, it is unfortunate that impact of pain on quality of life was not investigated. The manuscript should mention the lack of objective and measurable tools for anxiety and depression (HAD-A and S) and quality of life instruments such as OHIP. Validation of these care remain necessary (test-retest reliability, convergent and discriminative validity). [We have added a comment in the discussion](#) Control group could consist in chronic pain (temporomandibular for exemple) or acute pain (pulpitis). [We have added a comment in the discussion "pain or with other orofacial pain such as temporomandibular disorder".](#)

Such limitations should also be added within the discussion section. [We have added limitations in the discussion.](#)

Reviewer 3 report:

Dear Editor,

The authors have adequately addressed these reviewer's concerns, but there are, still, some methodological points to discuss. In my opinion, the choice of pain cards is influenced by socio-demographic profile of the patients. [We do not think the choice of cards is influenced by sociodemographic factors but by pain type, character and impact and the sample size is too small to perform such an analysis.](#) The authors added some information in the Methods section

but it should be better specified (age of education is important for choice of pain cards) and the choice of the cards should be evaluated and discussed in relationships of socio-demographic profile. These data are missing in the discussion. [We do not have education details.](#) Another point to evaluate and to discuss are the differences in choice of pain cards between women and men because these data are unclear in the tables and in the discussion. [The number of females was 88 vs 26 and the choice of cards so large that no meaningful data can be obtained from such an analysis. A note has been made in the discussion about future research in this area. "It may also be useful to determine if there are gender differences in choice of Pain Cards which potentially could be done once large samples are accumulated".](#)

The Authors could add this information.

Visual imagery, a tool to explore the impact of burning mouth syndrome.

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Abstract

Aim How photographic images ('Pain Cards') co-created by an artist and chronic pain patients could be used with groups of patients with burning mouth syndrome to facilitate characterisation of their pain and its impact on quality of life.

Method Ten groups of patients with burning mouth syndrome attending a two and a half hour information session in a facial pain unit were presented with 54 Pain Cards put in random order on a table. They were asked to pick one card which described the quality of their pain and one which reflected the impact of the pain on their lives. The total number of patients was 119 (divided into groups of 8-14) over a four-year period.

Results: 114 patients chose a Pain Card, 73 were used to phenotype the pain whereas 127 were used to describe the impact of the pain. The most frequently used Pain Card (13 times) was a pair of lips closed with a clothes peg, whereas most other frequently selected images were black and white. The choice of Pain Card and words used to explain their choice implied a neuropathic type of pain. Themes that are common are those of isolation, loss of confidence, low mood, decrease in activities and socialisation.

Conclusion: The Pain Cards chosen and the main themes support those found in the literature on BMS. The Pain Cards may help pain sufferers gain more empathy and support due to improved understanding by their health care providers.

Keywords : burning mouth syndrome, images, communication, pain

Introduction

Pain and its suffering remains very difficult to express and share with others as there are usually no visible signs and no biomarkers.^{1, 2 3} Our language often fails to get across the characteristics of pain and its emotional impact^{4, 5} and frequently pain is considered to be “normal” i.e something everyone expects to encounter.⁶ This is further compounded when patients are unable to verbally describe their pain due to a variety of reasons such as lack of language, disability or cognitive impairment. There have, therefore been attempts to use images to facilitate this process of helping patients describe their pain. McAuley⁷ developed a toolkit called “Pain pictures a better picture of chronic pain” in conjunction with a pharmaceutical company and Closs et al⁸ used this set of 12 pictograms to determine if they could be used to distinguish neuropathic pain from nociceptive pain. Padfield^{9, 10} on the other hand created photographic images with patients suffering from chronic pain, named Pain Cards, that could then be used by patients in pain consultations as a way to facilitate the expression and communication of their pain.^{11,12} The current study wanted to explore the use of these Pain Cards in a group setting rather than a one to one consultation as has been done previously.^{13,14} In addition this was done with a group of patients with a specific condition, burning mouth syndrome (BMS).

This chronic, rare condition occurring most frequently in post menopausal women¹⁵ has a significant impact on quality of life^{16 17}; and is often associated with anxiety, depression and other mental health problems.¹⁸⁻²¹ Patients feel abandoned, as medical and dental health care professionals do not have the training to offer further

management. Patients are often left with a sense that their condition is psychological in origin and feel labelled as “mad” which can lead to further isolation and distress.

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Throughout the UK there are very few specialist services, which specialise in treatment for or offer individualised treatment approaches to patients with a BMS diagnosis despite recommendations that a multi-disciplinary approach drawing on the biopsychosocial model is essential and the most effective treatment.²³

The objective of the current study was to see whether the Pain Cards could be used in this group of patients to determine if they could facilitate a broader discussion which could be shared with other sufferers and provide clinicians with increased insight into ways of understanding patients with BMS.

Methods

Patients

Patients diagnosed with BMS by oral physicians in a hospital setting using the ICHC criteria.²⁴ A management plan was discussed with patients, which included use of medication and an offer to attend an information session if the condition was having an impact on the quality of their lives. Those who were interested in attending were then referred to the information session by oral physicians or members of the facial pain service. The session was led by the clinical psychology service with the input of the oral physician. Inclusion criteria were male and female patients all above the age of 18 years old. Patients with significant psychological or developmental difficulties were not deemed appropriate for the group setting and where suitable were offered individual assessments and potential treatment with the psychology and

physiotherapy team respectively. In total 114 adult patients participated in the study in ten different groups, 88 women and 26 men. Of the seventy patients whose details were available the mean age was 63 with a range of 33-85 years. The duration of symptoms was mean 45 months with a range of 4-180 months. Fifty-one were married, 20 single, widowed or divorced. There was a range of socio-economic groups represented e.g. teachers, clerical, retail assistants.

Setting

A large facial pain unit within a hospital that sees over 700 new patients a year. Each group information session consisted of eight to 14 patients with some patients being accompanied by significant others. Each session lasted two and a half hours and in total 10 sessions were carried out over a period of four years.

Structure

The session was split into three parts; firstly, an interactive talk by a medical/oral clinician (JZ) lasting 45 minutes. During the first part patients had an extensive introduction to the general concept of persistent pain and more specifically BMS including its epidemiology, aetiology and common co-morbidities (JZ). In addition evidenced based treatment approaches were discussed in line with the Cochrane review on BMS.²⁵ Patients were then shown the Pain Cards. All patients were informed of the study and that the anonymised results would be used for a potential publication. All patients attending the teaching hospital sign a consent form agreeing to their data being used for research, verbal consent was implied when patients elected to pick cards and respond. The 54 Pain Cards were put on a table and patients were given roughly 5 minutes to explore the Pain Cards. They were then

invited to choose at least one Pain Card that reflected the characteristics of their condition and at least one Pain Card which reflected the impact of BMS on their lives. Patients were free not to choose a card, or to pick a Pain Card that another patient had already chosen and were asked to describe the meaning they attached to their images and say why they had selected them. Patients were told that they did not need to participate and were therefore free not to choose any of the Pain Cards. The responses were recorded by the medical consultant (JZ), including the Pain Card number chosen and the accompanying comments. This took around 45 minutes, depending on the size of the group. A group discussion lasting around one hour was subsequently led by a clinical psychologist (AF) and completed the session.

The images had been co-created by other patients with pain who worked with an artist (DP) to decide on the objects to be used and how the material was to be photographed. The methodology is described in other publications.⁹⁻¹² Patients who co-created the images with the visual artist gave their written consent for the images to be used in a variety of settings with appropriate acknowledgment. Ethics approval was obtained from NRES Committee London - Chelsea (REC reference 09/H0801/51). For the patients using the images verbal consent was obtained and generic written consent is obtained from all patients attending the teaching hospital for their data to be used for teaching and research.

Results

In total 114 patients took part in the study out of a total 119 invited to take part. Five patients did not choose a Pain Card either because they felt that none of the cards

resonated with them or they did not understand the instructions. Of the 54 Pain Cards eight were not chosen by any patients during the 10 sessions, Pain Card 43 was chosen 13 times. The most frequently selected Pain Cards (i.e. those chosen more than five times) to describe the character of the pain were: 3, 5, 23, 26, 27 and 43. Sixty three percent of patients chose two Pain Cards but 26 percent chose only one and nine percent chose three as shown in table 1. Six patients reported that they found it difficult to explain why they chose a Pain Card, three patients gave the same reasons as others, as shown in the tables.

Table 1 Number of cards chosen

Although 63% chose two Cards, only 73 Pain Cards were used to phenotype their pain and 127 of the Pain Cards were used for impact. Five cards were used interchangeably in some instances for reflecting both physical characteristics and its psychological impact. Table 2 shows the 24 Pain Cards used to phenotype pain 37 (32%) used it to describe its character but 31 (27%) also used them to describe the associated taste, location, timing and factors affecting pain. A red and rotten apple (Pain Card 26) was used to describe bad taste and inability to eat certain fruits especially citrus fruits. The Pain Cards were used to describe the pins and needles and burning nature of the pain by 42 (36%) of the patients.

Table 2: Pain Cards used to describe the characteristics of BMS

Sixty two percent of Pain Cards were chosen to describe impact of BMS as shown in table 3. Only one Pain Card was chosen for positive feelings. Pain Card 54 as light at the end of the tunnel, 60% used black and white, dark Pain Cards.

Table 3 Pain Cards chosen to describe impact and reasons for the choice

Pain Card 43 figure 1, lower part of the face closed with a clothes peg was one of the Pain Cards most frequently chosen (13 times) for both characteristics of the pain as well as its impact. Nine expressed the need to keep the mouth closed as it could help but four used it to highlight their reluctance to socialise.

Figure 1. Image of pain co-created by Deborah Padfield with Liz Aldous from the series *Face2Face*, 2008-2013 © Deborah Padfield

The second most popular, Pain Card 5 (figure 2) a representation of electrical wires, expressed the burning quality for many but one patient used it to describe how “copper has an unpleasant taste and signifies changes in taste”, a symptom associated with BMS. Pain Card 9 (figure 3), a bag tied to a leg was used by 11 patients to show the restricting effect of the condition, “it is a burden”, but in addition the bag represented the experience of pain being inflicted by some agent outside the body with the hope that it could be removed from the body by detaching it in some way .

Figure 2. Image of pain co-created by Deborah Padfield with Chandrakant Khoda from the series *Face2Face*, 2008-2013 © Deborah Padfield.

Figure 3. Image of pain from the series *perceptions of pain*, 2001-2006 © Deborah Padfield. Reproduced by kind permission of Dewi Lewis.

Pain Card 6, depicting a tight string round a wrist, was used both to express the restriction and tightness in the tongue felt by those with BMS but also of life itself due to the condition. Pain Card 21, a clenched fist, represented one patient’s feeling of being “useless and frustrated” and being unable to enjoy certain things such as food and wine because of the effect the condition has on taste. In contrast, another

patient used Pain Card 21 to explain how the condition affected her mood: “feeling low, angry, tense and at times frozen up”. Pain Card 29, a face with a partial mask, connoted despair and low mood. Pain Cards that included pins were particularly pertinent for patients as they demonstrated the tingling as well as metallic taste often described by patients with BMS and many likened these symptoms to a local anaesthetic wearing off.

Other key themes that the Pain Cards drew out revolved around difficulties within family relationships and breakdown of relationships, poor communication and lack of understanding as illustrated in table 3. A carer chose a picture of a twisted wire (Pain Card 49), reflecting that this represented feelings of being stretched to the limits trying to help and support their partner often feeling hopeless because they “could not work out how to help”. Another carer chose Pain Card 25 a shadow of a face to indicate that they felt as though their partner had become a “stranger in the family”.

One patient chose a Pain Card with a small rag doll sitting on an underground seat and reported that they would have placed the doll in an even larger landscape as they felt nobody understood their problem. For this patient the image represented feeling they had lost their confidence. In addition she suggested a new potential Pain Card: a hamburger burnt on the outside cut in half showing raw meat inside, signifying how her tongue felt.

Discussion

This is the first time that co-created visual images have been used with a group of patients suffering from chronic pain and additionally patients with a diagnosis of BMS. Most but not all patients engaged in the study, often one sentiment expressed

led to agreement from the group which can be explained by Charon's observation that narrative is shared.²⁶ The Pain Cards appeared to facilitate patients sharing their experience. Perhaps this sharing is further enhanced by the ways in which they are physically moved around and through the space they occupy on the table becoming a common shared space.

The specific Pain Cards more often chosen are more abstracted, less personalised, with a theme of splitting being apparent and of feelings of alienation and distance from a previous self or previous sensation. It is not possible to know whether these are therefore more intensified feelings for BMS patients, perhaps reflecting barriers to communication because of its effect on the mouth or whether it is as a result of specifically being asked to select Pain Cards reflecting the emotional impact.

In a previous study using these Pain Cards only one Pain Card of the face was in the most frequently selected group whereas in the current study the selections by the BMS patients included five Pain Cards depicting the face, or part of it, with a further three depicting body parts (two of the hands and one of half a person in black and white and half in colour).²⁷ This of course is not a surprising finding as the symptoms of BMS affect the mouth. In previous studies the dominant effect the Pain Cards had on consultations was to encourage discussion of the affective elements of pain experience.¹¹⁻¹⁴ In previous studies Padfield et al¹² found a preponderance of the Pain Cards being used depicted temperature and cutting, sharp type images. In addition Pain Cards frequently chosen suggested pain as being something done to the body by an outside agent, (external to the person as well as outside the frame of the image – so not visible) over which the subject of the image could be construed as having no control. This sentiment is equally reflected in the BMS patients'

selections, perhaps implying it is one of the core themes and emotional aspects associated with chronic pain conditions of any type. Apart from four Pain Cards none of the other cards selected most frequently in the earlier pain study, which mainly included patients with musculoskeletal pain, were selected frequently by the BMS group and vice versa. This begins to suggest there are particular characteristics of BMS and its impact that distinguish it from other types of chronic pain. Pain Card 45, which depicts medication, and was often chosen by pain patients was not selected more frequently than any others with the BMS patients indicating that medication might not be such a contested issue for this group.

Just as words so pictures can be interpreted in a wide range of ways depending on context. The Pain Cards BMS patients selected to describe the character of the pain were of sharp sensations or of sparks which are words often chosen by BMS patients from neuropathic pain questionnaires.²⁸ The only exception was an image of a rotting apple. However it is not possible to determine if these were diagnostically useful as there was no control group of patients with nociceptive pain or with other orofacial pain such as temporomandibular disorder. Closs et al⁸ working with a set of 12 pictograms which were drawn in order to differentiate between the quality of different types of pain also showed a lack of consistency when tested with a group of students. They found that one pictogram can be associated with over 200 words and could be interpreted under any of these headings: sensory, location, sensory, affective, temporal, literal and other condition.²⁹ These same themes are to be found in this study with predominance in the affective section, low mood, low self-esteem and isolation.

Patients in the BMS group were told that the Pain Cards had originally been co-created by an artist with chronic pain sufferers. As they were created with pain patients it is likely they have more credibility associated with them than if they had been arbitrarily created. It could be possible to conclude that this had the additional effect of giving the patients in the BMS sessions 'permission' to describe their pain as similarly baffling with equally devastating effects on their lives as the patients who had co-created them. The Pain Cards may thus enable communication by eliciting, exploring and validating not just the pain experience but also emotions such as depression and anxiety. By using the Pain Cards to facilitate discussion around impact especially with regards to mood may enable patients to improve their management of emotions and hence result in improved health outcomes.³² In making pain visible it was hoped that the Pain Cards also improve trust and 'believability', and so improve communication and rapport between doctor and patient.

One of the limitations of this study is that the sessions were not audio recorded so the exact wording used by the patients was not documented other than via hand written notes, thus losing some of the richness of the dialogue and making it difficult to arrange the Pain Cards thematically. There was no linkage of the psychosocial background of the patients with the choice of images nor of their subsequent outcomes as this was purely an exploratory study. This was because not all patients were referred to these sessions by the facial pain service. Some of the patients were seen in busy oral medicine clinics who do not ask patients to complete questionnaires so the sociodemographic, pain intensity and quality of life were not recorded. It is difficult to introduce a control group as each information session

brings up different issues. In the future it would be useful to test for the optimum number of Pain Cards, as the high number makes them difficult to use in one to one sessions where the patients have not had a prior chance to review them. This needs to be carefully balanced in order not to remove the very Pain Cards that are needed. As with words it might therefore be difficult to restrict the numbers.³³ We know that the pain experience remains highly personal, is influenced by context and needs to be managed by a multidisciplinary team.³⁴ It may also be useful to determine if there are gender differences in choice of Pain Cards which potentially could be done once large samples are accumulated .

This study explored the use of the Pain Cards as a way of facilitating conversations around the impact and experience of living with BMS. Generally patients responded well to the use of the Pain Cards and the Pain Cards appeared to resonate strongly with the patients and their experience of living with the condition. Perhaps making these Pain Cards more widely available for health care professionals to use in consultations could provide patients with another way to express their experiences and help them to feel more understood and supported. This could potentially be of special use in settings where there is no access to pain psychologists.

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Captions for figures

Figure 1. Image of pain co-created by Deborah Padfield with Liz Aldous from the series *Face2Face*, 2008-2013 © Deborah Padfield

Figure 2. Image of pain co-created by Deborah Padfield with Chandrakant Khoda from the series *Face2Face*, 2008-2013 © Deborah Padfield.

Figure 3. Image of pain from the series *perceptions of pain*, 2001-2006

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Table 1 Number of images chosen

Number of images chosen	Women n=88	Men n=26	total
0	3	2	5
1	18	8	26
2	56	16	72
3	9	0	9
4	2	0	2
Total images used	165	40	205

Table 2: Pain Cards used to describe the characteristics of BMS

Image	Reason for choice	Frequency
5	shock-like, burning, unpredictable, on fire, tingling, metallic taste	9
26	funny, nasty, reduced, bitter taste, hot, citrus makes it worse, eating makes it better	8

43	lip area of pain, uncomfortable, if shuts mouth no symptoms, poor taste, halitosis, eating makes it worse, eating makes it better so worry re weight gain	7
27	pins and needles, prickling	6
23	sharp element, pin pricks, crawling	6
3	shooting, stinging sparks, burning, quick, powerful pain	5
18	burning pain on fire, hot	4
2	location widespread, beyond the mouth, diffuse, no focus present continuously	4
38	burning, needles	3
14	metallic taste	3
6	burnt, radiating, tight tongue, numb	3
1	burning, intense sharp, fire	3
51	salty taste	1
39	red hot knife	1
36	needles	1
32	constant tingling, thick saliva, eating makes it worse	1
30	dry, feels like a stone in the mouth	1

28	pain is all over, better if holds head	1
24	greyness of the image is like the taste	1
21	on fire hot	1
17	tingling and burning	1
15	continuous	1
10	barbed wire, itchiness	1
7	Burning, radiating everywhere	1
TOTAL		73

Table 3 Pain Cards chosen to describe impact and reasons for the choice

Image	Reason for choice	Frequency
9	held back by pain, restricts activities, dragging down, pain pulls away from enjoyable activities, burden, wish to cut the string and be without this heavy bag	11
21	tense, full of pain, frustrated, angry, annoyed, useless, feel down, feel vulnerable	8
29	nothing is abnormal, anxious, cannot go on, despair, nobody knows what going through	7
6	unable to free himself from this tightness, hands tied due to BMS, stopped activates, restricts life, stops going forward	6
28	pain is too much, wants to hide and get away, despair, black hole and does not know how to get out, everything is a big effort.	6
30	if hold head tight things would improve, despair, wants a new head, seems a small problem but goes on and on	6
43	terrified of opening her mouth, doesn't want to socialise, stops communication	6

42	sad, low self esteem, miserable, do not know how to deal with problem, cannot distract, striving to put colour back into the face	5
19	feels wound up, tense, need to unwind, tongue twisted, feels down	4
45	too many drugs, does not work, life dominated by medications	4
49	cannot do things, lost so much as a result of pain, huge impact on life	4
5	feels everything is breaking, things are dislocated, poor quality	3
10	suffering pain everywhere diabetic neuropathy, mesh of nerves not working, irritates and changed personality	3
11	feels unbalanced on one side, lack of colour indicates limited potential, complex problem	3
12	cannot do the things I used, something wrong inside, looks horrible like the tongue	3
14	alarm bells ringing, things were not moving in unison, unable to concentrate, things are all over the place	3
34	brings back negative memories of dentists, anxiety	3

40	loss of pleasure in life, isolating, embarrassed that dribbles	3
41	loss of confidence, fed up, sorry for herself, cannot go out, isolated	3
44	mouth is disintegrating, others do not know how feel, self conscious about loss of teeth	3
50	living in a cloud, all joy has been taken out of life, shadow of themselves, one step away from everybody	3
52	wants a phone to be able to get people to help her, crying on the phone, does not want to speak when in pain	3
53	wants to be contacting other people, no longer sociable, shuts herself off	3
54	gives hope, light at the end of the tunnel, nobody understands, feels in the dark	3
2	miserable, face is vulnerable, cannot do anything	2
3	tense, frustrated, when distracted no pain feels elated	2
15	break in life, frustrating, everything is interrupted, cannot see an end to it.	2
17	constant generalised malaise, loss of pleasure in life	2
35	inability to socialise, two years to get diagnosis and fed up with investigations	2

51	too much pain, nothing helps	2
1	in the dark and not sure where she is going	1
4	represents widespread fibromyalgia	1
13	intricate and represents multiple symptoms	1
18	feel like shadowing a person	1
20	feels all tied up can't speak	1
25	suffocating as if something is covering her face, stopping her functioning, stranger to family	1
31	retreat into a ball to get away from everybody	1
32	pensive, not sure what to do about it	1
33	light feels getting better	1
Total		127

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Figure 1 low res



Figure 2 low res



Figure 3 low res