

# Cognitive Behavioral Therapy for Patients with Trigeminal Neuralgia: A Feasibility Study

**H. Clare Daniel, DClinPsy**  
Buckinghamshire Healthcare  
NHS Trust  
London, United Kingdom

**Jolyon J.I. Poole, DClinPsy**  
**Helene Klein, MSc**  
Eastman Dental Hospitals  
University College London Hospitals  
NHS Foundation Trust  
London, United Kingdom

**Cleo Huang, MBBS**  
University College London  
London UK

**Joanna M. Zakrzewska, MD**  
Eastman Dental Hospital  
University College London Hospitals  
NHS Foundation Trust  
University College London Biomedical  
Research Centre University  
London, United Kingdom

## Correspondence to:

Prof Joanna M. Zakrzewska  
Royal National ENT & Eastman Dental  
Hospitals  
UCLH NHS Foundation Trust  
4th Floor Central  
250 Euston Road  
London NW1 2PQ  
Tel +44 07702279686  
Email j.zakrzewska@ucl.ac.uk

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**Aims:** To test the feasibility and acceptability of a customized six-session cognitive behavioral therapy (CBT) group intervention for adults with recurrent trigeminal neuralgia (TN). **Methods:** Fifteen participants with TN were recruited from a specialist facial pain unit in London, United Kingdom. The effects of the group intervention were evaluated using validated self-report measures, which the participants completed before and after the intervention and at 1-month and 9-month follow-ups. A semi-structured interview was also used at the 1-year follow-up to gather qualitative feedback of the group intervention. **Results:** Participants reported an increase in confidence in managing everyday tasks in the presence of TN symptoms, a reduction in negative beliefs about pain, and an increase in engagement in meaningful activity. All patients completed the group intervention (100% retention rate). Qualitative feedback highlighted that the group CBT intervention was helpful, and no participants reported a worsening of mood or experience as a result of the intervention. **Conclusion:** The trends for improvement in several domains, plus the positive experiences of the participants, suggest that a CBT management program is acceptable and feasible for this population and should be further developed and implemented on a larger scale to determine its clinical efficacy. *J Oral Facial Pain Headache* 2021;35:30–34. doi: 10.11607/ofph.2664

**Keywords:** cognitive behavioral therapy, facial pain, fear, pain management, multidisciplinary, patient satisfaction, quality of life, trigeminal neuralgia

**T**rigeminal neuralgia (TN) is characterized by severe, predominately unilateral, episodic facial pain lasting a few seconds to minutes in the distribution of one or more branches of the fifth cranial nerve.<sup>1</sup> People experiencing TN often liken it to a sudden electrical shock and/or stabbing that is triggered by light touch and by activities such as eating and washing. Some attacks of pain appear to occur spontaneously. People can experience anything from 4 or 5 attacks a day to over 30, but can have periods of remission lasting for months. TN is unpredictable and significantly impacts quality of life (QoL).<sup>2–6</sup> Currently, the first-line management of TN is a range of anti-epileptic medications; eg, carbamazepine and oxcarbazepine. Although effective, these medications result in significant side effects. Surgical procedures can also be effective but can result in pain recurrence, and the percentage and time to recurrence varies for different procedures.<sup>7</sup> Functional MRI scans in 15 patients showed that areas in the brain associated with cognitive and psychologic processes were activated in patients with TN, especially if the pain was spontaneous.<sup>8</sup> More recent studies of resting-state functional connectivity show changes in the anterior cingulate cortex (ACC). TN patients have abnormal gray matter volume, which is related both to affect and memory and can worsen with disease severity.<sup>9</sup> Given these studies, the introduction of a psychologic approach to helping people manage TN-related pain might prove beneficial and reduce the psychosocial burden of TN.<sup>10</sup>

People with TN report feeling scared or fearful of the next attack and even during pain-free periods may curtail their activities for fear of experiencing an attack.<sup>2</sup> This fear and anticipation of pain, and the experience of the pain itself, can result in avoidance of a range of activities,

such as eating, brushing teeth, facial contact, going out in cold weather, social activities, and sometimes work.<sup>2–5,11</sup> Anecdotally, people with TN fear touch triggering an attack and so prevent loved ones from touching their face “just in case” the pain is triggered.<sup>12</sup> Reductions in mood and QoL can be compounded by the fact that TN is rare (lifetime prevalence of 0.3% [95% CI: 0.1% to 0.5%]).<sup>13</sup> This can contribute to people having to manage the impact of late diagnosis or misdiagnosis, feelings of isolation, and lack of understanding from others.<sup>2,12</sup>

Cognitive behavioral therapy (CBT) pain management programs have been shown to help people reduce the physical, psychologic, and social impacts of their persistent pain on their lives.<sup>14</sup> The aim of these programs is not to reduce or cure the pain, but to help people live well in the presence of it.<sup>15</sup> To the authors' knowledge, no studies have been published on the use of psychologic interventions to reduce the impact and distress in the context of TN. The aim of this study is to test whether a six-session group CBT program for patients with TN was feasible and acceptable.

## Materials and Methods

### Participants

The participants were recruited from a facial pain service at a London Hospital during the period of January to November 2014. This is a National Health Service UK specialist outpatient service.

### Inclusion/Exclusion Criteria

Participants with a primary diagnosis of TN who were not being considered for surgical intervention were invited to attend the group program. Participants had to commit to attending all sessions of the group program. Participants who were in the surgical pathway for TN were not invited to attend the group, nor were participants who could not commit to the sessions, had active suicidal ideation, and/or had significant drug/alcohol comorbidities.

### Demographics

Seventeen participants were initially identified from routine clinics. Two declined due to the distance to the clinic and because they were not able to commit to all sessions of the intervention. Therefore, 15 participants entered the group CBT intervention. There were more women ( $n = 11$ ), and the mean age of the participants was 59 years ( $SD = 10.29$ ). All participants had experienced TN between 5 and 10 years duration. All participants completed the program.

### Measurements

Self-report standardized questionnaires were administered before and after the group intervention and at 1- and 9-month follow-ups.

### Pain Self-Efficacy Questionnaire

The Pain Self-Efficacy Questionnaire (PSEQ) is a 10-item measure that assesses a person's level of confidence in managing everyday activities despite the presence of pain.<sup>16</sup> Each item is rated on a 7-point scale from 0 = not at all confident to 6 = completely confident. The measure has a maximum score of 60, and higher scores reflect stronger self-efficacy beliefs.

### Depression Anxiety and Positive Outlook Scale

The Depression Anxiety and Positive Outlook Scale (DAPOS) is an 11-item measure that assesses levels of depression, anxiety, and positive outlook in relation to pain.<sup>17</sup> Each item is rated on a 5-point scale from 1 = almost never to 5 = almost all the time. Five of the items are focused on depression, 3 on anxiety, and 3 on positive outlook. Higher scores reflect a stronger relationship with each construct.

### Pain Catastrophizing Scale

The Pain Catastrophizing Scale (PCS) is a 13-item self-report measure that investigates the degree to which a person has a negative bias about their situation, their future, and emotional response to pain.<sup>18</sup> Each item is rated on a 4-point scale from 0 = not at all to 4 = all the time. This measure has a maximum score of 52, and higher scores reflect greater catastrophizing.

### Chronic Pain Acceptance Questionnaire

The Chronic Pain Acceptance Questionnaire (CPAQ) is a 20-item measure that assesses acceptance of chronic pain.<sup>19</sup> Each item is rated on a 7-point scale from 0 = never to 6 = always. This measure has two subscales: pain willingness and activity engagement. The maximum score is 120, and higher scores reflect greater acceptance.

### The Graded Chronic Pain Scale

The Graded Chronic Pain Scale (GCPS) is a 7-item measure that assesses degree of pain intensity and pain disability.<sup>20</sup> Scores are grouped into grades (1 to 4), and higher scores reflect greater levels of intensity and disability.

### Data Analysis

This study was a within-subject design, with all participants completing the measures across the four time points. The dependent variables were scores on the five measures/questionnaires (PSEQ, DAPOS, PCS, CPAQ, and GCPS). The independent variable was time of completion, with four levels (preprogram, postprogram, 1-month follow-up, and 9-month follow-up). Given the small sample size and multiple questionnaires, inferential statistics were not appropriate, and so descriptive statistics are reported.

**Table 1 Mean (SD) Scores of the Outcome Measures at the Four Time Points and Effect Sizes**

Measurements	Time				Effect size (d)	
	T <sub>1</sub>	T <sub>2</sub>	T <sub>3</sub>	T <sub>4</sub>	T <sub>1</sub> -T <sub>3</sub>	T <sub>1</sub> -T <sub>4</sub>
<b>PSEQ</b>	37.17 (11.99)	47.17 (7.33)	45.62 (12.36)	42.89 (13.16)	0.69	0.45
<b>DAPOS</b>						
Depression subscale	10.50 (3.16)	8.00 (2.45)	7.55 (3.05)	6.44 (2.70)	0.95	1.38
Anxiety subscale	6.71 (2.40)	7.00 (2.94)	6.82 (2.89)	6.22 (3.19)	0.04	0.17
Positive outlook subscale	9.93 (2.76)	11.57 (2.23)	10.36 (4.52)	10.89 (3.69)	0.11	0.29
<b>PCS</b>	27.93 (15.67)	27.50 (9.21)	22.00 (9.64)	23.78 (15.67)	0.45	0.26
<b>CPAQ</b>	51.38 (17.59)	60.00 (13.63)	64.55 (17.18)	60.44 (19.81)	0.76	0.48

PSEQ = Pain Self-Efficacy Questionnaire; DAPOS = Depression Anxiety and Positive Outlook Scale; PCS = Pain Catastrophizing Scale; CPAQ = Chronic Pain Acceptance Questionnaire; T<sub>1</sub> = beginning of 6-week program; T<sub>2</sub> = end of 6-week program; T<sub>3</sub> = 1 month after end of 6-week program; T<sub>4</sub> = 9 months after end of 6-week program.

### Procedure

Potential participants were given verbal and written information on the CBT group intervention and were invited to attend. Participants opted in to the study and signed a consent form allowing their data to be used for the purpose of evaluating the intervention. Participants were informed that they could withdraw from participating in the intervention at any time without having to provide a reason and that participating in the study would not affect their usual care. The intervention was based on the services' existing pain management program, which used the widely cited CBT pain management model.<sup>14</sup> Participants completed outcome measures at the start of the group intervention and at the end of the six sessions. Participants also completed the outcome measures at the 1- and 9-month follow-ups. Last, participants were invited for an interview to give qualitative feedback on their experience of the intervention by a medical student (C.H.) not involved in the delivery of the intervention. These interviews were conducted between 6 and 17 months after the intervention and included the GCPS outcome measure.

### Details of the intervention

The group intervention was delivered by a clinical psychologist and a physiotherapist, both with over 10 years experience working in chronic pain services using a CBT model. One section of a session was delivered by either a clinical nurse specialist regarding medical management of TN or by a consultant in facial pain. The program was supervised by a senior psychologist (C.D.) who runs all the facial pain programs in the unit. The group intervention was based on the services' existing pain management program and adapted for TN. The sessions focused on the following topics: psychoeducation on understanding the pain mechanisms of TN; medical management of TN; mindfulness-based stress reduction principles and exercises; values-based goal setting; activity pacing; understanding the influences of thoughts, feelings, and behaviors in relation to the pain experience; working with unhelpful thoughts; managing

distressing emotions, developing communication skills with significant others and health care providers; sleep hygiene; facial movement exercises; and managing increases in pain/attacks of TN. The sessions were facilitated over six weekly sessions, with each session lasting 3 hours, equating to 18 hours of clinical time. Participants were given supplementary written material to support learning and were encouraged to practice skills and work toward individually set goals between sessions, which were reviewed at the beginning of each session. This structure has been shown to be effective for the psychosocial management of chronic orofacial pain (which does not have a TN focus) and more widely.<sup>19</sup> There were three groups consisting of five, six, and four participants. Given that the intervention was influenced by patient need, there were some small variations in the program content among the groups; eg, one group had a slightly longer session on sleep, as that had been a particular issue for the members of that group.

## Results

The mean scores of the outcome measures are calculated and presented in Table 1.

### Graded Chronic Pain Scale

At the first visit to the service, 10 participants scored grade 3 or 4, whereas at the 9-month follow-up, only 2 participants scored grade 3 and 1 scored grade 4, showing a general reduction in pain-related disability.

### Treatment Retention and Acceptability

All participants completed the 6-week intervention and two follow-ups at 1 month and 9 months, meaning there was a 100% treatment retention rate.

All participants were invited to give feedback on their experience of the intervention using an exit survey designed by the investigators. The survey included questions on their overall experience of the program, as well as specific questions that focused

on their experience of components of the program. Participants were asked to rate their experience of the program on a 1 to 5 scale (1 = poor and 5 = excellent). For these ratings, 73% ( $n = 11$ ) of participants rated the program as 5, 20% ( $n = 3$ ) rated it as 4, and 7% ( $n = 1$ ) rated it as 2. When asked what the most useful component of the program was, the most commonly reported were: education about TN; mindfulness/present moment awareness exercises; noticing and distancing self from common thinking habits; and working toward value-informed goals. On completion of the program, 47% ( $n = 7$ ) of participants reported subjective improvement in their mood, and 53% ( $n = 8$ ) of participants reported no subjective change in mood. No participants reported a worsening in their mood, and 47% of the participants reported that they thought the program should be more widely available. Patients continued to access care through the general practitioner or by attending a specialist outpatient clinic, with 2 attending the Emergency Department (1 patient was concerned they had taken too much carbamazepine in one dose, and the other patient attended because they had run out of medication).

## Discussion

The main aims of a feasibility study can include assessing the ability to recruit participants, designing suitable outcome measures, and assessing follow-up rates and response rates to questionnaires.<sup>21,22</sup> Fifteen participants entered and completed the CBT intervention. Qualitative feedback suggested that all aspects of the program were helpful, and participants experienced high levels of satisfaction with the intervention. These factors would suggest that a pain management program for patients experiencing TN is eminently feasible. These findings are in keeping with CBT interventions for other chronic health conditions.<sup>14</sup>

It is important not to place significant meaning on these data, given that this is a feasibility study with a sample size of 15. Although effect sizes were included for the purposes of guiding future research, the authors emphasize caution and do not feel the value in commenting on the effect sizes in any detailed way based on the number of participants. All questionnaires showed a trend in the desired direction. Although some changes were small and the statistical significance cannot be commented upon, examples such as the clinically significant reduction on the PCS measure were of interest, given the association of high PCS scores with negative QoL. Scores on the PSEQ increased, which suggests that participants increased their overall functioning in everyday living in the presence of pain. However, no change was found on the anxiety subscale

of the DAPOS. This may reflect the focus of the intervention, which is to increase functioning (ie, doing more things with difficulty) rather than on symptom reduction (ie, reducing difficulty). But given that anticipatory anxiety, which can lead to behavioral and situational avoidance, is a common and central figure of TN sufferers, this would warrant further exploration and the use of a measure of anticipatory anxiety. Overall, there is evidence to suggest that CBT interventions could be beneficial for patients with TN, with the potential to modify levels of pain catastrophizing and engagement in meaningful activity. The authors are continuing to monitor and evaluate the present intervention with larger numbers of participants, which will allow reporting and commenting on effect sizes. A multi-center study could also be conducted to test this intervention's generalizability with comparisons against a wait list condition, as this would overcome some of the methodologic limitations of the current study.

This study also highlighted two areas that the team would like to refine and develop further. First, a large number of self-report measures were used to cover the domains proposed by the multi-institutional Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT). A systematic review of outcomes used in patients with TN shows that none of these questionnaires have been used and that this is the first time that several different domains are being assessed.<sup>23</sup> It is essential to obtain balance between receiving the data required and not overburdening participants with questionnaires. A PhD is now being undertaken to determine the core outcome set for TN and to relate these to the measures currently used. Second, two participants who were initially identified for the CBT intervention declined participation due to traveling reasons. This is a common issue for patients, particularly any patients accessing specialist national services that are largely based in London. The authors hope to make their service more accessible in the future by providing additional ways of entering the pain management programs using teleclinics and online group interventions (which are currently being trialed and evaluated). This could potentially help minimize geographical distance and financial barriers to accessing hospital-based group interventions.

## Conclusions

Even during times of remission, TN can have a profound effect on QoL due to fears about future pain being triggered and avoidance behaviors. Based on the data collected for this feasibility study and data from the literature, there is a role for psychologic (cognitive-behavioral) interventions to support pa-



tients in reducing some of the negative consequences of experiencing TN. Further research should be conducted to evaluate efficacy with larger samples, as well as with studies examining the common psychologic factors that maintain fear during periods of remission.

## Highlights

- TN can have a significant impact on a patient's QoL.
- To the authors' knowledge, no study has been published on psychologic interventions for patients in distress living with TN.
- This study highlights the feasibility and accessibility of providing a psychologic intervention for this group of patients in a national specialist facial pain service.
- This study is the first step in further developing psychologic interventions for patients to live well with TN.
- CBT interventions have the potential to modify levels of pain catastrophizing and engagement in meaningful activity.

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