

Exploring patient satisfaction of a joint-consultation clinic for trigeminal neuralgia: Enabling improved decision-making

British Journal of Pain
2021, Vol. 0(0) 1–6
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/20494637211045877
journals.sagepub.com/home/bjp


Jolyon Poole¹ , Valeria Mercadante^{1,2}, Sanjeet Singhota³, Karim Nizam⁴ and Joanna M Zakrzewska^{1,2,4} 

Abstract

Background: Trigeminal neuralgia (TN) is a relatively rare condition which has a profound impact not only on the patient but also on those around them. There is no cure for TN, and the management of the condition is complex. The most effective forms of treatment are either through medication, neurosurgery, or combination of the two. Each option has risks and implications for the patient. As with all clinical decisions, it is important for patients to understand and be fully informed of the treatments available to them. A London UK unit adopted a joint-consultation clinic approach where the patient meets with both physician and neurosurgeon at the same time to discuss treatment options. The purpose of this evaluation is to understand patients' level of satisfaction with the joint-consultation clinic and evaluate utilisation of a clinical decision-making tool.

Method: Patients who had attended the joint-consultation clinic over a period of 12 months were invited to participate in a telephone or paper survey (N = 55). Responses were analysed using descriptive statistics and thematic analysis.

Results: Forty-one patients (77% response rate) participated in the survey, and the results were overwhelmingly positive for the joint-consultation clinic regarding satisfaction. The benefits were broad ranging including increased understanding, collaboration and confidence in decision-making.

Conclusions: A joint-consultation clinic comprising a neurosurgeon and a physician for the treatment of TN is valued by patients who become better informed and able to make decisions about their care. Positive application of clinical decision-making aids in this situation offers potential across specialities.

Keywords

Trigeminal neuralgia, multidisciplinary, patient satisfaction, neurosurgery, decision making

¹Eastman Dental Hospital, University College London Hospitals NHS, UK

²UCL Eastman Dental Institute, London, UK

³University of Birmingham, Birmingham, UK

⁴University College London, London, UK

Corresponding author:

Jolyon Poole, Eastman Dental Hospital, University College London Hospitals NHS, 179A Tottenham Court Road, London, UK.

Email: Jolyon.poole@nhs.net

Introduction

Trigeminal neuralgia (TN) is defined by the Headache Classification Committee of the International Headache Society as 'a disorder characterised by recurrent unilateral brief electric shock-like pains, abrupt in onset and termination, limited to the distribution of one or more divisions of the trigeminal nerve and triggered by innocuous stimuli'.¹ TN has a significant impact on mood and activities of daily living. It is further compounded by late diagnosis and inappropriate care-pathways.² TN is one of the few neuropathic pain conditions that can be successfully treated both medically and surgically.³ Patients, therefore, need to make some potentially difficult decisions which include remaining on their current medications with associated side effects or having neurosurgery procedures some of which are highly invasive. Each of these options carries different risks. In a study of decision making in hypothetical scenarios, 156 patients with TN marginally thought that surgical procedures offered the best chance of good quality of life.⁴ A survey among patients who underwent microvascular decompression showed that over 70% would have liked to have had surgery earlier.⁵ There is, therefore, a need for patients to have the opportunity to discuss all possible options open to them so that shared decision making can take place and the most appropriate treatment for the individual can be implemented as soon as possible.

There is growing evidence that patients can have better outcomes and experiences of healthcare treatment when supported with the use of decision-making aids, for example, have a greater perception of personal risk, feel that their values are taken into consideration and report fewer regrets if their choice of treatment results in complications.⁶ In order to make better decisions, patients with TN need to have access to both neurosurgeons and physicians at an early stage. In a study by the Danish Headache team, positive gain was demonstrated when patients were seen both by neurologists and neurosurgeons, albeit not at the same time but before any surgical procedure is carried out.^{7,8} Thus, opportunity for patients to have a discussion with both specialists enables them to come to a more shared informed decision. There are no data currently available on the value of both a physician and neurosurgeon to be physically present at the same face-to-face consultation. It is potentially a more expensive service to run, requires more co-ordination and so needs to show benefit.

This prospective service evaluation reviewed the care provided at one UK unit (London) where all patients with TN are first seen by an expert physician who phenotypes the patients, organises a thin cut high quality Magnetic resonance imaging (MRI) scan and is invited to a joint-consultation clinic. At the joint-consultation

clinic, the neurosurgeon discusses the result of the MRI and which surgical options are possible given the MRI findings and the medical history. Both neurosurgeon and physician provide their views on potential future management. The patient is given the Ottawa Personal Decision Guide^{9,10} which lists their own possible options to help them discuss these issues with others and to determine if they have other questions. After the consultation, the patient receives a letter explaining the surgical options as well as an information booklet from the Brain and Spine Foundation which includes details of a patient support group. The patient can decide at the time of the appointment whether they wish to go ahead with a surgical option at which point they will be put on a waiting list. If they want to think things through, they are given further review appointments with the physician or neurosurgeon and are provided with contact details to both services. At any point, the patient can opt to have surgery by telephoning the neurosurgery department, and there is no need for a new referral. This service has run for over 10 years and over 400 patients have attended. The primary aim of this service evaluation was to understand how patients experienced the joint-consultation clinic for TN. Although information on how patients experience the whole service is of interest to us, we were particularly interested in how patients experienced the clinical decision-making process for their care and what decisions they made about further treatment. The potential outcomes of this evaluation included feedback-informed ways of improving the patient experience of the TN service.

Methods

Design

The evaluation used a mixed-methods approach in the form of a paper or telephone survey containing both open and close-ended questions. The survey was based on the Picker Institute principles¹¹ which have been widely adopted in National Health Service (NHS) patient experience research. These principles cover different dimensions of patient experience which include access to reliable health advice, effective treatment delivered by trusted professionals, participation in decisions and respect for preference, clear information and support for self-care, attention to physical and environmental needs, emotional support, empathy, respect and involvement of, and support for family and carers and continuity of care and smooth transitions. Baseline characteristics, for example, demographics and outcomes from clinics, were collated from existing Trust electronic data systems which are routinely accessed as standard practice. Responses to close-ended questions on different aspects of their experience of the consultati¹² on were

Table 1. Demographics of survey responders and non-responders based on medical records.

	Responders	Non-responders
Number	41	14
Age (mean)	55.1	59
Gender	30 female, 11 male	11 female, 3 male
Diagnosis	38 TN and 3 SUNA	12 TN and 2 SUNA
No. who went on to have surgery	22	6
No. who had surgery and were now pain free	11 MVD, 2 RT, 2 GR and 1 SRS	3 MVD, 1 RFT and 1 SRS
No. who had surgery and continue to have pain and on medication	2 GR, 2 RFT and 2 MVD	1 SRS
No. currently on medication	29	7

GR: glycerol rhizotomy; MVD: microvascular decompression; RFT: radiofrequency thermocoagulation; SRS: stereotactic radiosurgery; SUNA: short unilateral neuralgiform pain with autonomic features; TN: trigeminal neuralgia.

collated and presented in chart form. A thematic analysis procedure identified common perspectives from the responses of the open-ended survey questions.^{12,13}

Sample

All patients with capacity to provide verbal informed consent who attended the joint-consultation clinic over the course of 12 months (January 2018 to December 2018) were included. The survey was conducted in Spring of 2020 which provided time for patients to have made decisions about their care. We excluded one patient who did not speak fluent English and one who had died. This left a sample of 55 patients (50 patients with a diagnosis of TN and 5 patients with Short-Lasting Unilateral Neuralgiform Headache Attacks (SUNA)).

Procedure

Patients were sent an invitation letter which included the survey and a pre-paid envelope to return the questionnaires (supplemental material). Those who did not return the questionnaires were contacted by one of two medical students who were not part of the unit (authors SS and KN) by telephone and given verbal information about the service evaluation. Patients were made aware that participation was optional and had no impact on their current or future standard of care. They were given the option of delaying their decision to participate in the evaluation and to decide a suitable time for the interview. On completion of the survey, patients were asked whether they have any further queries, questions or concerns regarding their participation and signposted accordingly. They were reminded that they had been given the Brain and Spine Foundation booklet and the Ottawa Personal Decision Guide.

Ethics

The evaluation project was approved and registered by the local hospital audit committee. As this was a service

evaluation, it was not considered necessary to obtain written consent.

Results

Of the 55 patients who were eligible, 24 answered the paper questionnaire and 17 replied to a telephone survey giving a total of 41 participants (77% response rate). One patient had died, and one said she was in too much pain to reply. The remaining 12 patients declined to participate or were not contactable.

Table 1 shows details of the treatments that both the respondents and the non-respondents had undergone and what the outcomes were based on the medical records. Of the respondents, 22 had undergone surgery following on from the clinic, and four of them previously had surgery and had opted to have further surgery. Of the 16 surgical patients who reported being 'pain free', four of them needed medications (two lamotrigine, one each of oxcarbazepine and baclofen). The other six surgical patients reported some pain and were on the following medications: two on carbamazepine, and one each on oxcarbazepine, pregablin and lamotrigine. Of the 19 patients who had not opted for surgery, nine were on oxcarbazepine, four on lamotrigine, three on carbamazepine, and one each on pregablin, phenytoin and cannabinoid. Half of the non-responders were on medications.

Quantitative responses

The responses to the closed-ended questions are shown in Table 2. The participants were asked to rate each statement using a scale from 1 to 7 (1 = not at all; 7 = very much so).

Qualitative responses

Patients were also asked in what ways the consultation met or did not meet their expectations. 39 responses

Table 2. Survey responses.

Components of the joint consultation	1 = not at all, %	2	3	4, %	5, %	6, %	7 = very, %	N/a, %
1 How helpful to have the surgeon explain TN and what the potential treatment options are?	0	0%	0%	2.4	4.9	14.6	75.6	0
2 How helpful to have the surgeon explain the operation and potential complications?	0	0%	0%	0	4.9	7.3	75.6	12.2
3 How helpful to be shown pictures of the operation?	0	0%	0%	0	4.9	14.6	31.7	48.8
4 How helpful was the Brain and Spine Foundation booklet?	2.4	0%	0%	9.8	22	9.8	36.6	19.5
5 How helpful was the letter summary outlining procedures?	0	0%	0%	7.3	7.3	24.4	48.8	12.2
6 To what extent did you feel involved in decision making?	0	0%	0%	4.9	0	19.5	75.6	0
7 To what extent did you feel supported in making decisions?	0	2.4%	0%	0	7.3	26.8	63.4	0
8 To what extent did you feel listened to?	0	0%	0%	0	4.9	9.8	58.5	26.8
9 To what extent did you feel your understanding of TN improved?	0	0%	0%	0	17.1	19.5	61	2.4
10 To what extent did you feel confident in proceeding with treatment?	0	0%	2.4%	7.3	2.4	19.5	65.9	2.4
11 Overall, how satisfied are you?	0	0%	2.4%	0	0	17.1	78	2.4

TN: trigeminal neuralgia.

Table 3. Identified themes with examples.

Theme	Examples
Theme 1: How information was given and received in this joint-consultation clinic	<p><i>Really helpful to have things explained in person. They covered everything I needed to know and put my mind at rest</i></p> <p><i>I was given a clear understanding of my condition and treatment options very clearly</i></p> <p><i>The results of MRI was explained well, all my treatment options plus implications of each one was clearly explained. I was given plenty of time to go away and make a decision</i></p> <p><i>Clarity, coherence, precision in terms of treatment options and diagnosis and all explained in layman's terms</i></p>
Theme 2: Feeling understood and listened to	<p><i>I felt listened to, the family felt involved, I felt comfortable and relaxed. I went in full of nerves and came out convinced to go ahead</i></p> <p><i>The reassuring language was a big thing. I am not a medical professional, but it was pitched at the right level in a way I could understand</i></p> <p><i>Excellent empathy, knowledge and compassion never rushed, always listened, given a lot of time</i></p> <p><i>They showed real concern and were kind and sympathetic. I felt I was in the best hands anyone could hope for</i></p>
Theme 3: Seeing two clinicians at the same time	<p><i>The professor and surgeon had a great partnership. I felt very satisfied I was very satisfied. The most positive thing was the joint approach...because it's quite scary</i></p> <p><i>(As) both professionals were there, they covered everything I needed</i></p> <p><i>Having one to one with the surgeon with ...present. Having all surgical procedures explained...giving me confidence to which treatment</i></p>

were recorded for how the consultation met their expectations, and themes were derived from these (see [Table 3](#)). There were not enough responses to generate themes for how the consultation did not meet expectations (one did not provide a response and one said they had wanted to be 'pain free' and this was not the case for their situation). Similarly, there were not

enough responses to generate ideas on improving the service.

Discussion

Fifty-five patients who attended a joint-consultation clinic for the treatment of TN were approached to

provide feedback on their experiences of accessing the service. The 77% response rate ($n = 41$ patients) constituted a fairly representative sample of all those attending the clinic. There was a higher number on non-responders for whom English was not the first language and only one had been excluded from the survey. This joint-consultation clinic in the UK is unique, and there are practical and financial implications for the use of this model. This is the first evaluation to our knowledge that looks to understand the patients' experience of this joint-consultation model which enables improved decision making. The responses are overwhelmingly positive for the benefits of having a joint-consultation model. Patients reported that there were broad-ranging benefits in terms of decision-making, collaboration and understanding which are important given the effects of living with TN.

The current management of this cohort with 51% opting to have surgery is in line with the study by Spatz et al.⁴ on decision making where there was a slight preference for surgical therapies. This number opting for surgery is much higher than reported by Heinskou et al.⁷ who at two-year follow-up reported that 27% of their 186 patients had opted for surgery, and Di Stefano et al.¹⁴ reported that 7% of the cohort of 178 was referred for surgery over a mean period of 7 years. These differences could be cultural, potentially due to fewer debilitating patients being seen or neurologist's higher threshold for referral to neurosurgeons. In this clinic, all patients are encouraged to attend even if they are not contemplating surgery because they are satisfied with their medical management.

The survey shows that patients were given the opportunity to understand the potential benefits and harms of these treatment options. The National Institute for Health and Care Excellence (NICE) and NHS England are working towards improving shared decision making, but Joseph-Williams et al.¹⁵ suggest that adoption of this in routine practise has been very difficult, and the one of the biggest challenges to implementation are the clinicians themselves.

Strengths of this study include that the researchers (two medical students) were independent of the Multi-disciplinary Team (MDT) team, and the outcomes are known for the whole cohort. On the basis of this study, we would suggest that all patients with TN should use a decision aid as part of informed consent in order to ensure high-quality patient-centred care given the significant differences in treatment options and outcomes. There are hundreds of decision aids many of which have been tailored for specific conditions. The Ottawa Personal Decision Guide is a generic one that is easy to use either in paper format or as a Portable Document Format (PDF) and has been used for over 20 years and is evaluated in a Cochrane systematic review.^{6,10} Patients with

TN have to decide whether to continue with medications that give significant side effects, are reversible and need to be used long-term or to opt for neurosurgery.¹⁶ Micro-vascular decompression which provides the best outcomes is a major neurosurgical procedure and therefore carries with it risks and potential for irreversible complications.³ The ablative procedures carry lower risk but may need to be repeated after a number of years.

It is suggested that one of the advantages of shared decision making and use of decision aids is that patients have fewer regrets about their choices although the systematic review by Stacey et al.⁶ showed it does not change satisfaction per se, and no difference was found on whether the decision aid was used before or during the consultation. In this evaluation, patients were given a range of written materials, a detailed letter, booklet on TN, details of access to a patient support group and a decision aid, but the evaluation did not determine which ones were most useful in helping them come to their decisions. More work could be done in determining how these are best used. We have no control group to determine the views of patients who were being managed without attendance at this clinic which is a limitation to the evaluation.

Clinical relevance

- Patients with TN face difficult decisions whether to opt for medications or neurosurgical treatments to obtain pain relief and better quality of life.
- Patients with TN attending a joint clinic with a neurosurgeon and physician show high satisfaction.
- It is important to provide patients with a range of materials to help them make their decisions about future treatments.
- Over 50% of patients attending an MDT clinic opted to have surgery.

Acknowledgements

We are grateful to Professor L Zrinzo and Mr Lewis Thorne, the neurosurgeons, for allowing us access to the patients. Dr Priya Thakkar provided early input into the aims and objectives of the study. Grateful thanks to T. Belai for preparing the questionnaires and sending them out. We are grateful to all the patients for responding to our survey.

Contributionship

J.M.Z., V.M., J.P. participated in the design of the study. S.S. and K.N. implemented it. All authors contributed to the evaluation of the results, the writing and approval of the final manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

J.M.Z. was partially funded from the oral health division of the National Institute for Health Research University College London Hospitals Biomedical Research Centre. Funding for data collection was obtained from the Facial Pain Research Foundation USA.

Informed consent

Patients were sent an invitation letter which included the survey and a pre-paid envelope to return the questionnaires. Those who did not return the questionnaires were contacted by one of two medical students who were not part of the unit (authors S.S. and K.N.) by telephone and given verbal information about the service evaluation. Patients were made aware that participation was optional and had no impact on their current or future standard of care. On completion of the survey, patients were asked whether they have any further queries, questions or concerns regarding their participation and signposted accordingly.

Ethical approval

(include full name of committee approving the research and if available mention reference number of that approval): UCLH RENT & Eastman Departmental Audit Lead – Sonita Koshal & Daniela Ion.

Guarantor

J. P.

ORCID iDs

Jolyon Poole  <https://orcid.org/0000-0003-4061-1300>
 Joanna M Zakrzewska  <https://orcid.org/0000-0001-7805-5851>

Supplementary material

Supplementary material for this article is available online.

References

- Headache A. Headache classification committee of the international headache society (IHS) the international classification of headache disorders, 3rd edition. *Cephalalgia* 2018; 38: 1–211. DOI: [10.1177/0333102417738202](https://doi.org/10.1177/0333102417738202).
- Allsop MJ, Twiddy M, Grant H, et al. Diagnosis, medication, and surgical management for patients with trigeminal neuralgia: A qualitative study. *Acta Neurochirurgica* 2015; 157: 1925–1933.
- Bendtsen L, Zakrzewska JM, Abbott J, et al. European academy of neurology guideline on trigeminal neuralgia. *Eur J Neurol* 2019; 26: 831–849. DOI: [10.1111/ene.13950](https://doi.org/10.1111/ene.13950).
- Spatz AL, Zakrzewska JM and Kay EJ. Decision analysis of medical and surgical treatments for trigeminal neuralgia: How patient evaluations of benefits and risks affect the utility of treatment decisions. *Pain* 2007; 131: 302–310.
- Zakrzewska JM, Lopez BC, Kim SE, et al. Patient reports of satisfaction after microvascular decompression and partial sensory rhizotomy for trigeminal neuralgia. *Neurosurgery* 2005; 56: 1304–1312.
- Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Systematic Reviews* 2017; 4: CD001431. DOI: [10.1002/14651858.CD001431.pub5](https://doi.org/10.1002/14651858.CD001431.pub5).
- Heinskou TB, Maarbjerg S, Wolfram F, et al. Favourable prognosis of trigeminal neuralgia when enrolled in a multidisciplinary management program - A two-year prospective real-life study. *The Journal Headache Pain* 2019; 20: 23. DOI: [10.1186/s10194-019-0973-4](https://doi.org/10.1186/s10194-019-0973-4).
- Heinskou T, Maarbjerg S, Rochat P, et al. Trigeminal neuralgia - A coherent cross-specialty management program. *The J Headache Pain* 2015; 16: 66. DOI: [10.1186/s10194-015-0550-4](https://doi.org/10.1186/s10194-015-0550-4).
- O'Connor AM, Drake ER, Fiset V, et al. The Ottawa patient decision aids. *Eff Clinical Practice* 1999; 2: 163–170.
- Hoefel L, Lewis KB, O'Connor A, et al. 20th anniversary update of the Ottawa decision support framework: Part 2 subanalysis of a systematic review of patient decision aids. *Med Decis Making* 2020; 40: 522–539. DOI: [10.1177/0272989X20924645](https://doi.org/10.1177/0272989X20924645).
- Picker Europe: surveys & toolkits [Internet]*. <http://picker.org> (2020, accessed 1 March 2020).
- Creswell J. Analyzing and Interpreting Qualitative Data. *Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research*. Pearson Education, Inc, 2012.
- Braun V and Clarke V. Using thematic analysis in psychology. *Qual Research Psychology* 2006; 3: 77–101.
- Di Stefano G, La Cesa S, Truini A, et al. Natural history and outcome of 200 outpatients with classical trigeminal neuralgia treated with carbamazepine or oxcarbazepine in a tertiary centre for neuropathic pain. *J Headache Pain* 2014; 15: 34. DOI: [10.1186/1129-2377-15-34](https://doi.org/10.1186/1129-2377-15-34).
- Joseph-Williams N, Lloyd A, Edwards A, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ* 2017; 357: j1744. DOI: [10.1136/bmj.j1744](https://doi.org/10.1136/bmj.j1744).
- Coats RO, Crossley KL, Conlin N, et al. Cognitive and sensorimotor function in participants being treated for trigeminal neuralgia pain. *Journal Headache Pain* 2020; 21: 91. DOI: [10.1186/s10194-020-01156-9](https://doi.org/10.1186/s10194-020-01156-9).