

Article type: Original Manuscript

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

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ABSTRACT

Background: Trigeminal Neuralgia (TN) is a relatively rare condition which has a profound impact not only on the patient, but 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. In one UK unit, a joint-consultation clinic is adopted 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.

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: 41 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 of 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. Furthermore, there could be a role for the use of clinical decision-making aids across other specialities.

Key words: trigeminal neuralgia, multidisciplinary, patient satisfaction, neurosurgery, decision making.

INTRODUCTION

Trigeminal neuralgia (TN) is defined by the Headache Classification Committee of the International Headache Society (IHS) ¹as “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 which are potentially compounded by late diagnosis and inappropriate care-pathways. TN is one of the few neuropathic pain conditions that can be successfully treated both medically and surgically. ² 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 carry 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. ³ A survey among patients who underwent microvascular decompression showed that over 70% would have liked to have had surgery earlier. ⁴ 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.

There is growing evidence that patients who are encouraged to make more informed decisions have better outcomes and better experiences. They may also report fewer regrets if their choice of treatment results in complications, which is important from a medico-legal perspective. To facilitate this process of informed consent, a wide variety of decision aids are used. A recent Cochrane review shows that their use does result in better informed patients as they have improved perception of risk and that decisions are based on their

personal values.⁵ In order to make better decisions patients with TN need to have access to both neurosurgeons and physicians at an early stage. This has recently been highlighted by the Danish Headache team.^{6,7} In the Danish service, however, although patients are seen both by neurologists and neurosurgeons before any surgical procedure is carried out, there is no joint assessment. Thus, there is no opportunity for patients to have a discussion with both specialists and so come to a more shared informed decision. There is no data currently on the value of both a physician and neurosurgeon to be physically present at the same face to face consultation. It potentially is a more expensive service to run, requires more co-ordination and so needs to show benefit.

In one UK unit, all patients with TN are first seen by an expert physician who phenotypes the patients, organises a thin cut high quality 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 neurosurgeons and physician provide their views on potential future management. The patient is given the Ottawa personal decision guide^{8,9} 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, 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 in 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 (please see supplementary material). The survey was based on the Picker Institute principles which have been widely adopted in 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, comprehensible 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 e.g. demographics, 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 consultation were collated and presented in chart form. A thematic analysis procedure¹⁰ was used to analyse the responses to the open-ended survey questions. Thematic analysis

is an appropriate method for analysing open-ended survey data as it enables common perspectives to be identified.¹¹

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 patients who do not speak fluent English. This left a sample of 55 patients.

Procedure

Patients were sent an invitation letter with the survey with 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.

The demographics and choices that both responders and non-responders made are shown in table 1.

INSERT TABLE 1

Of the respondents 22 had undergone surgery following on from the clinic, four of them had 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 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, one each on pregablin, phenytoin, cannabinoid.

Quantitative responses

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

INSERT TABLE 2

Qualitative responses

Patients were asked in what ways the consultation met or did not meet their expectations. 39 responses were recorded for how the consultation met their expectations and themes were derived from these (see Table 2). There were not enough responses to generate themes for how the consultation did not meet expectations (1 did not provide a response and 1 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.

INSERT TABLE 3

DISCUSSION

Fifty-five patients who attended a joint-consultation clinic for the treatment of trigeminal neuralgia were approached to provide feedback on their experiences of accessing the service. The 77% response rate (n=41 patients) constituted a representative sample of all those attending the clinic. 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 is important given the effects of living with trigeminal neuralgia.

The current management of this cohort with 51% opting to have surgery is in line with the study by Spatz et al 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 ⁶ who at two year follow-up reported that 27% of their 186 patients had opted for surgery and Di Stefano et al ¹² reported that 7% of the cohort of 178 were referred for surgery over a mean period of 7 years. These differences could be cultural, potentially due to less debilitating patients being seen or neurologists 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 get answers to what their options were, what the benefits and harms of these options were and which of these could happen to them. This is in line with the Shepherd et al ¹³ study on a clinician communication model. It also fulfils our duty of care to ensuring patients are provided with all options including that of no surgery and no medication. NICE and NHS England are working towards improving shared decision making but Joseph-Williams et al ¹⁴ 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.

One of the strengths of this study is the multidisciplinary team who did the evaluation as they were all independent of the 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 PDF and has been used for over 20 years and is evaluated in a Cochrane systematic review.^{5,9} 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.¹⁵ Microvascular decompression which provides the best outcomes is a major neurosurgical procedure and therefore carries with it risks and potential for irreversible complications.² The ablative procedures carry lower risk but may need 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 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.⁵ 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. Using multiple resources has meant that patients have been provided with educational material which can then help in the process of consent. A fully informed patient is therefore less likely to make a complaint. 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 trigeminal neuralgia face difficult decisions whether to opt for medications or neurosurgical treatments to obtain pain relief and better quality of life.
- Patients with trigeminal neuralgia 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.

CONTRIBUTIONS

JZ, VM, JP participated in the design of the study. SS and KN implemented it. All authors contributed to the evaluation of the results, the writing and approval of the final manuscript.

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.

FUNDING

JZ 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.

DECLARATION OF CONFLICTING INTERESTS

No authors have any conflict of interest

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