

Clinical Article

Patient satisfaction after surgery for trigeminal neuralgia – development of a questionnaire

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Received July 27, 2004; accepted June 3, 2005; published online August 9, 2005

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Summary

Objective. This project aimed to prepare a self complete patient satisfaction survey for patients who have undergone surgery for trigeminal neuralgia and then assess its reproducibility, validity and acceptability in one centre.

Methods. The questionnaire, for initial use in patients who had undergone posterior fossa surgery for trigeminal neuralgia, was designed after a systematic review of the surgical literature had been performed and discussions held at the US and UK Trigeminal Neuralgia Support group meetings. It underwent several changes after input from neurosurgeons, patients, copywriter and statistician and finally contained 44 questions, the SF12, Hospital Anxiety and Depression Scale (HAD), Brief Pain Inventory (BPI) and McGill Pain questionnaire (MPQ). From the total number of 413 patients in the database of one centre the questionnaire was sent with a covering letter to 305 patients, the rest had died (25), were lost to follow up (26) or did not meet the inclusion criteria (56). One patient had bilateral PSR. The completed questionnaires were evaluated by an independent physician, neurosurgeon and patient. A repeat questionnaire was sent to 10% of the patients to check reproducibility.

Results. The questionnaires were well completed with a final response rate of 92%. It appeared to be highly acceptable and reproducible but needed adjustment to improve its validity before being used in other centres and for all surgical procedures. A new questionnaire is proposed which could be used on an annual basis.

Conclusions. A questionnaire has been developed for use in patients who have undergone surgical management for trigeminal neuralgia and which is acceptable to patients.

Keywords: Posterior fossa surgery; trigeminal neuralgia; satisfaction survey.

Background

Trigeminal neuralgia can be managed medically or by a variety of surgical techniques. Together with their

healthcare professional patients need to make a decision about which surgery would be most suitable as all carry with them the risk of pain recurrence, complications and for posterior fossa surgery a 0.5% risk of death [16]. A recent workshop attended by over 200 patients of the US Trigeminal Neuralgia Association TNA (www.tna-support.org) concluded that patients wanted to know the following things: the probability of being pain free for at least 10 years, the type of complications that are likely to occur, their rate of occurrence, the length of time the complications persist for, how they are managed, what can be done if the operation fails or pain recurs later and whether one type of surgery may preclude future procedures.

A review of the literature does not provide all the answers as the quality of the reports is relatively poor [18]. There is only one prospective reported study in a group of patients undergoing radiofrequency thermorhizotomy that has assessed complications on a yearly basis and attempted to assess their impact on quality of life [17], there are none on posterior fossa surgery. The aim of this study was to prepare a patient centred satisfaction questionnaire which could be used in English speaking communities to assess outcomes after surgery, in the first instances after MVD or PSR. It would aim to: measure pain outcome, complications, social and psychological functioning and satisfaction. Its validity and reproducibility would be evaluated using a pilot centre that had a large number of patients as well as a long history

of following up its patients on short questionnaires. Standardised questionnaires would also be used. Quality of completion to such extended questionnaires would be assessed and whether outcomes affected response rate. It would attempt to measure satisfaction with outcome rather than satisfaction with process.

Method

HC, a neurosurgeon agreed that his patient group who had undergone posterior fossa surgery from 1982–2002 could be used for the pilot study, called the Bristol data. The centre has used an electronic database since 1992 which is maintained by research nurses. Research nurses do annual updates on all the patients through the use of a simple questionnaire (Are you pain free, and if not grade the pain in 1–3 categories and are you satisfied with the surgery on a scale of 1–100). The independent investigators, a physician (JZ), and a neurosurgeon (BL) who do not work in the area and therefore were highly unlikely to have encountered any of the patients were responsible for analysing the data and ensuring correct interpretation. A third person (a patient who has not had surgery) was used to input the data and validation of responses was done by one of the independent investigators (JZ) together with the patient.

– The questions chosen were based on a review of the literature and discussions among neurosurgeons.

Standard questionnaire choice

The McGill pain questionnaire (MPQ) has been shown to discriminate well between patients with trigeminal neuralgia and atypical facial pain [5, 15] and has also been used in patients who have undergone surgery [17, 19]. The Hospital Anxiety and Depression Scale (HAD) has been used in patients with trigeminal neuralgia and showed that it is sensitive to changes [17, 19]. The SF36 or SF12 is widely used in chronic pain patients and there is considerable normative data available [7]. The Brief Pain Inventory (BPI) is used by members of the Pain Society of the UK as a standard tool for assessment of all patients with pain [1]. The SF12 and BPI could be used to validate the new surgery specific questions.

Stages in the development and testing of the specifically designed questionnaire:

1. Patients' views on outcomes after surgery were ascertained during a US wide and UK TNA meeting
2. literature reviews as well as discussions with sociologists were used to draft the first self-complete questionnaire
3. participating neurosurgeon (HC) and his team (EV) commented on it
4. chairpersons of UK and US TNA sent it to ten patients asking them to comment on the structure, content, length, applicability, freedom from medical jargon and probability of completion
5. adjustments were made
6. for neurosurgeons outside the catchment area of the pilot neurosurgeon sent the second draft to ten of their patients who had had an MVD
7. further adjustments were done and the questionnaire was then read by a copywriter who designed the lay out and checked the final wording
8. a statistician (SK) provided further input
9. covering letter, signed both by the neurosurgeon and the principal independent investigator, assured the patients of anonymity, provided an offer of sharing the results, gave details of not only local hospital contact numbers but also those of the UK TNA

10. the investigators were given the complete database of patients (413) from which to obtain all the eligible patients
11. questionnaires were returned in stamped addressed envelopes to the independent investigator
12. non responders were re-mailed a reminder after four weeks and at ten weeks resent the package. Four patients (who had undergone a PSR) were telephoned (JZ) to ask them to complete the questionnaire
13. 10% of responders were re-mailed to check for reproducibility one month after completion of first questionnaire
14. internal validity was further assessed by comparing the patients responses with the department questionnaires that are annually sent out which just ask for overall satisfaction and presence of pain
15. definitions of what constituted a failure, recurrence, typical and atypical trigeminal neuralgia and other pain were agreed between the two independent investigators prior to the questionnaires being returned
16. all questionnaires which reported the presence of pain were independently assessed by the two independent investigators (JZ, BL) and differences were resolved by discussion and using comments provided in the database
17. ambiguities in replies were resolved by discussion between inputter (patient) and principal investigator (JZ). Patients were not telephoned to provide clarification
18. data was taken from the database and compared to data obtained on questionnaire in respect of complications and recurrence of pain
19. in those instances where a reply was not obtained the last questionnaire used by the centre was used to determine the pain status of the patient
20. based on the replies and after discussion with all authors a new questionnaire was prepared for use in all patients who had undergone any type of surgical procedure. This was then discussed with patients and piloted in 10 patients.

Ethical approval from the local hospital was obtained. A copy of the original questionnaire is available from the authors.

Criteria for including patients in the survey

1. Primary idiopathic trigeminal neuralgia.
2. Microvascular decompression (MVD) only group had significant cross-compression of the trigeminal root and no lesion at all was inflicted to the nerve, whereas partial sensory rhizotomy (PSR) group either had no vascular contact at all and a pure rhizotomy was carried out, or vascular contact was mild and a rhizotomy was carried out, in addition to mobilization of the vessel. No patient with ophthalmic division pain underwent rhizotomy.
3. First posterior fossa procedure.
4. Had operation 6 months before the survey was carried out.

Criteria for exclusion

1. Secondary cause of trigeminal neuralgia e.g. tumour.
2. Clinical evidence of multiple sclerosis.
3. Concurrent cranial nerve disorder e.g. hemifacial spasm.

Results

The initial questionnaire of 10 pages contained 41 questions on the specifically designed form, the HAD, the MPQ and the SF36. Nine patients provided information for this stage. Spelling mistakes, repetition, were noted. None considered the questionnaire too long. Patients also advised on types of complications they had encountered. Adjustments were made including

changing the name of the questionnaire to trigeminal neuralgia patient survey. The survey now had 45 questions on presence of pain, complications and their effect on quality of life, operation itself, its timing, their overall satisfaction and whether they would recommend it to others, the SF36, MPQ and HAD on 12 A4 sheets of paper. In the next stage (stage 5 in methods) 13 patients completed the full survey. One question was found to be poorly answered (ambiguous) and so was removed. The SF36 was considered repetitive and was changed to the shorter SF12. The copy writer changed the layout adding boxes for the respondents to mark rather than asking them to circle the correct answer and broke it up into sections. The whole survey was printed and put into a booklet format of 12 pages with a soft cover consisted of 44 questions, the SF12, HAD, BPI and MPQ in this order. Only patients with pain needed to complete the BPI and the MPQ.

The questionnaire was sent out in November 2002 and the response to it is shown in Fig. 1.

The centre's last response rate to their annual letter in 2001 was 83.5%. It provided similar data to the new questionnaire on recurrence rates (20% vs 22% at 10 years) and satisfaction (92–81% vs 89–72%) but there was no data on complications, reasons for dissatisfaction or quality of life.

Of the ten percent of patients re-surveyed 23 (85%) responded. The replies to all the questions was identical in 11, in 3 there was a difference in one question by one level and in 10 there were one level differences in the SF12 replies, so the kappa scores, which measure reproducibility, were high. Pain outcomes were unknown on 32 (11%) of the MVD only patients and 8 (11%) of the PSR patients. Ten patients did not complete the full questionnaire but provided data on their pain status, three were too ill (illnesses unrelated to the surgery) and seven replied only to the short annual questionnaire.

The mean follow up time for the MVD only group was 5.6 years with a range of 0–22 years and that of the PSR was 5.4 years with a range of 0–18 years. Some

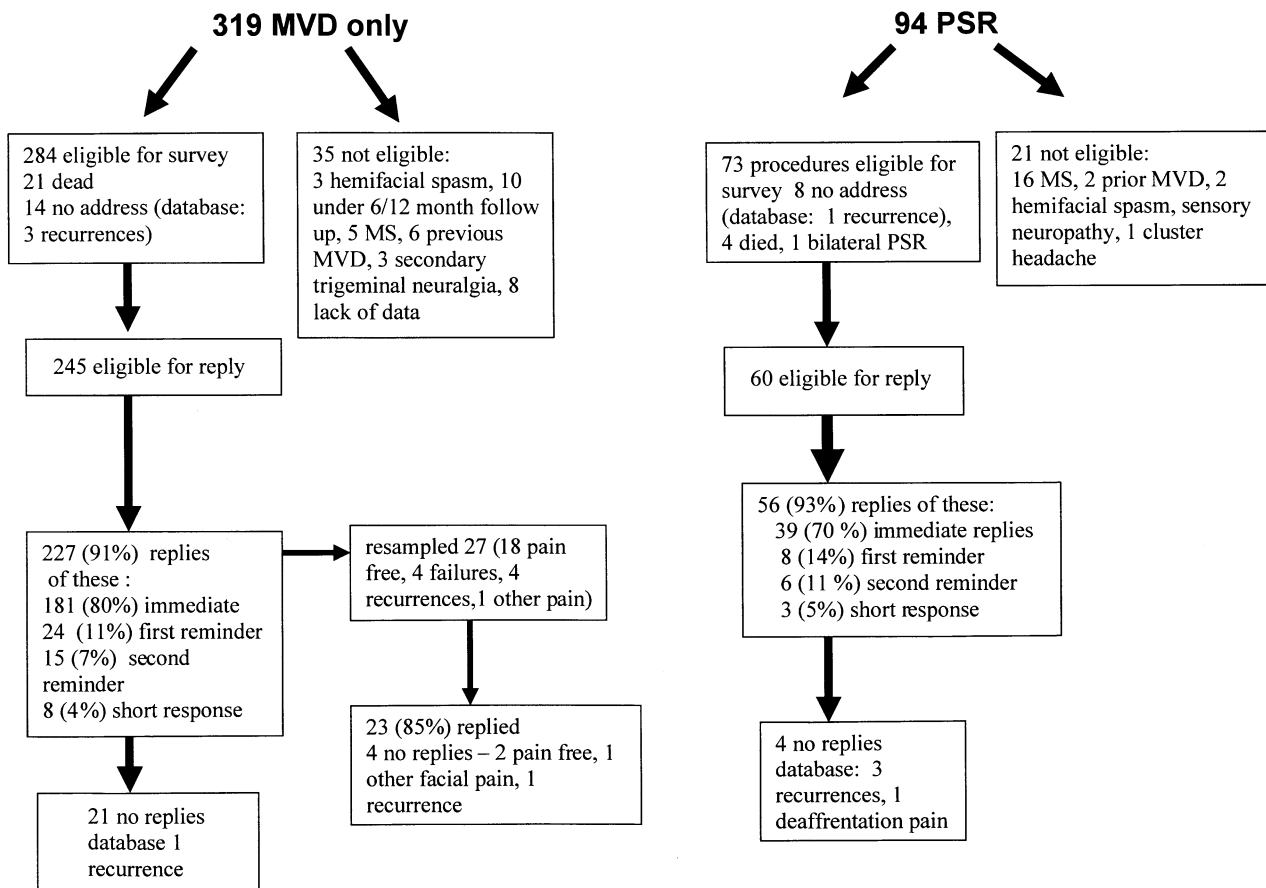


Fig 1. Flow of patients through the study and response rate to the questionnaire. Total number of patients in the database 413. MVD microvascular decompression, PSR partial sensory rhizotomy, MS multiple sclerosis, database data from units database

patients had never responded to any follow up. Recurrences had occurred in 65 (22.9%) of the MVD only group and 17 (23.3%) in the PSR group.

The level of pain reported in the main questionnaire corresponded with replies on the BPI and MPQ. There was consistency between patients who reported marked reduction in quality of life and satisfaction on the newly designed questions and poorer outcomes on the SF12 and HAD.

For the questionnaire to pick up those patients who had had a recurrence of pain but were now pain free after a second procedure it relied on patients completing the section on the operations that they had had and their timing. This section was surprisingly poorly completed and many patients did not know the exact name of the operation nor its timing. This data was therefore taken from the database and in the future would need to be added by the neurosurgical team. The rest of the questions were very well completed and many patients expressed satisfaction with the surgery as well as the attempt to collect data [20]. The questionnaire can be easily used to show which complications affect quality of life and whether this varies with the different types of surgery being performed and these can be seen in a further publication [20].

Analysis

There was a significant difference between the early responders (immediately responded) and the late responders (responded after the first or the second reminders) in terms of mean age ($P=0.05$). The early responders were about 4 years older on average than the late responders. Comparing the responders to the non-responders, two groups are significantly different in terms of the mean years post operation ($P=0.04$). On average, the non-responders were 8.2 years post operation, while the responders were on average 6.5 years post operation. No other factor was significant e.g. gender, duration of symptoms, satisfaction with result or recurrence of pain. There was no significant difference between MVD and PSR groups in response rate.

Discussion

McCulloch *et al.* [4] have emphasised the need for quality audited studies of surgical procedures given that randomised controlled trials are difficult to design and run and they advise the use of multi institutional studies to improve quality. This is the first attempt to

design a specific self complete post surgical satisfaction questionnaire for trigeminal neuralgia combined with well validated questionnaires used in evaluation of chronic pain patients in order to improve the quality of reporting of outcomes after surgery for trigeminal neuralgia. It also showed that it was reproducible and acceptable.

Current questionnaires

In over 200 published studies on this topic 32 reported the use of a questionnaire or interview (personal or telephone) to assess patient satisfaction and of these 8 were in patients who had an MVD [18]. One group has published its entire questionnaire as sent to patients [17] which also included the HAD and five others have published some questions or answers to questionnaires [10, 6, 8, 9, 11, 14], but only one of these was in patients who had an MVD [11]. The Barrow Neurological Institute [10] have their own non-standardised questionnaire and outcome measures for patients who have had radiosurgery. Only two studies have used standardised questionnaires, the HAD and MPQ [17, 19].

This is the only trigeminal neuralgia questionnaire that has attempted to follow the principles of questionnaire design and use as suggested by a systematic literature review, by McColl *et al.* [3].

Response rate

The excellent response rate on both long and short questionnaires shows that these types of questionnaires are acceptable to all patients, irrespective of outcome or length of questionnaire. Compliance may have been high as these patients are regularly surveyed, a fact patients appreciate. In other studies response rates vary from 90% to 64% [8, 14]. Oturai *et al.* [8] showed that the non responders tended to be older patients but like this study non responders were those who had their surgery a long time ago.

Value of the questionnaire

The high response rate and the independent analysis of the results has reduced bias and ensures the results are representative of the total sample operated on. The data collected is also in line with the recommendations put forward by Zakrzewska and Lopez [18] and endorsed by the three commentaries from other neurosurgeons at the end of the article. The design has enabled the analysis of

the MVD and PSR patients to be done separately which is important given the different types of complications that occur. It was however a cross sectional study and ideally this questionnaire should be used on a yearly basis in those patients who do not report 100% pain relief, satisfaction and quality of life on a short questionnaire. Consumers need and are keen to have an increasing voice in design of studies and should be involved from the start in such studies.

This survey has not picked up on immediate complications of surgery as the questionnaire was only sent to patients who had had surgery at least six months ago. It would be useful to administer a specifically designed one within three and six months of operation to pick up on early problems, which is the type of information many patients want to know. Baseline observations are also necessary a fact that Oturai *et al.* [8] comment on in their evaluation and only one study to date has reported on them in a group of patients having radiofrequency thermocoagulation [17].

The new questionnaire and its use

Completion of the study has shown that the specific questionnaire needs adjusting in terms of more explicit wording of some questions, number of questions used and its lay out in order to facilitate both completion and inputting. Currently it is not possible to score it across different domains such as satisfaction, quality of life but this could be developed in the newer design. A new questionnaire called the annual trigeminal neuralgia survey (Appendix 1) has therefore been proposed which could be used in all patients who have undergone surgery for trigeminal neuralgia and which it is envisaged would be administered on a yearly basis. The SF12 was found by patients to be repetitive and it is complex to score. The HAD scale can be replaced by two questions as suggested by Whooley *et al.* [13] and it is proposed to keep the BPI and the MPQ. Some of the patient responses may need validating by examination by a healthcare worker and patients are therefore encouraged to ask for a review appointment.

The future

There is a need to evaluate all the different surgical procedures using the same instrument and criteria and the use of this new questionnaire internationally would enable comparisons to be made between different forms of surgery and different units. A short form of the ques-

tionnaire could be used routinely for those patients who have indicated that they have no problems. If however the short form shows a change then the proposed new questionnaire should be sent.

The questionnaire could be used to audit each unit and would reassure patients that the treatments are assessed independently and objectively and ask the type of questions they themselves would like answered. Ideally a national database should be set up in each country which co-ordinates this process and would provide further evidence that high volume surgeons have improved results [2] and that national centres of excellence need to be created.

Results from such surveys would enable economic evaluations to be done based not only on the cost of the operation but also the monitoring and management of pain recurrences. These costs could be compared between different types of surgeries and medical management of the condition.

Conclusions

A questionnaire has been developed that could be used to collect data on all patients who have undergone surgery for trigeminal neuralgia and which is acceptable to patients. Results from it will enable patients to make more informed choices based on good evidence. Clinicians will also have improved guidelines on what to advise patients.

Acknowledgments

We thank TNA support groups of the US and UK, numerous patients, Mr. P. Bullock, Mr. P. Hamlyn, Mr. N. Mendoza and Mr. O. Sparrow, Yvonne Clarke, Anne Spooner and Jillie Abbott.

References

1. Griffiths DPG, Mitchell Noon J, Campbell FA, Price CM (2003) Clinical governance and chronic pain: towards a practical solution. *Anaesthesia* 58: 243–248
2. Kalkanis SN, Eskandar EN, Carter BS, Barker FG (2003) Microvascular decompression surgery in the United States, 1996 to 2000: mortality rates, morbidity rates, and the effects of hospital and surgeon volumes. *Neurosurgery* 52: 1251–1261
3. McColl E, Jacoby A, Thomas L, Soutter J, Bamford C, Steen N, Thomas R, Harvey E, Garratt A, Bond J (2001) Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients. *Health Technol Assess* 5: 1–266
4. McCulloch P, Taylor I, Sasako M, Lovett B, Griffin D (2002) Randomised trials in surgery: problems and possible solutions. *BMJ* 324: 1448–1451
5. Melzack R, Terrence C, Fromm G, Amsel R (1986) Trigeminal neuralgia and atypical facial pain: use of the McGill Pain Questionnaire for discrimination and diagnosis. *Pain* 27: 297–302

6. Mittal B, Thomas DG (1986) Controlled thermocoagulation in trigeminal neuralgia. *Journal of Neurology, Neurosurgery & Psychiatry* 49: 932–936
7. Newton-John T (2002) Measurement of pain in adults. In: Zakrzewska JM, Harrison SD (eds) *Assessment and management of orofacial pain*. Elsevier Sciences, Amsterdam, pp 87–104
8. Oturai AB, Jensen K, Eriksen J, Madsen F (1996) Neurosurgery for trigeminal neuralgia: comparison of alcohol block, neurectomy, and radiofrequency coagulation. *Clin J Pain* 12: 311–315
9. Petit JH, Herman JM, Nagda S, DiBiase SJ, Chin LS (2003) Radiosurgical treatment of trigeminal neuralgia: evaluating quality of life and treatment outcomes. *Int J Radiat Oncol Biol Phys* 56: 1147–1153
10. Rogers CL, Shetter AG, Fiedler JA, Smith KA, Han PP, Speiser BL (2000) Gamma knife radiosurgery for trigeminal neuralgia: the initial experience of The Barrow Neurological Institute. *International Journal of Radiation Oncology, Biology, Physics* 47: 1013–1019
11. Slettebo H, Eide PK (1997) A prospective study of microvascular decompression for trigeminal neuralgia. *Acta Neurochir (Wien)* 139: 421–425
12. Slettebo H, Hirschberg H, Lindegaard KF (1993) Long-term results after percutaneous retrogasserian glycerol rhizotomy in patients with trigeminal neuralgia. *Acta Neurochir (Wien)* 122: 231–235
13. Whooley MA, Avins AL, Miranda J, Browner WS (1997) Case-finding instruments for depression. Two questions are as good as many. *J Gen Intern Med* 12: 439–445
14. Yoon KB, Wiles JR, Miles JB, Nurmikko TJ (1999) Long-term outcome of percutaneous thermocoagulation for trigeminal neuralgia. *Anaesthesia* 54: 803–808
15. Zakrzewska JM (1995) *Trigeminal Neuralgia*. W.B. Saunders, London
16. Zakrzewska JM (2002) Trigeminal neuralgia. In: Zakrzewska JM, Harrison SD (eds) *Assessment and management of orofacial pain*. Elsevier Sciences, Amsterdam, pp 267–370
17. Zakrzewska JM, Jassim S, Bulman JS (1999) A prospective, longitudinal study on patients with trigeminal neuralgia who underwent radiofrequency thermocoagulation of the Gasserian ganglion. *Pain* 79: 51–58
18. Zakrzewska JM, Lopez BC (2003) Quality of reporting in evaluations of surgical treatment of trigeminal neuralgia: recommendations for future reports. *Neurosurgery* 53: 110–122
19. Zakrzewska JM, Thomas DG (1993) Patient's assessment of outcome after three surgical procedures for the management of trigeminal neuralgia. *Acta Neurochir (Wien)* 122: 225–230
20. Zakrzewska JM, Lopez BC, Kim SE, Coakham HB (2005) Patients' reports of satisfaction following microvascular decompression and partial sensory rhizotomy for trigeminal neuralgia. *Neurosurgery* 56: 1304–1312

Comments

The authors present a questionnaire for use in patients after surgery for trigeminal neuralgia. The questionnaire covers a variety of areas, including pain, impairments (hearing loss, numbness etc), and quality of life. It therefore addresses a number of key clinical questions, and will be of value in monitoring individual patients. The authors are to be commended for developing an easy to administer clinical tool, which will be potentially useful to other people managing these patients.

L. Wilson
Stirling

The project of setting up a questionnaire to quantify – as objectively as possible – the degree of patients' satisfaction after surgery for Trigeminal Neuralgia is a good and useful project, although when authors report on the result, they usually give definitions of what they consider: excellent, good, fair and bad outcome. Indeed, there is a need to unify assessment of outcome (results, side-effects and complications) among publications, to compare advantages/disadvantages of the various techniques proposed for treating Trigeminal Neuralgia, and also to compare results from team to team using the same technique.

A very interesting – and I must say “original” feature of this work, is that it started from lessons taken from a workshop attended by 200 patients of US “Trigeminal Nerve Association” (TNA), entitled “What patients want to know”. Another interesting feature is that the questionnaire was established and tested by a multidisciplinary team including individuals not directly implicated in the surgery. We hope that the questionnaire will enter into practical use, in spite of its very “detailed” character.

Marc Sindou
Lyon

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Annual Trigeminal Neuralgia Survey

This survey relates to the last operation you had for trigeminal neuralgia.

Name:

Today's Date:

Name of last operation:

Date of operation:

Age: Gender: Male Female

Please *tick or circle* the most appropriate answer. This section is about any pain you may have experienced following your **most recent operation** for your trigeminal neuralgia.

QUESTIONS:

ANSWERS:

1. Have you had any type of facial pain since your last operation?	<input type="checkbox"/> No (<i>please go to question 13</i>) <input type="checkbox"/> Yes												
2a. Does the pain you have now, feel the same as it did before your operation?	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure												
2b. If it does NOT feel the same, please indicate how it is different.	A) Still 'shooting' but <input type="checkbox"/> i) Less severe <input type="checkbox"/> ii) More severe <input type="checkbox"/> B) It is dull/achy now <input type="checkbox"/> C) Other: _____												
3. Following your most recent operation, when did you first experience the pain?	<input type="checkbox"/> Immediately <input type="checkbox"/> 1-6 months after the op <input type="checkbox"/> 7-12 months after <input type="checkbox"/> 1-2 years later <input type="checkbox"/> 3-4 years later <input type="checkbox"/> 5-6 years later <input type="checkbox"/> 6-7 years later <input type="checkbox"/> 8-9 years later <input type="checkbox"/> Over 10 years later												
4. Is the pain continuous?	<input type="checkbox"/> No <input type="checkbox"/> Yes (<i>please go to question 7</i>)												
5. If it is not continuous but, as a rule, intermittent (comes and goes in short bursts), how long does a single incident of pain last?	<input type="checkbox"/> Seconds <input type="checkbox"/> Minutes <input type="checkbox"/> Hours <input type="checkbox"/> Days												
6. How long do you usually go without any episodes of pain?	<input type="checkbox"/> Minutes <input type="checkbox"/> Hours <input type="checkbox"/> Days <input type="checkbox"/> Weeks												
7. How intense does the pain feel?	<table style="width:100%; border:none;"> <tr> <td></td> <td style="text-align:center;">Mild Discomforting</td> <td></td> <td style="text-align:center;">Worst imaginable</td> </tr> <tr> <td style="text-align:center;">0</td> <td style="text-align:center;">1</td> <td style="text-align:center;">2</td> <td style="text-align:center;">3</td> <td style="text-align:center;">4</td> <td style="text-align:center;">5</td> <td style="text-align:center;">6</td> <td style="text-align:center;">7</td> </tr> </table>		Mild Discomforting		Worst imaginable	0	1	2	3	4	5	6	7
	Mild Discomforting		Worst imaginable										
0	1	2	3	4	5	6	7						
8. Where is the pain?	<input type="checkbox"/> Same area as before the operation <input type="checkbox"/> Different area than before the operation												
9. Do any of these activities set the pain off?	<input type="checkbox"/> Washing face <input type="checkbox"/> Brushing teeth <input type="checkbox"/> Wind <input type="checkbox"/> Cold <input type="checkbox"/> Touch <input type="checkbox"/> Laughing <input type="checkbox"/> Talking <input type="checkbox"/> Eating <input type="checkbox"/> Other: _____												
10. Have you taken any medication for the facial pain since the last operation?	<input type="checkbox"/> No (<i>please go to question 13</i>) Yes: <input type="checkbox"/> Now and then as needed <input type="checkbox"/> Regularly												
11. Roughly how often in the past month have you been taking medication?	<input type="checkbox"/> Daily <input type="checkbox"/> 2-3 times a week <input type="checkbox"/> Less than 1x/week <input type="checkbox"/> Other: _____												
12. What drugs are you taking, and how many tablets a day?	Drug(s): Dose per day (in milligrams):												

This section is about complications you may have had as a result of the most recent operation for your trigeminal neuralgia

13a. If you had numbness before this operation has it changed as a result of this operation?	<input type="checkbox"/> No Yes: <input type="checkbox"/> Worse than before <input type="checkbox"/> Same as before															
13b. Following the operation, does any part of your face feel numb that was not numb before?	<input type="checkbox"/> No (<i>please go to question 17</i>) <input type="checkbox"/> Yes															
14. If yes, how soon after the operation did the numbness begin?	<input type="checkbox"/> Immediately <input type="checkbox"/> 1-2 months later <input type="checkbox"/> 3-5 months later <input type="checkbox"/> 6 or more months later															
15. How severe is the numbness (compared to stages of a dental injection wearing off)?	<table style="width:100%; border:none;"> <tr> <td></td> <td style="text-align:center;">None at all</td> <td style="text-align:center;">Mild</td> <td></td> <td style="text-align:center;">Moderate</td> <td></td> <td style="text-align:center;">Very severe</td> </tr> <tr> <td style="text-align:center;">0</td> <td style="text-align:center;">1</td> <td style="text-align:center;">2</td> <td style="text-align:center;">3</td> <td style="text-align:center;">4</td> <td style="text-align:center;">5</td> <td style="text-align:center;">6</td> <td style="text-align:center;">7</td> </tr> </table>		None at all	Mild		Moderate		Very severe	0	1	2	3	4	5	6	7
	None at all	Mild		Moderate		Very severe										
0	1	2	3	4	5	6	7									
16. How painful is it to touch this area of numbness?	<table style="width:100%; border:none;"> <tr> <td></td> <td style="text-align:center;">None at all</td> <td style="text-align:center;">Mild</td> <td></td> <td style="text-align:center;">Moderate</td> <td></td> <td style="text-align:center;">Very painful</td> </tr> <tr> <td style="text-align:center;">0</td> <td style="text-align:center;">1</td> <td style="text-align:center;">2</td> <td style="text-align:center;">3</td> <td style="text-align:center;">4</td> <td style="text-align:center;">5</td> <td style="text-align:center;">6</td> <td style="text-align:center;">7</td> </tr> </table>		None at all	Mild		Moderate		Very painful	0	1	2	3	4	5	6	7
	None at all	Mild		Moderate		Very painful										
0	1	2	3	4	5	6	7									
17. What degree of burning or other altered sensation do you have on the same side of your face as the operation site?	<table style="width:100%; border:none;"> <tr> <td></td> <td style="text-align:center;">None at all</td> <td style="text-align:center;">Mild</td> <td></td> <td style="text-align:center;">Moderate</td> <td></td> <td style="text-align:center;">Very severe</td> </tr> <tr> <td style="text-align:center;">0</td> <td style="text-align:center;">1</td> <td style="text-align:center;">2</td> <td style="text-align:center;">3</td> <td style="text-align:center;">4</td> <td style="text-align:center;">5</td> <td style="text-align:center;">6</td> <td style="text-align:center;">7</td> </tr> </table>		None at all	Mild		Moderate		Very severe	0	1	2	3	4	5	6	7
	None at all	Mild		Moderate		Very severe										
0	1	2	3	4	5	6	7									
18. Did the operation result in any hearing loss?	<table style="width:100%; border:none;"> <tr> <td></td> <td style="text-align:center;">None at all</td> <td style="text-align:center;">Mild</td> <td></td> <td style="text-align:center;">Moderate</td> <td></td> <td style="text-align:center;">Very severe</td> </tr> <tr> <td style="text-align:center;">0</td> <td style="text-align:center;">1</td> <td style="text-align:center;">2</td> <td style="text-align:center;">3</td> <td style="text-align:center;">4</td> <td style="text-align:center;">5</td> <td style="text-align:center;">6</td> <td style="text-align:center;">7</td> </tr> </table>		None at all	Mild		Moderate		Very severe	0	1	2	3	4	5	6	7
	None at all	Mild		Moderate		Very severe										
0	1	2	3	4	5	6	7									

19. If yes, has the hearing loss changed in any way?	<input type="checkbox"/> Lasted 1–6 months but now it's gone <input type="checkbox"/> Lasted 6+ months but now it's gone <input type="checkbox"/> It's still there, but has improved <input type="checkbox"/> It's still the same <input type="checkbox"/> It's getting worse
20. Do you feel unsteady on your feet as a result of the operation?	<input type="checkbox"/> No <input type="checkbox"/> Yes
21. Do you suffer from more dizziness than usual following this operation?	<input type="checkbox"/> No <input type="checkbox"/> Yes
22. Do you suffer from more headaches than usual following this operation?	<input type="checkbox"/> No <input type="checkbox"/> Yes
23. Following the operation do you have any difficulty with eating that you didn't have before?	<input type="checkbox"/> No <input type="checkbox"/> Yes, difficulty with: <input type="checkbox"/> Chewing food <input type="checkbox"/> Controlling dentures <input type="checkbox"/> Dribbling <input type="checkbox"/> Excessive biting of cheek <input type="checkbox"/> Muscles going into spasm <input type="checkbox"/> Other: _____
24. Have you got any problems with your vision that you didn't have before this operation? (please tick all that apply)	<input type="checkbox"/> No if yes please complete below <input type="checkbox"/> Blurred <input type="checkbox"/> Bits floating <input type="checkbox"/> Eyes do not focus well <input type="checkbox"/> Seeing double <input type="checkbox"/> Watering a lot <input type="checkbox"/> Eye infections <input type="checkbox"/> Other: _____
25. Have you got any other complications that we have not mentioned? If yes, please list.	
26. Please state how the complications (from questions 13–25) currently affect the quality of your life, if at all:	
Numbness	Not at all Slightly Moderately Severely
Burning sensation	Not at all Slightly Moderately Severely
Hearing loss	Not at all Slightly Moderately Severely
Unsteadiness	Not at all Slightly Moderately Severely
Dizziness	Not at all Slightly Moderately Severely
Headaches	Not at all Slightly Moderately Severely
Trouble eating	Not at all Slightly Moderately Severely
Trouble with vision/eyes	Not at all Slightly Moderately Severely
Other: _____	Not at all Slightly Moderately Severely

This section deals with your general views about the surgery

27. Looking back now, how would you consider the timing of your surgery?	<input type="checkbox"/> Done at the right time <input type="checkbox"/> Should have been earlier <input type="checkbox"/> Should have been later <input type="checkbox"/> Should have never been done
28. Overall how satisfied are you with your current situation in comparison to before the operation?	0 = Very unsatisfied Extremely satisfied 0 1 2 3 4 5 6 7
29. In the last month have you felt a lack of pleasure in life?	<input type="checkbox"/> No <input type="checkbox"/> Yes
30. In the last month have you felt depressed?	<input type="checkbox"/> No <input type="checkbox"/> Yes
31. Have you had any treatments other than medications for your trigeminal neuralgia in the past year? Please give details if yes.	<input type="checkbox"/> No <input type="checkbox"/> Yes: <input type="checkbox"/> Microvascular decompression <input type="checkbox"/> Posterior sensory rhizotomy <input type="checkbox"/> Radiofrequency thermocoagulation <input type="checkbox"/> Glycerol injection <input type="checkbox"/> Balloon compression <input type="checkbox"/> Gamma knife <input type="checkbox"/> Laser <input type="checkbox"/> Acupuncture <input type="checkbox"/> Cryosurgery <input type="checkbox"/> Other: _____

If you are in pain or if you have any complications, please complete the **Brief Pain Inventory and the McGill Pain Questionnaire attached.**

Any other comments, any other things you feel we should know about?
 (Please feel free to use the back of the paper)

Would you like a review appointment No Yes

THANK YOU for completing this questionnaire