

Could pain understanding by patients help the assessment of trigeminal neuralgia?

A compreensão da dor pelo paciente pode ajudar no tratamento da neuralgia do trigêmeo?

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ABSTRACT

BACKGROUND AND OBJECTIVES: To observe the efficacy of pain management by means of an educational proposal to address patients with trigeminal neuralgia, which is a chronic pain with high daily activity limitation rates.

METHODS: Eight patients being treated of trigeminal neuralgia participated in weekly meetings on pain in a general reference hospital. Patients had uncontrollable pain in spite of treatments so they would come very frequently to the hospital (once every one or two weeks). Patients were invited to participate in a series of meetings (four) to receive information and discuss about the disease and pain.

RESULTS: There has been increased interval between appointments for two patients, who went from weekly to biannual visits, and six patients were discharged with controlled symptoms.

CONCLUSION: Education on pain has helped its management and coping by patients, by means of understanding their condition, in addition to improving their abilities to deal with it, decreasing hospital visits due to less pain recurrence.

Keywords: Chronic pain, Elderly, Neuropathic pain, Patients assistance, Trigeminal neuralgia.

RESUMO

JUSTIFICATIVA E OBJETIVOS: Verificar a eficácia do tratamento da dor, por meio de uma proposta educativa para a abordagem de pacientes com neuralgia do trigêmeo, uma dor crônica com alto índice de limitações em atividades diárias.

MÉTODOS: Oito pacientes com neuralgia do trigêmeo em tratamento frequentaram encontros semanais sobre a dor em um

hospital geral de referência. Eles apresentavam dor incontrolável apesar dos tratamentos e por isso compareciam em atendimentos com alta frequência (1 vez a cada 1 ou 2 semanas). Eles foram convidados a participar de uma série de encontros (4) para receber informações e discutir sobre a doença e a dor.

RESULTADOS: Observou-se que houve um aumento nos intervalos de tempo entre as consultas de 2 pacientes, que passaram de visitas semanais para bienais, e 6 pacientes tiveram alta e controle dos sintomas.

CONCLUSÃO: Educação em dor auxiliou no seu manuseio pelos pacientes e em seu enfrentamento, por meio do entendimento de sua condição e no aumento de habilidades para lidar com ela, reduzindo visitas ao ambulatório por conta da menor recorrência de dor.

Descritores: Atendimento de pacientes, Dor crônica, Dor neuropática, Idosos, Neuralgia do trigêmeo.

INTRODUCTION

Trigeminal neuralgia (TN) is a facial pain syndrome characterized by extremely excruciating paroxysmal (clusters of sharp lancinating) shock-like pain^{1,2}. It causes intense suffering and high level of limitations, and crises and recurrence even after the correct treatment make patients anxious and insecure about their future^{3,4}.

Many treatments have been used for TN⁵⁻⁹, but only after 1940, anticonvulsants came to dominate, and are still currently used². Carbamazepine is the drug of choice with excellent initial results in 40 to 100% of patients^{1,10}. However, around 50-75% of patients need neurosurgery during the natural history of the disease^{1,6,8,10,11}.

Neurosurgical treatment for TN may be open surgery or percutaneous^{6,8,12-14}. Sensory and masticatory complications are frequent and recurrence rate is 25-50% in the first 5 years¹⁵. Secondary myofascial pain is present in 50% of patients, and coping with pain is complicated due to the severity of crises that occur.

Assessment with psychoeducational methods has been proposed^{16,17}. Such methods help dealing with crises and better understanding treatment and prognosis¹⁸. Medical appointments are not always enough to get away from all doubts^{17,18}. Problem-based learning strategy seems to be appropriate besides other options such as cognitive-behavioral therapy, much more used. Thus, the objective of this study was to propose a new model of assessment of TN based on patients' education.

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METHODS

Eight patients from the project protocol 551/03 (Ethics Committee Approval) with TN according to International Association for the Study of Pain (IASP) criteria¹⁹ were evaluated during an educational program consisting of lectures and discussion about their pain, current treatments, associated pain conditions and pain control strategies that could be performed by the individual aiming at relieving crises or avoiding pain triggering with practical and simple measures. All patients with TN had been treated for more than 2 years but still had residual pain. The reason they were chosen was that all of them were coming for weekly or fortnightly appointments at the hospital.

Patients' profile: TN is a relatively rare disease, and just few patients keep on coming to the hospital with an indefatigable search for a definitive cure because of intense suffering. The educational program consisted of contents about TN and individual doubts and limitations (Table 1). These 8 patients came for 4 meetings with a total of 16 hours of duration (one-week intervals between them). Specialists from different health areas were present (1 neurosurgeon, 2 dentists, 1 physiotherapist, 1 psychologist).

At the end of each lecture and discussion with the group, patients were encouraged to share their own experiences related to pain relief or during crises. Also during discussion patients identified in their histories symptoms or signs that were described by a specialist, stimulating the discussion. An accessible and clear language was used during the meetings, and patients were encouraged to ask about any doubt to be clarified.

The number of visits at the hospital, the need for new appointments, the intervals between consultations and qualitative aspects

of the intervention were considered for the final evaluation. The follow-up was of 3 years. During the complete period, observations of patients' behavior associated to visits at the hospital were performed. No patient missed any appointment and all came during the whole follow-up period or were contacted by phone.

RESULTS

Before the meetings, all 8 patients had appointments at the hospital every 15 days and often came every week in an urgency consultation due to their complaints about pain and intense suffering. They had been seen for more than two years without complete pain control.

After the educational meetings, patients returned to the appointments at the hospital to control TN, but differences in the schedule of the visits started to occur. All patients started to reduce the periodicity of visits, and the most striking change that occurred was that after 2 months, 6 of 8 patients did not come anymore to the appointments as they said it was not necessary anymore. The other 2 patients continued at the hospital but biannually, and they were referred for neurosurgery. When asked about the reasons for the improvement, they reported that they now understood their pain and knew all treatment choices, so they could participate actively when determining the moment for the surgery or could deal better with complications and side effects of treatments.

Age, gender, length of time with the illness, predominant residual symptoms, current or past attempted treatments can be observed on table 2.

Table 1. Issues discussed in each meeting

Meeting	Issue
First meeting	Trigeminal neuralgia: what is it? What is the cause? How to identify? Which are current treatments?
Secound meeting	Muscle pain of the jaw and its treatment: how to identify? Which measures can relief it?
Third meeting	Oral health: which are the commonest mouth diseases? How to prevent? How to identify? How to care of dental prosthesis?
Fourth meeting	Neurosurgical treatment: when is it indicated? Which are the success rates? Which are the risks, complications and sequelae?

Table 2. Characteristics of patients (n=8)

Ages (yo)	Gender	Duration of TN (years)	Residual symptoms	Current and past treatments
73	Female	5	Pain controlled with drug	CBZ 600 mg/day
59	Female	3	No pain or drug	CBZ before, indicated to neurosurgery
64	Female	4	Mild TN pain	CBZ 600 mg/day
72	Female	20	Pain controlled with drug	CBZ 400 mg/day
56	Female	2	Pain controlled with drug	CBZ 400 mg/day
52	Female	5	Pain controlled with during	CBZ 800 mg/day
62	Female	10	Now in remission period	CBZ 800 mg/day
65	Male	6	No pain or drug	CBZ before, indicated to surgery

TN = trigeminal neuralgia; CBZ = carbamazepine.

In this group, motivation was easily acquired as the issue of the meeting was deeply contextualized in their complaints and could promote a behavioral change. They got the independence from medical services and returned to their normal lives. The small size of the group did not allow statistical analysis.

DISCUSSION

TN is an excruciating pain and patients usually receive little information about their disease from the doctors. The rarity of the condition and the necessity of taking drugs for a long period of time with a lot of side effects or neurosurgery are important issues that indicate that information about pain and treatment is crucial at the assessment, especially in a biopsychosocial model aiming at quality of life. This preliminary study presented an education model for chronic facial pain as a possibility of taking care of these patients. For statistical evaluation, more patients and a control group would be necessary.

Although existing papers on therapeutic options for TN, the ignorance of health professionals and patients is still common and educational programs are urgent and necessary to avoid iatrogeny⁷. On the other hand, results of this kind of intervention depend on individual motivation and accessible language during explanations with scientific terminology^{20,21}. It is common that health professionals do not change their language into accessible words for patient's understanding^{20,22}.

TN is an idiopathic disease, which means "without etiology"^{1,2}. For patients it means that, even if many explanations are given about it, the definitive reason for the pain will remain obscure, even for the physician. In part, it can result in frustration and indifference, because they will not receive a defined and ready answer for this question. Patients search for explanations, but when they cannot find it as in TN, they get disappointed and lose interest²¹. When etiological factors are not understood, myths and religious legends are considered, and they should be worked out. Individual experience has often variations from the classical description and confuses patients²⁰.

This group was daily involved with their health professionals and focused on their individual complaints, despite they all had the same diagnosis (TN), and this has helped the interest and understanding of discussions. This motivation underlies the participation in the group resulting in understanding of their disease. In chronic conditions, this motivation helps when associated to the classical treatment¹⁶. The proposed technique in this study is simple, cheap and has shortened the distance between patients and health professionals creating independence between them²⁰. In normal situations the patient thinks that the health professional owns the knowledge and do not dare doubting or criticizing, accepting everything as truth or having difficulties to admit the non-understanding of something, and the professional thinks that explaining the disease is an impossible mission, especially when it is about advanced knowledge like physiopathology, synaptic molecular processing, or genetics²²⁻²⁴.

Pain education in this sample allowed patients to improve the understanding of their disease and increased their ability to deal with it, finally reducing visits because of recurrent pain.

CONCLUSION

This preliminary study shows the possibility applying an educational health model in pain education for patients, with a high rate of cost-effectiveness. The educational process may look more difficult, but a better self-control of pain observed by the reduction in hospital appointments may be an alternative for patients with chronic pain with difficult control. The understanding of the diagnosis helped treating TN in this sample.

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