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The broad treatment expectations of migraine patients

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Abstract The objective was to define the overall treatment expectations of migraineurs. Many studies have defined the expectations of patients regarding their acute migraine treatment but little information is available regarding overall expectations. During routine first visits to the author's headache clinic patients were asked about their expectations of treatment as well as demographics and headache characteristics. Demographics were recorded and expectations were compared between different forms of migraine and between females and males. One thousand seven hundreds and fifty patients were diagnosed with ICHD-II 1.1, 1.2, 1.5.1 and 1.6, 1207 with migraine and 543 with probable migraine. A percentage of 27.8 expected a cure from their treatment, 79.7% to be symptom-

free, 95.2% a reduction in frequency of headaches, 95.6% a reduction in severity of headaches and 95.5% an improved quality of life. Males had greater expectations for reduction in severity of migraines than females. Patients with migraine were more likely to expect a cure and a reduction in headache severity than patients with probable migraine. Patients with aura with every headache were more likely to expect reduced frequency of headache than patients with no aura. Some patients did expect a cure for their headaches and knowing patients' expectations may facilitate headache management and education, and achieve more realistic outcomes.

Keywords Expectations • Anticipation • Migraine • Headache • Patient

Introduction

Assessing migraine severity, disability, quality of life and medication responses has been the focus of recent studies [1–8]. Migraineurs' expectations have been well studied and defined, but only for the acute attack [9–14]. Overall treatment expectations have not been addressed. Education of the patient remains one of the

prime steps for their successful management. Without knowing an individual patient's expectations, an important opportunity for directing a patient's mindset toward a realistic goal may be lost. Realistic expectations are likely to improve patience and compliance with treatment paradigms.

This study focuses on overall treatment expectations and is not directed specifically to acute or preventive medication expectations.

This retrospective study using a large detailed clinical database in tertiary headache care was undertaken (1) to characterise the expectations of a large group of migraineurs attending a headache clinic, (2) to compare expectations in different forms of migraine (migraine with aura, migraine without aura, probable migraine, episodic and chronic migraine and (3) to evaluate expectations in males vs. females.

Patients and methods

Study population and study design

The study population consisted of consecutive patients treated by the author in his clinical practice. A detailed headache evaluation was performed and all responses were recorded in a database. The evaluation included a thorough neurological history, structured headache interview and a detailed neurological examination by the author or nurse practitioners trained in neurology and headache. All patients were evaluated by the author. Data were recorded in a database program designed by the author.

All patients studied met the International Classification of Headache Disorders, 2nd edition (ICHD-II) diagnostic criteria of 1.1 (migraine without aura), 1.2.1 (typical aura with migraine headache), 1.5.1 (chronic migraine) or 1.6 (probable migraine) [15]. Headache was present in all patients studied. Unremitting daily headache was excluded from the 1.5.1 group that this group may not reflect the expectations of patients without unremitting headache.

Patients were excluded from the study if they had (a) had no headache, (b) headaches thought to be related to trauma or injuries, (c) complicated neurological problems, i.e., underlying brain or systemic illness related to their headaches, (d) recent onset headaches, i.e., less than one month prior to study, (e) significant legal issues related to their headaches, (f) been seen prior to the initiation of the database, (g) declined to, or were cognitively not able to participate in the database interview or (h) had language or intellectual barriers.

This is a retrospective analysis of a large clinical database. Approval was obtained from an institutional review board for the use of the patients' information. The personal identities of patients were discarded when the data were downloaded to the statistical package.

Patient expectations questions

During routine first visits to the author's headache clinic, patients were asked five specific questions regarding their expectations of treatment:

- 1) Are you expecting a cure for your migraine?
- 2) Are you expecting to be symptom-free with treatment?
- 3) Are you expecting a reduction in frequency of your migraine headaches?
- 4) Are you expecting a reduction in the severity of your headaches?
- 5) Are you expecting an improvement in the quality of your life?

Statistical analysis

Descriptive statistics were obtained using SPSS version 11 for the Macintosh. Missing data were rare but, if present, that subject was excluded from analysis for the particular category being analysed. Descriptive statistics were used. Mann-Whitney *U* was used to compare expectations in patients with migraine vs. probable migraine, episodic vs. chronic migraine, migraine with aura vs. migraine without aura and in female patients with migraine vs. male patients with migraine.

Results

Demographic characteristics

Of the total of 1750 migraine patients seen by the author at the initial visit, 85.6% were females and 14.4% were males. The mean (\pm SD) age of patients was 37.67 \pm 12.0 years, the youngest being 13.0 years and the oldest 80.5 years. A percentage of 33.8 of patients were single, 60.2% married and 6.0% divorced. Almost 50% of the patients were college graduates. Ethnicity was not studied.

Headache diagnosis

Based on headache characteristics on initial evaluation, 1750 patients were diagnosed with ICHD-II 1.1, 1.2, 1.5.1 and 1.6 (total migraine population), 1207 were diagnosed with ICHD-II 1.1, 1.2 and 1.5.1 (migraine), 716 with ICHD-II 1.1, 1.2.1 (episodic migraine), 491 with ICHD-II 1.5.1 (chronic migraine) and 543 with ICHD-II 1.6 (probable migraine).

Expectations frequency (see Figure 1)

A percentage of 27.8 expected a cure for their migraines after treatment, 79.7% expected to become symptom-free, 95.2% expected reduced frequency of migraines, 95.6% expected reduced severity of migraine and 95.5% expected improved quality of life.

Patients with migraine (ICHD-II: 1.1, 1.2 and 1.5.1) were more likely to expect a cure ($p=0.000$) and to expect a reduction in headache severity ($p=0.033$) than patients with probable migraine (ICHD-II, 1.6).

No differences were seen in patients with episodic (ICHD-II: 1.1 and 1.2.1) vs. chronic (ICHD-II: 1.5.1) migraine in patients' expectations.

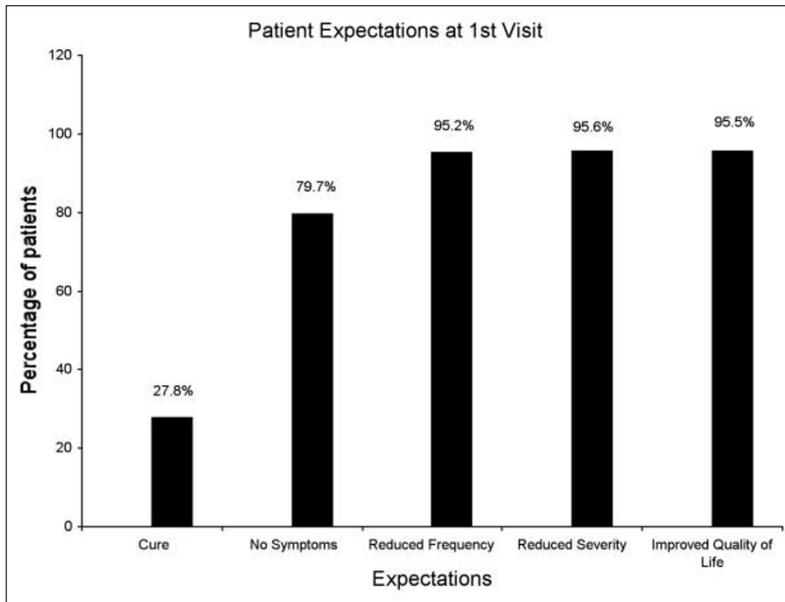


Fig. 1 Expectations of migraineurs

Patients with aura with every migraine headache (ICHD-II: 1.2.1 including only patients with aura with every headache) expected a reduction in severity ($p=0.009$) compared to patients with no aura (ICHD-II, 1.1).

No significant differences were seen in expectations of patients with migraine with varying percentage of aura (ICHD-II: 1.2.1 including patients with aura varying from 1% of migraine attacks to 99% of migraine attacks) vs. migraine without aura (ICHD-II: 1.1).

Males had significantly greater expectations for reduction in severity of migraines (ICHD-II: 1.1, 1.2 and 1.5.1) than females ($p=0.032$).

Discussion

Assessing a new patient's views, attitudes and expectations remains an important, but often neglected, part of patient management. In few conditions is this process as important as in headache and in migraine, in particular. While a thorough, extensive treatment plan for managing acute treatment, preventive treatment, advice on triggers such as stress, not eating and hormonal factors, modifying sleep abnormalities, treatment of comorbid conditions, management of women's reproductive issues, and allaying of fears are all very necessary, they are not likely to be fully successful without cooperation of the patient and addressing the patient's expectations. This study is unusual in attempting to gauge the patients' expectations in the broadest of contexts, not addressing specific treatment issues.

Patient satisfaction is dependent on expectations being met by outcome. If expectations are not met, satisfaction

is unlikely to be good despite the outcome. This study assesses more global expectations rather than specifically referring to acute or preventive strategies. Cure, absence of symptoms and reduction in frequency of headache expectations may reflect preventive strategies (medication, behavioural, trigger avoidance, treatment of comorbidity, treating sleep disorders), while expectations of reduction in severity of headache and expectations of improvement in quality of life may reflect preventive as well as acute treatment strategies.

In this study patients generally differentiated *cure* from *absence of symptoms*. In other words most patients did not feel a cure was likely but did feel that their symptoms would be controlled. They clearly anticipated that the frequency and severity of their headaches would be improved as well as their overall quality of life. This optimism is encouraging in any management programme. What influences expectations? This was not evaluated. Possibilities include the very fact of consulting a headache expert, being referred by another provider to someone perceived by that provider as having expertise in treatment of migraine, the reputation of the headache expert, or word of mouth with referral from other satisfied patients. Also possibly influencing the expectations is the fact that these specific questions of expectation were asked towards the end of a long period of data acquisition, very thorough and exhaustive, and possibly influencing the patient's perception of the likelihood of successful treatment.

The surprising finding of this study is that 25% of migraineurs expect a "cure" for their migraine. Unless this quarter of migraine patients are appropriately educated, the chance of success and satisfaction with treatment is

limited. This perception of possible cure, unless corrected, is likely to result in patients abandoning treatment plans and even no longer consulting headache providers when management fails to achieve expectations. An important issue not evaluated in this study is the outcome of treatment in relation to the original expectations. This is a study planned for the future.

Study's potential shortcomings

This study suffers from some imperfections. This is a study of a single headache clinic and not a population cross-sectional study. No diary documentation is avail-

able on the initial assessment, although some patients had documented headache profiles from prior provider evaluations.

Conclusions

Patients in general tended not to expect a cure for their headaches and interestingly differentiated between cure and symptom control. Patients had high expectations of improved frequency and severity of headache as well as improved quality of life. Knowing patients' expectations may facilitate headache management and education, and achieve more realistic outcomes.

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