

ORIGINAL ARTICLE

Perception of the validity of the Migraine Disability Assessment questionnaire in a population of patients with chronic migraine[☆]

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KEYWORDS

Disability Assessment Scale;
Disability;
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Abstract

Objectives: The Migraine Disability Assessment (MIDAS) questionnaire is the most frequently used instrument for assessing the level of disability in studies into migraine. This study aims to determine the level of completion of the questionnaire, assess the ease of use, and understand patients' subjective perception of the questionnaire's actual ability to measure disability.

Material and methods: We performed a prospective study of a sample of 78 patients with chronic migraine, determining their level of education and employment status. In a baseline visit, patients were trained to properly complete the questionnaire. At 3 months, we determined the total score and level of completion. Patients also completed a survey measuring ease of use of the questionnaire and patients' perception of whether the score accurately reflected their disability.

Results: Only 46% of patients fully completed the questionnaire. Sixty-nine percent reported finding it difficult to complete (this was influenced by patient's employment status but not by educational level). Sixty-two percent of respondents believed that the questionnaire did not fully reflect their own perception of their disability.

Conclusions: Although the validity and consistence of the MIDAS questionnaire are well documented, a high percentage of the study population reported finding it difficult to complete; many patients also considered that the questionnaire did not accurately reflect their disability. Understanding patients' opinions of the suitability of questionnaires used in consultation is crucial to improving completion.

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PALABRAS CLAVE

Disability Assessment Scale;
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Migraña;
Cuestionarios;
Migraña crónica

Percepción de la validez del cuestionario *Migraine Disability Assessment* por una población de pacientes con migraña crónica**Resumen**

Objetivos: El cuestionario *Migraine Disability Assessment* (MIDAS) es el instrumento más empleado para valorar el grado de discapacidad en los estudios de migraña. El objetivo del estudio es determinar el nivel de cumplimentación del cuestionario, valorar su facilidad de uso y conocer la percepción subjetiva del paciente sobre la capacidad del cuestionario para medir realmente su discapacidad.

Material y métodos: Estudio prospectivo sobre una población de 78 pacientes con migraña crónica. Se determina el nivel educativo y la situación laboral. En la visita basal se adiestra a los pacientes sobre la correcta cumplimentación del cuestionario. A los 3 meses se determina la puntuación total y el nivel de cumplimentación. Además los pacientes contestan una encuesta que mide: facilidad de uso y percepción del paciente sobre si la escala refleja su propia discapacidad.

Resultados: Solo el 46% rellena completamente el cuestionario. El 69% de los pacientes indica que el cuestionario no les resulta fácil de cumplimentar (resultado no influido por el nivel educativo, pero sí por la situación laboral de los pacientes). El 62% de los encuestados opina que el cuestionario no refleja completamente su propia percepción de discapacidad.

Conclusiones: Aunque está más que demostrada la validez y consistencia del cuestionario MIDAS, un porcentaje elevado de nuestra población reconoce que el cuestionario no es fácil de llenar y además es percibido por muchos de nuestros pacientes como un cuestionario que no refleja adecuadamente su discapacidad. Conocer la opinión de los pacientes sobre la idoneidad de los cuestionarios administrados en las consultas es crucial para mejorar su cumplimentación. © 2018 Sociedad Española de Neurología. Publicado por Elsevier España, S.L.U. Este es un artículo Open Access bajo la licencia CC BY-NC-ND (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

In order to accurately stratify the care needs of patients with migraine, it is essential to know the intensity and frequency of attacks and their general impact on the individual's daily life. Instruments measuring disability represent one of the most important tools for stratifying treatment needs. The Migraine Disability Assessment (MIDAS) scale is the most widely used instrument for assessing the degree of disability in patients with migraine.¹ It includes 5 questions addressing work, household work, and social and family activities. The score is calculated by adding the sum of days on which each activity was missed or productivity was reduced due to headache; this represents an explicit measure of the time lost due to the disease.¹

The questionnaire has been shown to be highly reliable, reproducible (independently of the population groups studied), disease-specific, and easy to qualify, and presents good internal consistency, reliability, and validity.^{1–3} However, the questionnaire presents known limitations, influenced by disease characteristics, patients' attitudes, and the characteristics of the questionnaire itself. Despite these limitations, numerous studies report the questionnaire's validity and professionals' high opinions of its clinical usefulness.^{4–6} However, to our knowledge only one study has addressed the degree of satisfaction with the scale and its perceived usefulness from the patient perspective.⁷

This study aims to measure the level of completion and the ease of use of the MIDAS questionnaire in a group

of patients with chronic migraine and to establish these patients' subjective perceptions of the questionnaire's ability and usefulness in accurately measuring their disability.

Material and methods

We conducted an observational, prospective, longitudinal study in a population of consecutive patients diagnosed with chronic migraine. We included patients diagnosed with migraine according to the criteria of the International Classification of Headache Disorders,⁸ and applied no restrictions based on age or sex. Data were recorded on the following variables: age, sex, level of schooling (no schooling, primary education, secondary education, higher education), and current employment status (unemployed, homemaker, employed, retired, student). At the baseline consultation, patients were instructed on how to correctly complete the questionnaire. At a follow-up consultation at 3 months, we determined the frequency of patients fully completing the MIDAS questionnaire and the 6-item Headache Impact Test (HIT-6)⁹ and recorded total scores on the scales. At the same consultation, patients were asked to respond to a survey on their opinions about 2 main aspects of the questionnaire: its ease of use and its ability to reflect their level of disability. Each item was assessed using a 5-point Likert-type scale, scored as follows: 1 = completely disagree; 2 = disagree; 3 = neither agree nor disagree; 4 = agree; 5 = completely agree.^{10,11} The study complies with the eth-

ical standards of the research ethics committee, and all participants gave informed consent to participate in the study. Statistical analysis was performed with SPSS version 19.0, with statistical significance set at $P < .05$. Data were collected in an Excel spreadsheet. The chi-square and Fisher exact tests were used to compare survey responses, with statistical significance set at $P < .05$. A descriptive study of the qualitative and quantitative variables was performed. Qualitative variables are expressed as absolute frequencies and percentages, and quantitative variables as means with standard deviations or medians with the number of valid cases.

Results

Sociodemographic and clinical description of patients

A total of 88 patients with chronic migraine were interviewed, 78 (88.6%) women and 10 (11.4%) men, with a mean age of 45.89 years (Table 1). Sixty-six participants were in active employment and 22 were not actively working (12 were students, 3 were unemployed, and 7 were retired). Regarding level of schooling, 2 had no schooling, 31 had primary education only, 30 had secondary education, and 25 had higher education.

Questionnaire completion and total score

A total of 75 patients (86.3%) attending the baseline consultation had completed the questionnaire to some extent. Forty-six patients (52.2%) fully completed the questionnaire, 29 (33%) were unable to complete every item, and 13 (14.8%) forgot to complete the questionnaire. Mean total score among those patients who fully completed the MIDAS questionnaire was 39.88 points, with 7.49 out of 10 points on the item measuring average pain intensity. At the baseline visit, all 88 study participants completed the HIT-6 questionnaire, with a mean score of 63.03. Demographic data from our sample are shown in Table 1.

No statistically significant differences in the level of survey completion were observed between patients with different levels of schooling, although we did find significant differences associated with employment status ($P < .05$). The percentage of individuals not fully completing the questionnaire was higher among patients in active employment than among those not in work (41% vs 26%).

Perceived ease of use of the questionnaire

Of the 75 patients who partially or fully completed the questionnaire, 40.8% agreed or completely agreed that it was easy to complete, with 52.60% considering it to be difficult (Fig. 1). No statistically significant differences were observed with regard to level of schooling or employment status.

Perception of the questionnaire's ability to reflect disability

Of the 75 patients who fully or partially completed the questionnaire, 28.4% agreed or completely agreed that the questionnaire accurately reflected their degree of disability, while 51.9% disagreed with this statement (Fig. 2). No statistically significant differences were observed with regard to level of schooling or employment status.

Discussion

This study was specifically designed to measure the level of completion of the MIDAS questionnaire, to evaluate its ease of use in a group of patients with chronic migraine, and to understand patients' perception of how accurately it reflects their disability. Only half of the participants completed every item of the questionnaire, and a high percentage did not consider it easy to complete. Finally, only one-quarter of participants considered the questionnaire items to accurately reflect their perception of their own disability.

To our knowledge, only one other study in the literature assesses patient perceptions of the MIDAS scale. Stewart and Lipton⁷ report that 92% of patients with headache considered the questionnaire to be easy to complete and that 98% considered it easy to score. They also report that 96% of patients had no difficulties understanding the questions. These data stand in clear contrast to our own results, which show that fewer than half of patients considered the questionnaire easy to complete; however, the 2 studies differ greatly in terms of patient selection and study methodology. In our study, patients received the questionnaire at a baseline consultation and submitted it at a follow-up visit, whereas in the study by Stewart and Lipton,⁷ they received the questionnaire by post and subsequently responded in a telephone interview. All participants in our study met diagnostic criteria for chronic migraine, whereas in the study by Stewart and Lipton,⁷ only 163 respondents met the International Headache Society criteria for migraine, with the remaining 253 participants presenting non-migraine headache. Stewart and Lipton⁷ did not conduct a differential analysis of the group of patients with migraine, mixing the results by MIDAS scale score independently of whether respondents had been diagnosed with migraine. The authors stratify the population according to MIDAS scale score, finding that 237 participants were classified as grade I (little or no disability), of whom 118 scored 0 on the scale. From the data presented by Stewart and Lipton,⁷ we may surmise that the sample includes a high percentage of patients not meeting diagnostic criteria for migraine, in whom headache had minimal or no functional impact; this constitutes a clear limitation for the extrapolation of these results to a population of patients with established diagnosis of migraine. Finally, if we analyse these authors' data for patients in the MIDAS grade III and grade IV groups (moderate and severe disability), the usefulness of the questionnaire ranges from 50% to 80%; furthermore, it is not stated whether or not these patients meet diagnostic criteria for migraine. This clearly contrasts with the findings from our study, which

Table 1 Demographic and clinical variables of the sample.

Variables	No. of patients	Mean	Standard deviation
<i>Age</i>	88	45.89	12.537
<i>Sex</i>			
Men	10		
Women	78		
<i>MIDAS score</i>	46	39.88	35.722
<i>HIT-6 score</i>	88	63.03	5.991
<i>VAS for pain</i>	88	7.49	1.390

HIT-6: 6-item Headache Impact Test; MIDAS: Migraine Disability Assessment; SD: standard deviation; VAS: Visual Analogue Scale.

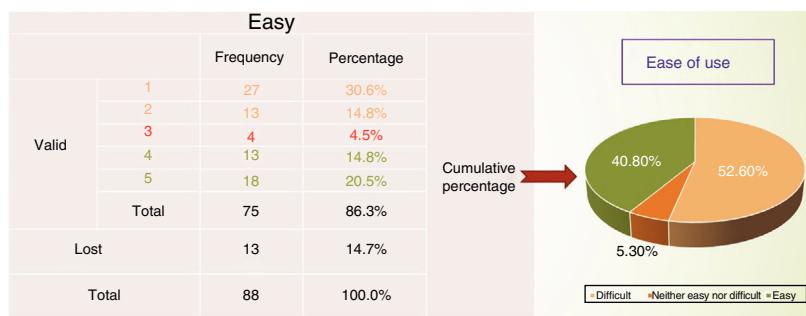


Figure 1 Perceived ease of use of the MIDAS questionnaire.

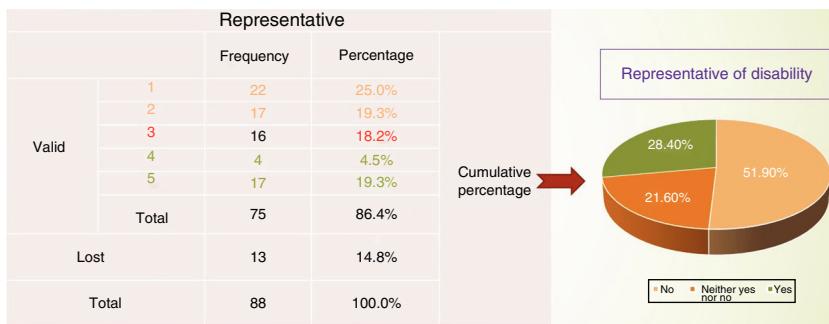


Figure 2 Perceived usefulness of the MIDAS questionnaire for reflecting disability.

includes a well-defined population of patients, all of whom were diagnosed with chronic migraine.

However, our findings on the extent to which patients were able to complete the questionnaire and their assessment of its ease of use do present several limitations, namely, the characteristics of migraine itself, patients' willingness to collaborate, and the design of the questionnaire.^{4–6} Firstly, the main difficulty of measuring disability in patients with migraine is a characteristic inherent to migraine itself: the fluctuating and highly variable nature of the disease, which hinders the definition of valid, reliable profiles of function and disability. Secondly, other limitations arise from patient characteristics: collaboration, employment status, and level of schooling. Data collection requires patients to be committed to completing the questionnaire, and we must trust the accuracy and validity of self-reported data. One relevant finding from our study was that one-quarter of patients did not submit the completed questionnaire, either because they forgot to complete it or due to lack of interest. Therefore, patients will require some level of training in order to understand the parameters of the scale and complete it correctly. Patients' employment status and changes in employment status between the various assessments may influence completion of the questionnaire, as individuals in active employment are able to complete all items, whereas students and unemployed or retired respondents are only able to complete the items related to social and/or domestic settings.⁶ Therefore, the patient's employment status at the time when they complete the questionnaire affects the level of completion and the total score, which may represent an obstacle for longitudinal evaluation of a single patient's progression if their employment situation changes during or after the evalua-

tion period. However, level of schooling did not interfere in the completion of the scale in our study. The final limitation arises from the characteristics of the MIDAS questionnaire itself. Sauro et al.¹² note that patients expressed difficulty understanding items 2 and 4 of the questionnaire, which require patients to define a 50% reduction in productivity in professional and domestic work; to answer these questions, patients must make a subjective judgement, potentially leading them not to complete these items or to complete them incorrectly. The use of a reduced MIDAS questionnaire recording activities for a period of one month instead of the longer 3-month period may facilitate completion of the questionnaire and reduce the variability observed.

The patients included in our sample had a low perception of the questionnaire's ability to accurately reflect their disability. We must be aware that the MIDAS scale has not been validated to assess quality of life; global quality of life in patients with migraine involves many other factors besides disability that are not addressed by the MIDAS questionnaire.^{12,13} Therefore, in clinical practice we must use several functional scales to evaluate different variables related to disability and quality of life as quickly and as easily as possible.

Conclusions

While the validity and consistency of the MIDAS scale are amply demonstrated, it is essential to understand the characteristics of the tests we use and to identify their strengths and weaknesses in order to evaluate their true clinical usefulness. This is especially true given that (as is the case in the present study) a considerable percentage of patients

find the questionnaire difficult to complete and consider that it does not accurately reflect their disability. Given the lack of published studies on patients' perceptions of the MIDAS questionnaire, future research should aim to evaluate patients' opinions of the questionnaires used in consultations. This analysis is essential to improving the completion of these instruments and to adequately evaluating the information they provide us in routine clinical practice.

Conflicts of interest

The authors have no conflicts of interest to declare. The study has received no funding from any company with financial interests in any product, equipment, or related items mentioned herein.

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