Development of the Headache Activities of Daily Living Index: Initial Validity Study

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Abstract

Purpose: The purpose of this study was to develop a novel instrument for assessing headache-related disability focusing solely on important activities of daily living.

Methods: Part 1: A literature search was conducted in PubMed and Google Scholar, supplemented by hand searches in bibliographies to retrieve the original article for any instrument for the assessment of headache-related disability. Each instrument was evaluated for item categories, specific item content, measurement scale format for each item, and instructions to users. Together, these features constituted the construct validity of these instruments. Qualitative evaluations of these results were summarized with respect to the adequacy of each component. Psychometric features such as reliability and validity were not assessed. Part 2: An existing instrument for assessing self-rated disability, the Neck Disability Index, was modified for content and format and subjected to 2 rounds of clinician and patient review. Item contents and formats received final consensus, resulting in a 9-item instrument: the Headache Activities of Daily Living Index (HADLI). This instrument was tested in a sample of headache patients. Cronbach α and individual item correlations were obtained. Principal Components Analysis was performed.

Results: Part 1: The search identified 6 reports on 5 preexisting instruments for self-rating of headache-related disability. Problems in content were found in all instruments, especially relating to the lack of items for specific activities of daily living. Problems were noted in most of the instruments for scaling and instructions with respect to the effect of headache on activities of daily living. Part 2: The authors first identified suitable items from an existing instrument for self-rating of disability. These were supplemented by items drawn from the literature. A panel of 3 clinicians and 2 laypersons evaluated these items. Two more focus groups of 7 headache sufferers each reviewed the new instrument. After this, a 9-item instrument for assessing activities of daily living in headache sufferers, the HADLI, was finalized. After this, 53 participants were recruited to study the face validity of the instrument. The sample consisted of 41 women and 12 men with a mean age of 37.3 (12) years; mean duration of headaches was 7.4 (8.3) years; mean frequency of headaches per week was 3.4 (2.4); and the intensity was 6 (2.4). The mean HADLI score was 26.2 (13.4), or 52%. There were no floor or ceiling effects for total score. The total Index Cronbach α was 0.96. The Principal Components Analysis identified one component which accounted for 75% of the variance.

Conclusions: The HADLI was created using theory and empirical-based methods. Face validity was assessed by focus group input and by first-level psychometrics. The HADLI has good face validity and is suitable for further reliability and validity testing. (J Manipulative Physiol Ther 2015;38:102-111)

Key Indexing Terms: *Disability; Headache; Activities of Daily Living; Questionnaire; Scale*

Headache has a high prevalence in Western society and accounts for a significant burden of health worldwide.[1–3] According to the World Health Organization (WHO),[4] migraine is ranked 19th as a cause of worldwide disability (12th for women). Assessing the disability associated with headache has been important at all levels of research, from individual patients to populations. The first instrument for assessing "disability" in headache patients appears to be the Headache Disability Inventory (HDI; or "Index") of Jacobson et al[5] published in 1994. Since then, several other instruments for assessing self-rated disability have been developed.[6–10] These instruments[5–10] are widely used and have been demonstrated to have good reliability and utility.

However, a review of their content with respect to their suitability for assessing specific activities of daily living (ADLs; see below) shows that although most of these widely used instruments included some general activity categories,

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Table 1. *Item Categories in HDQs (Number of Items Per Category)*

	HDI (Functional Items)[5]	HDQ[8]	HIT-6[7]	MIDAS[6, a]	BURMIG[9], Eurolight[10]	HADLI
Symptoms or emotional	13	3	4	0	Yes, but not tabulated	0
ADL: general	6	4	1	5	9	0
ADL: specific	6 (1 duplication)	2	1	0	2	9

ADL, activities of daily living; *BURMIG*, burden of migraine; *HADLI*, Headache Activities of Daily Living Index; *HDI*, Headache Disability Index (Inventory); *HDQ*, Headache Disability Questionnaire; *HIT-6*, Headache Impact Test; *MIDAS*, Migraine Disability Scale.

[a] Two items not included in the activities score.

none of them included only items related to specific ADLs; all of them include items on issues other than activity performances such as symptoms, severity of pain, quality of life, and demographic, social, and family-related information.

The need for a focus on ADLs is based on the recommendations of the IMMPACT consensus[11] and the WHO definition of disability,[12–14] which covers impairments, activity limitations, and participation restrictions. According to the WHO, "1] an impairment is a problem in body function or structure; 2] an activity limitation is a difficulty encountered by an individual in executing a task or action; while 3] a participation restriction is a problem experienced by an individual in involvement in life situations."[12,13] Given the fact that the concept of "impairment" is difficult to apply to most headache patients in that there is a dearth of both organic pathology as well as physiologic biomarkers in primary headaches,[1,2] both "activity limitations" and "participation restrictions" become paramount in determining disability.

Emphasis on ADLs is also grounded in Activity Theory,[15,16] which focuses on "activities" as the fundamental unit of analysis of individuals in that activities entail both the social framework for meaning of a person's behavior and an instrumental framework for an individual's interaction with the tools and affordances of their lived world. It is in activities that a person's disability with a health condition is best evaluated.

Based on this analysis, we propose the need for the development of a new instrument focusing as exclusively as possible on specific ADLs, which has clear instructions for effect on activities during episodes and which uses an item scale with sufficient gradations to permit precision and responsiveness. Therefore, this study presents a review of previously published instruments to assess headache-related disability (part 1), and, based on the results of that review, we report on the development of a novel instrument: the Headache Activities of Daily Living Index (HADLI), a 9-item instrument exclusively composed of items on specific, headache-related ADLs. This study presents the initial development and face validation of this instrument (part 2).

Part 1: Review of the Literature of Instruments to Assess Headache-Related Disability

Methods. To insure search efficiency, separate searches were first undertaken in PubMed with the key words "headache" AND "disability" along with "index," "inventory," "scale," "questionnaire," respectively. The primary target of this search was to identify the original article(s) on the development of headache-related disability instruments. Not included were (*a*) instruments strictly designed for assessing headache-related quality of life, (*b*) survey instruments on headache features that may have contained only a small number of activity-related items (usually "work"), (*c*) instruments to measure work loss exclusively, (*d*) studies in which the psychometric properties of the original instruments were assessed, (*e*) studies that used the original instruments to explore headache characteristics in specific samples, (*f*) studies of pediatric-related instruments, and (*g*) translation and cross-cultural validation studies of the original instruments. Iterative searches within PubMed were performed on "related articles." Citation analysis in Google Scholar supplemented this initial search, particularly when an original article for an instrument was identified. Searches were also performed in the archives of the 2 primary headache journals—Headache and Cephalalgia—with the key words "disability questionnaire." Once a point of redundant returns was reached, the search was declared successful with respect to the primary aim of identifying original articles.

A content analysis was then conducted of the instruments identified in the primary search, assisted by the material retrieved in the secondary searches. Critical issues were as follows: item categories, specific item content, measurement scale format for each item, and instructions to users. Psychometric features such as reliability and validity were not assessed.

With regard to item content, our analysis was based on the recommendations of the IMMPACT consensus[11] and the WHO definition of disability: "Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations."[12,13] Given that impairment is difficult to apply to most headache patients and given the lack of organic pathology in primary headaches,[1,2] we concentrated on activity limitations and participation restrictions.

A qualitative appraisal of these aspects of these instruments was then undertaken. As no validated scale appears to exist for this very specific purpose, we developed a set of criteria for appraisal. (1) For item content, we evaluated the number of items that applied directly to