

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 al⁵ published in 1994. Since then, several other instruments for assessing self-rated disability have been developed.⁶⁻¹⁰ These instruments⁵⁻¹⁰ 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 IMPACT consensus¹¹ 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 IMPACT consensus¹¹ 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

Table 2. Item Characteristics

	HDI (Functional Items) ⁵	HDQ ⁸	HIT-6 ⁷	MIDAS ^{6, a}	BURMIG ⁹ , Eurolight ¹⁰	HADLI
Headache pain severity scale		X		X ^a	X	
How often is HA severe			X		X	
HA freq		X		X ^a	X	
Lie down						
Days		X			X	
Wish they could			X			
“Miss” work or school		X	X ^b	X	X	
Ability to do work		X		X	X	X
“Miss” household chores		X	X ^b	X	X	
Ability to do household chores		X		X		
Daily routines	X					
“Miss” nonwork activities		X	X ^b	X	X	
Ability to do nonwork activities		X				
Recreation	X					
Too tired			X			
Irritated			X			
Concentration	X		X			
Socialize	X					X
Traveling	X					X
Reading	X					X
Driving						X
Personal care						X
Lifting						X
Sleep						X
Exercising						X
Recreation						X

BURMIG, burden of migraine; HA, headache; 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.

^b All in one question.

limitations of ADLs and to participation restrictions, also evaluating if they were specific to one activity or focused generally on a category of several activities. (2) For scale format, we evaluated the capacity of the scale to produce meaningful gradations and, therefore, to contribute to a higher level of responsiveness. (3) For “instructions,” we evaluated the context of applicability of the scale that the instructions provided to the respondent.

These evaluations were then summarized with the objective of determining whether it was warranted to develop a new instrument for assessing neck-related headache disability by focusing strictly on the assessment of ADLs. Evaluations related to instructions and to the scales used are noted in each section of **Results**.

Results. The 4 PubMed searches yielded 1076 selections. Based on our final inclusion criteria, 6 original reports on headache disability questionnaires were identified,^{5–10} yielding 5 instruments for review. Several reviews in the last decade^{17–19} confirmed that the first 3 of these instruments are now part of the headache outcome measures commonly used in research and practice, whereas the other 2 are too recent to have been widely applied.

Comparisons of the item categories and the item characteristics of 4 previously published instruments are shown in **Tables 1 to 4**, respectively, and described below.

1. The first scale for assessing headache-related disability appears to be the Henry Ford Hospital HDI (sometimes known as the Index).⁵ This is a 25-item scale with 2 domains: emotional (13 items) and functional (12 items). As seen in **Table 1**, the “functional” scale actually contains only 5 items directly related to the performance of activities (socializing is repeated once). The other functional items relate to feelings or beliefs about daily activities or symptoms related to activities (“concentration,” “tension”). Of these 5 activity-related items, 3 of them are phrased as general categories: “perform my daily routines,” “recreational activities,” and “socializing,” whereas 2 are about specific activities: “traveling” and “reading.” We rated the general “activity”-related items to be moderately adequate for a headache disability instrument, whereas the specific ADL items were inadequate in number. The scale used for each item in this questionnaire is a dichotomous YES/NO scale. This type of scale was

Table 3. Instrument Comparison: Scales

	HDI (Functional Items) ⁵	HDQ ⁸	HIT-6 ⁷	MIDAS ^{6, a}	BURMIG ⁹ , Eurolight ¹⁰	HADLI
Scales						
Yes/No	X				X	
Verbal scale			X			
Numerical rating scale (0-10)		X				
Ordinal					X	x
0-5 (for severity)						
1-7 (for time)						
No. of days				X	X	

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.

rated as inadequate for the responsiveness of the instrument.²⁰⁻²² This is because the lack of gradation in a dichotomous scale limits the capacity to measure change. If a respondent answered “yes” at one time point, their rating of the item would have to change completely in order to generate a new response of “no” (item effect would have to decrease to “none”). The item scale for the HDI was rated as inadequate.

The instructions included in the HDI are placed only at the beginning of the instrument and are deemed to be quite limited. While the respondent is instructed to “answer each item as it pertains to your headaches only,” there is no time frame provided which could indicate days, weeks, or months in the past for which the ratings must be done, nor is there any indication as to whether the rating is to be made for “when I have a headache” or “in general.” We rate the instructions for the HDI as inadequate.

2. The Migraine Disability Assessment Score (MIDAS)⁶ was first published in 1999. It is composed of 5 activity-related items and 2 severity items. Only 3 of the activity-related items are distinct: “school or work,” “household,” and “social/recreational.” These appear to cover a wide range of activity settings; however, the issue raised above about lack of specificity could affect the respondent’s ability to answer precisely for a given activity (again: school vs work, socializing vs recreation, etc). As such, we rated the items as somewhat adequate for general categories but inadequate for specific ADLs.

The instructions for this instrument do provide a timeframe of 3 months and require the respondent to consider all headaches in that period. We rated these instructions as adequate.

The instructions for the MIDAS relate to the answers required, which are in units of “days affected.” For 2 of the items—“school/work” and household activities—there are 2 items, one to rate “missed days” and the other to rate 50% productivity effect. These 2 items may be difficult for some respondents to provide an accurate response. It can be argued that a simple count

of days or productivity loss does not adequately provide a “self-rating” of disability, even as it provides information for an interpreter to use to make the determination of “level of disability.” Given the nature of the instructions, we rated the scale as inadequate, for the assessment of self-rated disability, although there is a high level of gradations available (number of days) and, therefore, a higher potential for responsiveness from this scale.

3. The Headache Impact Test (HIT-6)⁷ is composed of 6 items, only one of which is directly related to activities: “daily activities” (household work, work, school, social activities). Two items relate to the withdrawal of activity due to headache—“wish to lie down” and “feeling too tired to do activities.” All 3 items treat activities as one all-encompassing domain. As such, we rate the HIT-6 as inadequate for “disability related to activities.”

There are only instructions given in each item. These range from “when you have a headache” to “in the last four weeks” to “how often.” These are rated as adequate to the needs of the instrument.

The scale is a 5-point ordinal scale of frequency of effect: “never,” “rarely,” “sometimes,” “very often,” and “always.” This scale provides adequate gradation to promote high responsiveness.

4. Niere and Quin,⁸ developed an instrument for use in physiotherapy clinics ostensibly because “physiotherapists treat musculoskeletal dysfunction in a variety of headache types...” No other justification for this instrument was provided. The instrument is named the Headache Disability Questionnaire (HDQ).⁸ It consists of 9 items, only 3 of which are specifically about activities. For each of these, there are 2 separate items as discussed below in “scale.” These items are as follows: “work or school,” “housework or chores,” and “nonwork activities” (family, social, or recreational). These items were rated as nonspecific and, therefore, vulnerable to the same problems as noted above. The repetition for each item into “ability” vs “days affected” removes 3 items of 9, which could have addressed other

Table 4. Instrument Comparison: Instructions

	HDI (Functional Items) ⁵	HDQ ⁸	HIT-6 ⁷	MIDAS ^{6,a}	BURMIG ⁹ , Eurolight ¹⁰	HADLI
Instructions						
“When you have a headache...”		X	X			X
“identify difficulties you may be experiencing because of your (my) headaches”	X					
In the past 24 hours after you took your first dose of migraine medication, how much of the time did you...?					X	

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.

activities. As such, only 30% of the instrument is devoted to activities. The other 3 items relate to headache pain severity (2 items) and the need to lie down (withdrawal from activities). We rated the HDQ as inadequate with respect to disability related to activities. There are no general instructions that could provide an appropriate context for response; however, each item does contain a time-related context of “when you have a headache” or “in the “last month.” This variability may work against the accuracy and responsiveness of this instrument; however, the 10-point scale used for all items does improve the responsiveness of the instrument.

5. The most recent instrument is the Burden of Migraine (BURMIG)/EUROLIGHT instrument.^{9,10} This is a large questionnaire assessing many headache and demographic variables. This questionnaire included many of the items that had been developed for the BURMIG instrument. In the original article for this instrument,⁹ it was noted that items on disability had been obtained from the MIDAS instrument.⁶ These items on disability were included in a 77-item instrument assessing many other aspects and dimensions of headache that are not pertinent to the present review. Thus, a review of the BURMIG instrument will be subsumed in the review, here, of the EUROLIGHT.

Disability-related items are present in several sections of the EUROLIGHT,¹⁰ for a total of 12 such items. In 10 of these items, only 3 activity categories are referred to as follows: work or school, housework/chores, and family, leisure, or social. One item asks for the respondent’s satisfaction with all of these. The final disability-related item focuses on “child care” over the last 3 months. On the basis of a wide range of activities in each of the 3 main categories, we rated the EUROLIGHT questionnaire as adequate for general disability categories, but inadequate with respect to specific ADLs.

There are no general instructions for the instrument. Instructions are imbedded in the items. Five items are

included in one 6-item section on “Questions about yesterday” and only inquire as to the effect on ADLs over a single day. These same disability-related categories are then included in another 5-item grouping under the title “lost time because of your headaches” and require that the respondent provide a number of days over a 3-month interval. We rated the instructions as adequate.

Some items use an ordinal scale of 4 to 5 points; 5 items ask for the number of days lost for complete or partial activity reduction. For the activity-related items, the instructions and scales were deemed adequate. However, the framing of time intervals for assessing self-rated disability is somewhat confusing in that 5 items focus only on “yesterday” (and use 4-point scales), whereas 5 other items focus on the last 3 months but require only a number of days affected. Combining these 12 items into a singular assessment of self-rated disability would be problematic. In the original report, it appears that this combination of items was not studied separately. Only the items related to “headache-attributed lost time” were studied as a separate component (along with WHO quality of life items and the depression/anxiety items) in the evaluations of construct validity.

As such, there is no single, validated component, factor or even clear grouping of items related to self-reported disability in the EUROLIGHT questionnaire. Accordingly, we rated the scale for disability rating as inadequate.

These features of the 5 extant instruments are displayed in [Tables 1 to 4](#).

Based on our content and format analysis, it was determined that the development of a new instrument focusing as exclusively as possible on specific ADLs which had clear instructions for effect during episodes and which used an item scale with sufficient gradations to permit precision and responsiveness was worthwhile.

Part II: DEVELOPMENT AND VALIDITY STUDY OF THE HADLI INSTRUMENT

Methods. Phase 1: We first reviewed an instrument, the Neck Disability Index (NDI),²³ strictly for the applicability of its format and as a starting point for item content. The NDI was used as a template for the new instrument on account of the strong psychometric record of this instrument.^{24,25} Furthermore, it has been used as an outcome measure in several headache studies,^{26–37} although we would argue that this, in itself, is not appropriate. Therefore, the first set of possible items for inclusion in a new instrument was from the NDI items, which were deemed applicable to headaches. It should be stated at the outset that although we used an instrument for assessing neck pain–related disability as our template, it was not our intention to develop an instrument that would only be useful in cases where there might be suspected involvement of the neck in headache. The topic of the relationship between the neck and headache is not the focus of this article.

New items in addition to those retained from the NDI were then determined by the investigators after reviewing the extant instruments, keeping in mind the construct foundations from the WHO and Activity Theory, described above. An initial set of items including those retained from the NDI as well as 2 new ones (see [Results](#)) was developed. This list was reviewed by a panel of 5 reviewers (3 clinicians and 2 lay people) for applicability. The panel confirmed the suitability of this list of items, and new instructions were written for the new scale. Based on the analysis of the existing instruments, it was decided and confirmed in the panel that the items in the new scale would require the respondent to answer with respect to “when they have a headache.” This permits an unambiguous determination of the effect of headache on ADLs during an episode (as opposed to recall over an extended span of time in and between episodes). After this, new item detractors were written with language that was appropriate for headache sufferers. These detractor statements were reviewed by the panel and corrections and modifications made according to their recommendations. Only 1 iteration of this process was required. Once this stage was completed, the new instrument was named the HADLI.

The face validity of this scale was then appraised by a different focus group of headache sufferers recruited from adult staff at our institution. These 7 patients/participants were asked to review the Index for the appropriateness of the content as well as the format of the instructions, items, and detractor statements. Modifications were made according to the recommendations which were deemed by the whole group to be important. Two iterations of this process were required. At this point, the HADLI was deemed suitable for further psychometric testing.

Phase 2: The first-level psychometric properties of the HADLI were evaluated in a separate sample of headache sufferers attending a private pain rehabilitation clinic and a chiropractic college outpatient clinic. This phase of the

study was approved by the Research Ethics Board of the Canadian Memorial Chiropractic College (December 1, 2011; No. 1112X03).

Participants. Participants were recruited by advertisements and by direct solicitation. Eligible participants were men and women aged 21 to 70 years with any of migraine, tension-type, or cervicogenic headaches. Participants with obvious pathologies resulting in secondary headaches (vascular, cerebral, or other diseases) were excluded. Participants provided informed consent, acknowledging the confidentiality of their data.

Sample size estimate. Based on Linacre,³⁸ and given that the objective of this study was the investigation of the face validity of the HADLI (not the reliability), a sample size of 50 participants was considered to be suitable for obtaining useful, stable item estimates (with α at $P \leq .05$).

Procedure. Participants were encountered and consented in the clinical treatment rooms and asked to complete 1 version of the HADLI. Clinical and demographic data were also obtained. Participants were asked to indicate their headache type from a list that included “migraine,” “tension-type,” or “cervicogenic.” Participants provided data on total headache duration (months), severity (0–10 visual analog scale), and frequency (number per week). Each of 9 items in the HADLI is scored from 0 to 5, for a total score of 45. This is then converted to a percent score of 100.

Data analyses. We used Classical Test Theory in our analyses.^{39,40} Descriptive statistics were computed for demographic and clinical variables as well as for each item mean score (SD) and distribution of scores. Floor and ceiling effects were examined using 15% cutoffs for low and high instrument scores. Internal consistency was examined with Cronbach α ⁴¹ for total item correlation and for drop-item correlation (“r-drop”). The “factor” structure of the HADLI was examined with Principal Components Analysis.⁴² Statistical analyses were conducted on R version 3.1.1 (R Core Team, 2014. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL <http://www.R-project.org/>).

Full access to all study data was available to all authors.

Results. Phase 1: The NDI was reviewed for items that would be appropriate to the criteria described in the Introduction. It was determined that the items on symptoms—pain severity and headache frequency—would be removed because these are not activities in themselves. Items that were retained from the original NDI were as follows: personal care, lifting, reading, sleeping, work, concentration, and recreation. The item on “driving” was modified to include traveling, as prior studies with the NDI reported that people who do not drive a car found this item problematic.^{18,19} New items included the following: “exercising” and the only item

not directly related to an activity, “neck pain with headaches.” The first draft of the HADLI thus contained 10 items, 8 of which related to specific activities (89% of the scale), 1 item, concentration, which would affect the performance of any ADLs, and 1 item on “neck pain during headaches.”

The item scale from the NDI was retained because it has already proven to provide precision and responsiveness.^{24,25} The instructions for use were completely modified to relate directly to headache sufferers. This included both new general instructions at the top of the scale which specified that the period for self-rating was within 1 month, as well as specific instructions in each item. These were constructed as either “when I have a headache” or “because of headaches” in order to more precisely define the context for self-rating of each item.

The first draft of the HADLI was then evaluated by the first review panel, which consisted of 3 clinicians and 2 lay people, none of whom experienced headaches. This group rated all of the items in the first draft HADLI to be appropriate for headache sufferers. They recommended no changes to the main instructions for the whole scale. They recommended minor changes to 10 detractor statements which were accepted.

Then, a second focus group of headache sufferers, again, recruited from our institution’s adult staff, was used, which consisted of 7 women with a mean age of 42.7 (8.2) years, a mean duration of headaches of 20.8 (14.7) years, and a mean severity of headaches of 6 (1.5)/10. The average time to completion of the HADLI was 3 minutes. This focus group made recommendations to all aspects of the scale. Changes resulting from these recommendations were made to the main instruction text (different font; specifying “typical headaches”), the item instructions (different font; specifying “with headache” or “generally”), the item detractor statements (major changes were made to lifting and exercising), and the items.

With regard to the items themselves, although the initial focus group agreed that all the items in the first draft were appropriate, the second focus group suggested an additional item—“social activities.” This item was included, replacing an item that had been maintained from the NDI—concentration. The justification for this step was that “social activities” was more consistent with Activity Theory than concentration. The focus group also recommended removal of the item neck pain with headaches because this was not a specific ADL. This was done.

The final item set consisted of 9 activity items (100%): personal care, lifting, reading (but modified to include computers), sleeping, exercising, social activities, work, driving (but modified to include traveling), and recreation.

The focus group reached consensus on the items, instructions, and detractor statements, producing a final draft of the HADLI. The items and item characteristics in the HADLI are contrasted with the other 5 instruments in Tables 1 through 4.

Table 5. Results From Phase 2 for HADLI Items

Item	Mean	SD	R value	R-drop
Section 1 – Personal Care	1.7	1.3	0.76	0.71
Section 2 – Lifting	2.3	1.8	0.90	0.88
Section 3 – Reading (Book or Computer)	3.3	1.2	0.87	0.83
Section 4 – Sleeping (In General, Over the Last Week)	2.4	1.7	0.85	0.83
Section 5 – Exercising (Fitness, Weights: In the Last Week)	2.9	1.7	0.89	0.86
Section 6 – Social Activities	2.4	1.6	0.90	0.88
Section 7 – Work	2.7	1.5	0.82	0.78
Section 8 – Driving or Travelling	2.5	1.4	0.92	0.89
Section 9 – Recreation (Sports, Fun, Leisure)	2.6	1.6	0.96	0.95

HADLI, Headache Activities of Daily Living Index; R, Pearson correlation coefficient; SD, standard deviation.

Phase 2: Fifty-three participants were included, 41 women and 12 men who were recruited from June to November 2012. The mean age of these participants was 37.3 (12) years. The mean duration of headaches was 7.4 (8.3) years. The mean frequency of headaches per week was 3.4 (2.4), and the intensity was 6 (2.4). The proportions of participants with self-described migraines, tension-type, or cervicogenic headaches was 41%, 38%, and 31% (>1 headache type could be endorsed).

The mean HADLI score was 26.2 (13.4), or 52%. There were no floor or ceiling effects for total score, as less than 15% of participants scored in the lowest or highest 15%.

The item statistics are shown in Table 5.

Item 1, “personal care,” scored the lowest, whereas item 3, “reading (computer or book),” scored the highest. The total index Cronbach α was .96. R-drop for each item indicated a reduction in Cronbach α in each case, as expected. The Principal Components Analysis identified one component that accounted for 75% of the variance. This component was termed *activity disability*. The correlation between this component and the total HADLI score was 0.99.

DISCUSSION

This study was motivated by the question of whether a new instrument to assess headache-related disability was desirable. The existing instruments for assessing headache-related disability have been validated and have demonstrated good reliability and utility. However, our review of their content and format (Tables 1-4) prompted the conclusion that a new instrument focusing solely on ADLs was worthwhile and could make an important contribution to the management of headache patients.

The reason for modifying the NDI for this purpose was not because we purported that the relationship between neck pain and headache was important to preserve in the instrument. We have indicated that this topic was beyond the scope of this study. The primary reason for deciding to modify the NDI was that the format of this instrument has proven to have strong psychometric properties,^{24,25} which would likely extend to any instrument similarly formatted. Also, several of the items in the original NDI appeared fully suitable for inclusion in the HADLI.

We then undertook to modify the NDI nearly completely, using 6 existing items and developing 3 new items. The inclusion of any of these items was theory-driven, according to the WHO definition of disability^{12,13} as well as according to the principles of Activity Theory.^{15,16} All of the items in the new instrument are distinctive ADLs; each one is conceptually nonredundant, and, taken together, they span across a wide range of typical daily activities. Focus groups confirmed the construct validity of each of these items and of the item detractors as well as the item instructions.

Our comparisons of the items and the format properties of the HADLI vs the preexisting headache disability-related instruments (Tables 1-4) support the distinctiveness of this new instrument in that it is the only instrument whose items are exclusively ADLs and which has the largest number of such items. Also, the format of the HADLI offers important benefits with respect to the other instruments. The instruction related to the time frame of responses to the items ("over the last month") helps resolve the problem of the episodic nature of headaches and offers the respondent a more complete tableau of headaches from which to derive an average rating. The scale of each item is sufficiently large to overcome the limitations noted in the other scales and provides for greater responsiveness as a pretreatment-posttreatment outcome measure.

With respect to our findings in phase 2 of the present study, the participants appear to be typical of headache sufferers in that there were more women and participants were predominantly in the fourth decade of life, with chronic frequently occurring and moderately severe migraine, tension-type, or cervicogenic headaches.

Our results from phase 2 go further in supporting the psychometric properties and construct validity of the HADLI. Chief among these findings is that the HADLI has a strong single-component structure. The excellent internal consistency and the lack of floor and ceiling effects make it well suited for assessing the impact of headaches on a wide range of ADLs. These characteristics distinguish the HADLI among the other instruments reviewed here on the basis of being strictly an assessment of the effect of headache activity on ADLs as opposed to the fact that other instruments also include symptom severity and other psychological constructs.

LIMITATIONS

It may be argued that "yet another instrument for assessing headache-related disability" is not necessary. We contend that our review of the situation, presented in Tables 1-4, refutes this natural inertia and provides convincing justification for the current study.

Our study has not included many aspects of the psychometric properties of a new instrument, such as test-retest reliability and responsiveness. Rather, it has focused on face and construct validity, and further research into these other aspects is now warranted and strongly encouraged based on our positive findings.

Our study did not compare the HADLI to scores on any of the other instruments reviewed above. This is strongly urged for future work because this would give evidence of convergent validity.

CONCLUSION

Five existing instruments for assessing headache-related disability were reviewed for content related to assessing self-rated disability related to the performance of ADLs and were found to be deficient in several important categories. This provided justification for the development of a new instrument, the HADLI, which was created by significantly modifying the NDI. The face validity of the interim and final versions of the HADLI was confirmed by focus groups of patients and experts, resulting in a 9-item instrument consisting only of ADLs. The HADLI was then subjected to initial item analyses and found to have a strong single-component structure, strong internal consistency, and no floor or ceiling effects. As such, it is in suitable form for further psychometric and clinical research.

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CONTRIBUTORSHIP INFORMATION

Concept development (provided idea for the research): H.V.
Design (planned the methods to generate the results): H.V.
Supervision (provided oversight, responsible for organization and implementation, writing of the manuscript): H.V.
Data collection/processing (responsible for experiments, patient management, organization, or reporting data): G.L.
Analysis/interpretation (responsible for statistical analysis, evaluation, and presentation of the results): H.V., G.L.
Literature search (performed the literature search): H.V., G.L.

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Critical review (revised manuscript for intellectual content, this does not relate to spelling and grammar checking): H.V., G.L.

Practical Applications

- Existing instruments for assessing self-rated disability in headache are not limited to assessing ADLs alone.
- There is a need for a unidimensional instrument to assess ADLs in headaches.
- This study presents the initial validation study of just such an instrument: the HADLI.

REFERENCES

1. Rasmussen BK, Jensen R, Schroll M, Olesen J. Epidemiology of headache in a general population—a prevalence study. *J Clin Epidemiol* 1991;44:1147-57.
2. Rasmussen BK, Jensen R, Olesen J. Impact of headache on sickness absence and utilisation of medical services: a Danish population study. *J Epidemiol Community Health* 1992;42:443-6.
3. Stovner LJ, Hagen K, Jensen R, et al. The global burden of headache: a documentation of headache prevalence and disability world-wide. *Cephalalgia* 2007;27:193-210.
4. World Health Organisation. The World Health Report 2001. Available at: <http://www.who.int/whr/2001/en/index.html>. Geneva: WHO; 2001. p. 28. Last accessed 15 March 2006.
5. Jacobson GP, Ramadan NM, Aggarwal SK, Newman CW. The Henry Ford Hospital Headache Disability Inventory (HDI). *Neurology* 1994;44:837-42.
6. Stewart WF, Lipton RB, Whyte J, et al. An international study to assess reliability of the Migraine Disability Assessment (MIDAS) score. *Neurology* 1999;53:988-94.
7. Kosinski M, Bayliss MS, Bjorner JB, et al. A six-item short-form survey for measuring headache impact: the HIT-6. *Qual Life Res* 2003;12:963-74.
8. Niere K, Quin M. Development of a headache-specific disability questionnaire for patients attending physiotherapy. *Man Ther* 2009;14:45-51.
9. Andree C, Vaillant M, Rott C, Katsarava Z, Sandor PS. Development of a self-reporting questionnaire, BURMIG, to evaluate the burden of migraine. *J Headache Pain* 2008;9:309-15.
10. Andrée C, Vaillant M, Barre J, et al. Development and validation of the EUROLIGHT questionnaire to evaluate the burden of primary headache disorders in Europe. *Cephalalgia* 2010;30:1082-100.
11. Turk DC, Dworkin RH, Allen RR, et al. Core domains for chronic pain clinical trials: IMMPACT recommendations. *Pain* 2003;106:337-45.
12. World Report on Disability. Geneva, SZ: WHO, ISBN 978 92 4 156418 2; 2011.
13. ICIDH: International Classification of Impairments, Disabilities, and Handicaps: a manual of classification relating to the consequences of disease. Geneva: World Health Organization; 1980.
14. Badley EM. The ICIDH: format, application in different settings, and distinction between disability and handicap. *Int Disabil Stud* 1987;9:122-5.
15. Engeström Y. Activity theory and individual and social transformation. In: Engeström Y, Miettinen R, Punamäki R, editors. *Perspectives on Activity Theory*. New York, NY: Cambridge University Press; 1999. p. 19-39.
16. Miettinen R. Activity theory. In: Thorpe R, Holt R, editors. *Los Angeles, CA: SAGE*; 2009. p. 21-2.
17. Andrasik F, Lipchik GL, McCrory DC, Wittrock DA. Outcome measurement in behavioral headache research: headache parameters and psychosocial outcomes. *Headache* 2005;45:429-37.
18. Hoppe A, Weidenhammer W, Wagenpfeil S, Melchart D, Linde K. Correlations of headache diary parameters, quality of life and disability scales. *Headache* 2009;49:868-78.
19. Lantéri-Minet M, Duru G, Mudge M, Cottrell S. Quality of life impairment, disability and economic burden associated with chronic daily headache, focusing on chronic migraine with or without medication overuse: a systematic review. *Cephalalgia* 2011;31:837-50.
20. Kirshner B, Guyatt GH. A methodologic framework for assessing health indices. *J Chronic Dis* 1985;38:27-36.
21. Hankins M. How discriminating are discriminative instruments? *Health Qual Life Outcomes* 2008;6:36.
22. Pengel LH, Refshauge KM, Maher CG. Responsiveness of pain, disability, and physical impairment outcomes in patients with low back pain. *Spine* 2004;29:879-83.
23. Vernon H, Mior S. The Neck Disability Index: a study of reliability and validity. *J Manip Physiol Ther* 1991;14:409-15.
24. Vernon H. The Neck Disability Index: state of the art, 1991-2008. *J Manip Physiol Ther* 2008;31:491-502.
25. MacDermid JC, Walton DM, Avery S, et al. Measurement properties of the neck disability index: a systematic review. *J Orthop Sports Phys Ther* 2009;39:400-17.
26. Schofferman J, Garges K, Goldthwaite N, Koestler M, Libby E. Upper cervical anterior discectomy and fusion improves discogenic cervical headaches. *Spine* 2002;27:2240-4.
27. Erfanian P, Tenzif S, Guerriero RC. Assessing effects of a semi-customized experimental cervical pillow on symptomatic adults with chronic neck pain with and without headache. *J Can Chiropr Assoc* 2004;48:20-8.
28. McDonnell MK, Sahrman SA, Van Dillen L. A specific exercise program and modification of postural alignment for treatment of cervicogenic headache: a case report. *J Orthop Sports Phys Ther* 2005;35:3-15.
29. van Duijn J, van Duijn AJ, Nitsch W. Orthopaedic manual physical therapy including thrust manipulation and exercise in the management of a patient with cervicogenic headache: a case report. *J Man Manip Ther* 2007;15:10-24.
30. Mintken PE, Metrick L, Flynn TW. Upper cervical ligament testing in a patient with os odontoideum presenting with headaches. *J Orthop Sports Phys Ther* 2008;38:465-75. Epub 2008 Aug 1.
31. Riina J, Anderson PA, Holly LT, Flint K, Davis KE, Riew KD. The effect of an anterior cervical operation for cervical radiculopathy or myelopathy on associated headaches. *J Bone Joint Surg Am* 2009;91:1919-23.
32. Helmers KM, Irwin KE. Physical therapy as conservative management for cervical pain and headaches in an adolescent

- with neurofibromatosis type 1: a case study. *J Neurol Phys Ther* 2009;33:212-23.
33. Uthakhp S, Sterling M, Jull G. Psychological, cognitive and quality of life features in the elderly with chronic headache. *Gerontology* 2009;55:683-93. Epub 2009 Aug 18.
34. Obermann M, Nebel K, Riegel A, et al. Incidence and predictors of chronic headache attributed to whiplash injury. *Cephalalgia* 2010;30:528-34. Epub 2010 Feb 1.
35. Fernández-de-las-Peñas C, Cleland JA, Palomeque-del-Cerro L, Caminero AB, Guillem-Mesado A, Jiménez-García R. Development of a clinical prediction rule for identifying women with tension-type headache who are likely to achieve short-term success with joint mobilization and muscle trigger point therapy. *Headache* 2011;51:246-61 [Epub 2010 Nov 4].
36. Eriksen K, Rochester RP, Hurwitz EL. Symptomatic reactions, clinical outcomes and patient satisfaction associated with upper cervical chiropractic care: a prospective, multicenter, cohort study. *BMC Musculoskelet Disord* 2011;12:219.
37. von Piekartz H, Lüdtke K. Effect of treatment of temporomandibular disorders (TMD) in patients with cervicogenic headache: a single-blind, randomized controlled study. *Cranio* 2011;29:43-56.
38. Linacre JM. Sample size and item calibration stability. *Rasch Meas Trans* 1994;7:328.
39. Allen MJ, Yen WM. *Introduction to Measurement Theory*. Long Grove, IL: Waveland Press; 2002.
40. Novick MR. The axioms and principal results of classical test theory. *J Math Psychol* 1966;3:1-18.
41. Cronbach LJ. Coefficient alpha and the internal structure of tests. *Psychometrika* 1951;16:297-334.
42. Abdi H, Williams LJ. *Principal component analysis*. Wiley Interdiscip Rev Comput Stat 2010;2:433-59.