The Measurement of Helplessness in Rheumatoid Arthritis. The Development of the Arthritis Helplessness Index

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Abstract. We describe the development of the Arthritis Helplessness Index (AHI), a self-report instrument designed to measure patients’ perceptions of loss of control with arthritis. The participants in this research were 219 patients with rheumatoid arthritis (RA) who completed a quantity of mailed materials, including the AHI, functional measures and other psychological scales. Significant evidence of reliability and validity of the AHI was found. Greater helplessness correlated with greater age, lesser education, lower self-esteem, lower internal health locus of control, higher anxiety, and depression, and impairment in performing activities of daily living using a health assessment questionnaire. Over one year, changes in helplessness correlated with changes in difficulty in performing activities of daily living. The AHI appears to be a useful measure for further studies in RA and a valuable clinical tool in monitoring the psychological status of patients with RA. (J Rheumatol 1985; 12:462-467)

Key Indexing Terms: MEASUREMENT RHEUMATOID ARTHRITIS HELPLESSNESS

In addition to physical disability, rheumatoid arthritis (RA) is frequently associated with significant psychological difficulty. Early psychological studies which focused on the personality characteristics of RA patients failed to reveal significant evidence for the existence of a specific “arthritis personality.” Research using the Minnesota Multiphasic Personality Inventory (MMPI) has found a significant incidence of depression and hypochondriasis in RA patients, although little is known about psychological factors in relation to the clinical course of RA.

The study of the role of psychological variables in RA may benefit from the adoption of theoretical models that can explain empirical findings and guide further research efforts. The learned helplessness model appears to have significant relevance to the analysis of the relationship between psychological variables and health outcomes in RA. The construct of learned helplessness refers to performance deficits produced by past exposure to noncontingent outcomes which may lead to failure to perform beneficial health related behaviors in the face of a chronic illness. The largely unpredictable nature of the remissions and exacerbations in RA may contribute to considerable subjective uncertainty, feelings of personal helplessness, and passive resignation and other forms of dysfunctional coping behavior in many patients. Conversely, patients who learn to tolerate the unpredictable course of RA may be able to achieve better control over their disease.

The systematic study of learned helplessness in RA requires the use of reliable and valid measures to assess helplessness and related constructs. The literature, however, contains few, if any, measures of helplessness that are relevant to chronic disease. In their place, investigators have relied on measures of locus of control to assess the cognitive component of learned helplessness, even though a limitation of such measures is that they may not be predictive of health outcomes in persons with a specific disease condition. We have therefore developed a brief, easily completed 15-item scale, the Arthritis Helplessness Index (AHI), to assess patients’ perceptions of helplessness in coping with arthritis. A measure of helplessness should be significantly correlated with theoretically relevant variables reflecting a lack of personal control or self-efficacy, disturbances in mood such as increased anxiety and depression, and performance deficits as indicated by perceived difficulties or inabilitys in self-management and other health behaviors. We present initial evidence for the validity of the AHI by describing its relationship with measures of health...
locus of control, self-esteem, anxiety and depression, and functional capacity in a sample of patients with RA. Data concerning changes in helplessness over a one-year period are also presented.

MATERIALS AND METHODS

Patients. The study sample consisted of 219 patients who returned an 8-page printed booklet of self-report measures in a stamped, preaddressed envelope. These patients’ names appeared in the registry of the Vanderbilt University Arthritis and Lupus Center, which was compiled from rheumatologists in private practice in the community and the Clinic of the Division of Rheumatology and Immunology at Vanderbilt University. All patients had been independently diagnosed and informed that they had RA by a rheumatologist.

The 219 patients ranged in age from 16 to 81 (mean = 54.1 years) and had their RA for an average of 13.4 years (range = 1 to 53 years). Slightly more than 60% of the patients were female; 84.4% were white; 73.6% were married; and 12.7% indicated that they lived alone. The modal educational level was high school graduate (28.3%), with 8.5% indicating that they had obtained a college degree. Only 20.3% of the patients were employed full-time, and 5.7% were employed part-time. Forty-three percent reported being work-disabled by their arthritis, and 85.7% of those disabled were receiving financial benefits.

In addition, the sample of 219 included 60 RA patients who had completed questionnaires including the AHI, measures of functional capacity, and other psychological scales in a pilot study approximately 12 months earlier. The scores from patients who were in both this sample and the pilot study were used to analyze changes in helplessness and other variables over a 12-month period.

Arthritis Helplessness Index (AHI). The AHI consisted of 15 items measuring patients’ perceptions of their abilities (9 items) or inabilities (6 items) to control their arthritis (Table 1). Patients are asked to rate the 15 items using a 4-point Likert format by selecting one of the response options “strongly disagree,” “disagree,” “agree,” or “strongly agree” for each of the statements. The scoring for the 9 items indicating perceived control is reversed (Table 1) so that total scores for the scale have a possible range of 15 to 60, with higher scores indicating greater helplessness.

Other psychological measures. The Multidimensional Health Locus of Control Scale (MHLC) was used to assess general beliefs about control over health outcomes. This scale consists of 3 6-item subscales: (a) the Internal Health Locus of Control Scale (IHLSC) is a measure of health internality, i.e., the belief that one’s own behavior contributes to one’s health status, (b) the Powerful Others Health Locus of Control Scale (PHLSC) is used to assess the belief that one’s state of health or illness is dependent upon powerful other persons, e.g., health professionals, family, friends; and (c) the Chance Health Locus of Control Scale (CHLSC) is used to measure the belief that one’s health status is mostly a matter of fate, luck, or chance. For these studies, the MHLC was administered using the same 4-point Likert format as the AHI. To make MHLC scores comparable to other studies, the 4-point Likert format necessitated a revised scoring procedure in which “strongly disagree” = 1, “disagree” = 3, “agree” = 4, and “strongly agree” = 6. Scoring of the MHLC could range from 6-36 for each of the 3 subscales, with higher scores indicating greater internality (on the IHLSC) or externality (on PHLSC and CHLSC).*

*The revised scoring did not affect the internal consistency of the MHLC. As indicated by Cronbach’s alpha, the internal consistency was .77 for IHLSC, .69 for PHLSC, and .72 for CHLSC, reflecting comparable internality to that found for the population on which the MHLC was developed.

Table 1. Arthritis helplessness index

<table>
<thead>
<tr>
<th>Item</th>
<th>Item-scale r</th>
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</thead>
<tbody>
<tr>
<td>1. Arthritis is controlling my life.</td>
<td>.39</td>
</tr>
<tr>
<td>2. Managing my arthritis largely my own responsibility.</td>
<td>.20</td>
</tr>
<tr>
<td>3. I can reduce my pain by staying calm and relaxed.</td>
<td>.35</td>
</tr>
<tr>
<td>4. Too often, my pain just seems to hit me out of the blue.</td>
<td>.12</td>
</tr>
<tr>
<td>5. If I do all the right things, I can successfully manage my arthritis.</td>
<td>.57</td>
</tr>
<tr>
<td>6. I can do a lot of things myself to cope with my arthritis.</td>
<td>.39</td>
</tr>
<tr>
<td>7. When it comes to managing my arthritis, I feel I can only do what my doctor tells me to do.</td>
<td>.16</td>
</tr>
<tr>
<td>8. When I manage my personal life well, my arthritis does not flare up as much.</td>
<td>.44</td>
</tr>
<tr>
<td>9. I have considerable ability to control my pain.</td>
<td>.42</td>
</tr>
<tr>
<td>10. I would feel helpless if I couldn’t rely on other people for help with my arthritis.</td>
<td>.32</td>
</tr>
<tr>
<td>11. Usually, I can tell when my arthritis will flare up.</td>
<td>.09</td>
</tr>
<tr>
<td>12. No matter what I do, or how hard I try, I just can’t seem to get relief from my pain.</td>
<td>.38</td>
</tr>
<tr>
<td>13. I am coping effectively with my arthritis.</td>
<td>.43</td>
</tr>
<tr>
<td>14. It seems as though fate and other factors beyond my control affect my arthritis.</td>
<td>.21</td>
</tr>
<tr>
<td>15. I want to learn as much as I can about arthritis.</td>
<td>.16</td>
</tr>
</tbody>
</table>

Note: To compute helplessness score, reverse score items 2, 3, 5, 6, 8, 9, 11, 13, and 15.

Self-esteem was measured by a 10-item scale developed by Rosenberg, rated in 4-point Likert format. Self-esteem reflects the extent to which individuals either positively or negatively evaluate themselves. Scores on the self-esteem scale could range from 10-40, with higher scores indicating greater self-esteem.

Anxiety and depression were measured by the anxiety and depression subscales of the General Well-Being Schedule (GWBS), developed by Dupuy at the National Center for Health Statistics for use in a large sample survey as an index of mental health. The anxiety subscale has a possible range of 4-29 (a high score indicating a lack of tension/anxiety) and consists of 3 items with 6 response options and one 11-point bipolar scale.

The depression subscale also consists of 3 items with 6-point response options and one 11-point bipolar scale. A high score on this scale measures “cheerfulness” as opposed to depression. Patients are instructed to respond to GWBS items on the basis of how they have felt “during the past month.” In previous research, both the anxiety and depression subscales have been found to be highly correlated with the GWBS total (r = .88 and .87, respectively) and significantly related to each other (r = .70).
Measures of functional capacity. Functional capacity was measured using a modified Stanford Health Assessment Questionnaire. This questionnaire includes 8 activities of daily living (Table 2) in which patients rate their performance according to their degree of difficulty, change in difficulty, satisfaction, and degree of pain. The modified Stanford Health Assessment Questionnaire has been shown to have comparable reliability and validity to the lengthier version of this measure.

The degree of difficulty was assessed by the question: “Are you able to . . . ?” with patients rating their capacities according to a 4-point scale: “without ANY difficulty” (0), “with SOME difficulty” (1), “with MUCH difficulty” (2), “UNABLE to do” (3). The total difficulty score is expressed as the mean score for the 8 activities.

Change in difficulty was assessed for the identical 8 activities, with the patient being asked: “Compared to 6 months ago, how difficult is it NOW (this week) to . . . ?” Response options were “less difficult now” (0), “no change” (1), and “more difficult now” (2). The total change score is the mean score for the 8 activities.

Satisfaction or dissatisfaction with the patients’ capacity to perform the selected 8 activities was assessed by having the patients respond regarding each of the activities: “How satisfied are you with your ability to . . . ?” The response options were: “very satisfied” (0), “somewhat satisfied” (1), “somewhat dissatisfied” (2), and “very dissatisfied” (3). As above, the total dissatisfaction score is the mean score for the 8 activities, with a range of 0–3.

Pain was scored by asking “How often is it painful for you to engage in each of the 8 activities?” The response options were: “never” (0), “sometimes” (1), “most of the time” (2), and “always” (3). The total pain score is the mean score for the ratings of the 8 activities (range 0–3).

In addition, patients were asked to make a general rating of the extent to which they perceived themselves to be limited by RA by selecting one of 4 alternatives: 1= “I can do everything I want to do”;
2= “I can do most of the things I want to do”;
3= “I can do some, but not all, of the things I want to do, and have many limitations”;
4= “I cannot do hardly any of the things I want to do.” In the pilot study one year earlier, not all scales were included, but data were available for the AHI, MHLC, self-esteem scale, as well as functional capacity measures for difficulty and dissatisfaction. Scores on these measures were compared over the one-year period.

Statistical methods. Data from this study were analyzed using the Statistical Package for the Social Sciences (SPSS). The reliability of the AHI was evaluated by analyses of its internal consistency and stability over time. The validity of the scale was examined by computing Pearson product moment correlations with demographic, psychological, and functional capacity measures. Since many scales were correlated with patient’s age and educational level, partial correlation analyses were performed which controlled for age and educational level in examining relationships between the AHI and other measures.

RESULTS

Reliability of the AHI. The internal consistency of the AHI was evaluated by determination of Cronbach’s alpha, which was found to be .69 (N=173). While this reflects a significant level of internal consistency for a brief scale, it does suggest the possibility that the AHI may be a multidimensional measure. In this regard, items 4 and 11, which deal with the predictability of arthritis pain and flares, were unrelated to the AHI total (Table 1), suggesting perhaps that predictability may comprise a distinct component of this scale.

Test-retest reliability was determined in 60 patients who had completed a pilot version of the AHI 12 months earlier (Figure 1 — Panel A). Scores varied over a wide range in both administrations, with a mean decrease of one point across all patients. Although this is a lengthy time interval for assessing test-retest reliability, AHI scores over the 12-month period were significantly related to one another (r=0.53, p < 0.001).

Validity of the AHI: associations with demographic, psychological, and functional variables. The variables of sex, race, duration of disease, and whether or not patients lived alone, were not related to AHI scores. Higher age and lower educational attainment, however, were significantly related to greater helplessness (Table 3).

Considerable evidence for the construct validity of the AHI was found. One means of establishing the construct validity of a scale is to examine its relationship with other theoretically relevant variables. As a measure of helplessness, the AHI should be negatively related to internal health locus of control and self-esteem, and positively related to mood disturbances, chance health locus and control, and greater limitations in performing activities of daily living.

Table 3 reveals a very consistent pattern of relationships emerging between the AHI and these variables. Specifically, greater helplessness is related to the belief that one’s health behavior does not contribute to one’s health status, to greater depression and anxiety, and to lower self-esteem. The correlations between the AHI and these variables remain significant when adjusted for age and education. Significant correlations were also found between the AHI and all 4 indices of functional capacity — difficulty, change in difficulty, dissatisfaction, and pain. Helplessness was also significantly related to the general rating of perceived limitations associated with RA. Again, all correlations remain statistically significant after controlling for age.

Table 2. Activities of daily living included in the Modified Health Assessment Questionnairea

- a. Dress yourself, including tying shoe laces and doing buttons
- b. Get in and out of bed
- c. Lift a full cup or glass to your mouth
- d. Walk outdoors on flat ground
- e. Wash and dry your entire body
- f. Bend down to pick up clothing from floor
- g. Turn faucets on and off
- h. Get in and out of a car

*a See text for descriptions of questions and response options.
Fig. 1. Correlations between Arthritis Helplessness Index scores and Difficulty scores in the Activities of Daily Living section of the Modified Health Assessment Questionnaire

Panel A — Arthritis Helplessness Index measured in the same patients
Panel B — Difficulty Score measured in the same patients
Panel C — Changes over one year in the Arthritis Helplessness Index scores and Difficulty scores measured in the same patients

Table 3. Correlations between Arthritis Helplessness Index scores and demographic, psychological and functional variables

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Mean (Range)</th>
<th>Correlation with Other Scales</th>
<th>Correlation Adjusted for Age and Education$^b$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>54.1 (16-81)</td>
<td>0.29**</td>
<td>—</td>
</tr>
<tr>
<td>Duration of disease</td>
<td>13.4 (1-53)</td>
<td>0.09</td>
<td>0.03</td>
</tr>
<tr>
<td>Education</td>
<td>2.8 (1-7)</td>
<td>-0.30</td>
<td>—</td>
</tr>
</tbody>
</table>

Psychological Variables

Health Locus of Control (MHLC)

Indices
- Internal HLC
  - 20.2 (6-36)
- Chance HLC
  - 18.9 (6-36)
- Powerful others HLC
  - 20.8 (8-36)
- Self-esteem
  - 29.1 (21-40)
- Anxiety
  - 16.3 (3-28)
- Depression
  - 17.9 (3-28)

Functional Variables

- Difficulty
  - 0.9 (0-3)
- Change
  - 1.0 (0-2)
- Pain
  - 1.3 (0-3)
- Dissatisfaction
  - 1.2 (0-3)
- Perceived limitations
  - 2.7 (1-4)

$^*$ p<0.05  ** p<0.001

$^a$ See Materials and Methods for description of scales

$^b$ Correlations reported are second-order partial correlations, controlling for age and education.

$^c$ Education was coded as a discrete variable (1 = grade school, 2 = some high school, 3 = high school degree, 4 = some college, 5 = college degree, 6 = post graduate training, 7 = other training)

and education. Helplessness, however, was not significantly related to PHLC or CHLC scores.

Taken together, these findings indicate that helplessness in RA is related to cognitive, affective, and self-reported behavioral problems in individual patients, and thus appears to be a benchmark for disturbances in psychosocial adjustment.

Relation of changes in AHI and psychological indices to changes in functional capacity over 12 months. The availability of scores from the AHI, scales for internal health locus of control, self-esteem, difficulty and dissatisfaction from a pilot study one year earlier allowed comparison on these measures over the one-year period (Figure 1).
A similar trend in AHI and difficulty scores emerged over the one-year interval. As noted previously, AHI scores showed a mean decrease of one point, indicating somewhat less helplessness over time. The difficulty in activities of daily living scores also showed a mean decrease of one point, indicating modest but not significant improvement (Panel B). Of great importance, changes over one year in the AHI were highly correlated with changes in difficulty scores (r=0.52, p < 0.001) (Panel C). Of the 21 patients whose AHI scores decreased, only 3 had difficulty scores which increased, while only 6 of 23 patients whose difficulty scores decreased had AHI scores which increased.

Data over the one-year period also support the discriminant validity of the AHI. Evidence for the discriminant validity of a scale is seen when its correlations with other criterion measures are of greater magnitude than those of scales measuring different constructs. In addition to being highly correlated with changes in difficulty, changes in AHI were also significantly associated with changes in dissatisfaction scores (r=0.50, p < 0.001). In contrast, changes in IHLC scores were correlated significantly with changes in difficulty scores (r=0.38, p < 0.001), but not with changes in dissatisfaction scores. Conversely, changes in self-esteem were correlated with changes in dissatisfaction scores (r = −0.28, p < 0.05), but not with changes in difficulty scores. These results thus indicate that the AHI was superior to other psychological indices in tracking the clinical course of RA over a one-year period.

**DISCUSSION**

Our study has yielded significant initial evidence in support of the reliability and validity of the AHI.

Reliability studies showed the AHI to possess significant internal consistency. The stability over a one-year test-retest interval was statistically significant but at only moderate magnitude, thus allowing for sensitivity for changes in helplessness which occur over time.

Analysis of the internal structure of the AHI suggests that this scale may possess more than one dimension. Factor analytic studies of the AHI may prove useful in examining the different components of this scale and in revealing alternate scoring strategies. Future investigation of the test-retest stability of the AHI over a shorter time period is also recommended.

Evidence for the construct validity of the AHI was demonstrated in the pattern of relationships which emerged between the scale and measures of health beliefs, self-esteem, emotional states, and functional capacity. The correlations that were found fulfilled the theoretical premise that a measure of helplessness in RA should be related to cognitive and affective variables reflecting a lack of personal control or self-efficacy, disturbances in mood, and behavioral limitations.

Helplessness was associated with the belief that patients’ behavior did not contribute to their health status, but not with the belief that chance or powerful others controlled health outcomes. As expected, helplessness was also highly correlated with poorer self-esteem, as well as greater anxiety and depression, the 2 most common affective concomitants of helplessness and arthritis reported in the literature. Thus the AHI may serve to identify dysfunctional health beliefs and affective disturbances in RA.

The AHI was significantly positively correlated with patients’ concurrent reports of functional incapacity associated with their RA. Higher levels of reported helplessness were associated with higher levels of difficulty, dissatisfaction, and pain in carrying out activities of daily living, as well as the general percep-

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**Table 4. Correlations of changes in psychological and functional measures determined 12 months apart**

<table>
<thead>
<tr>
<th></th>
<th>AHI</th>
<th>IHLC</th>
<th>CHLC</th>
<th>PHLC</th>
<th>Self-esteem</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Health Locus of Control (IHLC)</td>
<td>-0.62**</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Chance Health Locus of Control (CHLC)</td>
<td>-0.02</td>
<td>0.49**</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Powerful Others Health Locus of Control (PHLC)</td>
<td>-0.11</td>
<td>0.08</td>
<td>0.01</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>-0.33**</td>
<td>-0.01</td>
<td>-0.12</td>
<td>-0.05</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Difficulty</td>
<td>0.52**</td>
<td>-0.38**</td>
<td>-0.43**</td>
<td>0.06</td>
<td>0.01</td>
<td>—</td>
</tr>
<tr>
<td>Dissatisfaction*</td>
<td>0.50**</td>
<td>-0.18</td>
<td>-0.24*</td>
<td>0.16</td>
<td>0.28*</td>
<td>0.65**</td>
</tr>
</tbody>
</table>

*See Materials and Methods for description of scales.
tion of worsening clinical status. Higher AHI scores were correlated with higher age and lower education, but not with duration of disease. Older and less educated patients may thus require more clinical assistance in learning to acquire control over their RA.

The studies over one year provide further support for the potential clinical utility and discriminant validity of the AHI. Changes in AHI scores were strongly correlated with changes in difficulty scores in individual patients, reflecting overall disease severity. Moreover, changes in helplessness were most strongly related to changes in functional status scores than changes in other psychological scales, including measures of self-esteem and internal health locus of control, over the one-year period.

It should be noted, however, that the AHI is a measure of perceived helplessness and not a measure of actual helplessness which should be reflected through a variety of objective behavioral indices. While the AHI correlates in a theoretically consistent manner with other self-report measures, whether perceived helplessness predicts deficits in the overt behavior of RA patients in such areas as self-care and compliance deserves empirical attention. Such data would further clarify the concurrent validity of this scale.

In summary, the AHI shows potential utility in both research and clinical settings. The measure is correlated with self-reported cognitive, affective, and behavioral dimensions of RA and with changes in health status. Therefore, the AHI may be helpful in the clinical evaluation and screening of patients who may benefit from psychosocial interventions that would complement their medical regimens. Such interventions may include biofeedback and relaxation techniques for pain control as well as physical therapy and educational programs that promote independence and better coping skills. As the experience of helplessness is common to a variety of medical conditions, the AHI may also serve as a useful general model for the development of tools with which to study helplessness in chronic illness.

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