Prevalence and Predictors of Disability in Valued Life Activities among Individuals with Rheumatoid Arthritis

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Key words: disability, functioning, rheumatoid arthritis
ABSTRACT

Objectives: Identify the prevalence of disability in wide range of life activities and identify factors associated with such disability using the Verbrugge and Jette disablement model as a framework.

Methods: Data were from a panel study of 548 individuals with rheumatoid arthritis (RA) interviewed annually by telephone. Valued life activity (VLA) disability was assessed using a 26-item scale rating difficulty performing each activity. Three types of summary measures were calculated: activities unable to perform, activities affected, and mean difficulty. Subscale scores were also calculated corresponding to obligatory, committed, and discretionary activities, as defined in the disablement model. Disease status measures were examined as predictors of VLA disability using multiple regression analyses.

Results: Half of subjects were unable to perform at least one VLA. Approximately 2%, 31.3%, and 40.2% were unable to perform at least one obligatory, committed, and discretionary activity, respectively. Almost all (95%) individuals reported at least one VLA affected by RA; 68.4%, 91.4%, and 92.5% reported at least one obligatory, committed, and discretionary activity, respectively, affected. Disease status measures were robust predictors of VLA disability, accounting for 22%-47% of the variation in VLA disability (with one exception). Adding HAQ to these models significantly increased (p<.0001) all model R²'s. HAQ score mediated the effects of many disease measures, consistent with the disablement model.

Conclusion: VLA disability was common, with more disability noted in committed and discretionary than obligatory activities. Because VLA disability has been linked to psychological well-being in previous studies, identification of factors that may protect against such disability is important.
Two models have driven the bulk of disability research. The first is that of the World Health Organization (WHO).[1] [2] [3] [4] Although useful in some situations, substantive problems have been reported in attempts to use the WHO model to guide research.[5] The second model was developed by Nagi, later amended by the Institute of Medicine, and then expanded by Verbrugge and Jette in their model of the “disablement process.”[4] [6] [7] This model encompasses four components:

- **Pathology:** Biochemical and physiological abnormalities, or disease, injury, or congenital/ developmental conditions
- **Impairments:** Dysfunctions or significant abnormalities in specific body systems that can have consequences for physical, mental, or social functioning
- **Functional limitations:** Restrictions in performing generic, fundamental physical and mental actions used in daily life in many circumstances
- **Disability:** Difficulty performing activities of daily life

The disablement process was described as a pathway progressing from pathology, to impairments, to functional limitations, to disability. Verbrugge and Jette also recognized that certain predisposing factors, termed “risk factors,” could affect the presence or severity of impairments, functional limitations, or disability.

When assessing disability, Verbrugge proposed that life activities be grouped into 3 categories:[3] [7] [8]

- **obligatory activities,** required for survival and self-sufficiency, including ADL-type activities such as hygiene and self-care, walking inside, walking outside, and using transportation or driving;
- **committed activities,** associated with one’s principal productive social roles, such as paid work, household responsibilities, child and family care; and
- **discretionary activities,** such as socializing, exercise, engaging in leisure time activities and pastimes, participating in religious or spiritual activities, and pursuing volunteer work or hobbies, or other activities that individuals engage in for relaxation and pleasure.

Disability research has focused on basic activities of daily living (ADLs; e.g., personal hygiene, transfers), independent activities of daily living (IADLs; e.g., preparing meals), and employment, corresponding to obligatory and some committed activities, and has thus ignored a great deal of daily life, particularly valued discretionary activities.[3] This emphasis reflects assumptions by researchers that ADLs, IADLs, and employment are a priori more important and that difficulty doing them is thus more significant. These assumptions may, in fact, not be true. Some activities are more important or more meaningful to individuals than others, and the person-specific meaning, or “value,” attached to activities may affect the impact of disability. The importance of individual priorities and values, and the failure of common functional assessments to take these individual values into account, has been recognized by some researchers, and studies have shown that a large proportion of activities that individuals deem to be important are outside the realm of ADLs, IADLs, and employment.[9] [10] [11] Functioning in discretionary, valued life activities (VLAs) may also be more strongly linked to satisfaction with function and psychological well-being than more basic, ADL-type levels of functioning.[12] [13] [14] [15] At the same time, as individuals begin to have difficulty with, and/or require more time to perform basic activities, discretionary activities may be relinquished in order to accommodate the additional time and energy requirements needed for basic activities.[16] [17]

Functional limitations and disability resulting from RA have been extensively studied. The majority of disability research in RA has focused on ADLs, IADLs, and work and has presented a consistent picture of impaired functioning in these domains.[18] [19] [20] [21] [22]
VLA Disability

Some research has focused on disability in a broader range of life activities, and the impact of RA may be seen in such activities. In a variety of studies, individuals with RA have reported significant limitations in their ability to perform general household cleaning activities, laundry, shopping or errands, cooking, and child and family care, and interference with performance of hobbies and pastimes and with sexual interest and activities. However, none of these studies has undertaken an assessment of the prevalence of disability among individuals with RA in which a broad range of activities, spanning obligatory, committed, and discretionary activities, was included.

This paper presents data on disability in a wide range of life activities, and also identifies factors that are associated with such disability using the Verbrugge and Jette model of disablement as a framework.

METHODS

Sample

The sample for the present study was drawn from the 2003 wave of the UCSF Rheumatoid Arthritis (RA) Panel Study (N=548). The UCSF RA Panel was constructed in 1982 from a random sample of rheumatologists practicing in Northern California. Participants have been recruited from lists maintained by participating rheumatologists of all persons with RA presenting to their offices over a one-month period, and expressing an interest to participate in the study. The original RA Panel consisted of 822 patients who were enrolled between June 1982 and July 1983. There were subsequently four additional enrollment periods in 1989-90, 1995, 1999, and 2003, during which 203, 131, 122, and 169 individuals were enrolled, respectively. Retention from year to year has averaged 93%; the 7% attrition includes deaths. The principal data source for the RA Panel is an annual telephone interview that includes questions on demographics, RA symptoms, comorbidities, and functioning. The study was approved by the UCSF Committee on Human Research.

Variables

Valued life activity (VLA) disability

The VLA scale has its roots in a study by Yelin et al. in which a measure of 75 life activities was developed based on time-budget survey research studies to determine the impact of arthritis.[28] Most of the activities assessed were things that one might do on an everyday or frequent basis, such as cooking, shopping for food, visiting with family, getting around the neighborhood, and being involved with hobbies and crafts. When this list was incorporated into the RA Panel interview, individuals were asked to rate how important it was to them to be able to perform that activity, as well as whether they had participated in each activity in the past six months. Ten activities that were reported by fewer than ten percent of the subjects (e.g., doing major maintenance outside the house, such as roofing; going to bars and nightclubs) were omitted. The activities were then grouped into 13 domains on a conceptual basis: home maintenance, housework, shopping and errands, nurturing activities, social communication and interaction, participation in social events, service activities, entertainment activities outside the home, sedentary leisure activities in the home, recreational activities, religious activities, transportation, and work. Domain categorizations were confirmed in two ways: with factor analyses of the importance ratings, and by examining the internal consistency (Cronbach’s α) of each domain.[25]
Over the past decade, the VLA scale has been modified and refined. Respondents have been asked over multiple waves to identify activities or activity domains in addition to those queried that have been affected by their condition. Revisions have been made to the VLA scale based on those accumulated responses as well as analysis of previous versions of the scale. The version of the VLA scale used in these analyses includes 26 activity domains covering obligatory, committed, and discretionary activities. The full text of the scale items is shown in Table 1. Activities were defined as obligatory, committed, or discretionary based on the definitions of these activity categories by Verbrugge.[3] [7] [8]

Assessment of disability with the VLA scale represents advancement over previous instruments in two ways. First, a wide spectrum of activities is included, ranging from obligatory activities, such as self-care, to discretionary activities, such as recreation and social participation. Second, the VLA scale takes personal value into account. Activities that are not applicable to an individual (e.g., “taking care of children” if the individual has no children) or are not important to the individual (e.g., “cooking” if the spouse does all of the cooking) are not included in scoring of the scale. Finally, unlike most disability indices, the VLA scale asks respondents to attribute performance difficulties to the health condition under study.

In the telephone interview, participants rated the difficulty of performing the 26 life activities, using a 4-point scale corresponding to the response scale of the HAQ (0 [no difficulty] to 3 [unable to perform]). Activities that participants deemed unimportant to them, or that they did not do for reasons unrelated to RA, were not rated and were not included in scoring.

Three types of VLA summary measure scores were calculated: the number of activities that individuals were completely unable to perform because of RA (UNABLE), the number of activities that were affected by RA (unable to perform or any level of difficulty; AFFECTED), and the average difficulty score (DIFFICULTY). These scores were calculated for the total VLA scale, and for the Obligatory, Committed, and Discretionary subscales.
<table>
<thead>
<tr>
<th>Subscale*</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>O</strong></td>
<td>1. <strong>Taking care of your basic needs, such as bathing, washing, getting dress, or taking care of personal hygiene.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>2. <strong>Preparing meals and cooking.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>3. <strong>Light housework, such as dusting or laundry.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>4. <strong>Heavier housework, such as vacuuming, changing sheets, or cleaning floors.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>5. <strong>Other work around the house, such as making minor home repairs or working in the garage fixing things.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>6. <strong>Gardening or working in your yard.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>7. <strong>Shopping and doing errands.</strong></td>
</tr>
<tr>
<td><strong>O</strong></td>
<td>8. <strong>Going to appointments, such as going to the doctor or dentist, or going to have your hair cut/done.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>9. <strong>Taking care of your children/grandchildren or doing things for them.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>10. <strong>Participating in activities with your children/grandchildren.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>11. <strong>Taking care of other family members, such as your spouse or parent, or other people close to you.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>12. <strong>Visiting with friends or family members in their home.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>13. <strong>Going to parties, celebrations, or other social events.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>14. <strong>Having friends and family members visit you in your home.</strong></td>
</tr>
<tr>
<td><strong>O</strong></td>
<td>15. <strong>Walking or getting around inside your home.</strong></td>
</tr>
<tr>
<td><strong>O</strong></td>
<td>16. <strong>Walking outside, just to get around, in the area around your home or other places you need to go on a regular basis. (This does not include walking for exercise.)</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>17. <strong>Participating in leisure activities in your home, such as reading, watching television, or listening to music.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>18. <strong>Participating in leisure activities OUTSIDE your home, such as playing cards or bingo, or going to movies/restaurants.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>19. <strong>Working on hobbies or crafts or creative activities, such as sewing, woodwork, or painting.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>20. <strong>Participating in moderate physical recreational activities, such as dancing, playing golf, or bowling.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>21. <strong>Participating in vigorous physical recreational activities, such as walking for exercise, jogging, bicycling, swimming, or water aerobics.</strong></td>
</tr>
<tr>
<td><strong>O</strong></td>
<td>22. <strong>Getting around your community by car or public transportation.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>23. <strong>Traveling out of town.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>24. <strong>Participating in religious or spiritual activities.</strong></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>25. <strong>Doing volunteer work.</strong></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>26. <strong>Working at a job for pay</strong></td>
</tr>
</tbody>
</table>

*O=Obligatory, C=Committed, D=Discretionary*
Predictors of VLA disability

Potential predictors of VLA disability were selected based on the Verbrugge and Jette model, and included measures of disease status and functional limitations. Measures of disease status, representing the “impairments” stage of the disablement model, included the following variables. Escalante and colleagues, in their test of the disablement model, also used these types of symptom measures to represent the impairment stage of the model.[32]

- Number of painful joints/joint groups, reported from a list of 17.
- Number of swollen joints/joint groups, reported from a list of 14.
- Rating of pain severity on the day of the interview, on a scale of 0 (no pain) to 100 (very severe pain).[33]
- Rating of fatigue in the past two weeks as none, very mild, mild, moderate, severe, or very severe. Ratings were grouped into two categories, none through moderate versus severe or very severe.
- Duration of morning stiffness, dichotomized as less than one hour versus one hour or more.
- Changes in the shape or appearance of hands or feet, assessed with the questions, “Has your RA [ever/in the past year] changed the shape or appearance of your [hands/feet]?” These questions were intended to assess joint deformities or structural derangements in the hands and feet, using lay terminology.

Functional limitations were assessed with the Health Assessment Questionnaire (HAQ), a widely used measure of basic functioning specifically developed to measure functioning among persons with arthritis.[33] Although the HAQ is generally used as a measure of disability, the majority of the individual items actually reflect functional limitations as defined by the Nagi and Verbrugge models. HAQ scores range from 0-3, with higher scores indicating greater limitations.

Analysis

Frequency distributions of difficulty ratings for each of the 26 valued life activities (VLAs) were tabulated, and means and standard deviations of scale scores were calculated. The proportion of activities in each category that individuals reported affected (or unable) was calculated (e.g., number of obligatory activities affected / 5 [the total number of obligatory activities assessed]). Factors associated with VLA disability were identified using multiple linear regression analyses, with VLA disability scores as dependent variables and measures of disease status and functional limitations as independent variables. The first set of regression analyses included number of painful joints, number of swollen joints, pain rating, fatigue rating, duration of morning stiffness, and joint changes in hands and feet, as well as age, sex, and duration of RA. The second set of analyses retained all of these variables and added HAQ score.
RESULTS

Subject characteristics

The majority of subjects (83.6%) were female. Mean age was 60 years and mean duration of RA was 18 years. Additional characteristics may be seen in Table 2.

Table 2
Subject Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>60.1 (13.2)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>83.6 (458)</td>
<td></td>
</tr>
<tr>
<td>Duration of RA</td>
<td>18.4 (11.9)</td>
<td></td>
</tr>
<tr>
<td>Pain rating</td>
<td>30.1 (26.9)</td>
<td></td>
</tr>
<tr>
<td>(0 = no pain, 100 = very severe pain)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe or very severe fatigue</td>
<td>18.7(102)</td>
<td></td>
</tr>
<tr>
<td>Morning stiffness duration 1 hour or more</td>
<td>20.3 (111)</td>
<td></td>
</tr>
<tr>
<td>Joint changes in hands</td>
<td>49.0 (268)</td>
<td></td>
</tr>
<tr>
<td>Joint changes in feet</td>
<td>37.6 (206)</td>
<td></td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>48.5 (266)</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>36.1 (198)</td>
<td></td>
</tr>
<tr>
<td>2 or more</td>
<td>15.4 (84)</td>
<td></td>
</tr>
<tr>
<td>HAQ score</td>
<td>1.02 (0.73)</td>
<td></td>
</tr>
</tbody>
</table>

Difficulty ratings for valued life activities.

Table 3 provides the means and frequencies of the difficulty ratings for individual activities. The activities most frequently affected by RA were in the committed and discretionary categories -- Committed: heavy housework (85%), minor repairs (82%), and paid work (73%); Discretionary: gardening (87%), physical activities (moderate, 80%, and vigorous, 78%), and hobbies (75%). These activities also had the highest mean difficulty ratings. Substantial proportions of individuals were unable to perform these activities. Obligatory activities had the lowest difficulty ratings, and there was little variability in ratings of specific activities. Both Committed and Discretionary activities exhibited a fairly wide range of proportions of individuals whose activities in that domain were affected and a wide range of mean difficulty ratings.
Table 3
Difficulty Ratings for Valued Life Activities: 2003 RA Panel (N=548)

<table>
<thead>
<tr>
<th>Difficulty rating (%)</th>
<th>n*</th>
<th>% affected</th>
<th>Mean difficulty rating (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Obligatory activities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic needs</td>
<td>548</td>
<td>41</td>
<td>.44 (.56)</td>
</tr>
<tr>
<td>Appointments</td>
<td>547</td>
<td>31</td>
<td>.36 (.58)</td>
</tr>
<tr>
<td>Walk inside</td>
<td>547</td>
<td>45</td>
<td>.49 (.59)</td>
</tr>
<tr>
<td>Walk outside</td>
<td>546</td>
<td>57</td>
<td>.69 (.69)</td>
</tr>
<tr>
<td>Car/transit</td>
<td>547</td>
<td>27</td>
<td>.32 (.58)</td>
</tr>
<tr>
<td><strong>Committed activities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Light housework</td>
<td>525</td>
<td>57</td>
<td>.71 (.75)</td>
</tr>
<tr>
<td>Meals/cook</td>
<td>520</td>
<td>59</td>
<td>.72 (.72)</td>
</tr>
<tr>
<td>Shopping/errands</td>
<td>542</td>
<td>57</td>
<td>.73 (.77)</td>
</tr>
<tr>
<td>Child care</td>
<td>272</td>
<td>60</td>
<td>.79 (.80)</td>
</tr>
<tr>
<td>Other family care</td>
<td>346</td>
<td>47</td>
<td>.66 (.85)</td>
</tr>
<tr>
<td>Heavy housework</td>
<td>512</td>
<td>85</td>
<td>1.33 (.91)</td>
</tr>
<tr>
<td>Paid work</td>
<td>317</td>
<td>73</td>
<td>1.31 (1.14)</td>
</tr>
<tr>
<td>Minor repairs</td>
<td>356</td>
<td>82</td>
<td>1.43 (1.06)</td>
</tr>
<tr>
<td><strong>Discretionary activities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure in</td>
<td>547</td>
<td>16</td>
<td>.17 (.41)</td>
</tr>
<tr>
<td>Religious/spiritual activities</td>
<td>415</td>
<td>30</td>
<td>.41 (.73)</td>
</tr>
<tr>
<td>Having others visit</td>
<td>538</td>
<td>40</td>
<td>.44 (.57)</td>
</tr>
<tr>
<td>Visiting others</td>
<td>536</td>
<td>35</td>
<td>.45 (.70)</td>
</tr>
<tr>
<td>Leisure out</td>
<td>534</td>
<td>46</td>
<td>.57 (.73)</td>
</tr>
<tr>
<td>Parties/events</td>
<td>529</td>
<td>47</td>
<td>.61 (.78)</td>
</tr>
<tr>
<td>Travel</td>
<td>524</td>
<td>57</td>
<td>.76 (.80)</td>
</tr>
<tr>
<td>Activities with children</td>
<td>305</td>
<td>66</td>
<td>.82 (.74)</td>
</tr>
<tr>
<td>Volunteer work</td>
<td>356</td>
<td>59</td>
<td>1.05 (1.14)</td>
</tr>
<tr>
<td>Hobbies</td>
<td>435</td>
<td>75</td>
<td>1.10 (.93)</td>
</tr>
<tr>
<td>Gardening</td>
<td>434</td>
<td>87</td>
<td>1.40 (.92)</td>
</tr>
<tr>
<td>Moderate physical activities</td>
<td>459</td>
<td>80</td>
<td>1.41 (1.06)</td>
</tr>
<tr>
<td>Vigorous physical activities</td>
<td>504</td>
<td>78</td>
<td>1.43 (1.11)</td>
</tr>
</tbody>
</table>

* Response frequencies vary as a function of the number of participants reporting that the activity either was not important to them or not applicable to them.
Almost half of the sample (49%) was unable to perform at least one VLA, with this being most frequent in Discretionary activities (40%; Table 4). The mean number of VLAs that participants were unable to perform was 1.65, again with the preponderance of these being Discretionary activities. Almost all participants (95%) reported at least one VLA affected by RA, with over half (68%) reporting an Obligatory activity affected, and over 90% reporting a Committed or Discretionary activity affected. The Committed and Discretionary frequencies were similar. The mean number of activities affected was 12. While the number of Discretionary activities affected was greater than the number of Committed activities affected, the proportion of activities queried in each domain affected was quite similar.

Table 4
Valued Life Activity Summary Scores

<table>
<thead>
<tr>
<th>Disability scores</th>
<th>All activities (26 items)</th>
<th>Obligatory (5 items)</th>
<th>Committed (8 items)</th>
<th>Discretionary (13 items)</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNABLE*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to perform at least one VLA</td>
<td>49.1%</td>
<td>1.6%</td>
<td>31.3%</td>
<td>40.2%</td>
</tr>
<tr>
<td>Mean (SD) number of activities</td>
<td>1.65 (2.75)</td>
<td>0.03 (.25)</td>
<td>.63 (1.22)</td>
<td>.99 (1.67)</td>
</tr>
<tr>
<td>Proportion of activities queried</td>
<td>6.3%</td>
<td>0.6%</td>
<td>7.9%</td>
<td>7.6%</td>
</tr>
<tr>
<td>AFFECTED†</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least one VLA affected</td>
<td>94.9%</td>
<td>68.4%</td>
<td>91.4%</td>
<td>92.5%</td>
</tr>
<tr>
<td>Mean (SD) number of activities</td>
<td>12.01</td>
<td>2.01</td>
<td>4.03</td>
<td>5.98 (3.77)</td>
</tr>
<tr>
<td>(7.40)</td>
<td>(1.87)</td>
<td>(2.38)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion of activities queried</td>
<td>46.2%</td>
<td>40.1%</td>
<td>50.4%</td>
<td>46.0%</td>
</tr>
<tr>
<td>DIFFICULTY§</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>.76 (.57)</td>
<td>.46 (.49)</td>
<td>.93 (.71)</td>
<td>.79 (.60)</td>
</tr>
</tbody>
</table>

* Unable to perform
† Affected by RA; i.e., either difficulty or unable to perform
§ Mean (standard deviation)

Predictors of VLA disability

The disablement model would predict that measures of disease status would predict functional limitations (in this case, HAQ), and that, in turn, functional limitations would predict disability. All disease measures were significant predictors of HAQ score and accounted for a substantial portion of the variance in HAQ (adjusted $R^2 = 0.45$; data not shown). In models including only symptom measures, age, sex, and duration of RA, the symptom measures were robust predictors of VLA disability, with model $R^2$'s ranging from 0.28 (for UNABLE) to 0.47 (for DIFFICULTY) for total VLA summary scores (Table 5). Model $R^2$'s were somewhat lower for the subscales (i.e., Obligatory, Committed, and Discretionary activities), but, with the exception of Obligatory UNABLE, all models were statistically significant and accounted for 22%-45% of the variance in VLA disability. Adding HAQ to the regression models significantly (P<.0001) increased the model $R^2$ in all cases, and changed the patterns of association. HAQ score appeared to mediate the effects of many of the disease measures, as would be predicted by the disablement model, and was a highly significant predictor of VLA disability scores in all cases.
Table 5
Predictors of VLA Disability

<table>
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<tr>
<th>UNABLE</th>
<th>Demographic and Symptom measures only</th>
<th>Adding HAQ to regression model</th>
</tr>
</thead>
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<td>Female</td>
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<tr>
<td>RA duration</td>
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<td>+a</td>
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<tr>
<td>Pain rating</td>
<td>+c</td>
<td>+a</td>
</tr>
<tr>
<td>Fatigue</td>
<td>+d</td>
<td>+d</td>
</tr>
<tr>
<td>A.M. stiffness</td>
<td>+d</td>
<td>+c</td>
</tr>
<tr>
<td>Hands</td>
<td>+a</td>
<td></td>
</tr>
<tr>
<td>Feet</td>
<td>+a</td>
<td>+b</td>
</tr>
<tr>
<td>HAQ</td>
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<td>+d</td>
</tr>
<tr>
<td>Model R²</td>
<td>.26</td>
<td>.01</td>
</tr>
</tbody>
</table>

| AFFECTED                      |       |            |           |              |       |            |          |              |
| Age                           | +a    |           |           |              | +c    |           |           |              |
| Female                        |       |            |           |              |       |            |          |              |
| RA duration                   | +c    | +b         | +b        | +c           | +d    |           | +b        | +b           |
| Pain rating                   | +d    | +d         | +d        | +d           | +d    | +c         | +b        | +d           |
| Fatigue                       | +d    | +d         | +d        | +d           | +c    | +b         | +c        | +c           |
| A.M. stiffness                | +b    | +b         | +a        | +b           | +a    | +a         | +a        | +a           |
| Hands                         | +a    | +a         | +a        | +a           |       |            |          |              |
| Feet                          | +c    | +c         | +c        | +a           |       |            |          |              |
| HAQ                           | +d    | +d         | +d        | +d           | +d    | +d         | +d        | +d           |
| Model R²                      | .35   | .33        | .27       | .32          | .60   | .58        | .47       | .52          |

| DIFFICULTY                    |       |            |           |              |       |            |          |              |
| Age                           | +a    | +b         | +b        |              | +a    |           |           |              |
| Female                        |       |            |           |              |       |            |          |              |
| RA duration                   | +d    | +b         | +d        | +d           | +d    |           | +b        | +b           |
| Pain rating                   | +d    | +d         | +d        | +d           | +d    | +b         | +b        | +b           |
| Fatigue                       | +d    | +d         | +d        | +d           | +d    | +c         | +c        | +d           |
| A.M. stiffness                | +d    | +d         | +d        | +d           | +d    | +c         | +c        | +c           |
| Hands                         | +a    | +a         | +a        | +a           |       |            |          |              |
| Feet                          | +d    | +c         | +d        | +c           |       |            |          |              |
| HAQ                           | +d    | +d         | +d        | +d           | +d    | +d         | +d        | +d           |
| Model R²                      | .43   | .34        | .38       | .42          | .75   | .61        | .69       | .69          |

Cells show the direction of significant predictors (positive or negative association).
Letters indicate significance level of variable in multiple regression models:
a= p<.05. b=p<.01. c=b<.001. d=p<.0001
Increase in R² for models when HAQ was entered was significant at p<.0001 in all cases.
DISCUSSION

VLA disability is common among individuals with RA. About half of this sample was unable to perform at least one VLA because of RA, and almost all reported at least one VLA affected by RA. Obligatory activities were the least affected, regardless of how VLA disability was defined. There was little difference between Committed and Discretionary activities when VLA disability was defined as the number of activities affected. However, the likelihood of being unable to perform at least one VLA increased from a very small percentage for Obligatory activities, to about 30% for Committed, to 40% for Discretionary, suggesting that Discretionary activities are the activities most commonly given up. Whether this is a voluntary relinquishment, to allow time and/or energy for other activities, or whether these activities are lost because of functional limitations and the increased physical demands of these activities requires further examination. The higher difficulty ratings seen for Committed activities may be an indication that these activities, necessary for meeting life roles, require more effort and thus leave less time and effort for more discretionary activities. This hypothesis is consistent with previous reports that when dealing with disability, people may give up some activities in order to have time and energy for others. [16] [17] [28]

The results of these analyses supported the Verbrugge and Jette disablement model, although the test of the model was limited by the lack of variables representing the “pathology” stage, such as laboratory measures of inflammation. Symptom measures, representing “impairments,” were associated with functional limitations (HAQ score). A number of studies have demonstrated the relationship between symptom measures (“impairments”) and HAQ score.[34] [35] Most research has treated the HAQ score as a measure of disability, but, in the context of the disablement model, all of the HAQ items except two (the “other activities” subscale) correspond to functional limitations, such as difficulty reaching, gripping, and arising. Previous work supports differentiation of the HAQ from measures of disability. For example, the overlap between decline in functioning measured by the HAQ and decline in functioning measured by a VLA-type measure is minimal. In one study, of 47 women who experienced a decline according to one of the measures, only 6 (13%) experienced a decline according to both measures.[12] Previous studies have also used HAQ as a predictor of disability, particularly work disability [19] [20] [21] [22] [23] [24] [25] [26] [27] [28], implicitly suggesting that what the HAQ measures is a precursor to disability.

As noted above, symptom measures were associated with functional limitations (HAQ). Functional limitations were, in turn, associated with VLA disability and mediated much of the relationship between symptoms and disability. Some symptom measures appeared to have direct associations with VLA disability in addition to the mediated associations. Fatigue and pain, in particular, had independent associations with VLA disability, even when taking HAQ into account, suggesting that these impairments (or symptoms) are more closely tied to disability than demographic characteristics and other symptoms. HAQ was by far the strongest predictor of VLA disability, regardless of how VLA disability was defined.

Use of three measures of VLA disability leads to the question of which measure is “best.” Previous research has focused on the loss of activities, or the equivalent of the number of activities individuals are unable to perform, and has shown robust associations with development of depression.[12] [13] However, the proportion of variation in the number of activities individuals were unable to perform that was explained by symptoms and functional limitations was considerably lower than the variation in the number of activities affected or difficulty explained by those variables, suggesting that the number of activities unable to perform may be influenced by additional, unmeasured factors. Further study is needed to determine which VLA specifications are best suited to which situations. For example, to predict long-term psychological outcomes, the “unable to perform” specification may be more sensitive, whereas to predict other outcomes another specification may be a better choice.

Why is it important to consider disability in valued life activities? The impact of disability is likely to vary according to the value that individuals place on affected activities. Performance of VLAs appears to be linked to psychological well-being more strongly than limitations in general function. Persons with RA who report high levels of depressive symptoms performed fewer VLAs than those who did not report depressive symptoms, and the loss of VLAs has been shown to be a stronger predictor of the subsequent onset of new depressive symptoms than decline in function as measured by the HAQ (i.e., HAQ).[12] [25] Disability in certain types of activities, specifically in recreational and social activities, appears to be especially linked to the onset of depressive symptoms.[13] Several other researchers have addressed the issue of personal value by
constructing “patient-specific” measures.[9] [38] [39] Although these measures appear to be useful for monitoring individuals, difficulties have been reported when using them in aggregate situations.[10] [40]

Another consideration is that as more effective treatments become available, patient goals will likely expand beyond simple preservation of ADLs. Measurement of a wider range of life activities coincides with these new expectations.

There are potential limitations to this study. It is possible that our assessment of VLAs was incomplete. In fact, as a result of open-ended queries about other activities that have been affected by RA, a new version of the VLA assessment is being developed and tested, to which additional life activities, such as sleep and intimate relations with partners, have been added. While this new measure may be more sensitive, there is no reason to believe that the overall tenor of these results would change as a result. It is also possible that factors other than those included here may affect the association of VLA disability with general health status assessments. For example, obesity may affect both functional limitations and disability. Unfortunately, a measure of body composition was not available for this cohort, although such data will be collected in the future, enabling examination of this association at that time. The RA Panel cohort may be unrepresentative of individuals with RA in some way; however, the cohort is very similar in measured characteristics to other large cohorts.[41] However, because participants were recruited from community rheumatologists rather than through an academic medical center or tertiary care center, it is probable that the distribution of disease severity and other relevant characteristics is more similar to the population of individuals with RA. Nonetheless, it is possible that individuals who visit rheumatologists for care are systematically different from those who do not; in particular, they may have less severe disease and less disability.

In summary, disability in valued life activities is very common among individuals with RA. Such disability appears to play a substantial role in individuals’ psychological status, as demonstrated in previous studies.[12] [13] Future research topics should include identification of factors associated with the development and progress of VLA disability, as well as factors that may protect against or ameliorate such disability. The latter is especially important, since these may represent targets for potential intervention.
Appendix A

Predictors of VLA Disability

<table>
<thead>
<tr>
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<th>Demographic and Symptom measures only</th>
<th>Adding HAQ to regression model</th>
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<td>.37</td>
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Cells show the direction of significant predictors (positive or negative association).
Letters indicate significance level of variable in multiple regression models:
   a= p<.05.  b=p<.01.  c=p<.001.  d=p<.0001

Increase in $R^2$ for models when HAQ was entered was significant at $p<.0001$ in all cases.
REFERENCES


Prevalence and Predictors of Disability in Valued Life Activities among Individuals with Rheumatoid Arthritis
Patricia Katz, Anne Morris and Edward Yelin

Ann Rheum Dis published online October 25, 2005

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