Difficulties in performing leisure activities among persons with newly diagnosed rheumatoid arthritis: a prospective, controlled study

I. Wikström, C. Book and L. T. H. Jacobsson

Objective. To compare leisure activities and associated factors in a group with recent onset RA and matched community-derived controls, to examine whether leisure activities are altered during the early years of disease and to seek predictors.

Methods. One hundred and forty-seven consecutive persons with early RA were followed for 0.9–5.9 yr. One hundred and forty-four RA patients were compared cross-sectionally at baseline with community-derived controls matched for age, gender and residential area. Leisure activities were evaluated with an interest checklist (20 domains). Socio-demographic variables, disease activity (DAS) and disability (HAQ) were evaluated as possible predictors for loss of participation in leisure activities at baseline and longitudinally (using area under the curve analyses).

Results. At baseline (mean disease duration 7 months) RA patients performed less (8.2 vs 9.9 domains, P < 0.001) but did not have significantly less interest (10.9 vs 11.4 domains, P = 0.15) in leisure activities compared with controls. Decrease in performed leisure activities was only significant in those with a low level of education. At baseline, in RA patients, low education (P = 0.035), age (P = 0.019) and HAQ (P < 0.001) significantly predicted performed leisure activity. No loss in performed leisure activities was seen during follow-up and no significant predictors were found for individual change.

Conclusion. Loss of performed leisure activities occurs early in RA and chiefly in those with low formal education. Disability was associated with early loss, but not with change during follow-up. Other factors, possibly related to individual personality and resources, may be more important for predicting changes in leisure activities.

Key words: Newly diagnosed RA, Leisure activities, Controlled, Longitudinal, Educational level.

Rheumatoid arthritis (RA) is a chronic inflammatory disease with a prevalence of about 0.5% [1] increasing with age [2]. The disease influences numerous aspects of life, for example functional ability, work, economic status, family/social relationships, psychological status [3] and leisure activities [4, 5]. Low formal education is a risk factor for poor functional status [6]. The predictors for loss of leisure activities and how early in the illness this occurs are unknown.

Leisure activities can be defined as activities, active or passive, engaged in my spare time and for free will, when all necessary work is done [7]. Having the possibility to freely choose and the opportunity to participate in the chosen leisure activities as well as a sufficient amount of time is of great importance [8, 9]. Participating in desired leisure activities has been shown to prevent depression in RA [10].

People with RA have a limited choice of and difficulties participating in leisure pursuits [5, 11, 12], but nevertheless patients can regain leisure activities [7]. Here the new more effective biological treatments may be beneficial.

The aim of this study was to compare the number of leisure activity domains (participating in or interested in) in a group with recent onset RA and a matched community-derived control group and explore associated factors, to examine whether leisure activities are changing longitudinally during the first few years of disease and to seek predictors for such changes.

Materials and methods

This was a prospective study of consecutive patients with early RA at the Rheumatology Clinic of Malmö University Hospital [13] (catchment area approximately 200000 adults, rural) and the Rheumatology Clinic of Trelleborg Hospital (catchment area approximately 63000 adults, urban and rural).

Ethics

The design of the study was approved by the medical ethics committee, Lund University and the subjects’ written consent was obtained [14].

Subjects

The study group. The study group consisted of 196 consecutive patients recruited between January 1997 and December 2002 with early RA living in the city of Malmö (n = 149), and in the countryside around or in the city of Trelleborg (n = 47) (Table 1). Inclusion criteria were RA according to the American College of Rheumatology [15] and a disease duration of 1 yr or less. A questionnaire concerning leisure activities [16] was answered at the first visit and again as a questionnaire by mail in July 2003.

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by 147 (75%) patients (see below) (Table 1). The mean (range) follow-up was 3.17 (0.9–5.9) yr.

The control group. To identify the pattern of leisure activity in the normal population, 196 individuals [response rate 144/196 (72%)] from the Swedish population census register were individually matched for age, gender and zip-code to the patients (at the time of inclusion). This was done to ensure comparability with the standard deviation were given for the interval and ratio scales.

Table 1. Socio-economic and disease characteristics (cases only) for cases and control group members

<table>
<thead>
<tr>
<th>Total RA cohort (n = 196)</th>
<th>Longitudinal data of RA patients (n = 147)</th>
<th>Cross-sectional data of RA patients (n = 144) and controls (n = 144)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at inclusion (yr)</td>
<td>60.1 (14.4)</td>
<td>58.7 (13.9)</td>
</tr>
<tr>
<td>Gender, female (%)</td>
<td>149 (76)</td>
<td>111 (76)</td>
</tr>
<tr>
<td>Duration (months)</td>
<td>6.8 (3)</td>
<td>6.9 (3)</td>
</tr>
<tr>
<td>RF positive, n (%)</td>
<td>120 (61)</td>
<td>92 (63)</td>
</tr>
<tr>
<td>DAS</td>
<td>4.69 (1.32)</td>
<td>4.66 (1.35)</td>
</tr>
<tr>
<td>HAQ</td>
<td>0.88 (0.60)</td>
<td>0.87 (0.59)</td>
</tr>
<tr>
<td>VAS pain (mm)</td>
<td>42.4 (27)</td>
<td>41.8 (27.8)</td>
</tr>
<tr>
<td>VAS global (mm)</td>
<td>45.2 (26.6)</td>
<td>45.3 (27)</td>
</tr>
<tr>
<td>Education, n (%):</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Low</td>
<td>142 (74)</td>
<td>106 (72)</td>
</tr>
<tr>
<td>High</td>
<td>50 (26)</td>
<td>41 (28)</td>
</tr>
<tr>
<td>Work, n (%):</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Full time</td>
<td>46 (23)</td>
<td>66 (45)</td>
</tr>
<tr>
<td>Part time</td>
<td>10 (5)</td>
<td>7 (5)</td>
</tr>
<tr>
<td>Not working</td>
<td>10 (5)</td>
<td>7 (5)</td>
</tr>
<tr>
<td>Retired</td>
<td>94 (48)</td>
<td>59 (41)</td>
</tr>
<tr>
<td>Leisure activities:</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Interested in (no of domains)</td>
<td>10.9 (3)</td>
<td>11.1 (2.9)</td>
</tr>
<tr>
<td>Performed (no of domains)</td>
<td>8.4 (2.9)</td>
<td>8.8 (3.2)</td>
</tr>
</tbody>
</table>

Results are presented as frequencies or means (s.d.). NA, not applicable.

Measures performed at baseline, after 6, 12, 18, 24, 36, 60 months and follow-up in the RA group

The following measures were performed:

(i) general pain (visual-analogue scale, VAS) during the previous week [17];

(ii) global assessment (VAS) disease activity during the previous week,

(iii) erythrocyte sedimentation rate (ESR) mm/1st h, and

(iv) C-reactive protein (CRP) measuring the activity of the disease,

(v) swollen and tender joints out of 28 [18] and the medical practitioner’s judgement of disease activity (1–5) to assess the activity of disease,

(vi) disease activity score (DAS28) statistically calculated from swollen and tender joints, ESR and global assessment (VAS) [19].

Measures performed in both the RA and control group

(i) Health Assessment Questionnaire (HAQ) range 0–3 [20], evaluated at inclusion, after 6, 12, 18, 24, 36 and 60 months and once in the control group.

(ii) Education: low standing for comprehensive school (depending on period up to 8 or 9 years of schooling), high standing for upper secondary school or secondary education to university level (depending on period over 8 or 9 years of schooling).

(iii) Occupational status: working full-time, part time, not working or retired.

(iv) Leisure activity scale [16]. This is a list of 18 domains validated in a Swedish population sample of 11272 subjects (age range 16–75 yr) in the early 1990s. Two new domains cooking and housework have been added [21]. The respondents are asked to check which of the 20 domains they perform, are interested in or find important. Subsequently, three outcomes for each of the 20 domains exist. The scale was answered once in the control group.

Statistics

The area under the curve (AUC) during the follow-up period was calculated for DAS, HAQ, VASpain and VASglobal. When computing AUC, the last value for the individual variable and patient was carried forward to the end of follow-up (1 July 2003). No data were missing for these variables. Mean values and the standard deviation were given for the interval and ratio scales. A P level of <0.05 was considered statistically significant. The change in performed leisure activities was calculated by subtracting the number of performed leisure activities (e.g. domains) at baseline from those performed at follow-up. A positive number indicates a gain in leisure activities performed. Multiple linear regressions were used to evaluate predictors for change in performed leisure activities. Change in the number of performed leisure activities was used as the dependent variable in these models. The number of leisure activities performed at baseline was always included as the independent variable, adding possible predictors one at a time. When evaluating possible factors associated with performed leisure activities at baseline, linear regression was used with the number of performed leisure activities at baseline as the dependent variable. In addition, a multivariate linear regression analysis was performed with gender and all bivariately significant variables as independent covariates. Results are presented as standardized coefficients.

Paired sample t-tests were used to compare results at baseline and follow-up.
Result

Cross-sectional comparison of patients at baselines with controls

Persons with early RA performed in fewer leisure activity domains [mean (s.d.) 8.2 (3.1)] compared with the control group [9.9 (2.6)] ($P < 0.001$) (Table 1). A loss was seen in both women (Fig. 1a) and men (Fig. 1b) occurring early in the disease, before the first study visit, on average 7 months after disease onset. This decrease was only significant among persons with a low level of education ($P < 0.001$).

Outdoor activities ($P < 0.001$), gardening ($P = 0.048$), music ($P = 0.011$), exercise ($P = 0.016$), ball sports ($P = 0.010$) and entertainment ($P < 0.001$) were performed significantly less frequently in female RA patients compared with control group members (Fig. 1a). For men with RA, outdoor activities ($P = 0.026$), watching TV or going to the movies ($P = 0.011$), attending arena sports ($P = 0.047$) and cooking ($P = 0.001$) were performed less frequently compared with the control group (Fig. 1b).

The leisure activity domains in which people were interested were similar in patients and controls (Table 1) and did not interact with level of education.

Factors independently associated and partially correlated with the number of leisure activity domains performed at baseline were age ($P = 0.019$, $\beta$(std) = −0.19), education ($P = 0.035$, $\beta$(std) = 0.13), HAQ ($P < 0.001$, $\beta$(std) = −0.27) and number of domains of interest ($P < 0.001$, $\beta$(std) = 0.63) in cases. In the control group age, being retired, HAQ and interest, but not educational level, were significant predictors.

Follow-up and predictors of change in RA patients

Among the 147 persons participating in the follow-up, no significant change in grouping level in performance or interest in leisure activity domains compared with baseline was found (Table 1). Disease activity [pain ($P < 0.001$), patient’s global assessment ($P < 0.001$), DAS ($P < 0.001$)] and disability [HAQ ($P = 0.003$)] improved significantly from baseline to follow-up (Table 1).

Predictors for performed leisure activities at baseline (age, education, HAQ, number of leisure activities interested in) did not predict individual changes during follow-up. Only the accumulated burden of disability, measured as AUC for HAQ, tended to predict such loss ($P = 0.059$, $\beta$(std) = −0.14), but only added insignificant extra explanation, compared with the model including just the number of performed baseline leisure activities ($R^2$: 0.19 vs 0.17).

Discussion

Persons with early RA perform fewer leisure activities compared with controls, a difference observed only among persons with low education. During follow-up no further changes in performance or interest in leisure activities were seen in grouping level, and the severity of the disease did not predict individual changes. Loss of leisure activities has been reported in previous studies but not in early disease [4, 5, 22–24].

The level of education is likely to be a marker for several aspects of life and personality. A higher level of education may result in higher income which may widen the range of activities from which to choose [25]. Furthermore, higher education may be a marker of a more active role in problem solving and addressing the problems caused by the disease [11, 29] as well as values and beliefs. These factors may all influence coping strategies. People who rely heavily on active behavioural coping strategies (analysing problems from various perspectives, seeking different solutions, using targets and seeing problems as a challenge) are more likely to be able to participate in leisure activities [11, 26–28]. Higher education has also been shown to be associated with a higher degree of exercise [28–31].

The fact that RA patients had a similar interest in leisure activities to control group members may indicate that this loss in performed leisure activities is not chosen.

It is remarkable that leisure activities did not improve despite reduced disease activity during follow-up. Possible explanations include disease activity not being sufficiently improved and lack of specific rehabilitation aimed at improving leisure activities. We have previously shown that active leisure activities increase after a 3-week rehabilitation programme [7].

Leisure activities that were lost in the present study differed to some extent between sexes. This is supported by others, who have found that motivation for participating in leisure activities are partly gender-specific [32, 33]. Frequently performed leisure activities such as outdoor activities and gardening appeared, however, to be lost to an equal extent in men and women.

Others have found that female gender and age over 55 limit physical activities in the community [34] as well as in chronic arthritis [22]. We could confirm the effect of age but not of gender in both patients and population control members. To be able to continue with leisure activities when retired has been found to be valuable both for satisfaction with life [22, 35] and for preserving intellectual ability [36].

Large and detailed reports on participation in activities in RA patients from the 1980s and early 1990s have reported loss in almost all domains of leisure activity [23, 24]. Explanations for our findings with more limited loss include the inclusion of patients with earlier and milder disease, a community-based control group including subjects with other diseases, and possibly the recently available better pharmacological treatment.

In our study disease activity did not predict loss of performed leisure activities, either at baseline or follow-up. Disability, on the other hand, seemed to have some effect early in disease but was not predictive of change during follow-up. This lack of association is partly supported by others [7, 37].

Some strengths of the present study are the population-based control group matched for age, gender and residency, and the regular detailed and complete follow-up of disease activity, pain, disability and medication. Unfortunately, some potential predictors were not evaluated at baseline, such as coping strategies [3, 11] fatigue [38, 39] and depression [10, 40, 41].

Conclusion

This study demonstrated an early loss in performed leisure activities in RA patients with low formal education. The modest impact of disability in very early disease and the lack of prediction by commonly used markers for disease severity during follow-up suggest that other factors, perhaps more related to personality and individual resources, are of greater importance for the long-term prognosis with regard to performing leisure activities.

<table>
<thead>
<tr>
<th>Rheumatology</th>
<th>Key messages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• RA patients with low education lose leisure activities early in the course of the disease.</td>
</tr>
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<td></td>
<td>• Markers of disease activities did not predict individual change in leisure activities during follow-up.</td>
</tr>
</tbody>
</table>

Acknowledgements

We thank rheumatologists Miriam Carlsson and Roger Hesselstrand, Trelleborg Hospital for valuable help with collecting the data.
Fig. 1. (a) The number of leisure activity domains performed by females with RA (n = 108) and control group counterparts (n = 108). (b) The number of leisure activity domains performed by males with RA (n = 36) and control group counterparts (n = 36).
References


