Physical, psychosocial and economic impact of rheumatoid arthritis: A pilot study of patients seen at a tertiary care referral centre

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ABSTRACT

Background: Rheumatoid arthritis is associated with marked physical disability. In addition, it has an impact on patients’ psyche and social well-being, and entails a major financial burden. The impact of the disease in different cultural and social backgrounds is varied. Limited data are available from India on this aspect.

Methods: Patients with rheumatoid arthritis satisfying the 1987 modified American College of Rheumatology criteria were included. Besides demographic data, functional impact was assessed using the Health Assessment Questionnaire (HAQ). The psychosocial impact was measured using the Health and Quality of Life Index (HAQ-DI). A study short form 36 (SF-36) with minor modifications. Data on direct and indirect health costs were collected by direct interview.

Results: The mean age of 101 patients (90 women) was 43.2 years and mean duration of disease was 8 years. Their mean (SD) HAQ score was 0.97 (0.69) with 8 patients having scores >2. On the SF-36 scale (0–100) the mean (SD) score for various domains were: physical functioning 49.90 (28.55), social functioning 55.51 (20.59), role limitation due to physical problems 32.67 (41.34), role limitation due to emotional problems 47.54 (40.08), mental health 47.36 (7.99), general health perception 52.38 (8.30), energy and vitality 58.56 (6.09), and bodily pain 49.26 (18.87). The summary score for physical component was 47.71 (4.81). While the physical component summary score had excellent negative correlation with the HAQ score (r = –0.84), correlation with the mental component summary score was poor (r = 0.32). The annual average total cost burden per patient was Rs 16 758, of which Rs 11 617 (67%) was spent on health services and the rest on non–health services (travel, home help and loss of wages).

Conclusion: Rheumatoid arthritis causes significant physical and social disability besides being an economic burden. Indian patients had good scores for mental and social health suggesting good family support systems or reluctance to express their feelings despite physical disability.


INTRODUCTION

Rheumatoid arthritis (RA) is a chronic autoimmune arthritis that causes significant morbidity and mortality and affects almost 1% of the global population. Patients with RA have a higher all-cause mortality as compared with age-matched controls, which has remained unaltered over the past 4–5 decades. It has been calculated that RA reduces the life span by 5–10 years depending on the age of onset. Patients with RA have a 7-fold higher risk of disability as compared with age- and gender-matched controls. They gradually lose their functional capacity and at the end of 15 years nearly 30%–50% of the patients are in functional class III/IV and need help for vocational/self-care activities. Along with functional disability, RA has an impact on the emotional and psychological functioning of the patient.

It has been suggested that one disease-specific and one generic instrument be used to assess the impact of the disease. Generic instruments measure broad aspects of the quality of life (QOL) and provide a general sense of the effects of an illness. The major limitation of generic QOL instruments is that they do not assess potential condition-specific domains of QOL. Because of this, they may not be sensitive enough to detect subtle treatment effects. In contrast, disease-specific instruments are more sensitive in detecting minor treatment effects.

The Stanford Health Assessment Questionnaire Disability Index (HAQ-DI) is the most widely used disease-specific tool in RA. It is a valid tool for the assessment of physical function in patients with RA. The Stanford HAQ is a scale of 20 activities of daily living (ADL) in 8 categories to assess functional disability, with four patient response options:

0 Without any difficulty
1 With some difficulty
2 With much difficulty
3 Unable to do

The 8 categories of two or three ADLs address dressing, arising, eating, walking, bathing, reaching, gripping and performing errands. The score for each category is the highest score among the two or three ADLs within the category; if the patient uses aids or
devices for that category, it is scored as 2. The total score is the mean score that is derived from 8 scores, one for each category. The total score for the HAQ-DI varies from 0 (no disability) to 3 (completely disabled).

The medical outcomes study short form 36 (SF-36) is an abridged version of 149 health status questions. SF-36 is a valid, disease-independent tool to assess the QOL. It measures health-related QOL along 8 different domains: physical functioning, role limitations due to physical problems, bodily pain, general health perception, vitality, social functioning, role limitations due to emotional problems and mental health. In SF-36 the scores are calculated for 8 subscales from 0 to 100 (0: worst; 100: best). Composite mental and physical component summary scores are also computed from a weighted linear combination of 8 individual subscales. Studies in patients with RA have revealed lower physical and mental scores as compared to the general population.

The impact on social and psychological domains is dependent on the functional status and support system in the society and ethnicity. In India, there is a strong family support system but poor social support system. Thus, it is likely that the impact of RA will be different in India. Further, RA also leads to considerable cost to family and society. In a recent review the annual cost of RA averages US$1503–16 504 (based on US$ costs in 2000) depending on the patient population and the country. Total medical costs were in the range of US$5720–5822 (based on costs in 1996) with the maximum amount being spent on inpatient stay. Indirect costs also have a major contribution to the economic burden of RA. In India, it is difficult to make an accurate assessment of economic burden as most patients with RA are homemakers and calculating their contribution in economic terms is difficult. We assessed the direct costs incurred on the disease such as cost of drugs, laboratory tests and travel for consultations. Indirect costs included loss of wages, need for home help, etc.

METHODS

One hundred and one patients with RA (1987 American College of Rheumatology [ACR] criteria) attending the RA clinic of a tertiary care hospital during a 3-month period were included in the study. Verbal informed consent was taken from all the participants.

Besides demographic data, duration and state of disease were recorded. Remission was defined as per the ACR criteria and all patients not fulfilling the remission criteria were classified as having active disease. Patients were also asked whether or not they were using disease-modifying antirheumatoid drugs. All patients who consented were administered the HAQ-DI and SF-36 questionnaires by a medical graduate (SC). Minor modifications were made in the questionnaires. In HAQ-DI, the type of chores for the category ‘performing errands’ was substituted by questions to suit Indian conditions, e.g. car was substituted by rickshaw/bus and vacuuming by sweeping. In SF-36 minor modifications included

1. Question number 23 was modified from ‘Did you feel full of pep?’ to ‘Did you feel full of energy?’
2. Question number 25 was modified from ‘Have you felt so down in the dumps that nothing can cheer you up?’ to ‘Have you felt so sad that nothing can cheer you up?’
3. Question number 28 was modified from ‘Have you felt downhearted and blue?’ to ‘Have you felt depressed?’

To assess the economic impact, expenditure incurred during the past 1 year on medicines, laboratory tests and travel to hospital was calculated and indirect costs of home help, loss of wages, etc. were asked for.

The data were analysed using SPSS software version 11 and Spearman rank correlation coefficient was calculated to assess any association between different variables.

RESULTS

There were 90 women among the 101 patients studied. Their mean age (SD) was 43.2 (11.69) years and the mean (SD) duration of disease was 8.1 (5.6) years. Ninety-six patients were on disease-modifying drugs. Active disease was present in 95 patients and 6 were in remission. The distribution of the HAQ-DI scores show that the mean (SD) HAQ-DI score was 0.97 (0.69) with 6 patients having a score >2 (Fig. 1).

On the SF-36 scale (0–100) the mean (SD) score for various domains was: physical functioning 49.90 (28.55), social functioning 55.51 (20.59), role limitation due to physical problems 32.67 (41.34), role limitation due to emotional problems 47.54 (40.08), mental health 47.36 (7.99), general health perception 52.38 (8.30), energy and vitality 58.56 (6.09) and bodily pain 49.26 (18.87). The summary score for the physical component was 37.95 (9.03) and that for the mental component 47.71 (4.81) (Table I, Fig. 1).

There was a good inverse correlation between physical disability as assessed by HAQ-DI and various domains of SF-36. The correlation with various physical domains was as follows:

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean (SD)</th>
<th>95% CI</th>
<th>Median</th>
<th>Interquartile range</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAQ</td>
<td>0.97 (0.69)</td>
<td>0.84–1.11</td>
<td>1</td>
<td>0.44–1.31</td>
</tr>
<tr>
<td>SF-36</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>49.90 (28.55)</td>
<td>44.26–55.54</td>
<td>50</td>
<td>25–75</td>
</tr>
<tr>
<td>Role functioning—physical</td>
<td>32.67 (41.34)</td>
<td>24.51–40.83</td>
<td>0</td>
<td>0–75</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>49.26 (18.87)</td>
<td>45.54–52.99</td>
<td>41</td>
<td>41–62</td>
</tr>
<tr>
<td>General health perception</td>
<td>52.38 (8.30)</td>
<td>50.75–54.02</td>
<td>52</td>
<td>45–57</td>
</tr>
<tr>
<td>Vitality</td>
<td>58.56 (6.09)</td>
<td>57.36–59.77</td>
<td>55</td>
<td>55–60</td>
</tr>
<tr>
<td>Social functioning</td>
<td>55.51 (20.59)</td>
<td>51.55–59.68</td>
<td>55</td>
<td>45–67.5</td>
</tr>
<tr>
<td>Role functioning—emotional</td>
<td>47.54 (40.08)</td>
<td>39.63–55.46</td>
<td>33.4</td>
<td>0–100</td>
</tr>
<tr>
<td>Mental health</td>
<td>47.36 (7.99)</td>
<td>45.79–48.94</td>
<td>48</td>
<td>40–56</td>
</tr>
<tr>
<td>Physical component summary</td>
<td>37.95 (9.03)</td>
<td>36.17–39.73</td>
<td>36.6</td>
<td>31.3–45</td>
</tr>
<tr>
<td>Mental component summary</td>
<td>47.71 (4.81)</td>
<td>46.76–48.67</td>
<td>47.6</td>
<td>44.3–51.2</td>
</tr>
</tbody>
</table>
physical functioning –0.778 (p<0.001), role limitation due to physical function –0.711 (p<0.001), physical component summary score –0.836 (p<0.001, Fig. 2). HAQ correlated well with the bodily pain (–0.755; p<0.001), emotional (–0.561; p<0.002) and social functioning domains (–0.610; p<0.001). However, there was no significant correlation with the global health domain, vitality domain and summary score for mental health (Fig. 2).

The mean (SD) annual income of the families was Rs 138 533 (74 397). The distribution revealed that 8% earned less than Rs 50 000, 30% earned Rs 50 000–100 000, 26% earned Rs 100 000–150 000, 18% earned Rs 150 000–200 000 and 18% earned more than Rs 200 000. The annual average total cost burden per patient was Rs 16 758, of which Rs 11 617 (67%) was spent on health services and the rest on non-health services (travel, home help and loss of wages). Among the direct costs, expenditure included those on medicines (Rs 9179), investigations (Rs 1974), hospital registration (Rs 100) and hospitalization (Rs 456; Table II). Among the indirect costs (Rs 5141 [17 233]) travel was a major expenditure (Rs 2453 [40 50]). Only 10 patients received complete reimbursement for their medical expenses from their employers while 15 received partial reimbursement. None of the patients had any medical insurance. The cost of treatment had no significant correlation with duration of disease or HAQ-DI due to a ceiling effect (Fig. 3) but it had a weak correlation with income (r=0.26, p<0.01).

DISCUSSION

Ours is possibly the first study in India to show that RA has a major economic impact and the cost does not increase proportional to disability due to limited income. Our data also show that RA has a considerable impact on the physical, emotional and mental health of patients. Further, the mental and social scores are better than the physical scores. There was a good correlation between HAQ-DI and the physical scores of SF-36.

Our patients had a mean HAQ-DI score of 0.97 at a mean disease duration of nearly 8 years. Cross-sectional studies from other countries have also found an average HAQ-DI score of 1.00
Our study in RA (n=101) (mean±SD)

<table>
<thead>
<tr>
<th>Item</th>
<th>Our study in RA (n=101) (mean±SD)</th>
<th>Ray et al.(^{21}) on Parkinson disease (n=32) (mean±SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average annual income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;Rs 60 000</td>
<td>138 533±274 397 (125 420–151 650)</td>
<td>67 356±44 088</td>
</tr>
<tr>
<td>Rs 60 000–120 000</td>
<td>36%</td>
<td>47%</td>
</tr>
<tr>
<td>&gt;Rs 120 000</td>
<td>54%</td>
<td>09%</td>
</tr>
<tr>
<td><strong>Average annual expenditure on treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct</td>
<td>11 612±10 415 (9788–13 446)</td>
<td>7392±4320</td>
</tr>
<tr>
<td>Medicines</td>
<td>9179±9361 (7529–10 830)</td>
<td>—</td>
</tr>
<tr>
<td>Investigations</td>
<td>1974±1989 (1623–2325)</td>
<td>—</td>
</tr>
<tr>
<td>Hospital registration</td>
<td>100</td>
<td>—</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>456±2002 (103–809)</td>
<td>—</td>
</tr>
<tr>
<td>Indirect</td>
<td>5141±17 233 (2115–8168)</td>
<td>—</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>16 758±22 200 (12 971–20 812)</td>
<td>—</td>
</tr>
</tbody>
</table>

Fig 3. Scatter plot showing the correlation between HAQ and total cost of rheumatoid arthritis.

at 7 years, 1.25 at 12 years and 1.5 at 18 years of disease.\(^{16–18}\) Thus our patients have comparable physical disability. However, when individual patients are followed up over time there is considerable variation seen in an individual’s HAQ score\(^{17}\) as HAQ-DI is a composite measurement of disability resulting from damage and activity of the disease. Thus, longitudinal studies provide a better measure of outcome.

In SF-36 scores, physical domains were more affected compared with mental health domains. SF-36 has been previously used in India on 40 patients with RA to measure QOL and mental health scores were found to be much higher than physical function scores; however, that study included a very select group of patients with RA enrolled for an anti-tumour necrosis factor agent trial.\(^{20}\) Another study from India involving patients with RA but using the WHO QOL-Bref scale made a similar observation, i.e. better scores on psychological, emotional and environmental domains as compared with physical domains.\(^{20}\)

The physical domains of SF-36 had excellent correlation with the HAQ-DI score, suggesting that both scales measure similar physical disability. The good correlation of social and emotional functioning with HAQ-DI score suggests that these components of health are influenced by physical disability. However, the summary score for the domains of mental health, energy and vitality were significantly higher than physical domain scores and did not show any correlation with HAQ-DI in contrast to a study from the UK.\(^{3}\) Similar observations have been made in Parkinson disease using a disease-specific QOL scale\(^{21}\) and in systemic lupus erythematosus using the WHO-QOL scale.\(^{22}\) This may suggest that the patients were well adjusted and received good support to cope with physical disability and illness. In India, the family support system is excellent and thus the immediate environment of the patient is supportive. This may partly explain the good mental scores. Another reason could be a reluctance to express their feelings, which can also explain the narrow dispersion in mental health, vitality and general health scores.

Spending nearly Rs 17 000 annually on RA means that almost 15% of the household income is spent on expenses related to the disease. Direct costs constituted two-thirds of the total costs. In the West, indirect costs are more than the direct costs due to loss of wages, home help, etc.\(^{7}\) In India, as most patients are either homemakers or men working in a joint family business or government jobs, loss of wages is not a major contributor to the cost of RA. In the only study\(^{21}\) available, in Parkinson disease, the annual expenditure was reported to be Rs 7372. This difference could be due to a difference in treatment for the two diseases as well as the lower average annual income of those patients compared with our group (Table II).

In most studies from the West, the cost of RA increases with the duration of the disease due to accumulation of damage.\(^{23}\) In contrast, we did not find any association with duration of the disease, as most patients could not afford joint replacement, special devices, biological agents, etc. A correlation has also been found between healthcare costs and SF-36/HAQ-DI scores.\(^{23}\) This is due to an increase in visits to the physician, hospitalization and drug costs with increasing disability. However, due to a ceiling effect on spending related to low income of the family we did not find a good correlation between HAQ and cost of treatment.

Our study has a few limitations. First, it is a cross-sectional study and HAQ and SF-36 can change over a period of time with control of disease activity. Second, SF-36 has not been validated in our population as an instrument for QOL. Third, the direct and indirect cost calculations are at best a rough estimate. Furthermore, our patient population consists of middle class people, so these data may not be applicable to the general population.

Thus, RA causes significant disability in all domains of health. Indian patients have better scores on mental health, probably due to a better family support system. Due to a low income, most patients cannot afford the current state-of-the-art treatment. Early effective treatment may not only postpone and retard disease progression, thereby improving the QOL, but also decrease costs...
by preserving productivity and reducing the need for surgery and admission to hospital. Data are beginning to accumulate on the excess costs associated with biological therapies and other new second-line drugs. There is a need to analyse the economic impact of RA in India in a larger sample size, so that policy-makers can provide ways to optimize the treatment of patients with RA.

ACKNOWLEDGEMENT

We acknowledge the technical help of Ms Catherine T. Schentag, Research Associate, Centre for Prognosis Studies in Rheumatic Diseases, Toronto Western Hospital, 399 Bathurst Street, Ontario, Canada M5T 2S8 in calculating SF-36 scores.

REFERENCES


Obituaries

Many doctors in India practise medicine in difficult areas under trying circumstances and resist the attraction of better prospects in western countries and in the Middle East. They die without their contributions to our country being acknowledged.

The National Medical Journal of India wishes to recognize the efforts of these doctors. We invite short accounts of the life and work of a recently deceased colleague by a friend, student or relative. The account in about 500 to 1000 words should describe his or her education and training and highlight the achievements as well as disappointments. A photograph should accompany the obituary.

—Editor