CONCISE REPORT

Living with rheumatoid arthritis: expenditures, health status, and social impact on patients

H M Lapsley, L M March, K L Tribe, M J Cross, B G Courtenay, P M Brooks, for the Arthritis Cost and Outcome Project Group

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Objective: To determine costs related to living with rheumatoid arthritis (RA), and to identify the association between health status—as measured by the Health Status Questionnaire short form-36 (SF-36) and the disease specific index Health Assessment Questionnaire (HAQ)—and the social impact of RA.
Methods: A prospective cohort study was carried out on 81 patients with RA who completed four consecutive three month cost diaries. The SF-36, HAQ, and social impact at baseline and one year follow up were also assessed.
Results: Women reported worse SF-36 physical function and HAQ scores than men and received more assistance from family and friends. Women spent more on non-prescription medication and devices to assist them than men. Older patients had higher expenditure on visits to health professionals, whereas younger patients spent more on prescription medication and tests. Pension status and membership of private health insurance schemes were important determinants in these differences in expenditure.
Conclusion: Costs increased with duration of disease, those with private health insurance had greater out of pocket costs (excluding membership fees), and those with pension support had fewer costs. Women were more affected by RA than men in health status, social impact, and out of pocket costs.

Rheumatoid arthritis (RA) is a disabling disease with significant costs to the health system and the patient.[1–4] In this study the costs to the patient, rather than to the healthcare system, were analysed together with measurement of the health status and social effect of RA on the patient. This paper reports on a subset of a large ongoing longitudinal study on the costs and self reported health status of people with RA in Australia.

The purpose of the analysis was to ascertain the participants' "out of pocket" costs from RA and to explore whether demographic details, health status scores, or perception of social effect were determinants of out of pocket costs.

METHODS

Participants were referred to the study by rheumatologists at St Vincent's Clinic, Sydney, Australia. Approval for the study was granted by the relevant institutional ethics committee. Both public (those who were only covered by the government funded health system) and private patients (those who subscribed to private health insurance) were included in this analysis. Patients undergoing joint replacement in this period were excluded from the analyses reported here.

The short form-36 Health Status Questionnaire (SF-36)[5] and Health Assessment Questionnaire (HAQ)[6] were completed at entry into the study and at the end of one year. No significant differences were found between baseline and one year scores, so the questionnaires completed at one year were used for further analysis.

In baseline questionnaires, participants were asked:

- "Has having arthritis affected your family or other close relationships?"
- "Do you have family, friends, or relatives who provide you with assistance?"
- "Have you had to change your living arrangements because of your arthritis?" Respondents who replied yes to these questions were asked to provide details.

The patients' out of pocket costs were collected prospectively through four cost diaries which each covered three months and which were based on a previously validated Australian cost of illness study.[7] To confirm that diaries were a valid means of collecting these data, in the initial phases of the study home visits were made to a random sample of respondents to compare their diary entries with actual receipts. Disease related expenditure reported by the participants included alterations to house, use of private and community services, special equipment for their assistance (including shoes and clothing), stay in hospital (related to arthritis but not including joint replacement), medications (prescription and non-prescription), visits to health professionals, and medical tests. Respondents were instructed to record all visits to health professionals and all purchased medications whether they were charged or paid a reduced rate with a pensioner concession—that is, they were covered by federal government funded Medicare or "safety net". Under this safety net, patients pay about $A3 for each prescription for items listed on the Pharmaceutical Benefits Scheme, until they reach a certain level of out of pocket expenditure (currently $A171.60) after which the health system covers the entire cost of medication. Those not covered by the safety net scheme pay about $AU20 until they reach a higher level of out of pocket expenditure (currently $A631.20), after which they pay $A3 for each prescription, the rate paid by patients with a pensioner's concession. Costs reported in the diaries were not inflated to current values; therefore, results reported here are 1994 prices.

The distribution of total expenditure for one year was significantly skewed to the left. There were two outliers because one participant purchased a new car and another made house alterations. Both of these major expenses were attributable to RA, so remained in the analysis. The non-parametric Mann-Whitney U test was used to analyse all costs, and total expenditure was log transformed for correlation and regression analysis.

Univariate analyses were conducted with log transformed total expenditure to identify variables that were significantly

Abbreviations: HAQ, Health Assessment Questionnaire; RA, rheumatoid arthritis; SF-36, short form-36 Health Status Questionnaire

Table 1 Description of study participants and results of analyses

	Mean	SD	Range
Number	81		
% Female	80		
Age (years)	58.2	11.22	32–77
Duration of disease	15.6	9.86	6 months–50 years
% Reporting other medical condition	48		
% Receiving pension	31		
% With private health insurance	77		
Health status:			
Physical function	47.13	27.83	
Role physical	38.29	41.57	
Bodily pain	50.43	22.96	
General health	49.92	22.93	
Vitality	49.29	22.25	
Social function	71.23	26.57	
Role emotional	63.82	45.16	
Mental health	73.85	17.14	
HAQ	1.28	0.73	
Total expenditure ($)	Men	Women	Significance
Mean (SD)	765.60 (1143.49)	1697.51 (2890.18)	
Median	366.92	759.55	p=0.013
Minimum	49.62	49.80	
Maximum	4462.19	20527.65	
Total expenditure ($)	<65 years	⩾65 years	Significance
Mean (SD)	1638.26 (2886.89)	1263.76 (2158.45)	
Median	797.75	362.32	p=0.029
Minimum	49.62	49.80	
Maximum	20527.65	9978.52	
Regression analysis*	R^2=0.468		
Variable	β	e^{β}	Significance
SF-36 general health	–0.431	0.650	0.000
Sex (0=male, 1=female)	0.197	1.218	0.038
Pension (1=yes, 2=no)	0.412	1.510	0.000
Private health insurance (1=yes, 2=no)	–0.281	0.755	0.005
Receive assistance from family/friends (1=yes, 2=no)	–0.177	0.838	0.073

*Other variables entered into the regression model were HAQ score, years with RA, and effect on relationships.

associated. Regression analyses were undertaken to determine the association between demographic, socioeconomic, and health status scores with total expenditure.

Seventeen independent variables were correlated with log transformed total expenditure. These were age (in years), sex, number of self reported comorbidities, pension status, years with RA, eight SF-36 scores, HAQ score at one year, and social impact questions, whether RA affected their relationships with other people, if they received assistance from family and friends, and if RA caused them to change their living arrangements. Backward regression analyses were run using significant univariate variables with total expenditure (log transformed) as the dependent variable.

RESULTS

Although the study involved considerable commitment from participants, 81 people (70%) provided one full year of data for analysis. There were no differences in age, sex, duration of disease, self reported comorbidities, or baseline HAQ score between complete and partial responders.

Table 1 shows the characteristics of these participants. Eighty per cent of respondents were women and the average age was 58 with a mean disease duration of 16 years. Although not shown in table 1, women had had RA for a significantly longer mean period (17 years) than men (nine years) (p=0.004).

Health status questionnaires

Figure 1 shows the SF-36 scores of study participants and those of the Australian general population.[8] Similarly, figure 2 shows HAQ scores of study participants and the general population in the northern Sydney area.[9] Men reported significantly better SF-36 physical function and overall HAQ than women, but for both health status assessments patients with RA were well below their age related peers.

Social aspects

Fifty three (65%) participants reported that RA affected their relationships, with younger participants more likely to report an effect than those aged 65 and older (p=0.021). Reduced opportunity for social interaction (n=24) was the most commonly reported effect followed by reduced opportunity for sport or outdoor activity (n=13). Of the thirteen respondents who indicated that their role as helper or carer for the family was affected, 12 were women.

Forty six (57%) participants reported receiving assistance from family, friends, or relatives. Women were more likely to report receiving assistance than men (65% and 25% respectively, p=0.008). Domestic indoor duties (70% of the 46 people) and shopping (41%) were the main areas, followed by carrying heavy items (20%), domestic outdoor (17%), driving and transport (15%), opening jars (15%), and personal hygiene (11%).

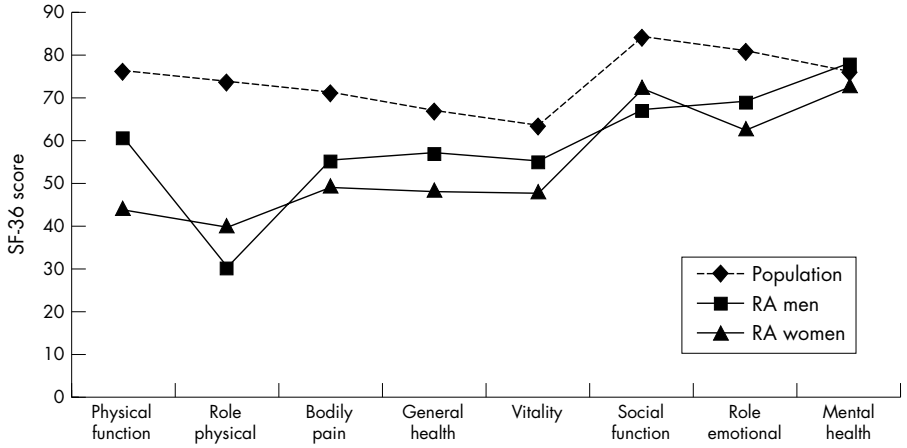

Figure 1 SF-36 scores of patients with RA and the Australian population (aged 55–64). The SF-36 is on a 0–100 scale; a higher score indicates better health.

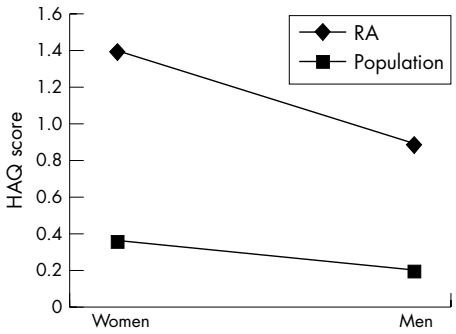

Figure 2 HAQ scores of patients with RA and an age related population (65–74 years); sample from Northern Sydney Area Health Service. HAQ score minimum=0, maximum=3; a higher score indicates greater disability.

Forty per cent of respondents reported having to change their living arrangements because of arthritis, including undertaking general household alterations (31%), moving house (28%), and changing daily routine (13%).

Out of pocket costs

All patients had out of pocket expenditure related to RA, spending on average $A1513 (SD $A2658) annually. The maximum yearly out of pocket expenditure on RA related health care was $A20 527, and the minimum expenditure was $A49. Women spent significantly more than men (median $A760 *v* $A367) and the younger group (<65 years) spent significantly more (median $A798 *v* $A362) than the older group (table 1).

All participants reported expenditure on prescription medication in the data collection period. Seventy seven per cent of women also reported expenditure on non-prescription medication whereas only 37.5% of men reported this (χ^2=9.35 p=0.002). Similarly, 63.1% of women reported expenditure on devices for assistance compared with only 18.7% of men.

Younger (<65 years) respondents spent significantly more on prescription medication and tests than older respondents. Older respondents spent significantly more on professional visits, with 44.4% incurring expenses, whereas 81.5% of the younger group reported some expense from professional visits.

Interrelationship between health status, social aspects, and out of pocket expenditures

Several variables were significantly correlated with the log transformed total out of pocket expenditure, including sex (p=0.015), which indicated that women spent significantly more, and years with RA (p=0.021), which showed that out of pocket costs increased as the disease progressed. Pension status and membership of private health insurance schemes were also significantly correlated with expenditure (p=0.010 and p=0.005), with pensioners spending less and members of private health insurance schemes more out of their own pockets (not including the membership payments, which would increase this difference). Those who reported that RA had an effect on their family and friendships spent significantly more (p=0.002), as did those who reported receiving assistance from family and friends (p=0.020).

The SF-36 general health (p=0.002) and HAQ (p=0.038) were significantly associated with total expenditure, showing that as general health declined, expenditure increased.

When these significant univariate variables were entered into backward regression, female sex, pension, private health insurance, SF-36 general health, and receiving assistance from family and friends were identified as significant independent predictors of total expenditure (log transformed). This model explained 46.8% of the variance (table 1).

DISCUSSION

Although there is a wealth of research on various aspects of the impact of living with RA both internationally[2 10–12] and in Australia,[1] until now there has been no Australian study combining health status, social impact, and out of pocket expenditure for people living with RA.

Our group has undertaken a similar study of patients with osteoarthritis (OA), finding that some of those with mild disease had no out of pocket costs in the year of data collection.[13] However, whereas the patients with OA tended to have better health status (using the SF-36) than the patients with RA the only significantly different score was general health. Poorer SF-36 general health scores were associated with increased out of pocket costs for the RA group but not the OA group. As well as these differences between OA and RA, a study of indirect and non-medical expenses showed that people with arthritis had expenditure nearly 2.5 times that of non-arthritic people, averaging $US889.52 and $US334.88 respectively, in 1992.[14]

Women reported worse health status, greater social impact, and had greater out of pocket costs than men in our study reported here. This could be partly attributed to the greater duration of disease of the women in the study population. It may also be explained in part by the sex differences in reporting and coping with illness. Van den Ende *et al* found in a comparison of objective and subjective reporting of functional

status that male patients with RA overestimated their functional ability considerably more than female patients.[15] This, coupled with the societal construct that women carry a greater load of domestic duties and acknowledge when they are helped, may explain some of the discrepancies in health status and social impact of RA between the sexes. The Australian Bureau of Statistics reported that women, even when working similar hours in paid work, spent more time on domestic duties than their male partners.[16] However, the difference in cost is not accounted for by this. Therefore it could be postulated that women purchase more pain relieving medication because they acknowledge their functional disability and want to improve it, and that they purchase more devices to assist them in their activities of daily living.

The other striking finding of this study is the impact of payment systems in Australia. Although out of pocket costs increased with duration of disease, pension status was significantly correlated with fewer costs suggesting that either a greater proportion of their purchases are covered by the government or that they are able to purchase less. Conversely, younger participants in the study had greater private health insurance membership, which was associated with greater out of pocket costs, even without the inclusion of membership fees.

CONCLUSION

People with RA report worse health status than their age related peers. Women are affected more by RA than men, resulting in the self reporting of poorer health status, greater social impact, and higher out of pocket costs. Those who are younger and with private health insurance are carrying a greater personal financial burden as a result of RA than their older counterparts who are covered by pensions.

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Authors' affiliations

H M Lapsley, School of Public Health and Community Medicine, University of New South Wales, Australia
L M March, M J Cross, University of Sydney, Department of Rheumatology, Royal North Shore Hospital, St Leonards, NSW 2065, Australia
K L Tribe, B G Courtenay, Departments of Medicine and Orthopaedics, St Vincent's Hospital, University of New South Wales, Australia
P M Brooks, Office of the Executive Dean (Health Sciences) University of Queensland, Australia

The Arthritis Cost and Outcome Project Group: C Bachmeier, C Cass, M Coolican, M Cross, B Courtenay, M Neil, L Pinczewski, S Quain, F Robertson, S Ruff

Correspondence to: Ms K Tribe, Arthritis Cost and Outcome Project, Level 4, Block 4, Royal North Shore Hospital, St Leonards, NSW 2065 Australia; k.tribe@unsw.edu.au

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