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The economic burden of disabling hip and knee osteoarthritis (OA) from the perspective of individuals living with this condition

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***Objective*. To estimate the direct and indirect arthritis-attributable costs to individuals with disabling hip and/or knee osteoarthritis (OA).**

***Methods*. An established population cohort with disabling hip and/or knee OA from two regions of Ontario, Canada was surveyed to determine participant and caregiver costs related to OA, and the predictors of these costs.**

***Results*. The response rate was 87.2%. Of 1378 respondents, 1258 had OA (mean age 73.1 yr, range 59–100). Sixty per cent ($n = 758$) reported OA-related costs. Among these individuals, the average annual cost was $12 200 ($CDN in 2002, where $1.00 CDN ≈ $0.81 US). Time lost from employment and leisure by participants and their unpaid caregivers accounted for 80% of the total. Men were less likely than women to report costs (adjusted odds ratio 0.54, $P < 0.0001$), but when they did their expenditures were significantly higher ($P = 0.004$). Greater disability was associated with higher costs: compared with individuals with WOMAC total scores <15, those with scores ≥55 were 15 times more likely to report costs, and their costs were 3 times greater (both $P < 0.0001$). Both the young (<65 yr) and very old were more likely to incur costs ($P < 0.0001$), and when they did their costs were higher ($P < 0.001$).**

***Conclusion*. Costs incurred were mainly for time lost from employment and leisure, and for unpaid informal caregivers. Failure to value such indirect costs significantly underestimates the true burden of OA. Costs increased with worsening health status and greater OA severity. After adjustment, men were less likely to incur costs, possibly due to greater social resources.**

KEY WORDS: Osteoarthritis, Burden of illness, Direct cost, Indirect cost, Survey.

Osteoarthritis (OA) has a major impact on functioning and independence and ranks among the top ten causes of disability worldwide [1, 2]. Symptoms and disability increase in prevalence with increasing age [3–5] and people with OA use health-care services at a higher rate than a representative group of all adults [6–8]. The number of people with OA disability is expected to double by the year 2020 [9, 10], thereby increasing the already significant economic burden of OA.

Cost of illness studies for OA have focused on the direct costs to the health-care system [10, 11] or on the direct, out-of-pocket expenditures by patients for items such as medications, assistive devices, transport and home adaptations [10, 12, 13]. Furthermore, most studies examined clinical populations who have accessed specialist care for their OA. These are unlikely to be representative of the costs incurred by those who neither seek nor receive such treatment. Only one study [14] has assessed the indirect patient costs of OA attributable to lost or foregone income and leisure time, and to date no study has evaluated the cost of informal care (e.g. help with personal care, household and yard chores provided by unpaid caregivers) necessitated by OA-related disability.

Informal care plays a major role in the total care provided to people with chronic diseases like OA [15]. With increasing efforts by governments to contain health-care expenditures by minimizing lengths of in-hospital stay for joint replacement surgery and shifting post-operative rehabilitation from an in-patient setting to home, the need for informal care is expected to increase. Failure to consider informal care costs not only underestimates the true burden of OA but also results in invalid comparisons of care options [15].

In addition to knowledge about the magnitude of costs, an understanding of the predictors of cost is important. Determining the cost drivers helps identify the subgroups most affected by disease. This provides the needed link between demographic trends and forecasts of future costs, as well as predicting the impact of policies targeting specific aspects of care.

The objectives of this study were: (i) to estimate the economic burden to individuals living with OA and their caregivers, incorporating estimates of both direct and indirect costs, including costs for informal care; and (ii) to identify factors that predict the likelihood of incurring OA-related costs and the magnitude of the economic burden.

Patients and methods

A population cohort of 2411 individuals aged ≥55 yr with disabling hip/knee arthritis was established between 1996 and 1998 [3, 16, 17]. In Phase 1, a screening questionnaire was sent to 100% of residents aged ≥55 yr in two regions (one urban and

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Table 1. Standardized questions used to estimate costs

Cost	Value
Direct costs	
Did you receive any community services during the past 3 months (i.e. transportation, homecare, visiting nurse, meals on wheels) because of your arthritis or joint problems? (If yes, the respondent was asked to indicate the nature of the service, the number of visits/hours per week, and the cost, if any.)	Cost reported by the respondent. These community service costs provide a component of patient direct costs. Patients were asked to report the actual cost for the service as other payers may have covered these costs. If costs were covered, this was reported.
During the past 3 months did you need any paid help with chores around the house because of your arthritis or joint problems? This can include cleaning, shoveling snow, shopping etc. On average, for how many hours in the past week did you need paid help with chores? ___ (if last week was unusual, tell me about a 'typical' week)	Average wage of a professional homemaker[a]
Did you purchase any equipment (i.e. aids or devices) such as bathroom equipment, wheelchair ramp, splints or canes during the past 3 months because of your arthritis or joint problems?	Cost reported by the respondent
Indirect costs born by the patient	
During the past 3 months, were you ever unable to do chores around the house because of your arthritis or joint problems, i.e. fatigue, pain or being in bed? On average, for how many hours in the past week were you unable to do chores ___ (if last week was unusual, tell me about a 'typical' week)	Average wage of a professional homemaker[a]
Respondents who were currently not working or able to work were asked if this was because of arthritis, and were asked to give their occupation at the time they stopped working.	Average wage of an individual employed in the same occupation as the respondent's last occupation[a]
Respondents who were currently working were asked:	
During the past 3 months, how much time did you have to take time off from your paid employment because of your health problems or to attend medical appointments?	Average wage of an individual employed in the same occupation as the respondent[a]
During the past 3 months how many days have you had difficulty working at your paid job, because of your health problems? (If no days enter 0).	
How many days ___ on average for how many hours each day ___. Please estimate by how many percent your work capacity was reduced ___%	
Indirect costs born by the caregiver	
During the past 3 months did your spouse, children or friends have to take time off from their paid employment because of *your health problems* or to attend medical appointments with you? (List all helpers, their relationship to subject and total hours off during past 3 months).	Average wage of an Ontario worker[a]
During the past 3 months did you need any unpaid help with chores around the house because of your arthritis or joint problems? This includes help from your spouse or family members. On average, for how many hours in the past week did you need unpaid help with chores ___ (if last week was unusual, tell me about a 'typical' week)	Average wage of a professional homemaker[a]

[a]From reference 26.

one rural) of Ontario, Canada. Ontarians have comprehensive, universal public health insurance coverage, thus eliminating barriers to health-care based on insurance status. Based on Phase 1 responses, respondents were selected for Phase II (the prospective cohort) if they reported: (i) difficulty with stair climbing, arising from a chair, standing and walking; and (ii) swelling, pain or stiffness in any joint lasting $\geq$6 weeks; and (iii) indication on a diagram of a 'troublesome' hip and/or knee. A validation study confirmed that 96% of Phase II completers had clinical signs of hip and/or knee arthritis.

In 1999, Phase II participants were invited to participate in a 5-yr prospective study. Of the original 2411, 229 had died and 79 were lost to follow-up; 2103 agreed to participate. Demographic information collected during Phase II included age, sex, socioeconomic status (annual household income, from all sources), employment [employed for pay (yes/no); farming (yes/no)], living circumstances (nursing home/independent with others/independent alone), self-reported health [Health Survey Short-Form (SF-36) General Health subscale (range 0–100)] [18–20], comorbidity (number of health problems for which they were receiving treatment or had seen a physician in the past year), whether they had seen a physician for arthritis in the previous year (yes/no) and/or had undergone hip or knee replacement surgery (yes/no). Arthritis severity was assessed using the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) total score (sum of scores on the pain, physical function, and stiffness scales, range 0–96) [21, 22]. Individuals with inflammatory arthritis, such as rheumatoid arthritis, were identified based on an unprompted self-reported physician diagnosis of any type of inflammatory arthritis, evidence on joint examination of inflammatory arthritis (performed as part of the validation study), and/or past or current use of disease-modifying anti-rheumatic drugs.

Of the 2103 who entered the prospective study, 179 were deceased, 185 lost to follow-up, and 159 unable to participate due to illness, leaving 1580 potential participants in the second year of the prospective study (May 2000 to March 2001). Telephone interviewers, using a standardized questionnaire, asked participants about costs related to their arthritis pain and disability. Table 1 shows these questions.

Direct costs were calculated as the sum of equipment costs (e.g. bathroom equipment, wheelchair ramp, splints or canes), out-of-pocket payment for community services (e.g. transport, homecare, visiting nurse, meals on wheels), and paid help (e.g. for cleaning, shovelling snow, shopping) in the previous 3 months due to their arthritis or joint problems. Costs due to prescription and non-prescription drugs or other treatments, e.g. physiotherapy,

were not evaluated because it was expected that, due to existing public insurance, few participants would incur these costs.

There is lack of consensus regarding the valuation of indirect (time) costs [23–25]. Our approach was consistent with previous analyses [23]. Indirect (time) costs were calculated as the sum of respondent and caregiver time lost from employment, respondent time unable to perform household chores, and unpaid caregiver time spent on household chores. Respondent time lost from employment was elicited through questions about time off and reduced productivity (Table 1). While these questions do not capture time reallocations due to health problems that occurred prior to the past 3 months, this is unlikely to be a major concern as 96.3% of respondents were retired.

Caregiver time lost from employment was estimated by asking about respondent disability and the amount of help received (Table 1). To ensure more stable estimates, all lost labour or productivity cost questions asked respondents to report costs over the previous 3 months; to reduce recall bias, leisure time costs were reported over the last week.

Respondent time lost from employment was valued using occupation-specific average wages for Ontario obtained from the 2001 Canadian census [26], adjusted by the average cost of employment benefits. Time where the respondent was unable to perform usual household work, which also reflects lost productivity, was valued using the human capital method: lost time was valued with a replacement cost approach using the average wage rate of an Ontario worker employed full-time in the 'visiting homemakers, housekeepers, and related occupations' industry [26]. Since we did not have information on caregivers' occupations, caregiver time lost from employment was valued using the average Ontario wage rate. Caregiver time taken from leisure was valued using the proxy good method [15, 24], in which the time required for informal care is valued at the wage rate of a market substitute, that of a professional homemaker. All costs were annualized and adjusted for inflation and are expressed in 2002 Canadian dollars ($1.00 CDN ≈ $0.81 US).

Logistic regression was used to predict the likelihood that an individual would report any OA-related costs. For those who reported costs, ordinary least-squares regression was used to predict the magnitude of the (log-transformed) total costs. Age and WOMAC total score were entered into the models as continuous variables; quadratic terms were included to assess the shape of their relationship with costs. For presentation purposes, these variables have been categorized. Interaction effects between age and sex and region, WOMAC score, and income permitted the possibility of age and/or sex-specific effects. Interactions involving region allowed effects to differ by region. Three subcategories of total costs were examined further: direct costs; costs of informal care; and employment-related costs.

Regression diagnostics (Hosmer-Lemeshow goodness of fit test for logistic regression [27]; residual analysis and tests for influential observations for ordinary least-squares regression [28]) were conducted. Model fit is presented using adjusted R^2 and C-statistics [29] for logistic regression, and R^2 values for ordinary least-squares regression. Continuous variables were compared using two-sample *t*-tests; proportions were compared using Fisher's exact test; ordinal variables were compared using Cochran–Armitage tests for trend. Tests of significance were two-tailed at the 0.05 level.

This research received ethical approval from our institutional ethics review board. Written consent was obtained from all participants.

Results

Cohort characteristics

Of 1580 potential year-2 participants, 1378 completed the interview (adjusted response rate 87.2%). The 1378 differed from the original cohort of 2411 in being slightly older (73.0 *vs* 70.5 yr, $P<0.0001$), more likely to be female (75.3 *vs* 72.6%, $P=0.0005$), to reside in the rural region (57.3 *vs* 54.8%, $P=0.004$) and to have level of education below high school (84.2 *vs* 80.9%, $P<0.0001$), but slightly less likely to have an annual income below $20 000 (59.3 *vs* 63.5%, $P<0.0001$). Those with inflammatory arthritis ($n=120$) were excluded, leaving 1258 individuals with OA in the final analyses.

Among year-2 follow-up respondents, mean age was 73.1 yr (range 59–100), 74.2% were female and 33.2% reported a household income greater than $20 000. Urban participants were more likely to be living alone than rural participants (38.8% *vs* 23.0%, $P<0.0001$); in both regions, females were more likely to be living alone than were males ($P<0.0001$ for both). Most participants were retired (96.3%); half reported at least one comorbidity in addition to their OA. Mean total WOMAC score was 35.7 (S.D. 17.1). Mean SF-36 General Health score was 50.5 (S.D. 23.6) (Table 2). In the previous year, 91.4% had seen a physician for arthritis, mainly their primary care physician, 10.6% had seen a rheumatologist (urban 16.9% *vs* rural 6.3%), 15.2% had seen an orthopaedic surgeon (urban 14.4% *vs* rural 15.8%) and 24 (1.9%) had undergone hip/knee replacement surgery.

Direct and indirect costs incurred by people with OA

Of 1258 respondents, 758 (60.3%) reported OA-related costs. Average total annual costs, for those who reported costs, were $12 200 (Table 3). Direct costs were reported by 283 (22.5%) respondents, and were relatively low, averaging $2300 for those who had any direct costs. In contrast, half the respondents specified indirect costs ($n=662$, 52.6%), and the average annual value, for those who incurred such costs, was $12 990. For those who reported OA-related costs, indirect costs accounted for, on average, 81% of their total economic burden. For respondents with indirect costs, informal care-giving contributed an average of 40% of the total.

Multivariable analysis of the likelihood of reporting costs

The likelihood of incurring OA-related costs (yes/no) was relatively constant up to age 75, after which it increased sharply ($P<0.0001$) (Table 4). Men were less likely than women to report costs but the sex difference depended on region ($P=0.006$). The likelihood of incurring costs fell with improved health (SF-36 General Health subscale), and rose sharply with increasing OA severity (WOMAC total score) ($P<0.0001$ for both). Even after adjusting for general health status, increasing number of comorbidities was associated with greater likelihood of incurring costs ($P=0.02$). Farming was associated with a lower likelihood of reporting costs ($P=0.006$). Adjusting for these factors, neither income nor living arrangements was a significant independent correlate of having incurred costs ($P=0.49$ and 0.24, respectively).

Multivariable analysis of the magnitude of costs

Total costs (direct + indirect costs) were skewed and therefore log-transformed before being modelled. The parameters obtained from least-squares regression are therefore interpreted as multipliers [e.g. the parameter estimate of 0.095 for sex (Table 5) indicates that men, on average, reported costs which were $10^{0.095}=1.24$ times higher than women, after adjusting for the other variables in the model ($P=0.004$)]. Unlike the probability of incurring costs, the magnitude of the costs increased steadily with increasing age ($P<0.0001$). Increased OA severity (WOMAC total score) was also associated with increased costs ($P<0.0001$). After adjusting for age, sex and arthritis severity,

individuals with higher annual household income reported lower costs ($P = 0.006$) (Table 5). Region, general health status, number of comorbidities, living arrangements and farming were not significantly associated with total costs.

Subcomponents of total cost

Direct costs to the individual. The probability of incurring direct costs (paid household help and the cost of assistive devices) increased with increasing age ($P < 0.0001$) and as the WOMAC score increased from 0 to 40, falling for very high WOMAC total score values. Adjusting for age and arthritis severity, rural women were significantly more likely to incur direct costs than was any other sex/region group (*P*-value for sex/region interaction = 0.017). Compared with rural women, both rural men and urban women were significantly less likely to incur direct costs [odds ratio (OR) = 0.41, $P = 0.0001$, 95% confidence interval (CI) = 0.26–0.64, and OR 0.51, $P < 0.0001$, 95% CI = 0.37–0.71, respectively]. Among urban respondents, however, men and women did not differ significantly ($P = 0.68$). Ever having farmed was also a significant predictor of incurring direct costs; current/past farmers had a lower probability of incurring direct costs (OR = 0.48, $P = 0.0001$) (Table 4).

Indirect costs: informal care (unpaid help). The probability of receiving unpaid help with chores increased with age, worsening WOMAC scores ($P < 0.0001$ for both), and poorer general health (SF-36 General Health subscale; $P < 0.0001$). Females were more likely to receive informal help than males ($P = 0.008$, OR 1.54, 95% CI 1.12–2.12). Rural residents were more likely than urban residents to report receipt of informal care ($P = 0.0004$, OR = 1.66, 95% CI = 1.25–2.12). Participants who lived alone, compared with those who lived with others or in a nursing home, were less likely to report unpaid help with chores ($P < 0.0001$, OR = 0.49, 95% CI = 0.35–0.68).

Indirect costs: employment-related costs. Age was the only predictor of employment-related costs. These costs (days missed, reduced productivity, and unemployment due to OA) accounted for 32.9% of the total economic burden for participants <65 yr.

TABLE 2. Cohort characteristics ($n = 1258$)

	Overall ($n = 1258$)	Rural ($n = 732$)	Urban ($n = 526$)	*P*-value[a]
Age (yr): mean (S.D.)	73.1 (8.3)	72.3 (7.9)	74.2 (8.8)	<0.0001
Sex (% female)	74.2%	72.5%	76.4%	0.13
Gross annual household income: *n* (%)	$n = 1032$	$n = 615$	$n = 417$	0.17
≤$20 000	59.6%	60.6%	58.0%	
$20 001–$40 000	30.3%	30.6%	30.0%	
>$40 000/yr	10.1%	8.8%	12.0%	
Living arrangements	$n = 1233$	$n = 717$	$n = 516$	<0.0001
Nursing home	0.5%	0.7%	0.2%	
Lives alone	29.6%	23.0%	38.8%	
Lives with others	69.9%	76.3%	61.1%	
Lives alone, by sex				
Females	35.2%	28.3%	44.3%	<0.0001
Males	11.4%	7.5%	17.7%	0.005
Employed for pay (%)	3.8%	4.6%	2.8%	0.067
Farmer	14.1%	21.3%	0.0%	
Professional	10.9%	3.3%	25.8%	
Labourer	7.6%	8.2%	6.5%	
Other	67.4%	67.2%	67.7%	
Full-time	64.1%	60.7%	71.0%	
Ever farmed (%)	14.7%	24.5%	1.1%	<0.0001
Not working due to OA	2.5%	2.9%	1.9%	0.36
Comorbidities				0.88
None	45.9%	46.6%	44.9%	
1	30.0%	28.8%	31.6%	
>1	24.2%	24.6%	23.6%	
WOMAC scores: mean (S.D.) (min–max)				
WOMAC total score[b] (0–96)	35.7 (17.1) (0–79)	33.9 (16.3) (0–69)	38.2 (17.8) (0–79)	<0.0001
WOMAC pain score (0–10)	7.4 (3.7) (0–17)	7.0 (3.6) (0–15)	7.9 (3.8) (0–17)	<0.0001
WOMAC function score (0–68)	26.1 (12.7) (0–57)	24.7 (12.2) (0–54)	28.0 (13.1) (0–57)	<0.0001
SF-36 General Health subscale score[c] (0–100): mean (S.D.)	50.5 (23.6)	52.8 (23.3)	49.3 (23.8)	<0.0001

[a] *P*-value comparing the two regions.
[b] Higher WOMAC scores indicate greater hip/knee pain and disability.
[c] Higher scores indicate better general health status.

TABLE 3. Direct and indirect costs of OA ($n = 1258$)

Costs	*n* (%) with non-zero costs	Mean (S.D.)	Median	Range	25th, 75th percentiles
Total	758 (60.3%)	$12 200 ($12 060)	$9580	$30 to $152 660	$3990, $15 970
Direct costs (i.e. purchase of assistive devices and/or paid help)	283 (22.5%)	$2300 ($2200)	$1630	$20 to $22 360	$1000, $3190
Indirect costs (i.e. formal and informal lost labour/productivity, caregiver time losses)	662 (52.6%)	$12 990 ($12 240)	$11 180	$110 to $149 470	$6390, $15 970
Percentages					
% of total cost due to indirect costs	Based on 758 who had costs	81.2% (34.1)	100%	0–100%	79.1%, 100%
% of indirect costs due to caregiver costs	Based on 662 who had indirect costs	52.1% (39.5)	50.0%	0–100%	13.3%, 100%

Discussion

Summary of findings

Arthritis and rheumatism affect an estimated 51.2% of Ontario's population aged ≥75 yr [4]; the majority of this burden is attributable to OA. For health policy makers and care providers to make evidence-based decisions about the most cost-effective ways to deal with the substantial economic burden attributable to OA, valid estimates of these costs are needed. While several cost of illness studies have been performed in OA, none to date has considered the economic burden to individuals with OA and their caregivers, incorporating estimates of both the direct and indirect costs, including costs for informal care. This study examined the OA-attributable costs from the perspective of a population cohort of individuals living with disabling hip/knee OA. As expected, greater OA pain and disability were associated with both greater likelihood of incurring costs and higher costs among those who reported costs. After adjusting for OA severity, individuals ≥75 yr were more likely to incur costs, but costs, for those who incurred them, were highest for individuals of working age (<65 yr). Although men were less likely than woman to report having costs, when they did, their expenditures were almost 25% higher. Other significant correlates of incurring costs (poorer general health status and comorbidities) did not predict the size of the costs, given that costs were incurred.

Table 4. Predictors of reporting non-zero OA costs: logistic regression results ($n = 1258$)

Predictor	Odds ratio[a]	95% CI	*P*-value
Age (yr)			<0.0001
<65	1.13	0.75, 1.71	0.564
65–69	1.03	0.68, 1.57	0.876
70–74 (reference group)	1.00	–	–
75–79	1.43	0.94, 2.16	0.095
80–84	1.95	1.20, 3.18	0.007
85+	9.07	4.14, 19.9	<0.0001
Sex × region interaction			0.031
Rural females (reference group)	1.00	0.28, 0.61	<0.0001
Rural males	0.41	0.36, 0.71	<0.0001
Urban females	0.51	0.26, 0.70	0.0007
Urban males	0.42		
SF-36 General Health subscale score (per unit increase)	0.84	0.78, 0.90	<0.0001
WOMAC total score			<0.0001
0–14 (reference group)	1.00	0.69, 1.78	0.686
15–24	1.10	1.11, 2.82	0.017
25–34	1.77	1.47, 3.83	0.0004
35–44	2.37	3.20, 9.43	<0.0001
45–54	5.50	6.99, 32.2	<0.0001
55+	15.0		
Number of comorbidities (per each additional condition)	1.22	1.05, 1.41	0.009
Ever farmed (baseline is 'never')	0.056	0.37, 0.84	0.006

The model had an adjusted R^2 of 38.6%. C-statistic = 0.82. There was no evidence of lack of fit (Hosmer-Lemeshow lack of fit test, $P = 0.93$).
[a]Odds ratios are adjusted for the other variables in the model.

Comparisons with previous OA cost estimates

The cost estimates from our survey are substantially higher than previous macrodiagnosis-based estimates, where global population costs have been assessed through linkage of data from a variety of sources (e.g. general population health surveys, administrative databases), not necessarily related temporally nor by diagnosis or disease severity [8, 30–34]. For example, in Canada the cost of arthritis and rheumatism was estimated at $5.9 billion (Canadian) in 1994 [30], or approximately $700 per patient per annum. Almost two-thirds (63.4%) of this amount ($3.7 billion) was attributed to lost productivity at work and home due to disability. In the present study, for those who reported costs the average economic cost ascribed to lost productivity was more than $3000 per person. The disparity in these cost estimates suggest that surveys designed explicitly to collect information on arthritis-related costs may produce a more accurate picture of OA costs than that obtained from general population health surveys. Furthermore, this demonstrates the importance of sample selection (incorporation of individuals with a wide range of OA severity) and underscores the need for standardized methods of assessing costs [15].

Two previous studies have examined OA costs from the perspective of the individual [8, 14] using self-report questionnaires. Both studies assessed direct costs to the individual, including prescription drug costs and expenditures for assistive devices and paid help. However, only the study by Gabriel *et al.* [8] assessed indirect costs due to lost wages and reduced productivity, and neither study considered informal care costs. Despite these

Table 5. Correlates of total (log-transformed) OA costs for individuals who reported costs: ordinary least-squares regression results ($n = 758$)

Predictor variable	Parameter[a] (s.e.)	Multiplier $=10^{\text{parameter}}$	95% CI for multiplier	*P*-value
Age (yr)				<0.0001
<65 (reference group)	0	1.000	–	–
65–69	−0.255 (0.047)	0.556	(0.422, 0.732)	<0.0001
70–74	−0.244 (0.045)	0.555	(0.449, 0.687)	<0.0001
75–79	−0.319 (0.042)	0.479	(0.391, 0.588)	<0.0001
80–84	−0.192 (0.045)	0.643	(0.532, 0.778)	<0.0001
85+	−0.205 (0.046)	0.624	(0.509, 0.764)	<0.0001
Sex (reference is female)	0.095 (0.033)	1.244	(1.012, 1.529)	0.004
WOMAC total score (0–96)				<0.0001
<15 (reference group)	0	1.000	(0.890, 1.230)	0.771
15–24	0.020 (0.067)	1.046	(0.885, 1.619)	0.210
25–34	0.078 (0.062)	1.197	(1.346, 2.300)	<0.0001
35–44	0.245 (0.059)	1.759	(1.664, 2.822)	<0.0001
45–54	0.336 (0.058)	2.167	(2.621, 4.452)	<0.0001
≥55	0.534 (0.059)	3.416		
Income (baseline is <$20 000)				0.006
≥$20 000/yr	−0.085 (0.031)	0.823	(0.709, 0.954)	

R^2 for the model was 29.0%.
[a]Parameter estimates are adjusted for the other variables in the model.

differences from our study, both studies documented substantial costs to the individual due to OA. Lapsley *et al.* [14] reported that the annual direct costs to the individual were, on average, $258 and $537 (Australian) per person for men and women, respectively. In Gabriel *et al.* [8], the average indirect non-medical expenditures (costs for home care, child care, lost wages and reduced productivity) were $281 (US), excluding wage losses.

These studies confirm the high personal economic burden to those who suffer from OA. Equally, if not more important, our study is the first to show that the economic burden borne by informal caregivers—costs that were not included in previous studies—is similar in magnitude to the economic burden for those living with OA.

Regional and individual differences in OA costs

Because the costs associated with OA are so high, it is important to understand them in more detail, paying attention to regional and individual differences. We found significant regional differences in the economic burden of OA. Individuals living in the rural region reported higher total costs and were more likely to incur both direct costs and costs associated with unpaid help. Possible explanations include greater availability of community services (which may be less expensive to provide in a densely populated urban region), less need for help due to differences in housing (e.g. urban apartment buildings), the greater propensity to report receipt of informal care ($P = 0.0004$, OR = 1.66, 95% CI = 1.25–2.12), and the availability of public transport, or other aspects of neighborhood culture and demographics in the urban *vs* rural region. It is important to understand the factors that contribute to these regional differences in unmet need.

Of note, past or current farmers (the majority of whom were rural men) were less likely than 'never farmers' to incur costs after adjusting for other factors. Whether this finding reflects differences in personality traits that influence care-seeking behaviour is unclear and warrants further attention.

Gender was related to economic burden in the rural but not the urban region. This result points to the importance of distinguishing between global results (e.g. on average, women incur more economic burden associated with OA than do men [14]) and regional results. In as much as differences in burden vary by region, the results also suggest that care programmes should be tailored to local requirements.

In addition to significant differences based on region, differences found were based on individual circumstances. Total costs included a component for the amount of time the participant was unable to perform household chores. If the participant received help from others, the amount of time spent unable to perform chores was reduced accordingly, thereby avoiding double counting. Living arrangements was not a significant predictor, overall, of incurring costs, nor did it predict the magnitude of costs, if there were any. However, living alone was associated with a significantly lower probability of receiving help. This suggests that the amount of help *required* is independent of living arrangements, once age, health, and disability are taken into consideration, but that the amount of help *received* depends on living arrangements. It appears that for people living alone, help was not available, rather than not needed. This finding, too, warrants further study. If confirmed, it may be particularly important, since older women are more likely than older men to live alone, and the number of elderly individuals living alone is likely to increase as the population ages.

We also found that the direct costs increased with increasing WOMAC score, as have others [14]. However, this was true only up to a point, and then decreased with further increases in WOMAC score. Possible explanations are that people with less disability do not qualify for provincially funded home care and so are paying directly for their care, or that individuals with severe disability have already purchased assistive devices (or are disabled to the extent that they no longer use devices to compensate). We need to understand not only total costs but also the components in order to predict the effect of various social programmes and to design programs meant to defray high costs.

Strengths and weaknesses of the study

The strengths of our study include its population-based design (representative of community-dwelling individuals with disabling hip and knee OA), large sample size, high survey response rate, and inclusion, for the first time, of costs of informal care. However, there are some limitations. Costs were self-reported and were based on recall (Table 1). To improve accuracy, respondents were asked to recall events only for the previous 3 months. Since all of the participants were at least 61 yr old at the time of this survey, the use of average wages may have underestimated lost productivity. Lack of information about the occupation of caregivers may have biased the evaluation of the lost caregiver time, although it is hard to determine the direction of this potential bias, which depends on whether low-income earners are more likely to act as caregivers than high-income earners. However, few of the participants were still working or unemployed due to arthritis, and very little of the caregivers' time was time spent away from employment, which may reflect the nature of chronic (as opposed to acute) disease situations. In unpublished data that examined caregiver time in more detail, time away from employment represented a small fraction of caregiver time. Even in a working-age population, most caregiving occurred after work and at weekends. Consequently, such time was drawn from time that might have otherwise been applied to either household work or leisure. Such time reallocations entail a significant opportunity cost even though they are not related to time lost from labour market work. Therefore, the inclusion of lost caregiver time is an important consideration when valuing the burden of chronic illnesses such as OA.

In Ontario, the cost of prescription drugs for people aged 65 and older is covered by a provincial insurance plan, subject to a modest co-payment and annual deductible. Our data, however, did not capture the cost of prescription drugs for those respondents who were younger than 65 or the cost of non-prescription drugs. Likewise, while the provincial health insurance plan covers all medically necessary care, including some chiropractic care and physiotherapy, our study did not include the direct costs of non-insured visits, such as massage therapy, acupuncture, which individuals with OA may use. Therefore, the direct costs estimated in our study underestimates the total amount spent on care.

Conclusion

From the perspective of individuals living with OA, this study demonstrated that the costs of OA are substantial and are due mainly to indirect costs. Further, we showed that indirect costs are split between those attributable to the individual with OA and those attributable to their caregivers, the value of caregiver time accounting, on average, for 40% of total indirect cost. Failure to incorporate caregiver costs undervalues the cost of illness and, more importantly, prevents an honest evaluation of the tradeoffs in choosing between various delivery and treatment options. Only by taking a broad perspective when examining the cost of illness can we recognize treatments that reduce costs, as opposed to shifting them from one party to another. An open dialogue on health-care policy requires knowledge of the full costs of care.

Rheumatology	Key messages
	• Failure to take indirect costs into account significantly underestimates the cost of OA borne by people with this condition and their caregivers, and prevents honest comparisons of different care options.

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