

# The Rising Burden of Rheumatoid Arthritis Surpasses Rheumatology Supply in Ontario

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## ABSTRACT

**OBJECTIVES:** Accurate data on the burden of rheumatoid arthritis (RA) are scarce, but critical in helping health care providers and decision makers to optimize clinical and public health strategies for disease management. We quantified the burden of RA in Ontario from 1996 to 2010 by age, sex and health planning region.

**METHODS:** We used the Ontario Rheumatoid Arthritis administrative Database (ORAD), a validated population-based cohort of all Ontarians with RA, to estimate the crude prevalence and incidence of RA among men and women, and by age group from 1996 to 2010. Burden by area of patient residence and rheumatology supply also were determined.

**RESULTS:** The number of RA patients increased over time, from 42,734 Ontarians (0.5%) in 1996 to 97,499 (0.9%) in 2010. On average 5,830 new RA patients were diagnosed each year. In 2010, the burden was higher among females (1.3%) than males (0.5%) and increased with age, with almost half of all RA patients aged 65 years and older. The burden was higher in northern communities (1.0%) than in southern urban areas (0.7%). During the study period, the number of rheumatologists practicing in Ontario remained unchanged (approximately 160).

**CONCLUSION:** Over a 15-year period, the number of RA patients more than doubled with no concomitant increase in the number of practicing rheumatologists. We observed considerable regional variation in burden, with the highest rates observed in the north. Our findings highlight the need for regional approaches to the planning and delivery of RA care in order to manage the growing burden.

**KEY WORDS:** Rheumatoid arthritis; prevalence; incidence; health services

La traduction du résumé se trouve à la fin de l'article.

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Rheumatoid arthritis (RA) is a chronic systemic autoimmune disease. Inflammatory polyarthritis is the primary clinical manifestation, mainly affecting small joints of the hands and the feet.<sup>1</sup> RA places significant burden on individuals and society, and is among the most disabling and costly of chronic diseases.<sup>2</sup> National guidelines recommend that RA care should include a rheumatologist.<sup>3</sup> Timely specialist care is important as it increases early exposure to treatment,<sup>4</sup> improves patient outcomes,<sup>5</sup> reduces disability, decreases the need for costly surgical interventions,<sup>6</sup> and thus reduces global disease burden.

Accurate population-based assessments of the burden of RA are critical to helping health care providers and decision makers anticipate the burden and to optimize clinical and public health strategies for disease management. Canadian data regarding the prevalence and geographic distribution of RA are limited. These data are important for accurate health human resource planning. Our primary aim was therefore to quantify the burden of RA in Ontario, and to map the geographic distribution of RA and rheumatology specialists across the province.

## SUBJECTS AND METHODS

### Setting and design

Canada's publicly funded health care system is universal and comprehensive for both hospital care and physicians' services. We per-

formed a population-based cohort study in Ontario, Canada's most populous province, which has a diverse, multicultural population.

### Patients and data sources

We used the Ontario Rheumatoid Arthritis administrative Database (ORAD), a population-based research cohort of Ontarians with RA

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generated from administrative databases using a validated case definition. Patients are included in ORAD if they are admitted to a hospital with a RA diagnosis or have at least three RA diagnosis codes over two years, with at least one provided by a specialist (rheumatologist, internist, or orthopedic surgeon). Once all criteria are met, incidence is defined as the first medical encounter for RA. This case definition yielded a sensitivity of 78%, specificity of 100% and positive predictive value (PPV) of 78% in identifying RA cases in a general population.<sup>7,8</sup> ORAD is developed from inpatient diagnosis codes identified using the Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD), which contains detailed information regarding all hospital admissions.<sup>9</sup> ORAD also includes physician billing diagnosis codes identified in the Ontario Health Insurance Plan (OHIP) Database.<sup>10</sup> Physicians are reimbursed by submitting claims to OHIP for medical services provided. One diagnosis code, representing the main “reason for the visit”, is provided with each claim.

ORAD records are linked to the Ontario Registered Persons Database to obtain information regarding members’ age, sex, place of residence, and vital status. Area-level population estimates were obtained from Statistics Canada Census for 1991 through 2011.<sup>11</sup> These datasets are linked in an anonymous fashion using encrypted health insurance numbers and they have very little missing information.<sup>12</sup>

Information on rheumatology supply was obtained by linking the ICES Physician Database (IPDB) with the OHIP database.<sup>13</sup> The quality of data in the IPDB is routinely validated against the Ontario Physician Human Resource Data Centre database, which verifies this information through periodic telephone interviews with physicians.

### Analysis

We used ORAD to estimate the number of individuals aged 15 years or older with RA each year from 1996 to 2011. We did not compute disease prevalence from 1991 to 1995 as administrative data were only available from 1991 onwards and all prevalent patients will appear as incident patients during the early years of study. Disease onset was defined as the first qualifying health services contact for which a diagnosis of RA was provided.<sup>7</sup> Only individuals with no such previous contacts for RA were counted as incident patients for the relevant year, and the incident population was calculated as census population minus prevalent patients from the previous year. Prevalent patients were carried forward for each year, and patients who died or moved out of the province were excluded from the numerator and denominator. Individuals who were less than 15 years of age were also excluded from both the numerator and the denominator. We identified the number of new (incident) RA patients each year, and computed the average annual number of new RA patients over the entire study period.

To characterize the RA patient population for 2010, we determined the age distribution of RA patients as well as the percent prevalence and incidence by age and sex. We also computed and mapped the prevalence of RA and rheumatology supply among Ontario’s 14 health service planning areas, known as Local Health Integration Networks (LHINs). Age- and sex-standardized rates by area of patient residence were also determined.

All analyses were performed at the Institute for Clinical Evaluative Sciences (ICES [www.ices.on.ca]) using SAS version 9.2

**Table 1.** Crude Prevalence and Incidence of RA by Year

| Year | Prevalence |            |      | Incidence |            |       |
|------|------------|------------|------|-----------|------------|-------|
|      | Count      | Population | %    | Count     | Population | %     |
| 1996 | 42,734     | 8,720,499  | 0.49 | 5523      | 8,682,077  | 0.06% |
| 1997 | 46,961     | 8,828,425  | 0.53 | 5546      | 8,785,669  | 0.06% |
| 1998 | 51,248     | 8,959,209  | 0.57 | 5731      | 8,912,234  | 0.06% |
| 1999 | 55,398     | 9,085,331  | 0.61 | 5662      | 9,034,053  | 0.06% |
| 2000 | 59,129     | 9,220,621  | 0.64 | 5429      | 9,165,200  | 0.06% |
| 2001 | 62,795     | 9,390,567  | 0.67 | 5495      | 9,331,423  | 0.06% |
| 2002 | 66,537     | 9,588,554  | 0.69 | 5614      | 9,525,743  | 0.06% |
| 2003 | 69,997     | 9,779,736  | 0.72 | 5414      | 9,713,187  | 0.06% |
| 2004 | 73,575     | 9,939,997  | 0.74 | 5641      | 9,869,989  | 0.06% |
| 2005 | 77,330     | 10,100,741 | 0.77 | 5815      | 10,027,150 | 0.06% |
| 2006 | 81,614     | 10,257,323 | 0.80 | 6431      | 10,179,982 | 0.06% |
| 2007 | 85,706     | 10,410,695 | 0.82 | 6220      | 10,329,070 | 0.06% |
| 2008 | 89,420     | 10,556,974 | 0.85 | 6046      | 10,471,253 | 0.06% |
| 2009 | 93,558     | 10,708,605 | 0.87 | 6490      | 10,619,171 | 0.06% |
| 2010 | 97,499     | 10,851,140 | 0.90 | 6395      | 10,757,575 | 0.06% |

(SAS Institute, Cary, NC). The study was approved by the Sunnybrook Health Sciences Centre Research Ethics Board in Toronto, Canada.

### RESULTS

The number of RA patients increased steadily over time, from 42,734 (0.5%) Ontarians in 1996 to 97,499 (0.9%) in 2010 (Table 1). The crude number of new patients identified each year varied from 5,523 patients in 1996 to 6,395 patients in 2010 (Table 1), and on average, 5,830 new RA patients were diagnosed each year.

The burden increased among both sexes over time, and as of 2010, the burden was higher among females (1.3%) compared to males (0.5%) (Figure 1).

In 2010, 72% of all RA patients were female and 44% were aged 65 years and older. The prevalence also increased with age: 15-24y (0.1%), 25-34y (0.2%), 35-44y (0.5%), 45-54y (0.9%), 55-64y (1.5%), 65-74y (2.1%), 75-84y (2.6%) to ≥85y (2.7%); and females had a higher prevalence than males in all age groups. As of 2010, the incidence also increased with age: 15-24y (0.01%), 25-34y (0.02%), 35-44y (0.04%), 45-54y (0.07%), 55-64y (0.10%), 65-74y (0.12%), 75-84y (0.13%); and females had a higher incidence than males in all age groups (Figure 2).

The overall crude prevalence of RA in 2010 was 899 patients per 100,000 adult residents. Geographic variation was evident by area of patient residence. Prevalence was higher in northern rural communities (e.g., 1,297 patients per 100,000) than in southern urban areas (e.g., Toronto: 748 per 100,000) (Table 2). The overall provincial per capita provision in 2010 was 1.5 rheumatologists per 100,000 population, ranging from 0.2 rheumatologists per 100,000 in the North East to 5.2 rheumatologists per 100,000 in Toronto Central (Table 2). Regional variation in rheumatology supply was also evident (Figure 3), and the number of rheumatologists remained constant over 1996-2010 with approximately 160 rheumatologists in Ontario.

### DISCUSSION

Over a 15-year period, we identified that the number of patients living with RA in Ontario has more than doubled, with no concomitant increase in the number of rheumatologists. Our data not only indicate that RA prevalence rates have increased significantly over time, but that the prevalence of RA is rising with increasing age, with around twice as many women as men being affected. Regional prevalence rates also illustrate the high burden of RA in all locales, especially in northern communities, highlighting the need

**Table 2.** Crude Rates by Area of Patient Residence According to Local Health Integration Network (LHIN) in 2010

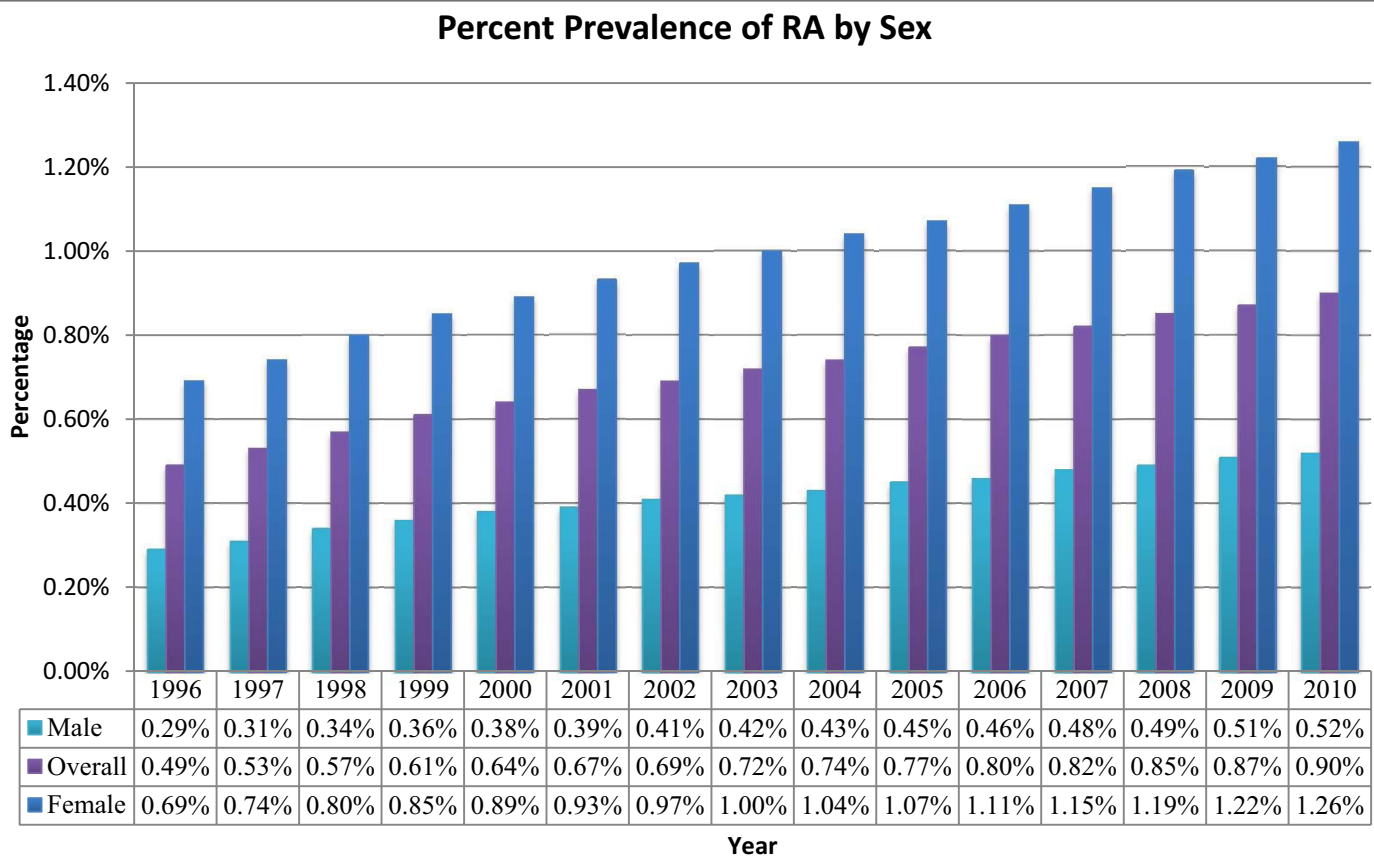
| LHIN No. | LHIN Description     | Count  | Population | Crude Rate per 100,000 | Standardized* Rate per 100,000 (95% CI†) | No. of Rheumatologists per 100,000 |
|----------|----------------------|--------|------------|------------------------|--|------------------------------------|
| 1        | Erie St. Clair       | 5063   | 533,985    | 948                    | 789 (767-812)                            | 0.7                                |
| 2        | South West           | 7088   | 789,224    | 898                    | 752 (734-770)                            | 1.1                                |
| 3        | Waterloo Wellington  | 4654   | 605,992    | 768                    | 710 (689-731)                            | 0.5                                |
| 4        | Hamilton Niagara     | 11,927 | 1,165,405  | 1023                   | 842 (826-858)                            | 1.6                                |
| 5        | Central West         | 5474   | 649,231    | 843                    | 846 (823-869)                            | 0.8                                |
| 6        | Mississauga Halton   | 7906   | 922,141    | 857                    | 821 (803-840)                            | 1.2                                |
| 7        | Toronto Central      | 7935   | 967,942    | 820                    | 726 (710-743)                            | 5.2                                |
| 8        | Central              | 10,611 | 1,419,577  | 748                    | 688 (674-701)                            | 1.3                                |
| 9        | Central East         | 11,528 | 1,299,053  | 887                    | 770 (755-784)                            | 0.9                                |
| 10       | South East           | 4074   | 414,221    | 984                    | 783 (757-809)                            | 1.4                                |
| 11       | Champlain            | 9497   | 1,027,281  | 925                    | 805 (789-822)                            | 1.8                                |
| 12       | North Simcoe Muskoka | 3040   | 376,987    | 806                    | 659 (635-684)                            | 0.8                                |
| 13       | North East           | 6256   | 482,452    | 1297                   | 1038 (1011-1066)                         | 0.2                                |
| 14       | North West           | 2314   | 197,649    | 1171                   | 1015 (972-1060)                          | 1.0                                |
| Overall  | All Ontario          | 97,499 | 10,851,140 | 899                    | 786 (778-788)                            | 1.5                                |

\* Standardized by age and sex based on 1991 census population.

† CI: confidence interval.

Note: 132 patients who were prevalent for RA in 2010 could not be assigned to a LHIN.

**Figure 1.** Percent prevalence by sex, 1996-2010

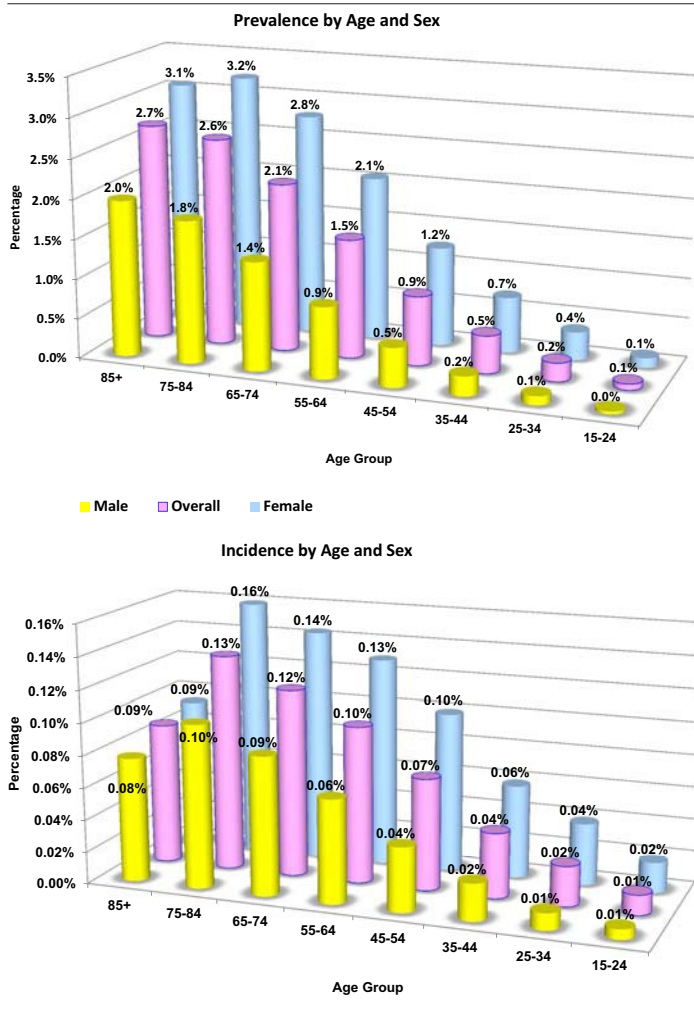


for regional considerations when planning for health care provision for RA.

Factors contributing to the increasing burden of RA may be reflective of an increase in the aging background population and increasing survival of RA patients. The highest prevalence estimates were observed in northern, rural communities of less dense population and also where there are few practicing musculoskeletal specialists.<sup>14,15</sup> Ontario is a large province covering 1,076,395 square kilometres and northern, rural communities constitute nearly 90% of the area of Ontario with a population of 800,000, which is only 6% of the total population for the province.<sup>16</sup> Regional differences may be reflective of the underlying patient demographics (ethni-

city, socio-economic status) and environmental exposures with RA risk (such as cigarette smoking, other air pollutants, occupational exposures, latitude)<sup>17-19</sup> that may be driving rates of RA in specific locales. For example, Toronto is comprised of a healthy immigrant population,<sup>20,21</sup> whereas northern communities have poor access to preventive health care services,<sup>22</sup> many Aboriginal communities,<sup>23</sup> higher rates of chronic disease (e.g., diabetes and cardiovascular diseases),<sup>24</sup> and lower vitamin D levels (due to the higher latitude)<sup>19,25</sup> all of which are associated with an elevated risk of RA development.<sup>26,27</sup> Further study is required to elucidate the reasons for regional variation. One interesting avenue for future research is to determine whether RA prevalence in certain regions is being

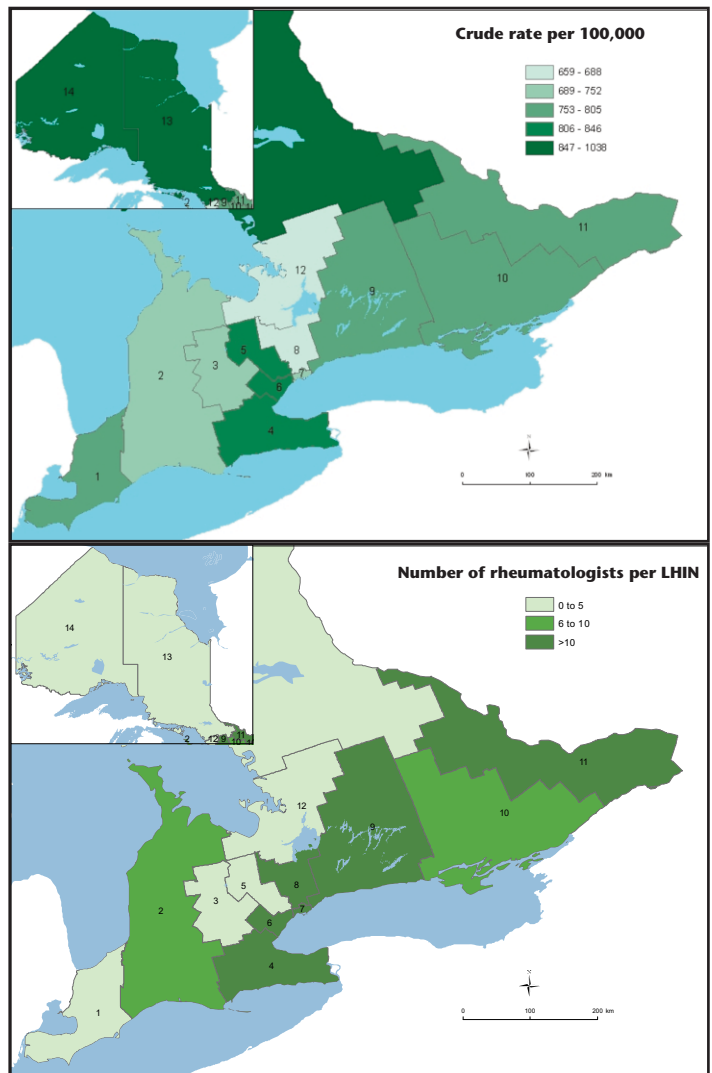
**Figure 2.** Burden by age and sex in 2010



driven by the high proportion of Aboriginal residents who live there (since there are multiple known genetic risk factors for RA, which could be driving risk in these populations).

The significant rise in the number of people with RA in Ontario, and the rapidity of this increase, calls for urgency in tackling this issue. Despite its rising prevalence and the associated cost burden on the system, RA has received relatively little attention compared to other chronic diseases with respect to optimizing models of care. Medications used to treat RA are typically prescribed and monitored by rheumatologists. Therefore prompt referral to rheumatologists to treat RA in the early stages is important to prevent joint damage and disability.<sup>5,6,28</sup> However, current evidence suggests that Ontarians living with RA are not receiving the right care at the right time.<sup>4</sup> Despite the fact that the number of RA patients has doubled over the past 15 years (from 42,734 in 1996 to 97,499 in 2010), the number of practicing rheumatologists has not been increasing,<sup>15</sup> which is likely to cause further strain on our health care system. For instance, the overall provincial per capita provision in 2010 was 1.5 rheumatologists per 100,000 population. If all RA care were equally distributed, each rheumatologist would have to provide care for at least 600 RA patients in addition to other rheumatology patients in their practice. Furthermore, our map of the distribution of rheumatologists illustrates that there are few rheumatologists in areas of the province where there is a particularly high burden of RA (such as northern communities). Thus, health human resources

**Figure 3.** A map of crude RA rates per 100,000 by area of patient residence and the regional distribution of rheumatologists by LHIN in 2010



Numbers on map represent the LHIN numbers. For the corresponding LHIN names, see Table 2.

shortages and geographic variation in the supply of rheumatology services and RA burden mean that access to quality care for RA continues to be a challenge in Ontario. Given that RA is considered a chronic, life-long disease, rheumatologists are required to provide decades of care for individual patients. Spontaneous remission is rare, and most patients will experience fluctuating symptoms with progression of damage over time.<sup>29</sup> Although drug treatment slows the disease process, few patients go into lasting remission.<sup>30</sup> Thus, many rheumatologists are unable to accept new patients into their practice due to the large burden of follow-up care required for chronic disease management. Since health human resources have not increased alongside the growing burden of RA, newer, more efficient models of care involving allied health professionals and family physicians working in shared-care models could allow better triaging and the co-management of stable RA patients. This would allow rheumatologists to assess new patients more efficiently. Rheumatology and primary care structures could also be expanded to include other interprofessional care providers (such as nurses, nurse practitioners, physiotherapists, occupational ther-

apists, pharmacists, etc.) to provide education and care in a coherent, and more organized way. With the aging population, better musculoskeletal training for primary care physicians is also important for recognizing and treating RA and other inflammatory conditions earlier. Exposure of medical students to the major advances in rheumatologic care could also result in more trainees choosing rheumatology as their specialty of choice.

Furthermore, the changing demographics of the RA population also have implications regarding new models of care. Senior rheumatology patients have special considerations compared to the younger population. Older patients tend to have more comorbidities (for example, cardiovascular disease) and the resultant polypharmacy can make management issues for rheumatologic conditions all the more challenging. As the population ages, there will be a greater number of seniors with RA who are *also* developing multiple co-morbidities, further complicating chronic disease management. Additionally, RA is not recognized as a significant chronic condition (like diabetes or renal disease) in most provinces. Never has there been a more urgent need for a coordinated, multi-partnered approach, to integrate RA into a broad chronic disease management strategy.

Health systems around the world are implementing integrated care strategies to improve quality, reduce or maintain costs, and improve the patient experience. The challenge for all health care systems is to improve health and the quality of care, while at the same time delivering value for money. The Ontario Best Practices Research Initiative and the Ontario Rheumatology Association (ORA) have been key advocates for new Models of Care in Rheumatology (MOC). Based on extensive research and physician input, the ORA-MOC working committee has been successful at defining the essential elements of a framework that ultimately focuses on facilitating quality and timely care for patients with inflammatory arthritis. Its vision is to establish a patient-centric model of care with the following key features: a continuum of care from primary to specialty providers, a network of interprofessional care providers for shared care in education, evidence-based treatments, treat to target approaches, and trackable and measurable outcomes. No incremental costs would be required; rather there would be a sustainable reorganization of the current systems with shifting and mobilization of existing drivers to optimize patient care delivery. And most importantly, the framework will have enough flexibility to accommodate different geographical regions and available resources. The Arthritis Programme (TAP) in Newmarket, Ontario is one example of a care model that delivers high-quality care.<sup>31</sup> It is through these models that we can learn and share best practices to achieve the goals that are necessary for optimal health of rheumatic disease patients.

Our main limitation is that health services data can only assess RA patients who sought and had access to health care providers. Therefore, we were unable to assess the population who rarely access care, and it is important to view our data as physician-identified disease burden. Furthermore, ORAD currently does not contain information on important risk factors for RA, such as ethnicity or education, and we were unable to explore the effects of specific factors on disease burden.

In conclusion, RA prevalence increased with age and was highest among females. The burden has also increased significantly over time. Regional prevalence rates illustrate the high burden of RA in

all locales, especially in northern communities, highlighting the importance of regional differences for planning for health care provision for RA. Our study provides a foundation for future analyses to characterize the current care patterns for patients with RA, which can be used to measure the effectiveness of new models of care. With the increasing RA burden and no concomitant increase in the number of practicing rheumatologists, never has there been a more urgent need to tackle the growing burden of RA to improve the timeliness and quality of care, in order to prevent potential harm to patients, society and the health care system.

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## RÉSUMÉ

**OBJECTIFS :** Les données précises sur le fardeau de la polyarthrite rhumatoïde (PR) sont rares mais essentielles pour aider le personnel soignant et les décideurs à optimiser les stratégies cliniques et de santé publique en gestion des soins thérapeutiques. Nous avons chiffré le fardeau de la PR en Ontario de 1996 à 2010 selon l'âge, le sexe et la région de planification sanitaire.

**MÉTHODE :** Nous avons utilisé la base de données administratives sur la polyarthrite rhumatoïde de l'Ontario (ORAD), une cohorte populationnelle validée de tous les Ontariens atteints de PR, pour estimer la prévalence et l'incidence brutes de la PR selon le sexe et le groupe d'âge de 1996 à 2010. Nous avons aussi déterminé le fardeau de la maladie selon la région de résidence des patients et l'offre en rhumatologie.

**RÉSULTATS :** Le nombre de patients atteints de PR a augmenté avec le temps, passant de 42 734 Ontariens (0,5 %) en 1996 à 97 499 (0,9 %) en 2010. En moyenne, 5 830 nouveaux patients par année ont reçu un diagnostic de PR. En 2010, le fardeau était plus lourd chez les femmes (1,3 %) que chez les hommes (0,5 %), et il augmentait avec l'âge : près de la moitié des patients atteints de PR avaient 65 ans et plus. Le fardeau était plus lourd dans les communautés nordiques (1,0 %) que dans les agglomérations urbaines du Sud (0,7 %). Sur la période de l'étude, le nombre de rhumatologues exerçant en Ontario est resté inchangé (environ 160).

**CONCLUSION :** Sur une période de 15 ans, le nombre de patients atteints de PR a plus que doublé, sans augmentation comparable du nombre de rhumatologues en exercice. Nous avons relevé des écarts régionaux considérables dans le fardeau de la maladie, les plus hauts taux étant observés dans le Nord. Nos constatations soulignent le besoin d'approches régionales en matière de planification et de prestation des soins de la PR afin de composer avec l'alourdissement du fardeau.

**MOTS CLÉS :** polyarthrite rhumatoïde; prévalence; incidence; services de santé