

Rheumatoid Arthritis Surveillance in Ontario: Monitoring the Burden, Quality of Care and Patient Outcomes through Linkage of Administrative Health Data

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Abstract

Rheumatoid arthritis (RA) is the most common chronic inflammatory joint disease. Using the Ontario administrative health data housed at the Institute for Clinical Evaluative Sciences, researchers have quantified the population-level burden and epidemiology of RA, mapped its geographic distribution in relation to rheumatologist supply, studied trends in access to rheumatology care and treatment and evaluated patient outcomes. The findings highlight the excess morbidity and mortality associated with the growing burden of RA in the face of a strained rheumatology supply, and raise urgent questions about how best to meet the needs of Ontarians with RA.

The Issue

Given the rising levels of chronic disease and multimorbidity in Canada, researchers and decision-makers are increasingly looking to administrative health data as an information source for chronic disease detection and surveillance. Rheumatoid arthritis (RA) is just one condition for which administrative data-based research on disease burden, quality of care and patient outcomes is helping to transform the lives of Canadians with chronic disease.

RA is the most common chronic inflammatory joint disease, affecting millions of people worldwide, and one of the most disabling and costly of all chronic diseases (Cross et al. 2014). At disease onset, RA is considered a medical emergency requiring prompt referral to a rheumatologist. To control symptoms

and inhibit disease progression, treatment guidelines include disease-modifying antirheumatic drugs (DMARDs), biologic agents such as anti-tumour necrosis factor agents and corticosteroids (Bykerk et al. 2012). However, uncontrolled RA activity can lead to irreversible joint damage requiring surgery, multiple comorbidities and premature mortality. Many factors contribute to increased morbidity and mortality in patients with RA, including immune abnormalities, organ system manifestations associated with the disease, genetic predisposition, the immunosuppressive and cytotoxic effects of treatments and, possibly, poor quality of care.

Here we highlight some recent Institute for Clinical Evaluative Sciences (ICES) research aimed at helping to improve the care and outcomes of patients with RA.

Key Findings

Optimizing Administrative Data Accuracy

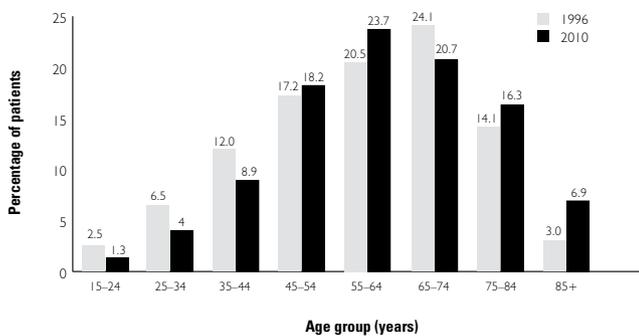
Validation of administrative data for identifying patients with various health states improves our understanding of when and how such data can be used for chronic disease surveillance and research. To assess the accuracy of administrative data for identifying RA patients, two independent validation studies were performed at ICES (Widdifield et al. 2013a, 2014a). This foundational work led to the establishment of the Ontario Rheumatoid Arthritis Database (ORAD), a validated, population-based registry. Derived by linking physician service claims,

hospital discharge abstracts and public health insurance records, ORAD is just one of several validated, ICES-derived chronic disease cohorts.

RA Burden and Epidemiology

The number of RA patients in Ontario increased steadily from 42,734 (0.5%) in 1996 to 97,499 (0.9%) in 2010. The crude number of new patients diagnosed each year varied from 5,523 patients in 1996 to 6,395 patients in 2010. After standardizing for age and sex, RA prevalence per 100,000 population showed a steady increase over time, from 473 in 1996 to 784 in 2010. Prevalence also increased with advancing age, and approximately twice as many women as men were affected. Age- and sex-standardized incidence per 100,000 varied from 62 in 1996 to 54 in 2010. Incidence rates were highest among women and also increased with age. Between 1996 and 2010, in keeping with the province’s aging population, the age profile of the RA population changed (Figure 1). As of 2010, 44% of persons with RA were 65 years and older, and 72% were female. Geographic variation was also evident, with prevalence being higher in northern rural communities than in southern urban areas (Widdifield et al. 2013b).

FIGURE 1. Age distribution of patients with rheumatoid arthritis in Ontario, 1996 and 2010



Timely Access to Specialty Care

Despite the increasing RA burden over the past decade, the number of rheumatologists in Ontario has remained relatively stable at 160, or 1.5 rheumatologists per 100,000 population (Widdifield et al. 2014b). Moreover, few rheumatologists are located in northern communities where RA prevalence is high (Widdifield et al. 2014b). Despite the shortage, access to rheumatologists has improved among patients newly diagnosed with RA (Widdifield et al. 2014c). Greater exposure to DMARDs for new or “incident” RA patients has also occurred

over time, reflective of the increasing access to rheumatologists (Widdifield et al. 2011). These findings also highlight improvements relative to RA guideline implementation (Bernatsky et al. 2009). However, established wait-time measure benchmarks are seldom achieved, as only 38% of RA patients are seen within four weeks from their referral date (the target is 100%) (Widdifield et al. 2014d).

Outcomes Important to RA Patients

Greater cumulative exposures to DMARDs within one year of RA diagnosis have been shown to be associated with reductions in the need for joint surgery (Widdifield et al. 2015a); this could reflect the joint-sparing effects of DMARDs. However, patients undergoing joint surgery are at higher risk for complications. Dislocation following total hip arthroplasty and infection following total knee arthroplasty are more common among RA patients compared with patients with osteoarthritis (Ravi et al. 2014a). Moreover, increased surgeon experience in performing joint arthroplasty in RA patients, irrespective of hospital factors, has been associated with a lower risk of surgical complications (Ravi et al. 2014b).

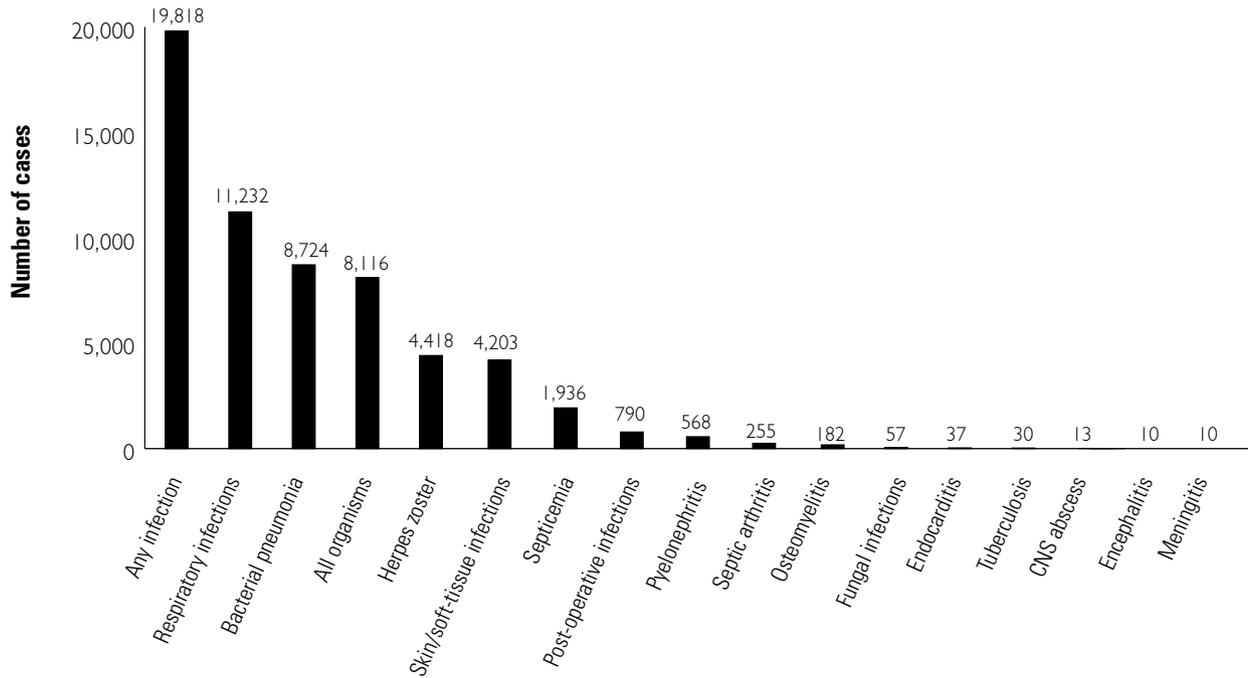
Experiencing a serious infection is relatively common in older adults with RA, occurring at a rate of 46 events per 1,000 patient-years. The most frequently occurring infections include respiratory infections (Figure 2). While the risk of infection was elevated for all DMARDs, the increased infection rate was most strongly associated with corticosteroid use. However, comorbidities also increased infection risk (Widdifield et al. 2013c). Mycobacterial infections while relatively rare in the general population are more common in RA patients and increase the risk of death (Brode et al. 2014). Biologic therapies and DMARDs also appear to be associated with mycobacterial infections (Brode et al. 2015).

All-cause mortality for Ontarians with RA has decreased over the past decade but remains elevated compared with the general population, with 40–50% more deaths among RA patients. This relative excess mortality is strongest among the younger age groups and has improved little over the last decade (Widdifield et al. 2015b).

Disparities in Care and Outcomes

Everyone deserves to receive similar high-quality care, yet patients in rural areas have reduced accessed to rheumatology care (Widdifield et al. 2014c), are more likely to experience adverse events (Widdifield et al. 2013c, Brode et al. 2014, Ravi et al. 2014a) and are at greater risk of early death (Widdifield et al. 2015c). Male patients are also at relatively greater risk of early death (Widdifield et al. 2015b). Finally, patients of lower socioeconomic status are less likely to receive timely rheumatology care (Widdifield et al. 2014c).

FIGURE 2. Number of cases of infection (overall, organ-specific and organism-specific) in a cohort of 86,039 Ontario seniors with rheumatoid arthritis



Implications

The increasing RA burden in Ontario and the significant morbidity and mortality associated with these patients suggest that efforts to address this disease are not meeting the burden it imposes. The number of RA patients has more than doubled in the past 15 years. Without a parallel increase in the number of rheumatologists, health human resources shortages and geographic variation in the supply of rheumatology services will further strain our healthcare system if policymakers fail to respond to the needs of this vulnerable population. Furthermore, the changing demographics of the RA population have implications regarding appropriate health services provision in delivering high-quality, patient-centred care. Compared with the younger population, older patients tend to have more comorbidities and the resultant polypharmacy can further complicate chronic disease management.

Some progress has been made in improving access to appropriate care for RA patients. However, much more can be done, particularly for patients in rural areas, who have poorer access to specialists and are more likely to experience adverse health outcomes. Proactive, tailored approaches are needed to provide appropriate care to such populations.

The significant morbidity and excess mortality among RA patients has implications for clinical decision-making, as these patients require enhanced vigilance in the management of

their pharmacotherapy and comorbidities. Their greater risk for surgical complications also has implications for surgical decision-making. Moreover, the finding that more experienced surgeons have fewer complications has important implications for surgical training and practice (Rodriguez-Elizalde et al. 2012).

In sum, administrative data have played a critical role in improving our understanding of the disease burden, quality of care and outcomes in Ontarians with RA. The growing RA burden is exceeding rheumatology supply, yet for rheumatologists to provide optimal care, they must see new patients sooner while monitoring existing patients more closely to prevent adverse outcomes. This challenges current models of care. Innovations are urgently needed if we are to keep pace with the growing needs of Ontarians with RA. **HQ**

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