

Patient Self-Care and Self-Management Resources

By Ms. Anne Lyddiatt

Searching for and finding reliable sources of information on how to live with and manage arthritis can be a daunting task. This is especially true for newly or relatively newly diagnosed patients who are not yet familiar with terminology, treatments, what constitutes reasonable expectations, and how to recognize a “get rich quick” scheme with a “cure” for a disease still waiting for a cure to be discovered. With over 100 types of arthritis, how can a patient find the information pertinent to their condition?

Most Canadians are unable or unwilling to commit to the educational program on arthritis based on the Stanford model consisting of six weekly two-hour sessions. The need for accurate information is as great as ever, but the preference is for less structured and more easily available information.

There can be differences in interpretation of self-care and self-management. Some patients and professionals regard self-care as looking after oneself and one’s arthritis, while others feel self-management is how they manage their disease on a daily basis and self-care is a separate issue. When searching for resources, it is a good idea to search both terms.

Some excellent resources are available online including RheumInfo, Joint Health, the Canadian Arthritis Patient Alliance (CAPA) website and newsletters, and The Arthritis Society website, to name a few. The challenge is finding a way to reach people when they are newly diagnosed and desperate for the answers and help they can find on these reliable sites. It remains an ongoing challenge to ensure that people can access information to understand their arthritis and the need to follow their treatment plan to enjoy the best possible quality of life.

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5) Performance Measurement

The First Canadian System-level Performance Measures for Inflammatory Arthritis

By Claire Barber, MD, PhD, FRCPC

When the Arthritis Alliance of Canada (AAC) developed an approach to Models of Care for inflammatory arthritis (IA) in 2014, a critical component of implementing this approach was evaluation. At the time, there were no existing system-level performance measures for IA care. We therefore embarked on a study to develop a set of performance measures to evaluate models of care for IA at a system level.

Through multiple rounds of an online modified-Delphi process, we gained broad input from 50 arthritis stakeholders including rheumatologists, allied health professionals, persons living with arthritis, and researchers. Participants rated the validity, feasibility, relevance and likelihood of using a proposed set of performance measures, which were identified based on a systematic review of the literature.

Six performance measures emerged for evaluating inflammatory arthritis care:

1) wait times for rheumatology consultation for patients with new onset IA;

- 2) percentage of IA patients seen by a rheumatologist;
- 3) percentage of IA patients seen in yearly follow-up by a rheumatologist;
- 4) percentage of rheumatoid arthritis patients treated with a disease-modifying anti-rheumatic drug (DMARD);
- 5) time to DMARD therapy in patients with rheumatoid arthritis;
- 6) number of rheumatologists per capita.

This constitutes the first set of system-level performance measures for evaluating models of care in IA. These can serve as an aid for health care decision-makers to identify and prioritize areas for improvement, and to measure outcomes of health system changes whose goals are to improve the care of patients with IA.

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Reference:

Barber CE, et al. Development of system-level performance measures for evaluation of models of care for inflammatory arthritis. *J Rheumatol* 2016; 43:530-40.