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August 1, 2015

Dr. Arthur Karasik, President
Ontario Rheumatology Association

Re: 2015 ORADE EULAR Report

Dear Dr. Karasik

I am grateful to the ORA for funding my attendance at EULAR 2015 in Rome, Italy. My attendance at the EULAR meeting and report back to the ORA executive and membership supports the mission of the ORA which is " to represent Ontario Rheumatologists and promote their pursuit of excellence in arthritis care in Ontario through leadership, advocacy, education and communications".

I will present my key learnings from the meeting as they relate to the four key pillars of the ORA. I will underline opportunities identified for the ORA to discuss and potentially pursue in the future.

Four Key Pillars of the ORA

1. Advocacy and Awareness

Patients and healthcare professionals from Denmark, Belgium, and Sweden presented on their experience in developing collaborative partnerships to create a patient-centric research agenda, a needs-based education program, and accessible, lay language research summaries and EULAR recommendations. ARD now publishes lay summaries of research papers which are translated into local lay language by a trained group of patients in Belgium. Canadian rheumatic disease patients have been trained by the Cochrane Collaboration to do lay summaries in French and English. We could partner with the Cochrane Consumer Group and negotiate with The Journal of Rheumatology to create lay summaries of pivotal scientific papers.

The keys to success in these collaborative partnerships were: section of patient volunteers, clarifications of role and expectations, training in technical and medical terminology, and using a communications model, The Dialogue model (Tineke Abma et al.), to ensure balanced participation and engagement. For future collaborations with patient groups, we might explore "The Dialog" method of engagement and participation.

A German rheumatic disease patient organization is reaching out to GPs and MSK specialists to provide patient information on self-management in early osteoarthritis. Trained patients may become a new human resource for knowledge translation and guideline implementation where there are known gaps in MSK care.

Creating dialogue with fellow patient organizations, such as Sjogren's Syndrome (SS) patients and oral cancer patients, led to health policy changes good for two patient groups facing similar difficulties with dental care. This is a brilliant idea, as our SS patients are have great difficulty getting coverage for dental implants from the Ministry of Health. I have written many times to the MOH on behalf of my patients without success.

In Denmark, patient counsellors learned that RA patients had a strong need for foot care by foot therapists, as hand and foot deformities, due to their RA, made it difficult to perform foot care by themselves. The Danish Rheumatism Association set out to document the scope of the problem among RA patients and suggested policy changes that could better the foot care of affected patients. Realizing and documenting the scope of the problem, analyzing and formulating the wanted policy change, planning the campaign (identifying fellow stakeholders, political allies, PR-strategy and finding a so-called "hook"), and executing the campaign strategy resulted in health policy change and coverage of foot therapy service for patients. SP0025-28

2. Research (rheumatology practice improvement)

When considering the gap between primary and secondary care, the most commonly touted solution is more musculoskeletal and rheumatological education for family medicine doctors (General Practitioners – GPs). UK GPs have proposed that the rheumatology – primary care education paradigm needs to shift, with rheumatology considering what it can learn from primary care. GPs are expert in managing uncertainty, weeding out important symptoms in messy prodromes of disease, dealing with multi-morbidity and polypharmacy, and transferring evidence based population level medicine and making it relevant to the individual. When did we last ask GPs to help us streamline our practice and management of co-morbidities in our patients?SP0119-121

Cardiff University has worked in collaboration with the Royal Colleges, Welsh and UK Government to undertake a program to shift attitudes on the management of work and health in everyday consultations. They have developed and piloted a face-to-face training program for Rheumatology team members (rheumatologists, nurse specialists, occupational therapists and physiotherapists) to address these issues and raise the importance of discussing work at an early stage in a patient's journey. To enhance this work Cardiff University has also developed and is piloting a tool to aid "shared decision-making" about work and health for both primary care and secondary care practitioners. SP0064-66

The UK has developed and validated health care quality indicators (HCQIs) for OA and RA and will be benchmarking rheumatology care in 6 EU rheumatology units in the near future. SP0235-238

3. Inter-professional Patient-centric Care Model

According to the Chronic Care Model, outcomes of health care for people with chronic musculoskeletal and rheumatic diseases (RMDs) depend on a productive interaction between the informed, activated patient and a prepared, proactive practice team. Overall, evidence from systematic reviews as well as individual clinical trials supports improved functioning following multi-disciplinary team care for a number of rheumatic disease patients. Research also illustrates that multi-disciplinary team care can be effective in several forms. This variation does not only include the professionals involved, but also the treatments provided (content, intensity, complexity), the setting (primary care, secondary care and/or community), the method of communication with the patient and among professionals (face-to-face contacts, telephone, videoconferencing or other web-based modes for communication), funding and the use of process and outcome measures for evaluation. As currently the right care is not consistently delivered to the right person, at the right time, in the right place or by the right team, challenges for the future are to identify the key components of effective multi-disciplinary team care interventions and how their implementation can be supported across health care services in different health care systems. For that purpose, the consideration of alternative, network-based models of engagement and collaboration for clinicians, consumers and other stakeholders and the optimization of the use of digital technologies, as well as formal evaluations of effectiveness and costs are indispensable. SP0094-96

The Centre Chronically Ill and Work (CCZW), is a knowledge centre that focuses on living and working with a chronic disease or disorder, and has been set up and is run by people suffering from a chronic illness, The main activity of the Centre is the "Certification of experts-by-experience: Work and Participation" (Certificering ervaringsdeskundigen Werk en Participatie), for which the Centre works closely together with seven national patient organizations. The certification of experts by experience is financed by the Dutch Ministry of Health, Welfare and Sports. The project is built around the philosophy that certain coaching and training skills are not (only) generated by knowledge but also by personal experiences. People with a chronic illness are being trained for 60-80 hours in a 6-9 months period to

make use of their own personal experiences (linked to their disease) in order to help others who are going through similar processes. The Centre works solely with professionals who have a degree in (patient) counselling or are trained in coaching. All coaches receive a certificate at the end of their training, which is accredited by Top Kairos, a Dutch training institute.

Work productivity is an important outcome for patients, so questions about absenteeism and presenteeism should be addressed in clinic and in clinical studies including clinical trials (RCTs). Early intervention may reduce the likelihood of work productivity loss and possible permanent work loss. There are more than 26 instruments available to measure absenteeism and presenteeism. These measures range from simple global measures (e.g. a visual analogue scale (VAS) to multi-item measures. Differences between measures also relate to the construct (e.g. productivity, ability to work, interference with work, instability), recall period (e.g. one day, 7 days, one month), reference (e.g. prior disease onset, colleagues) and attribution (e.g. generic, rheumatological condition). As part of the OMERACT worker productivity initiative and an EULAR-PRO study, UK researchers are investigating the meaningfulness of the different measures with an aim to recommend measures to be used in clinical practice, observational studies and RCTs. SP0064-66

4. Practice Efficiency (electronic medical record (EMR) systems)

Artificial Intelligence (AI) applications in medicine are expanding and now include clinical decision support systems (CDSS), speech recognition, and computer-aided interpretation of medical images. A CDSS can be integrated with an electronic health record (EHR), and improve quality of care by offering the consulting physician recommendations on the diagnosis and choices of treatment for a patient. It may also rationalize the number of investigations performed and thus have cost-savings implications for the health care system. SP 0042-44

A template of 8 primary care appropriate OA quality indicators was installed in 8 UK general practices and was triggered when the health care professional entered a morbidity code for OA. An evaluation study showed that it was feasible to use such a template to measure the quality of OA care. Assessment indicators were well-captured but, for example, consideration of physiotherapy was less so. An increase in some routinely recorded indicators (weight recording and prescription of paracetamol and topical NSAIDs was also seen after the template was introduced. The recording template and associated indicators are now being introduced to other general practices as a part of routine care. SP0235-238

Yours very truly,

Mary J. Bell, M.D., FRCPC
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Dictated but not read.