

# Educational Needs Assessment in Inflammatory Arthritis: Perspective from Rheumatologists, Nurses, and Patients

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## BACKGROUND

- Arthritis is one of the most chronic conditions and the most economically costly in Canada
- If untreated, may progress to irreversible damage and disability
- Still considered as “just aches and pains” and “normal part of aging” by lay public and some within the medical community

## STUDY OBJECTIVES

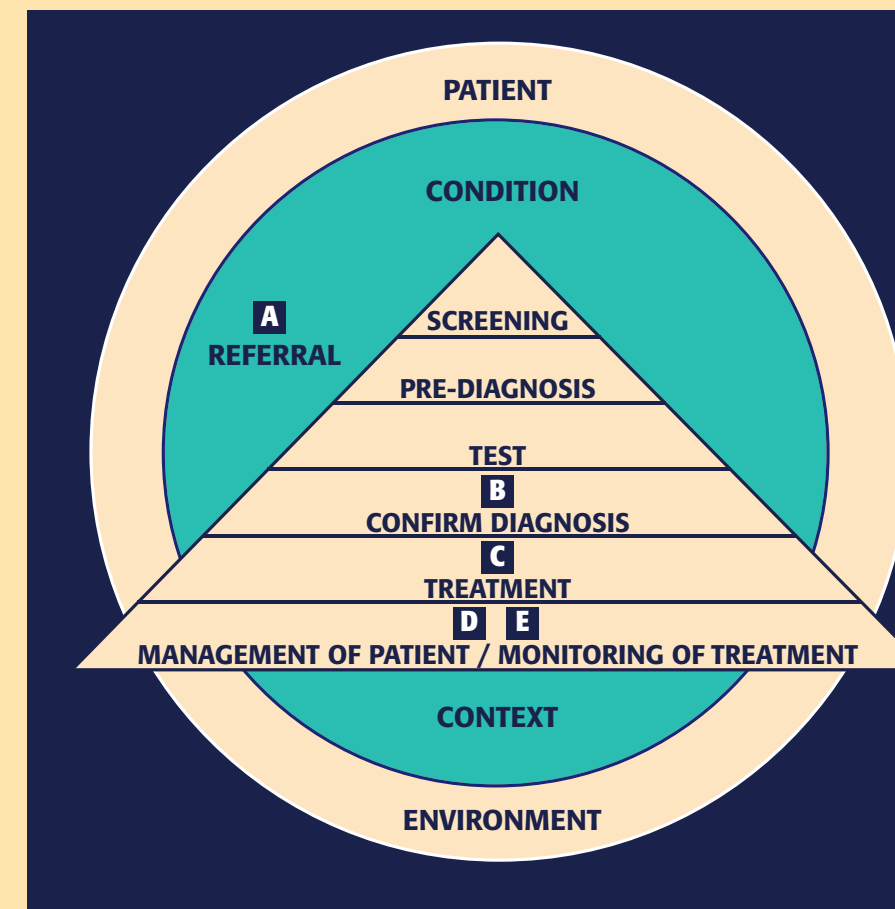
- Determine clinical care and educational needs of rheumatologists and nurses specialized in inflammatory arthritis
- Identify perceived and unperceived educational needs on multiple levels: Knowledge, skill, attitude, practice behaviour, context, and system
- Assess experience of patients diagnosed with / receiving care for inflammatory arthritis

## METHODS

Phase	Method
1	<b>Mixed-method:</b> Design of qualitative and quantitative data collection instruments <b>IRB / ethics review</b>
2	<b>Purposive sampling</b> <b>Qualitative data collection – Exploratory</b> <ul style="list-style-type: none"> <li>Rheumatologists – discussion group (n=6)</li> <li>Nurses specialized in rheumatology – discussion group (n=8)</li> <li>Patients – telephone interviews (n=8)</li> </ul>
3	<b>Quantitative online survey – validation and generalization</b> <ul style="list-style-type: none"> <li>Rheumatologists (n=50)</li> <li>Nurses specialized in rheumatology (n=21)</li> </ul>

## SAMPLE

Rheumatologists	Nurses specialized in rheumatology	Patients diagnosed with inflammatory arthritis
n=56	n=29	n=8
<b>Total n=93</b>		



## SUMMARY OF FINDINGS

- A** Suboptimal collaboration and lack of clarity on the roles and responsibilities of healthcare team
- B** Rheumatologists indicated being challenged to deliver a precise diagnosis in patients with early disease
- C** Despite high level of knowledge, rheumatologists and nurses reported lacking confidence in long-term effect of biologic therapy
- D** Rheumatologists and nurses reported providing inconsistent and incomplete patient education
- E** Rheumatologists indicated difficulty in providing optimal emotional and psychological support to patients

## FINDINGS

### A Suboptimal collaboration and lack of clarity on the roles and responsibilities of healthcare team

#### Limited and inefficient collaboration between rheumatologists and primary care physicians (PCPs)

*“I don’t know how much dialogue is occurring now between the doctors that I’m seeing. I think I’m the link that informs each of them of what the other one is doing or what kind of tests I’m undergoing.”*  
Patient

#### Rheumatologists and rheumatology nurses reported that:

- Referral notes from PCPs are:
  - Not specific (e.g. “sore joints”, “knee”)
  - Do not include data to support referral (e.g. labs / blood work / X-rays)
- PCPs struggle to recognize early signs of inflammatory arthritis and lack knowledge of optimal treatment options

#### Lack of consensus on roles & responsibilities of rheumatologists and nurses specialized in rheumatology

% of rheumatologists or rheumatology nurses who think they should:	Rheumatologists	Rheumatology Nurses
Complete forms for patients to receive medication	37%	43%
Provide emotional and psychological support	51%	67%
Provide recommendations regarding exercise programs	53%	86%
Advocate to government for better drug coverage	29%	57%

### B Rheumatologists indicated being challenged to deliver a precise diagnosis in patients with early disease

#### Rheumatologists reported several reasons:

- Overlap between symptoms of inflammatory arthritis and other causes of joint pain
- Inflammatory arthritis not objectively defined by laboratory investigation
- Specialized testing (e.g. MRI, ultrasound) for early signs of arthritis not readily available
- Rheumatologists may have to rely on and wait for other professionals to interpret results

#### However, rheumatologists indicated:

- Not always critical to differentially diagnose because treatment may be the same
- Confident in diagnosis only with patient examination

### C Despite high level of knowledge, rheumatologists and nurses reported lacking confidence in long-term effect of biologic therapy

- Only 39% of rheumatologists and 17% of nurses reported a high level of confidence in long-term effects of biologic therapy
- Rheumatologists reported high level of knowledge on biologic therapy features, but only moderate knowledge as to discontinuation of biologic therapy

*“Each treatment for each patient is a trial.”*  
*“Every patient is a grey area.”*  
Rheumatologist  
Rheumatologist

### D Rheumatologists and nurses reported providing inconsistent and incomplete patient education

#### Rheumatologists and nurses reported lack of confidence and skill in managing:

- Patients’ denial of disease / acceptance of treatment
- Patients’ goals and expectation of immediate relief
- Patients’ fear of drugs & side effects
- Patients’ beliefs regarding “alternative / natural” therapies

*“There is no time to educate, support, and answer questions.”*  
Nurses - Rheumatology

*“The key is the communication. If I had someone that I could talk to [...] who could take the time to explain what each of the doctors are doing and why, what is my role as a patient [...], someone that could take the time to help me understand things.”*  
Patient

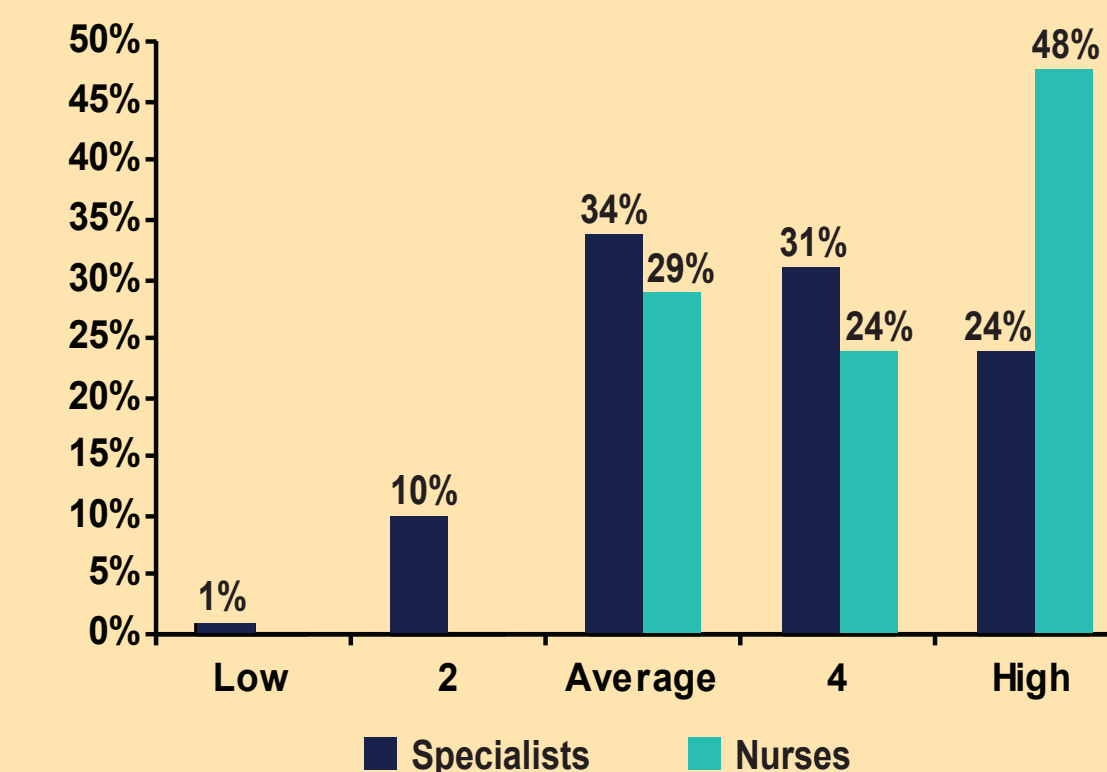
### E Rheumatologists indicated difficulty in providing optimal emotional and psychological support to patients

#### Rheumatologists acknowledged:

- Lack of formal training in dealing with emotional / psychological reactions following diagnosis
- Lack of skill in managing patients’ stress associated with the disease
- Struggle to set boundaries in their role as providers of this support
- Lack of financial incentives to provide this support

*“We are generally inadequate doing that (dealing with emotional reactions).”*  
Rheumatologist

#### Level of skill providing emotional support following diagnosis



## IMPLICATIONS

Findings may be used to stimulate the development of educational initiatives to address identified challenges and needs of healthcare professionals and to:

- Increase knowledge and confidence in diagnosing and assessing early inflammatory arthritis
- Increase knowledge and confidence in long-term treatment with biologic therapies
- Enhance management of patients’ emotional and educational needs by improving communication skills

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**Perspective from Rheumatologists, Nurses, and Patients**