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## OPTIMAL CARE IN RHEUMATOID ARTHRITIS: PRELIMINARY FINDINGS FROM A FOCUS GROUP STUDY

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### ABSTRACT:

**Context:** Chronic illnesses create huge burdens in our society. To lessen the impact, we must learn how to optimize care. One example is rheumatoid arthritis (RA), a devastating systemic disease affecting up to 1% of the population. Optimal outcomes depend upon aggressive medical treatment. Unfortunately, many patients do not experience optimal care trajectories.

**Objective:** To identify facilitators of optimal care, and potential barriers, for RA patients.

**Method:** The design was a focus group study. Patients were recruited using random sampling from the mailing list of the Quebec Arthritis Society. Individuals were eligible if they had a diagnosis of RA confirmed by a rheumatologist and sought care within the McGill Réseau Universitaire Intégré de Santé network. Health care providers were recruited using random sampling from mailing lists of professional associations. We planned 2-4 focus group meetings (90 minutes each) for each stakeholder group (patients, rheumatologists, family physicians, allied health care professionals). Each group was led by a trained moderator. Participants were asked to discuss five questions related to quality care. Qualitative content analysis, based on grounded theory, is the chosen means of identifying recurring themes and categories.

**Main findings:** Preliminary findings indicate the importance of good communication between family physicians, specialists, and allied health care workers. Final coding of transcripts and computer-assisted content analysis is being completed.

**Conclusions:** Qualitative methods can help inform efforts to optimize care in chronic diseases such as RA. Preliminary findings highlight the need for good communication among health care providers. Ultimately we hope to generate knowledge that can be transformed into better health for Canadians with arthritis and other chronic diseases. 2

## Context I

- Chronic illnesses create huge societal burdens
- To lessen the impact, optimized care is required.
- One example is rheumatoid arthritis (RA), a devastating systemic disease affecting up to 1% of the population.
- Optimal outcomes depend upon aggressive medical treatment. Unfortunately, many patients do not experience optimal care trajectories.

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## Context II

Recent work on RA care in Quebec\*

- With provincial billing data, determined care trajectories of newly diagnosed RA over a three year period.
- Of 13,237 new-onset RA in Quebec in 2000, just over a quarter were referred to a specialist.\*
- This concurs with recent data from British Columbia\*\*
- Even for those referred, time to referral was delayed on average >6 months (for many, >one year) in Quebec
  - Delays longer for older individuals, and persons of lower SES
  - Patients of lesser SES who live in areas with low proximity to specialty care experienced the *longest* delays

\* Feldman D, Bernatsky S, Haggerty J, et al Referral to rheumatology in newly diagnosed RA Arthr Care Res, 2007. (In Press)

\*\* Lacaille D, Anis AH, Guh DP, Esdaille JM. Gaps in care for RA Arthr Rheum 2005

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## Context III

Additional research on RA care in Quebec\*

- Primary care physicians surveyed regarding care of a typical case of new-onset RA
  - Significant number did not refer to a rheumatologist.
  - DMARD initiation prior to a rheumatology assessment is rare.
- Troubling since damage and disability are prevented by the early use of DMARD therapy
  - Current recommendations urge DMARD initiation ASAP (i.e. within first few months of symptoms).
  - Otherwise, severe joint damage follows.

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## Context IV

It is clear that Canadian RA patients are far from receiving optimal care



Remedies are urgently needed.

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## Objective:

- To identify facilitators of optimal care, and potential barriers, for RA patients.

## Methods:

- The design was a focus group study.
- Target groups included patients, family physicians, rheumatologists, therapists within the McGill Réseau Universitaire Intégré de Santé (RUIS) network

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## Methods II: Patient enrollment

- Individuals with established RA were recruited through invitation letters sent from a random sample of the mailing list of the Quebec Arthritis Society.
- Patients were eligible if they had a diagnosis of RA confirmed by a rheumatologist and if they had sought care within the McGill RUIS.

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## Methods III: Health care providers

- Health care providers (family physicians, rheumatologists, PT, and OT) were recruited through invitation letters sent from a random sample of the mailing list of the relevant professional colleges.
- Eligibility: Those within the McGill RUIS.

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## Methods IV

- Separate meetings (90 minutes) for each (patients, GPs, rheumatology, therapists).
- In each moderator-led group, participants discussed 5 questions related to quality care.
- Content analysis, based on grounded theory.
- *Study in progress, preliminary results presented.*

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Table 1a: Interview Questions for Patients

Question 1: What has your experience with seeking care to control your arthritis been like?  
 Question 2: What impeded/impedes you from contact with specialists?  
 Question 3: What factors impede/facilitate your journey toward health?  
 Question 4: In the first phases of our research program, we noted differences in care trajectories according to patient demographics and proximity to care. What might explain this?  
 Question 5: What changes would improve the care of RA patients?

Table 1b: Interview Questions for Primary Care Physicians\*

Question 1: With a patient with suspected RA, how do you respond?  
 Question 2: What health care should the patient receive?  
 Question 3: What facilitates/impedes you from providing optimal care?  
 Question 4: In the first phases of our research program, we noted differences in care trajectories according to patient demographics and proximity to care. What might explain this?  
 Question 5: What changes would improve the care of RA patients?

Table 1c: Interview Questions for Rheumatologists

Question 1: In your experience how do non-specialists respond to a patient with RA?  
 Question 2: What health care should patients receive?  
 Question 3: What facilitates/impedes you from providing optimal care?  
 Question 4: In the first phases of our research program, we noted differences in care trajectories according to patient demographics and proximity to care. What might explain this?  
 Question 5: What changes would improve the care of RA patients?

\*Also used for therapists

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## Results-Participants

- Three patient groups (total N=15)
  - 10 female, 5 male (reflects female predominance in RA).
- Two family physician groups (total N=9)
  - 2 females, 7 males
- Two rheumatology groups (total N=14)
  - 3 female, 11 male.
- Two therapist groups (total N=14)
  - 7 PT, 7 OT, all female.

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### Results: Key patient messages I

- Importance of good communication between family physicians, specialists, and allied health workers was stressed.
- Patients valued access to effective drugs, in concert with non-pharmaceutical strategies (exercise, therapy, education)

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### Results: Key patient messages II

- In remote areas (Abitibi-Témiscamingue), lack of access to physicians was flagged as a barrier  
“I haven’t seen a GP in four years!”
- Local physicians were described as overburdened and thus unable to provide the time that patients feel they need.
- Patients felt problems originated at the decision-maker level.
- Sense of helplessness characterized this group.

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### Results: Key messages from family physicians I

- Appreciated the importance of treating RA: proper treatment yields better quality of life
- Perception that RA diagnostic criteria were unclear/not useful to the practitioner.
- Lack of education among patients a barrier
  - e.g. patients may want short-term relief of immediate complaints, not appreciating the need for treatment to prevent later disability
  - Lack of education is worse for those of poor socioeconomic status

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### Results: Key messages from family physicians II

- Family physicians value their relationships with specialists
  - To protect the relationship, one might ‘economize’ referrals, referring only the very sick patients.
  - Acknowledged that as a result those less affected may not get optimal care.
- Suggestion for improving care: trained GPs with a special interest in rheumatology, to remove some of the burden on specialists.

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### Results: Key messages from rheumatology I

- Most barriers to optimal care for RA patients are at the level of the system, not the physicians.
- Rheumatologists do not believe rheumatology is valued by decision makers.
- Time constraints of specialists, inadequate access to other specialists.
- Increased lobbying in general public might lead to increase in resources for rheumatology depts.
- Support staff such as a nurse practitioner would help.
  - e.g. patient education, facilitating communication between caregivers, answering patient questions, etc.

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### Results: Key messages from rheumatology II

- Promotion of optimal RA care might raise awareness among non-rheumatology MDs.
- As a result rheumatologists might be sent more appropriate referrals, & thus be able to provide better care for RA/other urgent conditions.
  - One physician estimated 30% of consults require his care; the rest represent a misdiagnosis/referral to the wrong specialist
- Promotion of optimal RA care should include medical schools, where MSK training is too brief.

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### Results: Key messages from rheumatology III

- Better communication needed between specialists & other health professionals
  - On one occasion, a pharmacist advised a rheumatologist not to prescribe methotrexate (currently the 'anchor' drug)
- Patient education is crucial. Access to detailed information about their condition could improve care.

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### Results: Key PT/OT messages I

- Physiotherapy/Occupational therapy services underused, for many reasons:
  - Uninsured under provincial health plan; thus may be unaffordable to patients w/o private coverage
  - For such patients, hospital-affiliated clinics are available, but inadequate staff numbers, thus wait is long
  - Physicians and patients may not be aware of private services available to those with private insurance
  - Physicians focus mainly on pharmacological Rx
  - Patients may be resistant to therapy referral

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### Results: Key PT/OT messages II

- Other barriers to optimal RA care:
  - Lack of early education of RA patients.
  - Lack of public awareness with RA.
    - "RA is not (like) cancer, it (is not) media friendly".
  - Even if an RA patient is referred for therapy, not all therapists have expertise in treating RA
- To improve RA care require increased quantity and quality of teaching about rheumatic conditions in professional programs (universities).
- An 'arthritis center' may facilitate optimal care system. e.g. Vancouver's Mary Pack Arthritis Centre

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### Further work

- Audiotapes transcribed, reviewed to organize data into specific categories; coding of responses.
  - Annotation of items e.g. specific phrases, incidents, barriers/facilitators, and solutions
  - Clarification of major patterns and themes; labelling recurring themes/sub-themes.
  - Computer-assisted content analysis: establish links between categories, assess divergence.
- Further cycle of activities to determine applicability of findings within RUIS stakeholder communities, disseminate knowledge.

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### Conclusions:

- Qualitative methods, such as focus groups, useful in studying optimal care for chronic diseases such as RA.
- Our preliminary findings highlight the need for
  - Increased education regarding RA (lay people/professionals)
  - Adequate resources
  - Good communication

Projects such as this generate knowledge that might ultimately be transformed into better health for Canadians with arthritis and other chronic diseases.

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	<p>CANADIAN ARTHRITIS NETWORK</p>	<p>LE RÉSEAU CANADIEN DE L'ARTHRITE</p>	
			<p><b>Hope through Education, Support and Solutions</b></p>
	<p>Fonds de la recherche en santé <b>Québec</b> </p>		

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