Optimal care for rheumatoid arthritis: a focus group study

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Abstract Our study sought to identify barriers to optimal care for individuals with rheumatoid arthritis (RA). Our study was set in a population with universal access to comprehensive health care in the context of a university hospital health network. Using purposive sampling, we invited RA patients, health professionals, and decision makers from urban and rural regions to participate in structured focus group interviews. Content analysis was performed to determine themes emerging from the data. We identified four general themes. First, initial barriers to optimal care for people begin before primary care contact, at the level of the general population and/or related to primary care access. Second, many factors (at the patient, physician, and system level) influenced how quickly a patient is referred from primary to specialty care. Third, after referral, multiple comanagement issues influence patient outcomes. Fourth, optimizing RA care requires adequate resources. Participants emphasized the need for more education (of patients, of health care providers, and within the general community), better communication
Rheumatoid arthritis (RA) is a devastating inflammatory arthritis affecting up to 1% of the developed world. Without aggressive, early medical treatment with disease-modifying anti-rheumatic drug (DMARDs), severe damage can occur [1, 2]. However, many patients do not end up in this trajectory early enough to benefit maximally from rheumatology care [3–5]. Our team’s recent analyses of Quebec administrative data revealed that of all new-onset or suspected RA cases in the year 2000, only a small proportion (just over one quarter) were referred to relevant specialists [4]. Furthermore, rheumatology referral was delayed especially in patients of older age, lower socioeconomic status, and low proximity to specialty care. Our objective was to further characterize barriers to optimal care in RA using focus groups.

### Methodology

Our study took place in Quebec, Canada. In the Canadian setting, citizens primarily obtain health care through the public “universal access” system, which theoretically provides freely accessible primary and specialist care (inpatient/outpatient) without cost to the patient. Generally, patients are not registered in health care management organizations. Rather, patients seek out their own primary physician, who then supposedly functions as the “gate-keeper,” arranging referrals to specialists as needed. Referrals may also be made by one specialist to another. Patient-initiated specialty consultations are discouraged through physician reimbursement schedules.

Canada has 1.9 physicians per 1,000 citizens. Most physicians practice in the public system; a small number “opt out” of the public system, instead of providing fee-for-service care as an option for patients seeking treatment. At the present time, physician extenders (e.g., nurse practitioners) are not a prominent feature of Canada’s public health system. In many provinces, including Quebec, access to allied health care workers (for example, physiotherapy, occupational therapy, psychological counseling, social work, etc.) is restricted in the public system, requiring a physician referral to the limited services available at tertiary care centers. In Quebec, the public health insurance system includes a drug insurance plan covering drug costs for individuals ≥ 65 and younger persons without private coverage through their employer.

Our activities were conducted within the McGill Réseau Universitaire Intégré de Santé (RUIS) network, representing the population served by the McGill University Health Centre, which encompasses over 1.9 million lives. The McGill RUIS is divided into regions, with their own health agency (Agence). For feasibility, we focused on four regions within the McGill RUIS. We purposively chose two urban regions (Montreal and Montregie) and two areas that were more rural and/or remote (Outaouais and Abitibi-Témiscamingue). The framework for our study was the model of an ideal care trajectory as per Li et al. [6], where a patient moves from symptom onset to primary care contact, to rheumatology referral, and DMARD initiation, with successful ongoing treatment (Fig. 1).

We conducted structured focus group interviews, with purposive samples from our four regions, featuring the following stakeholder groups: (1) patients; (2) family physicians; (3) rheumatologists; (4) physical/occupational therapists; and (5) health care decision makers. We held several 90 min moderator-led focus group sessions for each of the primary stakeholder groups. Each was similarly structured, entailing five questions regarding health care experiences and barriers to or facilitators of optimal care. To avoid any sense of coercion or influence, even if unintended, the principal study investigators did not recruit subjects directly and did not attend the focus group discussions.

To contact potential participants with RA (consumers), we sent invitation letters to a random sample of the Quebec Arthritis Society mailing list and posted notices in rheumatology clinics within the relevant regions. Eligibility of potential participants was based on a rheumatologist-confirmed RA diagnosis and health care contact within the selected regions of the McGill RUIS. Similarly, we sent invitations to a random sample (using professional colleges rosters) of rheumatologists, family physicians, and therapists (physical and occupational therapy) practicing within the selected regions of the McGill RUIS. Health care decision-makers were purposively sampled; we invited representatives from the McGill RUIS full and executive committees from the directorship of major institutions within the McGill RUIS and representatives from the health agencies of our four regions.

We aimed to conduct at least two focus groups for each stakeholder group, with four to eight participants in each session. Since the largest population stakeholder groups...
were patients and family physicians, we held four groups for these participants and two for all others. The role of nursing was mentioned by all stakeholder groups in optimizing care. Hence, we added a sixth focus group for nurses, with purposive sampling.

The focus groups were conducted at various locations and times to accommodate participants. A professional moderator (MdC) led the group discussions. Investigators did not attend. The sessions were recorded and professionally transcribed. Qualitative content analysis of the focus group transcripts, to identify recurring themes from focus group discussions, was performed based on grounded theory. The transcripts were independently coded by the moderator and the comoderator and the results reviewed to arrive at a decision regarding major themes arising from the data. Further methodological details, including the focus group questions as presented, are available as supplemental material (ESM 1) in the online version of this journal article. Results were reviewed in a stakeholder workshop to confirm their validity.

Institutional review board approval was provided by McGill University, and written consent was obtained from all participants. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 1983.

**Results**

We held four groups for consumers (total N=18, 13 females, average age 58), four groups of family physicians (N=13, nine males), two groups of rheumatologist (N=14, 11 males), two therapist groups (N=14, all female), two decision-maker groups (N=9, six males), and one nurses’ group (N=4, all female).

The issues raised across stakeholder groups mapped into four theme areas. The first was that barriers to optimal care began before primary care contact at the level of the general population and/or related to primary care access (Table 1). The second theme identified specific factors influencing whether a rheumatology referral for suspected RA occurs promptly or not (Table 2). The third theme covered issues related to ongoing RA management (Table 3), and the final theme described resources needed (Table 4).
<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Persons with RA</th>
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<tr>
<td>a. There is a lack of awareness in the general population regarding RA.</td>
<td>[Even in my own family, there is no understanding of how serious RA can be]</td>
<td>[It’s difficult to educate because the disease is so rare]</td>
<td>[If only the public out there could realize that RA is a treatable condition.]</td>
<td>The knowledge in the population about what RA can do is very poor.</td>
<td>There are many who don’t understand the significance of their disease.</td>
<td>The message that people are responsible for their own health care maybe gets through the more education you have.</td>
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<td>b. Demographics (e.g., sex, age, socioeconomic status, SES) influence the rate at which persons seek care</td>
<td>Most males, it’s an effort just to get them to go to the doctor.</td>
<td>Patients (of lower SES) may have so many problems... it’s more difficult to (understand) the problem and realize that they may have RA.</td>
<td>People of a high socioeconomic class have better education so they are likely to know that (their symptoms) may mean something, so they come earlier to see a doctor.</td>
<td>Older patients may have this kind of ‘suck it up’ philosophy and don’t seek help... younger patients if there’s something the matter, they seek help right away...</td>
<td>Women are more health conscious.</td>
<td>[Women have regular screening... that means they see the family doctor more regularly... Pap tests... mammograms... it’s like an anchor.] [Those with lower SES may have many chronic social problems, creating passivity and delays in seeking care.]</td>
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<tr>
<td>c. Family physicians access is often a rate-limiting step for a patient seeking care.</td>
<td>I have to wait in line like everybody else. It never used to be that way. You used to be able to get in (to see a physician) quickly.</td>
<td>[Access to a family doctor is not always available.]</td>
<td>They have no general practitioners to go to. That’s a huge impediment.</td>
<td>...we don’t have enough family physicians... It’s a huge problem. Many people don’t have a family doctor and so they go to an Emergency Room (to seek arthritis care).</td>
<td>Access to a general practitioner is a huge problem.</td>
<td>[People need to have better access to family physicians.] [A patient might call their doctor and hear the clinic list is full, come in 3 months.]</td>
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Supporting statements are from the transcribed group recordings. Statements in square brackets are translated from French.
### Table 2: Many factors influence how quickly a patient is referred from primary to specialty care

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<td>a. If the family doctor does not recognize the symptoms of RA, and referral is delayed, joint damage is more likely to occur.</td>
<td>I had to tell my (family) doctor, I have some kind of severe arthritis attack, I did not think it was just the flu.</td>
<td>RA is one of the occasions where the specialists say ‘I want to see your patient quickly’ and the delay in the referral is actually extremely damaging. Most family physicians have trouble differentiating… So they have a strategy, maybe they try NSAIDs… If the pain doesn’t go away, then eventually they have to send them somewhere…</td>
<td>There are family doctors who delay referral but finally send the patient to a rheumatologist. However there are others who react quite well too.</td>
<td>With a disease like RA one can alter the course of the disease…before they get joint damage. You must get these cases early.</td>
<td>Some (family physicians) do a few tests and consult immediately… others wait too long…</td>
<td></td>
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<tr>
<td>b. Patient and physician factors (e.g., sex, patient socioeconomic status, rural residence) affect how quickly a patient obtains a referral for specialty care</td>
<td>Some people with a low SES feel intimidated by doctors, they lack confidence. People don’t want to travel a long distance to see a doctor.</td>
<td>Patients of lower SES may have so many problems… maybe it’s more difficult for them to understand the problem and realize that they have RA. (Female doctors) are more ready to admit that maybe they don’t know exactly what it is and they want to get an opinion. (Female doctors) pick up more of the stress level of a patient, are more willing to outsource care.</td>
<td>If you have money, you have more opportunity to go and seek out the referral. If you have money, you have more opportunity to go and seek out the referral.</td>
<td>The perception is that men don’t get RA, maybe the doctors don’t think of that diagnosis as quickly… women are more likely to get RA. So maybe they thought of that diagnosis earlier</td>
<td>Those of a high SES have more knowledge &amp; expect more. They don’t wait around. Those with few resources are at the mercy of physicians. (Female family doctors spend more time with patients.)</td>
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<td>c. Limited availability of rheumatology services impairs RA care delivery</td>
<td>There aren’t enough specialists to refer (RA patients). (RA is an emergency; it’s an emergency. But there is nobody to answer to that emergency.) When you get the referral, your waiting list is already quite long…</td>
<td>(RA is an emergency; it’s an emergency. But there is nobody to answer to that emergency.) When you get the referral, your waiting list is already quite long…</td>
<td>[Where I am, there is only 1 rheumatologist for 5 cities, each city an hour apart.]</td>
<td>In remote regions, patients don’t have access to specialists.</td>
<td>If you increase awareness, it wouldn’t do any good without physicians.</td>
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<td>d. An established rapport between physicians is important</td>
<td>There are some family doctors who just never refer. If you have rapport with a rheumatologist, you’re in a better position to say; I’d be much obliged if you could squeeze this guy in…</td>
<td>Communication between the physicians in the community and specialists… sort of channels the patients a little earlier. [There are some doctors that understand very well the importance of the team.]</td>
<td>[If you have a rheumatologist that you have easy access to, then you send your patient to the rheumatologist.]</td>
<td>If a doctor knows the rheumatologist &amp; calls to say, I am pretty sure this is RA, the rheumatologist would see the patient within a week.]</td>
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<td>a. Prompt initiation of medications is a key to optimal care.</td>
<td>[My rheumatologist provided the medications...he took good care of that.]</td>
<td>I prefer to have the diagnosis confirmed by a specialist before I started medication except for NSAIDs. I want advice from a specialist.</td>
<td>Family doctors aren’t comfortable with the medications, &amp; I don’t expect them to be.</td>
<td>[We see the difference in a patient who has been treated right away versus someone who has waited...their joints are affected, their morale is low.]</td>
<td>If they already have joint damage, it’s late in the course. So you have to find a way to get them early.</td>
<td>[Maybe family doctors are not at ease starting methotrexate. But they could work in consultation with rheumatology.]</td>
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<td>b. Optimal RA care requires improved communication on many levels.</td>
<td>I know that (the doctors) are harassed &amp; they’re hurried but I feel like I’m on an assembly line.</td>
<td>I do not know how rheumatologists manage to see all those patients. They never answer their phones. We can never talk to them.</td>
<td>A number of doctors who refer patients don’t read my consultation letter.”</td>
<td>In the system as a whole, there isn’t much of a connection between the rheumatologist and the family doctor</td>
<td>I love it when they say at a GP’s office have you tried calling the specialist. Just try. It is the most frustrating experience ever.</td>
<td>[Very few family doctors will pick up the phone and call the rheumatologist.]</td>
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<td>c. Both family physicians and rheumatologists have important potential roles in optimizing RA care, but these need to be clarified.</td>
<td>We need someone to take care of the whole person.</td>
<td>I want my patient with RA to see the rheumatologist, to have his support, to say “we stay on this drug, this is what you should check, what you should do.” That makes you confident in following jointly with the rheumatologist.</td>
<td>The other health care professionals become very, very important.</td>
<td>[The family doctors do not have much training in rheumatology, as soon as there is a rheumatologist involved, the family doctor doesn’t want to make treatment decisions.]</td>
<td>If you honestly think that after a 2 year formation (family physicians can function) not only as gatekeepers, but as providing continuity and taking charge of vulnerable clientele, then you are dreaming.</td>
<td>[Family doctors might rely too much on lab tests, or not order the right test...they need to know more if they are going to help manage RA]</td>
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<td>d. RA outcomes would be optimized by interdisciplinary care, which is often lacking.</td>
<td>[My pharmacist gives more information than my doctor.]</td>
<td>Physiotherapists are vastly understated.</td>
<td>We don’t have access to enough nursing occupational therapy, physiotherapy.</td>
<td>[Multidisciplinary is the way to go. It’s time that everyone (with arthritis) had the assistance of a team of professionals.]</td>
<td>These patients need to be followed in a multidisciplinary team.</td>
<td>Patients need a comprehensive care approach.</td>
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<td>e. Patient education allows active self-management and better outcomes</td>
<td>Every pill in my system, I read up on. I have to know what game I’m in.</td>
<td>Education is very important, that the patient understands they have a very serious illness...</td>
<td>Patients need education. As physicians, we’re poor at providing this.</td>
<td>Patients do not comply with drugs if they’re afraid of side effects; by the time they see the rheumatologist, they are in a flare up.</td>
<td>For a patient to be responsible for their health, they have to be educated.</td>
<td>[Education is one thing, but patients must have access to accurate information.]</td>
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Supporting statements are from the transcribed group recordings. Statements in square brackets are translated from French.
1. Initial barriers to optimal care begin before primary care contact at the level of the general population and/or related to primary care access. (Table 1)

Focus group participants believed that several barriers to seeking care existed that impeded a person with new-onset inflammatory arthritis from initial medical contact. These began at the level of the general population and family physician.

- There is a lack of awareness in the general population regarding RA. Across groups, there was a strong perception that most laypeople have little concept of what RA is or the importance of seeking care promptly for symptoms of inflammatory arthritis. “Even in my own family, there is no understanding of how serious RA can be.”

- Demographics (e.g., sex, age, socioeconomic status) influence the rate at which persons seek care. Participants perceived women as being more aware and active in the management of their disease. Health care professionals also pointed out that women are generally more comfortable seeking health care, as they often have more regular contact with physicians due to pregnancies, cervical, and breast cancer screening, etc. As well, women may be less hesitant than men in their requests.

In addition, across all stakeholder groups, it was felt that individuals with lower socioeconomic status often had many other problems (physical/psychosocial) that interfered with them seeking care. Patients with higher socioeconomic status were thought to be more educated and hence, be more aware of their symptoms, ultimately being more likely for a patient seeking care.

2. Many factors influence how quickly a patient is referred from primary to specialty care. (Table 2)

Multiple factors affecting referral practices were noted. The specific factors influencing whether a rheumatology referral for suspected RA occurs promptly were identified as follows:

- If the family doctor does not recognize RA symptoms, referral will be delayed, decreasing the chance of a good outcome. “RA is one of the occasions where the specialists say ‘I want to see your patient quickly’ and the delay in the referral is actually extremely damaging.” Rheumatologists described the difficulty that family physicians may encounter in recognizing RA. The disease may not appear frequently in a family physician’s practice, thus the physician might not recognize RA or be aware of the need for referral. Across stakeholder groups, it was also pointed out that some family physicians may be selective in referring, while others refer more readily because of their awareness that RA requires aggressive specialty care. Decision-makers also felt that family physicians were generally inadequately trained to deal with complex conditions like RA. Despite these perceptions, family physicians participants did emphasize the need for prompt treatment for optimal outcomes. The need for urgent specialist care was seen as a motivation for family physicians to make a phone call to a rheumatologist to request a prompt consultation, although it was often difficult to reach the specialist.

- Patient and physician factors (e.g., sex, patient socioeconomic status, rural residence) affect how quickly a patient is referred. Participants viewed persons with low socioeconomic status as having more psychosocial burdens, access to fewer resources, and being less assertive in their relationship with their physician. “Some people with a low SES feel intimidated by doctors, they lack confidence.” This likely led to lower chances of a prompt referral, as was emphasized by patients, health care professionals, and decision-makers alike. Therapists...
also described how younger age facilitates access to specialists, since arthritis is often seen as a “part of aging.” both on the part of the physician and the patient. Consumers agreed that accessibility is an important factor; doctors would be less likely to make a referral if they knew that the patient must travel a long distance to see a specialist.

Across groups, participants felt that female family physicians refer more, particularly when the diagnosis is initially unclear. Some focus group participants also noted tendency for female physicians to be more “patient-centred.” Female physicians were also perceived by allied care providers as taking more time in clinics than male physicians (often booking a lighter clinical schedule).

c. Limited availability of rheumatology services impairs care. “(RA is) an emergency, it’s an emergency. But there is nobody to answer to that emergency.” All stakeholder group participants felt that rheumatologists were a very limited resource, particularly in remote areas: This lead to hesitation, on the part of family physicians, to refer patients when it was not absolutely clear whether or not the patient required rheumatology services:

d. An established rapport between physicians is important. Given that rheumatology services could be hard to access, participants stressed the importance of rapport between the family physician and a rheumatologist. Family physicians and nurses agreed that family physicians with an existing professional relationship with a rheumatologist were more effective at getting an early referral than those without such connections. Across stakeholder groups, it was believed that specialists were better positioned to refer to other specialties as they generally work in close proximity to one another. In addition, specialists were felt to refer more quickly when they identify a disease that is outside their area of expertise. “Communication between the physicians in the community and specialists... sort of channels the patients a little earlier.”

3. The following important issues arise in the ongoing management of RA: (Table 3)

a. Prompt initiation of medications is a key to optimal care. In general, family physicians were not comfortable starting definitive therapy until the diagnosis was confirmed by a rheumatologist. “Family doctors aren’t comfortable with the medications, and I don’t expect them to be.” However, most focus group participants felt that delays in instituting therapy could lead to significant sequelae.

b. Optimal care requires improved communication on many levels. As before, family physicians indicated it was often difficult to reach the specialist. “I do not know how rheumatologists manage to see all these patients. They never answer their phones. We can never, never talk to them.” The difficulty was identified by other groups as well. Interestingly, this was referred to by the rheumatologists themselves, who felt overburdened by the volume of daily tasks and were concerned that this interfered with optimal care.

c. Both family physicians and rheumatologists have important potential roles in optimizing care, but these need to be clarified. The notion of clear roles and good communication in a partnership of care between family physician and specialist was discussed. “I want my patient with RA to see the rheumatologist, to have his support, to say ‘we stay on this drug, this is what you should check, what you should do.’” Decision-makers also emphasized comanagement.

d. RA outcomes would be optimized by interdisciplinary care, which is often lacking. “We don’t have access to enough nursing occupational therapy, physiotherapy.” All groups recognized the importance of interdisciplinary care. Consumers depended upon allied health care members, including therapists and pharmacists: Rheumatologists strongly agreed that optimal care would be facilitated by a more multidisciplinary approach including nurse practitioners, psychologists, physiotherapists, and occupational therapists. Like the physician groups, decision-makers and other health professionals emphasized that optimal RA treatment requires a multidisciplinary team, but noted that this wasn’t occurring in the current climate.

e. Patient education allows active self-management and better outcomes. Patient awareness, acceptance, education, and active self-management of care were emphasized by all stakeholder groups. All health care professionals agreed that education was crucial, and that the patient must accept the care that is offered in order for optimal results to be achieved. “Education is very important, that the patient understands they have a very serious illness...” Decision-makers also noted the importance of education and patient awareness, stressing that a well-informed patient contributes to the efficiency and quality of communication and interaction with the health professional.
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<tr>
<td>a. Adequate access to physician care is necessary.</td>
<td>There aren’t enough specialists to refer (RA patients) to.</td>
<td>Everybody is talking about treatment. You have to diagnose before you treat, and diagnosis depends directly on your access, be it to a primary care physician, be it to a team or be it a subspecialist.</td>
<td>If the patient needs some support, we should be able to feel that we can sit down and give them that support without feeling that I have to look at my watch because the waiting room is full and I have 6 phone calls and so on...</td>
<td>Patients need early contact with a rheumatologist.</td>
<td>So if your intervention &amp; treatment for the patients is based on the fact that the rheumatologist has 10 min, it’s poor.</td>
<td>[At minimum, patients have to have access to a doctor. many people don’t have access to a doctor.]</td>
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<tr>
<td>b. Better access to nursing, therapy, and other disciplines is needed.</td>
<td>Overlooking the team approach is really causing great harm to patients. I received great care from my specialist, but no other support or resources. I was told I had an incurable disease then I had to deal with everything on my own. A support team is needed in newly diagnosed RA.</td>
<td>Access to physiotherapy outside of public care for those who have private insurance is not even available.</td>
<td>We can give limited time to the patient. and we do not have access to sufficient nursing staff, occupational therapy, physiotherapy. The government does not help because they cut all the allied help. Try to get physio and OT help-none. If you (the patient) don’t have private insurance, you can’t get access.</td>
<td>Well, they’re not even referred to therapy. The doctors know the patient(s) wouldn’t get in...</td>
<td>Lack of community resources (a barrier) you have to keep moving, swimming is good but the pools are not accessible. Where are the patient(s) going to go?</td>
<td>There’s a whole network in between of rehabilitation facilities that are secondary level facilities and it’s like the toss of a coin as to who gets referred when and where. When ambulatory care (responsibility) was given more to the agencies in the community... the money was not given to new more nurses in the community or to have more physicians. So we have patients who need help... (but) we don’t have enough staff...</td>
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Supporting statements are from the transcribed group recordings. Statements in square brackets are translated from French.
Across stakeholder groups, the belief was voiced that more resources were needed. This included adequate access to physician care, to nursing, therapy, and other disciplines. “Overlooking the team approach is really causing great harm to patients.”

Participants discussed gaps at the systems level, in particular insufficient manpower and services. This was especially emphasized in remote areas, with limited access to rheumatology, other specialists, and allied health care providers. Across stakeholder groups, there was frustration expressing concern for lack of resources such as community pools and rehabilitation centers were extremely important. Poor access to these resources (especially in remote regions) impeded optimal care. However, even in urban areas there was a need for more resources, both in terms of manpower and community resources.

Conclusions

Our work provides insight regarding optimal care for persons with chronic diseases like RA. This project took place in the setting of access to care that is theoretically universal. We believe however that the relevance of our findings extends across populations with very different health care systems, since we found important elemental barriers (for example, at the patient and physician level) that exist even in a population with supposedly universal access to health care.

Certainly, patient-related factors have been identified as an important rate-limiting step in recent studies, in both North America and elsewhere [7, 8]. One qualitative study suggested that patient delay is often driven by a lack of awareness of RA as a potential diagnosis [9]. Patients tended to ascribe their symptoms to some prior event or activities (e.g., an injury) and sought primary care only when the duration or magnitude of symptoms refuted the patient’s self-explanation. To address this, with the input of our stakeholder partners, we plan to pilot a novel, low-cost, sustainable education program targeting persons presenting with rheumatic complaints, through a community pharmacy.

This lack of patient awareness is important, since cues from the patient are an important determinant of subsequent actions taken by a family doctor [10, 11]. This may in part explain why, even once a person with symptoms of new-onset RA present to primary care, rheumatology referral is often delayed [3, 5, 12, 13].

This focus group study builds on our earlier work, suggesting why certain demographic subgroups are particularly vulnerable. This sets the stage for further work on how these vulnerable populations may be better served. For example, family physicians are likely not aware of how biased referral patterns tend to be, which might be something to address in continuing medical education forums.

Our previous survey of Quebec family doctors demonstrated that DMARD initiation prior to a rheumatology assessment is rare [15]. In our focus group discussions, stakeholder groups (including family physicians themselves) acknowledged that family physicians do not generally have the experience necessary to initiate DMARD therapy. Given the relatively low prevalence of RA in the adult population, it is difficult for family physicians to gain the necessary expertise. However, the notion that clinical criteria for identifying patients with early inflammatory arthritis are ignored by family physicians is not supported by our work to date; moreover, we found family physicians eager to improve their practices. Hence, facilitating links between family physicians and rheumatologists is likely a vital step in optimising care.

Based on data from the Canadian National Physician Survey, the vast majority (91%) of rheumatologists, once they become aware of an urgent rheumatology referral, will see that individual within 2 weeks or less [14]. Hence, our next steps will include targeting the time between symptom onset and rheumatology referral, which appears to be a real potential window for opportunity, in terms of improving RA care trajectories. To this end, we are evaluating a user-friendly rheumatology referral form (Appendix), developed in workshops by our stakeholder partners (including both family physicians and rheumatologists). This includes information about “red flags” that should prompt a rapid referral which will, we hope, serve as both an educational tool for family doctors and a means of improving communication.

The strengths of our study include strong methodology and wide representation of stakeholders. Regarding patient representation, we note that the demographics (age and sex) of the subjects who participated were indeed consistent with an unselected RA population. However, though we tried to “cast a wide net” and use several sources of recruitment, we cannot be absolutely certain that our sample reflected the whole spectrum of persons with RA. It may be that our participants tended to be more assertive and educated than the general population; regardless, we believe the participants were able to provide insights that help us understand quite a spectrum of the population that we serve.

In summary, our work provides important insights regarding the existence of barriers to optimal RA care, even in the setting of a universal health care system. Our work provides an example of how research can assist...
stakeholder leaders in creating structured and incremental plans to improve health care delivery for persons with chronic diseases like RA.

Acknowledgments We thank Dr. Guy Morissette and Mr. Jim Gates for their assistance with research planning; Mr. Andy Chabot, who with the Arthritis Society of Quebec was instrumental in the success of the focus group and workshop activities; and all of the participants in the focus group discussions and the follow-up workshops. Sasha Bernatsky is a Canadian Arthritis Network scholar and is supported by the Canadian Institutes of Health Research (CIHR), the Fonds de la recherche en santé du Québec (FRSQ), and the Department of Medicine of the Research Institute of the McGill University Health Centre.

Disclosures None

Appendix 1a: Front page of referral template developed as one solution to improve care trajectories

Rheumatology Referral & Triage Form:
Please complete all fields & fax to ______________________

Date (dd/mm/yyyy): ______________________________
Referring MD Name: ______________________________
License #: ______________________________
Telephone: ______________________________
Fax: ______________________________
Address: ______________________________
Signature: ______________________________

Patient Name: ______________________________
DOB: ______________________________
RAMQ#: ______________________________
MGH or RVH#: ______________________________

Home #: ______________________________
Cell or Work #: ______________________________
Address: ______________________________

Do you consider this referral to be urgent? (see list on other side page) No Yes

If PATIENT HAS >3 SWOLLEN JOINTS OR INVOLVEMENT OF MCP/MTJ JOINTS OR AM JOINT STIFFNESS >30 MIN, SUSPECT RHEUMATOID ARTHRITIS & REFER URGENTLY.
Severe night-time pain and/or systemic symptoms such as fever or weight loss suggest serious pathology and should hasten referral for any rheumatic complaint.

ARE THERE PAINFUL JOINTS? No Yes:
Mark an X or line through any painful joints

List current treatment for rheumatic complaint: (NSAIDs, prednisone, physio etc.) & any prior treatment of relevance (& side effects, if any).

Is there morning joint stiffness lasting for > 30 minutes? Yes No
> 60 minutes? Yes No

Does the pain disturb sleep? Yes No
Has there been weight loss? Yes No

Summary of present illness (include SYMPTOM DURATION & any limitations of daily activities):

PROVISIONAL DIAGNOSIS:

Please fax any relevant reports (labs, imaging, specialist letters) with this referral sheet.
### Appendix 1b: Back page of referral template developed as one solution to improve care trajectories

<table>
<thead>
<tr>
<th>Triage Category</th>
<th>Including, BUT NOT LIMITED TO:</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergent</td>
<td>Suspected septic arthritis</td>
<td>Page rheumatologist on call, and Fax referral to:</td>
</tr>
<tr>
<td></td>
<td>Aggressive connective tissue disease or systemic vasculitis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Temporal Arteritis</td>
<td></td>
</tr>
<tr>
<td>Urgent</td>
<td>Suspected new-onset rheumatoid arthritis or inflammatory arthritis</td>
<td>Fax referral to:</td>
</tr>
<tr>
<td></td>
<td>Acute monoarthritis (non-septic)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Polyarthritis with functional impairment</td>
<td>If concerned regarding patient or patient's condition changes from initial referral, page the rheumatologist on call to discuss.</td>
</tr>
<tr>
<td>Semi Urgent</td>
<td>Difficult gout</td>
<td>Fax referral to:</td>
</tr>
<tr>
<td>Routine</td>
<td>Painful degenerative arthritis not responding to first-line treatment</td>
<td>Fax referral to:</td>
</tr>
</tbody>
</table>

Adapted from Alberta Health Services, Calgary Health Region, Medical Specialists & Medical Services Central Access & Triage, [www.departmentofmedicine.com/MAS/index.html](http://www.departmentofmedicine.com/MAS/index.html)

### References


