Quality improvement for rheumatoid arthritis care: results from a focus group

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Abstract

Objective

Complex treatment decisions in rheumatoid arthritis (RA) affect aspects of patients' physical, psychological and emotional well-being. We aimed to identify key attributes of patient-centered rheumatologic care for adults with RA through a qualitative study using patient focus group discussions in order to guide quality improvement efforts around optimisation of disease management.

Methods

Patients with RA were recruited from a large academic medical centre rheumatology clinic and its affiliate sites over one month and allocated into focus groups led by an experienced moderator. Focus groups were held until thematic saturation was reached. Patients' responses were examined, categorised into themes, and codified independently by three reviewers. We extracted statements identifying common themes from transcripts.

Results

Thirteen patients with RA were recruited and allocated into three focus groups. Mean age was 59.1±10.1 years and average RA disease duration was 17.8 years. All participants had experience taking at least one disease-modifying anti-rheumatic drug (DMARD). Following reviewer analysis of patients' responses, six common themes about quality RA care were identified including: the role and use of self-management strategies, the clinical environment, the health care delivery process, attitudes towards medication, insurance and medication access issues, and the impact of disease on lifestyle.

Conclusion

Themes uncovered in focus group discussions related predominantly to the clinical environment and patient-provider communication. These preliminary results identified the need to incorporate operational aspects of health care delivery into our assessment of the RA patient experience and formed the basis of a RA quality improvement programme targeting medication optimisation.

Key words

rheumatoid arthritis, focus group, chronic illness, quality improvement, patient experience

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Introduction

Rheumatoid arthritis (RA) is the most common autoimmune inflammatory arthritis in adults, affecting 1.3 million people in the U.S. (1-3). RA may be characterised by inflammation and destruction of synovial joints, and often causes debilitating pain and inability to perform daily tasks. The total annual societal cost of RA, which consists of insurance claims data, estimated costs of work-loss to employers, adaptations to home and work environments, and lost productivity is $19.3 billion (4).

Over last two decades, the use of targeted therapies has dramatically improved RA management and high adherence to RA treatment has improved efficacy of therapy (1). However, adherence to RA medications is 30–80% due to treatment complexity, and the severity of potential medication side effects (5). As patients with RA must learn how to effectively manage their illness throughout their life, it is important to understand the challenges they face. Importantly, the American College of Rheumatology's "treat-to-target" framework for RA management uses validated disease assessment tools to guide the treatment of early disease but is ineffective in the absence of medication adherence (6-8). Medication optimisation is of paramount importance in the treatment of RA due to medication side effects and high cost of many disease-modifying anti-rheumatic drugs (DMARDs). It implies that the appropriate medication is chosen for a patient in accordance with the patient's lifestyle and preferences. Medication optimisation also emphasises time-sensitive patient evaluation for response to medication treatment, another key feature of treat-to-target (6, 7). This study aims to identify key attributes of good quality, patient-centered rheumatologic care for adults with RA to ultimately guide quality improvement efforts around healthcare delivery and disease management.

Methods

Setting

This qualitative study used a focus group approach. Focus groups are a method used to gather patient perceptions, opinions, beliefs and attitudes on a specific topic. This study was completed at an academic medical centre affiliated within a large healthcare system. Human Subjects approval was sought and waived through an exemption for quality improvement by our institution's Institutional Review Board (IRB). Patients were eligible if they were at least 18 years of age, had a diagnosis of RA, were willing to participate in a focus group, and had experience taking RA medications.

Focus group design and recruitment

A behavioural scientist (MDI) experienced in focus group methodology developed the moderator guide (Table I) with input from the research team and led the focus group sessions. Focus groups were designed to include 4–8 participants who had varying RA disease duration and severity. The research team asked physicians to recommend patients for the focus groups. Twenty patients were recommended and contacted by the research team via phone and/or email, if available. Four patients did not respond to the invitation to participate, two declined participation due to the distance needed to travel, and one patient who tentatively agreed to participate was unable to join due to a scheduling conflict. Ultimately, 13 patients participated in this study.

Three focus groups of adults with a diagnosis of RA were conducted with each focus group consisting of 3–6 English-speaking patients. Attendance at the focus group sessions implied informed consent. Focus groups lasted 60–70 minutes, were audiotaped, and conducted until thematic saturation was reached. Thematic saturation is reached when no new themes are discovered during the focus group sessions (9). A medical transcriptionist not involved in the study transcribed all focus group audiotapes. The transcriptionist removed all personal identifiers from the transcripts. The study team provided remuneration for parking and lunch to patients for their participation.

Data analysis

Members of the research team, a behavioral scientist (MDI), a rheumatology fellow (CL), and a research assis-

Table I. Moderator guide.

A trained focus group monitor used this guide to lead all three focus group sessions.

Themes and questions for sessions:
Topics
1. RA medication experiences, attitudes, and perceptions
2. Attitudes and experiences as an RA patient in the clinic
3. Attitudes towards a "team approach" to care and what they envision for a "team approach"

Moderator questions:
1. What is your experience with taking RA medication(s)?
2. What are your goals for taking your RA medication(s)?
3. What has been your experience discussing your RA treatment goals with your rheumatologist?
1. What are the pros and cons of having this discussion?
4. What has been your experience discussing your RA treatment goals with your with other clinic providers?
5. What are some challenges you face taking your RA medications?
6. How do you define treatment success?
7. What has been your experience in the clinic?
8. Are there any things you would like to see happen differently in the clinic?
9. In what ways could we streamline or enhance your clinic experience?
10. What "team approach" to your RA care do you want or are willing to engage in?
11. How would you feel about having a clinical person, other than your rheumatologist help you with your RA treatments?
12. How would you feel about using an electronic patient portal prior to scheduled visits to share information with your rheumatologist and rheumatology team members?
13. Are there any other thoughts you would like to share with us about your RA treatment experiences before leaving?

tant (MF), independently examined and coded the transcripts, blinded to each other's results. The team used open data coding, defined as the process of breaking down, examining, comparing, conceptualising and categorising data the transcripts for themes and categories (10). The team then met to discuss themes and categories and used a normative group process to reach consensus regarding discrepancies in coding. In phase two, the team returned to the transcripts to identify quotes to illustrate the themes demonstrated in Table II.

Results

The mean age of the thirteen participants was 59.5 (range 28–73 years), with an average disease duration of 17.8 years. Ten patients (77%) were female, 11 (85%) were Caucasian, one was African-American, and one was Asian. Four participants (31%) completed high school, one (8%) completed some college, five (38%) graduated college, one (8%) completed a post-graduate degree, and data was unavailable for two of the participants (15%).

Six major themes with subthemes were identified from the transcripts (Fig. 1). The major themes identified included self-management strategies, impact of disease on lifestyle, clinical environment, health care delivery process, attitudes towards medication, and issues related to insurance as described as follows:

1. Role and use of self-management strategies

This theme addresses the role of personal self-care strategies patients used to manage their illness. Patients articulated concern about how to identify the proper diet and exercise to improve their RA symptoms. They were not always familiar with the resources available to learn about managing their illness, and often requested more information about disease management from their rheumatologists.

Patients expressed positive and negative opinions about the information physicians provided to them about self-care. One female patient stated, "Making sure I get more rest. That was something that I wish my doctor would tell me." Many patients agreed that they would prefer if their rheumatologists would provide more information about RA self-management strategies. As another patient remarked, "So they (medical staff) are very engaged in trying to bring other ideas… to people who have RA at these (support group meetings). … I pay a lot more attention to what I think I should be doing to manage my disease…" This patient was referring to the nurse-led support groups offered at the clinic to help patients learn self-management strategies. These statements suggested that patients may be receptive to learning about self-care through other clinical providers such as nurses or medical assistants.

2. Impact of disease on lifestyle

Nine patients reported concerns about how their diagnosis and medications interfere with their daily tasks, aging, and setting realistic treatment goals. One male patient noted that he feared being limited in his daily activities due to his disease progression and aging, stating; "But last year was the worst year of my life. I couldn't golf anymore. I couldn't ride my motorcycle. I couldn't kayak. I had a hard time doing anything… Do I worry about my future? Yes." Another female patient remarked, "I'm always active. So, I struggle with the pain, but I push my way through it because I just don't want it [RA] to take control of me." In these cases, patients identified fears about how their RA would limit them.

Participants also discussed the monthly nurse-led RA support groups as a method of learning about and coming to terms with their diagnosis. One female patient explained her attitudes towards support groups: "But maybe hearing other people's experiences and what their flow through the medication was, what happened to them. 'Oh, this didn't work, so then I tried this, and that really helped.' I can maybe see myself doing that occasionally, but not in any sort of structured way. But if there was a resource or other patients willing to talk, or something like that, I might use that in a more casual way."

Another patient explained why she did not consider support groups useful: "I'm not big into talking to other people about it. I'm not big into support groups – I feel like it's kind of dwelling on it, dwelling on the disease, where I just want to see my doctor for my appointments, take my medicine, and just like be done."

Table II. Categorisation of quotes by theme and category.

Theme	Category	Quotes
Self-management strategies	Complementary approaches	“If you go on a food regimen and you change your diet – and you cleanse your blood, that you’ll get better, but {my doctor} didn’t want to hear that. But I didn’t know if I wanted to live through the pain.”
		“I think resources on things like workouts that are good for people with arthritis, or groups of other arthritis patients that kind of want to work together”
		“But one thing that really helped was, I got an exercise bike. And just getting on that bike in my house, for 5–10 minutes, making myself, no matter how miserable I felt, the stimulation – it kind of helped my metabolism”
Clinical environment	Staff rapport and office climate	“My first experience was awful. The person forgot she had put me in a room and I was there – after the first hour, I should’ve gone out and said hey, what’s going on? She just forgot about me in there and the doctor thought I missed my appointment.”
		“Nice parking facility…and that young woman who is down there is so friendly”.
		“I mean, it’s usually a nurse or medical assistant that’ll bring me in… they’re all just very pleasant, very nice.
		“I think those [time trackers] are really silly – I feel like I’m at the Outback Steakhouse when they give you those”.
		“I liked it better in the old building, I have to say, because I think we were closer… if (the nurse) wasn’t busy, I just knock on her door and say, “Hi, how are you?” And talk to her and tell her if I was having a problem. I felt like I could talk to her. Now I’m over here, in this building, everybody’s separated”
		“Especially when you have people coming in that could possibly be in pain and be feeling miserable, and then you’re confronted with someone [clinic staff] who looks more miserable than you feel.”
		“For myself personally, I’ve had trouble getting through [on the phone]. And if you do get through, the person will connect you to a dead line or someone that’s not answering.”
	Care coordination	“I wish there was more of a team thing, well, if something hurts, then go see this other doctor or – I feel like I have a doctor for every part of my body… I don’t have this feeling that everybody’s kind of working on my whole body together.”
		“She [insurance liaison] printed out to me the three best and sent it to me so I could look at it before I actually signed on.”
		“A lot of times the nurse has already done some homework prior to the doctor calling me back. So, I think the staff down there is really good.”
		“The doctors here at XX hospital work very well. The point is though with the blood tests that’s something that could be improved. I try to coordinate blood tests between the different doctors (myself)”.
		“If it is a decision about which medication to take or to increase my medication or to deal with a side effect, I would frankly refuse to deal with a nurse or pharmacist. I would say, no I want to talk to the doctor”.
		“When I picked up the MTX at the pharmacy I looked at it and it says do not take alcohol. And I say to the pharmacist my doctor didn’t tell me I couldn’t drink. She was great (the pharmacist). She said, I’m going to tell you that this is a recommendation and especially when you are new on it, I would recommend that you do not drink. So, I didn’t drink for 6 weeks.” If she had said to me, oh, you can go ahead and drink, and it said on the medication don’t drink, I probably would not have done that without the doctor knowing and asking the doctor.”
		“I like that [my rheumatologist] talks to my primary. My primary talks to [my pulmonologist]. They all talk about this. So, they work together to try to help me through it.”
		“It’s every four months I have to come in, which feels like a lot.”
Health care delivery process	Technology and communication	“You get these reports. And there is something in the reports you don’t understand. So, you just choose from a dropdown menu a question about results and type a quick email.”
		“So, at times, the medication isn’t always doing what it needs to do, but with a little anti-inflammatory or prednisone from time to time to calm things down and things are – you know – pretty much at a steady rate. But {my doctor} is just wonderful to work with. She listens really well.”
		“I think Patient Gateway’s great. I love looking at my test results and I get a prompt every time something new is posted. So, I love it.”
		“I’ve been having a problem with, with Patient Gateway. I get kicked out of it a lot when I’m signed in.”
		“I remember when the first patient gateway started. And I wanted to send a note to her instead of bothering have her call and talk, and I had a question. I thought she could just answer it. But I called her office, and I asked her assistant if she was on patient gateway and if I could e-mail her, and she said yes. And I did, and then she called me annoyed that I used that mechanism”
		“Patient Gateway. I mean the doctor’s really responsive. Because in the past I’ve always had to go through a nurse to get a response back in the newer practices, and it’s not like that here”
	Trust	“My doctor here has been very wonderful working with me as a team to really discuss things and try to balance everything.”
		“But my doctor’s done a really good job of putting it all into context, um, and saying, “Here’s the risk,” and, again, monitoring, which feels really frequent for me, because it’s every four months I have to come in, which feels like a lot. But it all makes sense and it’s all worth it.”

Theme	Category	Quotes
Attitudes towards medications	Balancing RA symptoms and medications	"No, I need my prednisone." And for my arthritis and for my chronic cough. I just want to stay active. I do not want to be crippled or wheelchair or anything like that… I don't want to depend on anybody. I've always been independent, and I just want to stay independent".
		"Since I have RA, I go months without a drink… I miss it somewhat but maybe I'm worried that the other side is much worse. That is, has a bad effect on your medication and that is terrifying to me… I mean, that would be like you're really shooting yourself in the foot to do that, right?"
		"You know it's kind of like playing with (your medicine), and I find it a challenge sometimes because I don't like to take pills, so I am always trying to take less."
		"My doctor added that just don't drink on the days that you're taking medication because it could interfere with the efficacy of it so, you know, make sure that your daughter's wedding isn't going to be on the day that you take your six pills...And I found that to be reassuring."
	Fear	"I don't like side effects, they are scary…I know it's not good for you, but every time they take me off the prednisone, I get knocked down."
		"I live a very active life and would like to keep that. But I do have some other medical conditions that don't allow me to venture to taking some of the stronger medications right now, and I have a son at home on chemotherapy for Crohn's, who has some very severe rare medical conditions, so we have to be careful that we don't catch infections and bring them home to him."
		"But again, a sort of mental idea that I can't do something that I've normally done bothered me... my freedom was being imposed upon"
Issues related to insurance	Insurance company control over medications	"I haven't had any [issues with access]. Um, I also do the methotrexate and leucovorin, and it was like the miracle drug from the beginning."
		"Midstream for what I considered to be no reason at all, just because of cost, you have to switch... You start the whole approval process all over again... That stuff can be a little taxing"
Lifestyle	Social support	"I'm enjoying this [focus group] big time because I've never been able to sit with other people that have it [RA]."
		"And going on vacation through the airport. I could barely walk, and my girlfriend wanted to get me a wheelchair."
	Aging differently/Setting realistic expectations	"My mother is frail. Some of it is she thinks going up stairs is exercise. I wanted to be able to exercise so I wouldn't be in that situation. I wanted to not wake up in the night in pain".
		"I wanted to be able to do everything that I usually do without discomfort other than that old-age type discomfort"
		"Just try to be able to walk correctly, go to the gym, do some limited exercise. So, what I did was I adapted to that. So, I tried to take some long walks. And then if I go to the gym I do the elliptical and do the stationary bike and do some weightlifting. And that's all I try to do."
	Treatment goals	"right now, I consider myself lucky because I'm being able to do things again."
		"I got to that point where I couldn't even drive, and my – different medicines, I would be on it for six months to see if it would work and they just weren't working. And so there was a point in time where my hands and wrists were so bad that I couldn't even drive myself anywhere."
		"I want to be pain free. I'm very active – very active. I got six grandchildren and I'm always running here and there, and I'm very active in my church and plus, I'm in school-school for ministry."
		"And my goal was to hopefully, not have to go on that and to not get better and then get worse again after five or six years"
		"I think it's not have to walk with a cane. You know, be able to walk briskly, get outside. You know, play with my grandkids and-and that's it. And the other stuff is a nice dream, but…you have to realise that you can do what you can do, and the pain isn't worth it."

The research team categorised statements using open data coding and used a normative group process to reach consensus regarding discrepancies in coding. Quotes from the focus group transcripts were organised in Table II.

3. Clinical environment

Patients commented on physician accessibility and the clinical care environment. A few patients expressed worries that physicians are too busy and that they rush patients through their clinical visits. However, one patient noted time constraints are prevalent in medical care today saying, "That's [time limits] a disturbing aspect of medical care. And I think it is not affecting care here." Another patient added in response, "Don't mess with a successful system. I know you're under a lot of pressure to cut costs and be more efficient, but I think that the rheumatology department is extremely efficient."

Some patients expressed concerns about provider accessibility especially in urgent situations. One female patient who was having a negative reaction to her medication described her interaction with the clinic staff: "Nobody gets to see the wizard. I wanted to ask a fairly, I thought, generic question. If someone has symptoms such as this, should they not get an infusion? I could not get through to a nurse. … I said, 'Never mind. Thanks.' It was as if his (scheduler) goal was to just get me off the phone without bothering the nurse. I was very frustrated." In these examples, patients emphasise the importance of accessibility and ease of communication with their physicians and nurses.

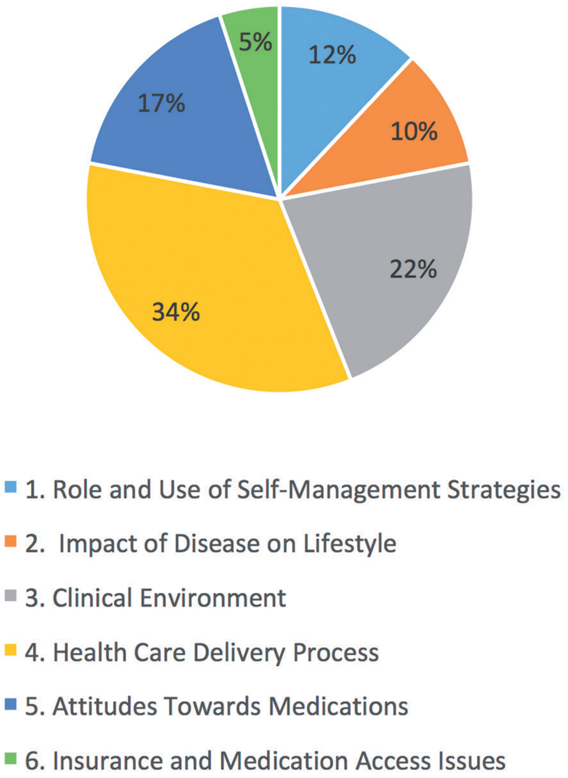

Fig. 1. Categorisation of statement themes.
Statements relating to the six themes were categorised and counted to quantify their contribution to focus group discussions.

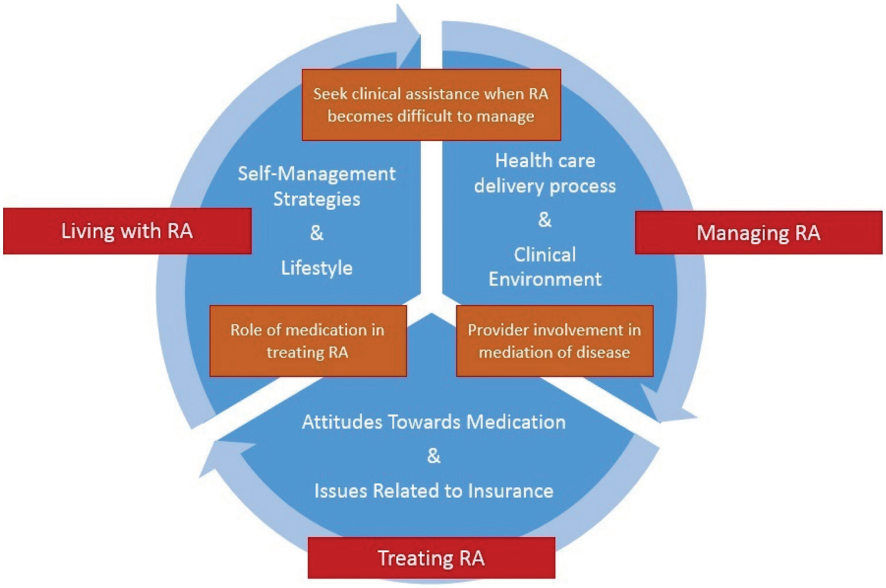

Fig. 2. Cyclical model of RA management.
When patients are feeling well, they focus on impact of RA on daily tasks (theme 1). When they need medical attention, whether it is for routine visits or disease flares, they often seek clinical assistance (theme 2). The third major theme, "treating RA", demonstrates that when a patient shifts to an experience of illness, they often seek treatment of their RA with medication.

4. Health care delivery process

This theme reflects the effects of technology and communication on patient care and the role of trust between patients and their health care providers. Patients expressed their general approval for the patient portal system that enables them to check their clinical visit notes and allows them to connect with their physicians over email. However, a few patients described difficulties adapting to an electronic system. One woman stated, "Would my mother be able to figure it out (electronic communication system)? No. If you are not English speaking, you might have a problem … I'm kind of a luddite, I have to have my children set up my printers."

Another patient noted that the electronic system enhanced her communication with her physician. "I was really surprised that I could have access to the doctor when I want to. I mean, she's really good with emails. I love the whole (electronic communication) system … My doctor gave me very helpful brochures. She drew pictures … When she decided on methotrexate … She listed all the reasons why we would start there. So, I felt pretty well informed."

Patients also commented on how they trust their physician to involve them in their RA treatment decisions. "My doctor thought I was really sensitive to (the idea of taking medications regularly) and let me come to grips with the idea before pushing meds on me… I feel like it's a partnership. I retain a lot of control. … I also feel so much confidence in (my) doctor's knowledge that I don't necessarily feel like I need to know everything. I can trust (the doctor's) judgment."

Another patient praised the use of shared decision making in her discussion with her rheumatologist:

"I love that [my doctor] had questions that were more qualifying, like not, how do you feel? It's like, how far can you walk? Those types of questions. And, I think at the early onset of arthritis, maybe there could be an emotional gauge, too. I mean, they do ask you those questions about, like, have you felt sad? Are you blue?"

5. Attitudes towards medications

A main concern expressed was how to determine when DMARD side effects were more severe than the pain caused by RA. One patient explained, "I'm just trying to take as little medicine as possible – but be without pain…I'd rather deal with the pain than the weird side effects…you feel sick or tired… and more serious issues as well."

Another patient noted that when her medications begin to relieve her RA symptoms, she is tempted to discontinue treatment due to concerns about medication side effects: "Sometimes a little bit of denial creeps in there and you're saying, 'Gee, do I really need to take this with the side effects, and everything, if I'm feeling so good?" In these examples, side effects of medications were indicative of poor adherence. Some patients could tolerate side effects or remained unaffected by them. One male patient noted, "Well, there's always side effects. You go to get your tooth taken out, and you're going to sign a paper in case you die on the chair. Everything is a gamble and you don't know…I haven't experienced anything yet."

6. Insurance and medication access issues

Since many patients were approaching eligibility for enrolment in Medicare, they expressed concern about switching medications due to medication coverage gaps. A few patients stated that they had difficulty with insurance coverage for certain biologic medications and had to discontinue medications that were improving their condition. One female patient explained, "It is really frustrating when the insurance companies can dictate [medications]. The doctor says, "You should be on this. This is what'll work for you," and then the insurance companies, who know very little about me…and yet they send me out a letter saying, "We're deciding that you can't have that medicine anymore. You feel like you don't have – and your doctor doesn't even have a hundred percent control over your disease or your treatment of your disease." In this example, insurance coverage of medications is identified as a major barrier to treatment.

Discussion

Six themes emerged from the focus groups and can be further divided into three overarching categories: 1) Living with RA (self-management and impact of disease on lifestyle), 2) Managing RA (clinical environment and health care delivery process), and 3) Treating RA (attitudes towards medications and insurance and medication access issues). These overarching themes relate to one another in a cyclical fashion (Fig. 2). When patients are feeling well, they become concerned with their disease state and focus on impact of RA on daily tasks (theme 1). When they need medical attention, whether it is for routine visits or disease flares, they may seek clinical assistance to help them manage their disease (theme 2). The third major theme, "treating RA", demonstrates that when a patient shifts to an experience of illness, they seek treatment of their RA with medication. Once they have been treated for their RA, patients would focus on tasks of daily living and so on. It is possible to use this paradigm to view the nature of managing many other chronic illnesses.

A few proposed models are used to illustrate the challenges of living with chronic illness such as RA. The cyclical model we describe is similar to the Shifting Perspectives Model (11), which describes chronic illness in a sociocultural and psychological context, in that patients are constantly shifting between experiencing states of wellness and illness and provides insight into the themes identified in our study. Additionally, our focus group themes were consistent with the findings of Flurey *et al.* 2014 (12), who reported that when a patient's RA symptoms are well-controlled by their medication, their RA shifts to the background, and when a patient's disease is flaring, their disease state shifts to the foreground. In our study, patients reported that when they are feeling "good", they do not feel they need their medication, and patients struggle to balance medication side effects with RA symptoms, especially pain.

Our findings also revealed that the health care delivery process and the clinical environment were key drivers of patient satisfaction, with over 50% of all statements pertaining to those two themes (Fig. 1). Therefore, it is important to examine how healthcare delivery can be optimised to treat the patient and their symptoms. Patients stressed the importance of physician accessibility and shared decision making in their treatment. They cited aspects of the physical clinic environment such as long wait times and feeling rushed through their clinical encounters as negative aspects of their care. These concerns identify a need to incorporate operational aspects of health care delivery into our assessment of the RA patient experience, and to explore quality improvement interventions that can influence patients' experience with receiving rheumatologic care.

Patients also noted that the implementation of an online patient portal helped ease communication with their provider and alleviated the stress of scheduling and commuting to in-person clinical visits. There is evidence that online patient portals increase patient engagement and improve health outcomes in the general population (13). In our sample, patients favoured online communication with their physicians over phone communication. This was a surprising finding considering the mean age of our participants. Previous studies have demonstrated that factors such as age, education level, and health literacy are significantly related to patient portal usage and that older RA patients are less likely to login to online patient portals (14).

Our participants also stressed the importance of shared decision-making and a strong patient provider relationship when choosing a treatment regimen. Patients reported feeling more in control of their disease when physicians asked questions about their emotional, social, and psychological well-being and included these factors in the decision to change treatment. Kvrgic *et al.*'s (15) investigation of patient-provider discordance in RA found that disease activity measures do not always provide a full picture of patients' subjective experiences of illness. This finding was supported by Acebes *et al.* (16) who found rheumatologists prefer more objective measures of remission while patients prefer subjective measures of remission. This discrepancy between provider and patient views of disease activity and remission supports a shared decision making approach to RA care. Similarly, Hulen *et al.* 2016 (17) and Barton *et al.* 2018 (5) advocated for a discussion between patients with RA and their provider regarding treatment goals. Our findings also demonstrate patients' desire to feel a partnership with their physician by having these patient-centered conversations about treatment.

Strengths and limitations

The use of an experienced moderator to lead focus groups strengthened the data quality. Focus group discussions, unlike individual interviews, stress the importance of social interaction between participants in forming attitudes and perceptions about a common issue. The moderator merely prompts the group discussion rather than leading the discussion (18). In this way, focus groups can reveal a more patient-centered understanding of an aspect of healthcare. Understanding the challenges facing individuals who have a chronic disease such as RA from the patients' perspective offers greater meaning and relevance to quality improvement research.

There were also limitations to this study. We recruited patients from a large academic health care system within the United States and thus opinions and perceptions of these patients cannot be generalised to patients from other countries or from other healthcare systems. Physician recommended patients for focus groups and this recruitment process may have introduced a bias towards gathering data on patients who had strong, trusting relationships with their rheumatologists, and therefore their views may not reflect the challenges of newly diagnosed patients. Similarly, all participants needed to have experience taking DMARDs to be included in the study, so the themes described in this group may not reflect the opinions of patients who do not take medication for their RA. Since the focus groups were only conducted in English, we cannot generalise these results to the non-English speaking RA population – especially because this study had a large emphasis on patient-provider communication. Though the moderator demonstrated objectivity, there is possibility of reporting bias if participants selectively reported information in the direction they perceived as of interest to the moderator.

Conclusion and future directions

Our findings demonstrate the feasibility and utility of employing focus groups to collect patient-centered perspectives on RA care delivery. These results helped inform a quality improvement initiative to optimise treatment satisfaction within the academic rheumatology practice. These data support the literature on the viability of patient engagement in research, and demonstrates the utility of patient involvement rather than its tokenism (19). Furthermore, this study encouraged a conversation among providers about the importance of documenting patient's functional goals for treatment. In future studies, we plan to compare physician documentation of patient goals and shared decision making with patient perceptions of treatment satisfaction and shared decision making.

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