Patient and Rheumatologist Perspectives on Tapering DMARDs in Rheumatoid Arthritis: A Qualitative Study

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ABSTRACT

Objectives: To understand the perspectives of patients and rheumatologists for tapering DMARDs in RA.

Methods: Using semi-structured interview guides, we conducted individual interviews and focus groups with RA patients and rheumatologists, which were audiotaped and transcribed. We conducted a pragmatic thematic analysis to identify major themes, comparing and contrasting different views on DMARD tapering between patients and rheumatologists.

Results: We recruited 28 adult patients with RA (64% women; disease duration 1-54 years) and 23 rheumatologists (52% women). Attitudes across both groups towards tapering DMARDs were ambivalent, ranging from wary to enthusiastic. Both groups expressed concerns, particularly the inability to 'recapture' the same level of disease control, while also acknowledging potential positive outcomes such as reduced drug harms. Patient tapering perspectives (whether to and when) changed over time and commonly included non-biologic DMARDs. Patient preferences were influenced by lived experiences, side effects, previous tapering experiences, disease trajectory, remission duration, and current life roles. Rheumatologists' perspectives varied on timing and patient profile to initiate tapering, and were informed by both data and clinical experience. Patients expressed interest in shared decision making (SDM) and close monitoring during tapering, with ready access to their healthcare team if problems arose. Rheumatologists were generally open to tapering (not stopping), though sometimes only when requested by their patients.

Conclusion: The perspectives of patients and rheumatologists on tapering DMARDs in RA vary and evolve over time. Rheumatologists should periodically discuss DMARD tapering with patients as part of SDM, and ensure monitoring and flare management plans are in place.

Keywords: rheumatoid arthritis, tapering, qualitative, DMARD, reduction, patient perspective, patient preference

Key Messages

- This study provides insight into how patients and rheumatologists approach tapering of biologic and non-biologic DMARDs.
- Perspectives vary and evolve over time with evidence available, disease and medication experiences, and life roles.
- Rheumatologists should discuss tapering options with patients regularly, ensuring flare monitoring and management support.

BACKGROUND

Novel therapeutic options and a treat-to-target approach have improved outcomes for patients with rheumatoid arthritis (RA) [1, 2]. Disease-modifying anti-rheumatic drugs (DMARDs) are often employed at high doses immediately at diagnosis and adjusted in an additive fashion to obtain disease activity control rapidly. However, long-term use of DMARDs can have significant physical, emotional, social, and financial burden [3, 4]. Side effects often occur [5, 6], and there is potential for rare serious harms. DMARDs may require support for injection administration, necessitate monitoring investigations, and generate out-of-pocket expenses for patients.

There is growing interest in exploring how to best taper DMARDs in RA patients who are in remission. Current guidelines recommend tapering of biologic therapy for patients who are in sustained remission [7, 8], and emerging evidence suggests tapering of conventional synthetic (cs) DMARDs may also be possible in some patients [9]. While tapering of biologic therapy in clinical practice has been successful when systematically offered to patients [10], tapering in routine care is uncommon and often involves non-biologic therapy [11]. This may stem from a challenge in identifying which patients are suitable for a reduction in treatment. It may also relate to patients and/or rheumatologists' beliefs, fears and attitudes towards tapering. To date, qualitative research has focused solely on patient preferences and attitudes for tapering biologic therapy [12-16].

The aim of this study was to gain insight into the perspectives, experiences and preferences of patients and rheumatologists for tapering both csDMARDs and biologic/targeted synthetic DMARDs in RA. We also sought to identify practice implications, and to develop emerging guidance for implementing tapering in a patient-centered way.

METHODS

Study design

We conducted a qualitative study with adult RA patients in two Canadian academic arthritis centers, and rheumatologists from across Canada, to understand tapering perceptions and preferences within a constructivist paradigm. This involved individual in-depth interviews, followed by sequential, broader perspective focus groups. A phenomenological methodological approach was used to understand patients' and rheumatologists' multiple social perspectives, and to support a comparison in analysis that could provide explanations for preferences and action. The University of Calgary Conjoint Health Research Ethics Board approved the study (REB17-0969). Signed, written consent was obtained from all participants.

Initial in-depth individual interviews

A multidisciplinary team of clinicians, researchers and patient partners developed initial interview guides for patients and rheumatologists, with *a priori* concepts identified in the published literature used to create initial questions. The interview guides included a series of open-ended questions and prompts to elicit experiences, preferences and priorities about tapering (conceptualized as both reducing or stopping) DMARDs for patients in sustained remission. Using these guides, a single researcher with qualitative experience (PH) recruited convenience samples of adult RA patients (n=6) and rheumatologists (n=4) in Calgary, and conducted semi-structured, in-depth individual interviews with the aim of establishing emerging themes. These initial in-depth findings informed the interview guide for the broader focus groups that followed.

Focus groups

We conducted six focus groups. Patients were recruited from rheumatology clinics and through RA patient networks in Calgary and Montreal, using purposive sampling to obtain different perspectives with respect to sex, disease duration and DMARD medication experience. Rheumatologists were recruited at

an annual investigator meeting of a 16-centre pan-Canadian early RA cohort (CATCH: Canadian Early ArthriTis CoHort) [17], and included both academic and community rheumatologists.

Members of the core team who interviewed patients (SB, PH) had no clinical relationship with them, and those who interviewed rheumatologists (SB, PH, GH) knew most of them as colleagues or acquaintances. All the interviews and focus groups were audio recorded and transcribed verbatim, and researchers (PH, AS) took field notes.

Analysis

We used a simplified framework [18], with responses applied to a data matrix, to identify patient and rheumatologist themes (and components of these themes) that could provide insight to their perspectives, and inform DMARD tapering guidance. Using Dedoose software (for the initial interviews), and NVivo (for the focus groups and individual interviews combined), a researcher (PH) sequentially coded the transcripts using a single coding scheme. As the emerging themes from the individual and group narratives contained similar structural elements, there were analyzed using a merged approach. Similarities and differences in the emerging themes were noted in both the individual and group narratives, and when new codes were identified in the focus groups, they were added to the initial codebook and revisited in the individual interview transcripts. This retracing and reviewing process ensured a consistent and rigorous coding analysis.

The core team (SB, GH, ALB and PH) reviewed these emerging initial codes, and finalized the codebook. Another researcher (TP) then used this to code all the interview transcripts independently. The core team then analyzed both sets of coded data to identify discrete distinctions or intersections between the two, and triangulate findings. Where appropriate, we compared patient and rheumatologist comments, noting findings that did not fit into comparisons of similarity or difference, and including these in our thematic

analysis. One researcher (PH) generated synthesis statements, organized according to the themes, which the core team reviewed and discussed and used to develop a comparative analysis of patient and rheumatologist (conscious and subconscious [19]) perspectives to tapering.

RESULTS

Characteristics of participants

Twenty-eight adults (18+ years) with RA and 23 rheumatologists participated in the qualitative interviews (Table 1). Patients included a wide range of disease duration, with current DMARD use split between biologic and non-biologic therapy. The rheumatologists were largely from academic practices, with most (70%) spending the majority of their time in clinical practice (Table 1).

Qualitative findings

Following an iterative, in-depth review and discussion process to triangulate findings, the identified themes were categorized into three overarching themes described in detail below, along with selected quotations. Participant demographics (e.g. age, sex) for the illustrative quotes were available for the individual interviews, but were limited during focus group, and did not inform our analysis, so they are not shown. Additional quotes are presented in *Table 2*.

Tapering perspectives

Wide variability in attitudes and preferences towards tapering

Patient attitudes towards tapering varied from acceptance to serious reservations about the consequences of tapering.

'As long as I'm feeling good, I really don't care what the drugs do to me because I figure that I know what the side effects of the disease are as well as the side effects of the drugs. And I'd rather go and take my chances with the drugs than the disease…' (Patient, focus group)

'I'd much rather deal with joint issues and pain than have an organ fail on me.' (Patient, individual interview)

Similarly, among rheumatologists, enthusiasm and willingness to recommend tapering medications to patients in remission varied. Some initiated these discussions routinely, whereas others did not, or raised tapering as an option only when patients verbalized concerns about side effects or long-term medication use. Many rheumatologists mentioned they would never stop all DMARDs.

We do tapering all the time as part of the contract… I tell the patients, because it's my belief and experience, that if you flare in a planned taper you will almost always respond to going back. (Rheumatologist, focus group)

I will bring this conversation up if they have had the disease for like decades and they are starting to show elevated liver enzymes or any abnormalities in blood work. Then I will be the one to initiate the conversation and ask if they're comfortable going down a little bit. (Rheumatologist, individual interview)

Perceived concerns and benefits

Both patients and rheumatologists expressed concerns about the potential consequences of tapering DMARDs. A common concern was return of symptoms, with increased severity and the risk of requiring more or different medications to achieve the previous level of disease control.

Honestly, I'm afraid of the recapture. Can I really recapture? If I'm not sure, and 85% do but 15% don't, those 15% are going to be difficult for me… I'm happy when they're doing well. I don't like to push it. (Rheumatologist, focus group)

My fear in reducing is going too far and you can't get back to where you were. And you've got to go a lot higher. (Patient, focus group)

Similarly, both patients and rheumatologists acknowledged the potential for reduced harm and patient burden as important benefits of tapering. These trade-offs impacted the decision on which medication(s) to taper, which was commonly csDMARDS. Patients also explained how balancing these harms and benefits can evolve and change over time. One rheumatologist suggested some patients might benefit from knowing whether they are able to taper, even if the tapering proved unsuccessful.

I wonder what effect the methotrexate and the plaquenil, in particular, have on that and, if I can reduce those, then maybe it's better for the longevity of my liver… It's hanging in just fine right now, but what's it going to be with another ten years? (Patient, focus group)

Sometimes it's very important for someone to fail to know why they're taking a drug because eventually when they're doing well if you don't fail you won't know why you are doing well. It's not a bad thing. I give patients that right. I say to them try and see what happens. (Rheumatologist, focus group)

Individual factors that influence decision making

Life roles and quality of life (QOL)

Patients and rheumatologists actively considered the impact a major tapering flare would have on social and working life roles, and QOL.

> *I still work for a living and I have a lot of responsibility. I do not want to take the chance that it'll affect me in some way. (Patient, individual interview)*

> *I might try to offer in cases where I think things are really, extremely, well controlled. But most of the time if they're feeling fine, they don't want to rock their boat. Essentially, they're happy that they're active and participating socially, and so we just make a decision that we're going to keep with what we're doing. Or maybe I won't even bring it up as an option… (Rheumatologist, individual interview)*

RA history and medication experience

Patients often weighed considerations about how severe their symptoms had been at their worst and how long it had taken to control inflammation against the potential short and long-term effects of RA medications. Rheumatologists considered the relative efficacy of different DMARDs, accrued joint/organ damage, initial presentation, co-morbidities, difficulty controlling inflammation, remission duration, along with patient and professional preferences, and perceived patient tolerance of DMARDs.

> *I went through a lot, a lot of pain before they figured out what was wrong with me. And when I decreased my dosage, I was back in pain… I'm tired of pain. (Patient, individual interview)*

> *I do think that I will tend to offer it to people who were diagnosed early, had a really good solid response, long duration of response, and are fairly easy to follow up with. (Rheumatologist, individual interview)*

Previous tapering experience

Outcomes of previous tapering experiences influenced both patients and rheumatologists.

> *…One time I went completely off, and my fingers started going numb and I couldn't pick things up, and we decided, okay, that's an experiment that didn't work. (Patient, focus group)*

> *And there were two patients last week, who over the last month started [tapering] by reducing their dose of hydroxychloroquine. And as soon as they reduced from 400 mg to 200 mg a day (in one case it was one month and, and another case it was two months), they started getting more morning stiffness. They did not feel that their disease was as controlled as it had been, and they went back to their previous dose… (Rheumatologist, individual interview)*

Patient-rheumatologist communication and shared decision making (SDM)

Both patients and rheumatologists described the need for good communication and trust in their relationship. Generally, these findings aligned with the values of SDM.

> *My experience is I think you have to have respect on both parts. The patient respecting the doctor; also the doctor respecting you what your wishes are… I'll take his opinion and then he gives me the ultimate decision -- of what I think would be best for me that would fit into my lifestyle. It's very mutual respect. (Patient, focus group)*

> *As long as you … do that in a way that is engaging with the patient, they're going to trust you. That's what it's all about. People will do things on their own. I know that. But, they'll learn something by doing it or not. If they do well, then you'll learn something. It's a mutual process*

here. I don't think there's any particular rule. I think all of us do the same thing at the end of the day. (Rheumatologist, focus group)

SDM, however, was not always enacted in practice. Some patients described being more likely to make decisions independently when there was low trust in their rheumatologist. Rheumatologists noted that conversations about tapering were often initiated only by patients. Thus, current medication regimens were often maintained as the norm, even in cases where tapering may have been appropriate.

I have done some of that on my own without professional advice. (Patient, individual interview)

'*Sometimes, you forget about it, and you realize that the patient has been stable for two years. Sometimes, it's 20 years. (Rheumatologist, focus group)*

External factors that influence decision making

Paucity of high quality evidence

Some patients said they wanted better evidence about tapering benefits and harms from trials, and specifically in people with similar circumstances. Rheumatologists explained they were not always able to provide this, which increased concerns and a sense of uncertainty for both.

I would have a high anxiety about the potential effect [of tapering], and would want to know pretty clearly what studies have been done, and what experience there was with respect to that type of tapering off to feel comfortable doing it. (Patient, focus group)

We just don't know in whom it's appropriate. And the terrified part, I think, is that if you lose disease control and they don't gain it back, that's really a disappointment for everyone and the patient suffers. (Rheumatologist, focus group)

Access to providers in clinic, and patient monitoring

Planned, fast, and reliable access to their rheumatologist should problems arise during tapering was important to patients and this affected their confidence about deciding whether to try tapering their DMARDs.

I'd also want to be assured that if I got into trouble, I wouldn't have to wait a week to see somebody. (Patient, focus group)

Some rheumatologists were concerned about the potential impact on their practice of extra appointments needed to monitor multiple tapering patients. Other rheumatologists were more confident that support to monitor patients could (and would) be accommodated.

There's no space… No follow-up spots. The capacity in clinic is often not there to see people more frequently than every six months. Even though medically it's optimal, sometimes, it's not possible. (Rheumatologist, focus group)

I can always accommodate patients, or at least [they can] see my nurse. (Rheumatologist, focus group)

Access to medications

A few patients and rheumatologists talked about out-of-pocket medication costs and access to insurance coverage as factors that may influence their decision to taper. A few mentioned that tapering conversations were less likely in patients with lower socioeconomic status. Some patients expressed concern that if they were to stop a costly medication, they may not have access to it in the future.

> *I find that it's also a matter of [insurance] coverage. So, if they have to pay out of pocket for methotrexate but not for biologics, then they tend to want to go off of those [that they pay for] and stay on the biologic. (Rheumatologist, individual interview)*

> *…if you have been approved and you come off it, will you get approved again? (Patient, focus group)*

Thematic synthesis

In comparing themes between patient and rheumatologists, similarities and differences emerged. Generally, patients approached the decision from a phenomenological perspective, viewing tapering in relation to how they currently felt, what they needed to be able to do in their everyday life, and their own experiences -- often informed by their own prior attempts to taper. Conversely, rheumatologists tended to view tapering through the lens of a prescriber, informed by their knowledge of the literature, and through a vicarious perspective, informed by how their patients experience tapering. These two different perspectives are illustrated in *Figure 1*. The perceived interest, patient-rheumatologist relationship, opportunity, and willingness to discuss these considerations together shapes how tapering decisions are approached (i.e. patient led, rheumatologist led or SDM), and is influenced by how the different factors identified in our themes play out at an individual level (e.g. communication style, monitoring approaches, evidence, and previous experience).

DISCUSSION

Our focus groups and interviews provided a rich understanding of patient and rheumatologist experiences, preferences and priorities towards DMARD tapering in RA. The considerations, experiences and influencing factors that drive patient and rheumatologist decision-making were often similar, but approached somewhat differently. Preferences towards tapering varied widely, and were influenced by the disease and medication history, and results of previous tapering experiences. Overall, many patients and rheumatologists expressed trepidation that tapering could lead to an unpredictable loss of disease control, worse quality of life, and an inability to recapture the same level of disease control. Yet at the same time, many also acknowledged the benefits of reduced side effects and medication burden. Routine consideration of tapering in appropriate patients would need to be supported by better, personalized evidence, strong patient-rheumatologist communication, a SDM approach, and ready access to care and medication in the event of flares.

Our study provides insight into potential reasons why tapering remains uncommon and not systematically approached in clinical practice. First, it is often not on rheumatologists' radar as there is not a current norm to discuss tapering as part of routine care. Rheumatologists are reluctant to 'rock the boat' in patients who are doing well on their current therapy. Second, evidence on tapering to date is sparse. While there is moderate quality evidence to support tapering of biologic therapy in patients who are in sustained remission [7, 8], patients often want to taper other DMARDs. Current clinical trials are also quite rigid in their approach to tapering (e.g. tapering the same medication in everyone at the same time) [20, 21], whereas tapering approaches in real world clinical practice need to be more flexible, to accommodate the range of patient preferences. Thus, there is a valid concern from both patients and rheumatologists over a lack of evidence to support their decisions at an individual level. Finally, there is ambivalence from

both rheumatologists (to suggest tapering) and patients (about trying it) and this ambivalence leads to inaction and maintenance of the status quo.

Stamp et al reviewed the available evidence on patient perspectives for tapering DMARDs in 2019 [14] and identified three qualitative or mixed-methods studies that assessed patient preferences on tapering of biologic therapy in the Netherlands [15] and UK [13, 16]. An additional study by Chan et al in 2020, assessed patient preferences for tapering biologics in New Zealand [12]. Common themes from this work include fears about recapturing disease control, having ready access to care, and the ability to rapidly re-escalate doses in case of a flare. Our study found similar themes, but adds to this literature by expanding to csDMARDs and comparing to rheumatologist attitudes and preferences. Importantly, it is clear that many patients and rheumatologists may prefer to reduce csDMARDs, due to a desire to reduce side effects or concerns with long-term toxicity. Rheumatologists share similar concerns to patients, albeit from a different perspective, which may act as an additional barrier to initiating and implementing tapering in practice.

Our findings, coupled with existing evidence, can inform emerging guidance for tapering DMARDs (*Table 3)*. We propose that the decision to taper needs to be flexible, ongoing, and consider the ambivalence, priorities, preferences, and RA trajectory of patients. When there is a decision to taper DMARDs, it is important that appropriate and timely information, support and follow-up care be in place. Patients require assurance of timely access to providers if they experience a disease flare, and may want to know whether tapering could potentially impact future access, particularly to biologic medications, if needed. Our results can also be used to help inform future quantitative studies on patient preferences (e.g. discrete choice experiments [22]) to quantify the relative importance of trade-offs relevant to treatment tapering.

Strengths of our study are the inclusion of both patient and rheumatologist perspectives, exploring experiences and attitudes towards tapering a wide range of DMARDs, and working closely with RA patient research partners throughout the entire study, from concept through to manuscript. Patients in our interviews were diverse with respect to age, disease duration and medication history. The sample of rheumatologists was large in comparison to other studies on RA medication perspectives [23, 24], and we included representation by region, sex, years in practice, and practice type (community/academic). The characteristics of patients (majority female, age range mid-fifties) and rheumatologists (half female, approximately 20% with <5 years practice duration) were similar to national samples [25, 26], though it was not the study's aim to match population level characteristics. Limitations of our study are that the majority of participants represent convenience samples from specialized arthritis centers, and therefore we may have missed issues related to tapering DMARDs in smaller office and primary care settings. The study was implemented before mandated switching to biosimilars was implemented in Canadian provinces, and before the COVID-19 pandemic.

In summary, this study adds new information about patient and rheumatologist perspectives on tapering biologic and non-biologic DMARDs for RA. They underscore the importance of a trusting open relationship between rheumatologists and patients where concerns can be discussed, and an individualized, adaptive approach to medication tapering in RA. Rheumatologists should discuss options with patients at regular intervals, as part of routine care, establishing an open and non-judgmental atmosphere, to explore preferences, concerns and needs, and encourage a SDM approach. When patients do elect to taper RA DMARDS, discuss appropriate expectations and timelines, along with a plan to monitor and self-manage symptoms and function, and address a sustained increase in RA inflammation.

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Data Availability Statement

Data cannot be shared publicly because of restrictions regarding sharing of data and informed consent of the participants. Data are available from the University of Calgary Conjoint Health Research Ethics Board (contact via chreb@ucalgary.ca) for researchers who meet the criteria for access to confidential data.

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529 **Table 1.** Focus Group and Interview Participant Characteristics

	Individual interviews	Focus groups	Total
Patients			
Number	6	22	28
Female, n (%)	2 (33)	16 (73)	18 (64)
Age, years, median (range)	59 (37-69)	66 (53-84)	64.5 (37-84)
Disease duration, years, median (range)	4.5 (4-11)	10 (1- 54)	7 (1- >50)
Medications			
Biologic or targeted synthetic (b/ts) DMARD only, n (%)	2 (33)	3 (14)	5 (18)
Conventional synthetic (cs) DMARD only, n (%)	3 (50)	11 (50)	14 (50)
Both b/tsDMARD and csDMARD, n (%)	0 (0)	3 (14)	3 (11)
Prednisone, n (%)	0 (0)	3 (14)	3 (11)
Rheumatologists			
Number	4	19	23
Women (n, %)	3 (75)	9 (47)	12 (52)
Years in practice (n, %)			
<5 years		2(10.5)	4 (17)

>5 years	2 (50) 2 (50)	17 (89)	19 (83)
Clinic setting (n, %)			
Academic	2 (50)	16 (84)	18 (78)
Community	2 (50)	2 (10.5)	4 (17)
Both	0 (0)	1 (5)	1 (4)
Clinical Time, n (%)			
<50%	0 (0)	7 (37)	7 (30)
≥50%	4 (100)	12 (63)	16 (70)

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Table 2. Thematic summary of findings with additional quotations

Theme	Patient perspectives	Rheumatologist perspectives
Tapering attitudes and preferences		
Wide variability in attitudes and preferences towards tapering	*My hope is that I can get off rheumatoid arthritis medication or even diminish my dosage even more if I can. (Individual interview)* *I would love to be drug free, but I've got a lot of stuff I want to do, and I want to be able to enjoy it, and I don't want to hurt… right now is what I want to live now, so that's what I'm going to do. If I can taper, great. If I can't, great. There's a lot of life to still go on, and I've got to get up tomorrow, so there's not much else you can do. I don't want to be in pain. (Focus group)*	*I like to treat people with the smallest amount of medication…that keeps their disease under control. (Individual interview)* *I'm very conservative. I'm old, and I worry about tapering because if something happens and I can't recover the patient. (Focus group)* *I think tapering or withdrawal of medications whether it's conventional DMARDS or biologics can happen. I think it's part of my practice. (Focus group)* *Well, it varies… Sometimes, you forget about it, and you realize that the patient has been stable for two years. Sometimes, it's 20 years. So, I'll tell them to start spreading the biologic injections. (Focus group)*
Perceived concerns and benefits	*I'd worry, "Okay, I cut back," boom, flare. Forget it. I don't want the flare-ups. I don't want the pain. (Focus group)* *…my main concern is that my hands won't work or my feet won't work and they'll be all gnarled and everything. I'll be in a wheelchair. So for now, you know, I, I guess I don't want to rock the boat for now if this is what's helping me. (Focus group)* *If I only had to take the pills once a week or you had an injection once a month I would take that over having to do daily pills for sure… (Individual interview)* *The Hydroxychloroquine can… do some eye damage. So she [doctor] says let's reduce… (Individual interview)*	*It's very hard to recapture somebody who had stopped methotrexate that had been doing well on methotrexate… Even when they stop it, it's very hard to recapture. With the biologics, usually you can recapture very easily, unless, as… somebody mentioned… they're developing antibodies and you need to change, to switch to something else. (Focus group)* *Pill burden is a, a big issue when it comes to compliance. (Individual interview)* *But patient preference is really important… That helps I think because there is some degree of patient preference and buy-in. Patients want to do well but they don't want to feel sick on drugs and they don't want to have fear of their disease state or fear of their drugs. (Focus group)*
Individual factors that influence decision making		

Life roles and quality of life (QOL)	*So you know, the contact sport and the impact sport I can maybe do without but the daily walks with the children and the dogs,… (Individual interview)* *I think about stuff like that and only because my job and my education and my, my, my career was you always had to question the decision that you're gonna make is if it was the right decision because it has massive negative results if it's wrong. And I've failed before and I've paid the price so I try to apply that to this, you know. (Individual interview)* *…time was a factor… I worked in the banking industry, right, so it was like I had to really plan my appointments around what was happening that day because I come from out of town… So that was a big deal. (Individual interview)*	*On the one hand if they're quite old, …generally you want to minimize [and] …simplify their medication regimens as much… But… you might have somebody who's in their 70's …and maybe is worried about disability because if they did have a flare it would …have a huger impact on them compared to somebody who's in their 20's who has a flare. (Individual interview)*
RA history and medication experience	*The worst drug for me is the prednisone, and I've had every side effect. Cataracts, yes that came within three months. What are some of the other things I've had that all relate to long-term steroid use? I put on an enormous amount of weight, which I've just recently…. There's a lot of side effects. (Focus group)* *I don't feel I've had any side effects at all. So I'm not really researching it or questioning the doctor or anything. If you've come across side effects, maybe that's something that would be an initiative to reduce. (Focus group)* *I was in bad, bad shape when they put me on it. So, I don't know. For me, these drugs are a bit of alchemy. Nobody can really say exactly what dose or even the tapering process. "Okay, so I feel really bad. If I don't take more, am I going to feel exponentially worse, or is this it?" If I thought this was it, I'd tough it out, maybe. I'd love to get*	*As I said, the patient adverse reaction history to the medications, because I, I wouldn't want them to get always nauseated and miserable after a Methotrexate injection because I feel like then it reduces their compliance. (Individual interview)* *But, my desires are [to] get rid of Plaquenil or Sulfasalazine, one or the other, or taper one, taper the other. Then… steroids first and then methotrexate… I still add leflunomide in people that tolerate stuff and all that before I go to biological but we start getting rid of the burden of the least effective drugs, if possible. (Focus group)* *…they all tend to be patients who have no damage, so if they've got no deformities, no erosions, they were, you know, relative early diagnosis, and I, I usually would say that we're not gonna try even to talk about this for about a year or a year and a half, just to make sure that they are in fact in sort of a solid*

	off them, but if it's going to be more joint damage or some more surgery. I just had a whole year of surgeries. (Focus group)	*remission, we don't run into any complications… (Individual interview)*
Previous tapering experience	*One summer I did go off the prednisone and by the end of the summer I have to crawl into Dr. X's office and he had to give a booster shot, so that was the end of that. (Focus group)* *I tried reducing and my swelling came back, that pain came back, so I went back to the regular dosage that was prescribed to me originally. …we had made the arrangement that if I did have a flare up to go back to full dosage. …we had already pre-discussed the whole plan of attack. And my flare up is not as much as my limbs flaring up, I get sharp shooting pains down the back, down the sides of my back and they came back, I went on my full dosage and they disappeared. (Individual interview)*	*There are some people who I think self-taper, so they'll be doing well and will come in and… say, 'Well I've only been actually taking it every 14 days even though it was meant to be every [7 days]'… (Individual interview)* *I would say most would accept it. Very few would say, 'Well, I'm scared. I don't want to reduce my dose', but then some of them would volunteer… 'Oh, yeah, I had bronchitis last winter, and I stopped it for four months, and nothing happened.' So, that would actually increase their confidence into spreading the dose. (Focus group)*
Patient-rheumatologist communication and shared decision making	*I really rely on my doctor to help me forge through this. (Focus group)* *I think that feedback loop is critical, because half of the battle in my mind is for the doctor to figure out what's going on and prescribe the right solution. The other side of it is to convince the patient why that solution is the right solution for them, and what are the, the good, the bad and the ugly aspects of what that solution is in the short, medium and long term. And what are the potentials for it changing over time. And not all those questions could be answered in a half hour doctor's appointment. (Individual interview)*	*In general, I try not to be too paternalistic in my practice. I kind of just try to provide information and explain to them you know, why my recommendation wouldn't be to taper. And when I present it that way, I would say 90% of the time they follow my advice. (Individual interview)* *I guess that's, that's the big conversation. I mean if they're on, if they, if they are really doing well on a biologic then I, and they're really motivated to get off the Methotrexate then I guess I'll have to live with it and, but again warn them that there are these potential consequences that we won't know about for a long time. I'll try and say can we just minimize the dose for a while and see if they can be comfortable on that lower dose. And you know, if, if they prefer to be on Sulfasalazine biologic then I'll accept that as an alternative as well. (Individual interview)*
External factors that influence decision making		

Paucity of high quality evidence	*I don't make decisions without knowledge and I most certainly don't give blind faith. I need to be educated before I make a decision on anything I do. (Individual interview)* *I want somebody to tell me why they want me to take something and I want somebody to show me the benefits, and I want somebody to tell me how long that's going to take. And I know everybody's different so they can't give me those answers. (Individual interview)*	*We don't have any good evidence and… people are doing it differently. (Focus group)* *Remember, most studies are only one year in terms of tapering. So, yes, 85-90% or more can recover, but what if you're the 10%? You've been doing well your whole life. You were on the drug. You've been on it for years. You taper it, and suddenly you flare, and you can't recover. You're in that 5% or 10%. It makes me nervous. That's all. I'm old, and it makes me nervous. (Focus group)* *There is no good data. The problem is there's no good data. (Focus group)*
Access to providers in clinic, and patient monitoring	*…it's a little tough even getting an appointment once every three months is tough. (Individual interview)* *I'd have, yeah I have no problem going to him and, and I, I, I know I'd have a pretty quick appointment and I'd be looked after very quickly I think… (Individual interview)* *I would also suggest rather than having just the physician appointments and an appointment as necessary, monitoring online. I'd like to see something like a patient portal where you could self-report what's going on… almost journaling or having a day by day diary so that you can report how you're feeling… So it becomes like a running history of your experience. (Focus group)* *…It would, it would have to be slow, but I'd also want to be assured that if I got into trouble, I wouldn't have to wait a week to see somebody. (Focus group)*	*…everyone I see has had you know, barriers with accessing care and so they're coming in with already a year's worth of symptoms. It, it's not even on the table for me anymore… (Individual interview)* *I will make sure that they have follow ups books sort of within 3 months again to just verify that they are in fact doing well. So, it does create a bit more work because you're trying to really make sure that they're doing all right. (Individual interview)* *In terms of like people living close or far away, yeah, I mean I guess you have to ask them, like if you did flare would you be able to get to me quickly, and certainly that would need to be taken into consideration. So maybe I would, maybe I would do the tapering in the summertime when it would be easier for them to drive in. (Individual interview)*
Access to medications	*A special authorization form can take several weeks to get through the hoops through your insurance company, and so you're sitting waiting*	*In my prior practice there were certainly people that could not afford their medications but that wasn't, that wasn't the group that was looking to taper. They were very poorly controlled already because they couldn't*

	for that authorization to come through… (Focus group) *Would I go get my prescription for, for [biologic] if I couldn't afford it? No. So yes, I have, I have done some of that [tapering] on my own without professional advice. (Individual interview)*	*afford their medications anyways. …I think of who have tapered they all tend to have insurance coverage, good jobs, higher socio economics. (Individual interview)* *…you know sometimes it depends on who's paying for their medications and then that really drives what they want to come off of. (Individual interview)*

Table 3. Implications for tapering DMARDs in RA.

Findings	**Implications for rheumatology practice**
Open communication and personalized discussions increase interest and confidence in tapering	Establish a non-judgmental atmosphere at visits where patients feel able to disclose a range of feelings about their RA disease, its impact on their life, and their perceptions of benefits and harms of current medications.
Attitudes and interest in DMARD tapering can vary widely and change over time	Assess attitudes and beliefs about the necessity of RA medication, and any related concerns. Provide personalized disease and medication education. Explore options at regular intervals, when appropriate, as part of ongoing care.
Previous tapering experiences affect perceptions of benefits and harms	Encourage patients to discuss previous experiences, including self-tapering, preferences, needs, and what they learned from tapering RA medications. Reassure patients that tapering is feasible and safe, and often successful, with appropriate supervision.
Rapid access to clinic, if needed, and a plan for close monitoring, is desired	Set expectations for tapering schedule, symptom monitoring and self-management. Discuss how you will each assess if tapering is working as intended. Describe signs that disease activity is increasing, when to contact the clinic, and specific care plan in case of a flare.
Current life roles can affect tapering interest and feasibility	Consider the potential impact of initiating tapering on a patient's quality of life, and how they may feel and be able to function in the short term. Is this the right time to initiate tapering?

Being able to rely on future access to medications in the event of a flare is a concern.	Work with (and support patients in working with) pharmacies and insurance companies, where possible, to ensure consistency and timely access to previous or new DMARDs in the event of a flare.

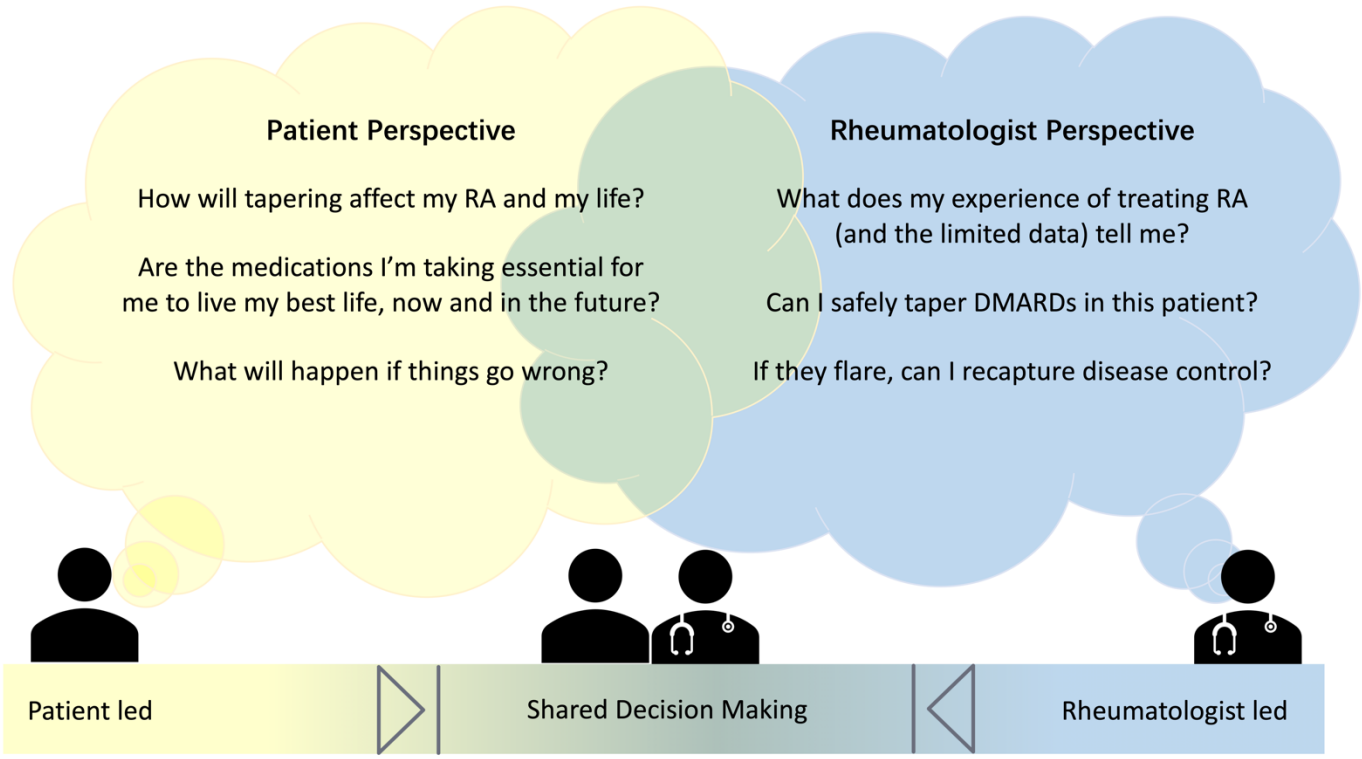

Figure 1. Perspectives of RA patients and rheumatologists and the different approaches to tapering