

Exploring strategies to support medication adherence in patients with inflammatory arthritis: a patient-oriented qualitative study using an interactive focus group activity

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Objective: Medication non-adherence is a substantial problem among patients with inflammatory arthritis (IA). Our aim was to explore IA patients' perspectives on strategies to support medication adherence.

Methods: We collaborated with a leading arthritis patient group and conducted a qualitative study on individuals with IA who were taking at least one medication for their IA. An experienced facilitator led participants through a focus group exercise where participants were asked to design, and then discuss, strategies and/or tools supporting medication use. We applied thematic analysis using an iterative, constant comparative approach.

Results: We studied six focus groups with 27 participants diagnosed with rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and comparatively under-represented conditions in this research area such as Sjögren's syndrome. Five themes emerged throughout the analysis. Two themes – 1) adapting to life with IA and 2) the complexities and dynamic nature of taking medications – describe learning to live with a chronic condition and the challenges encountered when using long-term medications. Three themes – 3) developing lifestyle strategies for medication use (eg, having physical reminders and prompts), 4) becoming informed about medications (eg, information at time of diagnosis, means of receiving information) and 5) receiving support (eg, from health care team members, from family) – offer perspectives on facilitators to medication use. From the relationship between the latter themes, a framework was developed that encompasses means of receiving information and support as actionable targets for patient-oriented adherence interventions for IA.

Conclusion: This patient-oriented study highlights the importance of developing timely adherence interventions for IA. Our findings also led to a framework describing means of receiving information, such as through digital media and support, including from health care team members and family, as actionable targets for patient-oriented adherence interventions for IA.

Keywords: inflammatory arthritis, medication adherence, concordance, facilitators, barriers, qualitative research, synthetic DMARDs, biologic DMARDs

Introduction

Long-term pharmacotherapy is paramount to the successful management of inflammatory arthritis (IA), as patients rely on medications to relieve symptoms, perform daily life activities and prevent irreversible joint and organ damage.¹ Systematic reviews synthesizing adherence rates as low as 10% in gout,² 25% in systemic lupus erythematosus (SLE)³ and 30% in rheumatoid arthritis (RA)⁴ are alarming, given the

association between non-adherence and adverse outcomes, including increased health care utilization,^{5,6} costs⁷⁻⁹ and decreased ability to work.¹⁰ Given this substantial burden of non-adherence among patients with IA, there is an urgent need for work in designing and evaluating interventions that promote and support treatment adherence. However, to date, such research has been disappointing, with less than half of published interventions reporting a significant impact on medication adherence or clinical outcomes.¹¹ These data support the importance of soliciting patient input to inform the development of successful adherence strategies and interventions.

Patient-oriented research, defined as meaningful and active collaboration in priority setting, conducting and translating research,¹² may provide an ideal opportunity to address the burden of non-adherence in IA. To illuminate practical strategies and solutions that may be operationalized into effective adherence interventions through a patient-centered lens, we conducted a patient-oriented qualitative study in partnership with a leading national arthritis patient group based in British Columbia (BC), Canada. Our objective was to explore IA patients' perspectives on tools and strategies to support chronic medication use using an interactive focus group activity.

Methods

Patient partnership

We partnered with the Arthritis Patient Advisory Board (APAB) of Arthritis Research Canada, a leading national consumer group of individuals living with IA who regularly collaborate in arthritis research.¹³ As we describe in further detail below, APAB members were engaged throughout the research process, including grant preparation (with one member appointed as a co-investigator on the study team), participant recruitment, focus group activity design and refinement, data analysis and interpretation and manuscript writing.

Study sample

Eligible participants were those who met the following criteria: 1) rheumatologist-confirmed diagnosis of IA, 2) 19 years of age or older, 3) currently taking medication (eg, disease modifying anti-rheumatic drugs [DMARD]) for their IA and 4) able to communicate in English. Participants were recruited from rheumatology clinics in the lower mainland of BC. APAB supported study recruitment through their various social media channels, including their

quarterly electronic newsletter, members' Twitter feeds and word-of-mouth advertising. Although we originally intended to include only patients with RA, APAB members recommended including a broader range of inflammatory arthritis, given that many conditions share similar treatments, and to ensure capture of rarer conditions that were less represented in prior qualitative research of medication use. As such, we purposively sampled participants on age, sex, type and duration of IA diagnosis and IA medication(s) prescribed to obtain diverse perspectives and experiences.

Study design and methodology

We used a qualitative approach for data gathering, specifically focus group methodology, as processes and interactions within focus groups more readily facilitate people's exploration and clarification of views than one-on-one interviews and can enhance the depth and breadth of the information obtained.^{14,15} We used a relatively novel technique of incorporating a group activity to focus the attention of the group on the core topic of the study.¹⁶ Specifically, a trained facilitator asked participants to describe or design at least one strategy and/or tool (whether hypothetical or currently available) that would support their medication use on color-coded labels and corresponding activity sheets provided. Participants were then invited to share their strategies/tools with the group and the facilitator used open-ended questions to promote discussion. To allow sufficient time for the activity and subsequent discussion, focus groups were formed with four to six participants. Each focus group interaction lasted approximately two hours and was audio recorded and transcribed verbatim for analysis. At least one study team member attended all focus group interactions as an observer, noting elements of participants' actions and interactions. APAB inputs for the focus group design included providing feedback on the topic guide to ensure the use of appropriate and accessible language that would effectively engage participants; furthermore, we conducted a pilot focus group interaction with six APAB members to identify areas for improvement in execution of the group activity. The uses of color-coded labels and activity sheets were a direct result of this pilot focus group with APAB, as we had originally proposed the uses of poster boards and cards attached with velcro, which were found cumbersome and potentially challenging for the target patient population.

Data analysis

Analysis of the focus group data was guided by thematic analysis informed by aspects of grounded theory¹⁷ and used an iterative, constant comparative approach.¹⁸ The first step in this approach was open coding, whereby each line of the transcript was ascribed individual codes that represented its main concept or phenomenon. This was an iterative process, since information from previous decisions helped to inform subsequent ones and vice versa. Constant comparison helped to identify patterns and similarities between data from different transcripts and notes were made to help inform subsequent steps in the analysis. The second step was axial coding, where codes were condensed and sorted; similar phenomena were grouped together and relationships between codes were explored and mapped. Finally, selective coding resulted in a final list of five higher-level themes and associated categories that captured the main ideas discussed by participants in relation to their experiences with the disease and medication use. This list was reviewed in relation to existing literature and theories on this topic and additional themes or categories were added. All six transcripts were subsequently reviewed and recoded according to these themes. Furthermore, APAB members provided input on study results during interim and final presentations on elucidated themes.

Results

We held six focus group interactions with a total of 27 participants, including 17 women and 10 men. As shown in Table 1, our sampling strategy achieved a broad representation of diagnoses, including RA, psoriatic arthritis (PsA) and ankylosing spondylitis (AS), as well as comparatively under-represented conditions in this research area (eg, Sjögren's syndrome and granulomatosis with polyangiitis). Nine participants had been living with IA for 5 years or less and 18 participants for over 5 years. Table 1 also shows current IA medications taken by participants; methotrexate was the most common medication taken by participants (n=15), either alone or in combination with another DMARD. A total of 13 participants were taking biologic therapy.

Five themes emerged from the analyses. The first two themes of 1) adapting to life with IA and 2) the complexities and dynamic nature of taking medications described the interrelated experiences of living with and taking medications for IA, with illustrative quotes for each theme and category provided in Table 2. Then three overlapping and interlocking themes of 3) developing lifestyle strategies for

Table 1 Characteristics of focus group participants

| Characteristics | Female (n=17) | Male (n=10) |
|---|---------------|-------------|
| Demographics | | |
| Age at focus group (years) | | |
| 20–29 | 2 | – |
| 30–39 | 1 | 2 |
| 40–49 | 3 | 2 |
| 50–59 | 3 | 3 |
| 60–69 | 5 | 2 |
| 70–79 | 3 | – |
| Preferred not to report | – | 1 |
| Highest level of education completed | | |
| High school or equivalent | – | 1 |
| Vocational/technical school | 3 | 1 |
| College/university | 14 | 8 |
| Time since inflammatory arthritis diagnosis | | |
| ≤ 1 year | 2 | – |
| 2–5 years | 3 | 4 |
| 6–9 years | 2 | 1 |
| 10+ years | 10 | 5 |
| Ethnicity | | |
| Caucasian | 11 | 7 |
| Asian | 4 | 1 |
| Others | 2 | 2 |
| Inflammatory arthritis diagnosis ^a | | |
| Ankylosing spondylitis | 4 | 1 |
| Adult-onset Still's disease | 1 | – |
| Gout | 1 | 1 |
| Granulomatosis with polyangiitis | 1 | – |
| Psoriatic arthritis | – | 5 |
| Rheumatoid arthritis | 11 | 4 |
| Sjögren's syndrome | 1 | – |
| Systemic lupus erythematosus | 1 | – |
| Current medication(s)^{a,b} | | |
| Traditional DMARDs | | |
| Azathioprine | 1 | – |
| Cyclosporine | 1 | – |
| Gold | 3 | – |
| Hydroxychloroquine | 3 | 3 |
| Methotrexate | 10 | 5 |
| Mycophenolate mofetil | 1 | – |
| Sulfasalazine | 1 | 1 |
| Biologic DMARDs | | |
| Abatacept | 1 | – |
| Adalimumab | 1 | 1 |
| Etanercept | 1 | 5 |
| Golimumab | 3 | – |
| Rituximab | 1 | – |
| Urate-lowering therapy | | |
| Allopurinol | 1 | – |
| Febuxostat | – | 1 |

Notes: ^aMore than one diagnosis or medication could be reported per participant.

^bPrescribed at time of focus group.

Abbreviation: DMARD, disease-modifying anti-rheumatic drug.

medication use, 4) becoming informed about medications and 5) receiving support collectively capture participants' perspectives on facilitators to medication use, as illustrated in quotes in Table 3.

Table 2 Illustrative quotes for themes on living with and taking medications for inflammatory arthritis**Theme 1: Adapting to life with inflammatory arthritis**

| Categories | Quotes |
|---|--|
| 1. Being diagnosed | "I was diagnosed with psoriasis in 2003... I think the lack of dealing with that head on made me, or caused it to have psoriatic arthritis." (PsA, etanercept) |
| 2. Losing identity | "...I've had to adjust a lot and it seems to be a continual process of adjusting to your new normal. And you've had to basically grieve the loss of your old self and get over yourself." (RA, SjS, cyclosporine, adalimumab) |
| 3. Accepting the disease | "And I too being diagnosed so young, I kept thinking I'm going to get past this. And I bet you it took me 25 years before I finally gripped that I've got this for life and that I'm going to have bad days and good days. So that was the real turning point for me where I finally started to be more accepting of it." (RA, methotrexate, golimumab) |
| 4. Experiencing personal, social and career impacts | "...and even the social implications because of the fact that a lot of times it's episodic or unpredictable. You can get up one day and you're feeling fine and the next day could be, like, okay I can't get up. And so even the implications for working or implications for social. You make plans with people and you have to cancel or postpone or something like that. Where before... So it does impact your life. It all impacts your feelings because it's emotions and you do go through a lot of emotions." (RA, SjS, cyclosporine, adalimumab) |

Theme 2: Complexities and dynamic nature of taking medications

| | |
|---|---|
| 1. Taking medications | <p>Managing multiple medications</p> <p>"...we started this whole regime of three or four drugs and the side effects on all of those." (RA, methotrexate, rituximab)</p> <p>Using needles</p> <p>"I'm going to have to psych myself up to do it. Even though I'm good with the needle and it doesn't hurt at all, it's a real psych up to do it. I always end up putting it all to the last thing at night." (RA, hydroxychloroquine, methotrexate, sulfasalazine)</p> <p>Frequency of taking medications</p> <p>"...I'd like to tell [drug companies] to make some pills that are more sort of like a methotrexate that you take once a week rather than every day or whatever. Make it last longer but somehow design it and such so that it's slow release." (RA, methotrexate)</p> |
| 2. Trialing medications | <p>"...if I'm not feeling well on the drugs that I'm on, that's when I'm back to see [my doctor] and then she reviews it and switches me to something else. But she doesn't keep me indefinitely on the same drug." (RA, methotrexate, golimumab)</p> <p>"Right now we're playing around too. I might have to switch in, like, three months to a different biologic. So that's not fun and always the daunting question of, 'What do you want to do?' I don't know what I want to do. I just want this to get better. That's all I want! Like, I don't care. Put me on what works." (AS, golimumab)</p> |
| 3. Being able to afford medications/getting access to medications | <p>"For me it's the cost... Based on what is covered... Because most of my medications are covered... The ones that aren't, I sort of intermittently take because I can't afford them." (GPA, methotrexate)</p> <p>"I understand that there is a protocol in place because the biologics are so expensive. But the suffering that we go through... and my rheumatologist is apologizing because she just wants to get me on the biologics but it's such a process to get there. And I think that's cruel and unusual punishment." (RA, gold)</p> |
| 4. Dealing with unwanted effects of medications | <p>Side effects</p> <p>"... I've had all kinds of strange illnesses and infections and rashes. I've had whooping cough, I've had pneumonia..." (AS, adult-onset Still's disease, methotrexate, sulfasalazine, etanercept)</p> <p>Long-term effects</p> <p>"I worry about long-term effects, being nauseous pretty well all the time. It feels sometimes like I just have a belly full of poison and I should purge it. That's what it feels like." (RA, hydroxychloroquine, methotrexate, sulfasalazine)</p> |
| 5. Not taking medications | <p>Intentionally</p> <p>"So I think there is a lot of psychological stuff that holds people back from taking the drugs because they do not want to accept this chronic condition." (PsA, methotrexate, etanercept)</p> <p>Unintentionally</p> <p>"Because if I'm out with friends or if I'm really tired after a long week, I will forget." (RA, hydroxychloroquine, methotrexate, tocilizumab)</p> |
| 6. Feeling better with medications | <p>"It's like a cloud has been lifted and I can function." (PsA, methotrexate, adalimumab)</p> <p>"And other times I really feel like it's making a big difference..." (RA, hydroxychloroquine, methotrexate, sulfasalazine)</p> |

Abbreviations: PsA, psoriatic arthritis; AS, ankylosing spondylitis; RA, rheumatoid arthritis; GPA, granulomatosis with polyangiitis.

Theme 1: Adapting to life with inflammatory arthritis

The theme of adapting to life with IA was captured in four categories: 1) being diagnosed, 2) losing identity,

3) accepting the disease and 4) experiencing personal, social and career impacts. At the outset of each focus group interaction, participants detailed receiving their diagnosis, including struggling to deal with their diagnoses and searching for

Table 3 Illustrative quotes for themes on strategies and supports for medication use in inflammatory arthritis**Theme 3: Developing lifestyle strategies for medication use**

| Categories | Quotes |
|--|--|
| 1. Making medication taking a routine | <p>"I self-administer my own meds with a pill case and I do that every morning. My regime is that I get my husband off to work and I get my meds ready in my pill case and I start in the morning. I start taking water and my meds." (RA, methotrexate)</p> <p>"And because I only take it morning and evening it's easier to be routine. But with my Enbrel and methotrexate, I have to take that once a week. So I try to keep it the same day so that I remember to take it." (AS, Adult-onset Still's disease, methotrexate, sulfasalazine, etanercept)</p> |
| 2. Planning ahead | <p>"But that's how I do it to make sure that I'm not running around taking a drug, feeling terrible and then you don't want to take it. So I always make sure there's a dead time." (PsA, methotrexate, etanercept)</p> <p>"Always make sure that you have some with you in case you forget to take it." (AS, adult-onset Still's disease, methotrexate, sulfasalazine, etanercept)</p> <p>"...okay, inject [methotrexate] Friday and you know you can be sick on Saturday." (RA, rituximab)</p> |
| 3. Having physical reminders and prompts | <p>"I would take that [medication] with my toothbrush. My pills would be bedside my coffee cup in another container and I would know that it would happen." (RA, methotrexate, rituximab)</p> |
| 4. Organizational tools | <p>"I have all my medication put in a bubble pack. That way I do not have to figure out what I'm going to take." (GPA, methotrexate)</p> <p>"I use a paper calendar. I put it in there. Every week there's a notation there to remind me because I inject once a week" (PsA, gout, etanercept, febuxostat)</p> |
| 5. Personal attitude | <p>"That's my biggest tool is trying to keep the spirit. I'm very determined that I'm going to try to make this be the least amount of impact. Even though I might never really get better, trying to stay chipper is more powerful than anything." (RA, hydroxychloroquine, methotrexate, sulfasalazine)</p> |

Theme 4: Becoming informed about medications

| | |
|---|---|
| 1. Information at the time of diagnosis | <p>"I just think that the patient education part is lacking in the beginning when I found out and that probably would have helped me, like, okay I have to take my medication." (AS, hydroxychloroquine, golimumab)</p> <p>"I would like to just highlight the education part of it. I think if you know what you're dealing with, what all the tools are right from the outset, that you can, most people can intellectualize their routine and how important it is and then find a tool that works." (PsA, gout, etanercept, febuxostat)</p> |
| 2. Information needs | <p>How to take medication</p> <p>"You could eat the wrong things in combinations with some medications if you don't know that you're not supposed to eat or drink, you know, like alcohol or whatever." (RA, SjS, cyclosporine, adalimumab)</p> <p>Side effects</p> <p>"Explain to me why it says I can possibly get cancer from this drug. Because I'm sure it's a reason like someone, I mean we've all googled it. Someone was taking the drug while they got cancer. But when I read it on my box of Enbrel, I'm thinking, 'oh dear this thing is going to give me cancer?' All of that information would be very helpful. I'd be less frightened to take Enbrel every week if I really knew why it said [that]..." (AS, etanercept)</p> <p>How the medication works/Importance of the medication</p> <p>"The knowledge is basically why I am taking this medication for. So that I understand that basically what it's going to do to my body. Is it going to work? And just basically educating myself from that drug and understanding how it's going to work in my body." (PsA, etanercept)</p> <p>Information from other patients</p> <p>"I guess there would have to be an initiative to, I guess, people like us who write down their experiences and it is verified by their doctors that this is their experience." (RA, hydroxychloroquine)</p> <p>Information for family members and caregivers</p> <p>"...But you go through this personal trauma and when your family is not as informed as you are, you know..." (RA, gold)</p> <p>Getting trusted information</p> <p>"And one thing for me that's really important is knowing that the information is trusted. And I know sometimes... I've gone to the Mayo Clinic or I've gone to Live Strong or some different sites like that. And comments are helpful when, you know, sometimes you read the comments and sometimes they're helpful and sometimes they're not. And what would be great would be if there were sort of doctor-approved comments or doctor-approved experiences." (RA, hydroxychloroquine)</p> <p>"...like it has to come from a reliable source on the Internet and not everybody knows what reliable sources are." (RA, SjS, cyclosporine, adalimumab)</p> |
| 3. Means of receiving information | <p>Arthritis group classes</p> <p>"Not everybody will do it [medication use] the same way. But I think having somebody here [at the arthritis centre] like one of the resource people emphasizing the tools because I don't remember anyone talking to me about how I will establish good habit and regimen and how to maintain it. I don't remember that happening in a conversation ever. I just figured it out for myself." (PsA, gout, etanercept, febuxostat)</p> |

(Continued)

Table 3 (Continued)

Theme 4: Becoming informed about medications

| Categories | Quotes |
|------------|---|
| | <p>Written resources</p> <p>"I find it helpful to have handouts, like to have a hard copy of something and not just in their head information because my head gets overloaded." (RA, methotrexate)</p> <p>Digital technologies</p> <p>"Well I use my rheumatologist and then we go through pros and cons. Then I go away and I always do research on the Internet." (PsA, methotrexate, etanercept)</p> <p>"So I think just having some...even maybe an app that would educate you about certain things. Like the knowledge that would come from a nurse or dietician." (RA, SJS, cyclosporine, adalimumab)</p> |

Theme 5: Receiving support

| | |
|---|---|
| 1. Support from health care team members | <p>Rheumatologist</p> <p>"Well I use my rheumatologist and then we go through pros and cons." (PsA, methotrexate, etanercept)</p> <p>Nurse</p> <p>"And also what helped when I was on Humira, a nurse came to help me with my injections. And so it was just like in the beginning. But that helped a lot just, you know, her teaching me." (AS, hydroxychloroquine, golimumab)</p> <p>Pharmacist</p> <p>"For me it's my pharmacist. I can ask them anything. They will answer me or if I need a printout of certain information of a drug then they will get that for me as well as I don't have access to the internet or a computer." (GPA, methotrexate)</p> |
| 1a. Challenges with health care team members | <p>Need for more time</p> <p>"I would have liked to have more of that [information] from both of my rheumatologists. I mean I think once I was diagnosed with ankylosing spondylitis, I then went home and looked on the internet what that was. I know I'm seeing a rheumatologist. This is something arthritic but can you spend 15–20 minutes explaining to me a disease that is going to affect me for the rest of my life. Not, 'you've most likely got ankylosing spondylitis. Here's Enbrel and let's try this.'" (AS, etanercept)</p> <p>"It would be nice if they [pharmacists] had more time to help you. But they're so busy. You go to them and, okay, they just kind of like read off what it says and they give it to you. 'Have you taken this before?'" (AS, hydroxychloroquine, golimumab)</p> <p>Communication between health care team members</p> <p>"My GP really knows nothing about what's going on except the faxes that she gets. My two rheumatologists do decently, you know, and then I saw somebody...and he's trying to talk to one but the other one is not talking. So you're doing a lot of work. It sometimes feels like a full-time job and, okay, who is going to treat me next. What am I doing?" (AS, etanercept)</p> |
| 2. Support from family | <p>"My husband is the only one who can give it [the injection] to me. We do it at home." (RA, gold)</p> <p>"And I think my kids because they are teenagers and they are always texting so I think they can text me and remind me to take anything." (RA, methotrexate)</p> <p>"But my mom constantly text messages me because she knows how much I dislike my medications and she's constantly on me with being 'Have you taken your pill?'" (AS, golimumab)</p> |
| 3. Digital technologies to support medication use | <p>Internet</p> <p>"Well I use my rheumatologist and then we go through pros and cons. Then I go away and I always do research on the internet because I'm always challenging the status quo." (PsA, methotrexate, etanercept)</p> <p>Smartphones</p> <p>"...the fact that most people now and especially baby boomers coming on stream who will likely get arthritis. They all have iPhones..." (RA, methotrexate, rituximab)</p> |
| 3a. Desired features of health apps | <p>"If you had an app that was kind of like the Fitbit app where you could organize all your medications with the dosage and the days and then have it just set reminders ... all in one. Because right now I have a calendar, I have a reminder like on my phone for time. I have someone text messaging me and I have the pharmacist calling. So if that could all be combined in one, that would be so incredibly helpful... If it was linked [to websites] where you can actually look at this is the side effect and these are the drug interactions... almost like an information thing. That would be a lot more helpful than having to go to all these things individually." (AS, golimumab)</p> <p>"I would like an Apple application. There are a couple out there and all they really do is remind you or they remind the person that you assign if you don't take your medication. But for me sometimes I push it back earlier or later. So I like the reminder of 'hey take your medication', and then actually ask, 'oh did you take your medication or did you take it the next day? And why did you change it?'" (PsA, methotrexate, adalimumab)</p> <p>"The other thing would be to do a non-techy app thing, which would be to develop a wheel that's divided into seven pieces of pie, so to speak, which has each day of the week on it and with only day being revealed and you turn it each day. And in there it says exactly what you're supposed to be taking that day." (RA, hydroxychloroquine)</p> |

(Continued)

Table 3 (Continued)**Theme 5: Receiving support**

| Categories | Quotes |
|-------------------|--|
| | "I would say, you know, an app where nobody sends you a message but it syncs between the pharmacy, my phone, my insurer, so that I'm not getting a message necessarily. But, you know, every day I've got to slide, okay, yeah I took my morning pills, I took my afternoon pills. When I've taken my Enbrel... something pops up and says, 'Would you like the pharmacy to re-order any more for you? Slide yes.' That could possibly report back even to my rheumatologist for how often I'm taking my drugs... It could link up to your insurer." (AS, etanercept) |
| 4. Other supports | "I was set up with well not a nurse but the drug company themselves. And they did everything for me from the special authority, like chasing down [my rheumatologist] to help to see if they processed it." (AS, hydroxychloroquine, golimumab) "For example, when I started on Enbrel I got an information kit in the United States. That's a whole different story. But you should see what you got. You got this great big fancy case and you got cold packs and a little travel thing. They must have put \$100 into that little thing so that you would buy their Enbrel." (PsA, etanercept) |

Abbreviations: PsA, psoriatic arthritis; AS, ankylosing spondylitis; RA, rheumatoid arthritis; GPA, granulomatosis with polyangiitis.

reasons for the onset of their condition – "I mean why did this happen to me? Is it genetic? Is it something that I ate?" (RA, methotrexate). Many also described the adjustment – both initially from being a healthy individual to having a diagnosis and the associated loss of identity, as well as with respect to long-term acceptance of living with a chronic condition. Through these, participants touched on "...big restrictions..." (RA, gold) imposed on them by their diseases, with impacts on families: "I've got a young kid and another one coming. So it's tough for me to do things at home with them" (AS, etanercept), on friendships: "...I think I've lost friends over it..." (RA, gold) and on careers: "[Doctor] had said a while ago to apply for disability and I didn't want to. I wanted to keep working" (AS, adult-onset Still's disease, methotrexate, sulfasalazine, etanercept).

Theme 2: Complexities and dynamic nature of taking medications for inflammatory arthritis

Intertwined with participants' experiences of their IA diagnoses were their experiences with medications, which were summed across six categories as complex and dynamic: "Every single drug they tried me on I have either a physical reaction or worse. So it's been a very long frustrating journey" (RA, gold). Four categories – 1) taking medications, 2) trying different medications, 3) being able to afford medications/accessing expensive medications and 4) experiencing unwanted effects of medications – capture the challenges experienced by participants in taking medications for their IA. For example, the first category included issues on managing multiple medications and administering medications, particularly the use of needles with the sentiment "...I hate needles..." (AS, hydroxychloroquine, golimumab) echoed across focus groups. Being able to afford medications or the process of accessing medications (particularly

biologics) was also identified as a challenge, as well as experiencing unwanted side effects of medications such as injection site inflammation, allergic reactions, nausea, infections and complications associated with other organs (eg, neurological complications) and worrying about long-term effects of chronic medication use. The fifth category, not taking medications, captures both intentional – "...I was very anti-drug. So when I was diagnosed, I was actually given a prescription for methotrexate, which I did not use" (RA, SJS, cyclosporine, adalimumab) – and non-intentional – "Because if I'm out with friends or if I'm really tired after a long week, I will forget" (RA, hydroxychloroquine, methotrexate, tocilizumab) reasons why participants did not take IA medications. Finally, despite challenges, we also identified a sixth category of feeling better with medications and how medications had positively impacted their IA: "It's like a cloud has been lifted and I can function" (PsA, methotrexate, adalimumab).

Theme 3: Developing lifestyle strategies for medication use

The third theme captures lifestyle strategies, both already implemented and suggested, by participants that support medication use. Consistent across focus groups was making a routine of taking medication, for example, at the same time each day or each week, or combining it with other daily activities that can serve as a reminder: "make that medicine so much part of your life that you do not think about it. It's like eating." (RA, methotrexate, rituximab). Facilitating the development of routines was planning ahead, for example, injecting methotrexate on weekends and having medications on hand at all times, as well as having physical reminders and prompts, such as placing medications with routine household items (eg, beside a toothbrush). Organizational tools such as blister packs obtained from pharmacies as well as pill cases were also found to be useful, along with calendars.

Theme 4: Becoming informed about medications

In the fourth theme, participants discussed various aspects of becoming informed about IA medications across three categories of: 1) receiving information at the time of diagnosis, 2) information needs and 3) means of receiving information. Participants touched on the importance of receiving sufficient information about medication at the time of IA diagnosis which some felt was lacking when they were diagnosed. Various information needs were captured in the second category including how to take the medication, side effects, as well as how the medication works and placing an emphasis on its importance: “I think the big one is impressing on a lot of people how important it is to take your medication and that missing a dose can be pretty disastrous for some people” (PsA, etanercept). Hearing about other patients’ experiences of living with IA and using prescribed medications was viewed mostly positively: “...and then from people who experience it. Just say, ‘Hey this is my experience and, you know, how it could progress. You can do this’” (AS, hydroxychloroquine, golimumab). In addition to their own information needs, some felt that education of family members would also be helpful:

And if I could add I think the education of your spouse or caregiver to know that having the medications needed to be done pretty well at the same time is going to make it easier for you to be able to make the commitments for social activities and things and for that to be part of the education process. It helps to just keep the whole thing on course, right? (RA, methotrexate, sulfasalazine).

Aside from the type of information, participants also emphasized the importance of being able to recognize whether information was credible or trustworthy; this was particularly important for information collected from the Internet. The final category identified means of receiving information about medications, including group classes, written resources and in particular, digital technologies.

Theme 5: Receiving support

This theme describes a number of means by which patients receive support, including functional and emotional, from individuals such as health care providers and family members as well as other tangible supports. The first category captures the importance of education from participants’ health care providers, including rheumatologists and nurses as well as pharmacists. However, participants also noted challenges with health encounters, particularly the need for more time, especially when explaining their conditions and

medications. The second category captures the importance of support from family, whether it is reminding participants to take their medications or helping administer medications. The third category captures the role of digital technologies in supporting medication use. Participants identified two main technologies – the Internet and smartphones – that they used, as well as anticipate other patients with IA using. Health apps were also discussed and within this subcategory participants described desired features and functions of medication taking apps, such as setting more detailed reminders for multiple medications (eg, including dosage information), cataloging information about missed or altered doses, recording side effects and synchronizing with the pharmacy and insurance company. Finally, within the fourth category, some participants also noted other supports, including patient support programs provided by drug companies for the use of biologics:

I was set up with, well not a nurse but the drug company themselves. And they did everything for me from the special authority, like chasing down [my rheumatologist] to help to see if they processed it (AS, hydroxychloroquine, golimumab).

Relationship between themes

From our analyses, there are two essential considerations for adherence – information (as captured in Theme 4) and support (as captured in Theme 5) and we outline a framework for patient-oriented adherence interventions for IA. In the framework shown in Figure 1, actionable targets for adherence interventions for IA represent potential areas for designing patient-oriented adherence interventions. These areas may be in the form of receiving support as captured by Theme 5. For example, an adherence intervention may be designed to facilitate encounters with health care team members to optimize patient support. Another target area for an adherence intervention for IA is through means of receiving support as captured by Theme 4, category 3. With this, an adherence intervention may be designed around arthritis group classes, written resources, or digital technologies as means to deliver information. Outside of the actionable targets but also key to this framework is Theme 4’s category 1 of “information needs” which represents inputs for these actionable targets in terms of patient-identified knowledge gaps that could be readily addressed by the interventions.

Discussion

We conducted a patient-oriented qualitative study using an interactive focus group activity to better understand IA patients’ perspectives on and experiences with chronic

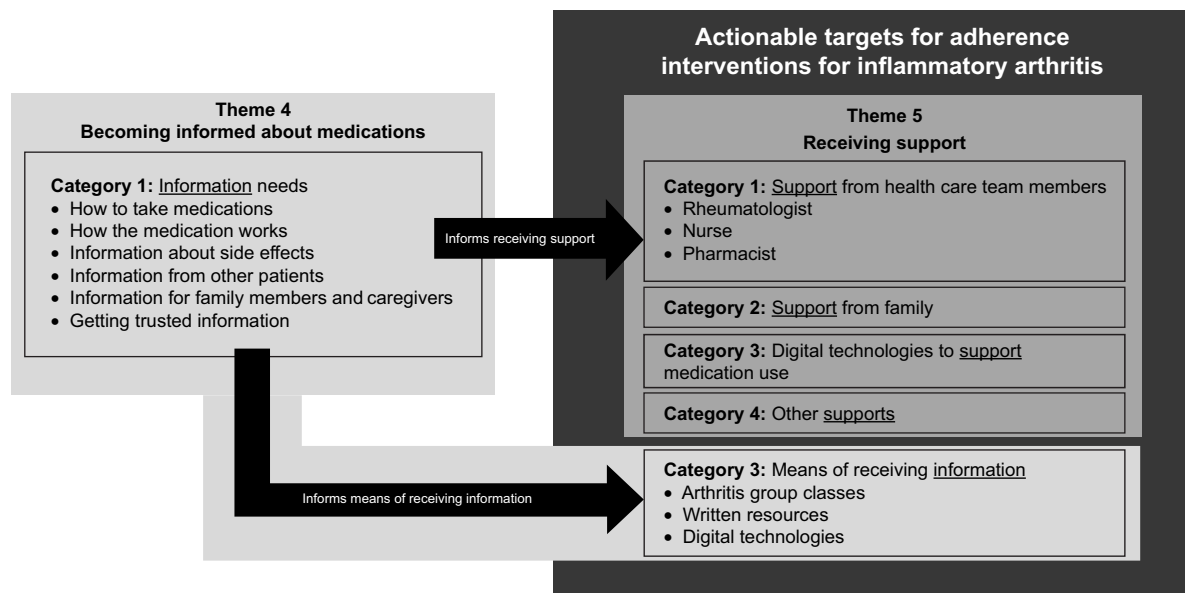


Figure 1 Framework for patient-oriented adherence interventions for inflammatory arthritis based on relationship between study themes on becoming informed about medications (Theme 4) and receiving support (Theme 5).

medication use. Findings of this study conducted in partnership with a national arthritis consumer group include participant accounts of the complexities and dynamic nature of living with and taking medications for IA. Our study also confirms the importance of having information and receiving support as key facilitators of taking medication and has expanded on these with categories describing when information should be delivered, what type of information is needed and the means of receiving information. Aside from identifying individuals who provide functional and emotional support (eg, health care team and family members), participants also identified other tangible supports for medication use including digital technologies. Taking these together lends itself to a framework for patient-oriented adherence interventions for IA that encompasses means of receiving information and support as actionable targets for patient-oriented adherence interventions for IA.

Aside from confirming recommendations, including those from the European League Against Rheumatism on patient education for people with IA as priority care,¹⁹ our finding on the importance of becoming informed about medications supports results from our prior systematic review of medication adherence interventions in IA, that those shown to have an impact on adherence outcomes included an educational component.¹¹ Perhaps more valuable, the current qualitative study identifies tangible areas for education development drawn directly from patients with IA such as when information should be delivered (ie, at the time of diagnosis) and what information is desired. With respect to the latter, our findings suggest that educational tools that effectively present how to take medications, how

medications work, including potential benefits in addition to the risks may be helpful to individuals with IA. Furthermore, patients with IA emphasized the need for information to be drawn from the experiences of other patients, which has been echoed in studies in RA²⁰ and SLE²¹ populations. For example, utilizing other patients' experiences may help to alleviate apprehensions about medication side effects, as identified in prior studies.^{22,23} Lastly, patient preferences for information delivery extended beyond the typical health care setting to patient groups, written resources and digital technologies, thereby highlighting future avenues for intervention development. Such informational tools and resources may be further bolstered by behavioral strategies that support daily medication use. Indeed, participants in the current study described specific strategies used to overcome the daily logistical challenges encountered with long-term medication use.

Study participants with IA indicated multiple opportunities to optimize medication adherence through functional and/or emotional support, namely by means of health care professionals, family and digital technologies. Indeed, the important role of health care providers in supporting medication use has been shown in recent qualitative syntheses among patients with RA,²⁰ systemic autoimmune rheumatic diseases,²⁴ and gout.²⁵ Importantly, our study adds a collective perspective from IA patients, including those living with less common forms of IA, on some of the challenges with health care providers, including the need for more time during encounters as well as improved communication, particularly when multiple providers are involved in a patient's care. Also, similar to prior qualitative inquiry in IA,^{22,23} our focus groups

articulated how family can provide reminders and assist with administering injections, all while having a deeper insight into the personal experiences and needs of the individual with IA. Aside from identifying the supporting role of family members, participants in our study also identified the need for information to be delivered to family members themselves.

In terms of other tangible supports, study participants identified the role of digital technologies which have indeed gained traction in supporting care in rheumatology, with implications for medication use.²⁶ With health apps forming a sub-category within this theme, participants identified a number of desired features such as the ability to organize medications or serve as a means to communicate a patient's medication taking to their rheumatologist or pharmacist. Indeed, the ubiquitous and accessible nature of digital technologies makes for potential adherence support tools. However, there remains need for work in this area. We conducted a scoping review and quality assessment and identified 704 smartphone medication adherence apps in Apple and Android platforms and noted that the primary function of the majority of apps was sending a reminder or alert to users to take their medication.²⁷ Apps specific to rheumatic diseases, such as SLE²⁸ and RA,²⁹ however focus on monitoring disease activity rather than medication use. As such, subsequent directions to optimize medication adherence may include building apps specific to IA that incorporate patient preferences such as dynamic follow-up after the initial dose reminder, access to reliable drug information and synchronization with pharmacies and insurance companies.

Strengths and limitations

The strengths of our study deserve comment. Unique to our study is the patient-oriented approach used to explore medication use among individuals with IA. Engaging APAB, a renowned arthritis patient organization in Canada, throughout the research enriched the execution of this study, including input on the use of patient-friendly language in the topic guide, opportunity to pilot and refine the focus group and embedded activity, as well as providing a "patient lens" to the interpretation and reporting of the findings. Further, strengthening our study is the use of focus groups, as group processes and interactions more readily facilitate participants' exploration and clarification of views and opinions as compared with one-on-one interviews, thereby enhancing the depth and breadth of the information obtained.^{14,15} Next, while the majority of focus group participants were individuals with RA, we were additionally able to recruit individuals with less common forms of IA that have generally been underrepresented in prior qualitative research in this area.

Moreover, our findings across these patient populations suggest largely shared experiences and perspectives on the topic, thereby broadening the applicability of our findings.

Nevertheless, potential limitations of our study also warrant discussion. Participant recruitment primarily took place in the metropolitan city of Vancouver; however, those living in rural communities in BC were also invited to participate through phone or videoconference, thereby broadening the representation of our sample and increasing the generalizability of our findings. Next, those who voluntarily participated in our study may be more likely to use their medications as prescribed and thus might not reflect the perspectives of "non-adherent" individuals. However, this is an inherent limitation of all voluntary research studies and is not limited to the current study.

Conclusion

This patient-oriented qualitative study conducted in the Canadian province of BC has enriched our understanding of the complexities of medication use in IA. Beyond confirming the roles of information and support as facilitators of medication use, we have established a framework that identifies practical and actionable targets for patient-oriented adherence interventions for IA.

Data availability

The datasets generated and/or analyzed during the current study are not publicly available as they contain information that could compromise participant privacy. Nevertheless, these data are available from the corresponding author on reasonable request.

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Ethical approval

Ethics approval was obtained from the Behavioral Research Ethics Board at the University of British Columbia (protocol

#H14-01460). All participants provided written informed consent.

Author contributions

All authors meet the conditions for authorship according to the IMCJE guidelines. All authors contributed toward data analysis, drafting and critically revising the paper and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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