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Article type : Original Article

## **Patient and caregiver priorities for medication adherence in gout, osteoporosis and rheumatoid arthritis: nominal group technique**

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This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1002/acr.24032

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### **Financial support**

The work reported in this manuscript was supported by a 2018 Arthritis Australia Project Grant.

## Abstract

**Objectives** This study aimed to identify and prioritize factors important to patients and caregivers with regard to medication adherence in gout, osteoporosis (OP) and rheumatoid arthritis (RA), and to describe the reasons for their decisions.

**Methods** Patients with gout, OP and RA, and their caregivers purposively sampled from five rheumatology clinics in Australia, identified and ranked factors considered important for medication adherence using nominal group technique and discussed their decisions. An importance score (scale 0-1) was calculated, and qualitative data were analysed thematically.

**Results** From 14 focus groups, 82 participants (67 patients, 15 caregivers) identified 49 factors. The top five factors based on the ranking of all participants were trust in doctor (importance score 0.46), medication effectiveness (0.31), doctor's knowledge (0.25), side effects (0.23), medication taking routine (0.13). The order of the ranking varied by participant groupings with patients ranking trust in doctor the highest whilst caregivers ranked side effects the highest. Five themes reflecting the reasons for factors influencing adherence were: motivation and certainty in supportive individualised care; living well and restoring function; fear of toxicity and cumulative harm; seeking control and involvement; and unnecessarily difficult and inaccessible.

**Conclusions** Factors related to the doctor, medication properties and patients' medication knowledge and routine were important for adherence. Strengthening doctor-patient trust and partnership, managing side effects, and empowering patients with knowledge and skills for medicine-taking could enhance medication adherence in patients with rheumatic conditions.

**Keywords** Adherence, focus groups, osteoporosis, rheumatoid arthritis, gout

### **Significance and Innovations**

- Trust in the doctor and doctor's knowledge, medication effectiveness and side effects and patients' medication taking routine and knowledge were factors important to patients and caregivers for medication adherence.
- Strengthening doctor-patient trust, balancing medication benefits and harms, and empowering patients with medication knowledge and skills to form effective routines are potential solutions for medication non-adherence that require further investigation.

### **Introduction**

Gout, osteoporosis (OP) and rheumatoid arthritis (RA) are common rheumatic conditions associated with pain, reduced quality of life and premature mortality (1-6). Medications can reduce symptoms, decrease flares and prevent joint damage in gout and RA, and fracture risk is roughly halved by OP treatments (7-11). However, adherence is low in these conditions.

For example, adherence may range from 10-46% in gout and 30-80% in RA (12, 13).

Approximately 50% of osteoporotic women discontinue prescribed treatment in 1 year (14).

Non-adherence is associated with increased disease activity, long-term joint damage in gout and RA and increased fractures in OP (12, 15-19).

Non-adherence is complex and multi-factorial (12, 13, 20, 21) and taking long-term medications for rheumatic conditions is challenging. Five dimensions of adherence are described by the World Health Organization, factors affecting adherence can be divided into: social/economic (e.g. medication cost, health literacy); health care team and system (e.g.

doctor-patient relationship); condition (e.g. symptom severity); therapy (e.g. immediacy of benefits, side effects); and patient related factors (e.g. knowledge, beliefs, self-efficacy) (22).

No adherence strategy has been effective across all patients, conditions and settings (23, 24).

It remains uncertain whether existing adherence interventions address the priorities and concerns of patients with rheumatic conditions. Caregivers also offer important insight into the patient's health status and may have a role in supporting adherence including organizing and administering medications (25). Because of this, the caregiver's perspective adds further to understanding adherence.

As part of the Outcome Measures in Rheumatology (OMERACT) – Adherence initiative (26), this study aimed to identify and prioritize factors influencing adherence for patients and caregivers in gout, OP and RA and to describe the reasons for these decisions. This can inform the development of patient-centered interventions for medication adherence in rheumatology and enable adequate evaluation of their effectiveness.

## **Patients and Methods**

### *Participant recruitment and selection*

Patients with gout, OP and RA and their caregivers (family member or friend involved in their care) were recruited from five rheumatology clinics in New South Wales, Australia.

The clinics were in rural, regional and metropolitan areas in private and public practices.

Participants were purposively sampled for diversity in demographic (age, sex, cultural and socio-economic backgrounds) and clinical characteristics (severity and duration of condition, type of medications), and experience with medications (level of adherence as

perceived by the doctor). Participants were eligible if they were aged 18 years or older, spoke English, and were prescribed disease-modifying anti-rheumatic drugs (DMARDs), urate-lowering therapy, anti-resorptive or anabolic therapy for OP. \$35 USD in local currency was offered to participants for travel expenses. Ethics approval was obtained for all participating sites. All participants provided informed consent.

### *Data collection*

The study combined two methods: focus groups and modified nominal group technique (27, 28), an approach used to generate patient and caregiver priorities in outcomes research (29, 30). The groups were convened from February to October 2018 in rooms external to rheumatology clinics. Rheumatologist AK, with training in qualitative research, facilitated all groups with a co-facilitator (KT/MC/KM/MG/SB/AT), who took field notes. The modified nominal group technique involved structured discussion to generate a list of ideas followed by a single round of individual ranking. This takes into account each participants' opinions and encourages equal participation (28). The focus group method was used explore participants' reasons for their choices. Each two hour session included: 1) discussion on experiences with medications, involvement in decision making, strategies used to enhance adherence, 2) group generation of factors important for adherence, which was supplemented with factors from previous groups and a literature review of adherence interventions in rheumatology (allowing participants to consider and discuss a greater number of factors)3) individual ranking of each factor; and 4) discussion of the reasons for rankings. The question guide (Supplemental Table 1) was developed with patient research partners (MDW/VE/MG/MSV) and pilot tested. Groups were convened by condition when feasible (four groups) and continued until data saturation (when no new ideas or factors were

identified in consecutive groups). Each patient completed the 5-item version of the Compliance Questionnaire in Rheumatology (CQR5) to estimate the level of adherence of the study population (31). Each group was conducted in English, audio-taped and transcribed verbatim. Participants were able to review and revise their transcripts.

#### *Data analysis*

*Qualitative analysis:* AK recorded field notes and used thematic analysis to inductively develop preliminary themes that explained participants' rankings. Thematic analysis is a form of qualitative analysis which captures patterns of shared meaning or 'themes'. Themes that emerge unite individuals' perspectives and experiences to form a comprehensive picture of the group's experience (27). The inductive approach is a 'bottom up' approach which begins from the data without a pre-existing model or theory (27). Preliminary themes were discussed and refined with co-authors and co-facilitators KT and AT for researcher triangulation. Transcripts were entered into HyperRESEARCH software (ResearchWare Inc. Version 4.0.1, Randolph, MA). AK coded transcripts line-by-line and revised preliminary themes to ensure the full range and depth of the data was captured. Results were sent to participants for feedback. The Consolidated Criteria for Reporting Qualitative Health Research was used in the reporting of this study (32) (Supplementary Table 2).

*Nominal group ranking:* An importance score (IS) which is the average of the reciprocal rankings was calculated for each factor. The reciprocal ranking is 1 over the ranking assigned by the participant for a factor. For example, if "side effects" is ranked 1<sup>st</sup> by one participant and 3<sup>rd</sup> by another, the reciprocal rankings will be 1 and 1/3 respectively. If the factor was not ranked by the participant, the reciprocal ranking was given a value of 0. The average of these



three reciprocal rankings 0.44, is the IS. The IS ranges from 0 to 1, with higher scores reflecting factors that are more valued by the participants. The IS incorporated 1) the importance given to the factor by the rank position and 2) the consistency of being nominated by participants. The IS was calculated for the entire group and analyzed in subgroups (gout/OP/RA-based on the predominant diagnosis of each participant; patients/caregivers; male/female). The analysis was conducted using statistical software R version 3.2.3 (R Foundation for Statistical Computing, Vienna, Austria). A detailed explanation is provided in Supplemental File 1.

## **Results**

### *Participant characteristics*

In total, 82 people (67 patients, 15 caregivers) participated in 14 focus groups comprising of three to ten participants (Table 1). Sixteen (20%) participants had more than one diagnosis (OP/RA, ten participants; gout/OP, three; gout/RA, two; gout/OP/RA, one), with the predominant diagnosis of each participant being gout (n=25, 30%), OP (n=20, 24%) and RA (n=37, 45%). Participants were born in 16 countries. Patients were aged 28-85 years (mean 66 years, standard deviation 12), and 42 (63%) were female. Patients with RA and OP were taking a variety of DMARDs or anti-resorptive therapy for their conditions (Table 1). All participants on urate-lowering therapy were on Allopurinol (n=20, 95%). Of the caregivers, 11 (73%) were spouses/partners and four (27%) were children of a patient. Using the CQR5, ten (15%) patients were 'low adherers', 54 (81%) were 'high adherers'. Fifty-nine additional patients declined participation in the study as they were unwell, overseas, disinterested in the topic, had work or childcare commitments, difficulty with transport or poor mobility.

### *Ranking of factors*

Participants identified 49 factors important for adherence (Figure 1, Supplementary Table 3). The top ten factors were trust in doctor (IS 0.46), medication effectiveness (0.31), doctor's knowledge (0.25), side effects (0.23), medication taking routine (0.13), medication necessity (0.13), medication satisfaction (0.13), reminders/organizers (0.12), medication knowledge (0.12) and medication monitoring (0.11). When IS was analyzed for patients versus their caregivers, differences were identified. For patients (n=64) the top three factors were trust in doctor (0.51), medication effectiveness (0.30), doctor's knowledge (0.24) and for caregivers (n=15) the top three factors were side effects (0.32), doctor's knowledge (0.32), medication effectiveness (0.31) (Supplemental Figure 1). The greatest difference between IS for patients and caregivers was for trust in doctor (0.51 vs 0.28 respectively, ranked 4<sup>th</sup> for caregivers).

By condition, participants with RA and OP had the same top three factors: trust in doctor (0.38, 0.56 respectively) medication effectiveness (0.33, 0.32), side effects (0.29, 0.25). The top three for gout were: trust in doctor (0.49), doctor's knowledge (0.28), medication effectiveness (0.26), with side effects ranked in 6<sup>th</sup> place (0.12) (Supplemental Figure 2).

By gender, the top three factors for females were trust in doctor (0.43), medication effectiveness (0.30), side effects (0.28). For males, the top three were trust in doctor (0.51), medication effectiveness (0.31), doctor's knowledge (0.23), with side effects ranked 7<sup>th</sup> (0.15) (Supplemental Figure 3). Most male participants had gout (16 patients and one caregiver, 52% of all male participants), reflecting their similarities in ranking.

## *Qualitative analysis*

Five themes explaining the participants' decisions were identified. Where themes apply to both patients and caregivers the term 'participants' has been used, otherwise themes related specifically to patients or caregivers have been specified. Illustrative quotations for each theme (Table 2) and a thematic schema showing the relationship between themes and factors (Figure 2) are provided.

### **Motivation and certainty in supportive and individualized care**

*“Where there is trust, you are bound to get on whatever the doctor says to you. If there is no trust, then there is no treatment effectively.” – Mr X, 50s, caregiver for wife with RA.*

Participants needed to trust the prescribing doctor to take medications. Participants developed trust if their doctor was empathetic, knowledgeable, took the time to listen, discussed options and individualized care to suit personal preferences and life circumstances. A trustworthy doctor would *“always do the right thing by you”*. Although a trustworthy doctor had good knowledge, not all knowledgeable doctors were trusted. The key difference was that participants felt the latter may lack genuine interest and care. Therefore, doctor's knowledge was ranked lower than trust. Participants had greater confidence in their medications if their specialists, general practitioners (GP) and/or pharmacists worked together to reach agreement on medications. Participants felt GPs and pharmacists had broader knowledge and responsibility for all their health conditions and medications and were reassured when they checked for drug interactions. They suggested that pharmacists and nurses could provide further medication education. Caregivers had a major role in supporting adherence as they

would administer and organize medications, continually remind patients to take medications and help patients emotionally cope and accept their illness and medications.

### **Living well and restoring function**

*“It’s very important for me to drink this, I don’t like this sickness. I want to be fit, I don’t want to struggle like this. I’m still young. I need to work, you know what I mean?” – Mr. Y, 30s, living with gout for 3 years, on Allopurinol.*

Patients with gout and RA were motivated to take medications to avoid perceptible symptoms such as severe pain and to enable performance of activities of daily living such as walking, showering, caring for children and working. The delay in medication benefit was difficult for patients with gout and RA, and during this time they could stop taking their medications. In addition, patients were not convinced of the need for long-term medications if they only had intermittent gout symptoms or were asymptomatic with OP. Patients were discouraged and confused by ongoing pain or swelling despite medications for gout or RA, or if they developed a new fracture on treatment for OP. One patient described decreasing the dose of allopurinol whenever he started to feel well, and patients with RA were tempted to stop DMARDs when they achieved remission, but would be motivated to restart if symptoms returned. Patients emphasized that their medications must have the overall effect of allowing them to live well. In addition to medications, they discussed the value of eating well, having a positive attitude and exercising. Some felt these lifestyle choices could reduce side effects and boost medication effectiveness.

## Fear of toxicity and cumulative harm

*“How long has the drug been on the market? Because there are side effects that maybe you only see after 40 years, but the drug has been in the market for five, so you have to wait to see what happens.” – Mrs A, 30s, caregiver of husband with RA.*

The potential need for life long medications was daunting for many patients. This was especially true for younger patients and those recently made aware of side effects such as liver toxicity with methotrexate. Even if no side effects occurred, participants had persistent fears of cumulative damage. Some caregivers felt a “*paranoia*” that long-term side effects are unknown until much later and concerns of an unhealthy dependence on medications developing. Patients would keep taking medications despite side effects which had a significant impact on their lives such as headaches or nausea because of the duration between follow up appointments or being unaware of alternative medications. Patients were often uncertain of their medications and felt like “*guinea pigs*” with prescriptions that were “*trial and error*”. When multiple medications were being taken, both patients and caregivers worried about drug interactions and whether medications were as effective, targeted the right condition, or impacted other conditions. Receiving conflicting information from different health professionals (e.g. dentists and rheumatologists on risks of OP medications) was confusing and heightened concerns. Alarming information could be found on the internet (e.g. methotrexate causing sudden death, or bisphosphonates being made from industrial cleaners) though some learned to overcome this by consulting their doctor or scrutinizing the information.

## Seeking control and involvement

*“I needed to know the side effects, ongoing effects of what I’m taking, and an understanding of why I’m taking them, how it’s going to affect me. It’s those things you think of when you go home, at night, you sit in front of the telly thinking why am I doing it?” – Mr. Z, 60s, living with gout for 4 years, on Allopurinol.*

Patients felt that acquiring knowledge about their medications and disease empowered them to self-manage their condition and share in decision-making. A major source of this information was their doctor or their pharmacist. Participants also used Google and Facebook but could be wary of their credibility. Monitoring in the form of blood tests for RA, gout and bone density scans for OP, helped patients feel secure in knowing whether their medications were working and were safe. Patients with established routines were confident with their adherence, especially those with longer disease duration. Patients had unique routines (e.g. keeping their medications in a visible place, having a pill box or phone reminders) and emphasized the importance of self-discipline in medication taking. When routine was compromised (e.g. weekends or overseas trips) or if their daily lives lacked routine (e.g. retirees or shift workers), patients had less control and poorer adherence.

## Unnecessarily difficult and inaccessible

*“Even my daughter has trouble opening them, and God bless, her hands work perfectly. She struggles with some of them, the methotrexate bottle in particular.” – Ms. B, 50s, living with RA for 6 years, on Methotrexate.*

Some barriers to managing medications were beyond the patient's control. Some found it difficult to be able to get a hospital appointment in time for their prescription, others were unable to afford multiple medications. Some patients with RA had difficulty with qualifying for biologics and were disheartened about having to take many medications they experienced side effects with. Patients with RA found it frustratingly difficult to open medication bottles. Pain when injecting biologics, or the taste of some medications made it unpleasant to continue with them. Patients were confused with the different names, packaging, shapes and colors that accompanied generic medications.

## **Discussion**

For patients with gout, OP and RA and their caregivers, factors related to their doctor (trust and knowledge), medication properties (effectiveness, side effects) and patient capabilities (knowledge, routine) were important with regard to adherence. Patients and caregivers valued supportive and trustworthy doctors, the ability to achieve a balance between medication benefits and harms and being involved and in control of medication management.

Relationships with health professionals, in particular with the prescribing doctor impacted patient and caregiver willingness to take medications. "Trust in the doctor" and "doctor's knowledge" were amongst the top three factors. To build trust, patients explained that doctors needed to demonstrate genuine interest and concern, impart knowledge around medication benefits, harms, and options, and foster understanding and agreement with other health care professionals. A systematic review and thematic synthesis of qualitative studies in gout demonstrated the impact of a negative doctor-patient relationship, with patients feeling they receive inadequate information and even dismissal and ridicule from their doctor (33). This

review also reported that providers themselves felt insufficiently trained and under-resourced to provide adequate care for gout patients. Qualitative studies in other rheumatic conditions including spondyloarthritis, systemic lupus erythematosus, systemic sclerosis, and vasculitis also showed that relationship with the rheumatologist and other health care professionals strongly influenced patients' perceptions and experiences of their medication (34, 35).

“Medication effectiveness”, in balance with “side effects” were important to patients and caregivers. Patients emphasized the need consider their broader health picture – that medications interacted safely and did not impact their other comorbidities, and that medication benefits balanced side effects to improve function and well-being. Participants mentioned that side effects could be better managed with closer follow-up and being able to communicate the side effects in between consultations.

“Medication knowledge”, establishing “medication taking routine”, and use of “reminders/organizers” were ranked in the top ten factors. Knowledge was important for adherence, as patients felt that it gave them better awareness and involvement in medication taking. Routine gave patients a sense of control and confidence in taking medications regularly. Reminders and organizers were tools that patients and caregivers used to maintain their routine. Although knowledge was valued by participants in this study, adherence studies suggest that education to improve knowledge alone is inadequate to change adherence (36, 37). Findings from a meta-analysis of adherence interventions echo participants' confidence in established medication taking routines and organization. Interventions that included habit analysis and training were more effective than interventions that did not (38).



There were differences in priorities across different conditions. For example, participants with gout ranked side effects much lower than OP and RA participants, possibly reflecting the differences in side effect profile for the medications of these conditions. Patients with RA reported a variety of DMARD related side effects and were particularly concerned about long-term medication harm. In OP, although osteonecrosis of the jaw and atypical femoral fractures are rare complications of anti-resorptive agents (39, 40), these were concerning, especially if patients felt inadequately informed. In gout, the risk of increased flares during initiation of allopurinol was worrying. However, reluctance to start allopurinol was reduced if patients were given a time frame of when this risk would be reduced. Having infrequent monitoring of uric acid levels in gout or bone density scans in OP, patients felt frustrated with the lack of positive feedback and validation of medication effectiveness as compared to RA.

Differences were also seen in rankings between patients and caregivers. Caregivers ranked side effects the highest, whereas patients ranked trust in the doctor the highest. A possible explanation is that caregivers may have less contact with the doctor than patients, whose fears may have been reduced by interactions with a trustworthy doctor.

This study included 82 patients and caregivers with diverse demographic and clinical characteristics and was conducted across five rural, regional and metropolitan centers. The use of focus groups with nominal group technique allowed prioritization of factors influencing adherence as well as insights into the reasons for their priorities. There are potential limitations. The transferability of the findings to contexts beyond Australia and other rheumatic conditions is uncertain. However, many themes identified in our studies are consistent with those identified in qualitative syntheses across many countries and cultures in RA (35) and gout (33). Coding was undertaken by one researcher, though three researchers

contributed to preliminary themes and all co-facilitators and co-authors gave feedback on themes. It is uncertain if the study included participants who were 'low adherers' as the sampling was in part based on a self-report questionnaire, which have been shown to overestimate adherence. It is unclear what impact this may have in terms of the factors identified and prioritized.

For clinical practice, this study highlights the critical role of health professionals, particularly the doctor, in the patient's acceptance of their medications. Closer collaboration and consistency among specialists, GPs and pharmacists, creating opportunities for patients to discuss side effects between clinic appointments, checking for drug interactions, providing feedback with drug monitoring and addressing the patients' goals of living well and improving function are potential patient-centered strategies to support medication taking.

An importance score was generated to quantify the relative importance of different factors. However, this study was designed to generate hypotheses that can be explored in future studies. A quantitative study with adequate power and an accurate measure of adherence could confirm whether highly ranked factors are truly correlated with adherence. In addition, the impact of these factors on adherence would be best explored in an intervention study. In contrast to the findings of this study, the majority of adherence interventions focus on patient-related factors (e.g. forgetfulness or lack of knowledge) as the cause of problems with adherence and there is a relative neglect of provider and health system related determinants (24). In addition, qualitative studies in gout and OP show health care providers perceive poor adherence to be predominantly related to factors such as lack of patient knowledge, number of medications, cost, family support, cognitive functioning of patients, side effects or warnings from the media or friends (41, 42). The results of this study suggest testing

interventions that incorporate a focus on provider-related factors. A meta-analysis reviewed correlational studies and experimental interventions involving training of doctors' communication skills in varying conditions. In this study there was a 19% higher risk of non-adherence among patients whose doctor communicated poorly compared to a doctor who communicates well (43). The odds of patient adherence were 1.62 times higher with doctor communication training than when a doctor receives no training (43). Another meta-analysis of adherence interventions in multiple conditions found that interventions targeting the health care provider were less effective than interventions delivered directly to patients (38). However, the healthcare provider targeted interventions in this meta-analysis may have focused more on cognitive interventions (i.e. changing the patients' medication knowledge and beliefs), rather than the quality of the patient-provider relationship.

Patient and caregivers' experience with their medications is complex. Factors related to the doctor, medication properties, and patient knowledge and medication taking routine were perceived to be important regarding adherence. Enhancing doctor-patient relationships, balancing medication benefits and harms within the context of an individual's unique set of comorbidities and goals, and empowering patients with medication knowledge and skills are potential solutions that require further investigation. Understanding and addressing patient-important factors in adherence could enhance the use of medications to help patients live well with their rheumatic conditions.

#### **Author contributions**

The research team in this study consists of health professionals (rheumatologists, nurses, pharmacists, psychologists), patient research partners, and adherence and outcomes research experts. AK, KT, MDW, SB, TD, MDV, VE, MG, GH, LM, MSV, DS, PT, BvdB and AT

contributed to study conception and design. AK, KT, KM, ATP and AT contributed to qualitative and quantitative data analysis. All authors contributed to data interpretation. AK, MC, TD, GH, IL, GM, LM, SO and PS in addition to those acknowledged above assisted with recruitment. AK takes responsibility for the integrity of the work and data analysis. All authors have contributed significantly to the study interpretation, manuscript drafting, revision and final approval.

### **Acknowledgments**

The authors would like to thank the participants for their contribution to this study. The authors would also like to thank the staff at each study site for assistance with recruitment:

Heather Jones, Diana Chessman, Kathy Gibson, Vivek Thakkar, Michael Oliffe, Helene Rickard, Ross Penglase, Annica Barcenilla-Wong, Fiona Niddrie, David Mathers, Joel Riley, Margot Patterson and Shelley Dunlop as well as Willemina Campbell and Rebecca Davey for their help with development of the question guide. Finally, the authors would like to thank Marie Schneider, our ESPACOMP liaison member.

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**Tables**

**Table 1 – Participant demographics**

**Table 2 – Themes and illustrative quotations**

**Supplementary Table 1 – Question guide**

**Supplementary Table 2 – COREQ checklist**

**Supplementary Table 3 – Ranking and description of all factors influencing medication adherence**

## **Figure Legends**

### **Figure 1 – Ranking of all factors for all participants**

### **Figure 2 – Thematic schema**

*Factors related to the doctor and medication properties were of highest priority in influencing medication adherence, with a focus on supportive individualised health care, and effectiveness outweighing harms for a patient to ultimately help a patient live well. Patients sought to be an empowered member of the team through greater knowledge and self-management skills. Despite supportive relationships, effective medications and self-sufficient patients, many other external barriers to acquiring and managing medications existed.*

### **Supplemental Figure 1 – Ranking of factors for patients versus caregivers**

### **Supplemental Figure 2 – Ranking of factors by condition**

### **Supplemental Figure 3 – Ranking of factors by gender**

**Table 1 – Participant demographics**

<b>Patients</b>				
	<b>RA</b>	<b>Gout</b>	<b>OP</b>	<b>All</b>
	(n=29)	(n= 21)	(n=17)	(n=67)
<b>Age (years) Mean (SD)</b>	62 (13)	68 (13)	71 (8)	66 (12)
<b>Gender (female) N (%)</b>	23 (79%)	5 (23%)	14 (82%)	42 (62%)
<b>Country of birth</b>				
Australia	13 (45%)	15 (71%)	15 (88%)	43 (64%)
Other:	15 (52%)	5 (24%)	2 (12%)	22 (33%)
Asia-Pacific	6 (21%)	3 (14%)	1 (6%)	12 (18%)
Europe	5 (17%)	1 (5%)	1 (6%)	7 (10%)
Africa	2 (7%)	0 (0%)	0 (0%)	2 (3%)
South America	1 (3%)	0 (0%)	0 (0%)	1 (1%)
Not specified	1 (3%)	1 (5%)	0 (0%)	2 (3%)
<b>Highest level of education</b>				
No school	1 (3%)	0 (0%)	0 (0%)	1 (1%)
Primary school	3 (10%)	2 (10%)	0 (0%)	5 (7%)
High school	7 (24%)	12 (57%)	11 (65%)	30 (45%)
Diploma/TAFE	8 (28%)	4 (19%)	2 (12%)	14 (21%)
University	8 (28%)	3 (14%)	3 (18%)	14 (21%)
Not specified	1 (3%)	0 (0%)	1 (6%)	3 (4%)
<b>Years since diagnosis</b>	20 (14)	14 (12)	8 (12)	15 (13)
Mean (SD)				
<b>Medication</b>				
<b>Any csDMARD</b>	Any csDMARD	Allopurinol	Bisphosphonate	
N (%)	22 (76%)	20 (95%)	5 (29%)	
<b>Any bDMARD</b>	Any bDMARD	None specified	Denosumab	
N (%)	12 (41%)	1 (5%)	10 (59%)	
<b>Any tsDMARD</b>	Any tsDMARD		None specified	
N (%)	3 (10%)		2 (12%)	
<b>None specified</b>	None specified			
N (%)	2 (7%)			

CQR5

Low adherer	3 (10%)	5 (24%)	2 (3%)	10 (15%)
High adherer	25 (86%)	14 (67%)	15 (88%)	54 (81%)
Not specified	1 (3%)	2 (9%)	0 (0%)	3 (4%)

### Caregivers

	RA	Gout	OP	All
	(n=8)	(n=4)	(n=3)	(n=15)
<b>Age (years) Mean (SD)</b>	55 (17)	51 (14)	63 (19)	56 (16)
<b>Gender (female) N (%)</b>	3 (37%)	3 (75%)	1 (33%)	7 (47%)
<b>Country of birth</b>				
Australia	2 (25%)	2 (50%)	3 (100%)	7 (47%)
Other:	6 (75%)	2 (50%)	0 (0%)	8 (53%)
Asia-Pacific	3 (37%)	2 (50%)	0 (0%)	5 (33%)
Europe	1 (12%)	0 (0%)	0 (0%)	1 (7%)
Africa	1 (12%)	0 (0%)	0 (0%)	1 (7%)
South America	1 (12%)	0 (0%)	0 (0%)	1 (7%)
<b>Duration of being a caregiver (Years) Mean (SD)</b>	9 (6)	6 (10)	3 (-)	8 (7)

RA, rheumatoid arthritis; OP, osteoporosis; SD, standard deviation; TAFE, Technical and Further Education (government run system providing education after high school in vocational areas); csDMARD, conventional synthetic disease-modifying anti-rheumatic drug; bDMARD, biologic disease-modifying anti-rheumatic drug; tsDMARD, targeted synthetic disease-modifying anti-rheumatic drug; CQR5, 5 item version of the Compliance Questionnaire in Rheumatology

**Table 2 – Themes and illustrative quotations**

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**Motivation and certainty in supportive and individualized care**

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Where there is trust, you are bound to get on whatever the doctor says to you. If there is no trust, then there is no treatment effectively. (*M, Caregiver of patient with RA, 50s*)

It's a waste of time if you don't trust the prescriber. You might as well find one that you can trust. End of story. (*M, Patient with OP, 70s, Zoledronic acid*)

She genuinely cares and shows sympathy as well. If I show her there's pain in certain parts, she actually looks at it. Like sometimes I say, she's a professor, but she doesn't mind to touch my foot. It's sort of... it's different. (*F, Patient with RA, 60s, Methotrexate/Tofacitinib*)

If (the doctor) doesn't know what he's doing, you're buggered. (*M, Patient with gout, 70s, Allopurinol*)

I found that sometimes you see different doctors, and they're only looking at their own plate. They're not looking at the big picture. They don't talk to each other, and I reckon that that sort of complex situation, they should have a pharmacy to overlook all the medication, balance the complications, the dosage and all those physical problems. (*F, Patient with OP, 60s, Zoledronic acid*)

I sort of introduced my specialist and everybody to my chemist... It's good, the communication between chemist and my doctors and specialists and stuff. It makes it a lot easier. (*M, Patient with gout, 50s, Allopurinol*)

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**Wanting to live well and restore function**

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When I got diagnosed, I couldn't walk. I couldn't drive my kids to school. I felt like a 90-year-old in a 30-year-old body, and I was in so much pain... so it's kind of like well, if I can take something that's going to make this better, despite reading the side effects, any medication has got side effects. But I need to get myself better. (*F, Patient with RA, 30s, Methotrexate/Sulfasalazine/Hydroxychloroquine/Etanercept*)

When they tell me to drink 500 a day, so I drink, I think one week. When the gout starts getting better, I just change it to 400. Now I stick to 400. (*M, Patient with gout, 30s, Allopurinol*)

I think that's sort of the difference. You got better, so you continue. But I don't see any difference at all. There's absolutely no difference. I don't get any pain relief, I get nothing. (*F, Patient with OP, 70s, previously on Risedronate*)

Yeah, I tend to think holistic approach. Working with medication, exercise, diet. I feel that all of that helps, but it might just help me, I don't know. I just think it does work. (*F, Patient with OP, 60s, previously on Alendronate*)

I'm now on four medications and one injection but still having massive issues medically,

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for not a great result. (*F, Patient with RA, 50s, Sulfasalazine/Leflunomide/Adalimumab*)

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### **Fear of toxicity and cumulative harm**

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But the Methotrexate and going through all the side effects, you want me to take this forever? I'm 26, and I'm supposed to just take this forever now, even though you've told me the effects it's going to have on my liver etcetera and that was their answer. (*F, Patient with RA, 20s, Methotrexate*)

How long has the drug been on the market? Because there are side effects that maybe you only see after 40 years, but the drug has been in the market for five, so you have to wait to see what happens. (*F, Caregiver of patient with RA, 30s, Methotrexate*)

Interviewer: You mentioned you were on methotrexate and it really made you feel very ill. For two and a half years you continued to take it...

Patient with RA: I had young children at the time, they were babies. I just felt like I had no life, or I was just spending my time in bed wanting to cry all the time because it just made me feel so ill. I was made to feel like it was all in my mind, that it was just my repulsion against the medication. (*F, Patient with RA, 40s, Leflunomide*)

It concerns me sometimes because I'm taking 14 pills in the morning. What's happening when they all go down, do they all agree with one another? ... how effective are they when you're taking so many? (*F, Patient with gout, 80s, Allopurinol*)

What confuses me is the dentists and the doctors give me a totally different answer on the incidence of problems. The dentist, 0.4%.. the doctor far less likely. (*F, Patient with OP, 60s, previously on Alendronate*)

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### **Seeking control and involvement**

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I wouldn't blindly take anything because the doctor said to take it. You've got to have the knowledge of the disease. There's a lot of information available, and you have to just do a bit of research (*F, Patient with OP, 70s, Denosumab*)

The only way to know whether it's effective or not is to monitor it, having the blood test. Not only effectiveness, it's actually monitoring the side effects as well. (*F, Patient with RA, 60s, Methotrexate/Tofacitinib*)

I've had arthritis for 50 years, so I'm really used to taking my tablets. I keep them on the kitchen table. I have to take them twice a day. I just take them because they're right in front of me. I don't forget. (*F, Patient with RA/OP, 70s, Sulfasalazine*)

If you're, as we've been, in bed a couple of days, you've got to change your routine totally. If the medication's in another room, you've got to change it. It's the discipline that I find helps. (*M, Patient with gout/OP, 80s, Allopurinol/Denosumab*)

Because she will at times forget to take, especially when she's got a morning shift starting at 6:30, so at times she forgets to take the tablet. By the time she finishes at 3:30 she's already tired, so she forgets to take the tablet (*M, Caregiver of patient with RA, 50s, Methotrexate*)

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### Unnecessarily difficult and inaccessible

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Like I'm on all these medications, I've had to be put on them before I get put on the Enbrel so that I qualify. So it was like whoa, so I'll have to take all these medications, all the side effects, before I get on this. (*F, Patient with RA, 30s, Methotrexate/Sulfasalazine/Hydroxychloroquine/Etanercept*)

I take 22 a day, costs me 130 bucks a month and I'm on the pension, you know. \$130 out of your pension. (*M, Patient with gout, 60s, Allopurinol*)

I don't like the taste. But I just take it because I know it's helping me. Sometimes as a patient I try things, I change the time. Sometimes I say because I don't like it, I'll wait until the evening. When I'll take it in the evening, sometimes I end up forgetting. (*F, Patient with RA, 50s, Methotrexate*)

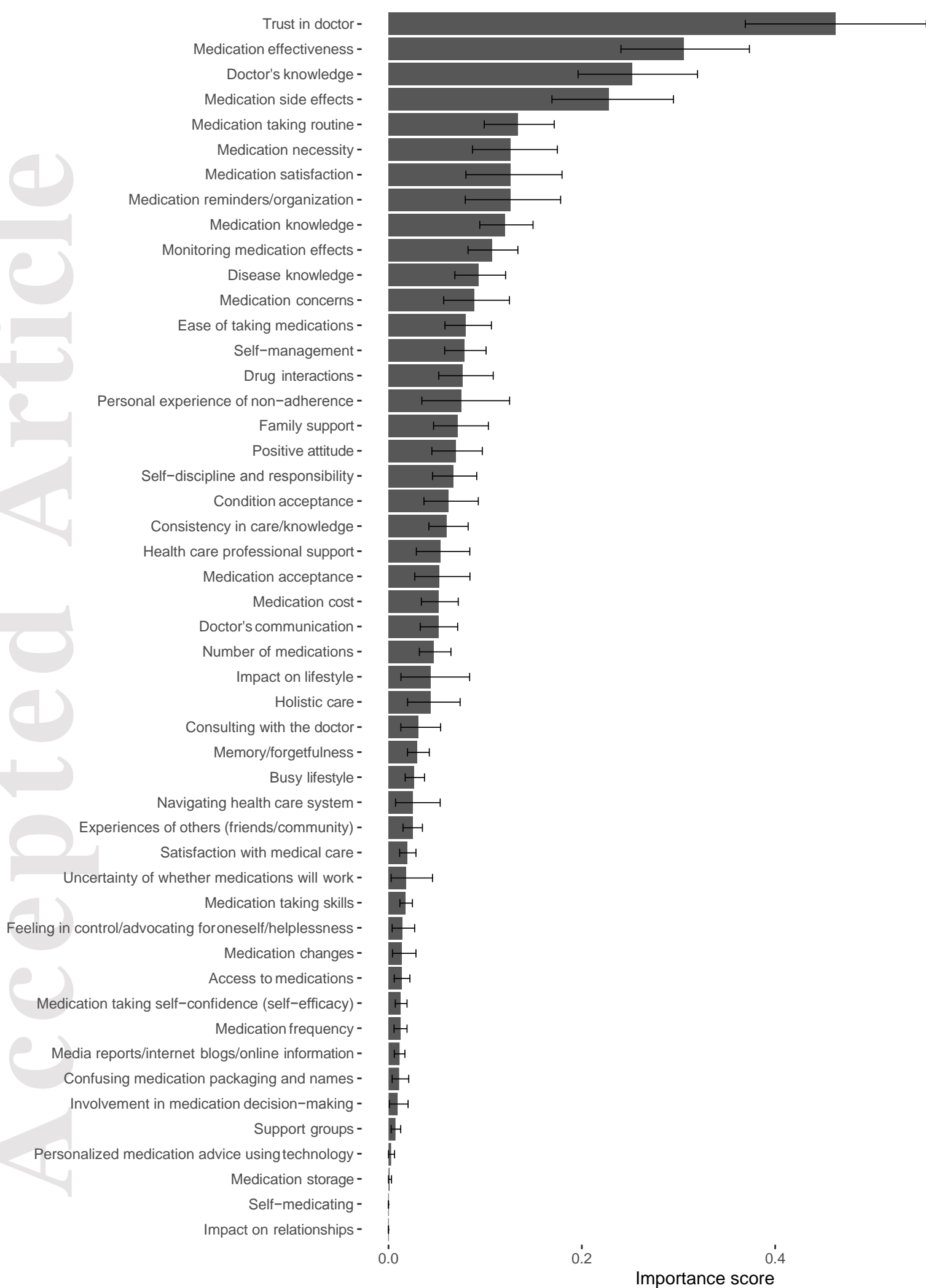
Wish they'd stop making generics. I don't know what I'm taking, because all the pills I take, every time I go to the chemist they seem to give me a different brand. I'm very confused with the number of medications that I take and the different names I'm presented with. (*F, Patient with gout, 80s, Allopurinol*)

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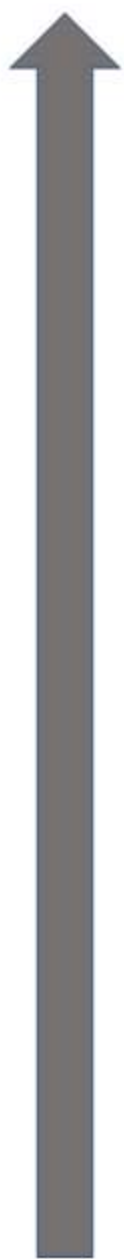
Information in italics indicate the gender, patient/caregiver status, age (years) and current disease modifying anti-rheumatic drug, urate lowering therapy or anti-resorptive therapy of the participant. M, male; F, female; OP, osteoporosis; RA, rheumatoid arthritis.

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INCREASING PRIORITY



Doctor related (trust/knowledge)

**Motivation and certainty in individualized care**



Medication properties  
(effectiveness/side-effects)

**Wanting to live well and restore function**



**Fear of toxicity and cumulative harm**



Patient related  
(knowledge/routines/reminders)

**Seeking control and involvement**



External barriers/facilitators

**Unnecessarily difficult and inaccessible**

