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Rheumatoid arthritis patients' motivations for accepting or resisting disease-modifying antirheumatic drug treatment regimens

Yomei Shaw, PhD¹, Ilinca D. Metes, BS², Kaleb Michaud, PhD³, Julie M. Donohue, PhD⁴, Mark S. Roberts, MD, MPP⁵, Marc C. Levesque, MD, PhD⁶, and Judy C. Chang, MD, MPH⁷

¹Graduate, Department of Health Policy and Management, University of Pittsburgh Graduate School of Public Health. Current affiliation: Research Fellow, National Data Bank for Rheumatic Diseases, Wichita, Kansas

²Doctoral Student, Department of Health Policy and Management, University of Pittsburgh Graduate School of Public Health

³Associate Professor, Division of Rheumatology & Immunology, Department of Internal Medicine, University of Nebraska Medical Center; Co-Director, National Data Bank for Rheumatic Diseases, Wichita, Kansas

⁴Associate Professor, Department of Health Policy and Management, University of Pittsburgh Graduate School of Public Health

⁵Professor and Chair, Department of Health Policy and Management, University of Pittsburgh Graduate School of Public Health

⁶AbbVie, Worcester, Massachusetts

⁷Associate Professor, Obstetrics, Gynecology and Reproductive Sciences and Internal Medicine, University of Pittsburgh School of Medicine

Abstract

Objective—Patient refusal of and nonadherence to treatment with disease-modifying antirheumatic drugs (DMARDs) can adversely affect disease outcomes in rheumatoid arthritis (RA). This qualitative study describes how RA patients' feelings in response to experiences and information affected their decisions to accept (agree to adopt, initiate and implement) or resist (refuse, avoid and discontinue) DMARD treatment regimens.

Methods—48 RA patients were interviewed about their experiences making decisions about DMARDs. The interviews were transcribed, coded, and analyzed for themes related to their internal motivations for accepting or resisting treatment regimens, using a narrative analysis approach.

Corresponding author: Yomei Shaw, shawyomei@gmail.com.

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Results—In addition to feelings about the necessity and dangers of medications, patients' feelings towards their identity as an ill person, the act of taking medication, and the decision process itself were important drivers of patient's decisions. For patients' motivations to accept treatment regimens, two themes emerged: 1) *desire to return to a "normal" life* and 2) *fear of future disability due to RA*. For motivations to resist treatment regimens, five themes emerged: 1) *fear of medications*, 2) *maintaining control over health*, 3) *denial of sick identity*, 4) *disappointment with treatment*, and 5) *feeling overwhelmed by the cognitive burden of deciding*.

Conclusion—Feelings in response to experiences and information played a major role in how patients weighed the benefits and costs of treatment options, suggesting that addressing patients' feelings may be important when rheumatologists counsel about therapeutic options. Further research is needed to learn how best to address patients' feelings throughout the treatment decision making process.

Key terms

rheumatoid arthritis; patient; decision; qualitative

1. Introduction

Current rheumatology guidelines recommend treating rheumatoid arthritis (RA) with disease-modifying antirheumatic drugs (DMARDs) to the target of low disease activity or remission (1–3). However, many RA patients are not prescribed treatment consistent with the treat-to-target (T2T) guidelines (4–7). One contributing factor to this is when patients resist (refuse to adopt, avoid initiating/implementing, or discontinue) DMARD medication regimens recommended or prescribed by physicians (8–9). Patients' resistance to DMARD treatment regimens can increase the risk of suboptimal treatment, prolong time spent with painful symptoms, and lead to progression of joint damage, diminishing patients' current and future quality of life (10–13).

Learning about RA patients' perspectives on decision making about medications is valuable for understanding nonadherence and treatment refusal. Previous qualitative studies reported that patients often have ambivalent beliefs and perceptions about DMARDs, sometimes leading them to struggle with decisions about taking these medications (14–16). Qualitative studies have also acknowledged the influence of emotions on RA patient decision making about medications (16–18). Psychology researcher Scherer (19) defines emotion as temporary episodes of intense mental and physical response to events, and feelings as the subjective experience of emotion episodes. Nota et al. (16) identified 'emotional impact' as a category of reasons reported by patients for not wanting to initiate DMARDs, distinct from concerns about medication risks. Patients reported reluctance to initiate DMARDs because doing so made them feel that they were now "seriously ill". Pasma et al. (17) found that patients did not want to initiate DMARDs because of negative feelings related to medication side effects, but also because of the perception that medications were "not natural", or that taking medications symbolized an unwelcome new status as a patient with a serious chronic illness.

It is not well understood how feelings in response to experiences and information shape patients' decisions to accept (agree to adopt, initiate or implement) or resist (refuse to adopt, avoid initiating/implementing, or discontinue) recommended/prescribed medication regimens. Our study objective was to qualitatively describe treatment decision making from the perspective of RA patients. Qualitative research methods explore a deeper, nuanced understanding of participants' thoughts and experiences expressed in their own words and allow the possibility for obtaining new insights previously undescribed or unimagined by researchers (20–22). In this article, we describe how feelings affected RA patients' decisions to accept or resist DMARD treatment regimens offered or prescribed by their rheumatologist.

2. Patients and methods

We recruited English-speaking participants from the University of Pittsburgh Rheumatoid Arthritis Comparative Effectiveness Research (RACER) registry, which followed over 1000 RA patients attending 2 private and 2 academic arthritis clinics in Pittsburgh from 2010–2016. RACER was an observational registry and did not employ specific treatment protocols. All RACER enrollees had a diagnosis of RA and were age 18 or older; 79% of enrollees were female and 10% were African-American. Beginning in October 2011, we recruited interview participants at their regular rheumatology clinic visits, by phone, and by letter. We chose a sampling strategy to allow us to capture a maximum diversity of patient perspectives on medication decision making (23). We continued recruitment until the following criteria were met: 1) thematic saturation among participants with and without experiences of medication side effects, and 2) representation of minority subgroups of RA patients including male and African-American patients. Informed consent was obtained before each interview. Participants were assured that their identities would remain anonymous. Each participant was compensated with a \$20 cash card and free parking. The study was approved by the Institutional Review Board of the University of Pittsburgh.

Data collection

The interviews were conducted by YS at two rheumatology clinics or a café near the participant's residence, depending on space availability and the participant's convenience.

The semi-structured interviews lasted 30–90 minutes each and were audio-recorded. First, participants were asked to describe their experiences of and attitudes towards RA and medications. Next, participants were asked to describe their experiences of and attitudes towards making decisions about medications (see Figure 1 for a summary of interview topics and Supplementary Appendix A for the full interview guide). This manuscript will focus on their emotional motivations for deciding to accept or resist DMARD treatment regimens.

Data analysis

The interviews were transcribed verbatim using Transana 2.53 software, and identifying information was removed. Following Crabtree and Miller's template organizing style (24), an initial template of codes was developed by YS based on the interview guide, preliminary

analysis of the first 15 interviews, and relevant conceptual models of medical decision making and the experience of chronic illness (25–28).

The template codebook was refined iteratively by having pairs of coders (YS and IDM or JCC) code 17 selected transcripts. Involvement of multiple coders is a type of investigator triangulation, where we sought to avoid analytic bias resulting from reliance on a single person's viewpoint (20). The coders individually coded each transcript, then met to compare coding and interpretation, adding, refining, merging or splitting codes where necessary. The final codebook was then used to recode all transcripts, and the coded statements were analyzed to identify major themes (YS). The authors used ATLAS.ti 7 software to manage the coding and analysis of the data.

Coded statements were analyzed in the context of patients' overall narratives of illness and medicine taking (29). First, a story of the sequence and context of events was reconstructed from patients' individual narratives. Second, we read the patients' narratives closely to learn about the meanings and feelings that patients associated with having RA, taking medications, and specific events. Third, we identified situations where patients had accepted (agreed to adopt, initiated or implemented) or resisted (refused to adopt, avoided initiating/ implementing, or discontinued) recommended/prescribed DMARD regimens (including dosage). Fourth, we examined groups of coded statements to identify patterns of events, feelings and decisions across patients. For example, statements coded with "concern for medication risk" were examined (with reference to the patient's full narrative) to identify the event triggering concern, the feeling in response to the event, and the subsequent decision. Similar sequences of events, feelings and decisions were grouped together and summarized as themes.

3. Results

Forty-eight RA patients were interviewed from November 2011 through April 2013. Participant characteristics are presented in Table 1. Their ages ranged from 36 to 90 years (mean=59.7 years), and their duration of RA ranged from 2 to 50 years (mean=14.6 years). Participants included 4 males, 8 African-Americans, and patients with and without experience of side effects due to RA medications (70.8% reported side effects). Most participants (91.7%) were currently taking DMARDs. Twenty-nine percent of participants reported resisting medications at some point in time.

Below we describe themes regarding patients' acceptance or resistance of DMARDs, providing illustrative quotations. Table 2 presents additional example quotations. Some patients reported feeling conflicted about their medications. As a result, themes of accepting and resisting medications were expressed not only by patients who accepted/resisted DMARDs, but also by those who felt ambivalent about their choices. Some patients also reported a change in their decision-making behavior, reflecting on how they gradually became willing to try medications they had previously refused.

Motivations for accepting DMARDs

For patients' motivations to accept DMARDs, two themes emerged: 1) *desire to return to a "normal" life* and 2) *fear of future disability due to RA*.

Desire to return to a "normal" life—Pain and fatigue symptoms due to RA heavily impacted patients' physical and emotional quality of life, profoundly disrupting their lives. Patients described being motivated to take DMARDs because they alleviated symptoms which were difficult to bear: "You can't believe how bad this hurts when it hurts. I mean it's totally disabling. So, anything you can do to make that pain not be there, you're going to do or you would be a fool, I guess." For some patients, alleviating pain was important enough to outweigh concerns about medication side effects:

I worry about the side effects, the liver disease, the risk with each individual pill. But what's worse, the RA, or what you may get? I'd rather have it [medications] and take the chance, than not have it and be in pain all the time.

Patients also reported negative feelings emerging as they struggled to live with RA. Alleviating symptoms was important to patients because it helped them to return to a "normal" life again and regain at least some of their pre-RA function.

[My goal for treatment is] to be able to function as normally as possible, with the disease. Cause I was to the point where I was almost constantly in bed, where I couldn't move. So I wanted to get as normal... my life back.

The desire to reclaim a "normal" life was associated with powerful feelings that drove patients to accept DMARD treatment. Patients felt a deep sense of loss when RA symptoms disrupted their "normal" lives, forcing them to give up activities (such as sports) or a way of life (such as carrying stylish handbags) they used to treasure. Patients felt shame and helplessness when confronted with their inability to fasten a child's ponytail, open a bottle of water, or get up after having fallen to the ground. They felt pressure from social and work roles to remain as independent as possible to avoid burdening their family or being seen as incompetent at work. Such feelings made patients willing to tolerate medications as a "necessary evil" in order to alleviate RA symptoms: "So I've kind of come to that point in my thought process, it's [medications are] kind of like the necessary evil that I have to put up with in order to feel generally good about my health and be able to function."

Fear of future disability due to RA—Fears about becoming disabled by RA also motivated patients to accept DMARDs. Some patients associated RA-related disability with being confined to a wheelchair or losing the use of one's hands—their fears were focused on being physically immobilized by the disease and becoming unable to lead an active, productive life. One patient felt so strongly about the importance of treating RA that when she encountered other RA patients who expressed doubts about taking medications, she warned them that RA would turn them into a "cripple":

I said, do you really realize what rheumatoid arthritis can do to your body? 'It'll mess up my joints a little bit.' I said, no no no. It will make you a cripple! You will be in a wheelchair. Your hands, your body will not work! Are you willing to risk that because you don't want to get around to it right now? Get busy!

Other patients associated RA-related disability with loss of independence and social isolation. As one subject stated, “That’s one of my biggest worries, is that I’ll get to the point where I can’t be taken care of, and I’ll end up in a home. And I don’t want that.”

Motivations for resisting DMARDs

Five themes emerged in patients’ discussion of their motivations for resisting DMARDs: 1) *fear of medications*, 2) *maintaining control over health*, 3) *denial of sick identity*, 4) *disappointment with treatment*, and 5) *feeling overwhelmed by the cognitive burden of deciding*.

Fear of medications—Fear of medications often led patients to resist taking DMARDs. Life-threatening adverse events could be traumatic, deeply impressing on patients the danger of their prescribed treatments. Chronic side effects such as nausea, fatigue, boils, and hair loss decreased patients’ quality of life and created feelings ranging from mild aversion to repugnance towards medications. These negative experiences and feelings led them to question whether the benefits of medications were worth the ill effects they suffered. Patients who hadn’t experienced side effects still worried about those they learned of from the internet, advertisements, drug information materials, or other patients.

Certain medications were viewed as aggressive treatments, leading subjects to prefer alternatives perceived as milder and more conservative. For example, one patient was reluctant to take methotrexate because she knew it was a cancer treatment:

I mean the drug itself scares me, just the name of the drug. Methotrexate. It sounds like some kind of big bad horrible thing that somebody’s putting in my body. Due to the fact that it’s a cancer pill, and then due to the fact that the side effects could be developing cancer, or lymphoma and different diseases...that doesn’t make me happy either.

Patients also perceived medications as unnatural, harmful chemical substances, preferring more ‘natural’ remedies such as adopting a gluten-free diet or consuming naturopathic supplements. Although the above-mentioned patient agreed to take methotrexate, she preferred a less threatening non-medication alternative: “I just wish there was an alternative, that I didn’t have to...Can I take less, or can I take something holistic or something that I know it’s not this chemical in my body for X amount of years.”

Maintaining control over health—Patients valued the feeling of being in control over their health—of being able to take actions to contribute to their health and limit the risk of negative health outcomes. Taking medications threatened patients’ sense of control over their health because it introduced uncertainty about whether they would suffer life-threatening adverse events. They also worried about addiction—becoming subject to the control of medications. Resisting medications limited patients’ uncertainty about health outcomes by reducing the risk of serious adverse events or addiction, helped patients avoid feeling vulnerable, and helped patients preserve a sense of control over their health. Patients sometimes preferred the predictable risks of RA to the unpredictable, more severe risks of certain RA medications.

Efforts to maintain control over health by resisting medications sometimes followed experiences of unpleasant or frightening side effects. One subject described avoiding medications after hospitalization for an adverse reaction to methotrexate:

But ever since then, just by taking it [medication] straight like that makes me very leery and I'm so scared of any pills. . I'm just like, I don't even want a painkiller, I'll just take a nap, I'll be all right. I'll put a heating pad, or something warm, maybe that'll do, stay off my feet, give myself bed rest. I try not to take pills, cause I'm scared. I can't afford to get sick and get wiped out for the little strength that I do have...

Because of this incident, the subject worried that taking other medications might cause other unpredictable reactions. She avoided medications when possible, sometimes even skipping prescribed medications. Maintaining careful control of her health was seen as necessary for preserving her remaining "little strength".

Denial of sick identity—Some patients resisted taking medications because they associated this action with being a sick person, a role which they rejected. They had difficulty accepting their RA diagnosis and the idea that they were no longer healthy. Inability to accept the diagnosis of RA even led one patient to avoid seeking any treatment until years later. One patient felt angry about developing RA:

At first I was like, I don't have rheumatoid arthritis. There's denial... And then I was angry. And I was angry at God. I was like, 'How could you let this happen to me? I serve you, I do this and... This isn't fair!'

Being told by doctors that she needed to take medications was upsetting, because she felt she had worked hard to manage her health: "So I resent the fact that I try to take very good care of myself, and I still have to take drugs."

Patients also resisted the idea of taking biologic medications because they were perceived as a 'last resort' reserved for the most severe cases of RA: "To me, injections is my last resort. And if I have to go there, and it doesn't work, then I'm hosed." Taking biologics had negative implications for patients because it signaled a poor outlook for their condition, and that few therapeutic options remained.

Another patient described the behavior of 'stoic' patients who avoided medications out of pride—for patients with this mentality, taking medication meant admitting that they are weak and unfit to take care of others. To maintain their role within the family as caregiver or someone who is reliable, they pretend to be unperturbed by symptoms and ignore prescribed treatments.

Disappointment with treatment—Feeling that their medication was not helping as much as expected was sometimes disillusioning, leading patients to consider discontinuing their treatment. One patient described feeling so dejected that she wanted to give up on treatment: "I emailed Dr. A, I said, 'I'm just getting sick of all this, I don't think nothing is helping me, I think I oughtta just chuck the whole thing.' And she said, no. Because then it'll really flare up."

Feeling overwhelmed by the cognitive burden of deciding—Patients found it overwhelming to navigate and process information about treatment options (and their accompanying risks) obtained from physicians, advertisements, and the internet. One subject described feeling overwhelmed by information on the internet:

And I read everything. When I got sick, every web site, everything that I could read on rheumatoid arthritis, I did. And it overwhelmed me. I became that person [I read about online]. And that person and that person. Cause I seen something about what I was feeling or what I was going through in every person...

Digesting available information in order to make a treatment decision caused anxiety—patients worried about making a poor decision and suffering negative health outcomes as a result. Unable to handle the cognitive burden of making a treatment decision, some patients preferred to postpone decision-making.

Patients also discussed how lacking certain kinds of information contributed to their feeling of uncertainty and made decisions more difficult. While lists of medication side effects were widely available, patients lacked information about the magnitude of risk for each side effect, which patients are at greater risk for each side effect, and how to manage risks. Patients desired guidance from physicians on interpreting risk information, and more information about the experiences of actual patients with medications—effectiveness, safety, and personal narratives about taking different medications. They valued being able to meet, ask questions, and compare experiences with other RA patients. Patients felt that more access to these kinds of information could have supported them throughout the difficult process of weighing the benefits and risks of treatment options.

4. Discussion

Quantitative and qualitative studies have shown that RA patients are often risk averse in decisions about DMARD treatment regimens, preferring to avoid the risks of therapy escalation even when they have active disease (30–33). Our study, by exploring RA patients' perspectives on their decisions about taking medications, provides insight into the thought processes that affect willingness to accept the risks of therapy.

For the patients in our study, feelings about illness symptoms or medication risks, identity as an RA patient, and the decision making process itself affected decisions about medications. Both RA and DMARDs were perceived as threats to health and well-being. Patients who chose to accept DMARD regimens often viewed medications as a “necessary evil”, while those who chose to resist DMARD regimens preferred the predictable risks of RA over the uncertain risks and rewards of treatments. Information that patients encountered about RA and treatments could have a negative emotional impact, contributing to decisions to resist DMARD regimens. For example, being overwhelmed by information about treatment options contributed to postponing treatment decisions, and the distress caused by a diagnosis spurred denial of the illness or treatment altogether.

In contrast with previous qualitative studies—which established the importance of engaging patients in shared decision making (18, 34–35) and providing information about medication

benefits, risks, and impact on daily life (14–17, 36)—our study describes how specific emotional experiences influenced RA patients' decisions about medicines. Our study used a narrative-focused approach to draw connections between specific experiences, their impact on feeling-states, and subsequent choices about medication use. This approach may be useful for exploring other beliefs influencing medication use among patients with chronic conditions, such as beliefs about alternative therapies. Patients in our study and others (37–40) have reported pursuing alternative therapies to avoid taking recommended medications.

Implications for clinical practice

Our findings suggest the need for interventions that better address negative feelings arising during patients' decision process. Such interventions may promote acceptance of recommended therapies and develop patients' confidence in navigating treatment decisions. Physicians, as patients' trusted advisors regarding illness and treatment, are in an ideal position to provide such emotional support. Strategies developed to help health care professionals recognize and respond to patient feelings in nephrology, oncology, and palliative care settings might be adapted for use by rheumatologists (41–45).

Decision aids have been developed to support RA patients' treatment decisions by informing them of medication benefits and risks (46–50). However, as shown in our study and Li et al. (47), providing patients with information does not always have the intended supportive effect, sometimes increasing uncertainty and frustration with the decision process. It is important for decision aid designers to present risk information in a balanced but unthreatening way. Including information about the size of treatment risks, whom they are most relevant for, and strategies for managing risks may help patients to put risk information into perspective. Additionally, providing peer support resources (e.g. patient narratives, online chat forums) may be a method of complementing the informational component of these decision aids.

Limitations

Interviewees were mostly female, and all were RACER enrollees, thus their views may not reflect those of patients in other settings. However, RACER enrollees were unlikely to be biased in favor or against medications, since RACER does not employ specific treatment protocols. Our efforts to include diverse subjects (with respect to gender, race, age, and experiences with adverse events) and a large number of participants (n=48 as compared to 15–30 in similar studies) helped ensure access to a wide variety of perspectives on medication taking.

Recall bias possibly affected what interview subjects discussed. We addressed this by asking subjects to clarify the reasons for their opinions and to elaborate on the concrete details of their experiences. This helped us to put their interpretation of events into perspective.

Our study focused on elucidating how patients make sense of taking/deciding about medications and was not designed to explore factors related to unintentional nonadherence or differences in patient perceptions towards various DMARDs. Experience with specific types of DMARDs was not considered during participant recruitment, and the interview protocol did not elicit attitudes towards specific types of DMARDs. Since willingness to

take DMARDs might vary with type of medication offered/prescribed, this would be a fruitful area for future study.

Conclusion

Using a narrative-focused approach, our study contributes a deeper understanding of how feelings in response to experiences and information influence RA patients' decisions to accept or resist DMARD treatment regimens. An increased awareness of patients' emotional experience of illness and treatment decision making may help clinicians communicate more effectively about treatment choices and facilitate uptake of recommended DMARD therapies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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SIGNIFICANCE AND INNOVATIONS

- This qualitative study contributes to a better understanding of the role that feelings play in how patients with chronic conditions weigh the benefits and costs of medication treatments.
- For the RA patients in our study, feelings such as pain, loss, helplessness, shame, fear, protectiveness, anger, disappointment, and anxiety played an important role in motivating decisions to accept or resist DMARD treatment regimens.
- Feelings in response to experiences of illness symptoms, medication side effects, identity as an RA patient, the act of taking medication, and the decision-making process itself affected patients' willingness to accept prescribed or recommended treatment.

- Experiences with RA symptoms
- Experiences, attitudes, and feelings towards living with and adapting to RA
- Expectations about the future course of their RA disease
- Experiences, attitudes, and feelings towards taking RA medications
- Experiences with alternative therapies
- Experiences and preferences regarding decision making about RA medications
- Relationship with rheumatologist (and/or other health care providers)
- Acquiring and making sense of information about RA and RA medications
- Interactions with other RA patients

Figure 1.
Topics discussed in the semistructured interviews

Table 1

Characteristics of interview participants (n=48)

Characteristic	Mean (range) or percent
Mean age in years	59.7 (36–90)
% Female	91.7%
% African American	16.7%
Mean duration of RA in years	14.6 (2–50)
% employed (full or part time)	37.5%
% receiving Social Security Disability Insurance	27.1%
% currently prescribed any DMARDs ⁺	93.8%
% currently taking any DMARDs ⁺	91.7%
% currently prescribed bDMARDs ⁺	43.6%
% currently prescribed csDMARDs ⁺	85.4%
% currently prescribed tsDMARDs ⁺	0.0%
% currently prescribed corticosteroids ^{&}	35.4%
% reporting experience of any side effects due to RA medications	70.8%
% reporting experience of serious adverse events [*] due to RA medications	31.3%
% reporting refusal/discontinuation/nonadherence to recommended or prescribed RA medications	29.1%
% reporting refusal of recommended RA medications	22.9%
% reporting nonadherence/discontinuation [#] of prescribed RA medications	18.8%

⁺Disease-modifying antirheumatic drugs (DMARDs) include biologics (bDMARDs), conventional synthetic DMARDs (csDMARDs), and targeted synthetic DMARDs (tsDMARDs).

[&]Some participants were prescribed corticosteroids to take as needed.

^{*}Using the US Food and Drug Administration's definition of serious adverse events

[#]This figure is based on patients' responses to a brief adherence questionnaire (administered at the time of the interview, see Supplementary materials Appendix B) as well as their discussion during the interviews.

Table 2

Example quotations for each theme

Motivations to accept DMARD treatment regimens	Example quotations
Theme 1: Desire to return to a “normal” life	“I was a very active person [before developing RA]. The only time I ever cried was when my mother-in-law made a comment that I used run everywhere. And then I...started to cry when she said that to me. Just losing my...Well I wasn't particularly athletic, but I just was very busy all the time, and losing that has been the worst thing for me. Although I still do things that most people my age don't do. I still mow my own lawn, and I've got a big lawn, and I paint my walls, and...”
	“When I had first started taking the medicine, and things seemed to magically clear up [...] I thought that I would never have another flare-up again. I was ecstatic. I was in a really bad place when it first started happening. My fingers were completely misshapen, like I said I couldn't open a jar, put in a ponytail holder, or work a car seat buckle. So it was like a miracle, when I first started taking them.”
Theme 2: Fear of future disability due to RA	“My nephew is also a doctor, although he's a podiatrist, and he told me if I didn't take the meds, I'd go downhill a lot faster. He said, It's going to be debilitating, and at some point, if you don't keep up treatment, you'll be in a wheelchair. You won't be able to get around. So I think that's putting it the way it is. So I try not to think about it, I get up each day and I do what I got to do to get through that day. And so far I'm succeeding. I'm not sitting in a ball crying.”
	“... I'm glad that I kept taking the medicine. Because if I would have stopped taking it because of something like hair loss, then where would I be physically? Cause I know a lot of people who have RA. People seem to talk about it who won't take the medicine, and they're all crippled up like a pretzel, and because they're afraid of the liver function problems and all that.”
Motivations to resist DMARD treatment regimens	
Theme 1: Fear of medications	“And I will tell you why I choose not to do that [avoid taking medicines for RA where possible]. Couple of reasons. I took plaquenil [hydroxychloroquine], and I was in the emergency room twice with head to toe hives. Dr. _____ had me on low doses of methotrexate, trying to increase my methotrexate dose and decreasing my prednisone so I could get off the prednisone, and then I started to lose my hair, so I panicked. I didn't call him, and I stopped it [the methotrexate]. And so the other reason is I know a lot of those medications depress your T-cells. I don't want my T-cells depressed, because I don't want to end up with a lymphoma or anything else. That scares me. So that's why I'm trying other things other than the drugs.”
	“Like I said, I read information [about the medications], and it's pretty scary when you read. I'd get to where I was turning off the TV or muting my TV when the Humira commercials would come on, because I didn't want to hear all the side effects.”
Theme 2: Maintaining control over health	“[When I was taking my previous medication] I would be drooling. Or I would be moving like I'm running a slow race. I wasn't able to maneuver in my house. I said no, I can't take that. I want nothing that would take my psyche or my independence from me to where I'd have to sit there like I'm a junkie. No no no no, I don't want that. Nh-nh. So God is good, the medicine I'm on, it works. If it gets worse, then I'll pray on it. Maybe we may try the infusion. But right now, I'm staying with what I got. I'm in control. I'm in control.”
	“I'm supposed to take it every week, but I refuse to after my experience [being hospitalized with serious infection] with Enbrel. And as long as I do fine with every week, I'm keeping it there. They say the risk isn't that much greater [if I took it every week], but...”
Theme 3: Denial of sick identity	“Back in the late 80s, early 90s, what happened was I got up one morning, and I went to stand up out of bed, and I fell down. And the backs of my ankles, my Achilles tendon, I couldn't put any weight on them. So I went to a hospital, podiatry hospital. They turned around and they diagnose me with rheumatoid arthritis. Well I turned around and said I don't have that. I didn't know that it was done through a blood test. So it was way back then, and I've been a hairdresser all my life. Very busy hairdresser, very busy. My hands would blow up like balloons. And I would ice them or I would wear those wristbands. So I was in denial, all those years. Never missed a day of work either. No matter what I had to do, I got through work. So all this time, I was thinking that was from cutting hair.”
	“And I hate to see people [other RA patients who don't seek treatment] who can do something about a disease ignore it and hope it'll go away. I said, putting your head in the sand, being an ostrich, ain't gonna make it go.”
Theme 4: Disappointment with treatment	“Sometimes I don't know, well what should I expect. I know when you're old, everybody has arthritis, but is everything supposed to... all this medicine that I take, is it supposed to... I know it's supposed to slow down the disease, but is it supposed to make the pain go away totally? Or am I supposed to just grin and bear it? Like I walk like an old person now! Like I'm 100 years old!”
	“As far as the inflammation, the swelling is unbearable. By the end of the day, if you measure yourself, you've gone 2–4 inches wider, than you did at the start of the day from just inflammation...If I didn't have a massager to do what I have to do with it on my joints. . sometimes in the morning, if I had a bad night and I wake up and I'm really sore, it

Motivations to accept DMARD treatment regimens	Example quotations
	takes me an hour of massaging every joint before I can get out of bed. That's my savior. And that, to me, massage works better than any pill that you could possibly give me. That's kind of where I'm at right now. I definitely need a point in time in between drugs or I can't tell you whether the drug's working or not. So I just took it upon myself to quit. And I feel better without it."
Theme 5: Feeling overwhelmed by the cognitive burden of deciding	"Cause sometimes, when you go to the internet, there's so much information [...] You're googling, you're like, what is this going to do? You keep going down and down [the search results]... so that's why I would like a little bit more information from the doctor's office."
	"If you're saying like, oh, here's a pamphlet on this this...No, to me, that means nothing to me. I don't know what any of that stuff means. [...] I never knew what NSAIDs [nonsteroidal anti-inflammatory drugs] was! What the heck is that mess! You could tell me all day long, this does this and this, and I could read all about it. After that, I'd say 90% of that stuff I don't even know, even what the side effects are, I don't understand it! Cause I'm not medically inclined! So to me, that means nothing. [...] When I read about all that stuff, I'm like, oh my god I don't want to take this stuff! It's gonna kill me!"