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ORIGINAL ARTICLE

# Patients' Considerations in the Decision-Making Process of Initiating Disease-Modifying Antirheumatic Drugs

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***Objective.*** **To explore what considerations patients have when deciding about disease-modifying antirheumatic drugs (DMARDs) and what information patients need to participate in the decision-making process.**

***Methods.*** **In-depth face-to-face interviews were conducted with 32 patients with inflammatory arthritis who recently consulted their rheumatologist and discussed initiating DMARDs.**

***Results.*** **Beliefs in the necessity of DMARDs, either for relief of symptoms or prevention of future joint damage, were reasons to initiate DMARDs. Furthermore, trust in the rheumatologist and the health care system was important in this respect. Patients expressed many concerns about initiating DMARDS. These related to the perceived aggressive and harmful nature of DMARDs, potential (or unknown) side effects, influence on fertility and pregnancy, combination with other medicines, time to benefit, and manner of administration. Participants also worried about the future regarding long-term medication use and drug dependency, and if a medicine proved to be ineffective, about the risks of future treatments and running out of options. To decrease uncertainty, participants wanted to be informed about multiple treatment options, both current and future. They not only wanted clinical information but also information on how the medications could affect their daily lives.**

***Conclusion.*** **Health education should inform patients about multiple treatment options, for the present as well as for the future. It should enable patients to compare treatments with regard to both clinical aspects as well as possible consequences for their daily lives.**

## INTRODUCTION

In recent years, significant progress has been made in treating inflammatory arthritis. Current guidelines allow a variety of substances, including nonsteroidal antiinflammatory drugs, corticosteroids, and disease-modifying antirheumatic drugs (DMARDs), both as conventional synthetic DMARDs and biologic agent DMARDs (1,2). These treatment approaches vary in time to benefit, dosage, and mode of application (e.g., oral, subcutaneous, intravenous), potential side effects and risks (e.g., toxicity), and costs (1,2). With the continuing introduction of new treatment strategies, patients as well as rheumatologists face increasingly complex decisions about how, when, and what to initiate. Choosing the best treatment is a process concerning both clinical aspects and patients' preferences.

Currently, patients' involvement in decision-making about medication is advocated (1), because it is both considered a patient's right (3) and is associated with positive effects on patients' satisfaction with health care, self-management, coping behavior, and adherence (4–7). In rheumatology, patients have a high need for information (4,8–10), and most want to participate in decision-making (9–13). Furthermore, patient participation is important because studies show that patients' and rheumatologists' beliefs about illness and treatment may differ. This difference includes how they rank the potential benefits and side effects of available treatment options and how they prioritize long-term outcomes (14–25). Therefore, high quality patient-physician communication about the choice of treatment is important.

Patient Decision Aids (PtDAs) are tools designed and implemented to prepare patients to participate in making specific and deliberate choices among health care options (26–30). PtDA differ from standard health education in various ways. First, PtDAs specifically state the decision being considered, and they emphasize the importance of patients' roles in decision-making. Second, PtDAs describe

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## Significance & Innovations

- Besides side effects and potential risks of the current proposed treatment, arthritis patients also worry about future treatments if the proposed treatment proves to be ineffective. Specifically, they worry about risks future treatments may bring and about running out of options. To decrease this uncertainty, patients need to be informed about all treatment options, for the present as well as for the future.
- Before deciding about disease-modifying antirheumatic drugs (DMARDs), arthritis patients want information with regard to both clinical features (e.g., potential side effects and risks, efficacy, manner of administration), as well as possible consequences for their daily lives (e.g., restrictions for driving a vehicle and alcohol consumption, how to fit the schedule for administration into their daily lives). Patients want practical information to stay in control of their life and daily activities.
- To reduce concerns about long-term medication use and the feeling of dependency, patients might benefit from information about recent developments regarding tapering DMARDs when persistent and long-term remission has occurred.

multiple treatment options (instead of 1). Finally, they help patients to get insight into their personal values and preferences (30,31). According to a recent systematic review, PtDAs have been shown to be effective for many different decisions and conditions (31). PtDAs can improve patients' knowledge about options, risk perceptions, feelings of being informed, and certainty about what matters to them (31). Furthermore, evidence indicates that PtDAs improve patient-doctor communication (31). Patients using PtDAs are more likely to reach decisions that are consistent with their personal values (31). In rheumatology, PtDAs are relatively new; only a few studies on PtDAs about DMARDs have been reported (32,33).

To develop a PtDA that encourages patients to think about personal values and prepares them to participate in decision-making, it is essential to understand how patients decide about DMARDs. A number of studies describe how arthritis patients think about these drugs (22,23,25,34,35); however, these studies were either retrospective (23), scenario based (22,25), or focused on adherence (34,35).

A theoretical framework often used to understand patients' considerations about medication is the Necessity/Concerns Framework (NCF) (36). The NCF states that 2 beliefs about medication are important: the perceived necessity for the medicine to maintain or improve their current and future health, and the perceived concerns about potential adverse effects of using the medicine. This theory has been developed and used extensively to understand nonadherence to medication but may also be helpful to understand patients' beliefs and considerations before initiating medication.

This qualitative study aims to deepen the understanding of patients' considerations when deciding about DMARDs and what information patients need to participate in the decision-making process. The results of this study have been used to develop a PtDA for initiating DMARDs.

## PATIENTS AND METHODS

**Participant selection and recruitment.** This study focused on patients diagnosed with rheumatoid arthritis, ankylosing spondylitis, or psoriatic arthritis, who recently (<1 month previous) consulted their rheumatologist and discussed initiating DMARDS. The participants were required to speak Dutch. During the study period (September 2011 to March 2012), all patients who visited the clinic and met the inclusion criteria were informed about the study by their rheumatologist and were asked to give permission for contacting them. In total, 34 patients were contacted by the researcher; 33 patients consented to be interviewed. Eventually, 1 participant cancelled the appointment without providing a reason. The remaining 32 interviews were held within 1 month from the consultation with the rheumatologist. According to the Dutch Medical Research Involving Human Subjects Act, no approval of the ethical review board was needed; only (nonintervention) studies with a high impact for patients have to be reviewed.

**Procedure.** In-depth face-to-face interviews were conducted by the first author (IN). The interviews were audio recorded and lasted 45–120 minutes (average 66 minutes). Depending on the patients' preferences, interviews took place at patients' homes or at the university. Patients were informed that the results would be reported anonymously and that they could withdraw from the study at any time. Before the interview, participants signed an informed consent form. We used a semistructured interview method where the order of questions followed the natural progression of the conversation (37). The first part of the interview assessed patients' considerations, questions, concerns, and information needs when deciding about DMARDs. The second part assessed patients' need for a PtDA about initiating DMARDs and patients' preferences for its content and design; these results will be reported elsewhere. The first 2 interviews were used for intermediate evaluation of the interview guide. Minor adjustments were made to ease the usability, and question 3 was added. The final interview guide can be seen in Supplementary Appendix A (available in the online version of this article at http://onlinelibrary.wiley.com/doi/10.1002/acr.22531/abstract).

**Analysis.** Interviews were transcribed verbatim and analyzed using ATLAS/ti 7.1, a qualitative analysis software application that allows overviewing the codes, linking statements, and visualizing connections between codes (38). First, the analysts (IN and CHCD) read the transcripts to familiarize themselves with the content.

**Table 1. Participant demographics and characteristics***

| | Synthetic DMARDs (n = 16) | Biologic agent DMARDs (n = 16) | Total (n = 32) |
|---|---|---|---|
| Sociodemographic variables | | | |
| Women | 11 (69) | 15 (94) | 26 (81) |
| Age, mean (range) years | 58 (31–76) | 50 (25–82) | 54 (25–82) |
| Married/living with a partner | 14 (88) | 14 (88) | 28 (88) |
| Education, years | | | |
| <12 | 5 (31) | 2 (13) | 7 (22) |
| 12–16 | 7 (44) | 13 (81) | 20 (62) |
| >16 | 4 (25) | 1 (6) | 5 (16) |
| Full-time and part-time employed | 9 (56) | 9 (56) | 18 (56) |
| Health-related variables | | | |
| Diagnosis | | | |
| Rheumatoid arthritis | 14 (88) | 14 (88) | 28 (88) |
| Ankylosing spondylitis | 1 (6) | 2 (12) | 3 (9) |
| Psoriatic arthritis | 1 (6) | 0 (0) | 1 (3) |
| Illness duration, mean (range) years | 5.6 (1–40) | 2.0 (0–15) | 7.8 (0–40) |
| No. previous DMARDs, median (range) | 1 (0–3) | 2 (2–7) | 2 (0–7) |

* Values are the number (%) unless otherwise indicated. DMARDs = disease-modifying antirheumatic drugs.

Then, 1 analyst (IN) selected relevant fragments (sentences or small paragraphs) related to both main themes: 1) patients' considerations when deciding about DMARDs, and 2) need for information and satisfaction with obtained information. Both analysts mutually and independently further categorized the fragments. To segment and reassemble the data, they used the principle of constant comparison (39) and a process of open coding, followed by axial coding and selective coding (39,40), until a final thematic framework was developed for each theme. Finally, the NCF (36), among others, was used to interpret the data. The individual findings were compared and analyzed until consensus was reached. After analyzing 27 of the 32 interviews, we found no meaningful new information in the last 3 interviews; hence, we concluded that saturation occurred, which was confirmed by the final 5 interviews. All quotes in this article were translated from Dutch to English by a professional translator.

## RESULTS

**Participant characteristics.** In total, 26 women and 6 men participated. Some participants (n = 5) discussed initiating DMARDs with their rheumatologist for the first time. Others (n = 27) had already used synthetic DMARDs or biologic agent DMARDS before. Those patients discussed changing to another DMARD. Table 1 lists subject demographics and characteristics. Figure 1 shows the status of the decision at the time of inclusion and the time of the interview.

**Patients' considerations and concerns.** We asked participants for their considerations, questions, and concerns regarding initiating DMARDs. Answers were grouped into 3 considerations in favor of (Table 2) and 2 considerations against initiating DMARDs (Table 3).

*Considerations in favor of initiating DMARDs.* Necessity, the first category, was based on the NCF. Necessity was often associated with a need for relief of symptoms. Some participants deliberately chose to initiate the medication to ease their symptoms. For example, some stated that they valued current quality of life over potential future adverse effects. Others were so desperately in need to ease their symptoms (e.g., pain), that they consented immediately to the proposed medication: "I would have accepted anything." In other cases, the perceived necessity was less associated with direct symptom relief, but rather with prevention of future joint damage.

Trust, the second category, exceeded the necessity component of the NCF. Some participants completely relied on their rheumatologist or the health care system. They did not have any considerations or concerns about initiating DMARDs and just started the prescribed medication without reviewing other options.

Relative benefit is the third and final category. It relates to benefits the drug may have compared to other options. Participants mentioned several benefits influencing their

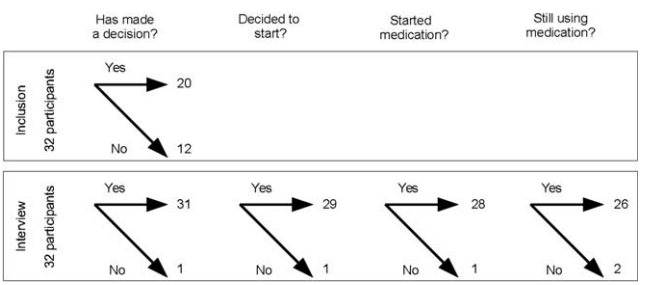


**Figure 1.** Status of decision at time of inclusion and interview.

**Table 2. Patients' considerations in favor of initiating various disease-modifying antirheumatic drugs***

| Category | Quotes |
|---|---|
| Necessity | |
| Symptom relief | The pain. You want to get rid of the pain. I've already had so many painkillers. You just want to try something else. |
| | I need to use it now. I want to have a good time, so the stuff just needs to work now! And well, what's it like when I'm 65, we'll see about that when I get there. That is something to worry about later, at least I'd be able to tell I've had a good life. |
| | Yes, so I'll accept anything. As long as it gets better. |
| Prevention of joint damage | I once knew someone with the same problems...but that person was already in an advanced stage, had new joints, was given an artificial hip and an artificial knee. But that person was of my age and...knowing that, I sort of thought, well, now I must act before it gets any worse. |
| Trust | |
| Trust in physician | So I presume they know what they're doing. No, in good spirits that we'll start, no. And let's see if it helps. |
| Trust in health care system | I still have a little faith in the health care system. |
| Relative benefits | |
| Lower risk of side effects compared to other drugs | Because of less... It had side effects though, but less... |
| Less frequent drug administration compared to other drugs | And that means not having to take all those drugs each day, since I only have to take this injection once in a fortnight. |

* All quotes are translated from Dutch.

decision to initiate the proposed medication, especially lower risks of side effects and less frequent and friendlier manner of drug administration.

*Considerations against initiating DMARDs.* The first category, concerns, originates from the NCF. Participants mentioned numerous concerns about initiating DMARDs. Many perceived DMARDs in general as aggressive and harmful medicines, making the participants doubt the necessity. More specifically, participants worried about both the number of potential side effects as well as specific side effects. The latter included risk of a weaker immune system, loss of hair, loss of vision, or risk of developing cancer. Some of the available DMARDs are relatively new drugs where robust long-term safety and efficacy data are lacking. This lack of information made many participants feel like a guinea pig. Younger participants also tended to worry about the influence on fertility and/or pregnancy. Some unexpectedly had to think about having children in the upcoming years. Participants also worried about the combination with other medicines, the time to benefit, and the manner of drug administration. Notably, many had concerns about future treatment of their arthritis, for example: "What if this drug does not work?" There may be a difference between synthetic DMARDs and biologic agent DMARDs. Participants facing the decision to initiate synthetic DMARDs worried about the side effects of both the current proposed drug as well as future options. As they assumed that doctors will first propose the drug with the lowest risks, they had concerns about what kind of risks future treatments would bring: "If this is the drug they start with [methotrexate], what will be the side effects of the next drug?" Participants facing the decision to initiate biologic agent DMARDs especially worried about the availability of future treatments, because they perceived initiating biologic agent DMARDs as the final option. Finally, some worried about the long-term use and dependency.

The second category, emotional impact, exceeded the concerns component of the NCF. Some participants considering DMARDs experienced an emotional impact; they realized they are seriously ill. First, having to take many (different) or a great quantity of drugs (volume, frequency, type) made some participants feel more ill and therefore reluctant to initiate DMARDs: "The more medication you take...the more ill you feel. Maybe even more than you really are." Second, some patients experienced an emotional impact because of the perceived severity of the proposed medication. Certain drugs, especially biologic agent DMARDs, were associated with aggravation of the disease: "This [initiating biologic agent DMARDs] is the next step... Now it gets serious... Because you now are privileged for initiating this category of drugs."

**Need for information and satisfaction with obtained information.** The need for information varied highly. Some wanted to know every detail: "I always get down to the details. Why? I don't know. I need to know what I'm taking and what to expect," and "I read everything. I know I shouldn't, because I only start to worry, but still..." Others were satisfied with the provided information: "For me it's actually quite plain. I just don't feel like going into that much further than I have to, until you start thinking you should do something. I think that...knowing too much...works obstructive. I follow my feelings... If you have little information, there's little to worry about."

We asked participants about the obtained information, from whom it was received, and how they valued

**Table 3. Patients' considerations against initiating various disease-modifying antirheumatic drugs (DMARDs)***

| Category | Quotes |
|---|---|
| Concerns | |
| Aggressive and harmful nature of medicine | Is this really necessary? I mean, it's not just an ordinary painkiller that you get prescribed. It is quite a strong medicine. |
| | I had hoped that it wasn't necessary [to start with biologic agent DMARDs] and that I could go on much further with the methotrexate. |
| Risks for side effects | Yeah, when I read all that, immediately I won't touch it, there are so many side effects. |
| | The long term risks. Well, they're the ones that really stick out and of which not much information is given. |
| | What I feared the most when taking this drug was that it has an impact on the immune system. I really find that very hard to accept. |
| | Well, and then I said, I only want to get better and not…serve as a guinea pig. |
| Influence on fertility and pregnancy | I was confronted with the question if I had any desire to have children. I mean, we haven't considered the option yet. We've only just started our relationship. |
| Combination with other medicines | And then I had to take all of that. And I think, "Oh, I'll be loaded with drugs. How will they all go together?" |
| Time to benefit | I ask myself, "Is it going to work?" You just don't know right away. You have to wait. |
| Manner of drug administration | Yes, he did discuss injections and the like, but I'd rather not, I'd rather not yet do that. |
| Future treatment | I was also thinking, if this is the drug they start with [methotrexate], what will be the side effects of the next drug? |
| | Once you start with this [biologic agent DMARDs], you can't go any further… With methotrexate you know that there's always something stronger, in case it doesn't work anymore, you can still move on. And now you know, well, that's it and there's nothing stronger anymore. [So I wonder] has the moment arrived that I should start with such drugs? |
| | And yes, the only thing is, for how long should you take it? And I just would like to know what comes next, for how long can you continue? Can I ever stop taking this? |
| Emotional impact | |
| Amount and number of drugs | The more medication I take, the more I must face the facts of having a number of conditions. I really am seriously ill. |
| Severity of drug | My first response [to the biologic agent DMARDs via infusion] was, "Oh my, we've gone down one step further." To put it like that. |

* All quotes are translated from Dutch.

it. Participants mentioned different sources of information, and most sources got both positive and negative remarks (Table 4). Whereas many patients were satisfied with the information provided by health professionals, sometimes the difference between the proposed options was not clear, especially concerning biologic agent DMARDs. Others found it difficult to comprehend contradictory information from different caregivers. Some participants had researched additional information on the internet about the proposed treatment options. This approach was mostly satisfying, as it confirmed the information the doctor provided. Some also read stories of peers. Not all participants valued that type of information, as they could not relate to those experiences. After deciding which treatment to initiate, participants received an information leaflet from the pharmacist and the package insert from the manufacturing pharmaceutical company. Relating to biologic agent DMARDs, the pharmaceutical company often provided additional material, such as books, CD-ROMs, DVDs, etc.

Most participants initiated the proposed medication. We asked them what information they would have liked to have before deciding to use the medication. Some mentioned they did not lack anything, while others gave clear examples. Many stated that they had discussed only 1 treatment option and would have liked to know more about other available treatments: "If they would have told me [about the wide range of options], then I would not have been so insecure…about, well…what awaits me." Knowledge about the wide range of possible treatments might have reduced concerns, because some feared "running out of options." Others wanted to compare treatment options with respect to potential benefits and risks and the consequences for daily life (e.g., influence on driving and alcohol consumption), as the following quotes illustrate:

"What [have] I missed? If he prescribes me methotrexate… maybe there are 10 other types of drugs with fewer side effects. But I don't know the names."

**Table 4. Opinions about information received through various sources***

| Source | Positive quotes | Negative quotes |
|---|---|---|
| Doctor/nurse | Very good explanation on the injections... She not only showed it, but made me try it myself. That way, you know you're doing it correctly. | I could choose, but the difference [between the biological injections] is not entirely clear to me. Except for the frequency of applying. |
| | The pros and cons were discussed. And the side effects... And whenever I've got any question, I can always ask or call. | The rheumatology nurse, the substitute rheumatologist, and my own rheumatologist all gave contradictory information. That wasn't easy. |
| Leaflet from hospital | So they gave me this booklet and just like I said, at such a moment you are caught off guard, so I liked reading about it all over. | I was given 5 leaflets and could make a choice. I read the documents. Well, they didn't contain much for a patient. It's no use. And then I said, "You choose." The leaflets really don't say much. |
| Internet | Well, what I saw, like I just said, was the same information I got from the rheumatologist, so I assume that's what I can rely on. | |
| | I think it's just a feeling... Whenever I think, oh well, this can't be true, I don't read [that website] any further. Then I'll return to reliable sites. And generally speaking, most of the doctor's and hospital's sites are. | |
| Online support groups | Yeah, and then I think, well yes, it's a bit more personal, a bit more realistic or so. You think, why yes, they really must have written it themselves. | I don't need anyone else. I'll find it out my own way. If I have to hear other people's. No, thanks. I would be happy to help, though. But I'm doing this for myself, and not in a group. |
| | It is of course nicely anonymous, so everyone is really very open. | Yes, it can be hard what people experience, I always have the idea that people who are doing not so fine write these things. |
| | | You feel and experience it yourself and that can be completely different for someone else. Like pain levels, they can be different for everyone. |
| Pharmacy | I always ask if I can combine it with all those other tablets...but the pharmacist takes that into account as well. | And why do they say at the pharmacist's that you cannot take this drug in combination with naproxen, so why is it prescribed then? That's funny. |
| Package insert | Yes, I mean the one in the box, the patient information leaflet, it is very informative, but not the one the rheumatologist gave. That one is actually quite scanty. | No, and then I think...yes...that is the same for all manufacturers of such medicines. They just want to cover themselves against legal actions, so they put in anything, so I think, I am not interested in that, am I? |
| | | When you start reading about the side effects a lot and dig into them, then you'll have it. It might not be the case, but somewhere inside you there's this little voice saying, "Oh, this is what I feel, so it must be this or that, because it's in the leaflet." |
| Pharmaceutical company† | Yes, you always get these very extensive leaflets [with the biological agents]. I like that, because they [the doctors] tell you all sorts of things and you don't remember most of it and...yes, you can go through a lot again in them. | Then you get your first batch of Humira with a mega large file containing all sorts of information: booklets and leaflets, plasticized and pens and covers to keep the stuff in. So I think, well, isn't that a bit exaggerated...I thought the rheumatologist's booklet gave sufficient information. |

* All quotes are translated from Dutch.
† Only relevant for patients who decided to initiate biologic disease-modifying antirheumatic drugs (in the Netherlands, advertising of drugs aimed directly at patients is prohibited).

"The package insert contains millions of things the doctor didn't say. They said...3 things that very often occur: nausea, fatigue, and...nothing else. And the package insert says...a million other things. That you can be restless, that your sexual life may get worse, that sort of things... I would have found that useful to know, to

consider taking this drug or another, because who would like their sexual life to deteriorate?"

"After taking the drip you're not allowed to drive. That's difficult for me. Well, difficult. It takes a bit of planning and arranging. But you must consider it, and I would really have liked to know that when considering the options."

"I like drinking a glass of red wine at night, but you can't have that for 3 days, can you? Well, I took just a small glass. But on the day before, the day of the treatment, and the day after, you absolutely shouldn't. You really have to consider that. I'd like to have known before."

Most participants were satisfied with the provided instructions for use, especially for the injections. However, some would have liked more information, especially when multiple drugs were prescribed with a complex time schedule for administration (e.g., methotrexate, folic acid, and a biologic agent DMARD). They would have liked to receive more help implementing the schedule in their daily lives. Additionally, some would have liked more assistance determining the start of the cycle of administration, since side effects disturbed their daily routine. These effects (e.g., nausea, vomiting, malaise, fatigue, and chills) often occur shortly after administering the drugs. The following quote illustrates this: "Taking methotrexate [which is administered once a week] makes me very nauseous. Then we adjusted the scheme and considered the best time for taking it. I deliberately did not choose to take it before the weekend starts, because suppose you keep being troubled by the side effects? I'd not want that over the weekend... I would have liked assistance with that sooner."

## DISCUSSION

This qualitative study explored what considerations patients had when deciding about DMARDs and what information patients need to participate in the decision-making process. The NCF (36) was used to structure patients' beliefs and considerations when deciding about DMARDs. In our population, necessity of DMARDs was often associated with direct relief of symptoms and sometimes with prevention of future joint damage. Yet many patients considered DMARDs in general as aggressive and harmful, making some patients doubt the necessity. This tension between necessity and negative beliefs about DMARDs has been described before (23,35,41,42). DMARDs have been described by patients as essential for managing arthritis, but also as "powerful," "strong," and "toxic" (35). Some reports show that patients are unwilling to take risks and are reluctant to change treatment even when disease activity is high (23,41); fear of loss of control over arthritis and the fear of side effects are major concerns. However, other studies have shown that patients are willing to initiate aggressive treatment in full awareness of the potential side effects (22). Discussing this tension with patients is important. Rheumatologists should inform patients about the long-term goals of the treatment, invite patients to share any concerns, and address potential misunderstandings about DMARDs.

Some considerations in favor of initiating DMARDs exceeded the considerations about necessity. First, trust in the physician and/or the health care system was mentioned as a strong motivator to initiate DMARDs, sometimes even without reviewing the pros and cons. This reliance on trust is in line with other studies (22,25,34,43). Although trust is essentially a good thing, it should not limit patients from reviewing the pros and cons. If patients completely rely on the expertise of their rheumatologist, they may fail to recognize the potential value of their own input (44). Since rheumatologists' and patients' beliefs about treatment differ (14–25), the input of patients is important. Moreover, patients' adherence to treatment might increase if the treatment matches their preferences. Second, benefits of the medicine compared to other drugs were often mentioned in favor of initiating a particular DMARD. These benefits may relate to a lower risk of side effects or to features that concern the potential impact on daily life, such as a less frequent drug dose and/or friendlier manner of administration. Future studies examining reasons for not starting certain drugs should include these relative benefits and the influence of trust in the physician.

Patients' concerns were related to the perceived aggressive and harmful nature of the medicine, potential side effects, influence on fertility and pregnancy, time to benefit, combinations with other medicines, and manner of administration. Most interestingly, patients also worried about future treatments. With regard to synthetic DMARDs, patients worried about what kind of risks future treatments would bring, as they assumed that their rheumatologist would start with proposing the mildest drug. With regard to biologic agent DMARDs, patients often worried that these drugs were the final option. This worry may be due to the Dutch stepwise treatment approach, which states that therapy with a biologic agent DMARD can only be prescribed to patients with at least moderate disease activity and in whom treatment with at least 2 synthetic DMARDs has failed. Finally, some patients were concerned about whether they would ever be able to stop using DMARDs once they started. Previous studies showed that arthritis patients worry about the future, especially about long-term medication use and their prognosis, due to the unpredictable course and varying disease activity (45–48). To our knowledge, no previous studies have reported patients' concerns about the availability and potential risks of future treatments. Therefore, patients need to be informed about all current and future treatments and their risks. Furthermore, patients have concerns about long-term medication use and fear dependency. Patients might benefit from information about recent developments regarding tapering DMARDs when persistent and long-term remission has occurred (1). It may be helpful to have a personal long-term treatment decision plan that lists and explains current and future available treatments and also highlights the possibility to taper medication in case of persistent and long-term remission.

Some patients experienced an emotional impact when considering DMARDs, because the topic made them realize they were seriously ill. Therefore, they were reluctant to start. Patients with chronic illness may experience an ongoing process of negotiation between resistance against medication and acceptance of their diagnosis (49). Then it is essential to ask what it means to initiate this treatment

and to evaluate alternatives that correspond better with patients' values.

Most patients were satisfied with the information they obtained. However, some indicated that they had missed information on how medication could affect their daily lives or how to minimize the impact of the administration schedule on their daily lives. The need to stay in control and the need for practical information are in line with studies showing that patients prioritize treatment outcomes related to quality of life (14–19,24). To increase patients' involvement in medical decision-making, it is essential to not only inform patients about clinical elements of the treatment, but also about the impact on lifestyle, control, and comfort.

The NCF, mostly used to explain adherence, proved useful for understanding patients' considerations about initiating DMARDs. Patients mainly weigh the necessity and concerns when considering initiating DMARDs. However, concerns should be assessed not only in relation to clinical elements of the treatment but also to the impact on lifestyle, control, and comfort. Furthermore, the NCF should be extended with such elements as trust and relative benefits. Finally, attention should be paid to the emotional impact, such as the patient realizing they are seriously ill.

The results of this study were used to develop a PtDA that includes all available DMARDs. It provides the opportunity to compare DMARDs with regard to both clinical information as well as practical information with possible consequences for daily life. The PtDA has a flexible information system to fulfill the needs of most users without overwhelming others. Furthermore, it includes value clarification exercises that acknowledge questions and concerns and that support patients to communicate their values with their rheumatologist.

Our results must be interpreted in view of the limitations of the study design. The participants in this study were recruited from two hospitals, thereby questioning the generalizability of the results. Our sample contained only a few patients who decided not to initiate the drugs. Whereas qualitative data have the advantage to gain new insights, they do not permit measurement of the impact of each of these factors on decision-making. More quantitative studies are needed to confirm our results.

From this study we conclude that patients should be informed about multiple treatments, both current and future. Information should enable patients to compare treatments with regard to both clinical aspects and possible consequences for their daily lives.

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### AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Ms Nota had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study conception and design**. Nota, Drossaert, Taal, van de Laar.

**Acquisition of data.** Nota.

**Analysis and interpretation of data.** Nota, Drossaert, Taal.

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