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Patient's Perspective of Shared Decision-Making in Rheumatoid Arthritis Treatment: A Grounded Theory Exploration

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Abstract

Current guidelines for rheumatoid arthritis (RA) treatment state that all decisions should be shared with the patient. Therefore, it becomes necessary to understand in-depth how patients with RA with different levels of health literacy and activation feel about sharing the decision with the health professional and how they experience this process. Grounded theory was used. Data collection included semi-structured interviews with 14 patients with RA. From the analysis of the patients' narratives, four categories were built: "Accepting the changes: non-shared decisions"; "The patient's rationale: why not share?"; "Reaching the requirements for sharing the decision: expanding the patient's autonomy"; and "Experiencing the sharing of the decision: 'there is no point in changing, if I do not use it'." The results revealed that patients do not feel involved nor prepared to make decisions regarding their pharmacotherapy, even though they often engage in decision-making on their own. Some feel invisible as they are not included in the process. Those who feel unprepared for sharing the decision recognize that they could achieve it by acquiring the necessary knowledge. The theoretical model developed explains that shared decision-making is a way to consider the patient's experiences with the use of medicines and prevent them from making helpless decisions.

Keywords

grounded theory, health literacy, patient activation, rheumatoid arthritis, shared decision-making

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Patient's Perspective of Shared Decision-Making in Rheumatoid Arthritis Treatment: A Grounded Theory Exploration

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Current guidelines for rheumatoid arthritis (RA) treatment state that all decisions should be shared with the patient. Therefore, it becomes necessary to understand in-depth how patients with RA with different levels of health literacy and activation feel about sharing the decision with the health professional and how they experience this process. Grounded theory was used. Data collection included semi-structured interviews with 14 patients with RA. From the analysis of the patients' narratives, four categories were built: "Accepting the changes: non-shared decisions"; "The patient's rationale: why not share?"; "Reaching the requirements for sharing the decision: expanding the patient's autonomy"; and "Experiencing the sharing of the decision: 'there is no point in changing, if I do not use it'." The results revealed that patients do not feel involved nor prepared to make decisions regarding their pharmacotherapy, even though they often engage in decision-making on their own. Some feel invisible as they are not included in the process. Those who feel unprepared for sharing the decision recognize that they could achieve it by acquiring the necessary knowledge. The theoretical model developed explains that shared decision-making is a way to consider the patient's experiences with the use of medicines and prevent them from making helpless decisions.

Keywords: grounded theory, health literacy, patient activation, rheumatoid arthritis, shared decision-making

The chronicity of rheumatoid arthritis (RA), the functional limitations that patients with this condition can present, the various therapeutic alternatives available and their adverse effects, as well as the possibility and need for constant adjustments in therapy (Ministério da Saúde – Ministério da Saúde, 2020; Smolen et al., 2020) emphasize the importance of consolidating patient-centered care (Voshaar et al., 2015). Respecting the values and preferences of individuals and incorporating them into clinical decisions are key characteristics of this care paradigm (Fisher, 2018). In this sense, some authors have emphasized that the achievement of sharing the decision with the patient is the pinnacle of person-centered care (Barry & Edgman-Levitan, 2012).

Shared decision-making assumes that patient and professional consider the available therapeutic alternatives as a team (Elwyn et al., 2012). These alternatives are described in detail by the professional, presenting the benefits and risks of each option. After providing sufficient information to the patient, the professional should help the patient explore these alternatives and form their own preferences so that they can decide what will be best (Elwyn et al., 2012; Elwyn et al., 2017). It is explicit in the main RA therapeutic guidelines that decisions should be shared between patient and rheumatologist (Ministério da Saúde, 2020; Mota et al., 2018;

Singh et al., 2016; Smolen et al., 2020). However, the degree to which decisions are shared regarding RA treatment still needs to be improved (Mathijssen et al., 2020).

Added to this context, decision sharing has been seen as an essential component of treat-to-target (Falzer, 2019; Singh et al., 2016; Smolen et al., 2020), a strategy that provides close monitoring of RA activity and treatment change if the goal is not achieved in a certain period (Smolen et al., 2016). Despite the effectiveness of this approach and the recommendation of its use in clinical protocols (Ministério da Saúde, 2020; Mota et al., 2018; Singh et al., 2016; Smolen et al., 2020), adherence to it is still not unanimous. Physicians point to the lack of time as one of the obstacles to its implementation (Haraoui et al., 2012). On the other hand, many patients who experience frequent changes in treatment report not understanding the reasons for these changes (Kumar et al., 2011), and the adjustments made in their pharmacotherapy are filled with uncertainty, anguish, frustration, and expectations with the possibility of improvement (Neves et al., 2021). Hence the importance of initiatives that foster patient involvement and the availability of professionals to share the decision, favoring the understanding and engagement in treat-to-target (Smolen et al., 2018).

Emphasizing the RA patients' perspectives on sharing the decision, Díaz-Torné et al (2020) found that 17.8% of patients share the decision with the professional, while 27.8% do not participate in the decision. The remaining patients even discuss the alternatives with the professionals, but the final decision is left to the patient (23.0%) or the physician (31.9%) (Díaz-Torné et al., 2020). Another quantitative research involving a large number of patients showed that individuals with RA have a lower preference for participating in the decision, and this preference is even lower among patients who find it more difficult to understand medical information (Mattukat et al., 2019). On the other hand, Oliveira et al. (2021) pointed out that, although most patients with RA investigated had difficulty understanding the information and its application in the health context, they considered themselves capable of acquiring skills for self-management of health, which can facilitate interventions for their greater engagement in their own care.

In this context, although RA treatment is very complex, and some quantitative studies and guidelines point to the fact that decision sharing should be implemented or improved, to the best of these authors' knowledge, no qualitative study has yet explored the experience of RA patients in this process, or what it means to them. Shedding light on the patient experience is an essential step for health professionals and health managers to rethink the care process within RA care and to empower patients to shared decision making. Given all this, this innovative qualitative study seeks an in-depth understanding of how patients with RA with different levels of health literacy and activation feel about sharing the decision with the health professionals and how they experience this process, so that their involvement in decision making may be promoted.

Finally, the authors of this article are pharmacists involved in qualitative inquiry and direct patient care. We research topics such as the patient illness/medication experience and decision-making in order to improve the care we provide in comprehensive medication management services. After implementing and providing this service to patients with RA and in view of the recommendations that decisions about the treatment of RA should be shared between patients and professionals, the need arose to understand the meaning of this sharing for the patient. This article is part of the doctoral thesis of the first author, whose main interest is to encourage patient autonomy and interprofessional decision-making. Our end goal is to help patients achieve better results through the control of RA and other health problems.

Methods Study Design

The patients' involvement in the therapeutic decision-making process, as well as its meaning for these individuals, is a complex phenomenon requiring methods that allow an in-depth investigation for its understanding. To achieve this objective, grounded theory was used, a methodological approach appropriate for when little is known about the studied phenomenon (Chun-Tie et al., 2019). The use of this methodology enables the study of action to be the focal point of the research, and the analysis of the process creates abstract interpretive understandings of the data (Charmaz, 2009). According to Charmaz, "grounded theory is constructed through our involvements and interactions with the people, perspectives and practices of the research, [...] offering an interpretive portrait of the world studied" (Charmaz, 2009, p. 25). By agreeing with Charmaz's position, the epistemological assumptions of this research become explicit, in which there is no clear separation between the researcher and the researched, since all knowledge is constructed from the processing of meanings in the researcher's mind (Daly, 2007).

Furthermore, by adopting grounded theory as a methodology, it was intended to develop a theory, based on data systematically collected and analyzed through the research process (Charmaz, 2009). Thus, through the establishment of plausible relationships of concepts and sets of concepts, the researchers sought to build a model for the phenomenon studied.

Sampling and Data Collection

In grounded theory, the sample is not previously defined; the data analysis is what leads to its definition. This process is called theoretical sampling, a strategy to obtain more selective data to refine and complete the emerging categories (Charmaz, 2009).

Thus, data collection began with the interview of a patient with adequate health literacy and high level of activation, measured through the instruments Short Version of the Test of Functional Health Literacy in Adults (S-TOFHLA) and Patient Activation Measure (PAM-13B; Carthey-Goulart et al., 2009; Insignia Health, 2019), respectively. The first patient interviewed was assisted by both the medical team and the pharmacists at an RA outpatient clinic of a public university hospital. From the initial analysis of this interview, new data were collected based on the themes of interest that emerged. The selection of the remaining participants was carried out as the research developed, seeking to include patients with different levels of health literacy and activation that were also followed-up in the same outpatient clinic.

For semi-structured interview, a list of preliminary questions was used and then were modified, discarded, or replaced during the progression of the research (Daly, 2007). Using the principles of grounded theory, guiding topics were used for the initial interviews, with open-ended questions that sought the interviewee's global perspective on sharing the decision with health professionals. As the data were being analyzed, categories and concepts began to emerge, which provided a greater focus for the subsequent interviews (Wimpenny & Gass, 2000), dispensing in some moments the use of the guiding topic.

Grounded theory enables the extraction of data from various sources, including from quantitative research (Chun-Tie et al., 2019). Thus, the responses to the instruments previously mentioned (S-TOFHLA and PAM-13B) were also used for better understanding of the phenomenon.

The sampling process continued until data saturation was reached, as recommended by Strauss and Corbin (1998). Saturation occurred when a rich description of the phenomenon was achieved, and the collection of new data stopped arousing new theoretical insights or revealing new properties of the categories or central themes (Charmaz, 2009). Therefore, the

number of participants selected for the research was guided by theoretical saturation, which was reached after interviewing 14 patients. All interviews were conducted by the first author and lasted between 24 and 54 minutes. The interviews were recorded and transcribed in full for data analysis.

The participants will be indicated as “Participant 1” (P1) to “Participant 14” (P14), and their main characteristics are presented in Table 1. All participants provided a signed informed consent form. This study was approved by the Ethics Committee of the Federal University of Minas Gerais (process number CAAE-25780314.4.0000.5149).

Table 1

Description of participants

Participant (gender)	Age (years)	Follow-up time in the outpatient clinic (years)	Health literacy	Activation
P1 (female)	56	07	Adequate	Level 4
P2 (male)	65	04	Adequate	Level 4
P3 (female)	40	07	Adequate	Level 4
P4 (female)	62	18	Adequate	Level 3
P5 (female)	56	10	Adequate	Level 3
P6 (female)	66	05	Adequate	Level 4
P7 (female)	69	07	Adequate	Level 4
P8 (female)	52	07	Marginal	Level 3
P9 (female)	45	07	Adequate	Level 3
P10 (female)	66	17	Marginal	Level 3
P11 (female)	62	11	Inadequate	Level 3
P12 (female)	72	22	Inadequate	Level 3
P13 (female)	62	07	Inadequate	Level 2
P14 (female)	45	16	Adequate	Level 4

Data Analysis

Data analysis began immediately after the first interview, as advocated by grounded theory. The analysis method involved a process of constant coding and comparison between data. The first interview was transcribed and then its line-by-line coding was performed; that is, each line of the transcript was named according to its meaning. This strategy induces the researcher to study the data rigorously, and begin to conceptualize the ideas (Charmaz, 2009). This first analysis directed the subsequent data collection.

Afterwards, each new interview, it was performed the line-by-line coding, always comparing the data within the same interview and between interviews. As the analysis evolved, the focused coding began, in which the most frequent and significant initial codes were used to integrate and organize larger amounts of data (Charmaz, 2009). Qualitative data analysis is a dynamic process. Thus, during the focused coding, it was necessary to return to the data to study them better, as well as resume the line-by-line coding for new data collected. Finally, the selective coding was performed, which consisted of the process of determining the central categories of the phenomenon (Strauss & Corbin, 1998). This whole process was carried out with the aid of NVivo® software for qualitative data analysis.

Throughout the analytical process, memos were written. Memos are an essential part of data analysis when using grounded theory, since they aid in the interpretation of the data and

encourage the adoption of a reflective stance by the researcher (Charmaz, 2009; Nagel, 2014). As the analytical process evolved, the memos were used to explain the characteristics of the codes, explore the relationships between them, and dialogue with the literature (Oliveira, 2016).

Results

The systematic data analysis allowed the construction of four main categories: "Accepting the changes: non-shared decisions;" "The patient's rationale: why not share?" "Reaching the requirements for sharing the decision: expanding the patient's autonomy;" and "Experiencing the sharing of the decision: 'there is no point in changing, if I do not use it.'" These categories explain how patients with RA feel about sharing the decision and especially how they experience this process.

Accepting the Changes: Decisions Not Shared

A patient with RA experiences many changes of medication during treatment, and at this moment, when faced with the various therapeutic alternatives available, sharing the decision would be emblematic. When telling the story of the changes, they recognize and describe the moments of experiencing ineffectiveness and adverse effects, which culminated in switching the medication. However, most participants did not describe how their preferences were considered at the time of switching, nor how they did not experience a discussion of the therapeutic alternatives available. Patients experience each change, but many do not experience sharing:

I was on adalimumab for a while, and it had a very positive effect on my body. After a while, it didn't do it anymore. So, the doctors decided to switch to golimumab (P3).

Then she (doctor) switched to certolizumab and leflunomide, which is one pill a day. I took certolizumab for about four years, everything was fine. Then she decided to change my medication. She thought it was time to change, instead of taking the certolizumab, she changed to the pill, Olumiant® (baracitinib). I have been using it for a month now (P13).

I took Arava® (leflunomide), then an injection, all with methotrexate. Then I took methotrexate with Arava, and then methotrexate with Adalimumab. I think it was because this medication was new, and they wanted to do an experiment to see if it would be better for me. But the knee was not responding to the medication. The knee was swelling, it was hot... So, they switched me to tocilizumab. So today I take tocilizumab and I take the methotrexate (P5).

Participants three and five have adequate health literacy and activation level four and three, respectively. On the other hand, P13 has inadequate health literacy and lower activation level (level two). Despite this difference, the three participants went through a process of medication switch without a discussion about the alternatives available to them at that moment and decided to accept the proposal made by the doctor. The speech of participant one illustrates the process of change of treatment for RA experienced by most patients interviewed: "he [doctor] always came with what he thought would work at that moment."

The act of accepting a recommendation without discussing or exposing their doubts and fears finds foundation in a paternalistic culture and is linked to the idea of obedience to the health professional which the patient carries:

What the doctor orders, what he prescribes for me, the medicines to take, I take.

I do not get into an argument. What he tells me to do, I am obedient. I do it (P2).

The agreement with the proposed treatment is also related to the trust that participants showed in the professionals who assist them:

I trust the doctors, what they say, and I just go with it. I take it very seriously, you know. Because this disease is not easy. It is not easy to live with it, so everything that passes I really grab with great strength, with great faith... I think this disease is very cruel. I think I am very well assisted there. I take the medication and everything, but I still have a lot of pain (P4).

Although patients do not participate directly in the choice of medication, they trust that the doctor's decision was based on the best outcome for them, considering the specificities of their disease. Furthermore, the participants emphasize how the suffering caused by the manifestations of RA, especially pain, makes them accept and put all their expectations of improvement in the prescribed treatment. The experience of pain makes patients more passive and more likely to adhere to what is being proposed, as long as it aims at the relief of that symptom.

On the other hand, participant three says that changes in the pharmacotherapy are always preceded by a clarifying conversation:

The doctors always talk to us. At least with me. The doctors always told me about the effects. Why I was changing, increasing or decreasing the doses (P3).

Even though in certain changes, patients do not effectively share the decision with the professional, an open explanation of what is being done, as reported by P3, can contribute to feeling confidence in the treatment and in the professionals. Understanding the reasons for the changes also makes the patients more aware of their treatment and able to discuss the medications they use with professionals.

Decisions not directly related to RA treatment are often not shared either as P1 reports:

Based on what I take, he (doctor) only talked to the nurse. Not with me. He talked to the nurse like this: "I'm not going to prescribe bupropion for her because it increases her pressure too much, her pressure is already high. I'm going to prescribe..." they talked among themselves and prescribed another drug (P1).

P1 recalls that she was not included in the discussion about the medication that would be prescribed to help her quit smoking. The patient's preference and opinion were not considered or consulted. Given her experiences, P1 states that the sharing of the decision between patient and health professional does not happen:

It doesn't happen here; it doesn't happen anywhere. Most of the time, the patient is there, and the doctor says: "I'm going to prescribe this for you" (makes a writing gesture). Thank you doctor, bye. It works like this. There is no doctor

who says: “I want to prescribe this medication, but it is like this and this other one is like this, what do you think?” (P1).

Not sharing a particular decision with the health professional opens the way for the patient to make decisions on their own, as it was revealed in the following category.

The Patient's Rationale: Why Not Share?

Most participants demonstrated that they often make decisions regarding their pharmacotherapy based on their experience with the use of medications. However, real patient involvement in shared decision-making has the potential to reduce the need for them to make decisions on their own or to adapt medications use to their daily reality.

When I started with rituximab, I did some tests that showed HBC... I don't know! Something about hepatitis. But it is not that I have hepatitis... it seems that I have already had contact with hepatitis. This drug that I use, it is like a little key to connect hepatitis. Do you understand? So, I am taking a medicine (entecavir) now that the infectious disease specialist prescribed to me, they call it prophylaxis. But until they managed to explain it to me, I stayed a long time without taking the medicine. I used to think: “I already take a lot of medicines. If I do not take them, I cannot walk, because it hurts too much. Why do I have to take a medicine for a non-existent disease?” (P1).

If P1 had participated actively in the decision to include entecavir in her pharmacotherapy from the beginning, the clarification would have happened faster, and the patient would not have spent a long period away from the health service and without adhering to the treatment. The participant's speech makes it clear how she was able to understand why she needed to use entecavir after receiving adequate information.

Like P1, all participants in this research demonstrated practicing self-management of health conditions and medications to some degree. However, they do not always have the knowledge and skills necessary to perform it effectively and safely; hence the importance of an exchange of quality information between patient and professional, which can improve the skills of the former. In this sense, achieving the sharing of the decision is an important way to prevent the patients from having to make decisions on their own.

The participants' narratives revealed that such decisions are most often made based on their experiences of adversity, resoluteness, and ambiguity with the daily use of medicines. These types of experiences have already been described by Nascimento et al. (2019). Patients transform their subjective experiences with the use of medicines into actions at every moment:

I was taking ranitidine; ranitidine does not solve anything for heartburn. I was taking ranitidine early in the morning fasting and, in the afternoon, I was taking bicarbonate. I went back to omeprazole. I know that it was changed, so I said: “I am not taking ranitidine, because it is not working. I will take omeprazole which solves everything. But I do not take it every day.” I take it every two or three days. I made that decision, and I will bear my consequences (P2).

P2 tells that he used omeprazole, and at a certain moment, his physician decided to switch to ranitidine. Without discussing the risks and benefits of the options, he accepted the switch and started taking ranitidine. However, based on his experience of adversity with the

use of ranitidine (i.e., maintenance of symptoms despite the use of the drug), the patient himself found a solution to his problem and went back to using omeprazole.

Adversity is also experienced when the medication causes an undesired effect in the patient. Participant ten, when experiencing an adversity with the use of leflunomide, decided to stop using it:

I stopped taking it because it was making me sick, right? Diarrhea. I was feeling unwell. I stopped taking it and then I stopped the discomfort that I was feeling (P10).

The speech of participant six exemplifies how the patient needs to understand well about her treatment to avoid that some decisions may put her at risk:

The secretary of the outpatient clinic called saying that there would not be an appointment with the rheumatologist, but that, as soon as the pandemic passed, she would communicate with me. And then I am taking the pill (methotrexate) every 12 hours, every day. But I think I miss the injection (injectable methotrexate), because that injection seems a miraculous thing. It is very good. It causes a little bit of nausea, but I do not mind the nausea because it is temporary. I looked at an old prescription, because I was going to take an injection after the pandemic had already started. With that, I lost total contact in the clinic, and it was more difficult every day. And when I saw that my wrists started to swell, I started to take this methotrexate like I used to take until the next appointment. You may buy the pill without a prescription order, but is not possible to buy the injection (P6).

Without access to injectable methotrexate and facing signs of RA activation, P6 replaced the injection by the tablet on her own. By claiming to use one tablet every day, every twelve hours, the patient reveals the use of an inappropriate dosage for oral methotrexate, exposing herself to an overdose of the drug, which increases the risk of toxicity, in addition to consequences for RA control. The usual dosage of methotrexate is three to eight tablets once a week.

The resoluteness experienced with the use of certain medications also leads patients to the decision to self-medicate:

All my joints hurt. All I know is they hurt. Like, I came here with a bad pain, and I even took an anti-inflammatory at my own account, because I was in a lot of pain. I took it and it improved a little. But I want something right. I want it to come from the doctor. I took it. I know I did wrong. I want something that the doctor prescribes correctly (P2).

P2 emphasize that he got better after the decision to use the medication. However, P2 does not consider his decision legitimate because he believes he needs something definitive. Despite having felt pain relief, the patients themselves condemned self-medication.

The experience of resoluteness arising from the improvement of pain with the administration of diclofenac, as well as the absence of a viable alternative, makes P4 maintain the use of the medication, even in the face of the warning of adverse drug effects:

And the pain medication... I still have to take some others on the side. I'm in a fight with them there (RA clinic), because the only one that relieves my pain is

diclofenac. Then she (doctor) said there is no way to take it. Then I said: I know the risk. She prescribed me Tylex® (acetaminophen and codeine). But what happens is that Tylex® is very expensive. So, there is no way to buy it like this to take more often. (...) So, I take the diclofenac today, tomorrow I take nimesulide. I take it alternately. But I take it, I have to take it. I take it at least once every day (P4).

The patient's narrative encourages reflection on the possibility of a different outcome with the practice of sharing the decision. From an open discussion about the possible therapeutic alternatives, including the cost of each one, professional and patient could have found together a solution for the patient's residual pain that minimized the risk related to the prolonged use of diclofenac.

The experience of complete resoluteness makes the participant feel that she no longer needs to use the medication:

Over time I saw that I didn't need it anymore. It's been a few years since I stopped. Then I went and told the doctor that I had stopped. The doctor was even a little bit angry with me. He said "ah, but you shouldn't have stopped so suddenly." And, to this day, I have never taken it again (P6, referring to fluoxetine).

P6's speech illustrates how important it is to periodically evaluate with the patient the need to maintain a certain medication. In this context, sharing the decision can make the discontinuation process safer for the patient.

The use of medications in patients' daily lives can also be an experience full of ambiguity. One of the participants says that she no longer perceives any benefit from the use of clonazepam, however, she continues to use it:

There is another drug that I take to sleep: clonazepam. I think I am ruining my body with this drug that does not make me sleep. I think I will even stop because taking something that is not solving anything for me... I am sure that it will harm something. I will stop taking this medicine. I think it is silly for me to continue. They don't like it. They say that I have to stop. Sometimes they give me drops to taper the drug... then I don't use it... I don't obey! I take the pill again. Switch to drops, I take some for two... three days... and then go back to the pill! I go to the primary care center, get the prescription order and continue to take the pill. I think that switching pills to drops is not going to solve it. But this is something that is for my own account. It is something that I have to do... We already talked about the sleeping drug. I'm going to work on that now too. I'm going to do that, so that I don't have to take it in drops, I'm going to take it, reducing the pieces, taking half... then going to a quarter... until the end (P12).

In P12's case, both physician and pharmacist explained to the patient that the risks of benzodiazepine use outweigh the benefits and proposed a gradual tapering scheme. However, there was no discussion about the patient's negative experience with the liquid oral form. Furthermore, leaving the tablet was not presented as an alternative to withdrawing. Therefore, pharmacist and physician did not achieve full decision sharing with the patient and were not successful in tapering the benzodiazepine. During the interview, P12 ended up finding a solution to suspend clonazepam by herself.

Sometimes patients do not make decisions on their own but suffer for not sharing the same therapeutic goals with the professionals who assist them. The joint definition of therapeutic goals is essential to achieve shared decision-making.

I said that it was not as good as the other (tofacitinib). But the doctor said that we have to take it to see if this one (rituximab) has a better effect. Until now, it hasn't (...). This one is more difficult. I stay all day in the clinic... the other one was only a pill. They changed it because I had been taking it for a long time and it was not having the same effect as they wanted. For me, it was good because at least I thought it was better at relieving the pain (P4).

Participant four remains using rituximab every six months in the hope of improvement. However, it is not clear to the patient the real reason for the switch. The experience she reports is a greater perception of pain improvement with tofacitinib. It is possible to perceive from the narrative that there is a lack of alignment between the therapeutic goals set by professionals and what the patient expects from her treatment. A conversation about the defined goals could prevent the patient from having her expectations frustrated.

The presence of divergent therapeutic goals also leads to a delay in the relief of adverse effects experienced by patients, as reported by P13:

I started to feel very nauseous. The effect was barely over, and I took it every Wednesday. Then, when it got to Sunday, it got a little easier... and then on Wednesday I had to take it again. So, it was torture. I couldn't even stand to see more methotrexate in front of me, because my stomach was already upset. And it took over 6 or 7 months to change it. That's when I came back and said I can't take it anymore. Then, after this time, they changed it for me. It's because they told me that I couldn't change it yet... that I should keep taking it for a while longer (P13).

In this case, a discussion about the patient's preferences, the available alternatives and the definition of a joint solution could have avoided the prolongation of the suffering, frequently reported by the participants.

Therefore, there is no doubt that there is meaning in the patients' complaints, as well as in each decision made by them. The participants' narratives show how they are able to exercise their own reason. The patient's rationale presented in this category should be an invitation for decisions to always be shared.

Achieving the Requirements for Shared Decision-Making: Expanding Patient's Autonomy

This category was divided into five subcategories that represent the characteristics and feelings of the participants regarding the decision-making process. Within this process, patients advance and reach fundamental requirements so that they can share the decision with professionals. In this sense, the subcategories are in a continuum of actions that can lead to sharing the decision. At one end is the patient who says that it is the doctor who should decide; and at the other end is the patient who recognizes him or herself as responsible for his or her health and, therefore, should participate in the decisions. Thus, as the patient advances in these subcategories, he or she is more prepared for shared decision-making with the professional.

“I am a Layman... It is the Doctor who has Knowledge.”

Some patients believe that they should not be involved in the decision-making because they are lay people. One of the participants says that discussing it would be in vain, since the professional is the one who masters the knowledge:

I am seeing a person, who is a trained doctor. He knows what he does. We can't participate, because we are laymen in the subject. The doctor will never discuss... professional, doctor, right? Then it gets difficult. Why should I discuss with a doctor? He's the one who knows about the cause! It's not me. I've just finished high school and that's all (P2).

For P2, the issue is simple: with no medical training, he would not be able to discuss his treatment with the health professional. It is noteworthy that P2 is a patient with adequate health literacy and high activation level, who recognizes that he does not participate in the decisions made by professionals. However, he brought several examples throughout his interview of decisions he made on his own. Participant 13, in turn, has inadequate health literacy and lower activation level than P2 and emphasizes that she is a lay person and that professionals know what is best for her:

You are the ones who know what will be best for me, because, at this point, I am a layperson. Right? There are doctors who will know which medicine is best. Just like I go to the doctor... the doctor gives me an option... I would simply answer that it is their opinion. I have been treated by them for a long time, so they will already know about the condition, they will know which medicine is best for me (P13).

Patients with different characteristics demonstrate not being aware that they have useful knowledge for discussion or that the professional can assist them in building knowledge. On the other hand, P1 emphasizes that she can make decisions with the professional as long as she receives the proper guidance, acquiring the necessary knowledge:

If he (professional) guided me, I would have total capacity to say, “not that one.” But for that I would have to have knowledge, which I don't have. There is no point in him coming up to me and saying: “oh there is dipyron, acetylsalicylic acid, and an antipyretic here, which one of the three do you want, you can choose.” Then I would say: “which one do you suggest?” Because he masters the knowledge. Not me (P1).

Implicit in P1's narrative is her understanding of what decision sharing really is.

Feeling Invisible and Unprepared

The perception of lack of knowledge addressed in the previous subcategory makes patients feel unprepared to share the decision with the professional, as highlighted by P12: " I don't understand about drugs. I don't understand anything. So, we are kind of, how should I put it... a little unprepared."

In addition to the feeling of unpreparedness, participants talk about feeling invisible during the decision-making process. Participant P14 describes the feeling of being present, but not being included in the discussion:

Most of the times, the professional keeps talking to the resident. Sometimes they keep exchanging ideas, the professional keeps asking what he thought, and we stay there in the background. They keep talking among themselves, and then the doctor who comes later usually takes a look, and says: “change this” or “do not change anything and she'll come back in a few months...” (P14).

P1 emphasizes that she does not participate in decisions and is used to invisibility:

So, you don't participate, it's like you're invisible. Most of the time, you are invisible. We are so used to this... We will even be amazed if a professional who treats us differently appears... who wants our opinion... wants you to interact with them. It will be even strange to tell you the truth (P1).

For P1, not being included is normal, she also emphasizes that being invited to participate in the decision would cause strangeness for being something not expected.

Recognizing the Effects of Medicines on the Body

When the patient recognizes the effects of the medication being used in his or her body and can use this information in the discussion with the professional, he or she is closer to experiencing a sharing of the decision. Participant P7, besides realizing the effectiveness of her pharmacotherapy for RA, demonstrates knowledge about what are the next expected changes in her treatment:

The injection started out as a 4-weekly injection. Then, it became an 8-weekly injection. The trend is to prescribe only one syringe, and I take two every 50 days. The next step is to switch to one (P7).

By experiencing a certain adverse reaction, patients end up acquiring technical knowledge about the unwanted effects that the medication can cause:

I took methotrexate... my eyesight, my eyes yellowed... it attacked my eyes quickly, methotrexate was out. Prednisone... I swelled up, I got swollen. Meloxicam caused the kidney problem... it was bad because I was taking it straight... they cut it (P2).

P3's narrative summarizes how recognizing the effects of medications and being able to express what they are feeling provides subsidies for the dialogue with the professional, allowing the patient to move towards shared decision-making:

I can read my body. I know what is happening with my body. So, when the doctor tells me something, or when he asks me something, I can tell him what I am feeling... how it is. When the doctor proposes me something, I already know if it is good for me or not. Of course, the doctor has the scientific knowledge of things. But I can read in my body if what he is proposing is going to be good for me or not... (P3).

Accessing Information: Difficulty, Reprehension, Fear and Power

Four components permeate the act of accessing information by patients, according to the results of this research: the difficulty of understanding it; the reprehension for seeking information; the fear of knowledge; and the power gained after acquiring knowledge. Before presenting these components, it is important to highlight that most participants reported not knowing the therapeutic alternatives available for the treatment of RA before using them:

I know the ones I've been through... that I've taken (P4).

Only after experiencing an exchange in their pharmacotherapy did P4 become aware of that therapeutic option. This statement goes against the premises of decision sharing, since the available alternatives should be discussed with patients. Patients face several difficulties when trying to perform an active search for information, as reported by one of the participants:

I think those (medicines) that have labels... I read everything, but most don't have them. So, there are some that I get at the public pharmacy and there's no label, there's nothing... I don't know how to look on the internet, so... But I also don't get it that much. Like rituximab, I had access to the label, I didn't understand much... but I didn't even question with him (professional)... no (P4).

In addition to the difficulty in accessing the label of some medications and not knowing how to search for information on the internet, P4 reinforces that she could not understand the information contained in the label for rituximab. A patient with health literacy classified as adequate reveals her difficulty understanding more technical data about the medication and that, in addition, she preferred not to take her questions to the professional. Her speech shows the urgency to make knowledge more accessible, which is necessary to patients.

Participant two said that he has always had the habit of reading the labels of the medications he uses. However, he emphasizes that such conduct is reprimanded:

Everything I take I read the label first. They told me it is wrong. Every medicine I take... like this one I bought: "be careful not to take too much because of your kidney." I already knew this because I had read it before. And the doctor told me not to read labels, because if you do, you end up not taking the medicine, all drugs have contra-indications, so you will never take medicines in your life (P2).

The patient experiences the conflict between liking to read labels to get to know the medicines he uses and the warning that reading it may hinder his adherence to treatment. In this context, P2 ends up incorporating in his speech the fear of unwanted effects that he may encounter when reading labels:

But it will scare you... the label also scares you... oh... the side effects... oh... I'm not going to take that medicine! It's no use, what do I read it for? I know that there will be side effects. But why do I want to know? How am I going to treat it? On what grounds? What am I going to do? (P2).

In addition to highlighting fear, P2 questions the reasons that lead him to read labels, since according to him he will not know what to do with the information he will find there. Unlike P2 who talks about his fear, but keeps reading labels, other participants report that they

prefer not to have access to information about the medicines and about RA to get away from negative experiences. P9 said:

I don't like to read too much because this thing is very... one person is with something damaged... the foot... the knee. Then I am afraid of getting like this too. And I don't like to see it because I get very upset. I am afraid... very shaken. But I don't like to read too much, because there are many negative parts. (P9).

P9's fear, as well as that of other participants, is to seek information, come across patients already with RA complications, and project similar pictures for their future. That is why it is so important that professionals and patients share information to prevent the patients from losing access to knowledge due to fear and to be able to openly discuss their prognoses. In addition, the professional can help the assisted person to find patients with inspiring experiences and stimulate the sharing of knowledge among them.

Knowledge is power! The following narratives demonstrate how having access, understanding and knowing how to use information increases the participants' safety regarding the use of medicines:

Do you know what led me to read its label (baracitinib)? Let me explain... because as soon as I started taking it, I started coughing... having a little itch here on the side of the throat. That's when I said: "let me read it." Because sometimes you take the medicine without precision; without knowing. And sometimes reading the instructions you can see: "sometimes it can cause this... sometimes it can cause that." So, all this is good for us to know. Then I did not stop with the medication, I saw that it does not have this. Then I said: "I will continue" (P13).

As previously presented, participant two in his speech brought up a very widespread idea that reading labels is synonymous with looking for adverse reactions, and that, therefore, negatively affects the use of medications. In contrast, P13 said that reading the information about baricitinib helped her understand that her symptom was not related to the medication, preventing her from discontinuing the use on her own. Participant six, on the other hand, says she became interested in reading labels after experiencing an incorrect dispensing in pharmacy:

I have this habit of reading it, because once I hurt myself and the doctor told me to take Miosan®. The pharmacist read the prescription wrong and gave me an anticoagulant drug. And I have a brother who is a pharmacist and he said: "but why are you using this medicine?" Then I said: "it's because I injured my foot yesterday, I twisted it"... and he said: "no, let's go to the pharmacy no." He put me in the car, we went to the pharmacy, then the pharmacist apologized a lot, took the medicine that I had taken only one pill and gave me the Miosan®. And from then on, this was a few years ago, I became afraid. I started to read all the labels. Because if I had known, I wasn't going to take the anticoagulant. I needed a medicine for pain at that moment" (P6).

After this event, P6 realized the need to know about the medications before using them. Her report confirms that the patient should be seen as one of the main lines of defense to preventing the inappropriate use of medicines.

Participant eight spent a long period at the beginning of her diagnosis, "in the denial phase... with inadequate treatment, because I had no knowledge," in her words. Today, she has

RA in remission and says she actively participates in her treatment, always in search of more knowledge:

I always like to clarify all the doubts. Knowing the mechanism of action of the medication... the possible side effects... I actively participate. I am always updated with everything about RA. I use reliable sites, which give me satisfactory answers. I like the Rheumatology Society of Minas Gerais a lot. And when I go to the clinic, I always make my little list at home with all my doubts (P8).

Unlike most participants, who do not know the available medications for RA before using them, P3 has already presented alternatives to discuss with her physicians:

I'm very curious, so I participate in rheumatic patients' groups, I follow blogs... so all this I always research. You know? And I have even asked doctors if some kind of medication would be good for my case. I research a lot about the medications I use... I'm not one who just reads the label... no! I go on forums, I see what people are feeling, what is on the label is not always what people are going to feel. I see what people are saying.... I research on websites, Instagram pages, with people who have pages... of doctors, inclusive, who talk to patients, I really like to follow these professionals. Because then I have a lot of information, you know? I think that I stay well informed. The doctor tells me... yes! But I have additional information when I research" (P3).

P3 details a search for information that goes beyond the label, recognizing that the patient will not feel everything that is in it and that he may experience some effects not yet described.

Therefore, the participant seeks to know what happens in the real world.

"Nobody Knows Better Than ME What is Best for Me"

Patients come even closer to shared decision-making when they realize that they must be their own advocates; that it is necessary to tell professionals what they consider best for them:

Once, when the medication was changed to biologicals, they wanted to give me a medication that I had to go to Belo Horizonte (the state's capital) once a month. I think it was in the hospital, I had to stay there for four hours, taking the medicine in the vein. This time, I said I found it too difficult... because of the difficulty of the trip... even because of my knee. I remember I said... I asked if there was no other way... that I was finding it too difficult. Then they said: "so try... look in your city if there is a way they can give you the medication there." I looked in the hospital there, as the hospital is very simple, it did not work. Then, they accepted to try this other medication and leave this one aside. I thought that it would be too difficult for me (P14).

P14 explains that the administration of an intravenous biological medication in hospital would be unfeasible for her. Thus, she explained that to the professionals and they adapted the medication to her reality, prescribing a biological with subcutaneous administration, which she can apply at home.

Participant three describes how the patient's participation in the decision is fundamental:

I think this is very important, because the doctor studied for this. But no one better than me, who lives it, to tell what is best for me. The doctors explain to me what each medication does. But, in the end, it is me who has to decide. I think this is very important, because it is my body... how I feel! I don't like it when the doctor simply says, "that's it and period." I always question... I ask: "why?" I ask if it will have any effect... what this will improve. I always ask. I think it is very important, because I am the one who lives it. The doctor studied for this, but it is my experience. So, I think it is very important to take into consideration what the patient feels, what the patient thinks. I will give the information to the doctor so that he can decide. So, I think it is a two-way street. I think the treatment is only effective when the doctor has the correct information (P3).

P3's narrative is very rich. It clarifies that the effects of the disease and the medication are felt by her; in her body. Therefore, her opinion, combined with the technical knowledge of the professional, is essential to reach the best decision.

Experiencing the Sharing of the Decision: "There is No Point in Changing, if I Don't Use It"

Five participants described moments when they experienced shared decision-making with the professional or came very close to it, considering its real meaning. One of the participants says that she weighed between using methotrexate tablets and going to the hospital for medication administration and witnessing patients in worse situations than her own:

Methotrexate, for example... I was reluctant to take the pill because there are 10 pills and the stomach gets upset. One day, I even said: "then I get a little depressed to go to the hospital to take it because I see many people in a worse situation than me and everything." Then they said to me: "you can take the pill." I did not want to (P5).

The patient evaluated what would be more comfortable for her and emphasizes that the decision was not to go back to the pills. Participant P8, like P5, experienced an undesirable effect with a medication, which influenced the decision about what her next treatment would be:

There was one that suggested me even chloroquine. I said: "I do not want chloroquine." When I took chloroquine, which was the first one that the rheumatologist gave me, I thought it affected my vision. When the doctor talked about chloroquine, and she had also talked about biologicals, in this case, I opted for biologicals. She explained me properly and I talked to her about chloroquine that I had already taken (P8).

Given the options provided, P8's previous experience with the use of hydroxychloroquine provided subsidies for her to discuss with the physician. Patient and professional then reached the decision to start a biological disease course modifier medication.

The experience of adversity associated with access to adequate information led the patient herself to bring a proposal for discussion with her physician:

The methotrexate was giving me too much nausea. I was not tolerating it. Just thinking that on Saturday I had to use it... I felt sick on Friday. The weirdest thing! So, I asked them to change to injectable. Because I had been researching and even the guy who handles my medication in the pharmacy said that the injectable would not give me so many side effects. So, I've been using the injectable. I no longer have nausea... I no longer have that bad feeling... I am no longer worried about taking it. It was a great relief (P14).

P14 was no longer tolerating the administration of oral methotrexate and advocated on her own behalf. Based on a well-founded suggestion, she obtained the agreement of her professional, which resulted in the solution to her problem.

Participant three, on the other hand, describes in her narrative almost the step-by-step of sharing the decision:

When we went to analyze the issue of hair loss, the doctors tried to switch to sulfasalazine (after discarding leflunomide, since the patient intended to get pregnant). I took it for a while, got sick and had hair loss too. Then, talking to the doctors, they said that the effects that methotrexate had in my body were more beneficial, more effective than sulfasalazine and then they proposed me to go back to methotrexate, despite being an injection, having all this complication, because it is annoying to be injected every week, but they asked me, right, what I thought was better. They think that methotrexate was better for me... that it was more effective, that with it I did not feel pain. So, I said: "let's go back." But the doctors always asked me what I thought, what I preferred, explained to me what each one would do for me. The doctors told me, but they always gave me this option of switching it or not. Because I also believe that they think like this: "there is no point in me changing if the person will not use it." Methotrexate really... it has the most positive effect... more effective in my body... I feel less pain with it. Then with the test with sulfasalazine (P3).

It is noteworthy that the participant begins her speech with the expression "we," including herself in the analysis, patient and professional act as a team. Then, she tells how the alternatives were explored during the exchange proposal, weighing pros and cons, and allowing her to form her own preference. The patient also emphasizes that she always had the option to switch it or not. For P3, changing sulfasalazine for methotrexate would mean going back to taking injections, since she had already experienced intolerance with the use of this oral medication. As the patient participated in the whole decision-making process, she adhered to the treatment and corroborated with her experience that methotrexate is more effective in her body.

Construction of the Theoretical Model

The main results of this research allowed the construction of the theoretical model presented below (Figure 1), which explains how patients experience the decision-making process.

The way decisions are made is represented in a continuum. At one extreme is the paternalistic decision, in which the professional makes the decision and communicates it to the

patient; at the other is the sharing of the decision between these actors. When they are not participating in the decision-making process, the patients tend to make decisions on their own, guided by the experience of adversity, resoluteness, or ambiguity with the use of medicines. Such decisions, without advice, can generate positive or negative results. On the other hand, when a decision is shared, the experience with the use of medicines will already be included based on the patients' values and preferences, as well as their knowledge about the effects of medicines. In this case, the patients assisted participate in the whole process and do not need to make decisions alone, which has the potential to harm them.

The place where the patients are in the continuum can vary with the type of decision. Regardless of their location, the patients are active since they are playing a role in the management of their own health. However, at one extreme the patients are not aware that they are making decisions, while at the other they recognize that they actively participate in their care.

Figure 1

Continuum of patient behavior facing the decision-making process



Discussion

The development of this grounded theory allowed for the understanding of how patients with RA experience decision sharing with the health professional and what happens when the decision is not shared. The construction of the results demonstrates in depth, from the perspectives of RA patients themselves and the extent to which they are involved in decision-making. The interviewed patients reported several moments of switching treatment for RA, in which they did not participate in the process of choosing the therapeutic option. Such a result is in line with quantitative findings in which most RA patients did not engage in a shared decision-making process prior to treatment selection (Lofland et al., 2017).

In this context, it should be noted that most of the eligible alternatives to treat RA are available at the Brazilian Public Unified Health System (SUS) (Ministério da Saúde, 2020). Unlike the trend presented in this paper, this availability should facilitate and encourage the joint decision between patient and professional. Binder-Finnema et al. (2019) showed that the difficulty of access to medicines available for RA through health plans in the United States hinders the process of sharing the decision. In this scenario, even if patient and professional are engaged in discussing the risks and benefits of the alternatives, the uncertainty of insurance coverage limits patient autonomy and choice, leaving the final decision totally dependent on who pays for the treatment (Binder-Finnema et al., 2019). Thus, the access to various therapeutic options by SUS puts Brazilian patients at an advantage. However, it may be necessary that the protocol for RA treatment not only mentions that decisions need to be shared (Ministério da Saúde, 2020), but includes specific guidelines on how to put sharing into practice.

Nota et al. (2016a) revealed that for patients to wish to be or not be involved in medical decisions is a difficult concept. In fact, during the interviews, many participants did not even consider the possibility of participating in the decisions about their treatments. However, little by little, they revealed situations in which they self-managed their health and, therefore, made decisions. Thus, many patients are not aware that they can be involved in decisions, nor that they decide on their own. The lack of knowledge by patients that they have the right to choose is a known barrier to sharing the decision (Joseph-Williams et al., 2014; Nota et al., 2016a) and needs to be overcome.

As it was possible to notice, some participants brought into their discourse the idea that they were passive, but they gave examples of active behaviors. One of the great legacies of this work is to make it explicit that not sharing the decision contributes toward RA patients making decisions alone. These decisions are made from adverse, resolute, and ambiguous experiences with the daily use of medication, corroborating what was established by Nascimento et al. (2019). The ability of patients to decide about stopping or continuing the use of a medication, after their own assessment of risks and benefits, as well as to modify their therapeutic regimen has already been discussed in the literature (Mohammed et al., 2016; Neves et al., 2021; Pound et al., 2005; Shoemaker & Ramalho-de-Oliveira, 2008). Thus, this paper extends the understanding of how these three general types of experiences, previously described are transformed by patients with RA into actions to switch, discontinue or maintain a certain medication, as well as to self-medicate (Nascimento et al., 2019). The construction of the results evidenced how shared decision-making has the potential to encompass these experiences, helping patients make safer decisions.

Self-management of health is described as something positive and often necessary for treatment success (Voshaar et al., 2015). Self-medication, on the other hand, which can be understood as a form of self-management, most often carries a negative connotation (Bissell et al., 2001; Montastruc et al., 2016). The participants themselves recognized such action as inappropriate, even after experiencing the relief of symptoms and, therefore, the normalization of life (Nascimento, 2018) as a result of taking this action. There are many discussions around the risks of self-medication (Locquet et al., 2017; Montastruc et al., 2016). The patients' narrative of this research points out that this practice is associated with not only negative, but also positive outcomes, and it confirms that acquiring knowledge is integral to safe self-management (Barton et al., 2018). The results presented here demonstrate how the sharing of information, and the decision itself, can bring more security to the self-medication process and even prevent the need for its occurrence.

To achieve shared decision-making, it is essential that there is a joint definition of the goals to be achieved (Elwyn et al., 2017). In the context of RA, considering the recommendations of the most current guidelines to "treat to target," a clear discussion about the goals becomes even more relevant (Ministério da Saúde, 2020; Smolen et al., 2020). However, the frustration caused by the divergence of therapeutic goals between patients and professionals was revealed by some participants. Other studies with patients with RA also found differences in the goals expected by patients compared to those set by professionals (Barton et al., 2018; Gibofsky et al., 2018). From this perspective, what really matters to patients needs to be included in the goals, and it is necessary that professionals are able to access and confirm the patient's goals when discussing the options (Barton et al., 2018).

One of the requirements for patients to engage in shared decision-making is access to information. The participants in this research experienced different feelings in the search for knowledge. Some patients described difficulty in accessing and understanding information. While others described searching the internet for information about the disease and medications to educate themselves and bring certain issues to discussion with physicians, similar to what Barton et al. (2018) found. Patients detailed how knowledge and the ability to apply it

empowers them to participate in decisions about their treatment, validating the postulate by Joseph-Williams et al (2014). In this sense, access to quality information should be facilitated. As stated by the American College of Rheumatology, patients should also be the target audience of recommendations for the treatment of RA and should use them in pharmacotherapeutic decisions during clinical encounters (Smolen et al., 2018). New protocols should focus on providing patients, evidence-based information, exploring risks and benefits to facilitate decision sharing (McCormack & Elwyn, 2018). It is important to emphasize that, in the setting where this study was conducted, no tool is yet used to support patients in shared decision-making. There are already some studies demonstrating the benefits of employing this strategy (Barton et al., 2016; Li et al., 2018; Nota et al., 2016b; Pablos et al., 2019).

Five participants described situations experienced by them that came close to the real concept of shared decision-making (Elwyn et al., 2017). Therefore, in this study, even patients with adequate health literacy and high levels of activation demonstrated that they are not involved enough in the decisions to achieve sharing. Corroborating international findings that decision sharing in RA is not yet a consolidated practice (Barton et al., 2020; Mathijssen et al., 2020). On the other hand, patients who achieved decision sharing showed greater adherence and greater satisfaction with treatment compared to other patients, as also already discussed in the literature (Lofland et al., 2017). In addition, as described in the theoretical model, patients who experience sharing tend not to make decisions without first discussing them with the professional.

The results of this paper bring several implications for clinical practice, some already presented throughout the discussion and others will be highlighted below. Even patients who felt unprepared showed a desire to be more involved in the decisions. Therefore, all patients need to be invited to participate in the decision and receive the appropriate subsidies for this process, before being classified as someone who is not able to share the decision.

Patients are different, have different contexts, and some are more advanced in the process of shared decision-making. Thus, moments of experience exchange among them about therapeutic options and sharing the decision with professionals can help patients overcome the barriers that prevent them from sharing decisions. Taylor et al. (2020) also suggest that group discussion about the different ways of administering RA medications can benefit patients and facilitate decision sharing. The use of the positive deviance approach could be useful in this context to foster shared decision-making among patients and improve the quality of care (Bradley et al., 2009). This strategy predicts a behavioral change, based on the example of individuals identified within a community, who deal with certain situations more effectively than their peers, despite the similarity of problems and available resources (Positive Deviance Collaborative – PDC, 2022). In this case, patients who achieve decision sharing with professionals would be the positive deviance. The effectiveness of this approach may be tested in future research.

Finally, given the RA patients' perspectives on shared decision-making, pharmacists, anchored in the philosophy of the comprehensive medication management service (Pestka et al., 2018), can contribute to this process and support them in the exercise of their autonomy by providing quality information about the therapeutic alternatives, exercising risk communication, making them aware of their role in care, and assisting them in setting the goals. Furthermore, the results of this research should inspire reflections by health professionals and health managers on the need to actively involve patients with RA in their own care process. Studies in this area should also be encouraged, given its relevance to health care as a whole and the need to delve deeper into the subject and investigate ways to better implement the shared decision-making process.

Although the present study was developed in a specific Brazilian outpatient clinic, the aim of qualitative research is not to generalize results, but rather to stimulate a reflection

process by the readers. This includes the evaluation of whether the results apply to the readers' reality, and how they may change it. Therefore, with the present study, it is hoped that health professionals and health managers feel invited to this reflection process and that other researchers can unravel further about shared decision making.

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