

What Matters to Patients with Rheumatoid Arthritis When Facing Medical or Non-Medical Treatment Decisions?

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Background: In rheumatoid arthritis care, patients and healthcare professionals regularly face health treatment decisions. Sorting out what matters to a patient as being relevant to a specific decision is therefore essential.

Methods: An explorative mixed-methods study was performed to investigate patients' values for health treatment decisions and their importance in order to develop a future decision aid on value clarification. Ten semi-structured interviews with patient partners were conducted followed by an online survey among the broader population of patients. Qualitative content analysis was performed. Data from the online survey were analysed descriptively and quantitatively.

Results: According to patients, 17 important health treatment decisions in rheumatoid arthritis care can occur. The most commonly reported decisions concerned the use of medication. A variety of values may guide patients' health treatment decisions. We found 66 values among four domains of values – decisional, situational, external and global. Among decisional values, reported main values were a) effectiveness of treatment on inflammation, functioning, pain and fatigue; b) avoiding negative side-effects; and c) keeping in good physical condition. In addition, situational values turned out to be a) staying independent; b) being able to meet people; and c) leading as normal a life as possible. Furthermore, patients prefer healthcare professionals who a) take comorbidity into account, b) have enough time, and c) take the patient seriously in their choices – the external values. Finally, as global values were expressed a) autonomy; b) self-image, and c) intimacy. All values are specified by underlying quotes, for example, the value effectiveness on inflammation; “That inflammation has got to go, because you’ve then got the risk that you’ll develop all kinds of things in the course of time”.

Conclusion: A variety of values may guide patients' health treatment decisions within rheumatoid arthritis care. Patients and professionals should discuss patients' values continuously.

Keywords: shared decision making, preference elicitation, patient-centered care, value clarification

Introduction

In rheumatoid arthritis care, patients and healthcare professionals (HCP) regularly face health treatment decisions. This is due inter alia to the high number of pharmacological and non-pharmacological treatment options, the lack of clear recommendations for specific treatments, the chronic character of the disease demanding long-term care, and multi-morbidity requiring care and coordination of care by several HCPs.¹ In recent years, shared decision making between HCPs and patients when facing a health treatment decision has gained ground in rheumatoid arthritis care. In shared decision-making,

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HCPs and patients share the best available evidence when faced with the task of making health treatment decisions – the “team talk”. This “team talk” includes an explanation on the patient’s health status, the possible treatment goals, the health treatment decision, the process of shared decision making and the roles of the HCP and patient in the shared decision making process. After the “team talk”, the HCP assists the patient in considering the treatment options and their possible benefits and harms – the “option talk”. In this stage the HCP and the patient elicit the patient’s values regarding the treatment options so that the patient can form informed preferences. The final decision depends on how the patient values the outcomes of the options– the “decision talk”.^{2,3} Shared decision-making is therefore an iterative approach and ensures that health decisions reflect patient values and preferences.³ Sorting out what matters to a patient as relevant to a specific health treatment decision is an essential part of shared decision making and is known as “value clarification”.⁴ In general, the theory of shared decision-making does not make a rigid demarcation between patient values and patient preferences.⁵ According to Froberg and Kane,⁶ patient preferences show the emphasis patients place on disease-related outcomes and include aspects of health, health care and other aspects that are important for the quality of life. Values refer to personal beliefs, desires and expectations of what is right or wrong. Value clarification is generally defined as the process of identifying what matters most to a patient when considering a given health treatment decision.⁴ This process is not easy to perform. Patient may experience challenges in clarifying their values and preferences as these are not only health or care related, but also concerns personal life, such as daily activities, family and friends, finances, culture. Specific communicative efforts between HCPs and patients are needed in this regard, such as acting collaboratively, respecting autonomy and having an empathic approach.⁷ Halgraves et al⁸ argue that conversations are needed in which the patient and the HCP can think, talk and feel their way through which option makes intellectual, practical and emotional sense for each individual patient. In addition, a decision aid could facilitate the communication on patient values within the process of shared decision-making.⁹ Several value clarification methods within decision aids are available to help patients think about the desirability of options or attributes of options within a specific decision context, in order to identify which option they prefer.⁹ Recent studies of shared decision-making and value clarification in rheumatoid arthritis care have underlined their added value for health outcomes - ie disease activity, pain and joint damage.^{10–12} Nevertheless, it is suggested that more

attention should be paid to patient values regarding health treatment decisions during consultations.¹³ To assist patients and HCPs with value clarification in daily practice of rheumatoid arthritis care, a generic decision aid on value clarification for a diversity of health treatment decisions might be beneficial.¹⁴ As a first step to the development of such an decision aid, we explored patients’ main values regarding important health treatment decisions within rheumatoid arthritis care. Our aim is to provide a first overview of “values that do matter to” patients with rheumatoid arthritis when facing health treatment decisions. Bertha Maat, Theo Foekens, and Gerardine Willemsen-de Mey are patient authors in this study.

Methods

Aim of the Study

This study aimed to identify patient values for important health treatment decisions in rheumatoid arthritis care. Specific research questions were what major decisions within rheumatoid arthritis care do patients face and, regarding these health treatment decisions, what are the patients’ main values?

Study Design

Our study was carried out among patients with rheumatoid arthritis. We used a mixed-methods sequential exploratory design to obtain a clear picture of important values concerning major health treatment decisions. Semi-structured in-depth interviews for exploring values concerning past health treatment decisions were followed by an online survey to validate the overview of values for future health treatment decisions among the broader population of patients with rheumatoid arthritis. For reporting our study, we used the consolidated criteria for reporting qualitative research and the Standards for Reporting Qualitative Research.^{15,16}

Study Population

Patient partners with rheumatoid arthritis of the National Association ReumaZorg Nederland (RZN), the commissioning organisation of this study, were chosen as the population for the qualitative part. These patient partners are trained to give a voice to all patients with rheumatoid arthritis instead of their personal experiences with rheumatoid arthritis (and its care) only, therefore able to present a wider view. Inclusion criteria for the patient partners were “being diagnosed with rheumatoid arthritis” and “having faced a health treatment decision in the past two months”. A period of two months was chosen in order to

minimise recall bias for the in-depth interviews. For the quantitative online survey of values regarding future health treatment decisions, we aimed to get the widest possible representation of patients with rheumatoid arthritis. The only inclusion criterion for this survey via Facebook and the RZN website was therefore “being diagnosed with rheumatoid arthritis”.

Data Collection

For the in-depth interviews, an invitation e-mail was sent by RZN to its 25 patient partners with rheumatoid arthritis at the end of March 2020. The e-mail addressed the aim of the study, the interview topics, the method of interview and its duration. Interviews with respondents were scheduled between 25 March and 6 April. In preparation for the interview, the ten respondents were asked to recall the health treatment decisions they had faced in the previous months and what “mattered to them” concerning these health treatment decisions. Data saturation was reached after ten interviews and recruitment of participants therefore ended at ten respondents. Because of the COVID-19 pandemic, all interviews were conducted via online video calls (Skype/WhatsApp). The interviews were held by one researcher (LC); a second researcher (HV) provided feedback on the interview process after the first and the fifth interviews. The interview guide addressed personal information, the impact of rheumatoid arthritis on daily life, decisions in rheumatoid care and values. Audio recordings were made with the permission of the interviewees, and informed consent was obtained. The interviews lasted 45 minutes on average. Following the in-depth interviews, an online survey was conducted between 18 May and 2 June 2020. The invitation for the online survey was distributed among members of RZN and published on the RZN’s website and Facebook. In addition, snowball sampling was used as participants were asked to forward the survey to other patients. A response of 126 participants was achieved. The online survey questionnaire, in Dutch language, addressed personal information and the general experience with facing specific decisions within rheumatoid arthritis care. In addition, it contained value statements on patient values regarding health treatment decisions in rheumatoid arthritis. These value statements were derived from a qualitative analysis of the in-depth interviews. The value statements were formulated by two authors (LC, HV) and cross-checked by one patient partner and two other authors (PP, GW). Participants could validate the

value statements by stating how much they thought it was “an important value when facing one of the 17 health treatment decision regarding rheumatic care”. For this purpose, a five-point scale of response categories (ranging from entirely unimportant to highly important) was used. The survey was developed using Qualtrics and took patients 20 minutes on average to fill in.

Data Analysis

Qualitative content analysis was applied to the transcripts using ATLAS.ti 8. First, three transcripts were coded by two researchers (LC, HV) to form an initial shared understanding and perspective on health treatment decisions and patient’s values. The remainder of the interviews were then coded for values by one researcher (LC), with reliability checks performed by the other researcher (HV). This process yielded initial salient values. Second, to grasp the complexity and volume of identified values, the model of Armstrong and Mullins¹⁷ was used to categorise the values into four domains. These four value domains are 1) decisional values, ie, the pros and cons of options; 2) situational values, ie, the impact of daily life; 3) external values, ie, the impact of others; and 4) global values, ie, the personal belief system. For all formulated value statements, underlying quotes are reported. In addition, descriptive analyses of the online survey data were made with SPSS 25.0.

Results

Study Population

The majority of study participants of both the semi-structured interviews (“I”, n=10) and the online survey (“S”, n=126) consisted of women (I=70%, S=90%). In both study groups, most respondents were aged 45–64 (I=80%, S=60%), half were diagnosed with rheumatoid arthritis at least 10 years ago (I=70%, S=49%), many experienced a high burden of rheumatoid arthritis in daily life (I=70%, S=54%), lived with a partner (I=50%, S=40%). Finally, 70% stated that they had one or more comorbid conditions (I=70%, S=74%) (Table 1).

Health Treatment Decisions

Patients face a diversity of health treatment decisions in rheumatoid arthritis care. The majority of participants in the online survey had to decide about starting the use of medication (S=62%), starting physical therapy (S=49%) or changing their medication (S=44%). Other treatment decisions included pain treatment (S=39%), decisions about the administration route for their medication (36%) and

Table 1 Study Population Within the Two Methods of Data Collection

	In-Depth Interviews (I)	Online Survey (S)
	%	%
Study population (n)	100 (n=10)	100 (n=126)
Sex		
Male	30	10
Female	70	90
Missing	0	1
Age		
18–44	0	17
45–64	80	60
≥ 65 year	20	21
Missing	0	1
Diagnosed with rheumatoid arthritis		
0–5 years	20	29
6–10 years	10	22
>10 years	70	49
Missing	0	0
Experienced a burden of rheumatoid arthritis		
Much/very much	70	54
A bit	30	36
Sometimes/no	0	10
Missing	0	0
Type of household		
Alone	30	28
With a partner	50	40
With kids	0	14
With kids and partner	20	18
Other diseases besides RA (multiple answers are possible)		
None	30	26
Cardiovascular disease	10	12
Gastrointestinal disease	10	11
Depression	10	10
Osteoporosis	10	11
Infection	10	6
Other	30	52
Missing	0	5

adding or reducing medication (S=35–32%). Less frequently mentioned were the treatment decisions about surgery of the joints (S=19%), decisions about health services (S=19%) or the care pathway (S=12%) and lifestyle coaching (S=8%) (Table 2).

Table 2 Treatment Decisions in Rheumatoid Arthritis Care Faced by Patients

	In-Depth Interviews (I)		Online Survey (S)	
	N	%	N	%
Study population	10	100	126	100
Health treatment decisions	10	100	124	100
1 Starting medication	9	90	77	62
2 Physio-, occupational, podo therapy	4	40	61	49
3 Changing of medication	10	100	54	44
4 Pain treatment	2	20	48	39
5 Route of administration	1	10	45	36
6 Adding new medication	6	60	44	35
7 Reducing medication	6	60	40	32
8 Surgery of joints	1	10	24	19
9 Alternative care	2	20	23	19
10 Mobility devices (eg wheel chair)	2	20	23	19
11 Care at home	0	0	20	16
12 Psychological support	2	20	16	13
13 Choice for healthcare professional/organisation	2	20	15	12
14 Fatigue treatment	0	0	14	11
15 Lifestyle coaching	0	0	10	8
16 Revalidation pathway	2	20	10	8
17 eHealth	1	10	2	2
18 Other	3	30	6	5

Values

Decisional Values – Pros and Cons of Options

For the majority of patients, the effectiveness of treatment is an important value in the process of making future health treatment decisions (Table 3). In particular, outcomes on inflammation, functioning, pain and fatigue were reported by patients. “I would like to keep the risk as low as possible and avoid developing all kinds of things in the course of time” [Interviewee 2, female, age 64, RA for 35 years]. Patients also prefer to avoid treatments with a risk of side effects. Another finding was the patient value emphasising a healthy lifestyle and keeping up their physical fitness. A healthy lifestyle was also preferred over using medication as treatment for rheumatoid arthritis.

Lifestyle changes work better than those medicines. If you weigh a hundred kilos and you’ve got joint pain, you can use as much prednisone as you want but it won’t help a fat lot. [Interviewee 4, female, age 70, RA for 24 years]

Finally, in order to make future treatment decisions, one prerequisite for patients turned out to be having an

Table 3 Values on Treatment Decisions in Rheumatoid Arthritis Care, by Patients

Value Domain	Statement	Quotes from Interviews	Importance	
			High or Very High	Average, Low or Very Low
			%	%
Decisional values				
1 Effectiveness	I do not want any inflammation	When it became clear that it was information, I did get a feeling of "That inflammation has got to go," because you have then got the risk that you'll develop all kinds of things in the course of time and that's something I can do without.	65	35
2 Effectiveness	Physically, I want to be able to function properly	There was an entire week recently when I was hardly able to move. It usually starts with the left or right arm not doing what it should, and if I am lucky it will all be okay again in twenty-four hours. But not this time.	65	35
3 Effectiveness	I do not want to be in pain	If rheumatism affects you badly, you can be in a lot of pain. So the first thing you want is to be rid of that pain.	62	38
4 Effectiveness	I do not want to be affected by fatigue	Sure, I am sleeping quite a bit better and more calmly now, so that's a gain. But I am in a bit more pain, and that's not much fun either. So I will probably start taking one more again.	61	39
5 Effectiveness	I take account of previous experiences on effectiveness with treatment when choosing a new one	And then I said, "I'm not ready for this" because the fear at that moment on my side was that if I were to stop taking the medication, the rheumatism would become very active again. And that made me think, "I'm not going through that again."	57	43
6 Effectiveness	I do not want any skin complaints	It's those skin infections, particularly on my arms. It's all completely trivial, but I do find it annoying.	44	56
7 Effectiveness	Physically, I want to be able to function properly in future too. Even if that means that my quality of life will be less than it is now.	I let myself be led by the question of whether it would permanently damage my joints.	40	60
8 Effectiveness	I want a good quality of life now, even if that means that my quality of life may be less in the future	Well, you know, it helps right now. My life is better now for it. And if I do get problems in five years' time, then at least I have had that better life.	34	66
9 Side effect	I avoid treatments that have a risk of side-effects	They were JAK inhibitors; I'd already heard a bit about them, including the risk of shingles. And the doctor was not really in favour of vaccinating against shingles, so I reckoned I really should not use the drug. That was also because I had quite a few illnesses when I was a kid.	n/a	
10 Side effect	I avoid treatments with a risk of unpleasant side effects that I have already had	Because I developed that abscess as result. And that's always a source of worry, of course, because you do not want to get another one. So I wanted to stop that altogether.	n/a	
11 Side effect	I am not worried about the side effects that a treatment can have	I never read about side effects beforehand ... I do not do that because then you'll start worrying about it; I just take the medicine and if something then is not right ...	n/a	

(Continued)

Table 3 (Continued).

Value Domain	Statement	Quotes from Interviews	Importance	
			High or Very High	Average, Low or Very Low
			%	%
12 Form of administration	I think the way medicines are administered is important – tablets, injections, infusions and so on.	My personal feeling was that I'd rather not have injections. Also because my hands are fairly deformed ... Then I knew that there was another option, to have an infusion, and so that's what I said.	n/a	
13 Healthy lifestyle	I take care about a healthy lifestyle (nutrition, sports, smoking, alcohol)	Particularly with a disease such as rheumatism. For many people, lifestyle changes work better than all those medicines. If you weigh a hundred kilos and you have got joint pain, you can use as much prednisone as you want but it will not help a fat lot.	60	40
14 Healthy lifestyle	I do everything I can to stay in good condition, which will help my treatment	Particularly for a disease such as rheumatism ... fitness really matters to me. Just being able to do things.	55	45
15 Healthy lifestyle	I want to use as little medication as possible	I do not want to keep taking things in blind faith all my life, doing what the patient leaflet says. I think that's a pretty hairy idea – just keeping taking the pills without ever questioning what you are doing.	45	55
16 Costs	I want the best treatment despite the expense (for me or for society)	So do you have to keep taking it for years because it's the cheapest medicine? Or is it perhaps more sensible to switch to a biological? And some people then fall by the wayside ... That's not the idea! Prescribing medicines must not be a purely financial issue.	48	52
17 Costs	I do not want to use expensive medicines	It costs so much money; if I stop, I will save twelve thousand euros a year. "The insurance will cover it" ... I am not saying that the system should change, but that the entire system – including the doctors – focuses on "Just take those medicines."	15	75
18 Overview	I want to have an overview of all possible treatments and their effects and side-effects	Exploring all the options, rather than feeling that there's only one correct choice. That's important to me.	45	55
19 Overview	I always want to have an overview of my physical health	What I find important is seeing the blood results; after all, they do give a picture of your overall condition ... I always found that overview important. I think it's important that you keep track of your condition and, as far as I am concerned, if there's anything wrong with me I could then go to the doctor and say, "You've got my details, and now I've got these symptoms."	44	56
Situational values				
20 Mobility	To be able to get from A to B myself without depending on others	Mobility matters a lot because I think it's important that I can still get to places. Otherwise I am really just stuck between four walls and that will drive me round the bend in the longer term.	61	39

(Continued)

Table 3 (Continued).

Value Domain	Statement	Quotes from Interviews	Importance	
			High or Very High %	Average, Low or Very Low %
21 Social contacts	To keep meeting my family, friends, acquaintances, colleagues	My mobility is limited, of course, and because I have been sleeping so badly, I no longer dare drive long distances. So that means a lot less face-to-face contact with my family, who live on the other side of the country. Once you realise that your social life is being limited by the knee, the choice is soon made: right, I will have a new knee.	61	39
22 Daily activities	I can find a balance between what I want to do and what I am able to do. If that does not work, I will go looking for a different treatment	We were busy in the garden yesterday and I know that if I do too much at that point, I will simply not be able to sleep that night because of the pain. So you are always looking to find the balance	51	49
23 Daily activities	To be able to keep doing my sport/hobby because I enjoy doing it	I really enjoy the sport – you run wonderful courses and you are outdoors.	49	51
24 Daily activities	To be able to keep doing my sport/hobby because I want to stay fit	My hobby is swimming, so I think it's very important that I can keep swimming. And because it helps me with my rheumatism too	46	54
25 Daily activities	I think it is important to be able to keep doing my sport/hobby for my social contacts	I really love the sport and of course the social contacts as well. You run a course with different people every time	33	67
26 Work	I think it is important to be able to keep doing my work because I enjoy doing it	I enjoyed my work and I simply wanted to keep working.	38	62
27 Work	I think it is important to be able to keep doing my work because I like being successful at my job	Back when I was working, I wanted my own business. But you do not want to endanger that because you are out of the running too often, for whatever reason.	20	80
28 Work	I think it is important to be able to keep doing my work because it gives me financial security	Well, I am the breadwinner at home so my job is important.	n/a	
29 Normal life	I want my life to be as little as possible about being ill so I never put limits on myself	You are just somebody with that disease. But you are not the disease. That's a very different approach to your health. So I do not listen to the restrictions about what I can and cannot do. I never do that. I do not put limits on myself.	36	64
30 Special circumstances	I want to go on holiday and adjust my treatment to suit (eg change of dose or tablets instead of injections)	Suppose you want to go for a lengthy journey. You can talk to the doctor about how we can then adjust the medication, so that the rheumatism activity remains under control but the journey is more feasible.	26	74
31 Special circumstances	I consider coronavirus at the moment in my choice of rheumatoid arthritis treatment (eg having a biological administered at home instead of in the hospital, and whether or not to phase out my biological)	All this coronavirus business ... I had to come last week for an infusion again, but I reckoned I felt a bit flu-like and I did not dare to. So I put it off until this week, but this week is just the same again and right now I do not really dare ring the rheumatology department.	21	79
32 Special circumstances	I take account of special events when choosing a treatment or therapy (eg a birth or funeral, etc.)	And during the period that my father was dying, I was well able to set the priorities about what was most important at that time, and the other things simply have to play second fiddle.	20	80

(Continued)

Table 3 (Continued).

Value Domain	Statement	Quotes from Interviews	Importance	
			High or Very High	Average, Low or Very Low
			%	%
33 Burden of treatment	I do not want my rheumatoid arthritis treatment to be too much of a burden (for instance having to take or inject medicines at fixed times)	Therapy compliance is incredibly difficult, because everyone says that they do it well, but if you keep track of things carefully then you actually forget half of them. Either you take them at the wrong moments, or you skip them altogether. You are thinking of other things ... and then you notice the next day that yesterday's is still waiting for you	17	83
External values				
34 Healthcare professional	The healthcare professional takes me seriously in the choice of treatment	It's more about the patient being able to have a say in the decision, within limits. If you go beyond that, as I have experienced myself, then you get told "I think it's fine that you're doing that, it's your choice, your decision" – but she does not take it seriously. The only things she takes seriously are what have been proved scientifically	64	36
35 Healthcare professional	The healthcare professional is genuinely involved with me	But I know that the orthopaedist is good at his job, so I hope that he's got enough empathy and that I can have a proper conversation with him.	58	42
36 Healthcare professional	I want to have a good bond with my healthcare professional	I have got a good relationship with them and I ended up with that therapist after the diagnosis. They backed me up completely and now I have got another therapist and they also keep asking, "OK, I can see it from your attitude: what are we going to do about it?"	57	43
37 Healthcare professional	During the treatment, I want the healthcare professional to take account of treatments that I am getting from other doctors or therapists	Specialists only look at what they themselves specialise in, not at the whole picture. So if you are patient, you have to keep thinking carefully about what's the smart thing to do and what is not. That's really difficult, because you do not have the knowledge.	57	43
38 Healthcare professional	I want the healthcare professional to be open to other options I come up with	It's nice that I now have to have this prosthesis, but how will that then affect my work? He was not open to that idea, I think. The diagnosis was for a knee prosthesis and that was that, full stop.	56	44
39 Healthcare professional	I want the healthcare professional to help me choose a treatment	I was also able to make that properly clear to the rheumatologist then. I said very calmly, "I need you because I can't do this by myself anymore. I don't have any feeling for it." And she took that on board, saying "In this situation, I think that these are indeed menopause complaints and that your joints are sufficiently inactive."	51	49
40 Healthcare professional	I want my healthcare professional to take my other conditions into account	Specialists only look at what they themselves specialise in, not at the whole picture. So if you are patient, you have to keep thinking carefully about what's the smart thing to do and what is not. That's really difficult, because you do not have that knowledge.	48	52

(Continued)

Table 3 (Continued).

Value Domain	Statement	Quotes from Interviews	Importance	
			High or Very High	Average, Low or Very Low
			%	%
41 Healthcare professional	I want the healthcare professional to radiate confidence.	The way a doctor presents themselves determines how much confidence you have in them, of course.	47	53
42 Healthcare professional	I want contact with my healthcare professional to be easy	So then I called the doctor and I said, "It was really bothering me this morning" and then he said, "OK, you'd better come round." Then I got those injections and they helped really quickly.	n/a	
43 Healthcare professional	I want a healthcare professionals to have time for me	I do get the feeling that I am taken seriously; the doctor does take time.	n/a	
44 Self	To feel certain about the choices for treatment	I reckon that how quickly the choice is made depends a lot on the feeling I have about it. When I do not get a good feeling, for instance about phasing out the rheumatism medicine, I have then asked very clearly first whether it's okay if I first think about it at home. I will have to come back in three or four months anyway and we can talk about it more then.	61	39
45 Self	I take account of previous experiences with rheumatoid arthritis treatment when choosing a new treatment	And then I said, "I'm not ready for this" because the fear at that moment on my side was that if I were to stop taking the medication, the rheumatism would become very active again. And that made me think, "I'm not going through that again."	n/a	
46 Friends and relatives	I want a good and friendly atmosphere at home, even though I am not feeling well	Because you are so knackered, you do not always react very politely during the day. You may be on a shorter fuse or simply unable to do some activities.	52	48
47 Friends and relatives	I do not want the people close to me (partner, children etc.) to worry about me	The kids know that I am doing that and that they can take me out and about without having to worry about what might happen to me. That keeps them calm, which is very important. It's a very safe feeling, that they are relaxed and able to enjoy going away with me much more than they did before.	47	53
48 Friends and relatives	I think it is important that the people close to me (partner, children etc.) support me and back me up in whatever choice I make for my treatment	And when I make that choice, the people at home will be behind me, and I know it.	43	57
49 Friends and relatives	I want to meet the expectations of those close to me (partner, children etc.)	I have occasionally chosen to start taking medicines again because I reckoned that I could not impose this on my wife and my daughter. That's happened twice	28	72
50 Friends and relatives	I think it is important that the people close to me have a role in the choices I make for my treatment	As long as you can talk about it together, it's often less of a burden. You are not going to start getting weird ideas, let us put it that way.	26	74
51 Other patients	I weigh up other people's experiences with rheumatoid arthritis in the choices I make for the treatment of my own rheumatism	I do speak to other people who have rheumatism as well. Then you can talk to each other about what you use and whether it works. But that does not mean that what works well for one person will be as good for the next.	19	81

(Continued)

Table 3 (Continued).

Value Domain	Statement	Quotes from Interviews	Importance	
			High or Very High	Average, Low or Very Low
			%	%
52 Colleagues	My colleagues should be able to see that I am fit to do my work	I get really annoyed when people I work say that I walk really badly. The fact that it's so obvious bothers me. Look, I am doing my job – I can do my rounds fine. But that pressure has made me think about it. I do not want to get problems at my work too.	19	81
Global values				
53 Self-image	I do not want to feel old	Because biologicals affect your resistance, I have to queue up to get a flu jab along with all the pensioners. I mean, I have got nothing against people aged over sixty-five but I am not that old myself yet.	n/a	
54 Self-image	I do not want to be seen as disabled	I found it very confrontational, having to sit there in a wheelchair. I know perfectly well that there are loads of people who go to the zoo or whatever in a wheelchair, that's true, but I am the one sitting in it now. I find that very confrontational.	n/a	
55 Self-image	I want people to see that I am capable of doing my job.	I get really annoyed when people I work say that I walk really badly. The fact that it's so obvious bothers me. That pressure has made me think about it. I do not want to get problems at my work.	n/a	
56 Self-image	I want to feel that I look good and well cared for	I went straight away to have a shower, wash, shave, get dressed ... and those nurses looked at me as if they were wondering what on Earth I was doing. I just simply want to look right. I do not like it if people see me in my pyjamas.	n/a	
57 Autonomy	I want to be able to make my own choices	Above all, it is my choice then because it's my body. I am the one who has to cope with it.	n/a	
58 Autonomy	I do not want to depend on other people for doing my everyday activities.	It's about being able to function independently yourself. Simply being able to ride your bike and do your own shopping – things like that. Simply the normal, everyday things.	n/a	
59 Autonomy	I want to be able to get around independently	Above all, not being able to decide for yourself where you go: your independence. That's the awkward thing, above all, that you become dependent on others for all kinds of things.	n/a	
60 Autonomy	I want to be responsible for my own life	I am the one who's responsible for my own health. Which also means that I do not want to run those kinds of risks ... The doctor helps me with that ... but she cannot cure me; I have to do that myself.	n/a	
61 Fitness	I want to stay fit	I want to keep my fitness up; that's important to me.	n/a	
62 Fitness	I want my resistance to remain good	I am letting my immune system guide me on the way, and I want ... to make it stronger, and medicines help that.	n/a	

(Continued)

Table 3 (Continued).

Value Domain	Statement	Quotes from Interviews	Importance	
			High or Very High	Average, Low or Very Low
			%	%
63 Intimacy	Intimacy and sexuality are important to me	Using all kinds of medicines that end up lowering your libido ... they also emphasise that ... but luckily it does not affect me all that much.	n/a	
64 Spirituality	Religion and spirituality are important to me	n/a	n/a	
65 Social participation	I want to feel useful	Because of my experience ... and that includes my experience in the care sector. Then I do get the feeling that I am doing something a bit useful.	n/a	
66 Social participation	I want to be part of society	Being part of society: I think that's the most important thing.	n/a	

Abbreviations: HCP, healthcare professional; n/a, not available.

overview of their health status – what are patient’ needs and treatment goals – and of possible effects on RA and the risk on side effects of each treatment option.

Situational Values – Impact of Daily Life

Staying independent and being able to keep meeting friends and family were described by patients as important situational values for future health treatment decision-making (Table 3). One of the interviewees stated,

Mobility matters a lot because I think it’s important that I can still get to places. Otherwise I’m really just stuck between four walls and that will drive me round the bend in the longer term. [Interviewee 2, female, age 64, RA for 35 years]

This also included the desire to continue a normal life, for example keeping up hobbies and playing sports as much as possible. “I am not the disease I don’t listen to the restrictions about what I can and can’t do. I never do that. I don’t put limits on myself.” [Interviewee 5, male, age 60, RA for 18 years]. For those patients with a job, values concerning their work also showed up as the following quotes illustrate: “Well, I’m the breadwinner at home, so my job is important” [Interviewee 1, female, age 58, RA for 18 years]. “It’s nice that I now have to have this prosthesis, but how will that then affect my work?” [Interviewee 1, female, age 58, RA for 18 years]. “Back when I was working, I wanted my own business ... you don’t want to endanger that because you are not able to work too often, for whatever reason.” [Interviewee 3, female, age 60, RA for 32 years]. These quotes show how

financial and practical considerations regarding job stability are important for some of the patients.

External Values – Impact of/on Others

The healthcare professional (HCP) turned out to have an important impact on patients for future health treatment decision-making (Table 3). First of all, as most patients with rheumatoid arthritis have multiple health problems, patients need an HCP who can help them with overall healthcare delivery. A female interviewee aged 58 who has had RA for 18 years [Interviewee 1] explained:

Specialists only look at what they themselves specialise in. As a patient, you have to keep thinking carefully about what is the smart thing to do and what isn’t. That’s really difficult, because you don’t have the knowledge.

Furthermore, patients stated they need an HCP who has time for them, who can be contacted easily and who takes them seriously in the choice of treatment. One interviewee, for example, complained:

It’s about being able to have a say in the decision. Although my HCP said ‘it’s fine that you’re choosing that’, she doesn’t take it seriously; the only things she takes seriously are what have been proved scientifically. [Interviewee 7, male, age 54, RA for 7 years]

In addition to this, patients take into account the burden they might put on the family or the household. “Because you’re so knackered, you don’t always react very politely during the day. You may be on a shorter fuse or simply unable to do some

activities” [Interviewee 2, female, age 64, RA for 35 years]. According to patients, future health treatment will be influenced by HCPs, friends and relatives but the majority of patients need to be certain about their own choice for treatment.

Global Values – Personal Belief System

“Autonomy” was expressed as a global value (Table 3). This included being able to make your own decisions, being responsible for your own life and getting around independently. Interviewee 2 [female, age 64, RA for 35 years] explained it as follows:

It’s about being able to function independently yourself. Simply being able to ride your bike and do your own shopping – things like that. Simply the normal, everyday things.

In addition, the “self-image” was mentioned by patients as being a value for future health treatment decisions. Self-image is related to wanting to look good and well cared for, to be seen as capable of doing the job, not wanting to feel old or to be seen as disabled. Other global values stated were “social participation, such as feeling useful” and “intimacy and sexuality”. As such, global values include the life priorities and beliefs that colour daily life, including the choices within rheumatoid arthritis care.

Discussion

This study aimed to investigate patients’ main values regarding important health treatment decisions in rheumatoid arthritis care. As patients and healthcare professionals face health treatment decisions regularly, we first investigated what major choices patients with rheumatoid arthritis do face regarding health care.

In addition, we explored patients’ main values regarding these important decisions. To our knowledge, this is the first study that gives an overview of main values regarding multiple treatment decisions in rheumatoid arthritis care. This overview of “values that do matter to” patients with rheumatoid arthritis when facing health treatment decisions is a first step to facilitate collaborative deliberation on important healthcare issues. This may be done by using the list of value statements in the consultation room when a healthcare professional and a patient are involved in a shared decision-making concerning a certain health treatment decision.

Our analysis identified a variety of values that patients do take into consideration when facing a health treatment decision within rheumatoid arthritis care. Consistently

with the literature,^{10–12,18,19,21} effectiveness of treatment (on inflammation, functioning, pain and fatigue) and avoiding negative side effects were stated as being very important when choosing a treatment option. Important situational values turned out to be staying independent; being able to meet friends and having a normal life. The decisional values coincide with the patient outcomes formulated in the standard set of outcome measures for inflammatory arthritis, including rheumatoid arthritis, by the International Consortium for Health Outcome Measurement (ICHOM).¹⁸ ICHOM collaborates with patients and healthcare professionals to define and measure patient-reported outcomes to improve the quality and value of health care. A way to meet this goal of personalised care is to include patients’ values in the decision-making process.²⁰ Other studies also emphasised the importance of situational values.^{19,21} Including existential dimensions of physical need, identity, social belonging and meaning in healthcare communication is of utmost importance for patients facing treatment decisions in long-term care.^{19,21} Furthermore, existing evidence supports our findings that patients prefer healthcare professionals who a) take comorbidity into account, b) have enough time for the consultation, and c) take the patient seriously in their choice of treatment.^{22,23} Patients valued a shared approach to decision-making for choosing the right treatment option and emphasised the importance of enhanced communication with healthcare professionals.²⁴ Finally, global values were expressed, such as autonomy, self-image and intimacy.^{25,26}

Our study provides valuable insights into patients’ values for health treatment decisions within rheumatoid arthritis care. Some of these values are included in well-known standardised questionnaires on the outcome of rheumatoid arthritis care, the so-called patient-reported outcome measures. These values could be regarded as population-based values. Nevertheless, in the clinical encounter, it is crucial that discussions with patients include an assessment of which treatments are most likely to support their needs, goals, and preferences, and that information that could affect their treatment decision-making be provided as transparently as possible.¹ As the values of patients are highly individualised, subjective and changeable over time, patients should continuously be asked to express their personal values for a specific treatment decision and treatment option.^{1,22} To assist patients and HCPs with value clarification in daily practice of rheumatoid arthritis care, a generic decision aid on value

clarification for a diversity of health treatment decisions might be beneficial.¹⁵ No such a value clarification tool for rheumatoid arthritis care exists currently in the Netherlands or internationally. A value clarification tool could help patients evaluate the desirability of options or attributes of options within a specific decision context, in order to identify which option they prefer.^{27,28} Value clarification tools are mostly digital tools with presentation of values in graphs and with links and hyperlinks to additional resources, adjusted for low-literacy patients.^{29–31} Several elicitation methods for values and preferences do exist, comprising matching methods, discrete choice experiments, multi-criteria decision analysis and other rating and ranking methods.¹¹ Further research is needed to find out what elicitation method for this tool would fit the best for the generic value tool for patients with rheumatoid arthritis.

Limitations

The results of our investigation should be interpreted in the context of its limitations. At first, a note should be made of the study population and external validity of our study results. Our study population is representative of the Dutch population of patients with rheumatoid arthritis in terms of age, sex and co-morbidity.^{32–34} Nevertheless, participants in our study may not reflect the views of patients of minority groups (migrants, low socioeconomic status) and it is therefore possible that we may have missed some values. Furthermore, no pregnant women were involved in our study, and no values on pregnancy or the desire to become pregnant and the use of rheumatoid arthritis drug were formulated, although other studies have shown its relevance.¹ Additionally, the majority of our population had been diagnosed with rheumatoid arthritis for several years and only a few young adults participated in it. This may have had an impact on values about treatment options. Future studies of the values for important rheumatoid arthritis treatment options should therefore apply the optimum variation sampling strategy in order to obtain a diversity of patient perspectives. Second, the internal validity of our qualitative study could be low as only experienced patient partners of RZN were included in the semi-structured interviews. Even so, semi-structured interviews turned out to be an appropriate tool for this study because they gave the opportunity to explore and gain more in-depth insights into values before the large-scale survey among other patients was designed.³⁵ Semi-structured interviews allowed for two-way communication. This was useful for

discovering values of interviewees that they were unaware of and gave the interviewer the opportunity to ask for elaborations.

Conclusion

In rheumatoid arthritis care, patients and healthcare professionals regularly face health treatment decisions. According to patients, 17 important health treatment decisions in rheumatoid arthritis care can occur. The most commonly reported treatment decisions concern the use of medication. A variety of preferences and values could guide patients' health treatment decisions. We found 66 values among four domains of values – decisional, situational, external or global. Patients and professionals should therefore elicit values continuously to improve therapy compliance, quality of care and quality of life.

Summary

In rheumatoid arthritis care, patients and healthcare professionals regularly face health treatment decisions. According to patients, 17 important health treatment decisions in rheumatoid arthritis care can occur. The most commonly reported treatment decisions concern the use of medication. A variety of preferences and values could guide patients' health treatment decisions. We found 66 values among four domains of values – decisional, situational, external or global. Patients and professionals should therefore elicit values continuously to improve therapy compliance, quality of care and quality of life.

Data Sharing Statement

All data are archived by the last author (HV).

Ethics Statement

No ethical approval from a medical ethics committee was needed under Dutch law (WMO) as the study did not involve any interventions designed as part of the study. Written informed consent to participate in this study and to publish anonymized responses was provided by the participants. This study was conducted in accordance with the Declaration of Helsinki.

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Author Contributions

All authors contributed to data analysis, drafting or revising the article, gave final approval of the version to be published, agreed to the submitted journal, and agreed to be accountable for all aspects of the work.

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