ORIGINAL ARTICLE



Sociocultural and moral narratives influencing the decision to vaccinate among rheumatic disease patients: a qualitative study

Amaranta Manrique de Lara¹ · Tirsa Colmenares-Roa¹ · Virgina Pascual-Ramos² · José Francisco Moctezuma-Rios³ · Irazú Contreras-Yañez² · Guillermo Arturo Guaracha-Basañez² · Everardo Álvarez-Hernández³ · Graciela Meza-López y Olguín³ · Ingris Peláez-Ballestas^{1,3}

Received: 7 February 2023 / Revised: 16 April 2023 / Accepted: 21 April 2023 © The Author(s), under exclusive licence to International League of Associations for Rheumatology (ILAR) 2023

Abstract

Introduction/objectives Vaccination is a process that involves individual, social, and ethical aspects, beyond public governance of vaccines or vaccination as a public health concern. The aim of this study is to describe the sociocultural and moral narratives that influence the decision to vaccinate in general and to vaccinate against COVID-19 specifically, among patients at the rheumatology units of two hospitals.

Methods Qualitative study involving individual semi-structured interviews following an interview guide. We conducted a thematic analysis using the ATLAS.ti software, with further triangulation to verify concordance and aid in the interpretation of the data from a medical anthropology framework and using a narrative ethics approach to gain insight into the participants' underlying moral values.

Results We interviewed 37 patients in total, along with 3 rheumatologists. Five core themes emerged from the analysis to understand the decision to vaccinate: (1) information about vaccines and disease, (2) perceived risk—benefit of vaccination, (3) the physician—patient relationship, (4) governance of vaccination programs, (5) attitudes towards vaccines. Individual and family experiences with vaccination are diverse depending on the type of vaccine. The COVID-19 vaccine, as a new medical technology, is met with more controversy leading to hesitancy.

Conclusions The decision to vaccinate among Mexican rheumatic disease patients can sometimes involve doubt and distrust, especially for those with a lupus diagnosis, but ultimately there is acceptance in most cases. Though patients make and value autonomous decisions, there is a collective process involving sociocultural and ethical aspects.

Key points

- The complexity of vaccine decision-making is better identified through a narrative, qualitative approach like the one used in this study, as opposed to solely quantitative approaches
- Sociocultural and moral perspectives of vaccination shape decision-making and, therefore, highlight the importance of including patients in the development of effective clinical practice guidelines as well as ethically justified public policy
- Sociohistorical context and personal experiences of immunization influence vaccine decision-making much more than access to biomedical information about vaccines, showing that approaches based on the information deficit model are inadequate to fight vaccine hesitancy

Keywords COVID-19 · Narrative ethics · Rheumatic disease · Sociocultural factors · Vaccination

Amaranta Manrique de Lara and Tirsa Colmenares-Roa have equally contributed to the work.

☐ Ingris Peláez-Ballestas pelaezin@gmail.com

Published online: 02 May 2023

Extended author information available on the last page of the article

Introduction

Vaccination is one of the great successes of global public health, which hinges on the availability and accessibility of vaccines, as well as on people's willingness to receive them. In the context of the COVID-19 pandemic, newly developed vaccines have been progressively made available since late 2020. However, immunization programs in different regions



have had to face changing trends of vaccine acceptance [1, 2]. Various studies have quantitatively measured the intent of people to vaccinate against COVID-19 [3, 4], focusing on the phenomenon of vaccine hesitancy: "delay in acceptance or refusal of vaccination despite the availability of vaccination services" [5].

Individual attitudes towards vaccines exist on a continuum from full acceptance to full refusal [6]. Understanding the reasons for these attitudes and the immunization behaviors they cause is fundamental for effective public health interventions and to better inform direct patient care. The attitudes of high-risk populations should be of special interest, including individuals with rheumatic and musculoskeletal diseases (RMDs), for whom vaccination rates against influenza are lower than advised, despite official guidelines [7]. Preliminary studies have found moderate willingness to receive a COVID-19 vaccine [8], despite being a population at higher risk of severe disease [9]. Contrastingly, quantitative studies have found that RMD patients in Mexico are highly accepting of the COVID-19 vaccine, related to perceptions of vaccine safety and efficacy, and the pandemic context [10].

The factors influencing the decision to vaccinate span individual, social, and moral aspects. Willingness to vaccinate is shaped by social elements like the media and religion, political factors, and personal characteristics like endorsement of conspiracy theories [11, 12]. In Latin America, high intent to receive a COVID-19 vaccine contradicts high degrees of fear towards side effects, a result of social factors like the handling of vaccine information and the politicized management of immunization programs [13].

Narrative approaches in the medical context have been highlighted to gain insight into individuals' values and goals, contextualized by life experiences that shape their interpretation and decision-making [14, 15]. Therefore, vaccine decision narratives can be used to identify the implicit and explicit values underlying vaccine decision-making [16], including the moral reasoning behind these decisions [15].

To provide a deeper and more complex understanding of vaccine decision-making, the aim of this study is to describe and relate the sociocultural narratives and underlying moral values that influence the decision to vaccinate in general and against COVID-19 specifically, among RMD patients at the rheumatology units of two public hospitals in Mexico City.

Materials and methods

Design

Qualitative study involving individual semi-structured interviews (June 2021–May 2022) following guides designed by an interdisciplinary team for patients (S1) and

rheumatologists (S2). Interview guides were designed based on a literature review, as well as patient, rheumatologist, and researcher experience, and tested with a pilot interview. Themes included biomedical and non-biomedical information about vaccines, risk perception, attitudes towards vaccines, and the physician–patient relationship.

Study population

Adult patients older than 18 years with a diagnosed RMD and the rheumatologists caring for them at two public hospitals in Mexico City. There were no exclusion criteria for patients or rheumatologists, to document the phenomenon in its full extent and comply with the requirements of qualitative studies.

Sample

Convenience sampling was used to select participants, approached face to face, taking into consideration a principle of data saturation for attitudes towards vaccines and information about vaccines. Given that data saturation tending towards vaccine acceptance was reached quickly, participants expressing doubt were intentionally scouted for.

All eight rheumatologists caring for the participating patients were invited, but only three interviews could be completed due to scheduling conflicts, considering the length of the interviews and the increase in demand once rheumatology services re-opened after the initial waves of the COVID-19 pandemic. However, data saturation was also reached for rheumatologist interviews, related to the homogeneity of the participating hospitals.

Data collection

Interviews were conducted by one of four female researchers (medical anthropologists, social worker, and bioethicist). Interviews lasted no more than 2 h and were recorded, transcribed (not returned to participants), and deidentified for analysis with a word processor. Interviews were conducted (in person and through videoconference).

Analysis

Interpretation of the data was done using a medical anthropology framework and a narrative ethics approach, to gain insight into the participants' underlying values and integrate them with sociocultural factors in their specific context. A codebook was created before the interview process, and emerging codes were added. Blind coding, analysis, synthesis, and interpretation were conducted by the interviewing medical anthropologists and bioethicist.

Results were triangulated by an interdisciplinary team to verify concordance of the categories and aid in the



interpretation. Analysis was supported by the *ATLAS.ti* software. Rheumatologists provided feedback on the findings, though we were unable to get patient feedback due to the pandemic limiting meeting opportunities.

Ethical considerations

Participants voluntarily agreed to aid in this study, following an informed consent process, with the option to end their participation at any time. Measures were taken to reach the highest level of health safety possible, given the hospital setting and the particular vulnerability of patients.

This study was approved by the Research Ethics Committees in both participating institutions, registered under DI/21/404-D/03/21 and CONBIOETICA-09-CEI-011-20,160,627.

Results

We interviewed 37 patients and 3 rheumatologists (Table 1). Five core themes emerged: (1) information about vaccines and disease, (2) perceived risk-benefit of vaccination, (3) the physician-patient relationship, (4) governance of vaccination programs, (5) attitudes towards vaccines.

Information about vaccines and disease

Patients have limited and simple knowledge about vaccines. They recount a vague involvement of the immune system in the generation of antibodies and the protective function of vaccines, often expressed in metaphorical terms (Table 2).

For example, they communicate ideas like "dead virus" or "small quantities of a virus," but not in biomedical terms. They express little knowledge about vaccine development, production, testing, and approval, despite the high levels of exposure to biomedical information during the pandemic.

The diversity of COVID-19 vaccines available in Mexico conditioned patients to acquire information about the differences between vaccines and to have different expectations, though not always based on biomedical knowledge, but rather on interpretations of past experiences (Table 2).

Patients' sources of information about the COVID-19 pandemic and vaccine are varied, including official reports, the news, the internet broadly, and other laypeople. Information distributed through social networks or through word of mouth is considered untrustworthy, despite being the most accessible, which patients think contributes to misinformation. It is easier for patients to receive and believe non-biomedical information over biomedical information, according to rheumatologists (Table 2).

Perceived risk-benefit of vaccination

Patients perceive risks at individual and collective levels.

At the individual level, patients express the risk of contracting severe COVID-19 and other transmissible diseases because of their preexisting RMD. This type of perceived risk leads to vaccine acceptance, seeing immunization as beneficial and a necessary source of protection, especially due to the pandemic context (Table 3).

Some patients also perceive the vaccines themselves as risky, varying across diagnoses and based on past experiences with other vaccines (Table 3). For example, patients

Table 1 Participant characteristics

Patients: 37	
Gender (women)	27 (72.9%)
Age (mean)	44.8 years (SD 12.1)
Schooling (mean)	11.4 years (SD 3.5)
Rheumatic diagnosis	Arthritis (RA) $(n=12)$
	Systemic lupus erythematosus (SLE) $(n=11)$
	Gout $(n=3)$
	Spondyloarthritis $(n=2)$
	Others $(n=8)$
COVID-19 vaccine acceptance	Full acceptance (54.05%)
	Acceptance after hesitancy (18.92%)
	Hesitancy (13.51%)
	Refusal (13.51%)
Rheumatologists: 3	
Gender (women)	1
Age (mean)	45 years (min. 33, max. 54)
Professional experience (mean)	15 years (min. 3, max. 24)



Table 2 Theme 1: information about vaccines and disease

Ouotes

I think [vaccines] act on the immune system, that they help it, because it controls diseases so that they don't harm the body as easily when a virus comes in...logically if we have a good immune system, like young people, they resist, but those of us who aren't young anymore, it messes us up more. (Rodrigo, 44 years, Anti-synthetase syndrome, M)

If they told me, which [vaccine] do you want? Maybe the one that people talk less badly about... I'm no expert to say, this is the best one! This is the worst one! I have friends, family who've already been vaccinated and they've had different ones... from what they told me [one of them] is terrible because it hurts and it knocks you out for a whole day, well yes, but not everyone. (Juan, 41 years, Gout, M)

At the end of the day we'll see them as ideas that are kind of... foolish for the community and that yes, unfortunately they're easier to spread than scientific ideas that do help (Santiago, 48 years, Rheumatologist with 18 years of experience, M)

with lupus associate the autoimmune mechanism of their disease with the vaccine's mechanism of action. Contrastingly, patients with gout do not associate the risk of the vaccine with their disease. Finally, for patients with rheumatoid arthritis, the vaccine is thought to worsen their joint symptoms.

In addition to concerns related to a rheumatic diagnosis, those who refuse the COVID-19 vaccine are primarily worried about the newness and the fast development, perceiving it as experimental and ineffective. However, all of these individual concerns about the risks of vaccination do not necessarily lead to refusal of the vaccine. Even patients who accept vaccines may express similar sentiments about safety, but they assess them as more beneficial and worth the risk (Table 3).

In terms of collective risk perception, vaccination is recognized as beneficial to the community by stopping the spread of disease. The benefits of vaccination for close social networks (the family) are highlighted, and the decision to vaccinate is made as a decision to protect others, especially children. However, this same concern for others can also motivate some to refuse vaccines for dependents due to a perceived high risk (Table 3).

The physician-patient relationship

Traditionally, discussions about vaccines are infrequent during medical consultations. Patients state that they have not received guidance about the suggested immunization schedules for their conditions. However, some participants refer previous physician recommendations against vaccinating, because of contraindications with their medications, specifically the influenza vaccine (Table 4).

Regarding the COVID-19 vaccine, many patients were able to ask or were thinking about asking a medical professional, especially their rheumatologists. All of those who received guidance were advised to vaccinate (Table 4).

Most participants who had been unable to ask their rheumatologists for guidance decided to accept the vaccine regardless, since they did not want to miss their assigned turn. Therefore, acceptance was based on criteria other than their physician's advice. The topic was briefly discussed with their rheumatologists during their next appointment. Patients received approval for vaccinating, though no further explanation was given about side effects or benefits.

 Table 3
 Theme 2: perceived risk-benefit of vaccination

Quotes

Honestly, I was worried about my autoimmune disease. I thought, if I don't get vaccinated I know that I don't have as many defenses, so the disease can be really severe for me, right? So yes, I was very eager to just get vaccinated already! (Hortensia, 40 years, Mixed connective tissue disease, F)

I did wonder what would happen with my disease when I got the vaccine, you know? One of my fears was exactly saying I have arthritis and if I already feel bad, then I'll feel worse. (Sofia, 50 years, RA, F)

I don't think the vaccine is as feasible as they say, because I feel it was made in a rush. I mean, for example, other vaccines that I've studied, a long time has passed for them to be made. (*Jimena*, 51 years, RA, F)

With [the COVID vaccine] there has been a lot of controversy because it was very fast, because they haven't researched it well and things like that. It is scary, but you have to do it anyway because it's not just you, right? It's your household, your family, your friends, and in some way, the fact of improving the situation in the country... I think it's necessary. (Carmen, 43 years, SLE, F)

It's not just you, it's everyone. For you to be spreading the disease to others and at no fault of their own... We have to think about them, about the consequences for them. (*Gaby*, 55 years, RA, F)

My siblings' children were born first, and we were like what's going on with their vaccines! Did they already get their first vaccine? I was very insistent that health was fundamental for them. (Carmen, 43 years, SLE, F)

One of the reasons I didn't allow my mom to be vaccinated, is because with her we've had a lot of health problems and trips to urgent care. (Belén, 41 years, RA, F)



Rheumatologists recognize that the topic of immunization in general does not come up during the medical consultation often or ever. Regarding COVID-19, they understand patients' concerns and that their explanations can help to decrease negative feelings by highlighting the low risk. Rheumatologists acknowledge patients' trust in them and willingness to ask about vaccination in general. However, they are critical of themselves, since they recognize the importance of vaccines, but they do not prioritize those conversations (Table 4).

Governance of vaccination programs

Patients had diverse opinions about the Mexican vaccine allocation strategy, which prioritized those most vulnerable to infection (frontline health workers and older adults). While many participants believe this to be an adequate strategy, some believe children should have been considered a vulnerable group. Even others consider that vaccines should have been distributed to the productive sectors of society first, who are at higher risk of exposure and of being spreaders. Interestingly, not many patients suggested that they themselves should have been given priority in the allocation of vaccines as a vulnerable population (Table 4).

Most patients recount satisfaction with their own experience receiving a COVID-19 vaccine and/or the experience of older family members they aided. Contrastingly, when asked about their overall opinions of the vaccination campaign

and the pandemic response generally, patients express more negative opinions, given a perceived influence of political interests. Even so, both patients and rheumatologists consider it appropriate that vaccination campaigns are publicly governed, seeing vaccines as a public and free resource that people should be able to benefit from equitably (Table 4).

Attitudes towards vaccines

Patients' narratives around these four themes come together to shape their diverse attitudes towards vaccines: the child-hood immunization schedule is accepted without a doubt; there is a feeling of complacency so that vaccines recommended for adults, such as influenza and tetanus, are thought of as unnecessary; and the COVID-19 vaccine, as a new medical technology, is surrounded by controversy leading to hesitancy. We therefore classify vaccine attitudes as full acceptance, acceptance after hesitancy, hesitancy, and refusal (Table 5).

Discussion

In Mexico, vaccine acceptance in general is most common among RMD patients [10]. For the COVID-19 vaccine, we also find overwhelming acceptance even considering doubts and, in a lesser proportion, hesitancy or refusal based on the social and public health processes of the pandemic

Table 4 Theme 3: the physician-patient relationship and Theme 4: governance of vaccination programs

Theme	Quotes
Theme 3: the physician–patient relationship	Once a doctor told me that, he was giving me treatment for rheumatoid arthritis and he said that I shouldn't get [the influenza vaccine]. I don't know if at that time or never. (<i>Diego</i> , 52 years, RA, M)
	Actually, when I got the vaccine, I did ask my rheumatologist first, I asked her if I could get vaccinated, and she said yes but that I should stop some of my medicines for the vaccine to be effective. (Sonia, 25 years, SLE, F)
	I told them which vaccines had live viruses, but there weren't many, I mean they asked very little, and I told them very little. (<i>Valentina</i> , 33 years, <i>Rheumatologist with 3 years of experience</i> , F)
	I think there are some fears Maybe they'd want us to tell them not to get vaccinated, but they can and they should get vaccinated, that's my answer If they ask about risks, I tell them it's the same, as if they didn't have any disease. (Camilo, 54 years, Rheumatologist with 24 years of experience, M)
	Usually there's some communication. Patients trust that they can come to us and ask if they can get the vaccine We noticed that we do need to start having conversations with them about vaccination, not just COVID, but influenza, pneumococcus, herpes, whatever they need, and we need to start changing that chip of spending at least five minutes on vaccines And we don't do that, I mean, just recently with [the pandemic] we started noticing that it's something we need to talk to them about (Santiago, 48 years, Rheumatologist with 18 years of experience, M)
Theme 4: governance of vaccination programs	It was a good decision [to start with older adults] any disease for them can be very, very severe. (<i>Alejandro</i> , 48 years, Gout, M)
	Well, those who should have been vaccinated first were children, young people, and people who are still of working age because they're the ones that more frequently go outside. (<i>Jimena</i> , 51 years, RA, F)
	[The pandemic] was handled very poorly, because it was used politically. First, they promised a lot of things they didn't do and won't be able to do. They released the vaccines now that we have elections. I saw that politically. But the way they handled the [vacination] campaigns when I went they treated us very well, gave us instructions, good day, come this way, sit down information, care, everything explained, everything everything as if this were the first world. (<i>Pedro</i> , 56 years, <i>Ankylosing spondylitis</i> , M)



very specifically. This phenomenon of COVID-19 vaccine acceptance among RMD patients parallels decision-making in Canada [17] and the USA [18].

Firstly, the degree of access to information is a determinant factor of vaccine attitudes. Misinformation, conspiracy theories, and mistrust of governments have been common themes among Latin American populations in the USA, who are hesitant to vaccinate and have low vaccination rates [19]. Disinformation among the general population is a global phenomenon, particularly encouraged by widespread use of social networks as sources for medical advice [20, 21].

Historically, strategies to address issues of vaccine uptake have been largely based on an information deficit model, attributing hesitancy to a lack of understanding or of accurate information, which has proven ineffective in the long-term [22]. Low impact of educational interventions has led some to suggest that attitudes towards vaccines may be rooted in something other than knowledge [23, 24]. Though participants in our present study show a level of discernment by being untrusting towards information shared through social networks and online, such as conspiracy theories, their decision to vaccinate is primarily influenced by other factors.

Patients' own experiences with other vaccines are integrated with the expectations they gain about the current vaccine from those around them. The acceptance of vaccines based on this kind of non-biomedical knowledge would suggest that interventions (i.e., vaccination campaigns) based on sharing experiences would be much more impactful than increasing biomedical knowledge. This has been shown when comparing the effectiveness of methods to discuss childhood immunization [25]. These non-biomedical sources of information must be trusted by the patient, highlighting the importance of community interventions with more horizontal approaches.

In terms of the physician—patient relationship, rheumatologists are highlighted as an important source of information

about vaccines. Even though clinical guidelines for immunosuppressed patients have urged specialists to take responsibility over vaccination, very few rheumatologists include these data in their records [26]. This trend is evidenced by the results of our interviews with both patients and rheumatologists. For the COVID-19 vaccine specifically, the urgency of the pandemic context encouraged these kinds of exchanges about vaccination that have not been present otherwise. Even so, these conversations were not possible in all cases due to lockdown, contrasting trends in other countries like Canada, where 75.9% of patients discussed COVID-19 vaccination with their medical team [17].

Importantly, trust towards medical professionals exists as separate from the lack of trust towards the public health infrastructure. This is evidenced by our participants' distrust towards the Health Secretariat and politicians, similar to the perceived lack of effective government-instituted public health measures in the rest of North America [17, 18]. The vaccination campaigns should be built emphasizing the role of health professionals who directly interact with patients and who may have a preexisting relationship [27], including the design of messaging centered on provider recommendations on top of efforts to increase vaccine literacy [28].

Non-biomedical and biomedical information shapes patients' risk—benefit assessments about vaccines, in conjunction with existing perceptions of vulnerability as susceptibility to disease [29]. Participants express vulnerability when talking about their preexisting conditions and their increased risk of COVID-19. However, since in a pandemic context everyone faces a degree of exposure to risk, participants deduce a general moral obligation to all which in this case is reflected in protective measures such as masking and vaccination. Additionally, the particular characteristics of a person (i.e., available socioeconomic resources, sociocultural context, and structural elements) create an overlapping layer

Table 5 Theme 5: attitudes towards vaccines

Classification	Quotes
Full acceptance	I got every [childhood] vaccine, every vaccine. I can tell you that my mom gave me every vaccine, as it should be, right? And my siblings, they all have all their vaccines too. (<i>Sofia</i> , 50 years, RA, F)
Acceptance after hesitancy	Well my question was knowing if the reaction [to the vaccine] could be stronger for me, because my immune system is a little bit lower. But the doctor told me that not really, I mean, if I'm going to have any reaction I would have it anyway, with our without my treatment because it's more about how my body reacts to things. So knowing that I always get a fever then I know I'll get a fever but that's it, right? I mean, nothing that I should be worried about. (Clarissa, 32 years, Vasculitis, F)
Hesitancy	No, I haven't [been vaccinated]. I want to ask my doctor if I should get vaccinated or, I don't know, because of the medicine I take, I have that doubt. I'm also doubting because well I haven't been vaccinated yet and I feel good, I've been good. So I'm kind of worried that I'll get it and then things get complicated, or I don't know. (<i>Leonora</i> , 46 years, Scleroderma, F)
Refusal	I said, I'm not going to get something they haven't tested, least of all with my disease, right? No, and when I read that adenoviruses are even part of, um, that they let the AIDS virus take hold, I said no, I don't want to know anything about vaccines and so I kept reinforcing I've read a lot and it has reinforced my decision not to get vaccinated. (<i>Zaira</i> , 52 years, <i>Vasculitis</i> , F)



of vulnerability [29, 30]. Therefore, participants recognize not only individual responsibilities of care but also structural ethical responses that provide special protections and safeguards towards those additionally vulnerable [30], i.e., vaccination campaigns prioritizing specific groups such as older adults and children [31]. This coincides with reports of frustration that people with RMDs were not prioritized for vaccination along with other high-risk groups [18]. Though many patients also touch on the potential harms generated by vaccines as a source of vulnerability, leading to fear and doubt as a distinctively ethical concern [31], most give less attention to this layer, resulting in a favorable risk—benefit analysis.

Though the factors influencing individual perceptions of risk-benefit are comparable to the phenomenon observed elsewhere [17, 18], these must be contextualized given the background of vaccination in Mexico. There exists a long tradition of vaccination programs, sometimes mandatory, which have led to the creation of a strong vaccination culture or norm among the general population, especially regarding childhood immunization: patients describe a non-decision where vaccine acceptance is seen as a default.

Defining and assessing psychological antecedents has been another prevalent approach to explore individual-level vaccine attitudes and behaviors. For example, confidence, complacency, constraints, calculation, and collective responsibility are proposed to underpin vaccine uptake [32]. Additionally, recent studies of vaccine hesitancy among parents [23, 33] and towards the COVID-19 vaccine specifically [24] have applied social psychological theories of morality to identify the key dimensions of moral judgment and decision-making.

Indeed, most participants express a process where various moral values like vulnerability and justice are integrated in vaccine decision-making. Importantly, though whether to vaccinate is an autonomous decision for patients, the narrative process reveals an understanding of the principle of autonomy beyond its traditional conception in the biomedical context as individual self-governance. Instead, autonomy is better understood from a relational perspective, where a

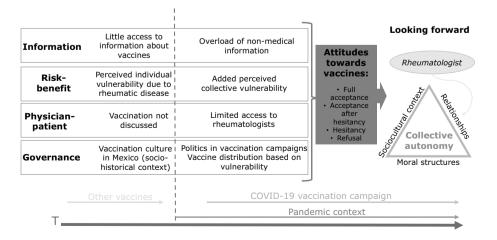
Fig. 1 Vaccine decision-making process. Mexican RMD patients express various attitudes towards vaccines, based on sociocultural and moral aspects, which inform their decision to vaccinate

person's self-determination is dependent on and shaped by their social relationships [34, 35]. In this way, patients narrate the vaccine decision-making process as shared and dynamic, affected by and affecting others [36]. Therefore, the participants' relationships, especially family and community, are part of their motivational structure, their moral identity, and their decision-making process.

The role of the rheumatologist in vaccine decision-making is outlined in existing guidelines. Rheumatology societies worldwide have published recommendations regarding COVID-19, focused on both clinical and vaccine guidance. These include the fundamental role of the rheumatologist as a source of evidence-based information and advice, and as part of a shared decision-making process considering vaccine policy in each country [37]. Vaccination programs should be individualized to account for each patient's needs, concerns, and preferences [38], as well as values and perspectives [37], identifying barriers of access such as fear, and ensuring patient understanding of risks and benefits [38]. Furthermore, some rheumatology societies urge that patients be included in the design of vaccine recommendations [38], as was done by the European Alliance of Associations for Rheumatology (EULAR).

Some limitations of this study include its timeline. Results may have differed if the study was conducted during a period of greater uncertainty about side effects when the campaign started [39]. Another limitation is the low number of rheumatologists interviewed compared to patients. Finally, the results of this study are relevant to a specific cultural context and might not explain vaccine attitudes in different contexts. However, localized approaches can lead to more informed global interventions, by highlighting the similarities and differences between populations of RMD patients.

In conclusion, Mexican RMD patients express a variety of attitudes towards vaccines, based on the sociocultural and moral narratives described above, which inform their decision to vaccinate (Fig. 1). We must think beyond individual autonomy in the medical setting, taking into consideration all





factors which strengthen patients' moral agency and capacity to make informed, autonomous decisions, especially in contexts where collectivism is a cultural value. Importantly, rheumatologists should consider themselves part of the social relationships that construct the collective autonomy of patients and prioritize having conversations about vaccines. Additionally, patients' sociocultural and moral perspectives of vaccination are fundamental to understand their specific concerns and beliefs, and to develop effective clinical practice guidelines as well as ethically justified public policy. Thus, patients should be included in this process. Finally, the complexity of values influencing the decision to vaccinate is better identified through a narrative, qualitative approach like the one used in this study, as opposed to solely quantitative approaches that require us to fit the participants' narratives into predetermined concepts of morality.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10067-023-06609-5.

Acknowledgements We thank the patients and participating rheumatologists for their time and insights. We would like to thank Lucy DeStefano-Pearce, MA, from Northwell Health for revising and editing a version of this manuscript. Partial data from this study was previously presented as an abstract at the ACR Convergence 2022 [1291310]' https://acrabstracts.org/abstract/sociocultural-and-moral-factors-influencing-the-decision-to-vaccinate-among-rheumatic-patients-a-qualitative-study/'.

Data availability Data are available on reasonable request. The data are available but must be requested from the researcher IP-B through a specific application request for the use of data, which will be evaluated by all groups.

Declarations

Disclosures None.

References

- Lane S, MacDonald NE, Marti M, Dumolard L (2018) Vaccine hesitancy around the globe: analysis of three years of WHO/UNICEF Joint Reporting Form data-2015-2017. Vaccine 36(26):3861–3867. https://doi.org/10.1016/j.vaccine.2018.03.063
- Lazarus JV, Ratzan SC, Palayew A et al (2021) A global survey of potential acceptance of a COVID-19 vaccine. Nat Med 27(2):225–228. https://doi.org/10.1038/s41591-020-1124-9
- Freeman D, Loe BS, Chadwick A et al (2022) COVID-19 vaccine hesitancy in the UK: the Oxford coronavirus explanations, attitudes, and narratives survey (Oceans) II. Psychol Med 52(14):3127–3141. https://doi.org/10.1017/S0033291720005188
- Palamenghi L, Barello S, Boccia S, Graffigna G (2020) Mistrust in biomedical research and vaccine hesitancy: the forefront challenge in the battle against COVID-19 in Italy. Eur J Epidemiol 35(8):785–788. https://doi.org/10.1007/s10654-020-00675-8
- MacDonald NE, SAGE Working Group on Vaccine Hesitancy (2015) Vaccine hesitancy: definition, scope and determinants. Vaccine 33(34):4161–4164. https://doi.org/10.1007/s10654-020-00675-8

- Larson HJ, Jarrett C, Eckersberger E, Smith DM, Paterson P (2014) Understanding vaccine hesitancy around vaccines and vaccination from a global perspective: a systematic review of published literature, 2007–2012. Vaccine 32(19):2150–2159. https:// doi.org/10.1016/j.vaccine.2014.01.081
- 7. Figueroa-Parra G, Esquivel-Valerio JA, Santoyo-Fexas L et al (2021) Knowledge and attitudes about influenza vaccination in rheumatic diseases patients. Hum Vaccin Immunother 17(5):1420–1425. https://doi.org/10.1080/21645515.2020.1816
- Felten R, Dubois M, Ugarte-Gil MF et al (2021) Vaccination against COVID-19: expectations and concerns of patients with autoimmune and rheumatic diseases. Lancet Rheumatol 3(4):e243-e245. https://doi.org/10.1016/S2665-9913(21)00039-4
- FAI2R /SFR/SNFMI/SOFREMIP/CRI/IMIDIATE consortium and contributors (2021) Severity of COVID-19 and survival in patients with rheumatic and inflammatory diseases: data from the French RMD COVID-19 cohort of 694 patients.
 Ann Rheum Dis 80(4):527–538. https://doi.org/10.1136/annrheumdis-2020-218310
- Guaracha-Basañez GA, Contreras-Yáñez I, Álvarez-Hernández E et al (2022) Factors associated to COVID-19 vaccine acceptance in Mexican patients with rheumatic diseases: a cross-sectional and multicenter study. Hum Vaccin Immunother 18(5):2049131. https://doi.org/10.1080/21645515.2022.2049131
- El-Far Cardo A, Kraus T, Kaifie A (2021) Factors that shape people's attitudes towards the COVID-19 pandemic in Germany-the influence of MEDIA, politics and personal characteristics. Int J Environ Res Public Health 18(15):7772. https://doi.org/10.3390/ijerph18157772
- Morales GI, Lee S, Bradford A, De Camp A, Tandoc EC Jr (2022) Exploring vaccine hesitancy determinants during the COVID-19 pandemic: an in-depth interview study. SSM Qual Res Health 2:100045. https://doi.org/10.1016/j.ssmqr.2022.100045
- Urrunaga-Pastor D, Bendezu-Quispe G, Herrera-Añazco P et al (2021) Cross-sectional analysis of COVID-19 vaccine intention, perceptions and hesitancy across Latin America and the Caribbean. Travel Med Infect Dis 41:102059. https://doi.org/10.1016/j. tmaid.2021.102059
- Barton A (2008) A narrative approach to bioethical decision making: the missing link between bioethics and conflict management?
 Conflict Resolut Q 25(4):497–509. https://doi.org/10.1002/crq.219
- Daryazadeh S (2019) Application of narrative in medical ethics. J Med Ethics Hist Med 12:13. https://doi.org/10.18502/jmehm. v12i13.1642
- Hopfer S, Clippard JR (2011) College women's HPV vaccine decision narratives. Qual Health Res 21(2):262–277. https://doi.org/10.1177/1049732310383868
- Butt IN, van Eeden C, Kovacs Burns K, Saxinger L, Clifford A, Cohen Tervaert JW, Yacyshyn EA (2022) COVID-19 vaccination perceptions in patients with rheumatic disease: a cross-sectional online survey. J Rheumatol 50(5):690–696. https://doi.org/10. 3899/jrheum.220765
- Shaw YP, Hustek S, Nguyen N et al (2002) Rheumatic disease patient decision-making about COVID-19 vaccination: a qualitative analysis. BMC Rheumatol 6(1):76. https://doi.org/10.1186/ s41927-022-00307-6
- Cáceres NA, Shirazipour CH, Herrera E, Figueiredo JC, Salvy SJ (2022) Exploring Latino Promotores/a de Salud (Community Health Workers) knowledge, attitudes, and perceptions of COVID-19 vaccines. SSM Qual Res Health 2:100033. https://doi.org/10. 1016/j.ssmqr.2021.100033
- Swire-Thompson B, Lazer D (2020) Public health and online misinformation: challenges and recommendations. Annu Rev Public Health 41:433–451. https://doi.org/10.1146/annurev-publh ealth-040119-094127



- Wang Y, McKee M, Torbica A, Stuckler D (2019) Systematic literature review on the spread of health-related misinformation on social media. Soc Sci Med 240:112552. https://doi.org/10.1016/j. socscimed.2019.112552
- 22. Dib F, Mayaud P, Chauvin P, Launay O (2022) Online mis/disinformation and vaccine hesitancy in the era of COVID-19: why we need an eHealth literacy revolution. Hum Vaccin Immunother 18(1):1–3. https://doi.org/10.1080/21645515.2021.1874218
- Amin AB, Bednarczyk RA, Ray CE et al (2017) Association of moral values with vaccine hesitancy. Nat Hum Behav 1(12):873– 880. https://doi.org/10.1038/s41562-017-0256-5
- Schmidtke KA, Kudrna L, Noufaily A et al (2022) Evaluating the relationship between moral values and vaccine hesitancy in Great Britain during the COVID-19 pandemic: a cross-sectional survey. Soc Sci Med 308:115218. https://doi.org/10.1016/j.socscimed.2022.115218
- Horne Z, Powell D, Hummel JE, Holyoak KJ (2015) Countering antivaccination attitudes. Proc Natl Acad Sci U S A 112(33):10321–10324. https://doi.org/10.1073/pnas.1504019112
- Cepeda-Perez AS, TelloWinniczuk N, Diaz-Borjon A (2021) Adherencia a las recomendaciones actuales de inmunización en pacientes con artritis reumatoide en México. Reumatol Clin 17:155–159. https://doi.org/10.1016/j.reuma.2019.04.004
- Bolsewicz KT, Steffens MS, Bullivant B, King C, Beard F (2021)
 "To Protect Myself, My Friends, Family, Workmates and Patients
 ...and to Play My Part": COVID-19 vaccination perceptions
 among health and aged care workers in New South Wales, Australia. Int J Environ Res Public Health 18(17):8954. https://doi.
 org/10.3390/ijerph18178954
- Patterson NJ, Paz-Soldan VA, Oberhelman R, Moses L, Madkour A, Miles TT (2022) Exploring perceived risk for COVID-19 and its role in protective behavior and COVID-19 vaccine hesitancy: a qualitative study after the first wave. BMC Public Health 22(1):503. https://doi.org/10.1186/s12889-022-12900-y
- 29. Colmenares-Roa T, Figueroa-Perea JG, Pelcastre-Villafuerte B et al (2022) Vulnerability as a palimpsest: practices and public policy in a Mexican hospital setting. Health 26(6):753–776. https://doi.org/10.1177/1363459320988879
- Luna F (2019) Identifying and evaluating layers of vulnerability
 a way forward. Dev World Bioeth 19(2):86–95. https://doi.org/ 10.1111/dewb.12206

- Curran EJ, John SD (2022) Must we vaccinate the most vulnerable?
 Efficiency, priority, and equality in the distribution of vaccines. J
 Appl Philos 39:682–697. https://doi.org/10.1111/japp.12588
- Betsch C, Schmid P, Heinemeier D, Korn L, Holtmann C, Böhm R (2018) Beyond confidence: development of a measure assessing the 5C psychological antecedents of vaccination. PLoS One 13(12):e0208601. https://doi.org/10.1371/journal.pone.0208601
- Heine F, Wolters E (2021) Using moral foundations in government communication to reduce vaccine hesitancy. PLoS One 16(11):e0259435. https://doi.org/10.1371/journal.pone.0259435
- Nedelsky J (1989) Reconceiving autonomy: sources, thoughts, and possibilities. Yale J Law Fem 1:7–36
- 35 Fan R (1997) Self-determination vs. family-determination: two incommensurable principles of autonomy: a report from East Asia. Bioethics 11(3–4):309–322. https://doi.org/10.1111/1467-8519.00070
- Gómez-Vírseda C, de Maeseneer Y, Gastmans C (2019) Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. BMC Med Ethics 20(1):76. https://doi.org/10.1186/s12910-019-0417-3
- Bass AR, Chakravarty E, Akl EA et al (2023) 2022 American College of Rheumatology Guideline for vaccinations in patients with rheumatic and musculoskeletal diseases. Arthritis Rheumatol. https://doi.org/10.1002/art.42386.10.1002/art.42386
- Furer V, Rondaan C, Heijstek MW et al (2020) 2019 update of EULAR recommendations for vaccination in adult patients with autoimmune inflammatory rheumatic diseases. Ann Rheum Dis 79(1):39–52. https://doi.org/10.1136/annrheumdis-2019-215882
- Kennedy EB, Daoust JF, Vikse J, Nelson V (2021) "Until I Know It's Safe for Me": the role of timing in COVID-19 vaccine decision-making and vaccine hesitancy. Vaccines (Basel) 9(12):1417. https://doi.org/10.3390/vaccines9121417

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.

Authors and Affiliations

Amaranta Manrique de Lara¹ · Tirsa Colmenares-Roa¹ · Virgina Pascual-Ramos² · José Francisco Moctezuma-Rios³ · Irazú Contreras-Yañez² · Guillermo Arturo Guaracha-Basañez² · Everardo Álvarez-Hernández³ · Graciela Meza-López y Olquín³ · Ingris Peláez-Ballestas^{1,3}

Amaranta Manrique de Lara amarantamanriquedelara@gmail.com

Tirsa Colmenares-Roa tirsac@hotmail.com

Virgina Pascual-Ramos virtichu@gmail.com

José Francisco Moctezuma-Rios jfmoctezuma66@yahoo.com.mx

Irazú Contreras-Yañez protocolosar@live.com

Guillermo Arturo Guaracha-Basañez guiyrmo_89@hotmail.com

Everardo Álvarez-Hernández everalvh@yahoo.com.mx

Graciela Meza-López y Olguín graciela 1410@hotmail.com

- Hospital General de Mexico "Dr. Eduardo Liceaga", Mexico City, México
- Department of Immunology and Rheumatology, Instituto Nacional de Ciencias Médicas Y Nutrición Salvador Zubirán, Mexico City, México
- Rheumatology Unit, Hospital General de Mexico "Dr. Eduardo Liceaga", Mexico City, México

