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Perspectives and experiences of COVID-19 vaccination in people with autoimmune and inflammatory rheumatic disease

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ABSTRACT

Objective: People with autoimmune and inflammatory rheumatic disease (AIIRD) are at an increased risk of morbidity from COVID-19. While COVID-19 vaccination is effective at reducing disease complications, there have been significant levels of vaccine hesitancy in people with AIIRD. We aimed to understand vaccine hesitancy and promote shared decision-making by describing the experiences and perspectives of people with AIIRD who had concerns with COVID-19 vaccinations.

Methods: Adults with AIIRD on immunosuppressive medications who expressed concerns regarding the COVID-19 vaccination were purposively sampled until thematic saturation. Individual semi-structured interviews were conducted and analysed using reflexive thematic analysis.

Results: Sixteen adults with an AIIRD were interviewed. Thematic analysis yielded four themes: heightened sense of vulnerability; determining individual suitability; desperate for freedom and relief; deterred by scepticism.

Conclusions: The perspectives of people with AIIRD towards the COVID-19 vaccination were shaped by a sense of vulnerability. The decision-making experience was challenging, resulting from struggles with handling information, dealing with external pressures, and facing negativity.

Practice Implications: A collaborative approach, involving close family and friends and avoiding negativity and pressure can improve engagement and support decision-making around COVID-19 vaccination. Clearly addressing potential risks of vaccination may prevent subsequent regret and hesitancy if they arise.

1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic has had devastating effects worldwide with over 6.8 million COVID-19 related deaths as of March 2023 [1]. COVID-19 is highly transmissible and is associated with high morbidity and mortality [2]. The vaccines developed against COVID-19 have been effective in reducing hospitalisation, severe illness, and death, and are crucial in long-term public health management of COVID-19 [3–5]. During the COVID-19 pandemic, there has been significant levels of vaccine hesitancy worldwide, with great variability between different populations [6–9].

Autoimmune and inflammatory rheumatic diseases (AIIRD) are disorders which involve self-reactive inflammatory or immune responses that manifests with inflammation of joints, muscles, and other organs. Immune dysregulation in AIIRD and treatment with immunosuppressive therapies make people with AIIRD more vulnerable to infections such as COVID-19. COVID-19 remains a major threat to people with AIIRD who are at higher risk of breakthrough infections and mortality (OR 1.74) [10,11]. The efficacy and safety of COVID-19 vaccination has been demonstrated amongst people with AIIRD on immunosuppressive medications [12–15] and are recommended amongst international rheumatology associations [16–18]. Some people with AIIRD may not perceive themselves as at increased risk [19], and significant proportions remain uncertain about getting COVID-19 vaccinations [20–24]. Concerns regarding COVID-19 vaccination include potential adverse events, uncertainty because of a perceived lack of long-term research and use of new technology, fear of worsening their rheumatic condition and interactions between medications and vaccination [23–25].

A key facilitator of vaccine uptake in people with inflammatory

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disease is reassurance from trusted healthcare providers particularly addressing concerns regarding COVID-19 vaccination safety and flaring of disease [21,26]. Recommendation from a healthcare worker, particularly by a rheumatologist, significantly increased odds of vaccine uptake [27] with 62% of people with AIIRD indicating that discussions with a medical professional influenced COVID-19 vaccination decision-making [28]. Other facilitators include encouragement from influential organisations, positive experiences with previous vaccination, and self-perception of having controlled disease [26]. The 5 C's is a model that assists in characterising the determinants of vaccine uptake by identifying five psychological antecedents: confidence, complacency, calculation, constraints, and collective responsibility [29]. Confidence refers to trust in the vaccination and the system that delivers it. Complacency refers to the perception of threat from the disease and the necessity of vaccination. Calculation of risk refers to individual engagement in information searching to determine personal risk of infection versus vaccination. Constraints include the psychological, sociocultural, and structural barriers to attaining vaccination. Collective responsibility describes the motivation to vaccinate to protect others through herd immunity.

An individualised approach to addressing vaccine hesitancy is required as various factors affect decision-making even amongst specific groups like people with AIIRD [24]. However, the specific methods in providing support to people in AIIRD is not yet well established within the context of the COVID-19 pandemic. To enable effective measures to promote vaccination uptake, it is important to understand the priorities, concerns, and experiences in people with AIIRD, areas not well explored in the literature. The aim of this study is to describe the experiences and perspectives of the COVID-19 vaccination in people with AIIRD and on immunosuppressive medications, who also had concerns with the COVID-19 vaccination. The insights gained can be used to empower decision-making in people with AIIRD, support healthcare providers to confidently discuss the COVID-19 vaccination by addressing the unique needs of this population and inform person-centred policy making decisions.

2. Methods

2.1. Study design

This was a qualitative semi-structured interview study that aimed to explore and describe the perspectives and experiences of the COVID-19 vaccination in people with AIIRD and on immunosuppressive medications, who had concerns with the COVID-19 vaccination. A constructivist grounded theory methodology was used [30]. This study was approved by the South Western Sydney Local Health District Human Research Ethics Committee (Ethics Approval Number 2021/ETH11426). The Standards for Reporting Qualitative Research was used to report this study (Appendix A) [31].

2.2. Participants

This study was conducted in a tertiary hospital in South Western Sydney, Australia. Participants were recruited by their treating physician in the rheumatology department, who consented their patients to be contacted by the investigators. Other sources of recruitment included consumer support networks Scleroderma Australia and Scleroderma NSW. Eligibility criteria included people aged ≥ 18 years old, English, Arabic or Vietnamese speaking, diagnosed with an AIIRD and on immunosuppressive medication. Recruiters were asked to invite patients who expressed concerns regarding the COVID-19 vaccination. Purposive sampling was utilized to ensure a diverse study population. Participants were recruited until thematic saturation was reached (i.e., when no new concepts emerged) [32].

2.3. Data collection

An interview guide was developed based on a review of the literature, including reference to the 5 C's model [29], and iterative discussion with people with lived experience of AIIRD, an expert panel including rheumatologists, a psychologist specializing in medication and vaccination use, and experts in qualitative research (Appendix B). The interview guide explored topics of information, decision-making, experiences, and barriers regarding COVID-19 vaccinations. Open-ended questions formed the basis of the interview, and follow-up questions were used to facilitate clarification and understanding of the participants' answers.

Recruitment for this study was from September 2021 to July 2022. This was amidst the COVID-19 delta wave, the second lockdown in NSW, and the roll-out of a third dose of the COVID-19 vaccination for susceptible populations [33,34].

The research team obtained informed consent from all participants included in the study. A semi-structured telephone or face-to-face interview was conducted by either DP, SF, AK, or MS. There were no pre-existing relationships between participants and their interviewers. AK is a female rheumatologist and SF is a female research manager and exercise physiologist. SF and AK are experienced with qualitative research and supervised DP and MS with data collection and analysis. Arabic interviews were conducted by MS, a female research assistant who is fluent in English and Arabic. DP is a male junior doctor. Interviews were audio-recorded and were transcribed and/or translated verbatim by external transcription and language services affiliated with the American Translation Association. The de-identified transcripts were cross-checked with the recordings before being imported into qualitative analysis software (NVIVO 12, QSR International Pty Ltd) for analysis. Participants were offered an honorarium for their participation.

2.4. Data analysis

Reflexive thematic analysis was used in the interpretation and analysis of data [35]. This method identifies, analyses, and reports patterns within qualitative data without using a pre-existing coding framework [35]. DP read transcripts multiple times and inductively developed a preliminary coding framework. This was discussed and refined with other researchers and a consumer research partner. All transcripts were coded line by line with existing codes being refined and new codes being added as they arose from the data. Groups of codes were organised into themes and subthemes. There were regular meetings between the co-authors (SF, CE, and AK) to discuss and refine emerging themes and subthemes. Participants were invited to provide feedback on preliminary results (member checking).

3. Results

A total of 35 people with AIIRD were invited to participate. Thematic saturation was achieved after 16 participants were interviewed. Of the other 19 invited participants, 14 were not contactable, and five declined to participate. Reasons for declining to participate included having personal commitments and being unwell. The participant characteristics are presented in Table 1. Most participants were female (n = 14, 87.5%). Ages ranged between 25 and 80 years old. Most (n = 14, 87.5%) participants had received at least one dose of the COVID-19 vaccination at the time of their interview. The most reported diagnoses were rheumatoid arthritis (RA) (n = 9, 56.3%) and scleroderma (n = 4, 25%). The most common ethnicities were Caucasian (n = 7, 43.8%) and Middle Eastern (n = 4, 25%). Of the interviews, 94% (n = 15) were conducted in English, and one interview was conducted in Arabic. The duration of the interviews ranged from 17 to 52 min.

Table 1
Participant Demographics.

Characteristic	Value
Sex	
Male	2 (12.5%)
Female	14 (87.5%)
Age, years	
20–29	1 (6.3%)
30–39	2 (12.5%)
40–49	6 (37.5%)
50–59	2 (12.5%)
60–69	3 (18.8%)
70 +	2 (12.5%)
Range (median)	25–80 (49)
Received COVID-19 vaccination	14 (87.5%)
Diagnosed AIIRD	
Rheumatoid arthritis	9 (56.3%)
Scleroderma	4 (25%)
Systemic Lupus Erythematosus	2 (12.5%)
Connective Tissue Disease	1 (6.3%)
Secondary Sjogren's Syndrome	1 (6.3%)
Large Vessel Vasculitis	1 (6.3%)
Polymyalgia rheumatica	1 (6.3%)
Inflammatory myopathy	1 (6.3%)
Immunosuppressive Medication	
Corticosteroid only	1 (6.3%)
Conventional DMARD only	10 (62.5%)
Biological/targeted DMARD	5 (31.3%)
Ethnicity	
Caucasian	7 (43.8%)
Middle Eastern	4 (25%)
Asian	3 (18.8%)
Hispanic	1 (6.3%)
African	1 (6.3%)
Level of education	
Tertiary	10 (62.5%)
Secondary	4 (25%)
Primary	1 (6.3%)

Table 2
Illustrative Quotations.

Theme/subtheme	Illustrative Quotes
Heightened sense of vulnerability	
Motivated by susceptibility	"When you're in a high risk situation, you're looking at it – like in my situation – you're looking at it a lot more closely compared to say somebody who's 20, healthy, no underlying problems." *40 s, scleroderma* **(A1)**
	"I still think, if I got COVID, I'm not going to survive it. Even though I'm vaccinated. I think I'm going to have a fight on my hands. But it's the best you can do, you know what I mean? To minimise the impact." *50 s, rheumatoid arthritis* **(A2)**
Fear of disrupting health	"You always worry that something's going to trigger, and it's triggering an autoimmune response, how do you know it's not going to cause the scleroderma to get worse?" *40 s, scleroderma* **(A3)**
	"I just didn't want to do anything that could potentially trigger and irritate my body even more because of the condition that I have, which has no cure. It just really stressed me out." *30 s, scleroderma* **(A4)**
	"I just felt like I was putting another poison into my body. I don't know how it's going to interact with everything else." *50 s, rheumatoid arthritis/ secondary Sjogren's* **(A5)**
Vaccine remorse	"Since I've had the vaccine, it's just gone into overdrive. Absolutely overdrive… I still regret it. Absolutely regret it. I should've held off." *70 s, rheumatoid arthritis* **(A6)**
	"Each time I had the vaccine I had all the negative immune responses, so it was incredibly tough. It wasn't something I wanted to do or looked forward to getting, but I knew I had to endure because of COVID, so that's why it's quite depleting, you could say, to find out it hasn't worked." *40 s, scleroderma* **(A7)**
Determining Individual Suitability	
Reassured by a trusted doctor	"If he says something I'll go 'okay!' and I'm much more comfortable. That's just the trust that you have, I guess, from a patient perspective." *40 s, scleroderma* **(B1)**
	"This is what my doctors are suggesting that it will help me, so I have to listen to the professionals. This is why I come to the doctor. Just helps to make that decision to go ahead and get vaccinated." *60 s, large vessel vasculitis* **(B2)**
Consulting with close companions	"First all of my family got it, my brother, my sister, it didn't happen anything to them as well, that added to my experience. Then I asked my brother, he booked an appointment for me." *30 s, rheumatoid arthritis* **(B3)**
	"Because my condition is, like, it's not hereditary but we all do have a different autoimmune condition so we all spoke about things that are bothering us or concerns. We spoke about the vaccine as well." *30 s, scleroderma* **(B4)**
Compelled by first hand experiences	"I'm more interested to see people's side effects and people's reactions and thoughts. It was more interesting and more comforting to know that people in my same position or in similar shoes have had their experiences." *30 s, scleroderma* **(B5)**
	"Everyone was saying oh, vaccines are not good, it's not suitable for everyone. But after that when I know some friends, she got it and nothing happened to her, that's when I decided to get it." *20 s, systemic lupus erythematosus* **(B6)**
Yearning for tailored advice	"It's a real conflict because there's no data, the doctors aren't saying, so the decision's on us whether we do it or not. That's a lot of pressure, you know? Because we don't know." *40 s, scleroderma* **(B7)**
	"I really would have loved that my GP actually read my case…and then explained to me how the vaccine is safe in my system. that's probably what would've

(*continued on next page*)

3.1. Thematic analysis

Four themes were identified: 1) heightened sense of vulnerability, 2) determining individual suitability, 3) desperate for freedom and relief, and 4) deterred by scepticism. Themes and subthemes are described in more detail below. Illustrative quotations for each subtheme are included in Table 2**,** and a thematic schema summarising the themes is presented in Fig. 1**.**

3.2. Heightened sense of vulnerability

Due to their underlying conditions and medications, people with AIIRD felt more vulnerable to COVID-19 as well as the adverse effects of the COVID-19 vaccine.

3.2.1. Motivated by susceptibility

Participants perceived that they were more susceptible to severe COVID-19 than the general population due to their underlying AIIRD. This susceptibility was a strong motivator for them to seek information and pursue the COVID-19 vaccinations (A1) even though some people felt that their vaccine was less effective for them because of their disease and/or medications. The reduced risk of severe COVID-19 provided by vaccination often outweighed fears or doubts about the vaccine. Some participants felt that if it weren't for their disease, they "would be a lot more blasé " about the decision to vaccinate (40 s, scleroderma).

3.2.2. Fear of disrupting health

The complex nature of the participants' disease raised concerns regarding detrimental interactions between COVID-19 vaccination and their health, in particular, if it would "flare" their disease, and if it was safe to use with their medications (A3, A5). Fears were exacerbated by hearing about severe side effects from friends, family, media, and online

Table 2 (*continued*)

Theme/subtheme	Illustrative Quotes
	made me feel a lot more assured." *50 s, rheumatoid arthritis/secondary Sjogren's* **(B8)**
Desperate for freedom and relief	
Pressure to vaccinate	"I feel like I was getting bombarded with, like it was a constant force. You can't do this if you don't get vaccinated, you'll be locked out of this, you can't go there." *30 s, scleroderma* **(C1)**
	"Information everywhere just felt like it was being forced onto people… I just wanted to make my own decision in my own time … At one point I thought, I've got to let go of this stress. I'm just going to have it so I can be on the ship with everyone else, it's easier." *50 s, rheumatoid arthritis/secondary Sjogren's* **(C2)**
Overwhelmed with handling information	"It's not easy to understand when you read it online, unless you're a doctor or some sort of medical person. I still don't, even though I had it explained to me. Most people don't really care because they're not that interested in any of this stuff, but when you're sick you just worry and think about what you put in your body." *30 s, scleroderma* **(C3)**
	"That was when she said a lot of information and I just shut down, I thought I'm not going to listen to anything you say. I just wasn't ready to make that choice yet." *50 s, rheumatoid arthritis/secondary Sjogren's* **(C4)**
Exasperated by unhelpful negativity	"It was a bit overwhelming with one of my doctors. He was just forcing it down my face and really getting annoyed with me. He basically said to me that if I got COVID without a vaccination, I would be in the ICU… Literally I walked out in tears because I just didn't, in my heart I didn't want to do it." *30 s, scleroderma* **(C5)**
	"The way she spoke about the vaccine and told me it was doom and gloom, I either get it or I die, that made me more angry. I just wanted to shut down the conversation. When you're spoken to like that, it doesn't give you the confidence to open up and have more of a discussion around it." *50 s, rheumatoid arthritis/secondary Sjogren's* **(C6)**
Seeking a path to normality	"It was to get my life back … I haven't seen my family, my family haven't been in my house for three years. I don't get to go outside anywhere or go to a movie or sit at a restaurant. I was very much hopeful that the vaccine would provide that level of comfort, and to take away the fear of getting COVID." *40 s, scleroderma* **(C7)**
	"It was basically, well, if you didn't get the shot, you didn't get the freedom. There was that sort of emphasis there in the media, social media and all that. … I said well, I'm going to get vaccinated for the sheer fact that I'm not going to rot away in this unit for the rest of my life." *50 s, rheumatoid arthritis* **(C8)**
Deterred by scepticism	
Distrust in scientific evidence	"There were no long-term studies. It was rushed under the emergency use powers, so it was able to be used … there's no long-term studies of this, none. We are the study." *70 s, rheumatoid arthritis* **(D1)**
	"A new vaccine coming up, of course it's going to be questionable.,. The question mark was always there in my mind, thinking why should we support them when we don't have enough information or research behind it." *60 s, rheumatoid arthritis/ connective tissue disease* **(D2)**
Suspicion of underlying agenda	"The more that went on, the more I distrusted that information, because it sounded to me like there was an agenda… the rheumatologist and the GP, the information that they provided was the least helpful… There were only two options, to get it done or get it done. There was no room for discussion or anything." *50 s, rheumatoid arthritis/ secondary Sjogren's* **(D3)**
	"There was. not enough TV airtime of the things that did go wrong… They never ever portrayed the fact that things do go wrong unless they want to… It was very one-sided on the news which comes from the government." *30 s, scleroderma* **(D4)**
Denial of danger	"That was my view. I mean, the chances of catching it were remote, in any case. You had more chance of being hit by Halley's comet than catching the virus. I thought I'd just stick it out." *70 s, rheumatoid arthritis* **(D5)**
	"I said no, I'm not taking it. I said it's just personal reasons, it's my religious reasons and I will not do it. I just said, I serve a true living God who I know will heal me, so don't worry about it." *60 s, rheumatoid arthritis/ connective tissue disease* **(D6)**

sources. Participants also wondered about whether their medications should be adjusted when getting vaccinated. In many cases this was not possible given the difficulties in managing their disease.

3.2.3. *Vaccine remorse*

The decision to proceed with COVID-19 vaccination was often surrounded by anxiety. Those who experienced a deterioration in health following vaccination, and those who struggled to control their symptoms, often felt frustrated and regretful that they had taken a risk that disrupted the fine balance of their disease (A6). These participants strongly expressed their reluctance to obtain further COVID-19 vaccinations. Some participants were disheartened by the persistent feeling of susceptibility to COVID-19 despite receiving the vaccination (A7). This feeling was due to the perception that the vaccination was less effective for them because of their disease and medications.

3.3. *Determining individual suitability*

People with AIIRD approached various sources to gain confidence and knowledge in determining the suitability of the vaccine for their individual context.

3.3.1. *Reassured by a trusted doctor*

Guidance was sought from doctors whom participants felt they had a strong and trusting relationship with. The guidance provided by a trusted doctor helped participants gain confidence in their decisions to vaccinate (B1). Participants would often turn to their medical team for clarification about confusing information that they would encounter from the media. Advice tailored to participants' disease which was provided by their specialist doctors was particularly valued by participants. Transparent discussions with their doctors regarding the ambiguity of COVID-19 vaccinations, and their AIIRD, was appreciated.

3.3.2. *Consulting with close companions*

The opinions, experiences and information from family, friends, and caretakers were valued by participants (B3). Verification of information with someone who was familiar, trustworthy, and knowledgeable, increased participants' confidence in accepting information. Furthermore, discussions with friends and family were more conducive to validating participants' concerns because they had similar medical literacy and understood how they thought. Relatives who had similar diseases were able to provide more relevant information to the participants' situation (B4). Participants felt they had more opportunities to seek ongoing clarification of new information with their close companions in contrast to the limited time they had with their doctors.

3.3.3. *Compelled by firsthand experiences*

'Firsthand' experiences from familiar people, or from others with similar diseases, provided supportive information valued by participants (B5). Participants found these firsthand experiences "more interesting and more comforting" (30 s, scleroderma), especially when faced with

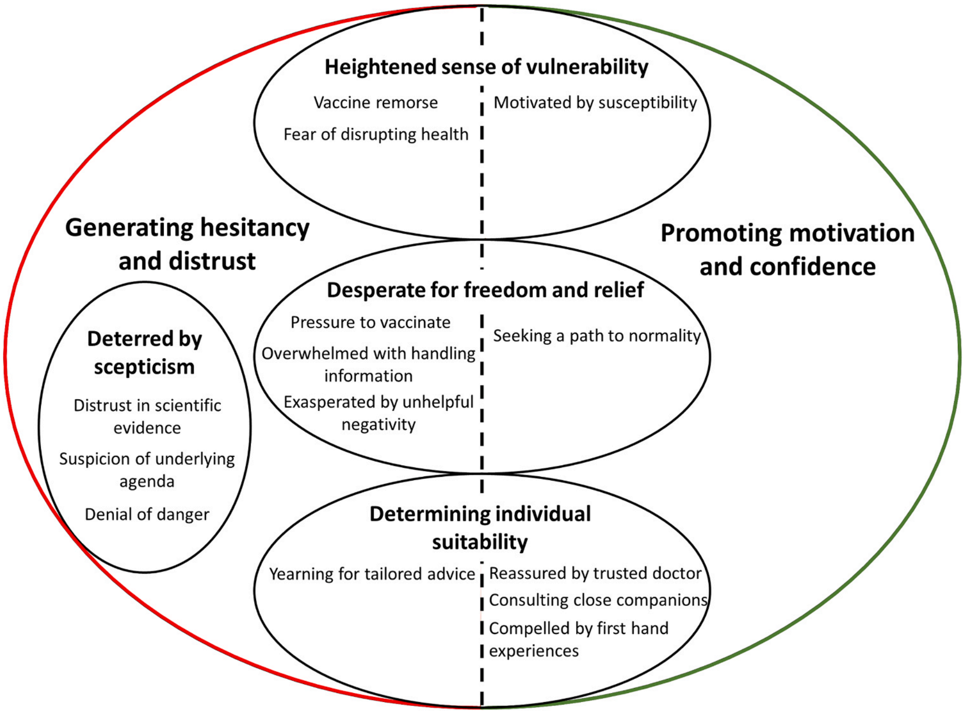

Fig. 1. Thematic Schema. A perception of increased vulnerability and a desire for returning to normality motivated people with AIIRD to be proactive in their decision making. Confidence in these decisions was promoted by individualized advice from trusted doctors, colleagues and similar others with first hand experiences. However, a lack of tailored and understandable information, encountering pressure and negativity and having a distrust of external authorities generated hesitancy in relation to COVID-19 vaccination.

uncertainty towards other information sources. Hearing about positive experiences made some participants feel 'more confident' in getting the vaccination, whereas hearing negative experiences made some participants 'nervous' and reluctant (B6). The experiences of people with similar medical conditions helped address specific concerns such as whether their disease would flare, and whether they could tolerate a vaccine with their impaired immunity.

3.3.4. *Yearning for tailored advice*

The advice provided by public health organisations and health professionals was perceived as generalised and did not account for the complexities of the participants' individual context. Participants yearned for their clinicians to consider their disease, medications, and overall health when providing advice (B8). Participants felt that personalised advice would make them feel more 'assured.' Furthermore, participants felt discontented when they were told to get the COVID-19 vaccination without having their concerns addressed. Some participants felt that they should have asked more about the potential risks instead of simply following the advice of their doctors.

3.4. *Desperate for freedom and relief*

Navigating through vaccine information was challenging and people with AIIRD were desperate to be free from the stress and anxiety of decision-making.

3.4.1. *Pressure to vaccinate*

Many external pressures to get vaccinated were encountered by participants, with some participants feeling that 'there was no choice' (70 s, RA). Participants felt they were 'getting bombarded' (30 s, scleroderma), with messages from the media and government to get vaccinated, or else they would face major consequences, such as losing their liberties in the community (C1). Participants felt that 'there was no room for discussion' (50 s, RA/secondary Sjogren's) with doctors, and that no alternatives to the COVID-19 vaccination were offered. Participants wished to have more time and freedom to assess their individual situation and make their own decision, however, one participant summarised 'it's just too hard not to be vaccinated' (50 s, RA/secondary Sjogren's).

3.4.2. *Information overload*

The sheer amount of new and changing information made participants feel overwhelmed. They struggled to simultaneously grasp the latest information, while also navigating the facts and misinformation. Participants wanted to understand the risks and benefits for their own situation but found that information from health authorities and the media were not easily interpretable by the layperson (C3). Being constantly confronted with COVID-19 vaccination information made participants feel fatigued and frustrated (C4). Some participants got vaccinated to move on from the stress of processing the information that confronted them.

3.4.3. *Exasperated by unhelpful negativity*

Constant reminders by the media, public health authorities, and health professionals that people with AIIRD were at substantial risk from COVID-19 fuelled the frustrations of participants (C5). Participants felt they were already aware of their susceptibility, so these messages contributed to their distress, and were unhelpful. Discussions with doctors that were 'doom and gloom' and being told that they 'either get it [the vaccine] or [I] die' made participants lose 'confidence to open up' and instead, want to 'shut down the conversation' (50 s, RA/secondary Sjogren's).

3.4.4. *Seeking a path to normality*

The COVID-19 vaccination gave hope to participants in returning to normality. Some participants got vaccinated so that they could be free to engage in the community without being restricted by government mandates (C8). Getting vaccinated also gave participants the confidence to socialise and lessen their perception of vulnerability (C7). Although the feeling of vulnerability was not completely negated, participants became accepting of their risk with COVID-19 and realised they needed to move on to have a fulfilling life.

3.5. *Deterred by scepticism*

Scepticism towards various aspects of the COVID-19 pandemic and vaccine deterred uptake and reduced confidence.

3.5.1. *Distrust in scientific evidence*

Some participants did not believe there was enough evidence supporting the safety and efficacy of the COVID-19 vaccination (D2). The distrust was reinforced by exposure to conflicting information and frequent changes in recommendations. The quick development of the vaccine raised concerns about long-term safety (D1). Some felt that data, particularly in relation to adverse effects, was being withheld and that the portrayal of a safe and effective vaccine is biased and untrue.

3.5.2. *Suspicion of underlying agenda*

Scepticism regarding stakeholders promoting the COVID-19 vaccination was expressed by some participants who were wary about whether the true intent was to protect people from COVID-19. The extensive promotion of the vaccine made participants question whether there was an underlying agenda, particularly whether there were financial gains from the government, pharmaceutical companies, doctors, and/or others who promoted the vaccine. Suspicions were also raised when they felt that there was no room for discussion and the only choice offered to them was to get vaccinated (D3).

3.5.3. *Denial of danger*

Some participants perceived their risk of getting severely ill from COVID-19 as negligible and therefore believe that COVID-19 vaccinations are unnecessary (D5). Comparisons were drawn between COVID-19 and influenza by some who felt the severity of COVID-19 was exaggerated. Some believed that they were protected by a higher power and had faith in 'leaving everything to God' (60 s, RA/ connective tissue disease). As such, they did not see the need to have the COVID vaccine, with some feeling that getting vaccinated did not align with their religious beliefs (D6).

4. Discussion and Conclusion

4.1. *Discussion*

A perception of increased susceptibility to COVID-19 and a desire to return to normality motivated people with AIIRD to be proactive with COVID-19 vaccine decision-making. Receiving individualised advice from trusted doctors, friends, family, and hearing firsthand experiences from people with similar conditions promoted confidence in these decisions. A lack of tailored advice, distrust towards authorities, and having to handle negativity and pressure whilst navigating through vaccine information made the decision-making process challenging and fostered hesitancy.

Vaccine hesitancy is a complex phenomenon with interplay between various individual and contextual factors [29]. Vaccination is particularly important in people with AIIRD who have an increased risk of COVID-19 morbidity, yet there has been significant uncertainty with COVID-19 vaccination within this population [20–24]. Our findings related well with several elements of the 5 C's model: confidence, complacency, and calculation. We found participants were not confident about COVID-19 vaccine safety and had concerns about potential adverse interactions with their disease and medications, a finding also reported in survey-based studies [20, 21, 36, 37]. They were aware of, and not complacent about, their increased risk to COVID-19 to vaccinate, consistent with findings by Felten et al. [38]. Our findings also demonstrated that people with AIIRD were engaged with risk calculation and information searching. A novel insight we identified was that the notion of 'taking a risk', which resulted in disruption of the fine balance of disease control, turned concerns regarding risks into remorse and regret and created hesitancy towards future COVID-19 vaccinations. Healthcare providers should carefully counsel people with AIIRD regarding the risks of adverse effects, discuss the approaches to managing flares, and reinforce the benefits of vaccination to prevent remorse and future hesitancy if an adverse effect does occur.

On the other hand, our findings did not correlate with constraints and collective responsibility. In the context of the COVID-19 pandemic, there was extensive promotion and efforts to facilitate vaccination in the community and hence barriers and constraints to the COVID-19 vaccination were less apparent. There was a greater focus on the individual, rather than attaining herd immunity, amongst our cohort which may suggest people with AIIRD considered themselves vulnerable and needing protection from the community.

Awareness of their disease complexity led to a desire for individualised information from various trusted sources and first-hand accounts to help facilitate decision-making. Receiving generalised advice from healthcare providers without acknowledgment of concerns was considered unhelpful and created dissatisfaction. Hearing the negative experiences of family and friends is a barrier to influenza vaccine uptake [26] and is consistent with our findings. Our study expands upon this by identifying friends and family as information sources who can help clarify and discuss COVID-19 vaccine information in a relevant and relatable manner. These findings show that people with AIIRD are seeking to understand their own risks and benefits of COVID-19 vaccination to guide their decision-making. Interventions to improve the decision-making experience should focus on assisting with the identification of relevant vaccine information. At the clinician level, involving close friends, family and caretakers with vaccine discussions, particularly those with similar conditions and positive vaccination experiences, may help with identifying and handling concerns and providing reassurance.

Our study also highlighted the challenging experience of COVID-19 vaccination decision-making for people with AIIRD. This challenging experience stems from difficulties gaining sufficient information and confidence in decision-making whilst handling fears and pressures. Having to constantly keep up with changing information and navigate misinformation made participants feel overwhelmed, fatigued, and frustrated. These feelings were compounded by being confronted by external pressures and bleak messages which added distress and discouraged participants from engaging with discussions about the vaccine. Our findings suggests that a didactic approach emphasising the negative consequences of not vaccinating is ineffective and can hinder reception of advice. We recommend for clinician to utilise techniques from motivation interviewing when discussing COVID-19 vaccines with individuals with AIIRD [39]. This involves a collaborative approach in listening to concerns, understanding another's position and identifying information needs free from judgment.

A strength of this study was the diversity in ethnicity, age, and AIIRD, improving the transferability of these results. However, it is a single-centre study and there were difficulties recruiting people who were non-English speaking, male and unvaccinated. Uptake of COVID-19 and influenza vaccinations may be lower amongst females [40,41]. Perceptions regarding vaccination may differ between the genders such as females having greater concerns regarding vaccine safety whereas men have lower perception of dangers of COVID-19 [41]. The gender imbalance in our study may skew the results to reflect the perspectives of females more than males, and potentially limit the transferability of these results across both genders. Similarly, there may be bias from under-representation of the non-English speaking population where there may be different experiences compared to those who are English speaking based on general population studies [42]. One possible reason for the difficult recruitment could be the feeling of stigma from expressing views that were considered ‘anti-vax’. Furthermore, after the first few weeks of recruitment, 95% of the general population had already received at least one vaccination and hence limited the recruitment pool for unvaccinated individuals [43]. Recruitment occurred over a dynamic period of the COVID-19 pandemic and there may have been changing perspectives and experiences during this period that were not explicitly explored in our study. There was a single data coder which may limit confirmability of the results as the understanding of the concepts identified and their properties may be restricted from analysis by a single coder. However, multiple investigators including a consumer research partner discussed the preliminary coding framework and analysis on multiple occasions to triangulate findings. Preliminary themes and subthemes were also sent back to participants for member checking to improve the confirmability of the results.

Vaccinations remain an important component of global and public health. The results of this study can guide clinicians in supporting vaccine decision-making in people with AIIRD who are more vulnerable to infections. Exploring whether perspectives and experiences towards vaccination have changed after the COVID-19 pandemic may be an interesting area of future research. It may also be useful to triangulate the views of people with AIIRD with their caretakers and doctors to identify common and opposing perspectives.

4.2. Conclusion

The perspectives of people with AIIRD towards the COVID-19 vaccination were shaped by a sense of vulnerability from immunosuppression and concern of disease flares. People sought an individualised assessment from trusted doctors and companions to help facilitate vaccine decision-making. However, struggling to deal with information overload, external pressures, and confronting fear, negativity and scepticism, made this a challenging experience. To improve motivation and confidence in decision-making there should be a focus on providing tailored information, communicating in a balanced, non-judgmental manner, and avoiding unnecessary pressure.

4.3. Practical implications

It is important for clinicians to recognise the difficulties and frustrations that people with AIIRD faced during the pandemic. Didactic approaches highlighting the negative consequences of not vaccinating should be avoided and a collaborative approach that addresses specific concerns. It may be helpful to address and prepare people with AIIRD for the adverse effects of vaccination to prevent subsequent regret and hesitancy if they do arise. Allowing hesitant people time to contemplate about vaccination and revisiting the topic later on can reduce pressure with decision-making and improve engagement. It may also be useful for clinicians to involve selected family and friends in sharing positive experiences with patients and help facilitate ongoing discussion about vaccination beyond the healthcare visit.

CRediT authorship contribution statement

Frade Stephanie: Writing – review & editing, Supervision, Project administration, Methodology, Investigation, Formal analysis, Data curation. **El-Haddad Carlos:** Writing – review & editing, Supervision, Methodology, Investigation, Formal analysis, Conceptualization. **Faasse Kate:** Writing – review & editing, Supervision, Methodology. **Brady Bernadette:** Writing – review & editing, Supervision, Methodology. **Kelly Ayano:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Peng David:** Writing – original draft, Methodology, Investigation, Formal analysis, Data curation.

Declaration of Competing Interest

There are no conflicts of interest to report from the authors.

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Conflicts of interest and sources of funding

This project is supported by the University of New South Wales, Faculty of Health and Medicine, School of Clinical Medicine, South-Western Sydney Campus. The funding body had no role in the design of the study; in the collection, analysis, or interpretation of data; or in writing the manuscript. There are no conflicts of interest to report.

Appendix A. Standards for Reporting Qualitative Research Checklist

No.	Topic	Item	Manuscript page no.
Title and abstract			
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	2
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4–5
S4	Purpose or research question	Purpose of the study and specific objectives or questions	5
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	5
S6	Researcher characteristics and reflexivity	Researchers’ characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers’ characteristics and the research questions, approach, methods, results, or transferability	7

(*continued on next page*)

(*continued*)

S7	Context	Setting/site and salient contextual factors	6–7
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation)	6–8
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5–6
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings)	5–8
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7–8
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	8, 26–27
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization / deidentification of excerpts	7–8
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach	5–8
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation)	7–8
Results/Findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8–14
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	8–14, 28–32
Discussion			
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	14–18
S19	Limitations	Trustworthiness and limitations of findings	17
Other			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	1
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	1

Appendix B. Semi-structured Interview Guide

Interview topic guide

1. Introduction

a. Could you describe in just a few words, your experience of living with COVID?
b. Looking back over the last two years during the pandemic, what would have helped you the most to live with (participant’s rheumatic condition)?

2. Information regarding vaccination

a. In terms of information about the COVID-19 vaccination, what is the best source of information for you? Why is this? Is there any other information you need? (includes trust and confidence in news, policy makers, social media and family/friends)
b. Did you discuss your vaccinations with your specialist or GP? How did you find these discussions?

3. Decision, experience and outcomes regarding immunisation

a. How do you feel about getting the COVID-19 vaccination? What makes you feel this way?
b. How has having (participant’s condition) affected your decision about getting the COVID vaccination? (Can also explore perceptions around vaccinations on reproductive health/impact on family and children)
c. Can you list the benefits of getting the COVID-19 vaccination for you?
d. Do you have any concerns about getting the vaccination?
e. Thinking about the good and worrying things about the vaccine, what has tipped your decision to have the vaccination?
f. For vaccinated participants: Could you describe your experience getting the vaccination? How did your experience compare with what you expected?

4. Other barriers to accessing vaccination

a. Was there anything that made getting the vaccination easier or more difficult?
b. Can you talk about the process of organising to get the vaccination? What was your experience like? (Including barriers related to language/ cultural differences, availability, affordability, accessibility, time) I would now like to move on and discuss your medications you take for your (participant’s condition)

5. Information about medication use and safety

a. Have you received any information about your medications in relation to COVID? Where did you get this information? How does this make you feel?
b. Do you feel you need more information about your medications in relation to COVID? What would you like to know?

6. Decisions, experiences and outcomes of medication use

a. How have you found taking your medications for (participant's condition) during the pandemic?
b. Have you made any changes to your medications? Why? What has influenced you the most?
c. Have your feelings about your medications changed during the pandemic? Why?
d. How do you feel about your risk of getting COVID-19? Why? Does your condition or medications influence this?

7. Other barriers to taking medications

a. Have you had any other difficulties in continuing with your medications during the pandemic? What could be done to help you more? (Include any language or cultural barriers, cost, accessibility, availability)

8. Do you have anything else you would like to share about the COVID-19 vaccination or your medications?

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