

ORIGINAL ARTICLES

Impact of COVID-19 on disease (self) management and well-being in people with Rheumatic or Musculoskeletal diseases across four European countries: a mixed methods study

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ABSTRACT

Background: Qualitative data on how the COVID-19 pandemic has affected the lives of people with rheumatic and musculoskeletal diseases (RMDs) in different European countries are lacking.

Objectives: To describe the impact of the first two waves of the COVID-19 pandemic on people with inflammatory RMDs concerning (self)management of their disease, interaction with the health care team, emotional well-being and overall health.

Methods: A mixed-methods study of adults (>18 years) with RMDs on immunosuppression from Cyprus, England, Greece, and Portugal took part on online focus groups (FG) after the first wave (July-August, 2020). The data was transcribed verbatim and thematically analyzed. Informed by the qualitative findings, a follow-up survey was developed for the same participants after the second wave, allowing to compare the perceived impact.

Results: Twenty-four patients (6 from each country; 21 women; 33-74 years range) participated. Three key themes were identified (with 3-7 subthemes each), focusing on the impact of COVID-19 on the: (i) individual, (ii) health settings, and (iii) work and community. Overall, qualitative results were similar across countries. The follow-up survey during the second wave highlighted a worsening of psychosocial aspects, e.g. sleep problems, stress, and isolation.

Conclusions: People with RMDs felt vulnerable and anxious, specifically about how to cope with isolation and difficulties in communicating with healthcare providers. The second wave had a more significant impact on patients. Healthcare providers and policymakers need to consider measures to ameliorate the longer-term impact that many may still face.

Keywords: COVID-19; Health Care delivery; mixed methods; Musculoskeletal diseases; Rheumatic diseases; Self-management.

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KEY MESSAGES

- The COVID-19 pandemic had a significant impact on people with rheumatic and musculoskeletal diseases (RMDs), affecting their disease management, interaction with healthcare professionals, emotional well-being, and overall health.
- The impact of the pandemic on patients' lives was qualitatively similar across the four European countries studied. These results suggest that a common approach may be suitable to support and address the challenges faced by people with RMDs during the pandemic, and in the longer term.
- The mixed-methods approach provided a comprehensive understanding of the impact of the pandemic on people with RMDs. This research method can be useful informing the development of tailored interventions and support for people with RMDs during future health crises.

INTRODUCTION

The COVID-19 pandemic in 2020 has created unprecedented challenges for people worldwide, with significant impacts on public health and the global economy. The number of lives lost was devastating, with over 6.8 million deaths due to COVID and an excess mortality of around 18 million by the end of 2021¹. Three years on, much has been clarified about the risks of developing this viral infection and the relevant preventive measures. Healthcare systems are still adjusting to this new crisis, both in the context of the current but also future pandemics. Disease management, which involves comprehensive and coordinated interventions and communication for specific groups of patients, encouraging self-management, to prevent complications, enhance overall health and quality of life while minimizing the cost of care² was disturbed.

Among the most affected, were people with compromised immune systems, including those with inflammatory rheumatic and musculoskeletal diseases (RMDs)³⁻⁶. RMDs encompass a wide range of conditions that affect the joints, bones, muscles, and other organs. People with inflammatory RMDs rely on immunosuppressive therapies to manage their symptoms and maintain their physical and mental health. However, the prescribed therapies can leave patients more vulnerable to infections, including COVID-19⁵⁻⁸ and prone to worse clinical outcomes^{3-6,9,10}. In addition, initially there was hesitancy because of concerns around COVID-19 vaccines safety in patients using immunosuppressive therapy^{11,12}. The pandemic has had significant impacts on the management of RMDs¹³. Many clinics and healthcare facilities have had to limit or suspend in-person appointments and procedures, contributing to sub-optimal and impersonal management and care for the patients¹⁴⁻¹⁶. This situation has led to delays in diagnosis and treatment, which come with long-term consequences^{13,17}. In parallel, the pandemic has had a significant impact on the mental health of people with RMDs^{15,18}. Some large surveys indicated that COVID-19 related-health care interruption had a significant impact on the physical, psychological, and social relationships of people with inflammatory RMDs^{19,20}. These people were more socially isolated during the pandemic than healthy individuals, which also led to worse disease activity and quality of care outcomes^{20,21}.

Considering these disruptive effects of the COVID-19 pandemic on healthcare systems and patients' lives, and the strong biomedical focus of the previous studies on this topic, with a lack of qualitative data, this study aimed to investigate the impact of the COVID-19 pandemic on disease (self) management, interaction

with healthcare providers, emotional well-being, and overall health in people with inflammatory RMDs, during the first two waves.

METHODS

Study design

This was a mixed methods study²² where the qualitative phase informed the subsequent quantitative phase, with two patient-research partners (PRPs) diagnosed with inflammatory RMDs (SM, RH) being a core part of the multidisciplinary research team (four clinical/academic rheumatologists, four nurses, one pharmacist, one medical sociologist) who have and contributed to all project phases.

Participants

The qualitative study was carried out during the first wave of the COVID-19 pandemic (July and August, 2020), while the survey was distributed during the second wave (February and March, 2021), to the same participants. The inclusion criteria consisted of adult people (≥ 18 years) living in four European countries (UK, Portugal, Greece, Cyprus), diagnosed with an inflammatory RMD (e.g. rheumatoid arthritis (RA), psoriatic arthritis (PSA), systemic lupus erythematosus (SLE), systemic sclerosis (SSC), other), with a disease duration ≥ 1 year, and receiving immunosuppressive therapy (glucocorticoids, conventional synthetic or biological or targeted synthetic disease modifiable anti-rheumatic drugs, DMARDs). Potential participants were invited through a variety of methods to volunteer, namely (i) a purposive selection²³, (ii) outreach through social media, and (iii) national patient associations, to take part in one interview and/or focus groups (FG). Participants indicated interest in participating via online survey platform, specific to each country. An Information Sheet about the study in the respective main language was provided. A researcher then contacted the volunteers by phone, to assess the inclusion criteria, answer possible questions about the study, and establish the preferred timing and methods to hold the FG (preferential) or individual interview. All participants signed a consent form before the FG or interview. If agreed, demographic (gender, age, educational level and professional status) and clinical data (disease, disease duration, DMARD treatment) were collected for sample characterization. Ethics approval was obtained by the Ethics Committee of the Health Sciences Research Unit: Nursing (UICISA:E) of the Nursing School of Coimbra (#690/06-2020).

Qualitative approach

For the qualitative phase, the team applied an inductive

approach and a thematic data analysis²⁴. A semi-structured interview/FG guide was developed by the research team, including 12 questions (Appendix 1). A pilot study with 3 participants was carried out in Portugal, which helped to refine the interview guide, to clarify the data collection process, and to confirm that the findings matched the aim and objectives of the study. The process and its findings were shared across the country teams, to ensure the adoption of similar procedures²⁵.

The interviews were conducted in the national language, guided by a local healthcare professional, between July and August 2020. Different methods were used for the virtual meetings, such as ZOOM®, Whataspp®, or Messenger® calls, always with video interaction (i.e. cameras on), although only the sound was recorded for transcribing. In the UK, the FG was conducted via a secure online platform. The FGs lasted an average of 77(±3) minutes. The information gathered was transcribed verbatim, anonymised, and translated into English by team members and a professional transcribing agency (in England), ready for data analysis by the team in Portugal.

Data analysis

The qualitative data analysis was assisted by a qualitative computer software programme, ATLAS.ti®. The five-step process for thematic analysis²⁶ was followed. The first step involved becoming familiar with the data by repeatedly reading and re-reading the transcripts.

Secondly, initial codes were generated, and then reviewed and refined in the third step to create themes. Fourthly, the team and the PRPs further examined and enhanced the themes to ensure they were coherent and meaningful. Finally, the findings were presented within an analytical framework (Figure 1) with its 3 key themes and subthemes. We considered both the social-ecological approach²⁷ and the Walsh’s Family Resilience Process²⁸ helpful to contextualize and strengthen the findings. This method allowed to identify patterns and commonalities across the data, and to generate a rich and detailed understanding of the phenomenon²⁹.

Data validation

The consistency of the data analysis was enhanced by two researchers (CC, AM) who discussed and carried out the qualitative analysis, at each stage and its findings were presented to experienced qualitative researchers in the core team (EN, HL, RF)²⁶. In this way, the researchers ensured that the identified themes were an accurate reflection of the data. Regular research team meetings were completed to clarify and reach a consensus on all the final themes and subthemes based on the data collected.

The inclusion of deviant instances ensured that the analysis was not biased towards only the most common experiences, but also captured the diversity of events of participants across the four countries. Furthermore, after the pilot study, the FG guide was adapted, and



Figure 1. Summary of the lived experiences of the first wave of Covid-19 pandemic by people with RMDs in four European countries

some questions were clarified, using layman's language and everyday wording, to improve the content validity²⁶, and ensure a better understanding of the questions by participants. Overall, these data validation strategies enhanced the rigour and trustworthiness of the qualitative data analysis and strengthened the confidence in the findings.

Quantitative approach

The quantitative part of the study aimed to further understand the impact of the COVID-19 pandemic upon people with RMDs by quantifying their experiences and perceptions and addressing the themes discussed in the qualitative phase. A survey was developed by the team, informed by the key themes and subthemes identified in the qualitative phase to assess whether problems identified during the first wave had improved or not, e.g. "do you feel less or more stressed?"; "do you feel less or more fearful to be infected by the coronavirus?"

The survey was distributed online during the second pandemic wave, between February and March 2021, and the same participants were invited as for the qualitative phase. The questions related to socio-demographics, disease management, access to healthcare, emotional well-being, and the impact of the pandemic on people's daily life. The statement items could be rated on a five-point Likert scale (much less to much more) where the middle position was labeled 'neutral'. The survey also included open-ended questions to allow participants to expand on their experiences and provide additional insights into the impact of the pandemic.

The survey results were analyzed using descriptive statistical analysis to summarize and present the participants' experiences and perceptions quantitatively. The data were analysed using SPSS® v.28.0 software.

RESULTS

Participants

During the recruitment process, a total of 52 patients contacted the team, with an interest in taking part in the study. 24 participants were selected purposively^{23,30}, with an equal number six participants from each of the four European countries (two focus groups of 3 participants in each, except in the UK, with 1 individual interview). The remaining 28 potential participants were contacted to thank for their willingness to participate and were informed about the reasons for not being selected (including failure to meet the inclusion criteria). Most participants were female (87.5%), and the average age was 48 years, range 33 to 74 years old. The overall educational level was high, no participants had less than secondary school education, and half

of the sample indicated an active professional status indicating they were in work employment. The most common diagnoses were RA (n=7), SLE (n=3) and Juvenile Idiopathic Arthritis (n=3), and more than two-thirds of patients were treated with bDMARDs, as shown in Table I.

Qualitative results

Three key themes were identified from the qualitative data, with the overall representation of the phenomenon under study depicted in Figure 1. Additional subthemes and individual testimonies from participants are presented in Table II.

Individual Person

Initially, participants were astonished, followed by "fear for myself and family" to become infected by the virus and not having immunity to be safe from the disease and death. Most entered "home isolation/lack of freedom", with a range of consequences, such as "missing physical/human contact" and affections that did lead to "psychological difficulties" and have an impact on the well-being of each person. Different ways to cope with the isolation were embraced, such as creating weekly schedules to be kept busy all day, all week, doing yoga on the balcony, and reading a novel, among other "coping strategies". Some have taken the "opportunity to slow down" their lives and enjoy more time with family.

Health Settings

"(Un)clear information about the risks" and conflicting information about the risk of infection did not help and raised doubts about attending hospital outpatient appointments or not, uncertainty whether to interrupt ongoing medication, among others. Some patients missed clinical appointments and faced medication problems, such as a medication shortage (chloroquine). Persistent stress and interruption of usual healthy activities have been pointed out as causes of the "disease flare-up" and inability to engage in "self-management" of the long-term condition.

The remote clinic appointments were generally well received, due to convenience of time and comfort. However, concerns were also raised about difficulties in communication with healthcare professionals (e.g. clinicians and nurses) and unfamiliarity with the new technologies, and impossibility to carrying out the physical examination. Doubts were expressed about whether "telecare is friend or foe".

In addition, uncertainty was highlighted by participants towards the efficacy of the rapidly and new vaccine development at that time, with conflicting information creating both "hope and suspicion about vaccines".

TABLE I. Characteristics of the participants

		CY	GR	PT	UK	Total
Gender	Male	0	1	0	2	3 (13%)
	Female	6	5	6	4	21 (87%)
Age (years), mean (standard deviation) [range]		43 (9) [33-53]	47 (13) [35-69]	49 (9) [39-64]	56 (13) [36-74]	48 (11) [33-74]
Educational level	University	5	4	1	0	10 (42%)
	College/ Secondary/ High School	1	2	5	6	14 (58%)
Professional Status	Active	3	4	3	2	12 (50%)
	Unemployed	1	1	0	0	2 (8%)
	Retired	2	1	3	4	10 (42%)
Diagnosis	RA	--	2	2	3	7 (29%)
	SLE	3	--	--	--	3 (13%)
	JIA	--	2	1	--	3 (13%)
	Other*	3	2	3	3	11 (46%)
Years since diagnosis, mean (standard deviation); [range]		14 (5) [10-23]	21 (11) [3-36]	18 (6) [7-23]	23 (17) [9-52]	19 (11) [3-52]
Immunosuppressive therapy	glucocorticoids	4	3	1	0	8 (33%)
	csDMARDs	4	3	2	3	12 (50%)
	bDMARDs	3	4	6	4	17 (71%)

cs/b DMARDs – conventional synthetic or biological disease modifiable anti-rheumatic drugs; RA – Rheumatoid Arthritis; SLE – Systemic Lupus Erythematosus; JIA – Juvenile Idiopathic Arthritis. *Other diagnoses include Still’s disease, Psoriatic arthritis, Sarcoidosis, Spondyloarthritis, Polymyositis, Juvenile Rheumatoid Arthritis, Sjogren’s syndrome and Wegener’s granulomatosis. CY – Cyprus; GR – Greece; PT – Portugal; UK – United Kingdom

Work & Community

At the beginning of the pandemic patients reported how the 24-hour dominance of “mass media” was overwhelming and caused them “persistent stress”, with many reporting the need to stop watching TV. One finding highlighted the challenge faced by people with RMDs in disclosing their condition at work in the context of Covid-19 and its potential impact on their compromised immune system. This “lack of awareness by colleagues and fear of disclosure” of their long-term conditions resulted for some in lack of support and fear of discrimination at work.

Quantitative results

The survey comparing the experiences and perceptions between the first and second Covid-19 waves were responded to anonymously by all participants, and the results are summarized in Figure 2.

During the second wave participants experienced more sleep problems (Q10, 67%), fatigue (Q9; 54%, with no improvement reported here) and pain (Q8, 50%). Their emotional well-being deteriorated, with over 46% of participants reporting feeling more stressed (Q1), and 46% indicated sadness (Q3) and isolation (Q5, 46%). Financial worries were also a significant concern (Q7), with over 41% respondents worried

about their financial situation. Over 42% felt more fearful during the second wave (Q2). The items with less variation from the first to the second wave (see grey bars) related to perceived support from others, namely friends and colleagues (Q18; 75% neutrals), family (Q17; 67%) and from the rheumatology team (other than clinicians) (Q14, 63%).

DISCUSSION

The COVID-19 pandemic has had a significant impact on the disease (self) management and overall well-being of people with inflammatory RMDs^{3-7,31}. The disruption of healthcare service in this period has posed significant challenges, especially for people with long-term diseases. It is important to appreciate that the impact of the pandemic on people with RMDs goes beyond physical health concerns^{13,15,32,33} and includes social, psychological, and economic consequences. For example, due to the pandemic, people have had increased feelings of isolation, anxiety, and stress, which can exacerbate existing mental health conditions^{15,34,35}. The financial impact of the pandemic, such as job loss or reduced work hours, has also challenged the ability of people with RMDs to access healthcare and/or afford

TABLE II. The 3 key themes with additional sub themes

Key theme	Sub-themes	Quotes
1) Individual	Fear for myself and family	<p>“And I have a small child, and I am also afraid for him and my husband (...) and the panic sets in at home.” (PT)</p> <p>“To catch the virus and not have immunity to being able to defend me and, sincerely, is a fear to die.” (PT)</p> <p>“I was also very concerned about my husband who cared for patients who came over the virus.” (CY)</p> <p>“The only thing I was afraid of is that a member of my family may get sick and that I would not have been by his/her side even though I would have wanted to.” (CY)</p> <p>“I also have to do my blood tests every month and (...) I'm afraid to go in [hospital], I don't want to be near a hospital.” (UK)</p>
	Home isolation/lack of freedom	<p>“Freedom, I still haven't been able to fully recover freedom, no!” (PT)</p> <p>“Even today I did not leave my house with the feeling of freedom. I am very cautious; I still feel deprived of my freedom.” (CY)</p> <p>“I was isolated and had little contact with other people.” (CY)</p> <p>“I was staying home. Didn't go anywhere.” (GR)</p> <p>“You feel lonely.” (GR)</p>
	Missing physical/human contact	<p>“Missing physical/human contact.” (GR)</p> <p>“...furthermore, you lose physical contact. I like to see other people's face.” (GR)</p> <p>“What seemed trivial to us: a kiss, a hug, a caress on the face (...) we stopped doing that [social direct contact].” (PT)</p>
	Psychological difficulties	<p>“It was a stressful period for me.” (CY)</p> <p>“I struggled with my mental health. I've always struggled with anxiety.” (UK)</p> <p>“Maybe this is the reason the flare-ups occurred as a result of the persistent stress.” (CY)</p>
	Coping strategies	<p>“I created schedules (...) to be occupied all day.” (PT)</p> <p>“I did exercise on the balcony or yoga.” (PT)</p> <p>“I had poetry, reading, writing. I prepared two books: the 5th edition of a collection with Greek poems and a book with theatrical plays. This way, I pushed back all this massive information that was provided by the media.” (GR)</p> <p>“Occupy the days with other things: watching TV series, watching movies, learning to make cakes, cooking (...)” (PT)</p>
	Opportunity to slow-down	<p>“Positive aspects were staying at home and having time with my children.” (CY)</p> <p>“(...) it was brilliant, you know, to be able to do things together, go out in the garden do a bit of gardening and then we'd sit and have a drink (...) was great.” (UK)</p> <p>“I always worked hard as I had a second job and I always had other priorities or obligations. When the lockdown was imposed, I had the opportunity to spend some quality time with my child.” (CY)</p> <p>“I got the time to 'slow down' and to manage better my work and my studies. I used to spend 3-4 hours in commuting...so, during Covid-19, I had more spare time and I could relax...” (GR)</p>
	Time to family	<p>“I had never spent enough time with my child because I always worked hard as I had a second job and I always had other priorities or obligations.” (CY)</p> <p>“The lockdown was beneficial for my family. It was a nice experience because we stayed at home with our 5 children.” (CY)</p> <p>“We had a great time without any tensions, and we came closer as a family.” (CY)</p> <p>“I think for all that, I think it's like I said family time, the fact that, you know, my partner would never have time off like this to spend with my daughter, which is amazing, and for the three of us to spend time together.” (UK)</p>
	(Un)clear information about risks	<p>“There was a time when I was a little misinformed [about continuing or not the medication] oh how can I be [stay] safe.” (UK)</p> <p>“I feel that mainly because of my condition (...) there was no information at the beginning on any website about Covid.” (UK)</p> <p>“I felt like it was kind of sweeping general statements [under the carpet] at the beginning and I felt like, well one moment I felt like I was getting information that said ‘oh actually you're not that at risk’ and then the next minute I was getting information that made me feel really at risk.” (UK)</p>
	Medications: shortages and fears about risks	<p>“There was big stress about medications. Especially for hydroxychloroquine, when everybody was looking to buy some of that. Sometimes, I couldn't find my medications” (GR)</p> <p>“I felt though insecure that I did not already have the next packet [of medication] in time.” (CY)</p>
	2) Health settings	

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TABLE II. Continuation

Key theme	Sub-themes	Quotes
2) Health settings	Flaring and self-managing	<p>"Every day, at 1pm, I went out for a walk and exercise." (GR)</p> <p>"... I could better manage my time and to think about future plans." (GR)</p> <p>"All my doctors' appointments were cancelled. I had to call his [doctor's] office via phone in order to ask questions as needed." (CY)</p> <p>"I took full responsibility for my time." (UK)</p>
	Telecare: Friend or foe?	<p>"What scares me is that... I like technology, but there is some kind of estrangement/alienation." (GR)</p> <p>"I like a lot the remote consultations. I think there are a lot of positive aspects (...)" (PT)</p> <p>"(...) because if [consultation] becomes remote it's a very different experience than face-to-face. I'm not brilliant on the telephone. I've realised I much prefer Facetime and Zoom conversations to telephone calls and I think (...) people are still very reluctant to go [to the hospital outpatient clinic]" (UK)</p>
	Hope vs suspicion about vaccines	<p>"I have some concerns about the vaccine... about the safety of the vaccine." (GR)</p> <p>"So I'm less pessimistic that, you know, this [vaccination] is not going to be an easy thing [intervention]." (UK)</p> <p>"I believe a vaccine will be released in the next six months and life will continue." (CY)</p> <p>"I hear that they [government] will ask vulnerable groups to have the vaccine first (...) Why is that? we will be again the innocent victims." (GR)</p>
3) Work and community	Persistent stress: Mass media	<p>"The media terrified me a lot (...). I stopped watching the news." (CY);</p> <p>"I stopped switching on the TV to see the news, I felt that it [the news] made me worse." (PT)</p> <p>"I was overwhelmed with anxiety when I watched world news through the media." (CY)</p> <p>"I stopped watching the news [to reduce anxiety/panicking]" (CY)</p>
	Lack of awareness and disclosure of RMD	<p>"There was no information at the beginning at all on any websites to do with Covid and the condition that I have." (UK)</p> <p>"I do not want to notify my employers [about my RMD] is because I do not want to feel helpless. I want to live a normal life." (CY)</p> <p>"...because we [patients] look quite well and normal and (...) a lot of people don't understand it [our RMD]" (UK)</p>

CY – Cyprus; GR – Greece; PT – Portugal; UK – United Kingdom

their medications^{36,37}.

The qualitative thematic analysis of this study revealed a range of emotions and experiences related to the COVID-19 pandemic. One of the most prevalent themes was fear of becoming infected with the coronavirus and infecting loved ones, as well as concern about the potential consequences of COVID infection, such as hospitalization or death. This worry was compounded by the uncertainty and unpredictability of the infection, with patients expressing concern about the lack of clear information and guidance from healthcare professionals and government agencies.

Communication is another important theme that emerged from this study. Many expressed frustration and concern about the barriers to contact healthcare professionals during the pandemic, which made it difficult for them to manage their pre-existing health conditions. On the other hand, the importance of clear and prompt communication with healthcare professionals was also highlighted, with some noting that regular check-ins and phone consultations helped them feel supported and better able to manage their RMD conditions.

The pandemic did impact on people's emotional well-being. Many expressed feelings of loneliness and isolation, as well as frustration and disappointment with the lack of personal contact and physical touch from loved ones. On the other hand, some noted the positive impact of the pandemic on their relationships with family and friends, as it allowed them to spend more quality time with them. The importance of family support was highlighted. Many individuals relied on the emotional and practical support provided by their loved ones. Additional coping strategies that participants talked about were attending to hobbies and turning to religion for support to deal with their stress during this time. The subthemes were similar across countries, except for the impact of spirituality that applied specifically to Portuguese patients, which highlights an important cultural dimension among participants. Similar results were found in other studies where loneliness, isolation and lack of personal contact, were identified by different authors³⁸⁻⁴¹.

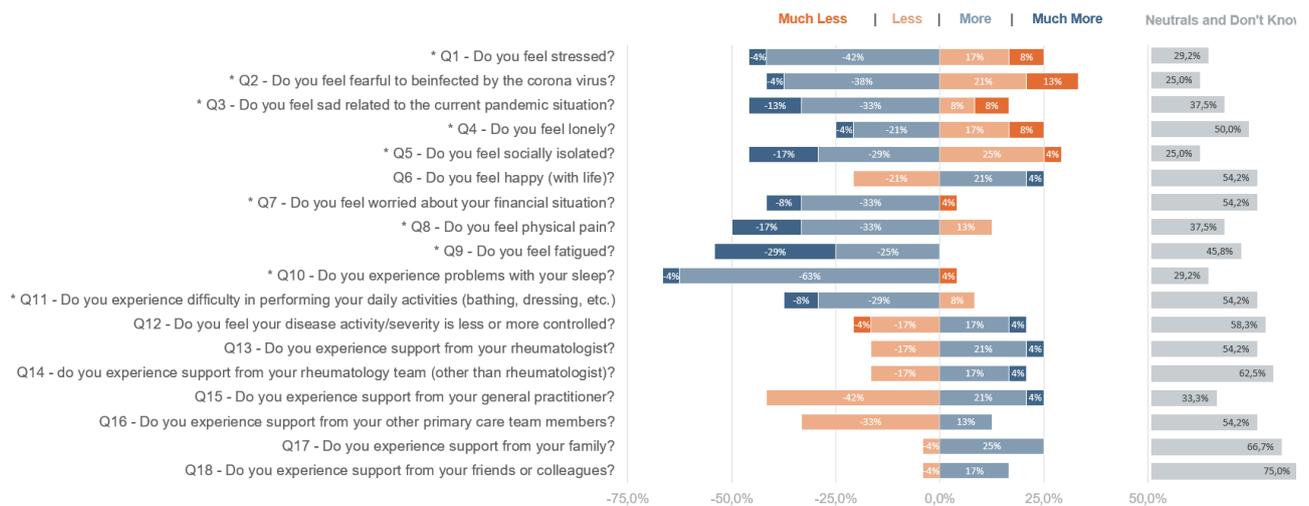


Figure 2. Disease management and well-being of people with RMDs (n=24) from four European Countries comparing the first and second waves of the Covid -19 pandemic

* Negative values represent decrease in the Disease management and well-being, while positive values represent improvement in those statements. Colors represent the response to the question as formulated. Some questions with * (eg: 1, 2, 3, 4, 5, 7, 8, 9, 10, 11) were formulated as negative statements, meaning that answers “more” and “much more” represents a deterioration in the disease management and well-being.

Furthermore, the pandemic affected their daily lives. Some patients discussed the adjustments they had to make to their regular routines to stay safe and avoid contracting the virus. These included wearing masks, using hand sanitiser, avoiding crowded places, and working and socialising remotely. Patients expressed concerns about being unable to adhere to their medical treatments, due to medication shortages and difficulty obtaining prescriptions.

Overall, the study’s results emphasize both the negative and positive impacts of the pandemic on people with RMDs. In the quantitative survey, most reported feeling less or much less supported by their primary care team members and general practitioner, with only a small percentage reporting feeling more or much more supported. This suggests that access to healthcare and support for people with RMDs may have worsened during the pandemic. Similarly, many respondents experienced more difficulty with their sleep and felt more fatigued, while others felt more physical pain. Many reported they felt much happier with their life and less socially isolated, suggesting patients may have found ways to adapt and cope with the pandemic.

The need for ongoing support and care for people with RMDs during the pandemic by those around them and the healthcare team, with dedicated strategies to address the negative impact on emotional well-being and quality of life, requires attention. Many participants experienced a lack of support from healthcare professionals, which was identified as a challenge in the qualitative phase. General practitioners were of additional support in this phase, providing phone call

clarifications. In addition, participants reported stress, fear of a situation, and social isolation, which were also identified as themes in the first phase. In the dimension of healthcare delivery, many participants faced medication supply problems and difficulties accessing healthcare. Remote services were generally well received, and concerns were expressed about communication between patients and healthcare professionals along with the new inclusion of technology. In work and community settings, many seems to struggle with disclosing their disease and faced a lack of awareness and support from their colleagues. The survey results confirmed the keys and subthemes in the qualitative phase about the impact of the COVID-19 pandemic on people with RMDs.

Our study findings highlighted the importance of offering appropriate support and resources to address the various challenges patients had to face. These may include tailored interventions to support disease management, improved access to telehealth services, and support for mental health and financial well-being. By addressing the unique needs of people with RMDs during the pandemic, healthcare professionals can work closely with patients towards mitigating the negative impact of the pandemic, supporting them in their self-management and overall well-being.

STRENGTHS AND LIMITATIONS OF THE STUDY

This mixed-methods study has provided a comprehensive understanding of the broad impact of the COVID-19

pandemic on people with RMDs. There are, however, important study limitations. The purposive sample consisted of people who had accessed higher education, which may influence their perception of the impact of COVID-19 in their lives. Disease activity was not assessed, which is likely to affect patient perceptions and experiences, namely the emotional well-being. Due to the small sample, the findings are not generalizable. Still, they provide an indication of first-hand experiences in people with rheumatic diseases across four European countries and how they coped (or not) with the challenges brought on by the COVID-19 pandemic. Finally, the study did not explore the experiences of healthcare professionals, who played a crucial role in the care of patients with RMDs during the pandemic. This was beyond the scope of the study.

CONCLUSION

This study highlighted the need for a comprehensive approach supporting patients with RMDs during a health crisis. The findings underscore the importance of clear communication between patients and healthcare professionals, social support where possible, and adaptability in navigating the challenges within the healthcare system of a pandemic. The study's results may have important implications for healthcare providers and policymakers, suggesting a need for tailored interventions and support for people with RMDs during an acute situation like a pandemic. These findings may inform the development of meaningful support bespoke to individual needs, during unfolding, beyond COVID.

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SUPPLEMENTARY MATERIALS

APPENDIX 1. Semi-structured interview/focus group guide

Topics addressed in the semi-structured interview

1. Can you please remember when you first heard about the COVID-19... what were your first thoughts or concerns?
 - a. Can you give me one example, please?
 - b. You have mentioned that you felt (afraid? Stressed out?), what do you mean specifically and why?
2. What were the most significant experiences for you during the first weeks?
3. How about your disease (IF not mentioned already!), how did you manage it?
 - a. Different questions to explore this deeper: pharmacological and non-pharmacological management (difficulties, solutions, etc...)
 - b. How did your life-style changed after all this?
4. Do you remember the first days after the lock-down (ASSUMING the person was in lock-down), what was the most important things for you to do first?
5. After all this time, how do you feel this pandemic may affected you until now and possible for the future?
6. How about your interaction with your family and carers? How did you manage it?
7. How do you see (your) life in the near future?
8. What were the most negative aspects of this experience?
9. Have you seen positive aspects in this experience? Which/Why?
10. What would you like to see changed in the future?
11. Overall, what was the most meaningful experience to you?
12. Do you want to add something not yet addressed in this interview?