

BMJ Open Exploring the physical, psychological and social well-being of people with rheumatoid arthritis during the coronavirus pandemic: a single-centre, longitudinal, qualitative interview study in the UK

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ABSTRACT

Objective Rheumatoid arthritis (RA) is an autoimmune, inflammatory, systemic condition that requires specific drug treatment to suppress disease activity and prevent joint deformity. To manage the ongoing symptoms of joint pain and fatigue patients are encouraged to engage in self-management activities. People with RA have an increased incidence of serious illness and mortality, with the potential to impact on quality of life. This study explored patients' experiences of living with RA on physical, psychological and social well-being as well as their ability to employ self-management skills during the coronavirus pandemic.

Design Qualitative, longitudinal (baseline, 16 September to 23 November 2020 and after 2–4 months, 11 January to the 17 January 2021), semistructured telephone interviews.

Setting A rheumatology service based in a community hospital.

Participants 15 adults with RA.

Main outcomes Data were analysed using interpretative phenomenological analysis.

Results Five themes were identified that related to impact on (1) fear: the dominant emotion, (2) social connections and work practices, (3) physical health, (4) identity and (5) self-management as a coping mechanism. The overriding emotion was one of fear, which remained high throughout both interviews. The negative impact on social well-being increased as the pandemic progressed. Conversely, physical health was not affected at either time point, although participants reported difficulty in interpreting whether physical symptoms were attributable to their RA or COVID-19. Recognition of increased vulnerability led to a reassessment of self-identity; however, respondents reported using previously learnt self-management techniques to cope in the context of the pandemic.

Conclusions The main impact was on emotional and social well-being. Levels of fear and vulnerability which affected self-identity remained high throughout the pandemic and the impact on social well-being increased over time. Physical health remained largely unaffected.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Use of longitudinal interviews to capture changes in patients' well-being and self-management.
- ⇒ Involving patient research partners in research design, developing and piloting the topic guides and analysing the data.
- ⇒ A more diverse sample of patients (younger and working) may have led to a wider range of experiences being explored.
- ⇒ Extending the duration of the longitudinal study to more than two data collection periods might have shown different findings.
- ⇒ By nature people who take part in qualitative research probably are different to those who decline

Self-management skills were used to maintain a sense of well-being.

INTRODUCTION

Patients with rheumatoid arthritis (RA) have an increased risk of serious illness, infection and death due to their auto immune condition, immunosuppressant medication and related comorbidities, such as heart disease.¹ All these factors make patients more susceptible to poorer outcomes from COVID-19. One of the aims in managing RA is to support patients to develop self-management skills to optimise physical, psychological and social function.²

People considered at greater risk of severe illness from COVID-19 due to their medical conditions and treatment such as immunosuppressant therapies were classified as being clinically extremely vulnerable and were required to shield.³ Shielding involved having to stay at home and avoid all face-to-face

contacts for 12 weeks, which was likely to have an effect on well-being.⁴ Shielding was introduced in England on 21 March 2020 and officially ended on 19 July 2021. At the outset of the pandemic, the British Society for Rheumatology developed risk stratification criteria to identify patients who are at the greatest risk of poor outcome from COVID-19 infection, based on a combination of age, medication and comorbidities.⁵

For patients not required to 'shield' the effect of the pandemic may still be considerable, in terms of not being able to attend for face-to-face rheumatology consultations or engage in normal self-management activities such as attending local leisure facilities which were closed during the lockdown.⁶

We aimed to explore the experience of patients with RA during the coronavirus pandemic in terms of the impact on physical, psychological and social health and the use of self-management strategies.

METHODS

The theoretical framework for the study was interpretative phenomenology. The aim of interpretative phenomenology is to understand what the person's experience is and then uncover the meaning of the experience for the individual. This approach enables the participants, in this case people with RA, to describe in depth their perceptions and experiences of managing their arthritis during the coronavirus pandemic.⁷ Interpretative phenomenology is particularly useful for understanding under-researched, or new phenomena,⁸ such as the area of focus of this study.

Participant selection

The reporting of this study is based on the Consolidated Criteria for Reporting Qualitative Health Research.⁹

Patients with RA were recruited from a rheumatology department in a community hospital. Potentially eligible patients were identified from a rheumatology clinical database. The idiographic focus (and similarities within the sample) was the lived experience of rheumatoid arthritis, but within that, we wanted to understand a range of perspectives. Purposive characteristics included age, gender, shielding and non-shielding status. To obtain a sample size of 15–20 patients and anticipating a response rate of approximately 40%, 40 patients were mailed an expression of interest (EOI) letter inviting them to participate. If a positive response was received, then a consent form and participant information sheet was posted or emailed depending on the participant's preference. Fifteen patients returned an EOI form and participated in the study. There is no definitive sample size for an interpretative phenomenological study but to embrace its idiographic commitment smaller concentrated samples are commonly used and the average sample size tends to be between 1 and 12 participants.^{10 11} Our larger sample size was informed by the concern that some participants may become unwell (with COVID-19 themselves) and

would not be available for the second interview. Thankfully our concerns were unfounded.

Data collection

Participants participated in two semistructured telephone interviews with the same interviewer (PC). Interviews were conducted at baseline (16 September to 23 November 2020) and at 2–4 months (11 to 27 January 2021). The interviewer was not known to the participants, was not working within rheumatology and was employed as a research manager.⁹ Field notes were made after the interview.⁹

The topic guides (see online supplemental file) were reviewed by members of the study group and two patient partners, then refined after two pilot interviews. Both topic guides focused on the impact on physical, psychological and social well-being and self-management. The second topic guide used the participants' previous narrative, to explore the impact on well-being of significant events during the pandemic, including the reintroduction of national restrictions in November 2021. Access to healthcare was also explored. The interviews were digitally recorded, transcribed verbatim and pseudonymised.

Data analysis

Interpretative phenomenological analysis was undertaken by two members of the research team. No software was used. Analysis was conducted by hand, and Microsoft word files were used to manage the data.⁹ Analysis was undertaken within participant before looking for patterns across participants. Each transcript was read repeatedly to ensure familiarisation with the data and to identify themes, which related to significant phrases from the interviews. Over the course of three research group meetings, emergent themes were noted, which informed the development of superordinate themes across the data set to provide an ongoing framework for the analysis. Connected themes were then clustered together. Transcripts were not returned to participants.⁹ The findings were shared with the two patient partners, so that their interpretation of the data could be included.

Patient and public involvement

Two patients with RA were involved in all stages of the research. This included the design of the study (interviews rather than focus groups), preparing public facing information (invitation letter, patient information sheet and consent form), informing the content and piloting of the topic guides and data analysis. Our public and patient information representatives, who are included as authors on this paper, were similar to our study population in terms of age and experience of living with RA.

RESULTS

Fifteen patients were recruited from the rheumatology department of a community hospital, of which 14 had RA and 1 patient had Adults Still's disease. Disease duration

was an average of 22±13 years (range 1.5–46 years). The sample included 9 women and 6 men, with ages ranging from 46 years to 79 years. The majority of participants were retired (n=10), with one currently out of work and the remaining employed (n=4). All participants were Caucasian, and 11 of the 15 participants were married. Six (40%) of the 15 participants had been advised to shield. The interviews lasted between 23 min and 60 min and data saturation occurred after the first 10 participants, in both interviews.⁸ Five further interviews were undertaken as we were concerned about the potential loss to follow-up in people who had a long-term condition.

Qualitative findings

Interpretative phenomenological analysis identified five themes, which is related to (1) fear: the dominant emotion, (2) social participation and work practices, (3) physical health, (4) identity and (5) self-management as a coping mechanism.

Fear: the dominant emotion

At the start of the pandemic, participants experienced feeling low and frightened, which led to helplessness and resentment at not being able to control the situation.

There were a couple of times during the lockdown period where I did feel low and on one occasion I did make myself a telephone appointment with one of my GP's (man aged 55 years, interview 1).

I'm not generally a nervous, frightened person but I think I was quite frightened by the unknown (woman aged 61 years, interview 1).

The thing that's jumped out at is the fact that in February we were living a normal life and then suddenly you can't and you learn from that that life isn't in our hands we don't control it, we've got no control over it (woman aged 78 years, interview 2).

I felt a little bit of resentment that despite my best efforts something might get me that was totally out of my control (man aged 55 years, interview 2).

In order to maintain a sense of control and well-being, some participants introduced their own method of shielding.

I did a kind of modified shielding in that I didn't completely isolate. I was very selective about where I went and that I think was a protective factor in terms of physical and psychological health (man aged 47 years, interview 1).

For two participants, the first lockdown had a positive effect on their emotional well-being.

And when everything started to shut down ironically I was much better (man, aged 71 years, interview 1).

The overwhelming emotional response was one of fear.

The fear of what might happen, you know where it was going, I think yes it was tough (woman, aged 61 years, interview 1).

Right from the very beginning I have been utterly paranoid about it. I knew that if I caught this COVID I would be dead, I would not survive it (man, aged 71 years, interview 2).

Feelings of fear were influenced by drug treatments for RA.

It means that if we contact COVID in any sort of way within a week we would probably be in hospital in intensive care and we would die because of the drugs we're on (woman, aged 73 years, interview 2).

Information from different official sources and the media influenced the fear participants experienced.

I got a letter from the NHS saying I'm very vulnerable so I then took it far more seriously and then I got bombarded with texts and letters from the government, NHS and my GP and it frightened the life out of me then so I shielded (woman aged 75 years, interview 1).

I basically don't look at the news any more on the television 'cos I feel that that's just basically negative all the time. I've got enough of that in reality without them piling it on all the time (man aged 66 years, interview 2).

The level of fear increased between the two interviews due to more contagious variants, the increasing number of deaths and knowing people who had the virus.

We're more frightened this time if I'm honest because this new variant is really going mad everywhere and it seems to be more contagious so that's frightened us if I'm 100% honest (woman aged 75 years, interview 2).

I think I'm a lot more frightened of the virus than I was. I think obviously the numbers going up, I think because I personally know a lot more people, I think it was a bit more remote during the first lockdown (woman aged 61 years, interview 2).

For a few participants, the fear diminished as the pandemic progressed, as more was learnt about the virus.

But I think maybe sort of the fear is probably lessening as I learn more (woman aged 46 years, interview 2).

Social connections and work practices

Participants clearly missed social contacts with other people, including friends and family. The effects on social well-being became more pronounced as the pandemic progressed.

You miss your family, you miss your mates, who go to the footie with you and you feel isolated at times (male aged 54 years, interview 1).

It's getting worse really 'cos you just don't feel as though you speak to anybody (woman aged 75 years, interview 2).

The telephone became the main method of social interaction.

Well my sister, they're on Zoom but I haven't done that I thought no it's ok I'll just ring her up and speak to her over the phone (man aged 55 years, interview 2).

Of the four participants who were working, three had been forced to work remotely. For one participant, continuing to work in the same way reinforced their self-identity and self-worth, while others working remotely often felt disconnected, missed the interaction with colleagues and worried about returning to the workplace.

I've got work booked in and still enjoying it that sense of purpose I think that has quite an impact in terms of mental health I think that whole idea of occupation, occupying your mind and your body and your time (man aged 47 years, interview 2).

When you're at home there's just not that connection at all, it's just not the same you just don't feel the same I feel really really worried about going back to work (woman aged 57 years, interview 1).

I do miss that, the office banter and silly stuff that goes on (woman aged 46 years, interview 1)

One participant found it less stressful and safer working from home.

Yes it wasn't too bad actually, I think a lot of the stress that some people probably went through I didn't have because I was able to work from home (woman aged 46 years, interview 1).

I miss being with my colleagues obviously but it's not worth dying for is it (woman aged 46 years, interview 2).

One participant stopped working due to being unable to meet sales figures, as potential clients were focused on providing healthcare during the pandemic.

I wasn't enjoying the role because some of the expectations were above and beyond what any reasonable person could be expected to do, so I kind of jumped ship (man aged 55 years, interview 2).

Physical impact

Surprisingly, despite the emotional impact of the pandemic, the majority of participants had not experienced an increase in the physical symptoms of their RA, which may relate to being on established and effective drug treatment.

Well they put me on a certain injection two or three years ago which works wonders and I feel great (woman aged 73 years, interview 1).

For the few participants who had experienced an increase in physical symptoms during the pandemic, it had a profound impact on their independence as indicated by

the participant below, who on reflection, identified that the stress of working at home, while starting a new job may have contributed to an increase in her symptoms.

I couldn't do anything I couldn't even do my teeth I couldn't hold my toothbrush. It's ridiculous, it sounds absolutely ridiculous and I feel embarrassed by saying it but I couldn't (P6 woman aged 57 years, interview 1).

Some participants had difficulty interpreting whether physical symptoms were related to their RA or associated with COVID-19.

I've had very severe pain there's a double fear really a fear that maybe they're Covid symptoms because the whole body aches and you begin to think oh am I getting Covid (woman aged 61 years, interview 2).

Identity

For participants, their perception of risk and the requirement to self-isolate impacted on self-identity and personal feelings of vulnerability and autonomy.

Not only with having the arthritis and the immune system compromised with drugs, you realise the age group and you think oh God I'm in that age group now. So then you realise you are vulnerable (man aged 66 years, interview 1).

Some participants felt being placed in a high risk group reduced their ability to make autonomous decisions and did not equate with their own self-perception.

I don't like being treated as vulnerable or incapacitated because that then implies that I can't make judgments for myself because I'm in a weak position and I want to make my own choices and weigh it up against the evidence (man aged 55 years, interview 2).

I wouldn't like to think of myself in that category, clinically extremely vulnerable, yes I've got issues with my joints and what have you and the tablets I'm on but I'm not an asthmatic or have heart failure so I don't classify myself as being that (woman aged 57 years, interview 2).

One participant felt that her identity as a person living with RA was threatened by the pandemic.

It was almost like I wasn't special any more, you know everybody was in that position, everybody was vulnerable and it's almost you can begin to feel that people maybe don't care about you as much as they did before because everybody is really caring about themselves (woman aged 61 years, interview 1).

Self-management

Participants applied self-management techniques they had learnt for their RA to address the impact of the pandemic of their well-being. This included stress management, pacing, enlisting the help of others and exercise.

What I've tried to do is not get too stressed out, I mean experience has taught me that if I do get stressed out very often, not always, but it does sometimes lead to the condition flaring up, so I have tried my utmost not to get too stressed out about things (man aged 55 years, interview 1).

I'm pretty certain that I will no longer have that crash and burn mentality. I now do far more pacing, I understand the need to work within my body's capabilities and accept that (man aged 71 years, interview 1).

Going to bed earlier and getting more sleep so I could rest because that's quite important with Rheumatoid (woman aged 75 years, interview 1).

DISCUSSION

This study explored the impact on physical, psychological and social well-being of people with RA during the coronavirus pandemic using longitudinal interviews. Key findings were the significant impact on psychological well-being in terms of the high and prolonged levels of fear experienced. Restrictions on social participation had a bigger impact as the pandemic progressed. Vulnerability affected perceptions of self-identity; and self-management skills used to cope with the symptoms of RA were successfully employed.

To contextualise these findings, we have used the concept of biographical disruption. The term was originally used by Bury,¹² to describe the effect a chronic illness such as RA can have on a person's social and cultural experience and self-identity. Biographical disruption can occur following a 'fateful moment' or a 'turning point',^{13 14} which leads to the individual feeling a range of negative emotions, including fear, shock, tension and a feeling of defeat.¹⁵ The onset of the coronavirus pandemic can be regarded as a 'fateful moment' in which the patients we interviewed also experienced feeling low and fearful. The pandemic has impacted on everyone's biographies but not equally or in the same way. Similar emotional reactions have been identified in other studies in people with rheumatological conditions during the pandemic, including stress, anxiety and depression.^{16 17}

In our study, the dominant emotional reaction was one of fear. This was influenced by patients' having RA, taking medication to suppress the immune system and other comorbidities. Several surveys focusing on patients with rheumatoid arthritis have demonstrated similar factors influencing this emotional response of fear, including medication use, the increased likelihood of being infected and an increased risk of dying with COVID-19.^{18 19} Communications, which have been criticised for being overconfident but under-evidenced,²⁰ from health professionals and the government informing a large majority of people that they were 'clinically extremely vulnerable' and needed to self-isolate, increased feelings of vulnerability and heightened the fear.

The level of fear increased across the two interviews as the pandemic progressed. This increase in fear was influenced

by the discovery of new contagious variants, the increasing number of deaths reported in the media and participants having personal knowledge of someone who had died as a result of COVID-19. A cross-sectional study of older adults in Bangladesh, which aimed to assess the perceived fear of COVID-19 and its associated factors, showed that having a close friend or family member diagnosed with COVID-19 was associated with a significant rise in fear.²¹ Our study population was predominantly an older age group and as most deaths related to COVID-19 occurred in the older population (74% of the total COVID-19 deaths occurred among those who were aged 65 years and above),²² this may also have contributed to their levels of fear. Although fear of being unable to obtain RA medications during the pandemic has been identified as contributing to perceptions of fear in other studies,^{18 19} this was not something our participants reported. This may be due to the differences in provision of healthcare, with our study participants being recruited from a nationalised healthcare system setting, compared with previous studies' participants being recruited from privatised care (Australia and USA).^{18 19}

Two characteristic features of biographical disruption, changes in social relationships and alterations to self-identity¹⁵ were particularly pertinent to our patients. The pandemic led to participants reflecting differently on their concept of self as they realised their increased vulnerability to COVID-19. Some participants were uncomfortable with this perceived threat to self-identity. They chose to interpret their risk in their own context and decided against total self-isolation in order to safeguard their emotional well-being. This exploration of the effects of shielding on self-identity is unique to this study, and the authors do not know to the best of their knowledge of another study which explores this. Considering the importance of self-identity and how widespread self-isolation has been during this pandemic, it warrants further attention.

The requirement for some patients to shield meant that traditional means of support, such as meeting friends and family, were no longer available. Our participants may have been more vulnerable to social isolation due to their age as older people are often functionally dependent on family members or support from community services.²³ As the pandemic progressed and the impact on social well-being became more pronounced, participants reverted back to using the telephone in preference to online methods of communication, which again may reflect the older age of our population.

Although some participants found it difficult to attribute any new symptoms to either their arthritis or COVID-19, the majority of our participants remained physically well, with no reported increase in the activity of their arthritis. Sloan *et al* describe a similar experience in people with lupus whose pain and fatigue improved, implying that lockdown lifestyles may confer well-being benefits for some people with chronic diseases.²⁴ This contrasts with findings from other studies, which identified that COVID-19-related distress was highly associated with increased symptoms and disease activity.^{17 25} The advancement in the pharmacological



management of RA has enabled more patients to maintain a sense of normality in their lives, reducing the likelihood of biographical disruption affecting their physical well-being. Biographical reinstatement may be a more appropriate descriptor than biographical disruption as when this concept was first introduced by Bury,¹² there was a limited range of pharmacological interventions to suppress disease activity.²⁶ Maldonado *et al* propose the 'concept of shifting normalities' to describe how people with RA move between different types of normality,²⁵ with movement dependent on any change in the severity of symptoms, efficacy of treatment, the ability to adjust to illness or the influence of contextual factors.²⁵

One way of addressing biographical disruption is to interpret the new experience with different valued meanings.¹⁵ Our participants were able to transfer the self-management skills they had learnt in relation to their RA to a different context, COVID-19, to maintain their identity. Self-management refers to the day-to-day activities an individual undertakes to reduce the impact on their health status.²⁷ Donnelly *et al*, in a qualitative systematic review, identified the importance of self-esteem (self-worth and value) and self-efficacy as influencing whether patients with RA were successful in using self-management techniques.²⁸ Participants in our study were able to use the resilience and accumulated knowledge that they had used to manage one type of biographical disruption (having RA) to another source of biographical disruption (that of the pandemic).

Self-management resources and the use of remote means of communication can have a positive effect on psychological well-being throughout the pandemic and mitigate some of the feelings of social isolation.²⁴ Such resources include goal setting, relaxation, exercise and mindfulness techniques.²⁴ Although there has recently been an increase in older adult internet and technology use,²⁹ many older adults still have limited digital access.²⁹ A participant in our study acknowledged digital forms of communication used by friends and family; however, the participant reverted back to using the telephone as their primary means of communication as the pandemic continued. This presents an opportunity to use trained volunteers with RA to provide ongoing telephone peer support, and other opportunities for telesocialisation.^{30 31}

We are planning to publish another paper reporting on patients' experiences of healthcare during the pandemic. Our preliminary findings show that both the bespoke home drug surveillance service which was created and remote consultations were well received and the main challenges involved communications with GPs. Our participants remained physically well during the pandemic, which may have influenced their mainly positive experience of healthcare.

The study raises important issues for those providing healthcare to people with RA, including effective communication with awareness of its likely impact in increasing fear, using pre-existing self-management strategies to enhance well-being, and recognition of the potential for social

isolation especially given the challenges of none face-to-face communication. While participants did not report significant physical impacts of the pandemic, the psychological effects remained suggesting that people may have benefitted from access to resources to manage fear.

The strengths of this research included the use of two longitudinal interviews, at 2–4 monthly intervals, to explore changes in well-being in people with RA during the pandemic. Other studies investigating experiences of the pandemic in those with chronic illnesses have been more of a snap shot, such as single time point surveys or interviews.^{17–19} However, given the novelty of a pandemic of this scale and the continual updates/recommendations from government,²⁰ it was important to take a longitudinal approach. The involvement of research group members and two patient partners in double coding and interpreting the data enhances the credibility of the findings. Although the participant sample included in this study gave a diverse representation of age of disease onset (range 20–66 years old), disease duration (1.5–46 years) and a spread of men and woman, we acknowledge that the sample was primarily in older individuals and solely of Caucasian ethnicity. Further research focusing on a diverse sample of patients, including those of a younger age and from different ethnic groups, would be beneficial in understanding wider experience and would likely identify different impacts due to known social differences in the experience of the pandemic in these populations.^{32 33} Furthermore, future work purposively sampling for patients with active disease may have led to a wider understanding of the roles of self-management and symptom identification than was seen in the range of experiences being identified in our population. Socioeconomic data which could have impacted on well-being were not collected.

Given the novelty of this longitudinal work and the exploration of biographical disruption, specifically on self-identity, we suggest that future research could expand on this in order to understand the impact of the pandemic on self-identity and social role (including work) in younger people with RA.

Conclusion

The main impact for patients with RA was on psychological well-being, where the dominant emotion of fear remained prominent during both interviews. The impact on social well-being was more marked in interview 2 as the pandemic progressed. Despite the constant presence of fear and vulnerability, there was no increase in the physical symptoms of RA over time, although some participants found interpreting physical symptoms difficult in the context of COVID-19. The realisation that RA increased the risk of contracting COVID-19 led to feelings of vulnerability and a reassessment of self-identity. Participants were able to transfer self-management skills to a new context to maintain a sense of well-being.

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