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Exploring the Impact on Physical, Psychological and Social Wellbeing of People with Rheumatoid Arthritis during the Coronavirus Pandemic: A Longitudinal Interview Study.

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Exploring the Impact on Physical, Psychological and Social Wellbeing of People with Rheumatoid Arthritis during the Coronavirus Pandemic: A Longitudinal Interview Study.

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Competing Interests

None of the authors have any competing interests to declare.

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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 wellbeing as well as their ability to employ self-management skills during the coronavirus pandemic.

Design

Qualitative, longitudinal (baseline and after 2-4 months), semi-structured telephone interviews.

Setting

A rheumatology service based in a community hospital.

Participants

15 adults with rheumatoid arthritis.

Results

Five themes were identified which related to impact on i) emotional wellbeing, ii) social participation and work, iii) physical health, iv) identity and v) self-management as a coping mechanism. The overriding emotion was one of fear, which remained high throughout both interviews. The negative impact on social wellbeing 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. 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 wellbeing. Levels of fear and vulnerability which affected self-identity remained high throughout the pandemic and the impact on social

wellbeing increased over time. Physical health remained largely unaffected. Self-management skills were used to maintain a sense of wellbeing.

Strengths and Limitations of the Study

- Use of longitudinal interviews to capture changes in patients' wellbeing and selfmanagement
- 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
- Most respondents' inflammatory disease was well controlled so we have limited data on the impact on patients with uncontrolled inflammation



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]

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 co-morbidities.^[3] Patients identified as being at significant risk from COVID-19 were required to "shield". Shielding involves patients having to self-isolate which is likely to have an effect on wellbeing.^[4] 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.^[5]

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. [6] Interpretative phenomenology is particularly useful for understanding under-researched, or new phenomena, [7] 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.^[8]

Patients with RA were recruited from a rheumatology department in a community hospital. Potentially eligible patients were identified from a rheumatology clinical database and were

purposively sampled to ensure a representation of age, gender, shielding and non-shielding status. To obtain a sample size of 15-20 patients, 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. 15 patients returned an EOI form and participated in the study.

Ethical Approval

Ethical approval was granted by Camden and Kings Cross research Ethics Committee REC reference: 20/HRA/3406. Written and email consent (for those participants who were shielding) was obtained and reconfirmed prior to the interviews.

Data Collection

Participants participated in two semi-structured telephone interviews with the same interviewer. Interviews were conducted at baseline (16th September - 23rd November 2021) and at 2 - 4 months (11th - 27th January 2021). The interviewer was not known to the participants, was not working within rheumatology and was employed as a research manager.

The topic guides (Figures 1 and 2) 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 wellbeing and self- management. The second topic guide (Figure 2) used the participants' previous narrative, to explore the impact on wellbeing of significant events during the pandemic, including the reintroduction of national restrictions in November 2021. Access to healthcare was also explored but is not reported here. Demographic data including gender, age, disease duration, occupational and marital status was collected (see Table 1). Full topic guides are available in an online supplemental appendix. The interviews were digitally recorded, transcribed verbatim and pseudonymised.

Data Analysis

Interpretative phenomenological analysis was undertaken by 2 members of the research team. 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 3 research group meetings, themes were refined and further coding took place until a final coding framework was agreed. Connected themes were then clustered together. The findings were shared with the two patient partners so that their interpretation of the data could be included.

Patient and Public Involvement (PPI)

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 to 46 years). The sample included 9 Females and 6 Males, with ages ranging from 46 years – 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. 40%.) 6 of the 15 of participants had been advised to shield. The interviews lasted between 23-60 minutes and data saturation was achieved after 10 interviews. Patient characteristics are shown in Table 1.

Qualitative Findings

Interpretative phenomenological analysis identified five themes which related to impact on i) Emotional wellbeing, ii) Social participation and work, iii) Physical health, iv) Identity, and v) Self-management as a coping mechanism.

The Impact on Emotional Wellbeing

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." (P4 interview 1).

"I'm not generally a nervous, frightened person but I think I was quite frightened by the unknown." (P1 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." (P15 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." (P4 interview 2).

In order to maintain a sense of control and wellbeing 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." (P5 interview 1).

For two participants the first lockdown had a positive effect on their emotional wellbeing. "And when everything started to shut down ironically I was much better." (P9 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." (P1 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." (P9 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." (P10 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." (P14 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." (P8 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." (P14 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." (P1 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." (P3 second interview).

Impact on Social Participation and Work

Participants clearly missed social contacts with other people, including friends and family. The effects on social wellbeing 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." (P4 interview 1).

"It's getting worse really 'cos you just don't feel as though you speak to anybody." (P8 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." (P7 interview 2).

For some participants, continuing to work in the same way reinforced their self-identity and self-worth, whilst others who were forced to work remotely 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." (P5 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." (P6 interview 1).

One participant stopped working due changes in his work role 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". (P4 interview 2).

Physical Impact

For the majority of the participants there had been no increase in the physical symptoms of their RA

"Well they put me on a certain injection two or three years ago which works wonders and I feel great." (P10 first interview).

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

"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 first interview).

Some participants had difficulty interpreting whether muscle pain was 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." (P1 interview 2).

The Impact of the Pandemic on Self-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." (P8 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 judgements for myself because I'm in a weak position and I want to make my own choices and weigh it up against the evidence." (P13 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." (P6 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." (P1 interview 1).

Self-management

Participants applied self-management techniques they had learnt for their RA to address the impact of the pandemic of their wellbeing. 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." (P4 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." (P9 interview 1).

"Going to bed earlier and getting more sleep so I could rest because that's quite important with Rheumatoid." (P14 interview 1).

DISCUSSION

This study explored the impact on physical, psychological and social wellbeing of people with RA during the coronavirus pandemic using longitudinal interviews. Key findings were the significant impact on psychological wellbeing 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 biological disruption. The term was originally used by Bury (1982),^[9] to describe the effect a chronic illness such as RA can have on a person's social and cultural experience and self-identity. Biological disruption can occur following a 'fateful moment' or a 'turning point',^[10,11] which leads to the individual feeling a range of negative emotions including fear, shock, tension and a feeling of defeat.^[12] 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. Similar emotional reactions have been identified in other studies in people with rheumatological conditions during the pandemic, including stress, anxiety and depression.^[13,14]

In our study the dominant emotional reaction was one of fear. This was influenced by patients' RA, taking medication to suppress the immune system and having other co-morbidities. 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.^[15,16] Communications, which have been criticised for being overconfident but under-evidenced, ^[17] 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 even just having a close friend or family member diagnosed with COVID-19 was associated with a significant rise in fear (1.44 95% CI 0.12, 1.68, p = 0.024).[18] 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),[19] 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. [15,16] this was not something our participants reported. This may be due to the differences in provision of health care, with our study participants being recruited from an NHS (nationalised health care system) setting, compared to previous studies' participants being recruited from privatised care (Australia and USA).[15,16]

Two characteristic features of biological disruption, changes in social relationships and alterations to self-identity, [12] 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 wellbeing. This exploration of the effects of shielding on the 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.^[20] As the pandemic progressed and the impact on social wellbeing 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 distinguish 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, Gordon and Lever et al (2021) describe a similar experience in people with lupus whose pain and fatigue improved, implying that lockdown lifestyles may confer wellbeing benefits for some people with chronic diseases.[21] This contrasts with findings from other studies which identified that COVID-19 related distress was highly associated with increased symptoms and disease activity.[14,22] 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 biological disruption affecting their physical wellbeing. Biological reinstatement may be a more appropriate descriptor than biological disruption as when this concept was first introduced by Bury (1982)[9] there was a limited range of pharmacological interventions to suppress disease activity.[23] Sanderson et al (2011) proposes the 'concept of shifting normalities' to describe how people with RA move between different types of normality, [23] with movement dependant on any change in the severity of symptoms, efficacy of treatment, the ability to adjust to illness or the influence of contextual factors.[23]

One way of addressing biological disruption is to interpret the new experience with different valued meanings.^[12] 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.^[24] Donnelly et al (2020), 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.^[25] Participants in our study were able to utilise the resilience and accumulated knowledge that they had used to manage one type of biological disruption (having RA) to another source of biological disruption (that of the pandemic).

Self-management resources and the use of remote means of communication can have a positive effect on psychological wellbeing throughout the pandemic and mitigate some of the feelings of social isolation.^[20] Such resources include goal setting, relaxation, exercise and

mindfulness techniques.^[20] Although there has recently been an increase in older adult internet and technology use,^[26] many older adults still have limited digital access.^[27] 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 tele-socialisation.^[28]

The strengths of this research included the use of two longitudinal interviews, at 2 - 4 monthly intervals, to explore changes in wellbeing in people with RA during the pandemic. Other studies in 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. [14-16] However, given the novelty of a pandemic of this scale and the continual updates/recommendations from government,[17] it was important to take a longitudinal approach. The involvement of research group members and 2 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 males and females, 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.^[29,30] 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 wellbeing was not collected.

Given the novelty of this longitudinal work and the exploration of biological 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 wellbeing where the dominant emotion of fear remained prominent during both interviews. The impact on social wellbeing was more marked in interview two 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. The realisation that RA increased the risk of 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 wellbeing.

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Figure 1: Topic Guides for the 1st Participant Interviews

Topic Guide for Interview 1

- When you first were aware of COVID did you take any extra precautions?
 - When did you become aware?
 - At that time what did you understand to be a risk, where did you get your information on risk?
 - Was the information about risk clear for you to understand, were you confident about risk and precautions?
- Can you describe your experience of living with arthritis during this period (<u>i.e.</u> the period of lockdown)?
 - Consider physical, general health
 - Psychological (anxiety, depression)
 - Social (impact of social participation, impact on social interaction with family, friends, groups)
 - Occupational impact (ability to work, understanding from employers, financial impacts)
 - Describe what a typical day involved during lockdown and what differences are there now
- · Can you think of any specific impact there has been on your arthritis?
 - Treatment and ability to engage with rheumatology
 - o Coping with your arthritis (physically, mentally)
- · Can you share what it has been like to try and manage your arthritis during this time?
 - Has the way you manage your arthritis changed if so how?
- What have been the key challenges and the key benefits (if any)?
- Have you sought help for your arthritis, if so can you tell me about this?
 - Use of telephone/internet sources of support (is this new for you or have you used before)?
 - o What have been the benefits and challenges of using remote contact?
 - Could things have been done differently or better?
- · Can you describe whether your health needs have changed?
- Can you describe any contact you have had with the rheumatology service during the period of lockdown and since?

- Consider remote consultations
- Advice line (telephone and emails)
- Community blood tests
- Explore their perceptions of these, what was helpful/unhelpful, were they frequent enough, what was the quality like, could they have been better?
- Can you think of any support that would have been helpful for you to receive from the rheumatology team during this period?
 - What could have worked better?
- Have there been any advantages/unexpected benefits as a result of Covid-19?
 - For you and your arthritis
 - With the engagement with rheumatology
 - o For your general health and wellbeing
- What are your thoughts about the future?
 - Do you think that Covid-19 will have a long lasting impact on your arthritis?
 - o Do you think that you are better prepared now for something similar in the future?
- Is there anything else you would like to share about your experience?
 - For example the impact lockdown and shielding may have led to other people helping out more (friends, family, agencies), how did you feel about that?
- . Is there anything that you thought I would ask about but haven't?

Figure 2: Topic Guides for the 2nd Participant Interviews

Topic Guide 2

- Since our last interview on (date of previous interview):
 - How, if any, has your arthritis changed since our last interview (consider increase in symptoms, impact on physical, psychological and social function)?
 - Has the way you have been managing your arthritis changed since we last spoke?
 - Some people we have talked to are working (e.g. in employment, or doing voluntary work), if that applies to you, can you tell me your experiences since the last interview?
- How did you feel during the period of national restrictions in November that were similar to the main lockdown earlier in the year?
 - How have your thoughts, feelings, and behaviour varied from those during the first lockdown period?
 - Can you describe any activities (behaviours) that you are engaging in now that you were not doing during lockdown?
 - What has been the wider impact on your family and friends?
 - Have you felt fearful about COVID-19 (if so, has this fear increased or decreased since the first lockdown and if so what has influenced this change)?
 - Have you felt vulnerable/at risk, if yes, can you explain why (and what actions you have taken to reduce your vulnerability/risk)? If no, can you explain why you don't feel vulnerable?
 - o What measures are you using in lockdown to help keep yourself safe (e.g. mask wearing)? Are you still using these measures and how do you feel about using them?
 - o The term 'clinically extremely vulnerable' has been used to describe people at high risk. What are your thoughts about this?
 - o What effect has the media's reporting of the pandemic had on your behaviour?
- The next set of questions are about any consultations you have had for your arthritis or any other medical conditions.
 - o If you have attended for an appointment have you noticed any measures that have been taken to try to reassure you and make you feel safe (if so what have these been)?
 - \circ $\:$ How effective do you feel the measures you have noticed have been at keeping you safe?
- Since our last interview have you had a consultation over the telephone or via a computer screen/video about your arthritis or other health conditions?

- o What worked well, what are the benefits to you?
- What didn't work so well, for example some people like to have someone present at a consultation (e.g. partner, familly, friend), is this something that is important to you (if so, why?)
- How did/do feel about having the consultation on your own?
- If you have had or were going to have a telephone or video consultation, would it be important to you that it was with a doctor or health professional that you know (if yes why, if no why)?
- What kind of information have you been accessing about your arthritis and what do you think about it?
 - Is the internet something that you (or a family member) have used to access information about your arthritis?
 - o Has your use of the internet changed as a result of the pandemic?
 - Have you had to develop new IT skills to access information, if so what has this involved?
 - How challenging have these new skills been to develop?
 - Has there been any help from family members/friends to develop new skills?
 - Have you had to develop new skills in other areas during the pandemic (e.g. booking appointments online, accessing online exercise classes, video meetings with friends)?
- The UK Government has approved a vaccination programme throughout the UK.
 - Do you plan to have the vaccine? (Explore response
 - o Will having the vaccine change your behaviour? If yes, how?
 - Should people with RA be a priority for a vaccine?
 - Do you think the vaccine will be effective for you?
- Is there anything that we have not discussed that you would like to share about your experience?

SUPPLEMENT 1. COREQ CHECKLIST

No	Item	Guide questions/description	
Don	Domain 1: Research team and reflexivity		
Pers	Personal Characteristics		
1.	Interviewer/facilitator	Dr Paul Campbell.	
2.	Credentials	PhD	
3.	Occupation	Research Manager	
4.	Gender	Male	
5.	Experience and training	7+ years' experience as a researcher in long term outcomes for those with musculoskeletal pain, psychological and psychosocial factors related to pain and disability.	
Rela	Relationship with participants		
6.	Relationship established	PC had no relationship with the participants and was not employed by the rheumatology department they were recruited from.	
7.	Participant knowledge of the interviewer	The participants had no prior knowledge of the researcher. Prior to conducting the interviews PC introduced himself and explained his background (a researcher with no experience of rheumatology) and explained the purpose of the research.	

No	Item	Guide questions/description	
8.	Interviewer characteristics	PC has a background in psychology which was demonstrated in the use of clarification questions during the interviews. This helped to ensure the correct interpretation of what the participants were expressing was understood.	
Dom	Domain 2: study design		
Theo	Theoretical framework		
9.	Methodological orientation and Theory	Interpretative phenomenology.	
Parti	Participant selection		
10.	Sampling	Purposive sampling.	
11.	Method of approach	Mailed an invitation.	
12.	Sample size	15	
13.	Non-participation	All participants approached consented to be part of the study and completed both interviews.	
Setti	Setting		
14.	Setting of data collection	Virtual telephone or video interview.	

No	Item	Guide questions/description
15.	Presence of non- participants	Only the interview and participant were present.
16.	Description of sample	Patients with rheumatoid arthritis.
Data	collection	
17.	Interview guide	Interview guides created by the research team and piloted with patient partners.
18.	Repeat interviews	Interviews were repeated. Interviews at two time points were included in this analysis, however, patients were invited to take part in two more (total of 4) which will be reported in a later publication.
19.	Audio/visual recording	Interviews were voice recorded and transcribed verbatim. Did the research use audio or visual recording to collect the data?
20.	Field notes	Field notes were made after the interview.
21.	Duration	Interviews lasted between 23-60 mins.
22.	Data saturation	Data saturation was reached at 10 interviews.
23.	Transcripts returned	Transcripts were not returned to patients for comment.
Domain 3: analysis and findings		

No	Item	Guide questions/description	
Data	Data analysis		
24.	Number of data coders	Two researchers (SR and PC) coded the data.	
25.	Description of the coding tree	Five themes were identified and reported in the results.	
26.	Derivation of themes	Themes were derived from the data interpretively.	
27.	Software	No software was used. Analysis was conducted by hand and Microsoft word files were utilised to manage the data.	
28.	Participant checking	Participants were not asked to provide feedback on the findings; however the patient partners did.	
Repo	Reporting		
29.	Quotations presented	Quotations utilised, with participant number and interview number identified.	
30.	Data and findings consistent	Data presentation was done within the five themes, as was discussion of findings.	
31.	Clarity of major themes	Major themes were discussed within the findings.	
32.	Clarity of minor themes	We explored the nuances within the themes and have included deviant cases in the results.	

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Exploring the physical, psychological and social wellbeing of people with rheumatoid arthritis during the coronavirus pandemic: a single centre, longitudinal, qualitative interview study in the UK.

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Competing Interests

None of the authors have any competing interests to declare.

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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 wellbeing as well as their ability to employ self-management skills during the coronavirus pandemic.

Design

Qualitative, longitudinal (baseline, 16th September to 23rd November 2020 and after 2-4 months, 11th January to the 17th January 2021), semi-structured telephone interviews.

Setting

A rheumatology service based in a community hospital.

Participants

15 adults with rheumatoid arthritis.

Main Outcomes

Data were analysed using interpretative phenomenological analysis.

Results

Five themes were identified which related to impact on i) fear: the dominant emotion, ii) social connections and work practices, iii) physical health, iv) vulnerability and v) self-management as a coping mechanism. The overriding emotion was one of fear, which remained high throughout both interviews. The negative impact on social wellbeing 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. 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 wellbeing. Levels of fear and vulnerability which affected self-identity remained high throughout the pandemic and the impact on social wellbeing increased over time. Physical health remained largely unaffected. Self-management skills were used to maintain a sense of wellbeing.

Strengths and Limitations of this Study

- Use of longitudinal interviews to capture changes in patients' wellbeing and selfmanagement
- 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 2 data collection periods might have shown different findings
- By nature people who take part in qualitative research probably are different to those who decline

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. 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 wellbeing. Shielding was introduced in England on 21st March 2020 and officially ended on 19th 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.

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. 15 patients returned an EOI form and participated in the study. There is no definitive sample size for an IPA study but to embrace it's idiographic commitment smaller concentrated samples are commonly utilised and the average sample size tends to be between 1-12 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.

Ethical Approval

Ethical approval was granted by Camden and Kings Cross research Ethics Committee REC reference: 20/HRA/3406. Written and email consent (for those participants who were shielding) was obtained and reconfirmed prior to the interviews.

Data Collection

Participants participated in two semi-structured telephone interviews with the same interviewer (PC). Interviews were conducted at baseline (16th September - 23rd November 2020) and at 2 - 4 months (11th - 27th 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 supplementary 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 wellbeing and self-management. The second topic guide used the participants' previous narrative, to explore the impact on wellbeing 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 2 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 3 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 (PPI)

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 to 46 years). The sample included 9 Females and 6 Males, with ages ranging from 46 years – 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. 6 (40%) of the 15 participants had been advised to shield. The interviews lasted between 23-60 minutes 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 lose to follow up in people who had a long term condition..

Qualitative Findings

Interpretative phenomenological analysis identified five themes which related to i) Fear: the dominant emotion, ii) Social participation and work practices, iii) Physical health, iv) Identity, and v) 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." (Male aged 55yrs, interview 1).

"I'm not generally a nervous, frightened person but I think I was quite frightened by the unknown." (Female aged 61yrs, 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." Female aged 78yrs, 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." (Male aged 55yrs, interview 2).

In order to maintain a sense of control and wellbeing 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." (Male aged 47yrs, interview 1).

For two participants the first lockdown had a positive effect on their emotional wellbeing. "And when everything started to shut down ironically I was much better." (Male, aged 71yrs, 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." (Female, aged 61yrs, 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." (Male, aged 71yrs, 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." (Female, aged 73yrs, 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." (Female aged 75yrs, 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." (Male aged 66yrs, 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." (Female aged 75yrs, 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." (Female aged 61yrs, 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." (Female aged 46yrs, interview 2).

Social Connections and Work Practices

Participants clearly missed social contacts with other people, including friends and family. The effects on social wellbeing 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." (Female aged 70yrs interview 1).

"It's getting worse really 'cos you just don't feel as though you speak to anybody." (Female aged 75yrs, 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." (Male aged 55yrs, interview 2).

Of the 4 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 Whilst 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." (Male aged 47yrs, 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." (Female aged 57yrs, interview 1).

"I do miss that, the office banter and silly stuff that goes on". (Female 46yrs, 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. (Female 46yrs, interview 1)

"I miss being with my colleagues obviously but it's not worth dying for is it (Female 46 yrs, 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". (Male 55yrs, 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." (Female 73yrs, 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 whilst 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 Female 57yrs, interview 1).

Some participants had difficulty interpreting whether physical symptoms was 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." (Female 61yrs, interview 2).

Vulnerability

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." (Male 66yrs, 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 judgements for myself because I'm in a weak position and I want to make my own choices and weigh it up against the evidence." (Male 55yrs, 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." (Female 57yrs, 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." (Female 61yrs, interview 1).

Self-management

Participants applied self-management techniques they had learnt for their RA to address the impact of the pandemic of their wellbeing. 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." (Male 55yrs, 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." (Male 71yrs, interview 1).

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

DISCUSSION

This study explored the impact on physical, psychological and social wellbeing of people with RA during the coronavirus pandemic using longitudinal interviews. Key findings were the significant impact on psychological wellbeing 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 (1982),^[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' RA, taking medication to suppress the immune system and having other co-morbidities. 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 health care, with our study participants being recruited from an NHS (nationalised health care system) setting, compared to 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-identity, [15] 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 wellbeing. This exploration of the effects of shielding on the 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 wellbeing 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, Gordon and Lever et al (2021) describe a similar experience in people with lupus whose pain and fatigue improved, implying that lockdown lifestyles may confer wellbeing 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 wellbeing. Biographical reinstatement may be a more appropriate descriptor than biographical disruption as when this concept was first introduced by Bury (1982)[12] there was a limited range of pharmacological interventions to suppress disease activity. [26] Sanderson et al (2011) proposes 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 (2020), 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 utilise 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 wellbeing 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 tele-socialisation.^[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 wellbeing, 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 wellbeing in people with RA during the pandemic. Other studies in 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 2 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 males and females, 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 wellbeing was 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 wellbeing where the dominant emotion of fear remained prominent during both interviews. The impact on social wellbeing was more marked in interview two 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. 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 wellbeing.

Data availability statement

No additional data was available.

Authors' Contributions: Research idea and study design: SR, AH, ZP, SH, PC, FM, MB and KR: data acquisition: PC and SR: recruitment: SR and AH: data analysis/interpretation: SR, AH, ZP, SH, PC, FM, MB and KR. Each author (SR, AH, ZP, SH, PC, FM, MB and KR) contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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Figure 1: Topic Guides for the 1st Participant Interviews

Topic Guide for Interview 1

- When you first were aware of COVID did you take any extra precautions?
 - When did you become aware?
 - At that time what did you understand to be a risk, where did you get your information on risk?
 - Was the information about risk clear for you to understand, were you confident about risk and precautions?
- Can you describe your experience of living with arthritis during this period (<u>i.e.</u> the period of lockdown)?
 - Consider physical, general health
 - Psychological (anxiety, depression)
 - Social (impact of social participation, impact on social interaction with family, friends, groups)
 - Occupational impact (ability to work, understanding from employers, financial impacts)
 - Describe what a typical day involved during lockdown and what differences are there now
- · Can you think of any specific impact there has been on your arthritis?
 - Treatment and ability to engage with rheumatology
 - o Coping with your arthritis (physically, mentally)
- · Can you share what it has been like to try and manage your arthritis during this time?
 - Has the way you manage your arthritis changed if so how?
- What have been the key challenges and the key benefits (if any)?
- Have you sought help for your arthritis, if so can you tell me about this?
 - Use of telephone/internet sources of support (is this new for you or have you used before)?
 - o What have been the benefits and challenges of using remote contact?
 - Could things have been done differently or better?
- · Can you describe whether your health needs have changed?
- Can you describe any contact you have had with the rheumatology service during the period of lockdown and since?

- Consider remote consultations
- Advice line (telephone and emails)
- Community blood tests
- Explore their perceptions of these, what was helpful/unhelpful, were they frequent enough, what was the quality like, could they have been better?
- Can you think of any support that would have been helpful for you to receive from the rheumatology team during this period?
 - o What could have worked better?
- Have there been any advantages/unexpected benefits as a result of Covid-19?
 - For you and your arthritis
 - With the engagement with rheumatology
 - o For your general health and wellbeing
- · What are your thoughts about the future?
 - Do you think that Covid-19 will have a long lasting impact on your arthritis?
 - o Do you think that you are better prepared now for something similar in the future?
- Is there anything else you would like to share about your experience?
 - For example the impact lockdown and shielding may have led to other people helping out more (friends, family, agencies), how did you feel about that?
- . Is there anything that you thought I would ask about but haven't?

Figure 2: Topic Guides for the 2nd Participant Interviews

Topic Guide 2

- Since our last interview on (date of previous interview):
 - How, if any, has your arthritis changed since our last interview (consider increase in symptoms, impact on physical, psychological and social function)?
 - Has the way you have been managing your arthritis changed since we last spoke?
 - Some people we have talked to are working (e.g. in employment, or doing voluntary work), if that applies to you, can you tell me your experiences since the last interview?
- How did you feel during the period of national restrictions in November that were similar to the main lockdown earlier in the year?
 - How have your thoughts, feelings, and behaviour varied from those during the first lockdown period?
 - Can you describe any activities (behaviours) that you are engaging in now that you were not doing during lockdown?
 - o What has been the wider impact on your family and friends?
 - Have you felt fearful about COVID-19 (if so, has this fear increased or decreased since the first lockdown and if so what has influenced this change)?
 - Have you felt vulnerable/at risk, if yes, can you explain why (and what actions you have taken to reduce your vulnerability/risk)? If no, can you explain why you don't feel vulnerable?
 - o What measures are you using in lockdown to help keep yourself safe (e.g. mask wearing)? Are you still using these measures and how do you feel about using them?
 - The term 'clinically extremely vulnerable' has been used to describe people at high risk. What are your thoughts about this?
 - o What effect has the media's reporting of the pandemic had on your behaviour?
- The next set of questions are about any consultations you have had for your arthritis or any other medical conditions.
 - If you have attended for an appointment have you noticed any measures that have been taken to try to reassure you and make you feel safe (if so what have these been)?
 How effective do you feel the measures you have noticed have been at keeping you
- Since our last interview have you had a consultation over the telephone or via a computer screen/video about your arthritis or other health conditions?

- o What worked well, what are the benefits to you?
- What didn't work so well, for example some people like to have someone present at a consultation (e.g. partner, family, friend), is this something that is important to you (if so. why?)
- o How did/do feel about having the consultation on your own?
- If you have had or were going to have a telephone or video consultation, would it be important to you that it was with a doctor or health professional that you know (if yes why, if no why)?
- What kind of information have you been accessing about your arthritis and what do you think about it?
 - Is the internet something that you (or a family member) have used to access information about your arthritis?
 - o Has your use of the internet changed as a result of the pandemic?
 - Have you had to develop new IT skills to access information, if so what has this involved?
 - How challenging have these new skills been to develop?
 - Has there been any help from family members/friends to develop new skills?
 - Have you had to develop new skills in other areas during the pandemic (e.g. booking appointments online, accessing online exercise classes, video meetings with friends)?
- The UK Government has approved a vaccination programme throughout the UK.
 - Do you plan to have the vaccine? (Explore response
 - o Will having the vaccine change your behaviour? If yes, how?
 - o Should people with RA be a priority for a vaccine?
 - Do you think the vaccine will be effective for you?
- Is there anything that we have not discussed that you would like to share about your experience?

SUPPLEMENT 1. COREQ CHECKLIST

No	Item	Guide questions/description
Dom	aain 1: Research team and refle	exivity
Pers	onal Characteristics	
1.	Interviewer/facilitator	Dr Paul Campbell.
2.	Credentials	PhD
3.	Occupation	Research Manager
4.	Gender	Male
5.	Experience and training	7+ years' experience as a researcher in long term outcomes for those with musculoskeletal pain, psychological and psychosocial factors related to pain and disability.
Rela	tionship with participants	
6.	Relationship established	PC had no relationship with the participants and was not employed by the rheumatology department they were recruited from.
7.	Participant knowledge of the interviewer	The participants had no prior knowledge of the researcher. Prior to conducting the interviews PC introduced himself and explained his background (a researcher with no experience of rheumatology) and explained the purpose of the research

No	Item	Guide questions/description	
8.	Interviewer characteristics	PC has a background in psychology which was demonstrated in the use of clarification questions during the interviews. This helped to ensure the correct interpretation of what the participants were expressing was understood	
Dom	aain 2: study design		
Theo	oretical framework		
9.	Methodological orientation and Theory	Interpretative phenomenology.	
Parti	Participant selection		
10.	Sampling	Purposive sampling.	
11.	Method of approach	Mailed an invitation.	
12.	Sample size	15	
13.	Non-participation	40 patients were mailed an expression of interest letter (EOI). 15 patients returned their EOI form and consented to participate in the study	
Setti	Setting		
14.	Setting of data collection	telephone interview.	

No	Item	Guide questions/description	
15.	Presence of non-participants	Only the interview and participant were present	
16.	Description of sample	Patients with rheumatoid arthritis	
Data	collection		
17.	Interview guide	Interview guides created by the research team and piloted with patient partners.	
18.	Repeat interviews	Interviews were repeated. Interviews at two time points were included in this analysis, however, patients were invited to take part in one more (total of 3) which will be reported in a later publication.	
19.	Audio/visual recording	Interviews were voice recorded and transcribed verbatim.	
20.	Field notes	Field notes were made after the interview	
21.	Duration	Interviews lasted between 23-60 mins.	
22.	Data saturation	Data saturation was reached at 10 interviews.	
23.	Transcripts returned	Transcripts were not returned to patients for comment.	
Dom	Domain 3: analysis and findings		
Data	Data analysis		

No	Item	Guide questions/description	
24.	Number of data coders	Two researchers (SR and PC) coded the data.	
25.	Description of the coding tree	Five themes were identified and reported in the results.	
26.	Derivation of themes	Themes were derived from the data interpretively.	
27.	Software	No software was used. Analysis was conducted by hand and Microsoft word files were utilised to manage the data	
28.	Participant checking	Participants were not asked to provide feedback on the findings; however the patient partners did.	
Repo	Reporting		
29.	Quotations presented	Quotations utilised and the summary information of sex and age included.	
30.	Data and findings consistent	Data presentation was done within the five themes, as was discussion of findings.	
31.	Clarity of major themes	Major themes were discussed within the findings	
32.	Clarity of minor themes	We explored the nuances within the themes and have included deviant cases in the results	

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Exploring the physical, psychological and social wellbeing of people with rheumatoid arthritis during the coronavirus pandemic: a single centre, longitudinal, qualitative interview study in the UK.

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Competing Interests

None of the authors have any competing interests to declare.

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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 wellbeing as well as their ability to employ self-management skills during the coronavirus pandemic.

Design

Qualitative, longitudinal (baseline, 16th September to 23rd November 2020 and after 2-4 months, 11th January to the 17th January 2021), semi-structured telephone interviews.

Setting

A rheumatology service based in a community hospital.

Participants

15 adults with rheumatoid arthritis.

Main Outcomes

Data were analysed using interpretative phenomenological analysis.

Results

Five themes were identified which related to impact on i) fear: the dominant emotion, ii) social connections and work practices, iii) physical health, iv) identity and v) self-management as a coping mechanism. The overriding emotion was one of fear, which remained high throughout both interviews. The negative impact on social wellbeing 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. 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 wellbeing. Levels of fear and vulnerability which affected self-identity remained high throughout the pandemic and the impact on social wellbeing increased over time. Physical health remained largely unaffected. Self-management skills were used to maintain a sense of wellbeing.

Strengths and Limitations of this Study

- Use of longitudinal interviews to capture changes in patients' wellbeing and selfmanagement
- 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 2 data collection periods might have shown different findings
- By nature people who take part in qualitative research probably are different to those who decline

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. 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 wellbeing. Shielding was introduced in England on 21st March 2020 and officially ended on 19th 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.

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. 15 patients returned an EOI form and participated in the study. There is no definitive sample size for an IPA study but to embrace it's idiographic commitment smaller concentrated samples are commonly utilised and the average sample size tends to be between 1-12 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.

Ethical Approval

Ethical approval was granted by Camden and Kings Cross research Ethics Committee REC reference: 20/HRA/3406. Written and email consent (for those participants who were shielding) was obtained and reconfirmed prior to the interviews.

Data Collection

Participants participated in two semi-structured telephone interviews with the same interviewer (PC). Interviews were conducted at baseline (16th September - 23rd November 2020) and at 2 - 4 months (11th - 27th 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 supplementary 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 wellbeing and self-management. The second topic guide used the participants' previous narrative, to explore the impact on wellbeing 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 2 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 3 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 (PPI)

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 to 46 years). The sample included 9 Females and 6 Males, with ages ranging from 46 years – 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. 6 (40%) of the 15 participants had been advised to shield. The interviews lasted between 23-60 minutes 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 lose to follow up in people who had a long term condition..

Qualitative Findings

Interpretative phenomenological analysis identified five themes which related to i) Fear: the dominant emotion, ii) Social participation and work practices, iii) Physical health, iv) Identity, and v) 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." (Male aged 55yrs, interview 1).

"I'm not generally a nervous, frightened person but I think I was quite frightened by the unknown." (Female aged 61yrs, 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." Female aged 78yrs, 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." (Male aged 55yrs, interview 2).

In order to maintain a sense of control and wellbeing 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." (Male aged 47yrs, interview 1).

For two participants the first lockdown had a positive effect on their emotional wellbeing. "And when everything started to shut down ironically I was much better." (Male, aged 71yrs, 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." (Female, aged 61yrs, 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." (Male, aged 71yrs, 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." (Female, aged 73yrs, 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." (Female aged 75yrs, 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." (Male aged 66yrs, 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." (Female aged 75yrs, 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." (Female aged 61yrs, 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." (Female aged 46yrs, interview 2).

Social Connections and Work Practices

Participants clearly missed social contacts with other people, including friends and family. The effects on social wellbeing 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." (Female aged 70yrs interview 1).

"It's getting worse really 'cos you just don't feel as though you speak to anybody." (Female aged 75yrs, 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." (Male aged 55yrs, interview 2).

Of the 4 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 Whilst 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." (Male aged 47yrs, 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." (Female aged 57yrs, interview 1).

"I do miss that, the office banter and silly stuff that goes on". (Female 46yrs, 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. (Female 46yrs, interview 1)

"I miss being with my colleagues obviously but it's not worth dying for is it (Female 46 yrs, 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". (Male 55yrs, 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." (Female 73yrs, 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 whilst 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 Female 57yrs, interview 1).

Some participants had difficulty interpreting whether physical symptoms was 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." (Female 61yrs, 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." (Male 66yrs, 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 judgements for myself because I'm in a weak position and I want to make my own choices and weigh it up against the evidence." (Male 55yrs, 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." (Female 57yrs, 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." (Female 61yrs, interview 1).

<u>Self-management</u>

Participants applied self-management techniques they had learnt for their RA to address the impact of the pandemic of their wellbeing. 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." (Male 55yrs, 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." (Male 71yrs, interview 1).

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

DISCUSSION

This study explored the impact on physical, psychological and social wellbeing of people with RA during the coronavirus pandemic using longitudinal interviews. Key findings were the significant impact on psychological wellbeing 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 (1982),^[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' RA, taking medication to suppress the immune system and having other co-morbidities. 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 health care, with our study participants being recruited from an NHS (nationalised health care system) setting, compared to 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-identity, [15] 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 wellbeing. This exploration of the effects of shielding on the 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 wellbeing 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, Gordon and Lever et al (2021) describe a similar experience in people with lupus whose pain and fatigue improved, implying that lockdown lifestyles may confer wellbeing 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 wellbeing. Biographical reinstatement may be a more appropriate descriptor than biographical disruption as when this concept was first introduced by Bury (1982)[12] there was a limited range of pharmacological interventions to suppress disease activity. [26] Sanderson et al (2011) proposes 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 (2020), 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 utilise 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 wellbeing 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 tele-socialisation.^[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 wellbeing, 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 wellbeing in people with RA during the pandemic. Other studies in 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 2 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 males and females, 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 wellbeing was 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 wellbeing where the dominant emotion of fear remained prominent during both interviews. The impact on social wellbeing was more marked in interview two 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. 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 wellbeing.

Data availability statement

No additional data was available.

Authors' Contributions: Research idea and study design: SR, AH, ZP, SH, PC, FM, MB and KR: data acquisition: PC and SR: recruitment: SR and AH: data analysis/interpretation: SR, AH, ZP, SH, PC, FM, MB and KR. Each author (SR, AH, ZP, SH, PC, FM, MB and KR) contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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Figure 1: Topic Guides for the 1st Participant Interviews

Topic Guide for Interview 1

- When you first were aware of COVID did you take any extra precautions?
 - When did you become aware?
 - At that time what did you understand to be a risk, where did you get your information on risk?
 - Was the information about risk clear for you to understand, were you confident about risk and precautions?
- Can you describe your experience of living with arthritis during this period (<u>i.e.</u> the period of lockdown)?
 - Consider physical, general health
 - Psychological (anxiety, depression)
 - Social (impact of social participation, impact on social interaction with family, friends, groups)
 - Occupational impact (ability to work, understanding from employers, financial impacts)
 - Describe what a typical day involved during lockdown and what differences are there now
- · Can you think of any specific impact there has been on your arthritis?
 - Treatment and ability to engage with rheumatology
 - o Coping with your arthritis (physically, mentally)
- · Can you share what it has been like to try and manage your arthritis during this time?
 - Has the way you manage your arthritis changed if so how?
- What have been the key challenges and the key benefits (if any)?
- Have you sought help for your arthritis, if so can you tell me about this?
 - Use of telephone/internet sources of support (is this new for you or have you used before)?
 - o What have been the benefits and challenges of using remote contact?
 - Could things have been done differently or better?
- · Can you describe whether your health needs have changed?
- Can you describe any contact you have had with the rheumatology service during the period of lockdown and since?

- Consider remote consultations
- Advice line (telephone and emails)
- Community blood tests
- Explore their perceptions of these, what was helpful/unhelpful, were they frequent enough, what was the quality like, could they have been better?
- Can you think of any support that would have been helpful for you to receive from the rheumatology team during this period?
 - What could have worked better?
- Have there been any advantages/unexpected benefits as a result of Covid-19?
 - For you and your arthritis
 - With the engagement with rheumatology
 - o For your general health and wellbeing
- · What are your thoughts about the future?
 - Do you think that Covid-19 will have a long lasting impact on your arthritis?
 - o Do you think that you are better prepared now for something similar in the future?
- Is there anything else you would like to share about your experience?
 - For example the impact lockdown and shielding may have led to other people helping out more (friends, family, agencies), how did you feel about that?
- . Is there anything that you thought I would ask about but haven't?

Figure 2: Topic Guides for the 2nd Participant Interviews

Topic Guide 2

- Since our last interview on (date of previous interview):
 - How, if any, has your arthritis changed since our last interview (consider increase in symptoms, impact on physical, psychological and social function)?
 - Has the way you have been managing your arthritis changed since we last spoke?
 - Some people we have talked to are working (e.g. in employment, or doing voluntary work), if that applies to you, can you tell me your experiences since the last interview?
- How did you feel during the period of national restrictions in November that were similar to the main lockdown earlier in the year?
 - How have your thoughts, feelings, and behaviour varied from those during the first lockdown period?
 - Can you describe any activities (behaviours) that you are engaging in now that you were not doing during lockdown?
 - o What has been the wider impact on your family and friends?
 - Have you felt fearful about COVID-19 (if so, has this fear increased or decreased since the first lockdown and if so what has influenced this change)?
 - Have you felt vulnerable/at risk, if yes, can you explain why (and what actions you have taken to reduce your vulnerability/risk)? If no, can you explain why you don't feel vulnerable?
 - What measures are you using in lockdown to help keep yourself safe (e.g. mask wearing)? Are you still using these measures and how do you feel about using them?
 - The term 'clinically extremely vulnerable' has been used to describe people at high risk. What are your thoughts about this?
 - What effect has the media's reporting of the pandemic had on your behaviour?
- The next set of questions are about any consultations you have had for your arthritis or any other medical conditions.
 - o If you have attended for an appointment have you noticed any measures that have been taken to try to reassure you and make you feel safe (if so what have these been)?
 - \circ $\:$ How effective do you feel the measures you have noticed have been at keeping you safe?
- Since our last interview have you had a consultation over the telephone or via a computer screen/video about your arthritis or other health conditions?

- o What worked well, what are the benefits to you?
- What didn't work so well, for example some people like to have someone present at a consultation (e.g. partner, family, friend), is this something that is important to you (if so. why?)
- o How did/do feel about having the consultation on your own?
- If you have had or were going to have a telephone or video consultation, would it be important to you that it was with a doctor or health professional that you know (if yes why, if no why)?
- What kind of information have you been accessing about your arthritis and what do you think about it?
 - Is the internet something that you (or a family member) have used to access information about your arthritis?
 - o Has your use of the internet changed as a result of the pandemic?
 - Have you had to develop new IT skills to access information, if so what has this involved?
 - How challenging have these new skills been to develop?
 - Has there been any help from family members/friends to develop new skills?
 - Have you had to develop new skills in other areas during the pandemic (e.g. booking appointments online, accessing online exercise classes, video meetings with friends)?
- The UK Government has approved a vaccination programme throughout the UK.
 - Do you plan to have the vaccine? (Explore response
 - o Will having the vaccine change your behaviour? If yes, how?
 - o Should people with RA be a priority for a vaccine?
 - Do you think the vaccine will be effective for you?
- Is there anything that we have not discussed that you would like to share about your experience?

SUPPLEMENT 1. COREQ CHECKLIST

No	Item	Guide questions/description
Dom	aain 1: Research team and refle	exivity
Pers	onal Characteristics	
1.	Interviewer/facilitator	Dr Paul Campbell.
2.	Credentials	PhD
3.	Occupation	Research Manager
4.	Gender	Male
5.	Experience and training	7+ years' experience as a researcher in long term outcomes for those with musculoskeletal pain, psychological and psychosocial factors related to pain and disability.
Rela	tionship with participants	
6.	Relationship established	PC had no relationship with the participants and was not employed by the rheumatology department they were recruited from.
7.	Participant knowledge of the interviewer	The participants had no prior knowledge of the researcher. Prior to conducting the interviews PC introduced himself and explained his background (a researcher with no experience of rheumatology) and explained the purpose of the research

No	Item	Guide questions/description	
8.	Interviewer characteristics	PC has a background in psychology which was demonstrated in the use of clarification questions during the interviews. This helped to ensure the correct interpretation of what the participants were expressing was understood	
Dom	aain 2: study design		
Theo	oretical framework		
9.	Methodological orientation and Theory	Interpretative phenomenology.	
Parti	Participant selection		
10.	Sampling	Purposive sampling.	
11.	Method of approach	Mailed an invitation.	
12.	Sample size	15	
13.	Non-participation	40 patients were mailed an expression of interest letter (EOI). 15 patients returned their EOI form and consented to participate in the study	
Setti	Setting		
14.	Setting of data collection	telephone interview.	

No	Item	Guide questions/description	
15.	Presence of non-participants	Only the interview and participant were present	
16.	Description of sample	Patients with rheumatoid arthritis	
Data	collection		
17.	Interview guide	Interview guides created by the research team and piloted with patient partners.	
18.	Repeat interviews	Interviews were repeated. Interviews at two time points were included in this analysis, however, patients were invited to take part in one more (total of 3) which will be reported in a later publication.	
19.	Audio/visual recording	Interviews were voice recorded and transcribed verbatim.	
20.	Field notes	Field notes were made after the interview	
21.	Duration	Interviews lasted between 23-60 mins.	
22.	Data saturation	Data saturation was reached at 10 interviews.	
23.	Transcripts returned	Transcripts were not returned to patients for comment.	
Dom	Domain 3: analysis and findings		
Data	Data analysis		

No	Item	Guide questions/description	
24.	Number of data coders	Two researchers (SR and PC) coded the data.	
25.	Description of the coding tree	Five themes were identified and reported in the results.	
26.	Derivation of themes	Themes were derived from the data interpretively.	
27.	Software	No software was used. Analysis was conducted by hand and Microsoft word files were utilised to manage the data	
28.	Participant checking	Participants were not asked to provide feedback on the findings; however the patient partners did.	
Repo	Reporting		
29.	Quotations presented	Quotations utilised and the summary information of sex and age included.	
30.	Data and findings consistent	Data presentation was done within the five themes, as was discussion of findings.	
31.	Clarity of major themes	Major themes were discussed within the findings	
32.	Clarity of minor themes	We explored the nuances within the themes and have included deviant cases in the results	