

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	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.
AUTHORS	Ryan, Sarah; Campbell, Paul; Paskins, Zoe; Hider, Samantha; Crawford-Manning, Fay; Rule, Katrina; Brooks, Michael; Hassell, Andrew

VERSION 1 – REVIEW

REVIEWER	Walker-bone, Karen University of Southampton, MRC LEU
REVIEW RETURNED	20-Sep-2021

GENERAL COMMENTS	<p>The authors have carried out a rigorous longitudinal qualitative study amongst adults with RA during the COVID pandemic exploring thematically the impacts of the pandemic. I have some small suggestions:</p> <ol style="list-style-type: none">1. I felt concerned that the man with Adult Onset Still's might be identifiable from this draft manuscript by the way the data are presented as AOSD is uncommon and so few participants were working? Have the authors considered this and could they do more to reduce any risk of this?2it. Despite the fact that the pandemic has been a lifechanging event for all of us alive, there is a slight feeling in my mind as to what we can learn from this research that might apply beyond the pandemic? Have the authors thought about this? Could they e.g. add a paragraph that thinks through what the learning here is for future care of RA patients or for future planning for pandemics, for healthcare providers or for policy makers? Is there likely to be any lasting effect of these findings on the individuals, their disease, their care or their broader health?3. I understand their findings about healthcare amongst people with RA are not reported in this paper but I wondered if they do impact on findings within this paper? Rheumatology clinics were cancelled and blood tests postponed, GP appointments were very difficult to get etc.. is there a sense that these healthcare problems fed into e.g. the fear or loss of identity? For example, I am interested in the person who thought that the pandemic had made her feel "less special"??4. It is a shame that there were only 4 working participants. It seems that one worked from home but what about the others? Were there any other work comments that could be included under that theme? It seems to be much more about "social function" as currently presented?5. I am familiar with "shielding" and "clinically extremely vulnerable" as I have been based in the UK through the pandemic but wonder if these need more careful explanation for readers
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	<p>outside the UK so that they would be able to compare with what happened in their own country?</p> <p>6. Is another possible limitation that of "participation bias"? I know that qualitative research does not need to be representative BUT is there a possibility that people who agreed to participate were in some way systematically different from people who did not..?</p>
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REVIEWER	Dures, Emma University of the West of England, Nursing and Midwifery
REVIEW RETURNED	21-Sep-2021

GENERAL COMMENTS	<p>Thank you for the opportunity to review this qualitative study reporting the experiences of patients with rheumatoid arthritis (RA) living through the COVID-19 pandemic. This is an interesting, timely and valuable study, strengthened by the longitudinal design and the involvement of patient partners throughout. Below are areas that could benefit from clarification or additional details.</p> <p>Methodology</p> <ul style="list-style-type: none"> • The methodology references [6 & 7] cite interpretative phenomenological analysis (IPA), which is well suited to the authors' aims of exploring participants' experiences. However, there are points where the alignment with IPA is not clear. One example is "a representation of age, gender, shielding and non-shielding status" - IPA studies tend to have an idiographic focus and recruit purposive, homogeneous samples, yet the authors refer to representation/variation. • Why did the authors interview 15-20 participants? This is a large sample for IPA, especially as analysis is usually conducted case by case. • The longitudinal design is to be commended. It would be interesting to know more about how data from the two timepoints were integrated (e.g., whether analysis was within participant before looking for patterns across participants). • "Access to healthcare was also explored but is not reported here": this is intriguing because IPA offers insights into how an individual makes sense of a phenomenon in a particular context. Are the authors saying that access to healthcare was not part of this sense making process even though the interviews explored living with RA during a pandemic? Why were these data not integrated into the analysis? • It would be helpful to have some more detail on the analysis process, including how the coding framework used was used (after "themes were refined, and further coding took place" but before "connected themes were then clustered together"). In IPA it would be usual to see terms such as 'emergent' and 'superordinate' themes. • The authors refer to 'data saturation' after 10 interviews: is that 10 first interviews or interviews with the first 10 participants (i.e., 20 interviews). Data saturation has become a contested term and it would be good to understand what the authors mean here and the implications for conducting 30 interviews with 15 participants, if the data collected did not contribute to the analysis in a meaningful way. <p>Analysis and reporting the findings</p> <p>The theme labels do not give the reader much sense of the theme content or the interpretive analytical process that informed it. The authors might consider using more evocative labels:</p>
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	<ul style="list-style-type: none"> • In the first theme, the authors write that “The overwhelming emotional response was one of fear”. That seems to convey more than the generic label ‘The Impact on Emotional Wellbeing’. • The theme labelled ‘Impact on social participation and work’ seems to comprise excerpts about social connection with others. • “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” - with no context, it is not clear what to make of this of this excerpt and how it contributes to insights into living with RA during COVID-19. • This theme does not seem substantial or particularly insightful. The first data excerpt is about a treatment that the participant has found beneficial for a few years. It would be helpful to be explicit about what this means, otherwise it seems as though the labels are mapped onto the study aims rather than generated through the analytical process. • “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). The important thing is the participant’s perception about why this happened and how they made sense of it in relation to the pandemic. It would be good to expand on this. • “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). This excerpt seems to be about fear, which links to the first theme. • “The Impact of the Pandemic on Self-identity”: every data excerpt mentions vulnerability; is that the essence of this theme and a more useful label? <p>Discussion</p> <ul style="list-style-type: none"> • “To contextualise these findings, we have used the concept of biological disruption”. The term that Bury used was ‘biographical’ rather than ‘biological’ disruption. It provides a way of making ‘theoretical’ sense of participants’ experiences, rather than providing context. • The authors could consider adding more about COVID-19 and shielding, including the guidance and recommendations. The pandemic has impacted everyone’s ‘biographies’, but not equally or in the same way. It would be good to bring that out. • The inclusion of the statistics from the Mistry et al. study is not very helpful without more details. It might be best to remove them and simply make the point that “having a close friend or family member diagnosed with COVID-19 was associated with a significant rise in fear”. • “... distinguish any new symptoms to either their arthritis or COVID-19”: should this read ‘attribute’? • “Self-management resources and the use of remote means of communication”: do the authors mean support for self-management ‘via’ remote means or are these distinct points? • “The realisation that RA increased the risk of COVID-19”: can the authors clarify what ‘risk of COVID-19’ refers to – is it contracting the virus, becoming seriously ill, experiencing long-COVID, and/or risk of death? <p>I hope this feedback is helpful</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1:

1. I feel concerned that the man with Adult Onset Still's might be identifiable from this draft manuscripts by the way data is presented as AOSD is so uncommon and so few participants were working?

Table 1 that contained participant characteristics has been removed to maintain the anonymity of the participants.

2. Despite the fact that the pandemic has been a life changing event for all of us, there is a slight feeling in my mind as to what we can learn from this research that might apply beyond the pandemic? Have the authors thought about this? Could they e.g. add a paragraph that thinks through what the learning is here for future care of patients or for future planning of pandemics for healthcare providers or for policy makers? Is there likely to be any lasting effect of these findings on the individuals, their disease, their care or their broader health?

The following paragraph has been added to the discussion:

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.

3. I understand their findings about healthcare amongst people with RA are not reported in this paper but I wondered if they do impact on findings within this paper? Rheumatology clinics were cancelled and blood test postponed, GP appointments were very difficult to get etc. Is there a sense that these healthcare problems fed into e.g. the fear or loss of identity? For example I am interested in the person who thought that the pandemic had made her feel 'less special'.

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.

We do not feel that these results impact directly on the findings we have reported in this paper. This has been added to the discussion.

The participant you refer to who felt 'less special' was referring to her experience as always being looked after by her family due to her increased susceptibility to infections attributed to her RA.

Whereas the pandemic, which led to the wider population suddenly being susceptible to the virus had reduced her perception as being special as everyone was now in a similar risk situation.

4. It is a shame that there were only 4 working participants. It seemed that one worked from home but what about the others? Were there any other work comments that could be included under than theme? It seems to be more about 'social function' as currently presented.

The theme title has been changed to 'Social connections and work practices' to more accurately reflect the data.

The following sentence has been added to clarify the number of participants who had been forced to work remotely: Of the 4 participants who were working, three had been forced to work remotely.

The following quotes have also been added to provide more weight to this section.

"I do miss that, the office banter and silly stuff that goes on. (P3 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. (P3 interview 1).

“I miss being with my colleagues obviously but it’s not worth dying for is it (P3 interview 2).

We have acknowledged that a limitation of our study is that we did not have a more diverse sample e.g. younger and still in employment.

5. I am familiar with “shielding” and “clinically extremely vulnerable” as I have been based in the UK through the pandemic but wonder if these need more careful explanation for readers outside of the UK so that they would be able to compare with what happened in their own country?

The following information about COVID-19 and shielding has been added to the introduction.

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 (Office for National Statistics 2020). 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 (4). Shielding was introduced in England on 21st March 2020 and officially ended on 19th July 2021.

Reference: Office for National Statistics (2020): Coronavirus and shielding of clinically extremely vulnerable people in England; 20th May to 3rd June

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicalvulnerablepeopleinengalnd/28mayto3june2020>

6. Is there another possible limitation that of “participation bias”? I know that qualitative research does not need to be representative BUT is there a possibility that people who agreed to participate were in some way systematically different from people who did not?

By nature, people who want to take part in qualitative research probably are different to those who decline. This has been added as a limitation.

The potential participants who did not return an expression of interest form did not appear to be different in terms of our purposive sampling characteristics e.g. age, gender, shielding and non shielding status but as each experience is unique it may be that some of the potential participants who did not take part would have had different experiences to share. Although we were reassured that the experiences we have captured from a large sample have provided detailed insights into the effects of the pandemic on wellbeing.

Reviewer 2

Section 1: Methodology

1. The methodology references (6 and 7) cite interpretative phenomenological analysis (IPA) which is well suited to the authors’ aims of exploring participants’ experiences. However there are points where the alignment with IPA is not clear. One example is “a representation of age, gender, shielding and non shielding status” IPA studies tend to have an idiographic focus and recruit purposive, homogeneous samples, yet the authors refer to representation/variation

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.

This has been added to the paper.

2. Why did the authors interview 15-20 participants? This is a large sample for IPA, especially as analysis is usually conducted case by case.

We acknowledge that there is no definitive sample size for an IPA study but to embrace its ideographic commitment smaller concentrated samples are commonly utilised (Smith, Flowers and Larkin 2009) and the average sample size tends to be between 1-12 participants (Coyle 2014). Our larger sample size was informed by the concern that some participants may become unwell (with COVID 19 themselves) and have to drop out of the study affecting the number of participants who were available for the second interview. Thankfully our concerns were unfounded and all participants

were able to participate in both interviews. The fact that data saturation occurred after 10 participants (i.e. 20 interviews) would indicate that a smaller sample would have sufficed.

Refs:

Coyle D (2014) Phenomenology. In A McIntosh-Scott, T Mason, E Mason-Whitehaed and D Coyle (ed) Key concepts on Nursing and Healthcare Research pp116-124. London Sage.

Smith JA, Flowers P and Larkin M (2009) Interpretative phenomenological analysis: theory, methods and research. London Sage.

3. The longitudinal design is to be commended. It would be interesting to know more about how data from the two timepoints was integrated e.g. whether analysis was within participant before looking for patterns across participants.

Analysis was undertaken within participant before looking for patterns across participants.

4. "Access to healthcare was also explored but is not reported here" this is intriguing because IPA offers insights into how an individual makes sense of a phenomenon in a particular context. Are the authors saying that access to healthcare was not part of this sense making process even though the interviews explored living with RA during a pandemic? Why were these data not integrated into the analysis.

We are planning to publish another paper reporting on patients' experiences of healthcare during the pandemic. Our preliminary findings show that 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.

We do not feel that these results impact directly on the findings we have reported in this paper. This has been added to the discussion.

5. It would be helpful to have some more detail on the analysis process, including how the coding framework was used (after "themes were refined and further coding took place" but before "connected themes were then clustered together"). In IPA it would be usual to see terms such as 'emergent' and 'superordinate themes'.

More detail has been provided regarding the analysis and the following statement added "emergent themes were noted which informed the development of superordinate themes across the data sets to provide an ongoing framework for the analysis".

6. The authors refer to 'data saturation' after 10 interviews; is that 10 first interviews or interviews with the first 10 participants (i.e. 20 interviews). Data saturation has become a contested term and it would be good to understand what the authors mean here and the implications for conducting 30 interviews with 15 participants, if the data collected did not contribute to the analysis in a meaningful way.

Data saturation occurred after the first 10 participants, in both interviews. Five further interviews were undertaken as we were concerned about the potential lose to follow up in people with a long term condition.

Section 2: Analysis and reporting of findings

1. In the first theme the authors write that "the overwhelming emotional response was one of fear". That seems to convey more than the generic label 'the impact of emotional wellbeing'. The theme title for the first theme has been changed from 'the impact of emotional wellbeing' to 'fear: the dominant emotion'.

2. The theme labelled 'impact on social participation and work' seems to comprise excerpts about social connections with others.

The theme title has been changed to social connections and work practices.

3. “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” with no context. It is not clear what to make of this excerpt and how it contributes to insights into living with RA during COVID-19.

More context has now been provided to support this quote as it illustrates that the impact of the pandemic led to this participant leaving his job.

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

4. This theme does not seem substantial or particularly insightful. The first data excerpt is about a treatment that the participant has found beneficial for a few years. It would be helpful to be explicit about what this means, otherwise it seems as if the labels are mapped onto the study aims rather than generated through the analytical process.

We agree with the reviewer that this is not a particularly substantial theme but as RA has a physical impact on the individual in terms of pain, fatigue and sometimes functional disability we thought it was important to include.

The following introduction to the theme has been included. Surprisingly despite the emotional impact of the pandemic the majority of participants had not experienced an increase in the physical symptoms of their RA.

More context has been provided for the first quote i.e. which may relate to being on established and effective drug treatment. This is to illustrate that being on effective drug treatment might have been associated with the pandemic not have a negative effect on physical health.

5. “I couldn’t do anything I couldn’t even do my teeth I couldn’t even hold my toothbrush. It’s ridiculous, it sounds absolutely ridiculous and I feel embarrassed by saying it but I couldn’t (p6 first interview). The important thing is the participant’s perception about why this happened and how they made sense of it in relation to the pandemic. It would be good to expand on this.

The patient’s perception as to why this happened has now been added i.e. the stress of working at home whilst starting a new job may have contributed to an increase in her physical symptoms.

6. “I’ve had very severe pain there’s a double fear that maybe they’re covid symptoms because the whole body aches and you being to think oh am I getting covid (p1 interview 2). This excerpt seems to be about fear, which links to the first theme.

Whilst we agree with the reviewer that this theme relates to fear, we feel that, as the fear was related to the interpretation of physical symptoms, it is appropriate to keep the quote in this section.

7. “The impact of the pandemic on self-identity’: every data excerpt mentions vulnerability: is that the essence of the theme and a more useful title.

The title of this theme has been altered to vulnerability.

Discussion:

1. “To contextualise these findings we have used the concept of biological disruption” The term Bury used was ‘biographical’ rather than ‘biological’ disruption. It provides a way of making ‘theoretical’ sense of participants’ experiences, rather than providing context.

Thank you. ‘Biological’ has been replaced with ‘Biographical’ throughout the discussion.

2. The authors could consider adding more about COVID-19 and shielding, including the guidance and recommendations. The pandemic has impacted everyone's 'biographies' but not equally or in the same way and it would be good to bring this out. The following information about COVID-19 and shielding has been added to the introduction.

On 21st March 2020 'shielding' was introduced in England for people considered to be 'clinically extremely vulnerable' to contracting COVID-19. Shielding involved having to stay at home and avoid all face to face contacts for 12 weeks. Shielding officially ended on 19th July 2021.

The observation that the pandemic has impacted on everyone's 'biographies' but not equally or in the same way has been added to the discussion.

3. The inclusion of the statistics from the Mistry et al study is not very helpful without more detail. It might be best to remove them and simply make the point that "having a close friend or family member diagnosed with COVID-19 was a significant rise in fear". The statistics relating to Mistry et al's study have been removed.

4. ... "distinguish any new symptoms to either their arthritis or COVID-19": should this read 'attribute'?

'Distinguish' has been replaced with 'attribute' as suggested.

5. "Self-management resources and the use of remote means of communication" do the authors mean support for self-management 'via' remote means or are these distinct points? These are distinct points.

6. "The realisation that RA increased the risk of COVID-19" can the authors clarify what 'risk of COVID-19 refers to-is it contracting the virus, becoming seriously ill, experiencing long-COVID, and/or risk of death. This has now been clarified and the following added to the text: 'increased the risk of contracting COVID-19.

VERSION 2 – REVIEW

REVIEWER	Walker-bone, Karen University of Southampton, MRC LEU
REVIEW RETURNED	19-Nov-2021

GENERAL COMMENTS	The authors have taken on board all the suggestions made by both reviewers and the editor.
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REVIEWER	Dures, Emma University of the West of England, Nursing and Midwifery
REVIEW RETURNED	15-Nov-2021

GENERAL COMMENTS	The authors' revisions address the feedback points raised in the original view. The only thing to add is that the theme titles are not exactly aligned between the abstract and the main text. In the abstract, the fourth theme label refers to vulnerability and in the text it refers to identify.
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VERSION 2 – AUTHOR RESPONSE

We wish to thank the reviewers for their comments. The one requested revision was as follows, 'The theme titles are not exactly aligned between the abstract and the main text. In the abstract the 4th theme label refers to vulnerability whereas in the text it refers to identity.' We have now aligned the 4th theme in the abstract and in the text to 'identity' and trust this is satisfactory.