

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	LONG COVID AND THE ROLE OF PHYSICAL ACTIVITY: A QUALITATIVE STUDY
AUTHORS	Humphreys, Helen; Kilby, Laura; Kudiersky, Nik; Copeland, Robert

VERSION 1 – REVIEW

REVIEWER	Fraser Kennedy Kennedy Occupational Health UK
REVIEW RETURNED	20-Dec-2020

GENERAL COMMENTS	<p>The paper provides some useful insights into patients' personal experiences and perceptions during the coronavirus pandemic. It highlights the isolating aspects of the pandemic, the difficulties participants experienced in accessing trusted sources of information and the current lack of detailed guidelines on physical activity during recovery from COVID-19. As a qualitative study that employs reflexive thematic analysis, the stated objective is open-ended ('to explore the lived experience of Long Covid...'), is based on a very small sample and the themes are generated by the authors' interpretation of the data collected. As such, it is difficult to draw generalisable conclusions from the study - as acknowledged in the 'Limitations' section - and the study is not specifically reproducible.</p> <p>The small sample size and potential selection bias of participants are major impediments. The participation rate was 18 cases out of 35 people invited to contribute to the study (51%) and the 35 were drawn from a population of 2023 registered cases in the 'RICOVR' database, i.e. less than 1% of the overall population. The stratification system used to identify the 35 cases lacks detail. Importantly, the paper omitted discussion of the possible reasons for almost half of those invited (17/35 people) declining to participate in the study, nor the potential sources of bias arising. However, there was acknowledgment in the Limitations section that the participants were recruited from a research interest database that might not be representative of the Long COVID population as a whole.</p> <p>The complexity of 'Long COVID' is highlighted in their Introduction section - 'a multi-system disease associated with a complex array of respiratory, neurological, cardiovascular, gastrointestinal, musculoskeletal, rheumatological, dermatological and immunological symptoms ranging in severity, frequency and duration.' - but the rest of the paper does not elucidate constraints to publication of precise recommendations for the long COVID population and draws questionable inferences. Frontline health</p>
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	<p>workers have not been able to refer to generic guidelines due to an absence of evidence-base research to date. Also, one long COVID case may have chronic fatigue without evidence of organ damage or hyperimmune response, whilst another may have severe myocarditis and pericardial effusion or kidney damage. Guidance on appropriate physical exercise will differ substantially among long COVID cases and recommendations will have to be tailored to individuals' particular clinical status. For some cases, precise physical activity recommendations may have to be based on individual medical assessment by a specialist. There may be a legitimate case for exploring a broader theme of healthcare resourcing and ease of access to suitable specialists, but this was not developed within the paper.</p> <p>Neither was there reference to the role of academic centres of well-being, behavioural science and sports medicine in developing authoritative guidelines on physical activity through collaboration with cardiologists, respiratory physicians, musculoskeletal practitioners and other specialists - which could provide valuable support to hard-pressed primary care and other frontline health care workers.</p> <p>It is surprising that the themes presented did not explore in more depth participants' fears relating to a novel health threat, including fear-avoidance behaviours, which are likely to have impacted adversely on their physical activity. Also, there was limited exploration of participants' need for validation of their long COVID symptoms. The study could have provided a valuable opportunity to develop more understanding of the potential basis for individuals' fears, their beliefs about risk and ill health, their locus of control, their expectations of a health care system under duress, the quality of support received from family, friends, local community etc.</p> <p>The Conclusions section simplifies the sometimes variable opinions of participants as regards the value of internet sources of information and support. On page 11 it is stated that 'Whilst the online research and social media communities were deemed broadly supportive, they could also lead to anxiety, by accentuating negative experiences and creating doubt about longer term prognoses:'. One participant is quoted as saying : 'But now I've backed off from these groups, because there are some really horrid stories.' On pages 13 and 14, it is stated: 'Most participants had experimented with graded approaches to exercise and activity, using resources found online, although for many this advice had been confusing'. However, page 18's Conclusions uncritically states: 'The rapid and highly motivated ability of online communities to become trusted sources of information for self-management is also highlighted'. There are a couple of typographical/ typesetting errors, e.g. an unneeded 'of' in line 92 on page 4 and a repetition of 'suggests that' in line 401 on page 18.</p> <p>I hope these comments are useful.</p>
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REVIEWER	Dr Tom Kingstone Keele University, UK
REVIEW RETURNED	04-Jan-2021

<p>GENERAL COMMENTS</p>	<p>Dear Author,</p> <p>I have now had chance to review your manuscript entitled: Long Covid and the role of physical activity: a qualitative study.</p> <p>Overall, I found this manuscript very interesting and commend the research team for conducting this piece of unfunded research. Whilst the manuscript is of good quality and has many strengths I felt there were several areas for improvement, hence the recommendation of major revisions. I provide the following suggestions to help support the team to revise the manuscript.</p> <p>Abstract The themes described in the abstract lack relevance in context of the title of the paper – further suggestions are provided below.</p> <p>Introduction The introduction seems very brief. Further elaboration and critique of published qualitative research on Long Covid is required. Please also check for additional Long Covid qualitative studies too.</p> <p>Methods For context, could brief details be provided regarding the characteristics of people registered on the RICOVR database? 'Written consent was collected from all participants prior to interview.' For clarity, please state how consent was recorded? Online form, by post, by email? Need additional information here. 'After interviewing these 18 participants, the research team were satisfied that no new themes were being identified and recruitment ceased.' Does this relate to the concept of saturation? If so, how? Please cite an adequate source.</p> <p>Findings It would be helpful to introduce the themes at the head of the results section (after participant characteristics); this would provide the reader with clear sign-posting. In all honesty, I found the presentation of themes a little disjointed. In my view, the first two themes require further analytic work to support story telling in this paper. How do they relate to physical activity in the context of Long Covid? They seem to relate more to help-seeking for Long Covid more generally. In contrast, themes three and four are excellent.</p> <p>Discussion Some important points are discussion in this section but the authors could go further. Further reflection on the meaning of activities of daily living would add further depth to the discussion. Try to pick up on some of the points raised in the results section in relation to identity and consider wider literature on illness and identity here. Further discussion on the role of age could offer something interesting here. Look to the gerontological literature for emerging research involving older adults or wider theory - to me, participants describe different levels and purposes of physical activity which are individually meaningful (might this relate to theory of needs? biographical disruption also seems relevant in context of identity). It seems to me that an individualised understanding of pacing is needed – one size does not fit all. Expectation based on previous levels of physical activity and the meaning of specific activities</p>
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	<p>based on biographical factors (such as life-stage, desire for independence) seem important in making sense of pacing. Please reconsider some of the language used in the discussion section to suit a more academic style e.g. ‘...whilst also helping them safely pursue the benefits of PA that were SO BADLY DESIRED.’</p> <p>Limitations ‘Qualitative research of this kind necessitates a small sample size which naturally limits the generaliseability of the research.’ – this statement rather misses the point of qualitative research. I agree that digital exclusion is an important limitation. In the context of physical activity, could the authors reflect on geographical characteristics of participants e.g. urban, rural, level of deprivation as these factors may be more relevant to the aims of the paper.</p> <p>Conclusions This section could be strengthened with a reflection on implications for research and clinical practice.</p> <p>The paper requires a thorough proof-read to check for typos.</p> <p>I trust these comments are clear and helpful. Despite my recommendation, this remains a very interesting manuscript and with further improvement should add to the growing evidence base on long COVID.</p>
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VERSION 1 – AUTHOR RESPONSE

Comment	Response
Reviewer 1	
The paper provides some useful insights into patients' personal experiences and perceptions during the coronavirus pandemic. It highlights the isolating aspects of the pandemic, the difficulties participants experienced in accessing trusted sources of information and the current lack of detailed guidelines on physical activity during recovery from COVID-19.	We thank the reviewer for the positive appraisal of the work and have endeavoured to retain these strengths in our amendments.
As a qualitative study that employs reflexive thematic analysis, the stated objective is open-ended ('to explore the lived experience of Long Covid....'), is based on a very small sample and the themes are generated by the authors'	We agree with the reviewer here about generalisability of the findings. As stated by reviewer 2, generalisability is not the primary aim of in qualitative work. Nevertheless, we acknowledge this in the limitations section.

<p>interpretation of the data collected. As such, it is difficult to draw generalisable conclusions from the study - as acknowledged in the 'Limitations' section - and the study is not specifically reproducible.</p>	
<p>The small sample size and potential selection bias of participants are major impediments. The participation rate was 18 cases out of 35 people invited to contribute to the study (51%) and the 35 were drawn from a population of 2023 registered cases in the 'RICOVR' database, i.e. less than 1% of the overall population. The stratification system used to identify the 35 cases lacks detail.</p>	<p>We have addressed these comments and updated the text. Please see page 6, line 11 - to page 7, line 1</p>
<p>Importantly, the paper omitted discussion of the possible reasons for almost half of those invited (17/35 people) declining to participate in the study, nor the potential sources of bias arising. However, there was acknowledgment in the Limitations section that the participants were recruited from a research interest database that might not be representative of the Long COVID population as a whole.</p>	<p>We have made an update to the paper based on the reviewer's comments. Please see page 21, line 18 – to page 22, line 21</p> <p>Whilst it is important to ensure that potential participants have a right to choose whether they decline/withdraw from research studies without judgement, we have acknowledged in the limitations section the potential for recruitment bias towards people particularly interested in physical activity.</p>
<p>The complexity of 'Long COVID' is highlighted in their Introduction section - 'a multi-system disease associated with a complex array of respiratory, neurological, cardiovascular, gastrointestinal, musculoskeletal, rheumatological, dermatological and immunological symptoms ranging in severity, frequency and duration.' - but the rest of the paper does not elucidate constraints to publication of precise recommendations for the long COVID population and draws questionable inferences. Frontline health workers have not been able to refer to generic guidelines due to an absence of evidence-base</p>	<p>We welcome comments from the reviewer on the complexity of long COVID and its multi-system nature. We agree that there has been a lack of clear guidance for recovery and further work is needed to address this.</p> <p>The primary aim of this study was to explore the lived experience of people with long COVID and not to specifically develop or provide guidance for recovery. However, we do think this is an opportunity to improve the paper and have added an additional section in the discussion titled; "Implications for Long COVID rehabilitation".</p>

<p>research to date. Also, one long COVID case may have chronic fatigue without evidence of organ damage or hyperimmune response, whilst another may have severe myocarditis and pericardial effusion or kidney damage. Guidance on appropriate physical exercise will differ substantially among long COVID cases and recommendations will have to be tailored to individuals' particular clinical status. For some cases, precise physical activity recommendations may have to be based on individual medical assessment by a specialist. There may be a legitimate case for exploring a broader theme of healthcare resourcing and ease of access to suitable specialists, but this was not developed within the paper.</p>	<p>Please see page 21, lines 3-14</p>
<p>Neither was there reference to the role of academic centres of well-being, behavioural science and sports medicine in developing authoritative guidelines on physical activity through collaboration with cardiologists, respiratory physicians, musculoskeletal practitioners and other specialists - which could provide valuable support to hard-pressed primary care and other frontline health care workers.</p>	<p>We fully endorse the reviewer's calls for multi-disciplinary work to support long COVID recovery and have previously published in this area: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7347343/</p> <p>It is an oversight in our manuscript to not underline this.</p> <p>We have addressed this on page 21, lines 3-14</p>
<p>It is surprising that the themes presented did not explore in more depth participants' fears relating to a novel health threat, including fear-avoidance behaviours, which are likely to have impacted adversely on their physical activity.</p>	<p>As a result of the reviewer's input we have expanded Theme 3 to include reasons underpinning either a willingness to push through with physical activity (e.g. benefits outweigh the risks, perception of incremental improvement) OR a fear-avoidant approach (e.g. fears about long-term damage, unpredictability of symptoms, cautious medical advice or lack of monitoring). Please see page 13, line 3 – to page 14, line 10.</p>
<p>Also, there was limited exploration of participants' need for validation of their long COVID symptoms.</p>	<p>In response to other comments from both reviewers, we have sharpened the focus of the paper towards physical activity during long COVID. As a result, this particular point is now</p>

	<p>somewhat out of scope, nevertheless we have made reference to this in the extended background section.</p>
<p>The study could have provided a valuable opportunity to develop more understanding of the potential basis for individuals' fears, their beliefs about risk and ill health, their locus of control, their expectations of a health care system under duress, the quality of support received from family, friends, local community etc.</p>	<p>The reviewer has identified an important opportunity to develop the manuscript and we have addressed the potential basis for individuals' fears on page 13, line 3 – to page 14, line 10.</p> <p>Beliefs about risk and ill health / locus of control have also been added to the discussion section, framed within self-regulation theory. Page 20, lines 4-16.</p> <p>We have also expanded our points about older participants drawing on life experience in Theme 4 page 15, lines 14-19 and explored further the expectations of a health care system under duress in Theme 2, see page 11, lines 11-17.</p> <p>The quality of support from family and friends is now explored via an explanatory paragraph and quote within Theme 4, see page 17, lines 5-15.</p>
<p>The Conclusions section simplifies the sometimes variable opinions of participants as regards the value of internet sources of information and support. On page 11 it is stated that 'Whilst the online research and social media communities were deemed broadly supportive, they could also lead to anxiety, by accentuating negative experiences and creating doubt about longer term prognoses:'. One participant is quoted as saying : 'But now I've backed off from these groups, because there are some really horrid stories.' 'On pages 13 and 14, it is stated: 'Most participants had experimented with graded approaches to exercise and activity, using resources found online, although for many this advice had been confusing'. However, page 18's Conclusions uncritically states: 'The rapid and highly motivated ability of online communities to</p>	<p>We agree that we originally presented the online communities as positive in the discussion and overlooked an opportunity to address the potential negatives for some participants (e.g. forums creating anxiety, information being shared so quickly but sometimes creating confusion).</p> <p>To address this, Theme 2 now highlights challenges associated with online groups/information as they relate specifically to PA (e.g. lack of consensus over graded activity, challenges with critical appraisal /interpretation for individuals). Our changes can be seen on page 12, lines 4-21.</p> <p>These points are further elucidated in the discussion (see page 19, lines 3-15). We have also removed '<i>The rapid and highly motivated ability of online communities to become trusted sources of information for self-management is also highlighted</i>' from the conclusion.</p>

become trusted sources of information for self-management is also highlighted'.	
There are a couple of typographical/ typesetting errors, e.g. an unneeded 'of' in line 92 on page 4 and a repetition of 'suggests that' in line 401 on page 18.	We have addressed typographical errors.

Reviewer 2	
<p>Introduction The introduction seems very brief. Further elaboration and critique of published qualitative research on Long Covid is required. Please also check for additional Long Covid qualitative studies too.</p>	<p>On reflection we agreed that the introduction could be improved based on reviewer 2's comments. Please see page 4, line 12 – to page 5, line 17.</p> <p>We have also made additional points in the limitations section re the limitations of qualitative studies – see page 25, lines 1-3.</p>
<p>Methods For context, could brief details be provided regarding the characteristics of people registered on the RICOVR database?</p>	<p>We have added a table to the methods section to address the comments made here by reviewer 2</p>
<p>'Written consent was collected from all participants prior to interview.' For clarity, please state how consent was recorded? Online form, by post, by email? Need additional information here.</p>	<p>We have now stated how consent was recorded – please see page 7, line 10.</p>
<p>'After interviewing these 18 participants, the research team were satisfied that no new themes were being identified and recruitment ceased.' Does this relate to the concept of saturation? If so, how? Please cite an adequate source.</p>	<p>We have now addressed this – please see page 7, lines 12-13.</p>
<p>Findings It would be helpful to introduce the themes at the head of the results section (after participant characteristics); this would provide the reader with clear sign-posting.</p>	<p>This is a helpful suggestion and we have amended the manuscript to reflect this. Please see page 9, lines 9-11.</p>

<p>In all honesty, I found the presentation of themes a little disjointed. In my view, the first two themes require further analytic work to support story telling in this paper. How do they relate to physical activity in the context of Long Covid? They seem to relate more to help-seeking for Long Covid more generally. In contrast, themes three and four are excellent.</p>	<p>We have considered the comments made here by reviewer 2 and agree that there is an opportunity to develop the themes further to show how they relate specifically to PA (e.g. absence of specialist advice and support – this also relates to reviewer 1 comments).</p> <p>We have re-visited the data and made some significant changes, with particular reworking of themes 1 and 2. This means that the theme of 'isolation' is no longer central nor are some of the general help-seeking findings. We could not see how this could be retained in moving towards a stronger focus on PA. We believe that these changes improve the quality of the paper - given the scope of our study – and helps to ensure the paper makes a meaningful contribution to what is currently known about the lived experience of people with long COVID.</p>
<p>Discussion Some important points are discussion in this section but the authors could go further. Further reflection on the meaning of activities of daily living would add further depth to the discussion.</p>	<p>In response to the reviewer's helpful suggestions we have provided further discussion about ADLs, in particular their importance for mental wellbeing. Please see page 17, line 19 to page 18, line 3.</p>
<p>Try to pick up on some of the points raised in the results section in relation to identity and consider wider literature on illness and identity here.</p>	<p>We'd like to thank the reviewer for highlighting an opportunity to enhance the discussion of our findings related to identity and age (theme 4)</p>
<p>Further discussion on the role of age could offer something interesting here. Look to the gerontological literature for emerging research involving older adults or wider theory - to me, participants describe different levels and purposes of physical activity which are individually meaningful (might this relate to theory of needs? biographical disruption also seems relevant in context of identity).</p>	<p>See page 19, line 17 to page 21, line 2.</p>
<p>It seems to me that an individualised understanding of pacing is needed – one size does not fit all. Expectation based on previous levels of physical activity and the meaning of specific</p>	<p>We have reviewed and revised the narrative here as we agree with comments made by the reviewer.</p> <p>Please see page 18, lines 4-13.</p>

activities based on biographical factors (such as life-stage, desire for independence) seem important in making sense of pacing.	
Please reconsider some of the language used in the discussion section to suit a more academic style e.g. ‘...whilst also helping them safely pursue the benefits of PA that were SO BADLY DESIRED.’	We have reframed this section and made changes throughout the manuscript to enhance the quality of the writing.
Limitations ‘Qualitative research of this kind necessitates a small sample size which naturally limits the generaliseability of the research.’ – this statement rather misses the point of qualitative research.	There is a conflict identified here between reviewer 1 and 2’s comments about the purpose of qualitative research. We agree that generalisability is not the purpose of qualitative research. We have reworded this section - see page 21, lines 21-24.
I agree that digital exclusion is an important limitation. In the context of physical activity, could the authors reflect on geographical characteristics of participants e.g. urban, rural, level of deprivation as these factors may be more relevant to the aims of the paper.	We agree that this would be an interesting area for future research AND a key factor in providing equity of access to long COVID support clinics. We have therefore added to our limitations section – page 22, lines 3-11.
Conclusions This section could be strengthened with a reflection on implications for research and clinical practice.	Recommendations for future research are now highlighted throughout the discussion section. This includes a discrete section on “Implications for rehabilitation.”
The paper requires a thorough proof-read to check for typos.	We have addressed typographical errors.

VERSION 2 – REVIEW

REVIEWER	Dr Tom Kingstone Keele University, UK
REVIEW RETURNED	23-Feb-2021
GENERAL COMMENTS	Dear authors Thank you for submitting your revised manuscript. I am satisfied that previous comments have now been addressed. The changes have significantly enhanced the quality and insight of this research; the end product is a highly citeable piece of work. I

	<p>consider the increase in word count (to 4,500) to be justified, as it has allows for more coherent and informative storytelling through use of participant data - this will be vital for future qualitative synthesises. The manuscript now has a much clearer focus on physical activity, which I believe to be both original and imperative to informed care for people with ongoing needs following COVID infection.</p> <p>I am happy to endorse this for publication.</p> <p>With kindest regards</p>
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