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LONG COVID AND THE ROLE OF PHYSICAL ACTIVITY: A QUALITATIVE STUDY

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3 1 **LONG COVID AND THE ROLE OF PHYSICAL ACTIVITY: A QUALITATIVE STUDY**
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3 21 **ABSTRACT**
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6 22 **Objectives**
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8 23 To explore the lived experience of Long Covid with particular focus on the role of physical
9
10 24 activity
11

12
13 25 **Design**
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15 26 Qualitative study using semi-structured interviews
16

17
18 27 **Participants**
19

20 28 18 people living with Long Covid (9 male, 9 female; aged between 18-74; 10 White British, 3
21
22 29 White Other, 3 Asian, 1 Black, 1 mixed ethnicity) recruited via a UK-based research interest
23
24 30 database for people with Long Covid
25
26

27
28 31 **Setting**
29

30 32 Telephone interviews with 17 participants living in the UK and 1 participant living in the US
31

32
33 33 **Results**
34

35 34 Four themes were generated. Theme one highlights the physical and social isolation
36
37 35 experienced by people with Long Covid, compounded by a lack of support and advice from
38
39 36 medical professionals. Theme two describes how participants sought information and
40
41 37 validation through online sources and communities. Theme three captures the challenges
42
43 38 associated with managing physical and cognitive effects of Long Covid including fatigue and
44
45 39 'brain fog' whilst trying to resume and maintain activities of daily living and other forms of
46
47 40 exercise. Theme four illustrates the battle with self-concept to accept reduced function
48
49 41 (even temporarily) and the fear of permanent reduction in physical and cognitive ability.
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53 42 **Conclusions**
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57 43 This study provides insight into the challenges of managing physical activity alongside the
58
59 44 extended symptoms associated with Long Covid. Findings highlight the need for greater
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3 45 consensus around physical activity-related advice for people with Long Covid and improved
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6 46 support to resume activities considered important for wellbeing.
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48 **Article Summary**

49 **Strengths and limitations of this study**

- 15 50
- 16 • To our knowledge, this paper is the first to explore the role of physical activity in the
17 lived experience of Long Covid using a qualitative approach
 - 18 51
 - 19 52 • The study design enabled in-depth inquiry of lived experiences in a diverse sample
 - 20 53 • Inductive thematic analysis ensured descriptions and interpretations of the lived
21 54 experience were tested and found to be grounded in the data
 - 22 55 • Participants were recruited from members of a Long Covid research interest
23 56 database who registered via an on-line form, meaning study findings might not
24 57 capture the views of digitally excluded populations
 - 25 58
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60 This study received no external funding.

61

62 **Competing interests**

63 All authors have completed the ICMJE uniform disclosure form
64 at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the
65 submitted work; no financial relationships with any organizations that might have an
66 interest in the submitted work in the previous three years; no other relationships or
67 activities that could appear to have influenced the submitted work.

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69 INTRODUCTION

70 To date, more than 30 million cases and 1 million deaths of COVID-19 have been reported
71 worldwide (1). The medical and research community has focused on understanding COVID-
72 19 pathophysiology and supporting treatment of acute cases of COVID-19 (2). Whilst the
73 majority of people infected recover, a significant proportion experience 'Long Covid',
74 showing severe symptoms for weeks and even months post-infection, irrespective of age
75 and in the absence of underlying health conditions. Long Covid appears to be a multi-system
76 disease associated with a complex array of respiratory, neurological, cardiovascular,
77 gastrointestinal, musculoskeletal, rheumatological, dermatological and immunological
78 symptoms ranging in severity, frequency and duration (3-6). Preliminary findings from
79 magnetic resonance imaging investigations also show that ~70% of 'low-risk' individuals
80 testing positive for COVID-19 present signs of impairment in one or more organs four
81 months after symptom onset (7). Research highlights common characteristics of Long Covid
82 including severe fatigue and impaired physical and cognitive function, inhibiting activities of
83 daily living (3,8,9). Engaging in physical activity (PA) has been reported to trigger the onset
84 of acute symptoms (e.g. rapid heartbeat and shortness of breath) and post exertional
85 malaise, (3). One hypothesis is that persistent symptoms are caused by organ dysfunction
86 induced by the virus, potentially compounded by deconditioning of physical fitness as a
87 result of sedentary behaviour (10-12). Physical exertion exacerbates fatigue and higher
88 likelihood of prolonged sedentary periods (3,8) creating a negative cycle.

89

90 The response to Long Covid is accelerating, reflected in a dynamic themed review by the
91 National Institute of Health Research (NIHR) on 'Living with Long Covid' (9) and NHS England
92 plans to establish of 'post-COVID syndrome' clinics (13). To date, there has been no formal

1
2
3 93 research exploring the role of PA in the management and rehabilitation of Long Covid. This
4
5 94 study explores the lived experience of people with Long Covid - including the role of PA - to
6
7
8 95 inform the design and implementation of rehabilitation support.
9

10 96

13 97 **METHODS**

15 98 **Participants and recruitment**

18 99 Interviews were conducted with English-speaking adults aged >18years who self-identified as
19
20 100 recovering from COVID-19, were not hospitalised (did not receive in-patient treatment) and
21
22 101 had experienced a recovery period lasting 3 weeks or more, a timeframe consistent with
23
24 102 definitions of 'post-acute COVID-19' at the time of study initiation (14). Ethical approval was
25
26 103 granted by Sheffield Hallam University. Participants were recruited from a COVID-19 research
27
28 104 interest database (the RICOVR database) established by the Advanced Wellbeing Research
29
30 105 Centre (AWRC) at Sheffield Hallam University (15). At the time of the study, 2023 people were
31
32 106 registered on the AWRC database. In line with current guidance, a positive COVID-19 test was
33
34 107 not a prerequisite for participation (14, 16).
35
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41
42 109 Purposive selection was used to ensure that the sample reflected a range of ages, genders
43
44 110 and ethnicities. Database members were stratified by age group, gender and ethnicity, then
45
46 111 selected chronologically according to the date that they registered with the RICOVR
47
48 112 database. Two rounds of invites were sent by email; if invitees did not respond after two
49
50 113 weeks or decided not to participate, we sent a new invite to the next person registered on
51
52 114 the database (demographically matched). A total of 35 people were invited to participate;
53
54 115 21 responded to indicate interest. Respondents were provided with full details about the
55
56 116 research and invited to an informal telephone discussion with the interviewer (HH) to
57
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1
2
3 117 discuss the research aims and procedures. 18 people took up this opportunity; all
4
5
6 118 subsequently decided to proceed. Written consent was collected from all participants prior
7
8 119 to interview. 17 participants were residing in the UK one was living in the US. After
9
10 120 interviewing these 18 participants, the research team were satisfied that no new themes
11
12
13 121 were being identified and recruitment ceased.

14
15 122

17 123 **Patient and public involvement**

18 124 During study design, the AWRC Public Involvement in Research Group (17) reviewed study
19
20 125 aims and all materials. The group provided feedback to refine documents including
21
22
23 126 clarification of language in the participant information sheet, rewording of interview
24
25 127 questions and the addition of information about support for carers in the post-interview
26
27
28 128 support document.

29
30 129

31 130 **Interview procedures**

32 131 A semi-structured interview guide was developed to elicit participants' stories about their
33
34
35 132 lived experience of Long Covid and the role of PA within that experience. Open questions
36
37
38 133 explored four broad topic areas: (i) illness and recovery trajectory, (ii) sources of support (iii)
39
40
41 134 experiences of PA (iv) future priorities and concerns. All interviews were conducted during
42
43
44 135 September and October 2020 via telephone with the exception of 2 interviews carried out
45
46
47 136 using Zoom video conferencing to suit participants' needs. All interviews were conducted by
48
49
50 137 HH, an experienced female qualitative researcher in public health and exercise psychology.
51
52
53 138 Interviews were audio recorded and limited to a maximum of 45 minutes to limit any
54
55
56 139 cognitive burden for participants. Participants were not reimbursed but were signposted to

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3 140 information detailing sources of support within and beyond the University should any
4
5 141 distress have been caused by the interview.
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11 143 **Data analysis**

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13 144 All recordings were transcribed verbatim by a professional transcription service. Transcripts
14
15 145 were sent to participants for review; one participant responded with clarifications which
16
17 146 were included in our analysis. Reflexive thematic analysis with inductive, semantic coding
18
19 147 (18) was used to interpret the data. Consistent with recommendations, we did not set out
20
21 148 to achieve inter-coder reliability (19). Instead, multiple researchers coded the transcripts to
22
23 149 encourage reflexivity and ensure our analysis considered different possible interpretations.
24
25 150 Two researchers (HH and LK, both with postgraduate psychology qualifications, training and
26
27 151 experience in qualitative interviewing) reviewed 50% of the transcripts each. HH and LK
28
29 152 independently developed preliminary coding frameworks presenting initial themes, which
30
31 153 they compared and refined with input from a third researcher (NK) who had read a cross
32
33 154 section of the transcripts. Following discussion with a fourth researcher (RC) HH, LK and NK
34
35 155 returned to the transcripts to sense-check candidate themes and ensure that they offered
36
37 156 an appropriate representation of the data, at which point themes were defined and named.
38
39 157 Final themes are presented below along with illustrative participant quotes.
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50 159 **RESULTS**

51 160 **Participants**

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54 161 Table 1 displays sample characteristics for the 18 people who participated.
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164 *Table 1: Participant Characteristics*

ID	Sex	Age group	Ethnic group	Place of residence
1	Male	55-64	White - Irish	UK
2	Female	45-54	Asian or Asian British - Indian	UK
3	Male	35-44	White - British	UK
4	Male	18-24	Black or Black British - Caribbean	UK
5	Male	45-54	White - British	UK
6	Male	65-74	White - British	US
7	Female	25-34	Mixed - White & Asian	UK
8	Female	65-74	White - British	UK
9	Male	35-44	Asian or Asian British - Indian	UK
10	Male	65-74	White - British	UK
11	Female	18-24	White - British	UK
12	Male	18-24	White - British	UK
13	Female	65-74	White - British	UK
14	Female	55-64	White - British	UK
15	Male	45-54	White - Other	UK
16	Female	35-44	White - Other	UK
17	Female	35-44	White - British	UK
18	Female	45-54	Asian or Asian British - Indian	UK

165

166

167 **Physical, social and medical isolation**

168 All participants described a profoundly isolating experience. Most participants reported

169 difficulty accessing healthcare services during the initial phase of their illness. Many felt

170 their symptoms were not serious enough to warrant emergency care, yet access to GP

171 services was denied, delayed or limited:

172 *“when you phoned your GP up they just referred you back to 111. So I was in this*173 *cycle of not being able to get any help, so all these symptoms were coming out and I*174 *just didn't know who to turn to really” (IV10)*

175

176 Participants described significant debilitation, with their physical function drastically

177 reduced and in most cases, at least several weeks of being virtually housebound. Basic

1
2
3 178 activities of daily living including self-care and housework became challenging or
4
5
6 179 impossible:

7
8 180 *“The slightest thing was an effort in a way I’ve never ever conceived before, it’s the*
9
10 181 *most fatigued I have ever been... things like changing my bedding, I did in stages like*
11
12 182 *one pillow case and then later in the day I’d do another pillow case, it was that sort*
13
14 183 *of level of difficulty with day-to-day tasks.” (IV2)*
15
16
17

18 184

19
20 185 Along with national lockdown restrictions, this constituted a physical isolation compounded
21
22 186 by limited public health messaging and media coverage about Long Covid that created an
23
24 187 additional sense of social isolation. Public health messages were seen as portraying the
25
26 188 COVID experience in binary terms: either requiring hospitalisation or being ‘mild’ enough to
27
28 189 recover at home within a short time frame (2 weeks). Meanwhile, media outlets primarily
29
30 190 reported mortality, hospitalisation and new case statistics. Neither narrative matched the
31
32 191 experience of our participants:
33
34
35

36
37 192 *“Unless I’m wrong, I don’t think the government have said anything. They don’t put it*
38
39 193 *in their statistics. So they talk about death rate, they talk about hospital cases and they*
40
41 194 *talk about new cases, but they don’t talk about people who are still struggling months*
42
43 195 *on.” (IV7)*
44
45
46

47 196

48
49 197 *“For quite a long time while I was lying at home floored by this; they were just saying*
50
51 198 *that younger people should be fine and that it’s the older generation that we need to*
52
53 199 *protect and it was just, I felt, kind of selfish and a bit like well that’s just wrong...”*
54
55 200 *(IV11)*
56
57
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59 201
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1
2
3 202 The sense of isolation was most acutely felt through the lack of answers and support
4
5 203 forthcoming from frontline healthcare professionals. All participants reported feeling
6
7
8 204 variously let down by the level of practical intervention offered to them (e.g. direct
9
10 205 treatment; tests and access to results), limited medical knowledge and awareness of Long
11
12
13 206 Covid. Most participants reported that interactions with healthcare professionals fell well
14
15 207 below meeting their psychological support needs (e.g. feeling believed, space to talk
16
17
18 208 through their worries, advice about the likely disease path):

19
20 209 *“They [doctors] didn’t know how to handle the information. The guidance wasn’t there*
21
22 210 *for them. They didn’t know who to refer to. They didn’t know if they could refer... But*
23
24 211 *I did not feel heard. And I think as a patient I felt extremely lost from what should have*
25
26 212 *been a service that could signpost and support and recognise distress and uncertainty,*
27
28 213 *there was very little acknowledgement of that.” (IV9)*
29
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35 215 Others conveyed that although medical advice was limited, they appreciated being listened
36
37 216 to and believed. Although early medical interactions had been disappointing, there was
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40 217 recognition that medical knowledge was catching up. Indeed, the penultimate participant
41
42 218 we interviewed had been formally diagnosed by her GP as having Long Covid, reflecting an
43
44
45 219 emerging understanding amongst clinicians.

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47 220

48 49 221 **Seeking validation and answers**

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53 222 The lack of understanding and explanation from trusted support sources led all participants
54
55 223 to seek information and validation online. Social media forums provided a community which
56
57
58 224 normalised the experience and suggested coping strategies:
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3 225 *“People post videos, talks, articles, and that has been my main source of*
4
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6 226 *information... So rather than sitting round worrying, I’ve known that this is a*
7
8 227 *problem, it’s not just me being a bit anxious or a bit of a hypochondriac, it’s normal if*
9
10 228 *you’ve had this virus, and that’s been brilliant” (IV12)*

229

15 230 In addition, most participants adopted a researcher role, reading scientific articles and
16
17
18 231 health resources to better understand what was happening to them:

20 232 *“And then obviously I’ve been reading a lot of evidence papers as well. So I’ve been*
21
22
23 233 *looking up stuff like that as well and trying to get the research from that side of*
24
25 234 *things and trying to form my own opinion and diagnosing myself” (IV18)*

235

30 236 Professional advice often arrived after information had already been accessed online:

32 237 *“They [physiotherapist] offered loads of advice just about pacing really. But I think at*
33
34
35 238 *that point because of all the communities that have sprung up everywhere online*
36
37 239 *people had already been sharing this information.” (IV3)*

240

42 241 Whilst the online research and social media communities were broadly deemed as
43
44
45 242 supportive, they could also lead to anxiety, by accentuating negative experiences and
46
47 243 creating doubt about longer term prognoses:

49 244 *“So I initially found it very useful, because I didn’t feel like I was making it up, I didn’t*
50
51
52 245 *feel like I’m on my own completely here. But now I’ve backed off from those groups,*
53
54
55 246 *because there are some really horrid stories. And when I’m mentally low I don’t need*
56
57 247 *to hear how other people are really struggling and have it as well. And then also some*
58
59 248 *people are a few months ahead of me in the support groups. And I want to have a little*

1
2
3 249 *bit of hope that I'll get better. But if I see people still struggling at seven/eight months*
4
5 250 *and two months ahead of me, they're worse off, it just doesn't help me." (IV7)*
6
7

8 251

9
10 252 **Learning how to balance symptoms and activity**

11
12
13 253 All participants described physical and/or cognitive fatigue which came in cycles or
14
15 254 episodes. This manifested as physical lethargy, a lack of coordination and/or brain fog
16
17
18 255 resulting in significant debilitation and often confinement to bed:

19
20 256 *"I felt from the very beginning that I was in a cyclic washing machine if you like,*
21
22 257 *because I would say on a two week basis I was seeing the symptoms recycling." (IV1)*
23
24

25 258

26
27 259 *"I'm used to feeling tired, feeling fatigued, but this is on another level. I've gone from*
28
29
30 260 *being able to go out and run; at times I couldn't cross the room. I struggled to get*
31
32 261 *upstairs... I described it as wearing a suit of armour...and on top of that I get this lack*
33
34 262 *of coordination. I can't grip things. I can't manipulate things with my hands. It's like*
35
36 263 *trying to do things wearing ski gloves... And then, on top of that, it is this brain fog.*
37
38 264 *It's like... in my younger days, when I was drunk...you have to focus and you have to*
39
40 265 *do things very slowly and carefully." (IV5)*
41
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46
47 267 Consequently, participants described losing the freedom to engage with routine activities.

48
49 268 Any physical or cognitive activity could result in the onset of severe fatigue, resembling
50
51
52 269 post-exertional malaise. In addition, PA often triggered acute symptoms including heart
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54 270 palpitations, breathlessness, joint and muscle pain:
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1
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3 272 *“So if I do something physical I suffer. If I walk I suffer in my legs. If I do something with*
4
5
6 273 *my hands I suffer with my hands. If I start to think too much I then get a foggy head. If*
7
8 274 *I type an email on the computer and it goes on too long, I then can’t think enough to*
9
10 275 *shut the computer down.” (IV5)*

11
12
13 276

14
15 277 Participants differed in their attitudes to these relapses. Some considered them worthwhile,
16
17 278 either because with each relapse followed a small improvement in baseline function, or it
18
19 279 was considered a price worth paying for the sense of normality, control and positive affect
20
21 280 that the activity provided:

22
23
24
25 281 *“So as much as I’m enjoying [walking the dog], it has the knock on effect. But that is*
26
27 282 *getting less and less, so the more I’m doing the better I’m feeling afterwards. I think*
28
29 283 *[relapses are] all part of it, just got to get on with it and push myself a little bit harder*
30
31 284 *and then hopefully I’ll get better quicker. It doesn’t put me off.” (IV17)*
32
33
34

35 285

36
37 286 Others believed it was not worth the risk and feared the potential of long-term damage that
38
39 287 could be caused:

40
41
42 288 *“...I’ve always been one of those people that things well, you know, you push through*
43
44 289 *it...But this you just can’t. And this is something that I’m becoming more afraid of that*
45
46 290 *I think maybe I need to properly back off from as much daily activity as I can to recover*
47
48 291 *from this because I’m scared that I will eventually end up as probably a 50% to a 60%*
49
50 292 *of what I was previously, permanently, or for a longer term.” (IV5)*
51
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54 293

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57 294 Medical advice regarding physical activity was sparse. Most participants had experimented
58
59 295 with graded approaches to exercise and activity, using resources found online, although for
60

1
2
3 296 many this advice had been confusing. Whilst navigating conflicting sources of advice, other
4
5
6 297 challenges included difficulties establishing a safe, consistent baseline for activity amidst daily
7
8 298 unpredictability in symptoms:

9
10 299 *“There’s obviously people that have had... different types of viruses, and they’re all*
11
12
13 300 *claiming that doing exercise and whatnot is harmful for your recovery.” (IV04)*

14
15 301

16
17
18 302 *“Everything that you read is pace yourself, pace yourself. But that’s really hard to do,*
19
20 303 *because until you’ve overdone it you don’t know how much you can do without*
21
22 304 *overdoing it, if you see what I mean, so learning by default. Which isn’t the best way,*
23
24 305 *but I guess what’s enough for me might not be enough for somebody else.” (IV08)*

25
26
27 306

30 307 **Adapting to an altered life**

31
32 308 There is a clear sense that this illness is experienced as life altering. Many participants
33
34 309 described a loss of ‘self’ and/or narrated a substantial impact on their identity. Some
35
36 310 participants made sense of this as a ‘pre’ and ‘post’ COVID life, others described it as a
37
38 311 journey, and all were struggling with the notion that this changed self may or may not
39
40 312 become permanent:

41
42
43 313 *“My biggest concern is that nobody knows the prognosis. I’m hearing some people*
44
45 314 *getting better and some people aren’t and my biggest worry throughout all of this is*
46
47 315 *if this is it, if this is going to be permanent... But it’s just that not knowing and being*
48
49 316 *in limbo for such a long time and for the foreseeable that I find the most difficult.”*

50
51
52 317 *(IV16)*

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55 318

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1
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3 319 The prospect of permanent disablement was distressing for all participants, but whereas
4
5 320 older participants drew on life events such as previous illness to make sense of their current
6
7 321 experience, we found that younger participants (e.g. those 18-24) particularly struggled with
8
9 322 their incapacitation, coupled with the loss of their usual face-to-face social networks and
10
11 323 coping mechanisms:

12
13 324 *“I just want my life back, it’s getting a bit tedious. I see myself just becoming a*
14
15 325 *burden, I don’t want to live my life like that. I don’t want to feel like a burden to my*
16
17 326 *mum, I just want to go back to life” (IV4)*
18
19
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23 327
24
25 328 The majority of participants had been unable to resume activities that were previously
26
27 329 central to their core identity (e.g. a parent, an employee, an active person). Anything that
28
29 330 provided a sense of normality helped to refute the idea that this new identity was
30
31 331 permanent (a prognosis that was both feared and resisted). Participants for whom PA was a
32
33 332 core feature of their self-concept prior to contracting COVID-19 referred to this as a strong
34
35 333 motivator in their desire to improve functional capacity and return to pre-Covid PA
36
37 334 behaviour. Awareness that they had previously been able to achieve high levels of fitness
38
39 335 fostered a belief that at least some return to fitness might be possible:

40
41 336 *“I just wanted to go in the garden... I wanted to be normal. I think normality was a*
42
43 337 *massive thing in my head.”(IV14)*
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49 338
50
51 339 *“I’ve been a runner and then a cyclist for many years so I had the intent of getting back*
52
53 340 *in the walking. And then as soon as I could I got back in the cycling a little bit”. (IV06)*
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3 342 Some participants had reached a point of 'reluctant acceptance', not necessarily arrived at
4
5 343 peacefully but through exasperation and for some, a degree of self-defeat. Participants
6
7
8 344 described needing to give themselves permission (or seeking it from others) to rest and
9
10 345 adjust their energy expenditure and lifestyle accordingly:

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12
13 346 *"I think I've just got to the point where I've accepted my new norm, so I've just been*
14
15 347 *told rest and give it time."*(IV17)

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17 348
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19
20 349 *"I tend to be fine, I'll just go out and exercise and recover and nothing's really held me*
21
22 350 *back whereas this has humbled me and made me realise I need to be more careful. So*
23
24 351 *I guess there's a bit of self-learning going on there. But I would rather be ignorant and*
25
26 352 *healthy but that's not really an option."*(IV15)

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29 353
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31
32 354 Participants' lives had been so disrupted that many had experienced a re-examination and
33
34
35 355 shift in priorities:

36
37 356 *"I feel I have learnt a lot about my own resilience...And I feel there's an opportunity for*
38
39 357 *change. I might reduce my hours going forward. It's difficult but I might try and balance*
40
41 358 *my work-life balance a bit more and pace myself."*(IV9)

42 43 44 359 45 46 47 360 **DISCUSSION**

48 49 361 **Addressing the impact of Long Covid**

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51
52 362 Participants described isolating experiences exacerbated by fragmented and largely
53
54 363 unsupportive medical care which echo previous reports (20). Whilst participants
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56
57 364 acknowledged the difficulties associated with diagnosing and treating a novel and
58
59 365 undetermined syndrome, early care experiences had negatively impacted many
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3 366 participants' physical and emotional health. This reflects research indicating that survivors
4
5
6 367 of COVID-19 could be at increased risk of adverse mental health including anxiety (21). Our
7
8 368 findings substantiate the need for holistic support addressing the physical and psychological
9
10
11 369 impacts of Long Covid, reflected in guidance for the establishment of "post-COVID
12
13 370 syndrome assessment clinics" (13).

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15 371

17 372 **Resuming and maintaining 'normal' activity**

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20
21 373 Activities of daily living (e.g. housework, gardening) and outdoor activity were referred to as
22
23 374 crucial links to normality, and vital for mental health. Our findings indicate that people
24
25 375 experiencing Long Covid need better support to manage their symptoms, especially fatigue,
26
27 376 whilst also helping them safely pursue the benefits of PA that were so badly desired. This
28
29 377 might include support to establish a baseline and upper threshold for activity which takes
30
31 378 into account the apparent relapse-recovery cycle common to our participants' experience.
32
33 379 People with Long Covid need to feel competent and confident to apply principles of pacing
34
35 380 and many will require monitoring to provide reassurance about the safety of PA whilst
36
37 381 experiencing other symptoms like rapid heartbeat or shortness of breath. Given the
38
39 382 complexity of the recovery process – particularly in terms of PA - the direct involvement of
40
41 383 people with Long Covid in the design of services to support recovery appears critical.
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49 384 Our findings reflect concerns regarding the potential risk of long-term damage associated
50
51 385 with post-exertion malaise and PA. Participants differed in their attitudes towards relapse,
52
53 386 some believing they were constructive to recovery whilst others feared danger to long-term
54
55 387 health. This paradoxical role of PA in relation to relapse and recovery reflects previous
56
57 388 qualitative studies involving people with physically limiting conditions such as multiple
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3 389 sclerosis (22). Parallels have been drawn between Long Covid and myalgic
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5 390 encephalomyelitis (ME) and/or chronic fatigue syndrome (CFS) (23). Recently, NICE
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7
8 391 withdrew a recommendation to prescribe graded exercise therapy for patients with ME/CFS
9
10 392 following concerns it could cause harm to some patients (24). It is imperative to establish
11
12 393 consensus, adding to what is already known (14) regarding PA-related advice specifically for
13
14 394 people with Long Covid, including the identification of individual phenotypes for whom PA
15
16
17 395 might or might not add value to their recovery.

21 396 **Access to information and the role of the internet**

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23
24 397 Isolation and a lack of support left our participants with no choice but to self-manage and
25
26 398 self-organise. The internet offered a crucial tool for accessing support, validation and
27
28 399 information about how to manage the Long Covid experience. This information was
29
30 400 disseminated much faster online than it could be filtered through to frontline GPs. Previous
31
32 401 research suggests that suggests that online support communities can readily address the
33
34 402 support needs of people with long-term conditions that are currently unmet offline (25).
35
36 403 The ability of online groups to provide access to rapidly-changing information inaccessible
37
38 404 or unavailable offline (26, 27) was characteristic of our participants' experiences. For the
39
40 405 majority of our participants, online Long Covid communities were a place to relate and
41
42 406 empathise with others, similar to other communities whose illness experiences may have
43
44 407 been medically contested (28, 29). Online communities have been described as pooling
45
46 408 collective knowledge derived from the lay expertise of members with a vested interest in
47
48 409 advancing the self-management of their condition (25). The information being shared is thus
49
50 410 vetted and validated by the online community itself (30,31). In the Long Covid forums
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52
53 411 described by our participants, lived experience became more valuable than medical advice
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3 412 available offline. The credibility of “expert patients” (32) within online Long Covid forums
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5
6 413 might have been enhanced by the presence of many medical professionals living with Long
7
8 414 Covid and acting as key contributors to these communities (33). Nevertheless, the novelty of
9
10 415 Long Covid also meant that the lay expertise of members was sometimes dependent on
11
12 416 learning from patients with other apparently similar conditions. In the case of graded
13
14 417 exercise therapy, this had potential to cause confusion where advice was controversial or
15
16 418 disputed by some patients.
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21 419 **Limitations**

22
23 420 This study aimed to provide in-depth exploration of the lived experience of Long Covid.
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25 421 Qualitative research of this kind necessitates a small sample size which naturally limits the
26
27 422 generalisability of the research. We took steps to recruit a broad sample in terms of age,
28
29 423 gender and ethnicity, but our participants were recruited from a research interest database
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31 424 indicating a level of engagement and access to online research that might not be
32
33 425 representative of the Long Covid population as a whole. Future studies should seek to
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35 426 represent those from digitally excluded populations (34) in lived experience accounts of
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37 427 Long Covid, to further understand social and cultural sensitivities surrounding the
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39 428 experience.
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48 430 **CONCLUSIONS**

49
50 431 This study provides insight into the challenges of managing physical activity alongside the
51
52 432 extended symptoms associated with Long Covid. Findings highlight the need for greater
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54 433 consensus around physical activity-related advice for people with Long Covid and improved
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56 434 support to resume activities considered important for wellbeing. The rapid and highly
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3 435 motivated ability of online communities to become trusted sources of information for self-
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6 436 management is also highlighted.
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9
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12
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14

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18 441 **REFERENCES**

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4 570 **Author statement**

5 571 HH: developed the research question, participant recruitment, data collection, data
6 572 analysis, manuscript preparation

7 573 LK and NK: data analysis; manuscript preparation

8 574 RC: developed the research question, secured funding for the research, acted as project
9 575 advisor and manuscript review

10 576

11 577 **Data availability statement**

12 578 Complete transcripts are not available as they pose a risk to participant confidentiality. All
13 579 other study materials are available on reasonable request.

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COREQ Checklist

No.	Item	Guide questions	Response	Included in manuscript?
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	HH	Y pg. 6
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	PhD, MSc, BSc	Y pg. 7
3	Occupation	What was their occupation at the time of the study?	Researcher	Y pg. 7
4	Gender	Was the researcher male or female?	Female	Y pg. 6
5	Experience and training	What experience or training did the researcher have?	Qualitative research in exercise psychology, public health	Y pg. 7
6	Relationship established	Was a relationship established prior to study commencement?	No	Y pg. 5
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Pre-interview discussion with participants took place to establish aims and background of the researcher	Y pg. 5
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	Background in public health and exercise psychology	Y pg. 7
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded</i>	Reflexive thematic analysis	Y pg. 7

		<i>theory, discourse analysis, ethnography, phenomenology, content analysis</i>		
10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Purposive from a research interest database	Y pg. 5
11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Email	Y pg. 5
12	Sample size	How many participants were in the study?	18	Y pg. 6
13	Non-participation	How many people refused to participate or dropped out? Reasons?	14 non-responders to email invitation; 3 non-responders following participant information being sent	Y pg. 5-6
15	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Home / telephone interviews	Y pg. 6
16	Presence of non-participants	Was anyone else present besides the participants and researchers?	No	Y pg. 6
17	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Demographic table included	Y pg. 8
18	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Semi-structured interview guide	Y pg. 6
19	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No	n/a

20	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording	Y pg. 6
21	Field notes	Were field notes made during and/or after the interview or focus group?	No	n/a
22	Duration	What was the duration of the interviews or focus group?	45 minutes max	Y pg. 6
23	Data saturation	Was data saturation discussed?	Y	Y pg. 6
24	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Y	Y pg. 7
25	Number of data coders	How many data coders coded the data?	3	Y pg. 7
26	Description of the coding tree	Did authors provide a description of the coding tree?	n/a	n/a
27	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from data	Y pg. 7
28	Software	What software, if applicable, was used to manage the data?	n/a	n/a
29	Participant checking	Did participants provide feedback on the findings?	Y via lay summary review – in progress	N
30	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Y	Y pg. 8-16
31	Data and findings consistent	Data and findings consistent	Y	Y pg. 8-16
32	Clarity of major themes	Were major themes clearly presented in the findings?	Y	Y pg. 8-16

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	33	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Y	Y pg. 8-16
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BMJ Open

LONG COVID AND THE ROLE OF PHYSICAL ACTIVITY: A QUALITATIVE STUDY

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Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Rehabilitation medicine, Sports and exercise medicine, Public health, Infectious diseases
Keywords:	PUBLIC HEALTH, QUALITATIVE RESEARCH, REHABILITATION MEDICINE, COVID-19

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3 1 **LONG COVID AND THE ROLE OF PHYSICAL ACTIVITY: A QUALITATIVE STUDY**
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3 1 **ABSTRACT**

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6 2 **Objectives**

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8 3 To explore the lived experience of long COVID with particular focus on the role of physical
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10 4 activity

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13 5 **Design**

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15 6 Qualitative study using semi-structured interviews

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18 7 **Participants**

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20 8 18 people living with long COVID (9 male, 9 female; aged between 18-74; 10 White British, 3
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22 9 White Other, 3 Asian, 1 Black, 1 mixed ethnicity) recruited via a UK-based research interest
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24 10 database for people with long COVID

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27 11 **Setting**

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29 12 Telephone interviews with 17 participants living in the UK and 1 participant living in the US

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32 13 **Results**

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34 14 Four themes were generated. Theme one describes how participants struggled with
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36 15 drastically reduced physical function, compounded by the cognitive and psychological
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38 16 effects of long COVID. Theme two highlights challenges associated with finding and
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40 17 interpreting advice about physical activity that was appropriately tailored. Theme three
41
42 18 describes individual approaches to managing symptoms including fatigue and 'brain fog'
43
44 19 whilst trying to resume and maintain activities of daily living and other forms of exercise.
45
46 20 Theme four illustrates the battle with self-concept to accept reduced function (even
47
48 21 temporarily) and the fear of permanent reduction in physical and cognitive ability.

49
50
51 22 **Conclusions**

52
53 23 This study provides insight into the challenges of managing physical activity alongside the
54
55 24 extended symptoms associated with long COVID. Findings highlight the need for greater

1 clarity and tailoring of physical activity-related advice for people with long COVID and
2 improved support to resume activities important to individual wellbeing.

4 **Article Summary**

5 **Strengths and limitations of this study**

- 6 • To our knowledge, this paper is the first to explore the role of physical activity in the
7 lived experience of long COVID using a qualitative approach
- 8 • The study design enabled in-depth inquiry of lived experiences in a diverse sample
- 9 • Inductive thematic analysis ensured descriptions and interpretations of the lived
10 experience were tested and found to be grounded in the data
- 11 • Participants were recruited from members of a long COVID research interest
12 database who registered via an on-line form, meaning study findings might not
13 capture the views of digitally excluded populations

15 **(Word count 4,594)**

1 INTRODUCTION

2 As of January 2021, more than 93 million cases of COVID-19 have been reported worldwide
3 (1). Whilst the majority of people infected recover within weeks, many people experience
4 persistent symptoms, irrespective of age and underlying health conditions, termed 'long
5 COVID' (2,3). Long COVID appears to be a multi-system disease associated with a complex
6 array of respiratory, neurological, cardiovascular, gastrointestinal, musculoskeletal,
7 rheumatological, dermatological and immunological symptoms ranging in severity,
8 frequency and duration (3, 4-6). Symptom surveillance surveys have reported estimates of
9 long COVID (defined as symptoms lasting ≥ 12 weeks) affecting 10% of people testing
10 positive for COVID-19 (7). Preliminary findings from magnetic resonance imaging
11 investigations also show that ~70% of 'low-risk' individuals testing positive for COVID-19
12 present signs of impairment in one or more organs four months after symptom onset (8). In
13 a recent survey, the three most debilitating symptoms of long COVID were identified as
14 fatigue, shortness of breath, and cognitive dysfunction. 89% of survey respondents also
15 reported that mental and/or physical exertion triggered the relapse of symptoms (post-
16 exertional malaise)(4).

17
18 Along with personal accounts (9), qualitative studies have provided valuable insight into the
19 lived experience of long COVID (2,10,11). People with long COVID describe an illness
20 trajectory and heterogeneous symptomology that did not conform to initial expectations
21 and was not acknowledged in public health advice (2,10,11). This has posed challenges for
22 the medical profession, who have lacked evidence-based guidance to treat and support
23 patients. Individual experiences of medical care have varied from well-meaning but
24 inconclusive, to disbelief (2,10,11). This lack of understanding about long COVID extends

1 beyond the medical and scientific communities to employers, family and friends, leaving
2 many people feeling frustrated and isolated in their self-management efforts (2,10,11) and
3 increasingly turning to online communities of people with long COVID for validation and
4 advice (2,10,11).

5
6 A commonly reported approach to self-management for long COVID is pacing (2, 9, 11). This
7 involves the strategic use of physical and mental energy reserves, with the aim of
8 preventing or mitigating symptom flareups (12,13). Formal guidelines now include the Pace,
9 Plan and Prioritise principles (12,13). Nevertheless, the role of physical activity (PA) in the
10 management and rehabilitation of long COVID remains unclear. It is hypothesised that
11 persistent debilitating symptoms are caused by organ dysfunction induced by the virus, but
12 symptoms are likely to be compounded by deconditioning as a result of sedentary
13 behaviour (14-16). Whilst it is evident that PA can exacerbate symptoms, it is unknown how
14 PA influences the broader recovery trajectory, and how individuals have managed this
15 aspect of their recovery. This study explores the lived experience of people with long COVID
16 – focusing on the role of PA - to inform the design and implementation of rehabilitation
17 support.

19 **METHODS**

20 **Participants and recruitment**

21 Interviews were conducted with English-speaking adults aged >18 years who self-identified
22 as recovering from COVID-19, were not hospitalised (did not receive in-patient treatment)
23 and had experienced a recovery period lasting 3 weeks or more, a timeframe consistent with
24 definitions of 'post-acute COVID-19' at the time of study initiation (17). Ethical approval was

1 granted by Sheffield Hallam University. Participants were recruited from a COVID-19 research
 2 interest database (the RICOVR database) established by the Advanced Wellbeing Research
 3 Centre (AWRC) at Sheffield Hallam University (18). At the time of the study, 2022 people were
 4 registered on the AWRC database (see table 1 for characteristics). Consistent with other long
 5 COVID research, a positive COVID-19 test was not an inclusion criterion (17, 19).

7 *Table 1: Characteristics of people registered on the RICOVR database at study commencement*

Total: 2022		
Sex	n=	%
Male	28	13.4
Female	219	81.8
Undisclosed	575	4.7
Age		
18 - 24	28	1.4
25 - 34	219	10.8
35 - 44	575	28.4
45 - 54	686	33.9
55 - 64	337	16.7
>64	86	4.3
Undisclosed	91	4.5
Ethnic Background		
White	1794	88.7
BAME	120	5.9
Undisclosed	108	5.3

8
 9
 10 Purposive selection was used to ensure that the sample reflected a range of ages, genders
 11 and ethnicities. In accordance with UK demographic estimates (20), we aimed to recruit 15%
 12 of participants from black and minority ethnic (BAME) groups, and 85% from the White
 13 British population, with an even sex ratio. To achieve a wide spread of ages, 2-3 participants

1 were selected from each age category (18-24; 25-34; 35-44; 45-54; 55-64; ≥65 years).
2 Database members were stratified by age group, gender and ethnicity, then selected
3 chronologically according to the date that they registered with the RICOVR database. Two
4 rounds of invites were sent by email; if invitees did not respond after two weeks or decided
5 not to participate, we sent a new invite to the next person registered on the database
6 (demographically matched). A total of 35 people were invited to participate; 21 responded
7 to indicate interest. Respondents were provided with full details about the research and
8 invited to an informal telephone discussion with the interviewer (HH) to discuss the
9 research aims and procedures. 18 people took up this opportunity; all subsequently decided
10 to proceed. Participants completed a written consent form returned via email prior to
11 interview. 17 participants were residing in the UK; one was living in the US. After
12 interviewing 18 participants, the research team were satisfied that thematic saturation was
13 reached (21) and recruitment ceased.

14

15 **Patient and public involvement**

16 During study design, the AWRC Public Involvement in Research Group (22) reviewed study
17 aims and all materials. The group provided feedback to refine documents including
18 clarification of language in the participant information sheet, rewording of interview
19 questions and the addition of information about support for carers in the post-interview
20 support document.

21

22 **Interview procedures**

23 A semi-structured interview guide (supplementary file) was developed to elicit participants'
24 stories about their lived experience of long COVID and the role of PA within that experience.

1
2
3 1 Open questions explored four broad topic areas: (i) illness and recovery trajectory, (ii)
4
5 2 sources of support (iii) experiences of PA, and (iv) future priorities and concerns. All
6
7 3 interviews were conducted during September and October 2020 via telephone with the
8
9 4 exception of 2 interviews carried out using Zoom video conferencing to suit participants'
10
11 5 needs. All interviews were conducted by HH, an experienced female qualitative researcher
12
13 6 in public health and exercise psychology. Interviews were audio recorded and limited to a
14
15 7 maximum of 45 minutes to limit any cognitive burden for participants. Participants were not
16
17 8 reimbursed but were signposted to information detailing sources of support within and
18
19 9 beyond the University should any distress have been caused by the interview.
20
21
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28 11 **Data analysis**

29
30 12 All recordings were transcribed verbatim by a professional transcription service. Transcripts
31
32 13 were sent to participants for review; one participant responded with clarifications which
33
34 14 were included in our analysis. Reflexive thematic analysis with inductive, semantic coding
35
36 15 (23) was used to interpret the data. Consistent with recommendations, we did not set out
37
38 16 to achieve inter-coder reliability (24). Instead, multiple researchers coded the transcripts to
39
40 17 encourage reflexivity and ensure our analysis considered different possible interpretations.
41
42 18 Two researchers (HH and LK, both with postgraduate psychology qualifications, training and
43
44 19 experience in qualitative interviewing) reviewed 50% of the transcripts each. HH and LK
45
46 20 independently developed preliminary coding frameworks presenting initial themes, which
47
48 21 they compared and refined with input from a third researcher (NK) who had read a cross
49
50 22 section of the transcripts. Following discussion with a fourth researcher (RC) HH, LK and NK
51
52 23 returned to the transcripts to sense-check candidate themes and ensure that they offered
53
54 24 an appropriate representation of the data, at which point themes were defined and named.
55
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RESULTS

Participants

18 people took part in an interview (see Table 2 for sample characteristics).

Table 2: Participant characteristics

ID	Sex	Age group	Ethnic group	Place of residence
1	Male	55-64	White - Irish	UK
2	Female	45-54	Asian or Asian British - Indian	UK
3	Male	35-44	White - British	UK
4	Male	18-24	Black or Black British - Caribbean	UK
5	Male	45-54	White - British	UK
6	Male	65-74	White - British	US
7	Female	25-34	Mixed - White & Asian	UK
8	Female	65-74	White - British	UK
9	Male	35-44	Asian or Asian British - Indian	UK
10	Male	65-74	White - British	UK
11	Female	18-24	White - British	UK
12	Male	18-24	White - British	UK
13	Female	65-74	White - British	UK
14	Female	55-64	White - British	UK
15	Male	45-54	White - Other	UK
16	Female	35-44	White - Other	UK
17	Female	35-44	White - British	UK
18	Female	45-54	Asian or Asian British - Indian	UK

Four themes were identified: *the interconnection of physical and psychological symptoms; lack of clear and consistent PA-related advice; learning to balance symptoms and activity; adapting to an altered life*. Themes are described below with illustrative participant quotes.

Interconnection of physical and psychological symptoms

Participants recounted their experiences of long COVID in detail, describing diverse individual illness trajectories and varied patterns of symptoms presenting throughout the

1
2
3 1 body. All participants described significant debilitation, with their physical function
4
5 2 drastically reduced. This meant several weeks, and in many cases months, of being virtually
6
7 3 housebound. During this period, basic activities of daily living including self-care and
8
9 4 housework became challenging or impossible, and formal exercise was unconceivable:

10
11
12
13 5 *“The slightest thing was an effort in a way I’ve never ever conceived before, it’s the*
14
15 6 *most fatigued I have ever been... things like changing my bedding, I did in stages like*
16
17 7 *one pillowcase and then later in the day I’d do another pillowcase, it was that sort of*
18
19 8 *level of difficulty with day-to-day tasks.” (IV2)*
20
21
22

23 9
24
25 10 *“It has affected me to the point of like debilitating...I’ve had to contact the school and*
26
27 11 *say I can’t do the one-way system to drop off. So literally I drop my son off right*
28
29 12 *outside the school so I don’t have to walk the 10 minutes’ walk around the one-way*
30
31 13 *system. I can’t do that.” (IV7)*
32
33
34

35 14
36
37 15 The combination of physical and cognitive symptoms added to an overall sense of
38
39 16 debilitation:

40
41
42 17 *“So if I do something physical I suffer. If I walk I suffer in my legs. If I do something*
43
44 18 *with my hands I suffer with my hands. If I start to think too much I then get a foggy*
45
46 19 *head. If I type an email on the computer and it goes on too long, I then can’t think*
47
48 20 *enough to shut the computer down.” (IV5)*
49
50
51

52 21
53
54 22 Physical and psychological impacts of long COVID were interlinked. For some participants,
55
56 23 prolonged and unexpected physical incapacitation had emotional implications including
57
58 24 lowered self-esteem, frustration and guilt about not being able to fulfil everyday
59
60

1 responsibilities. Some participants believed that stress was a specific trigger for physical
2 symptoms:

3 *"I'm the wrong generation to just not go to work. So I know I couldn't go to work but*
4 *I felt guilty about not going to work... once I knew every week that I had to be in*
5 *touch I'd get really anxious because I knew I couldn't string a sentence together or*
6 *even send a proper email."* (IV14)

7
8 *"You see, stress brings it on and that makes it really bad."* (IV13)

9 10 **Lack of clear and consistent PA-related advice**

11 Participants had varied expectations of how the healthcare system could support them with
12 PA. Some were deterred from help-seeking by unhelpful responses or a perception that they
13 did not meet the threshold for help. Others acknowledged the constraints facing clinicians,
14 yet felt compelled to seek advice about unnerving symptoms. Questions about how to
15 manage PA challenged the expertise of medical professionals, who lacked an evidence-base
16 for this novel condition and were unable to provide conclusive advice. Consequently,
17 participants sought information and validation online. Social media forums provided a
18 community which normalised the long COVID experience and provided coping strategies. In
19 addition, most participants adopted a 'researcher' role, reading scientific articles and health
20 resources to better understand their condition:

21
22 *"I think the GP that I've managed to speak to has been trying his best, but he is a*
23 *little bit unsure himself you see.... the most things that have been useful are the*
24 *support groups on Facebook, I hate to say it but that's where I've found most of my*

1
2
3 1 *information. And then obviously I've been reading a lot of evidence papers as well. So*
4
5
6 2 *I've been... trying to form my own opinion and diagnosing myself" (IV18)*
7
8
9 3

10 4 As a consequence, professional advice about PA often arrived after information had already
11
12
13 5 been accessed online:

14
15 6 *"They [physiotherapist] offered loads of advice just about pacing really. But I think at*
16
17 7 *that point because of all the communities that have sprung up everywhere online*
18
19
20 8 *people had already been sharing this information."* (IV3)
21
22
23 9

24
25 10 Whilst information accessed online was broadly helpful, it lacked specificity for long COVID:

26
27 11 *"There's obviously people that have had... different types of viruses, and they're all*
28
29 12 *claiming that doing exercise and whatnot is harmful for your recovery. I'm not sure if*
30
31 13 *you've heard of something called ME, a lot of people are stating... don't do graded*
32
33 14 *exercise... don't do none of that..."* (IV4)
34
35
36 15

37
38
39 16 Some participants also struggled with digesting online information, finding long periods of
40
41 17 concentration difficult. One participant highlighted the challenges associated with critically
42
43 18 appraising evidence:

44
45
46 19 *"... I don't really have any knowledge of just medical sciences or have the ability to*
47
48 20 *just go and start reading the journals of the latest publications... the common person*
49
50 21 *can't do that."* (IV12).
51
52
53 22

54
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56 23 **Learning how to balance symptoms and activity**
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1 Participants described a loss of freedom to engage with routine activities; any physical or
2 cognitive activity resulted in the onset of fatigue. Some participants considered these
3 relapses worthwhile, either because with each relapse followed a small perceived
4 improvement in baseline function, or because it was considered a price worth paying for the
5 sense of normality, control and positive affect the activity provided:

6 *“So as much as I’m enjoying [walking the dog], it has the knock-on effect. But that is*
7 *getting less and less, so the more I’m doing the better I’m feeling afterwards. I think*
8 *[relapses are] all part of it, just got to get on with it and push myself a little bit harder*
9 *and then hopefully I’ll get better quicker. It doesn’t put me off.” (IV17)*

10
11 Some participants were deterred from PA by seeing others with long COVID experience a
12 symptom relapse. The severity and unpredictability of their own symptoms caused others to
13 fear potential adverse events, along with the absence of any guarantee that permanent
14 damage would not be caused by PA:

15 *“I read about pacing and I haven’t tested myself, so I’m not exercising and I think*
16 *that’s a big thing for me... So when I’m reading other people saying they get tired*
17 *when they exercise, maybe that’s put me off from trying that. Maybe it’s the fear of*
18 *not knowing.”(IV9)*

19
20 *“...I’ve always been one of those people that thinks well, you know, you push through*
21 *it....But this you just can’t. And this is something that I’m becoming more afraid of that*
22 *I think maybe I need to properly back off from as much daily activity as I can to recover*
23 *from this because I’m scared that I will eventually end up as probably a 50% to a 60%*
24 *of what I was previously, permanently, or for a longer term.” (IV5)*

1

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6 2 Participants were especially discouraged from PA by symptoms such as breathlessness and
7
8 3 heart palpitations. Where medical advice was sought or provided, this tended to err on the
9
10 4 side of caution and thus reinforced decisions to avoid PA:

11
12
13 5 *My heart rate being high is a worry. I do experience chest pain and constant tightness*
14
15 6 *on my chest, which again is a worry. And I've never felt as if I could really push myself...*
16
17 7 *And my doctor has said... well don't push it, you may do more harm than good by*
18
19 8 *pushing too much. Which again doesn't help me an awful lot..." (IV1)*
20
21
22

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23
24
25 10 Most participants established personal strategies for managing PA based on trial and error.
26
27 11 All described a limited energy reserve that must be used wisely, planning their days according
28
29 12 to personal schedule and priorities. Activities tended to be selected based on their benefit to
30
31 13 wellbeing and/or responsibilities, e.g. walking, getting outdoors and fulfilling caring duties:

32
33
34
35 14 *"I have to try and think well if I need to be around to look after my kids or something*
36
37 15 *in particular in a day I need to be very, very careful of what I do the day before." (IV5)*
38
39

16

40
41
42 17 *"I do the physical things that look after my mental health. So going outside and getting*
43
44 18 *some fresh air looks after my mental health, and it in doing so helps the other*
45
46 19 *symptoms, if that makes sense. So I focus on those a lot. So on a sunny day I'll go*
47
48 20 *outside, because blue skies do me the world of good." (IV7)*
49

21

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51
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54
55 22 This process of pacing and energy conservation was not without challenges. Many
56
57 23 participants expressed a desire for better monitoring and support to manage PA, and bespoke
58
59 24 long COVID guidance for establishing a safe, consistent baseline for activity:

1
2
3 1 *“Everything that you read is pace yourself, pace yourself. But that’s really hard to do,*
4
5
6 2 *because until you’ve overdone it you don’t know how much you can do without*
7
8 3 *overdoing it, if you see what I mean, so learning by default. Which isn’t the best way,*
9
10 4 *but I guess what’s enough for me might not be enough for somebody else.” (IV8)*

11
12
13 5
14
15 6 *“...what I found with the advice for chronic fatigue syndrome is there seems to be, I*
16
17 7 *don’t know, I’m kind of just assuming this and making it up but it seems that there’s*
18
19 8 *more of a standard pattern; whereas with this it seems that no two days are alike so*
20
21 9 *it’s really hard to find a baseline because it’s so erratic.”(IV3)*
22
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11 **Adapting to an altered life**

30 12 There is a clear sense that long COVID is experienced as life altering. Many participants
31
32 13 described a loss of ‘self’ and a substantial impact on their identity. Some participants made
33
34 14 sense of this as a ‘pre-’ and ‘post-’ COVID life, others described it as a journey. Whilst the
35
36 15 prospect of permanent disablement was distressing for all, many older participants drew on
37
38 16 life events such as previous illness to make sense of their current experience:
39
40
41
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44

45 18 *“...I’m self-aware when it comes to my health and my mood and I think I’m just*
46
47 19 *accepting of it rather than wanting to change it or be negative about it” (IV13)*
48
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50
51

52 21 In contrast, younger participants (e.g. those aged 18-24) struggled with their reduced
53
54 22 function:

55
56
57 23 *“I just want my life back, it’s getting a bit tedious. I see myself just becoming a*
58
59 24 *burden, I don’t want to live my life like that.” (IV4)*
60

1
2
3 1
4
5
6 2 The majority of participants had been unable to resume activities that were previously
7
8 3 central to their core identity (e.g. a parent, an employee). Any activity that provided a sense
9
10 4 of normality thus helped to refute the idea that this changed identity was permanent (a
11
12 5 prognosis that was both feared and resisted). Participants for whom PA was a core feature
13
14 6 of their self-concept previously referred to this as a strong motivator in their desire to
15
16 7 improve functional capacity and resume PA:
17

18
19
20 8 *"I've been a runner and then a cyclist for many years so I had the intent of getting back*
21
22 9 *in the walking. And then as soon as I could I got back in the cycling a little bit". (IV6)*
23
24

25 10
26
27 11 *"I've always been physically active... So it was somewhat testing myself, somewhat*
28
29 12 *being hard headed and driven and also hoping that I'm actually fine, it's all over now*
30
31 13 *and I can get back to playing basketball soon..." (IV15)*
32
33
34

35 14
36
37 15 Some participants had reached a point of 'reluctant acceptance', not necessarily arrived at
38
39 16 peacefully but through exasperation and for some, a degree of self-defeat. Participants
40
41 17 described needing to give themselves permission (or seeking it from others) to rest, and
42
43 18 some described a shift in priorities:
44
45

46
47 19 *"I'm just desperate to get back to exercise but I've had to learn that I can't, and a lot*
48
49 20 *of mindfulness and patience and... the supportive people around me just helping*
50
51 21 *basically, just listening."(IV3)*
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1
2
3 1 *“...I feel there’s an opportunity for change. I might reduce my hours going forward. It’s*
4
5 2 *difficult but I might try and balance my work-life balance a bit more and pace*
6
7 3 *myself.”(IV9)*
8
9

10 4
11
12
13 5 Family and friends played a significant role in participants’ ‘journeys’. While participants’
14
15 6 symptoms were severe and physical function was most disrupted, friends and family acted
16
17 7 as informal carers, supporting self-care activities such as cooking. They also provided
18
19 8 emotional support, although as with medical professionals, this was sometimes contingent
20
21 9 on an understanding and awareness of long COVID that developed gradually. Over time,
22
23 10 family and friends became important PA companions, often adjusting their own PA
24
25 11 behaviour to match the level of the person with long COVID and providing a reassurance
26
27 12 that fostered confidence in activities such as walking:
28
29

30
31
32 13 *“I started going out every day and trying to do a bit more of a walk at home where it*
33
34 14 *was relatively safe, my mum was there, she would walk with me and look after me.”*
35
36 15 *(IV11)*
37
38
39

40 16 41 42 17 **DISCUSSION**

43 18 **Resuming and maintaining ‘normal’ activity**

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46
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48 19 Our findings illustrate the impact of long COVID on the energy reserves of individuals which
49
50 20 is consistent with previous reports (10,11). Our study highlights the importance of activities
51
52 21 of daily living (ADLs, e.g. housework, gardening) and outdoor activity to the normality and
53
54 22 mental health of people with long COVID interviewed. ADLs have been defined as
55
56 23 fundamental skills required for independent living (25) and are often used to assess physical
57
58
59
60

1 function. Participants prioritised and selected these activities based on their individual
2 meaning, balancing what was physically possible against what provided the biggest return
3 on investment in terms of feeling normal, engaged in family life or what boosted their
4 mood.

5 Our findings indicate that people experiencing long COVID need better support to manage
6 their symptoms, especially fatigue, whilst also helping them safely pursue the potential
7 benefits of PA. As in previous research (11), participants reported that guidance about PA
8 was not always tailored to the complexity of long COVID. In particular, they lacked support
9 on how to establish a baseline and upper threshold for activity which accommodated the
10 erratic relapse-recovery cycle common to our participants' experience. Our research
11 suggests that pacing needs to be individualised, considering biographical factors such as life-
12 stage as well as current physical function and activity history. Many people will also require
13 monitoring (either via a professional or self-monitoring tools) to provide reassurance about
14 the safety of PA whilst experiencing other symptoms like rapid heartbeat or breathlessness.

15 Our findings reflect concerns regarding the potential risk of long-term damage associated
16 with post-exertion malaise and PA. Participants differed in their attitudes towards relapse,
17 some believing they were constructive to recovery whilst others feared danger to long-term
18 health. This paradoxical role of PA in relation to relapse and recovery reflects previous
19 qualitative studies involving people with physically limiting conditions such as multiple
20 sclerosis (26). Parallels have been drawn between long COVID and myalgic
21 encephalomyelitis (ME) and/or chronic fatigue syndrome (CFS) (27). Recently, NICE
22 withdrew a recommendation to prescribe graded exercise therapy for patients with ME/CFS
23 following concerns it could cause harm (28). It is imperative to establish consensus, adding

1 to what is already known (17) regarding PA-related advice specifically for people with long
2 COVID, including the identification of individual phenotypes for whom PA might or might
3 not add value to their recovery.

4 **Access to information and the role of the internet**

5 For the majority of our participants, online long COVID communities provided opportunities
6 to relate and empathise with others (2,10,11). Online communities pool collective
7 knowledge derived from the lay expertise of members (29). Information being shared is thus
8 vetted and validated by the online community itself (30,31) and such groups can provide
9 access to rapidly-changing information that is inaccessible or unavailable offline (32, 33).
10 Advice about PA was accessed online much quicker than it was cascaded via medical
11 professionals. The novelty of long COVID however, meant that the lay expertise of members
12 was sometimes dependent on learning from patients with other apparently similar
13 conditions. In the case of graded exercise therapy, this had potential to cause confusion
14 where advice was controversial or disputed by some patients. Most participants also
15 experimented with pacing and graded exercise without support from a health professional,
16 risking potential damage to their health.

18 **Influence of psychological characteristics on PA behaviour**

19 Previous research involving people with long COVID has reported a substantial impact on
20 identity (10,11). Our study extends these findings; people for whom PA was a core aspect of
21 their identity pre-COVID were more inclined to push themselves physically, willing to risk
22 relapses or view them as constructive. Their mental health was also more contingent on
23 being able to undertake PA. PA identity has previously been associated with commitment,

1 ability and self-regulation, with research suggesting that identity-behaviour discrepant
2 situations can create negative affect (34). Further research could explore the relationship
3 between PA identity and physiological and psychological responses to exertion and relapses
4 in people with long COVID.

5 The common-sense model (CSM) of self-regulation (35) could provide a useful theoretical
6 framework for understanding PA behaviours in people with long COVID. The model
7 illustrates how deviations from 'normal self' (e.g. onset of symptoms and disruption of
8 function) interact with illness beliefs (e.g. drawing on past illness experiences) to appraise
9 the threat level of long COVID symptoms. This results in the activation of treatment action
10 plans (in this case, PA choices and behaviours) that are mediated by social influences (e.g.
11 family/friends, mass media) (36). The CSM highlights a number of attributes that influence
12 appraisal of health threats and subsequent behaviours, including expectations about the
13 timeline for a given illness and perceived efficacy of self-management behaviours. In our
14 study, these factors affected participants' likelihood of continuing to engage in PA;
15 participants who felt that PA had a positive effect were more committed to maintaining PA.
16 In contrast, some participants re-evaluated their PA behaviour over time, reducing PA when
17 symptoms continued longer than expected or if they perceived PA to be harmful.

18 Whilst the aim of our study was not to undertake a comparative analysis, we were alerted
19 to potentially important age-related differences. Specifically, we noted that amongst
20 younger participants the debilitating physical symptoms of long COVID appeared to have a
21 particularly negative impact on participants' sense of self and, for these participants,
22 adjusting to an uncertain future presented significant psychological struggle. Future work
23 could examine the particular psychological- and identity-related challenges of long COVID

1 experienced by differing age cohorts. Sociological theories of illness including 'biographical
2 disruption' (37) might offer a potentially useful explanatory framework for such work.

3 **Implications for Long COVID rehabilitation**

4 The range of symptoms, severity, frequency and duration associated with long COVID (38)
5 presents significant challenges for the publication of precise recommendations for PA in
6 people with long COVID. Recommendations need to be tailored to individuals' clinical status
7 and in some cases will require medical assessment by a specialist.

8
9 Our findings endorse ongoing efforts to establish holistic models of care that address both
10 the physical and psychological impact of the condition (39). They also highlight the limited
11 capacity of primary care to provide PA-specific support. We agree with calls for multi-
12 disciplinary work to support people with long COVID (40) highlighting the potential role of
13 sports medicine and the need for collaboration between centres of wellbeing, behavioural
14 science and professionals from a range of medical specialties.

15 16 17 **Limitations**

18 In our study, seventeen out of thirty-five people invited chose not to participate. We did not
19 ask non-responders to provide a reason for declining participation, and thus cannot
20 speculate on their personal choices, but the scope of our study indicates a potential for
21 response bias towards people with a particular interest in PA. Qualitative research of this
22 kind is typically based on small samples and is not intended to be generalisable, seeking
23 instead to provide trustworthiness and sufficient context to allow readers to make their
24 own transferability judgement (41). To date, inconsistent diagnoses of long COVID has made

1 it difficult to ascertain the demographic profile of people with long COVID at a population
2 level, with women disproportionately represented in symptom studies (42) and qualitative
3 research (10,11) along with people of higher educational background (10). We took steps to
4 achieve a diverse sample in terms of age, gender and ethnicity, but did not collect
5 information on socio-economic status or geographical characteristics of participants, so are
6 unable to draw firm conclusions about how these factors may influence our findings.
7 Nevertheless, our participants were recruited from a research interest database indicating a
8 level of engagement and access to online research, and our sample might not be
9 representative of the long COVID population as a whole. Inclusion of people from digitally
10 excluded populations (43) and a wide range of demographic profiles is important for future
11 research and a key factor in providing equity of access to long COVID support.

12

13 **CONCLUSIONS**

14 This study provides insight into the challenges of managing PA alongside the extended
15 symptoms associated with long COVID. Findings highlight the need for greater clarity and
16 tailoring of PA-related advice for people with long COVID and improved support to resume
17 activities important to individual wellbeing.

18

19 **Acknowledgments**

20 The authors thank all participants of this study for sharing their time and experiences.

21

22 **Contributorship statement**

23 RC initiated the idea for the study. HH designed the protocol and secured ethics for the study
24 with support from RC. NK undertook stratification of database participants. HH undertook
25 recruitment including invitations to take part, provision of participant information and collecting

1 written informed consent. HH carried out all interviews. HH and LK undertook initial data
2 analysis and developed preliminary coding frameworks. HH, LK and NK reviewed and refined
3 themes with oversight from RC. HH prepared the manuscript and all authors edited and revised
4 the final version.

5 **Competing interests**

6 All authors have completed the ICMJE uniform disclosure form
7 at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the
8 submitted work; no financial relationships with any organizations that might have an
9 interest in the submitted work in the previous three years; no other relationships or
10 activities that could appear to have influenced the submitted work.

11 **Funding statement**

12 This study received no external funding.

13 **Data sharing statement**

14 Complete transcripts are not available as they pose a risk to participant confidentiality. All
15 other study materials are available on reasonable request.

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UNDERSTANDING COVID-19 RECOVERY, PHYSICAL ACTIVITY AND WELLBEING

Interview Guide

Recovery experience

Can you start by telling me about your COVID-19 experience? What happened, and how have you been recovering since?

What support have you had to recover?

- Probe re: support from different groups inc. employer, GP, hospital, friends/family, other survivors
- Role of social media/govt information (see if participant raises unprompted)
- What support has been missing so far or do you think you might need in the future?

Role of physical activity

How has physical activity and exercise played a part in your COVID-19 experience?

- For example, how have your physical activity levels been affected?
- Has physical activity been an issue (positive or negative) in your recovery so far?

Future outlook

What are your priorities (and/or concerns) for your health and wellbeing going forward?

Positive experiences

What have been the positives from your experience?

Other

Is there anything else we haven't covered that you think is important to mention here?

COREQ Checklist

No.	Item	Guide questions	Response	Included in manuscript?
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	HH	Y pg. 8
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	PhD, MSc, BSc	Y pg. 8
3	Occupation	What was their occupation at the time of the study?	Researcher	Y pg. 8
4	Gender	Was the researcher male or female?	Female	Y pg. 8
5	Experience and training	What experience or training did the researcher have?	Qualitative research in exercise psychology, public health	Y pg. 8
6	Relationship established	Was a relationship established prior to study commencement?	No	Y pg. 7
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Pre-interview discussion with participants took place to establish aims and background of the researcher	Y pg. 7
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	Background in public health and exercise psychology	Y pg. 8
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded</i>	Reflexive thematic analysis	Y pg. 8

		<i>theory, discourse analysis, ethnography, phenomenology, content analysis</i>		
10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Purposive from a research interest database	Y pg. 6-7
11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Email	Y pg. 7
12	Sample size	How many participants were in the study?	18	Y pg. 7
13	Non-participation	How many people refused to participate or dropped out? Reasons?	14 non-responders to email invitation; 3 non-responders following participant information being sent. Reasons for refusal addressed in limitations.	Y pg. 7, pg.21
15	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Home / telephone interviews	Y pg. 7-8
16	Presence of non-participants	Was anyone else present besides the participants and researchers?	No	Y pg. 7-8
17	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Demographic table included	Y pg. 9
18	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Semi-structured interview guide	Y pg. 8

19	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No	n/a
20	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording	Y pg. 8
21	Field notes	Were field notes made during and/or after the interview or focus group?	No	n/a
22	Duration	What was the duration of the interviews or focus group?	45 minutes max	Y pg. 8
23	Data saturation	Was data saturation discussed?	Y	Y pg. 7
24	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Y	Y pg. 8
25	Number of data coders	How many data coders coded the data?	3	Y pg. 8
26	Description of the coding tree	Did authors provide a description of the coding tree?	n/a	n/a
27	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from data	Y pg. 8
28	Software	What software, if applicable, was used to manage the data?	n/a	n/a
29	Participant checking	Did participants provide feedback on the findings?	Y via lay summary review – in progress	N
30	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Y	Y pg. 10-17
31	Data and findings consistent	Data and findings consistent	Y	Y pg. 10-17

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4	32	Clarity of major themes	Were major themes clearly presented in the findings?	Y
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7	33	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Y
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