

COVID-19 rapid evidence review

Barriers to and the facilitators of, timely referral to specialist care

The views and experiences of patients, their families and carers

November 2021

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Introduction

Healthcare Improvement Scotland conducted a rapid qualitative evidence review as part of the collaborative guideline development work undertaken by the Scottish Intercollegiate Guidelines Network (SIGN), the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners (RCGP) on managing the long-term effects of COVID-19. The rapid evidence review sought patient, family and carer views and experiences relating to the barriers to and facilitators of timely referral to specialist care.

The guideline covers the care of people who have signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 4 weeks and are not explained by an alternative diagnosis.

Methods

Key question

What are the barriers to, and the facilitators of, timely referral to specialist care?

The protocol for this rapid evidence review is included in appendix 1.

Literature search

The knowledge management team at Healthcare Improvement Scotland identified relevant evidence through systematic searches of the primary and secondary literature up to 29 June 2021 (see appendix 2 for details). Resources searched include bibliographic databases, grey literature sources, and preprint databases.

Results from the literature searches (40 records after de-duplication) were screened for relevance using their titles and abstracts. Two reviewers independently screened all titles and abstracts.

Following screening, potentially relevant studies identified (6 studies¹⁻⁶) were then assessed in full text by two reviewers working independently to determine whether they met the inclusion criteria (see appendix 1). Three additional studies which was identified in searches for separate questions were also examined.⁷⁻⁹ Three studies were excluded following examination of the full text as they did not address the research question. See appendix 3 for the study flow chart of included studies and appendix 4 for a list of excluded studies, with reasons for exclusion.

Data extraction

Two reviewers independently extracted descriptive data on each study (see table 1). Details extracted from the studies included: the country in which the study was conducted, the methods of data collection and analysis used, the phenomena of interest, setting / context / culture, participant characteristics and sample size, and a description of the main results (themes) reported in each paper.

Quality assessment

The five studies used in the review were critically appraised independently by two reviewers using the CASP qualitative checklist (<https://casp-uk.net/casp-tools-checklists/>).

Data synthesis

Thematic synthesis was not undertaken due to the very limited amount of relevant information which was identified.

Key results

Included studies

A summary of the five included studies is presented in table 1.^{1, 2, 7-9} Details of the study citations can be found in appendix 5.

Table 1: summary of qualitative studies in the rapid evidence review

Study [country]	Methods for data collection and analysis	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results	Comments
Taylor et al 2021 [UK] Subset of a larger study Kingstone et al 2020	Semi-structured interviews. The topic guide was developed by the researchers in collaboration with experts by experience. The topic guide was modified iteratively throughout data collection and analysis. Inductive and interpretive	Experiences of people with persisting symptoms following suspected or confirmed COVID-19 infection in March or April 2020	UK Participants recruited via Facebook and Twitter with snowball sampling	Doctors (n=13, 2 male, 11 white British) Sample size was determined by inductive thematic saturation, which was judged to be the point at which no new codes or themes were developed from the analysis.	Themes: <ul style="list-style-type: none"> • making sense of symptoms • feeling let down • using medical knowledge and connections • wanting to help and wanting to be helped • becoming a more empathic doctor. 	Theme most relevant to this key question was using medical knowledge and connections

	thematic approach, applying principles of constant comparison.					
Ladds <i>et al.</i> (2020) ¹ [UK]	Individual narrative interview (telephone or video) or participation in an online focus group (two trained facilitators, experiences of symptoms elicited, and positive and negative interactions with health services) Constant comparison	Experience of the development, course and resolution of long-term symptoms of COVID-19 What services were accessed (or tried to access), and what were patients' experiences of those services? Ideas for improving the management of the condition and the design	Community / discharged from hospital or never hospitalised	Total sample = 114 people 55 interviews (40 female/15 male) Median age 48 (range 31-68) 5 hospitalised for COVID-19 (50 not) 59 focus group participants (40 female/19 male) Median age 43 (range 27-73) 6 hospitalised (53 not)	Five themes: (i) the illness experience (ii) accessing care (iii) relationships (or lack of) with clinicians (iv) emotional touchpoints in encounters with health services (v) ideas for improving services	Section on accessing care provided some information

	method of data analysis	and delivery of services				
Ladds et al (2021) [UK]	As above	to explore the experiences of healthcare workers with long COVID to develop a set of quality standards and potential care pathway model for management of long COVID.	Community / discharged from hospital or never hospitalised	43 respondents who were healthcare workers 81% female 84% white	Themes: <ul style="list-style-type: none"> • Uncertainty • use of mindlines • support groups and communities of practice • therapeutic relationships and roles • professional identity and practice • suggestions for service improvement. 	Within the mindlines theme the practical use of professional contacts to secure specialist referral was mentioned.
Kingstone 2020 [UK]	Semi-structured interviews. Topic guide was developed by the research team in collaboration with 'experts by experience'.	Explore the symptoms that people with confirmed or suspected COVID-19 infection are continuing to experience following recovery from the acute	UK Participants recruited via Facebook and Twitter with snowball sampling	24 Adults with COVID onset March/April 2020 – none had been hospitalised Majority white British Unclear when interviews conducted –study submitted Sept 2020	Themes: <ul style="list-style-type: none"> • the 'hard and heavy work' of enduring and managing symptoms and accessing care • living with uncertainty, helplessness and fear, particularly over 	The themes around accessing care/finding right GP were relevant to this question. Participants described COVID-specific work that they had to do in order to

	<p>The topic guide was modified iteratively as data generation and analysis progressed in parallel.</p> <p>Thematic analysis was conducted applying constant comparison techniques.</p>	<p>infection, and to understand their experiences of primary care support and which interventions (if any) they have found to be helpful.</p>			<p>whether recovery is possible</p> <ul style="list-style-type: none"> • the importance of finding the 'right' GP (understanding, empathy, and support needed) • recovery and rehabilitation: what would help? 	<p>demonstrate first that their symptoms are real, that they really are 'long-haulers', and then attempt to persuade healthcare professionals and provider systems to help them.</p>
<p>Maxwell 2020 [UK]</p>	<p>Focus group with with some members of the Long Covid Facebook group.</p> <p>Agreed a summary report with them.</p>	<p>Understanding of the new phenomenon 'ongoing Covid19' in people who do not recover after a short period of illness</p>	<p>Unclear/ not specified</p>	<p>Long Covid Facebook members.</p> <p>Likely Sept 2020</p> <p>Query nine participants – identities known but not disclosed.</p>	<p>Four overarching themes emerged:</p> <ul style="list-style-type: none"> • expectations • symptom journey • being doubted • support. 	<p>Key point relevant to this question:</p> <p>Lack of diagnosis makes accessing services difficult. Primary care, community and helpline staff need better training and knowledge about</p>

	No detail provided on how analysis conducted.					the ongoing effects of Covid19.
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Quality assessment

Critical appraisal of the evidence is presented in appendix 6. The qualitative research methods used were interviews and focus groups.

All the studies recruited participants through social media and/or online support groups. This convenience sampling arguably resulted in biased samples since people who are active on social media or online support groups are likely to differ from the general population (for example, younger age) and may be more vocal about their experiences of COVID-19. All acknowledged skewed sample characteristics including mainly white ethnicity, over-representation of women, and a generally younger age group.

None of the studies described or discussed potential biases arising from the relationship between researchers and study participants.

Findings

Given that few study participants had been referred to specialists it was not possible to develop robust analytical themes based on the small amount of content relating to the key question.

Context

It is important to consider that all included studies were conducted after the first pandemic wave, between May 2020 and September 2020 and so reflect early experience of post Covid-19 syndrome.

Barriers

Barriers to specialist referral identified by study authors were:

- Lack of recognition or understanding about the condition.^{1, 2, 8, 9}
- Symptoms not being taken seriously.⁷
- General practitioners being unaware of local specialist rehabilitation services.²
- A lack of clearly defined care pathways for patients with long term persisting symptoms.^{2, 9}

“He didn’t seem to have any idea what it could be. I felt fobbed off. I said I’m worried – there are articles and news outlets that I’ve been reading and I want to know what’s happening to me – people are having strokes, blood clots. I haven’t been to hospital but I’m concerned I’m still getting these effects. He said ‘oh you’ll be fine you’ve only had it mildly’.” (Ladds, 2020 p8)²

“My last interaction with my GP was in June. I asked about my lungs, and he said, ‘What do you want me to do about it? You tell me. I have no idea.’”(Ladds, 2021, p61)¹

“And my GP wasn’t really very interested in it. I think at my kind of insistence she discussed with a medical consultant at the hospital, and the consultant said, “Well, that’s normal for COVID. That’s what people are experiencing, so there’s no investigations needed”, which to me didn’t feel remotely reassuring.” (Taylor 2021, p837) ⁷

Facilitators of specialist referral were identified. The first related to the experiences of doctors and other health professionals with persisting symptoms.^{1, 7}

- The use of contacts or colleagues to navigate the system and access investigations or specialist reviews.^{1, 7}
- Seeking a private consultation to confirm and validate the illness.²
- Self advocacy²

“I’d messaged a friend from medical school who’s a cardiologist as I was wondering about pericarditis... I’ve always tried to be a good patient and go through my GP and things, but it wasn’t working. So that’s when I started messaging people and calling in favours.” (Taylor 2021, p838)⁷

Abbreviations

CASP	critical appraisal skills programme
GP	general practitioner
NICE	National Institute for Health and Care Excellence
RCGP	Royal College of General Practitioners
SIGN	Scottish Intercollegiate Guidelines Network

Appendix 1: review protocol

RQ 12: What are the barriers to, and the facilitators of, timely referral to specialist care?

Criteria	Notes
Population	<ul style="list-style-type: none"> • Adults and children who are experiencing new or ongoing symptoms: <ul style="list-style-type: none"> ○ 4-12 weeks from onset of acute COVID-19 illness ○ 12 weeks from onset of acute COVID-19 illness • Families or carers (formal or informal) of the person who was referred • Healthcare professionals responsible for referral
Exposure	<ul style="list-style-type: none"> • Referrals to integrated multidisciplinary clinic for post-COVID-19 syndrome or equivalent local service(s) • Referrals to other specialist care for assessment or treatment • Referrals to psychology/IAPT services or liaison psychiatry • Experience of no referral despite PCS symptoms
Comparators	Not applicable
Outcomes/evaluation/approach	<ul style="list-style-type: none"> • Quantitative data on proportion of respondents reporting the barrier or facilitator related to referral.

	<ul style="list-style-type: none"> • Qualitative data on views and experiences about barriers and facilitators to referral. • Time to first appointment • Time to first assessment • Time to first treatment
Settings	Any
Subgroups	<ul style="list-style-type: none"> • Groups as defined in the EIA for example, age, sex, ethnicity, including: <ul style="list-style-type: none"> ○ Children and young people ○ Healthcare workers ○ Older people • Diagnostic status of acute COVID-19 (e.g. confirmed or high clinical suspicion) • Treatment setting for acute COVID-19, including: <ul style="list-style-type: none"> ○ Hospitalised for acute COVID-19 ○ Non-hospitalised for acute COVID-19 ○ Care or residential homes)
Study types	<ul style="list-style-type: none"> • Systematic reviews of qualitative studies • Qualitative studies that collect data from focus groups and interviews • Qualitative and quantitative studies that collect data from questionnaires/surveys • Mixed method study designs (including qualitative evidence that matches the above study designs only)
Countries	UK studies are preferred.

	Where there are no UK studies, evidence from other countries will be considered on a case-by-case basis with input from the Expert Panel to determine applicability to the UK healthcare system.
Timepoints	Any timepoint more than 4 weeks from initial COVID-19 illness

Appendix 2: literature search strategy

Information Scientists at Healthcare Improvement Scotland conducted systematic literature searches to identify qualitative literature on patient/carer views and experiences relating to long-term effects of COVID-19 relating to COVID-19. A full list of resources searched is available on request.

In databases not specific to COVID-19 research, search results were limited to 2020/21 as the year of publication. All search results were limited to English language.

The Information Scientists excluded records relating to views or experiences of healthcare for conditions other than COVID-19 during the pandemic, to acute episodes of COVID-19 illness, and records relating to the views of healthcare staff who were not also patients.

Table 2: databases searched

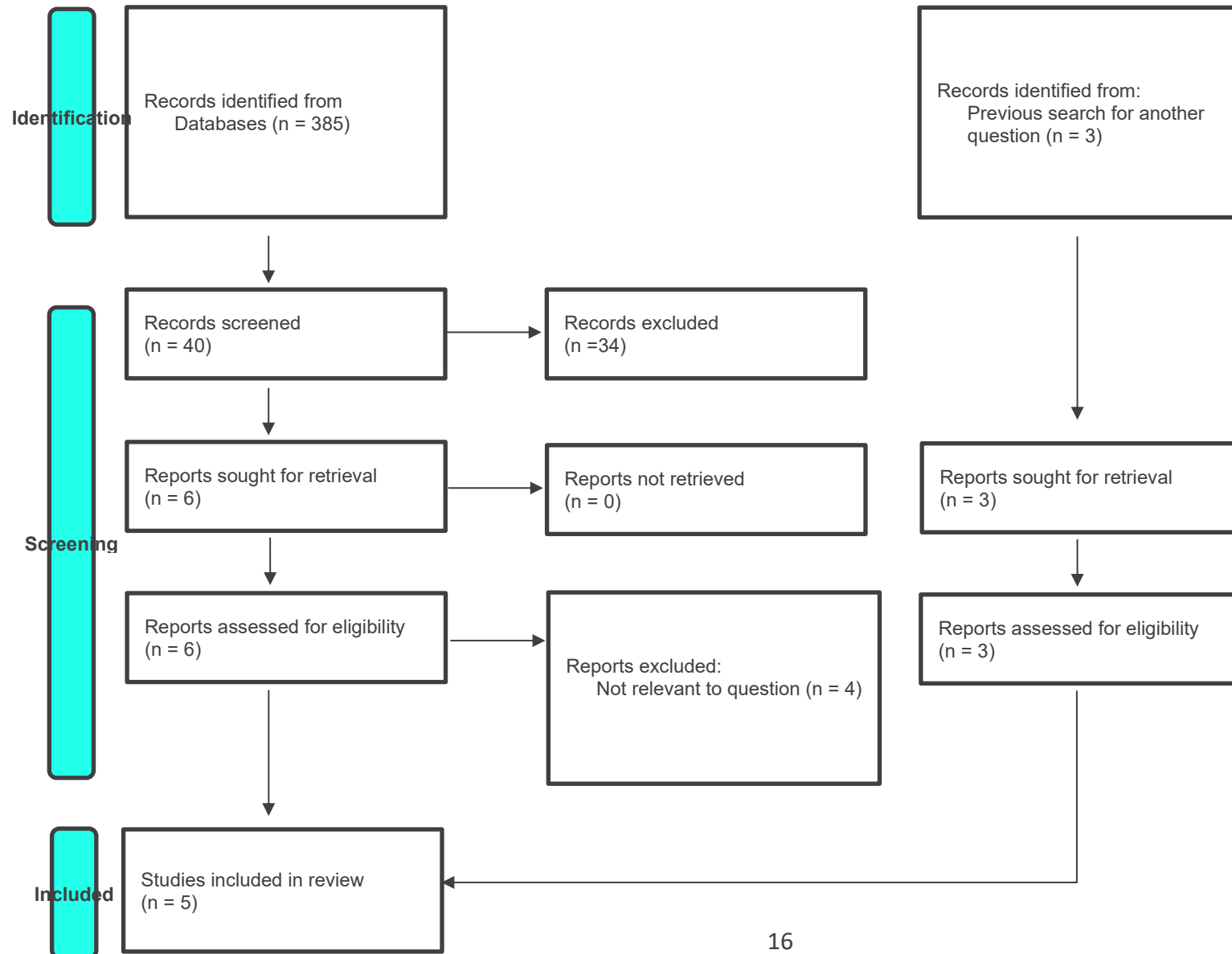
Database	Platform	Segment searched
Pubmed LitCov	Pubmed	All
WHO database of publications	-	2020, 2021 English language
Proquest COVID	Proquest	All
Epistemonikos	-	2020, 2021 English language
MedRxiv	-	2020, 2021 English language

bioRxiv	-	2020, 2021 English language
Medline	Ovid	2020, 2021 English language
PsychInfo	Ovid	2020, 2021 English language
Web of Science Core Collection	-	2020, 2021 English language
Cinahl	EBSCOHost	2020, 2021 English language

Database strategies

Full details of database search strategies are available on request.

Appendix 3: study flow diagram



Appendix 4: excluded studies

Studies excluded at title and abstract screening

A full list of articles excluded at the screening of titles and abstracts stage is available on request.

Studies removed at full text screening

Table 3: studies rejected at full text screening

Study	Reason for exclusion
O'Brien, H., et al. (2021). "An integrated multidisciplinary model of COVID-19 recovery care." <i>Ir J Med Sci</i> 190(2): 461-468.	No qualitative information on barriers/facilitators to referral
Inzitari, M., et al. (2020). "How a Barcelona Post-Acute Facility became a Referral Center for Comprehensive Management of Subacute Patients With COVID-19." <i>J Am Med Dir Assoc</i> 21(7): 954-957.	No qualitative information on barriers/facilitators to referral
Pinto, M., et al. (2020). "Post-Acute COVID-19 Rehabilitation Network Proposal: From Intensive to Extensive and Home-Based IT Supported Services." <i>Int J Environ Res Public Health</i> 17(24). Dec 2020	No qualitative information on barriers/facilitators to referral
Salawu, A., et al. (2020). "A Proposal for Multidisciplinary Tele-Rehabilitation in the Assessment and Rehabilitation of COVID-19 Survivors." <i>International Journal of Environmental Research & Public Health [Electronic Resource]</i> 17(13): 07. July 2020	No qualitative information on barriers/facilitators to referral

Appendix 5: citations for included studies

Ladds E, Rushforth A, Wieringa S, Taylor S, Rayner C, Husain L, et al. Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC Health Serv Res.* 2020;20(1):1144. Epub 2020/12/22.

Ladds E, Rushforth A, Wieringa S, Taylor S, Rayner C, Husain L, et al. Developing services for long COVID: lessons from a study of wounded healers. *Clin Med (Lond).* 2021;21(1):59-65. Epub 2021/01/23.

Taylor AK, Kingstone T, Briggs TA, O'Donnell CA, Atherton H, Blane DN, et al. 'Reluctant pioneer': A qualitative study of doctors' experiences as patients with long COVID. *Health Expectations.* 2021;24(3):833-42.

Maxwell E. Living with Covid19. National Institute for Health Research. 2020.

Kingstone T, Taylor AK, O'Donnell CA, Atherton H, Blane DN, Chew-Graham CA. Finding the 'right' GP: a qualitative study of the experiences of people with long-COVID. *BJGP Open.* 2020;4(5). Epub 2020/10/15.

Appendix 6: study quality assessment

Table 4: critical appraisal of studies using the CASP qualitative checklist

CASP criteria	Yes/No/ Can't tell	Comments
Study: Taylor <i>et al</i> 2021 (Kingstone <i>et al</i> 2020)		
Was there a clear statement of the aims of the research?	Yes	Aims clearly stated.
Is a qualitative methodology appropriate?	Yes	Qualitative methodology highly appropriate as exploring participants' experiences. Qualitative methodologies are suitable for this study due to the exploratory nature of the research questions, which seek to reveal perspectives and understandings, and interpret the experiences of people with COVID-19.
Was the research design appropriate to address the aims of the research?	Yes	Qualitative methodology, with semi-structured interviews. Good justification provided at start of methods section for choice of qualitative methodology.
Was the recruitment strategy appropriate to the aims of the research?	Yes	Recruitment strategy involved social media (Facebook & Twitter) and snowball sampling. Appropriate strategy to recruit sample in short timeframe but may be biased (social-media users and arguably more vocal individuals, largely self-identified as having long COVID). Bias not discussed by authors - focus on effective strategy with Twitter being particularly fruitful.
Was the data collected in a way that addressed the research issue?	Yes	Methods appropriate and clearly described. Topic guide modified iteratively. The topic guide was developed by the research team in collaboration with 'experts by experience' (people who were suffering with persistent symptoms) in one-to-one discussions with one author, and at a Clinical Commissioning Group support group in which the author participated. Data collection continued until the research team members were confident that saturation, at a thematic level, had been reached.
Has the relationship between researcher and participants been adequately considered?	Can't tell	Little reflexivity - told that one of the authors is also a long term COVID-19 sufferer but no discussion of potential bias.

Have ethical issues been taken into consideration?	Yes	Ethical approval from University ethics committee - appropriate as not recruited via NHS. Research ethical by current standards - social media posts for recruitment followed by information sheet & written informed consent - consent reconfirmed at start of interview - confidentiality implied (audio recordings sent to professional transcription service, codes used for analysis & reporting, participants should not be identifiable from article).
Was the data analysis sufficiently rigorous?	Yes	Data analysis described and applied thematic analysis cited. Two researchers analysed data, saturation discussed, although there could be more clarity around how themes were identified. Good spread of participant quotes used.
Is there a clear statement of findings?	Yes	Findings clearly presented and flow from the raw data (quotes). Findings answer research question. The findings used mostly quotes which is appropriate for applied thematic analysis - descriptive. Appears credible from use of quotes, two researchers, feedback from participants and other experts by experience (people with COVID-19). Illustrative data are provided to support the analysis; data extracts are identified by participant number with sex and age reported in brackets for context.
How valuable is the research?	-	Results are valuable - provides insight into experiences of long COVID which are to date under-researched. Experience of long-term COVID-19 and accessing care can be used by healthcare professionals to inform support/management of people with long COVID and help healthcare professionals to understand the condition. The findings from this study will provide important contributions to the development of flexible, person-centred interventions for people recovering and rehabilitating from COVID-19.
Study: Ladds <i>et al</i> (2020) Ladds <i>et al</i> (2021)		
Was there a clear statement of the aims of the research?	Yes	Sets out rationale for the work and three questions to be answered.

Is a qualitative methodology appropriate?	Yes	Question about what services accessed could be answered using survey techniques, but other aims are to describe experiences and to measure beliefs about service design which are clearly served by qualitative approaches.
Was the research design appropriate to address the aims of the research?	Yes	Use of focus groups and interviews appropriate to gather qualitative information; tried to adjust for under-represented groups. Interim broad thematic analysis and then use of constant comparative methods; informed by relevant theories."
Was the recruitment strategy appropriate to the aims of the research?	Yes	Social media call and direct contact with support groups. Snowballing and eligibility screening. Additional steps taken to correct gender and ethnicity skew. Drew on social media to get to a group of individuals for which there was no other group established.
Was the data collected in a way that addressed the research issue?	Yes	Focus groups and interviews appropriate for gathering the necessary data. Interviews were not based upon prespecified questions as narrative wanted - this seems appropriate. Focus groups - appropriate number of participants (3 to 12) and timing (90 mins), participants could leave if tired; two trained facilitators. First ten interviews transcribed in full and used to identify themes; subsequent interviews only transcribed in part but seems reasonable and justified. Focus groups transcribed in full. Patients were involved in data analysis and also checking data.
Has the relationship between researcher and participants been adequately considered?	Can't tell	Does not specifically mentioned role of researchers, although notes that participants were involved in all aspects of the study. Research overseen by an independent advisory group with patient representation and a lay chair which met 3-monthly. The study was planned, undertaken, analysed and written in collaboration with people with long COVID.
Have ethical issues been taken into consideration?	Yes	Ethical approval was sought and received. Consent was collected either by email or verbally at the beginning of the audio or videotape. Participants informed of right to withdraw or change testimony at any stage.

Was the data analysis sufficiently rigorous?	Yes	Have put yes, but mostly likely due to constraints of the word count, there is limited information given; no real explanation of how the theories used to explain the data were chosen. Note potential limitation that only the first 10 interviews were transcribed in full, with selected parts of others added for speed. Analysis informed by multiple theoretical constructs.
Is there a clear statement of findings?	Yes	Without seeing the raw data, it is difficult to be entirely clear whether the findings reflect the information gathered, however they are explicit and clear. The 'fit' of the data with existing theories is discussed. No discussion of credibility and conflicting evidence was only presented for one theme. Unclear whether examples selected to emphasise chosen themes or if data were unanimous.
How valuable is the research?	-	While the authors acknowledge the shortcomings in the range of participants within the sample studied, the sample seems wide enough to at least start to guide practice in this area. Excellent discussion of results in theoretical contexts.
Study: Maxwell (2020)		
Was there a clear statement of the aims of the research?	No	There is no clear statement of the aims of the research. Text suggests that the aim is to gather experience to inform others and improve understanding around the issues of long-term symptoms of COVID-19.
Is a qualitative methodology appropriate?	Yes	Aimed to capture the experience of people with long-term symptoms of COVID-19.
Was the research design appropriate to address the aims of the research?	Can't tell	Only detail is that a focus group was held - no methodology description included in publication and no details described. Number of patients involved not stated. Sampling / recruitment methods not stated.
Was the recruitment strategy appropriate to the aims of the research?	Can't tell	No details provided. It appears to be a convenience sample of people in COVID-19 Facebook group – this would facilitate fast recruitment but most likely a biased sample (of Facebook users).
Was the data collected in a way that addressed the research issue?	Can't tell	Focus group used, but no details given for data collection, saturation, conduct of group, researcher role, etc.

Has the relationship between researcher and participants been adequately considered?	Can't tell	No information included.
Have ethical issues been taken into consideration?	Can't tell	No details provided.
Was the data analysis sufficiently rigorous?	No	No analytical methodology. Themes described but unclear how these were synthesised. Several quotations used in each theme with narrative interpretation of the participants' views included. No clear link between summary statements and the number of participants who provided them.
Is there a clear statement of findings?	Yes	Findings presented clearly with good range of participant quotes - no detail on credibility or way of judging credibility. Clear description of themes, but mixture of attribution of views of individuals and views of the whole focus group. Majority of themes were not supported by examples in favour of and contrary to overall theme.
How valuable is the research?	N/A	Although scant detail on methodology and methods this does provide useful information on people's experiences of living with long-term symptoms of COVID-19. The authors do justify their approach based on the lack of research conducted to date.

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