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Experiences of living with long COVID and of accessing healthcare services: a qualitative systematic review

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ABSTRACT

Objective To explore the experiences of people living with long COVID and how they perceive the healthcare services available to them.

Design Qualitative systematic review

Data sources Electronic literature searches of websites, bibliographic databases and discussion forums, including PubMed LitCovid, Proquest COVID, EPPI Centre living systematic map of evidence, medRxiv, bioRxiv, Medline, Psychinfo and Web of Science Core Collection were conducted to identify qualitative literature published in English up to 13 January 2021.

Inclusion criteria Papers reporting qualitative or mixed-methods studies that focussed on the experiences of long COVID and/or perceptions of accessing healthcare by people with long COVID. Title/abstract and full-text screening were conducted by two reviewers independently, with conflicts resolved by discussion or a third reviewer.

Quality appraisal Two reviewers independently appraised included studies using the qualitative CASP checklist**.** Conflicts were resolved by discussion or a third reviewer.

Data extraction and synthesis Thematic synthesis, involving line-by-line reading, generation of concepts, descriptive and analytical themes, was conducted by the review team with regular discussion.

Results Five studies published in 2020 met the inclusion criteria, two international surveys and three qualitative studies form the UK. Sample sizes varied from 24 (interview study) to 3,762 (survey). Participants were predominantly young white females recruited from social media or online support groups. Three analytical themes were generated: (i) symptoms and self-directed management of long COVID; (ii) emotional aspects of living with long COVID, and (iii) healthcare experiences associated with long COVID.

Conclusions

People experience long COVID as a heterogeneous condition, with a variety of physical and emotional consequences. It appears that greater knowledge of long COVID is required by a number of stakeholders, and that the design of emerging long COVID services, or adaptation of existing services for long COVID patients should take account of patients' experiences in their design.

Strengths and limitations of this study

- This is the first qualitative review on people's experiences of long COVID and of the healthcare services available to them.
- This review highlights a range of important issues associated with long COVID and accessing healthcare, which can be used to inform service delivery and design.
- Only 5 qualitative studies were eligible for inclusion in this review.
- Participants in the included studies were predominantly younger, female, and users of social media or online support groups.

INTRODUCTION

The long-term effects of COVID-19 are recognised increasingly as being heterogeneous and complex in nature. At the start of the COVID-19 pandemic there was a widespread perception that COVID-19 was an acute infection that resulted in death or recovery after 2 weeks.[1] However, many people experienced wide-ranging and fluctuating symptoms for weeks or months after confirmed or suspected COVID-19 infection. As these experiences were shared, on social media and other outlets, the term 'long COVID' was generated by patients.[2] There remains no internationally agreed definition of long COVID, as COVID-19 is still a relatively new disease, with ongoing research on the long-term effects.[3] Greenhalgh *et al* [4] suggested "post-acute COVID-19" for symptoms lasting beyond 3 weeks after onset, and "chronic COVID-19" for those lasting beyond 12 weeks. Recent UK guidelines defined "ongoing symptomatic COVID-19" as signs and symptoms lasting 4-12 weeks and "post-COVID-19 syndrome" as signs and symptoms developing during or after COVID-19 and continuing beyond 12 weeks.[5 6] As this systematic review is concerned with lived experience, we will use the patient-generated term long COVID to encapsulate all these definitions.

Symptoms of long COVID vary widely, can relapse and remit, and can affect those hospitalised and ventilated,[3] as well as those with so-called mild COVID-19, during the acute phase.[4] Little is known about long-term sequelae in asymptomatic patients, with this recently highlighted as an important area for future research.[3] Potential long-term effects include central nervous system, psychosocial, cardiovascular, pulmonary, haematologic, renal and gastrointestinal symptoms, as well as widely reported persistent fatigue, dyspnoea, joint and chest pain.[3] Estimates of long COVID rates vary from 10%[4] to 35%[7] with the true rate yet to be determined. Therefore, with over 108,000,000 confirmed COVID-19 cases globally as of 30th January 2021,[8] there are now a large number of people at risk of long COVID.

Healthcare services specifically for long COVID are evolving. For example, some specialist centres have been set up in parts of the UK,[9] and there has been a global call for the development of rehabilitation programmes and services for long COVID patients.[10] In order for healthcare services to meet patients' needs, it is important to understand the experience of long COVID and of accessing healthcare services from patients' perspectives. There is a growing body of qualitative research on the lived experience of long COVID, and to date, no published synthesis of this literature. The aim of this qualitative systematic review was therefore to explore the experiences of people living with long COVID and their perceptions of the healthcare services available to them.

METHODS

A qualitative systematic literature review was undertaken based on an *a priori* protocol (available on request) and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.[11] This review updates a review undertaken by the authors to inform the production of the Scottish Intercollegiate Guidelines Network (SIGN), National Institute of Health and Care Excellence (NICE) and

Royal College of General Practitioners (RCGP) guideline on the management of long COVID.[5] [6]

Inclusion criteria

Full details of the inclusion criteria for the review are given in supplementary file 1.

Participants: Individuals experiencing long COVID whether suspected or confirmed by diagnostic test, with no restriction on duration of symptoms. We excluded studies on the views or experiences of healthcare for conditions other than COVID-19 and those relating to the views of healthcare staff, unless they were patients themselves.

Phenomena of interest: people's views on and experiences of living with and managing long COVID, and on the healthcare services available to them.

Context: studies from any country and any setting.

Types of study: systematic reviews of qualitative studies; primary qualitative studies; qualitative components of mixed method studies.

Information sources and search strategy

An information specialist (CM) carried out a search in October 2020. Sources searched included: PubMed LitCovid, Proquest COVID, EPPI Centre living systematic map of evidence, medRxiv, bioRxiv, Medline, PsychInfo, and Web of Science Core Collection. A full list of resources searched is available in supplementary file 2. Published studies, grey literature and pre-publication articles were sought. In databases not specific to COVID-19, search results were limited to publications in 2020. All searches were limited to English language. A search update was conducted on 13 January 2021.

Bibliographic database searches applied adapted versions of the qualitative research filter by DeJean *et al* (2016)[12] and a filter for patient experience literature developed by combining terms from papers by Selva *et al* (2017)[13] and Wessels *et al* (2016)[14]. The search strategy for Medline is available in supplementary file 2. Search strategies for other bibliographic databases are available on request.

Study selection

Citations were uploaded to EndNote software and duplicates removed. Records were screened against the inclusion criteria based on titles and abstracts by two reviewers independently (JH, DM). The same two reviewers then assessed full text of potentially relevant articles. Disagreements were discussed and referred to a third reviewer where necessary (KM, MN).

Data extraction

Two reviewers independently extracted descriptive data from each study (KC, JH, KM, DM, MN), using a data extraction template designed specifically for this review. Details extracted from the studies included: country in which the study was conducted, method of data collection and analysis, phenomena of interest, setting / context / culture, participant characteristics and sample size, and a description of the main results.

Quality appraisal

Included studies were critically appraised by two reviewers independently (KC, JH, KM, DM, MN, JH) using the CASP qualitative checklist (https://casp-uk.net/casp-tools-checklists/). Discrepancies were discussed and referred to a third reviewer if required.

Data synthesis

Thematic synthesis was undertaken on the findings from included studies.[15] This involved: (i) line-by-line reading of each study by two reviewers independently (JH, KM, MN) to identify initial concepts; (ii) grouping similar concepts into initial descriptive themes and sub-themes, and (iii) generating the final analytical themes. These were discussed and agreed by the review team (KC, JH, KM, DM, MN) throughout the process.

Patient and public involvement

As a systematic review focussed on published and grey literature no primary research involving patients was conducted. The original synthesis that this review updates, was subject to review by an expert group that included several members with lived experience of long COVID, and a targeted public consultation which included groups representing those with experience of this condition.

RESULTS

Search results

The literature search identified 269 articles. A further two studies were identified from reference lists. After removal of duplicates and title/abstract screening, seven articles were evaluated as full-text. The main reasons for excluding articles were no qualitative element to the research, no patient involvement and not meeting our definition of Long Covid (we were interested in studies relating to symptoms over 4 weeks duration). Out of the seven fully evaluated articles, one study was excluded because it did not use qualitative methods or contain data on direct patient experience. A second study which was initially included was later excluded after it was withdrawn from pre-publication by the authors. A PRISMA flow diagram depicting the study selection process is provided in figure 1.

[INSERT Figure 1 PRISMA diagram]

Characteristics of included studies

Five studies were included in the thematic synthesis (table 1).[1,16-19] Three studies conducted focus groups or interviews with patients from the UK and two studies, from the Patient Led Research group, conducted international surveys with most responses coming from the USA and the UK. Sample sizes varied from 24 interviews to 3,762 survey respondents, and were generally weighted towards young, white, female participants. In the focus groups the median age was 43 while in the social media groups most responders were aged 30-49 years. All studies focussed on adults not children.

[INSERT Table 1 Study characteristics]

Methodological quality

Studies were of variable methodological quality. Three met most of the criteria on the CASP checklist (table 2) and thus were considered of high quality, and two met fewer criteria. No studies were excluded on the basis of quality as all were considered to offer valuable content despite the limitations identified.

[INSERT Table 2 CASP]

All five studies recruited participants through social media and/or online support groups. While this is understandable given the need to quickly access participants for whom no established groups or organisations existed, this convenience sampling may have resulted in bias. 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. Three included studies acknowledged skewed sample characteristics including mainly white ethnicity, over-representation of women, and a generally younger age group.[16,18,19] Limited demographic information was provided on participants, particularly in Maxwell (2020),[1] making it difficult to determine which population groups may have been missed by these studies.

None of the studies discussed potential biases arising from the relationship between researchers and study participants. This is despite people with lived experience of long COVID symptoms being among the study authors, or performing data analysis in some studies.[16,17,19] This participatory research approach can be considered to represent both a strength and a weakness. Having authors and researchers with experience of long COVID analyse data is beneficial in bringing lived experience to the interpretation of data. However, it may also introduce bias for the same reason.

Several other quality issues were noted. In the study by Kingstone *et al* [17], participants received a compensation voucher for their time, which may have influenced decisions on whether to participate. Ladds *et al* [18] only fully transcribed the first 10 out of the 55 interviews (the remaining interviews were partially transcribed). This was due to the urgency of the work and limited resources plus a perceived lack of need to duplicate previously discovered themes. This may have introduced bias. Finally, Maxwell [1] reported very limited methodological details, making it difficult to determine how the research was conducted or the number of people involved in the focus group.

Review findings

The initial stages of thematic analysis resulted in the generation of 138 descriptive themes. These were then refined into 54 sub-themes, which were attributed to 11 higher order themes using an iterative process, with continuous discussion between reviewers. Further review and refinement of themes resulted in three overarching analytical themes: (i) symptoms and self-directed management of long COVID; (ii) emotional aspects of living with long COVID; and (iii) healthcare experiences associated with long COVID. Figure 2 shows the relationship between the final three themes and the initial 11 higher order themes. Full details of descriptive themes and sub-themes are available in supplementary file 3.

[INSERT Figure 2 Mindmap of themes]

Symptoms and self-directed management of long COVID

Evidence from all the included studies[1 16-19] showed that people with long COVID experience a wider range of symptoms than the three symptoms officially recognised as acute COVID-19: high temperature, new continuous cough, and change or loss of sense of smell or taste. One individual stated:

"From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia."[1]

The symptoms experienced by patients with long COVID varied in severity from relatively mild to potentially life-threatening symptoms that required hospital admission. Symptoms also fluctuated over time with new symptoms appearing at different stages of the illness and in different parts of the body. Each symptom was experienced for a prolonged but variable length of time, with a cumulative effect in many cases.

People identified a disconnect between their lived experiences, official advice, and public perception of the illness. It was felt that the public perceived the illness as a binary condition – either mild and easily treated at home or serious and requiring hospitalisation – with no variation or allowances made for ongoing symptoms.

"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us."[17]

The literature showed that people believed they would require a short recovery period and would be back at work in two weeks, a belief mirrored by employers and the public. The lived experience, for some, was quite different:

"After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms..."[1]

"I had to take two weeks off, had to work from home for four, but had to return for two weeks with fever as my employer would not give me more time [...]."[16]

This discordance between expectations and experience seemed to have a direct effect on the mental and emotional state of those experiencing prolonged illness, often leading to uncertainty about what to do about their symptoms. People described needing to adjust their lifestyle, including pacing themselves and setting realistic goals, in order to self-manage their symptoms. A number of patients described attempts at self-care such as taking supplements or trying therapeutic massage.

Many people turned to social media and support groups (online or face-to-face) for support and found them to be a valuable way to share experiences, knowledge and resources with others in a similar situation. This communication helped to validate patient experiences and provided reassurance they were not alone in their struggle with long-term symptoms.

"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have."[18]

However, there were also reports of anxiety and depression triggered by knowledge garnered from these online groups.

" …Internet support groups, yeah on the Facebook groups that I'm on, I mean to be honest, I try not to read that group too much because it depresses me, makes me a bit anxious."[17]

Emotional aspects of living with long COVID

For many patients there was a feeling that their self-identity was affected by long COVID. People reported an impact on how they viewed themselves, before and after their illness. There was a feeling they had to reconsider who they were and what they could do within the context of family and work. The phrase "compared with how I used to be" was used by multiple participants[17]. Ladds *et al* (2020)[18] commented on the concept of a "spoiled identity" where an identity as previously "healthy, independent and successful" was perceived to be threatened.

Interviews with doctors and other clinicians who had experienced long COVID showed that many were worried about the impact of cognitive deficits on their ability to perform their jobs.

"[T]he medicolegal aspect is huge …. and it's scary to not be able to recognise potentially where you have deficits because if you can't recognise them then that's an unknown unknown in what can you do with that."[18]

There was a sense of stigma associated with long COVID, with people experiencing a sense of shame and blame (internally generated stigma) and expressing fears that employers and others in the community may stigmatise them for having long COVID (externally generated stigma). Family members were considered to be affected by long COVID and were seen as also requiring support. One interview participant described the impact her symptoms had on her family and how she felt they did not believe her:

"I think, at first, they just thought, 'Oh, for god's sake, she's napping again'. I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted …."[17]

Patients described experiencing a range of emotions as part of their illness journey. Anxiety was often related to multiple aspects of the illness including uncertainty about the cause of symptoms, concern that they may never recover completely, and anxiety due to not being believed by healthcare professionals, family and friends.

"…. I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not "I'm going to die right now", but definitely "I'm never going to get better from this" kind of feeling."[17]

Patients also expressed a strong desire to find acceptance and understanding about their experiences of long COVID, both among healthcare professionals and family and friends.

"... one of my friends did say after quite a while, "I'm not being awful, but do you think a lot of it's in his mind?" and I said "no". I was quite upset about that…"[17]

Similarly, there was a widespread perception that healthcare professionals doubted patients' descriptions of long COVID, ignored patient concerns, misdiagnosed symptoms, or were dismissive of patient experiences. This lack of knowledge affected people's feelings around their healthcare experiences.

Healthcare experiences

Across all of the studies, participants expressed concerns relating to the lack of knowledge, information and understanding about long COVID among healthcare professionals. While the reason behind this lack of knowledge was understood, there was a general feeling that there needed to be acknowledgement of this gap within the healthcare community.

"Well yeah, I feel like there's a lack of knowledge. And I really wasn't able to get any answers, I know, you know this is obviously a novel illness. But just even for one doctor to look into it a bit and come back to me, didn't happen."[17]

The absence of knowledge and information about long COVID symptoms was reported to create anxiety and confusion for patients. Ladds *et al* (2020)[18] found that this confusion was intensified by the lack of medical knowledge, understanding and guidance from healthcare professionals. There were also reports of conflicting or inconsistent advice from health professionals.[18]

Some professionals did recognise the limitations of their own knowledge[18] and referred patients to online support groups. Focus group participants suggested they would rather be told that the professional did not have the knowledge required to address their illness, if that was the case. The importance of finding a General Practitioner (GP) who was understanding, empathetic and who provided support to those experiencing long COVID is highlighted in this quote:

"I have to say it was a really powerful experience speaking to the GPs ... the two more recent ones, actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful."[17]

Along with this perceived lack of knowledge, multiple perceived barriers to healthcare access were reported, along with a general perception among participants that health services and doctors were too busy dealing with cases of acute COVID-19 to have capacity to deal with anything else, including patients with long-term symptoms. This perception appeared strengthened by the difficulties people experienced when trying to access primary care, especially if they were seeking a face-to-face consultation.

"I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful, particularly as I didn't have, and never have had, a cough or fever"[1]

In general, study participants found accessing care to be "complex, difficult and exhausting".[18] This difficulty in accessing care and perceived lack of access, led to patients describing how they felt they had to manipulate the inflexible algorithm-driven systems in order to receive care, which led to feelings of guilt and anger. Some patients described creative solutions they had come up with to help them access healthcare, while others reported resorting to private healthcare to access tests. Many patients felt they needed to conduct their own research and construct their own care pathways, taking the lead in arranging consultations with specialists and circumventing bottlenecks in the system. This was reported as a route often employed by medical professionals who themselves were suffering from long COVID.

Those who reported experiencing long-term symptoms described a perceived lack of support within the system. Some individuals described how NHS111 (a national telehealth helpline in the UK) had directed them to their GP who then directed them back to NHS111.[18] There was what appeared to be a lack of guidance for those who did not need to be admitted to hospital but were no longer in the acute phase of the illness.

Patients who felt they had received satisfactory care and access to healthcare were generally those who had been offered follow-up appointments and who felt their healthcare providers gave them ongoing support, even if that was in the form of a video or telephone call.

Telemedicine was widely used to facilitate interactions with healthcare services. However, it was generally perceived by patients to have limitations. Remote consulting with primary care was viewed by some patients as potentially limiting direct access to GPs, disrupting continuity of care (people often could not see the same GP every time), and making the communication of symptoms more challenging. Some patients felt that strict adherence to protocols for telemedicine-delivered care affected patient safety or led to mismanagement of their care.

"... I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I'm really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don't really sound too out of breath over the phone …. I really felt at that point right if you could see me you would see that I am really like broken"[18]

A positive view expressed in relation to telemedicine was that it increased accessibility of primary care during periods of societal restrictions aimed at controlling the spread of COVID-19.

"My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track."[19]

When asked to describe desirable features of healthcare services or service delivery for patients with long COVID, research participants asked for face-to-face assessments and talked about the need for 'one-stop clinics' with multidisciplinary teams (MDT) who could look at their wide-ranging symptoms and treat them holistically. A case manager to oversee individual patients and ensure that all aspects of their care was considered was suggested, along with meaningful referral pathways and criteria.

"What would be most helpful is if all main hospitals could have a Covid clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, we are having such a range of symptoms that GPs are struggling to know what to do with you"[1]

Other participants spoke about wanting to be listened to, to be believed and understood, and to be offered practical advice on coping.

DISCUSSION

To our knowledge, this is the first synthesis of findings from qualitative studies on peoples' experiences of living with long COVID and accessing healthcare services for this condition. Our main findings were threefold. Firstly, that the lived experience of long COVID is highly variable and perceived as being at odds with public perceptions and official guidance on COVID-19. Secondly, that there are significant emotional consequences of living with long COVID that need to be understood by a number of stakeholders. Finally, that people with long COVID report a range of positive and negative healthcare experiences that can be used to inform the development of new, or adaptation of existing, services for this important patient group.

Covid-19 is a new illness, first declared a public health emergency by the World Health Organization on 30th January 2020.[20] The implications across the globe and stress on healthcare services are unprecedented. It is perhaps unsurprising that knowledge of long COVID is perceived as underdeveloped; there is no agreed definition of long COVID and the long-term sequelae are to a large extent unknown.[3] Many people in the included studies turned to social media and patient-led support groups, due to perceived lack of understanding from family, employers and healthcare professionals.[1 17-19] Indeed, the term long COVID originated from social media postings.[2] Whilst these groups were seen by some as reassuring and supportive, for others they generated anxiety. Social media and support groups are widely used for other health conditions,[21] but are generally considered complementary to healthcare services; part of the "jigsaw" that makes supported self-management successful.[22] Therefore, there appears to be a need for more widespread understanding of and information about long COVID, and people with lived experience are ideally placed to contribute their expert opinion.

Our review highlighted a number of emotional consequences of long COVID including the impact on people's identities, employment, and relationships with family and healthcare providers. Emerging models and recommendations for managing long COVID all highlight the need for psychological inputs.[23-25] It is perhaps more complex to address the wider emotional consequences highlighted by this review; however, understanding and information as described above and targeted at various levels (e.g. healthcare professionals, patients, public, employers) appears to be indicated.

In addition to lack of knowledge, the review found a number of barriers to accessing healthcare, with reports of unhelpful messaging and complex processes to navigate. Healthcare professionals with long COVID were more able to navigate this complex system than non-professionals, suggesting a potential inequality. Telemedicine, rapidly rolled-out in many countries as a way of maintaining healthcare during the pandemic,[26] was not always seen as beneficial. As new models for managing long COVID emerge, these findings may be useful for ensuring that services are patient-centred.[27] The finding that patients want multidisciplinary, holistic services is congruent with the well-documented multi-organ nature of COVID-19, and heterogeneous nature of long COVID symptoms.[3]

Strengths and limitations

Our review has highlighted a range of important issues associated with long COVID and accessing healthcare, from the perspective of people with this condition. The review is limited by the small number of qualitative studies (n=5) that have been published to date, and will benefit from being updated as further research becomes available. The majority of studies were conducted in the UK, there was over-representation of younger and female, white, participants, and all studies recruited participants via social media or online support groups. Therefore, the findings apply to this population, and it is possible that other groups of people with long COVID have different experiences and views. We limited our search to studies published in English, therefore it is possible that we missed studies published in other languages. We did not exclude studies on methodological quality, resulting in the inclusion of one study with limited methodological details resulting in a low CASP score. However, the validity of appraisal of qualitative research is debated in the literature,[28] and we are confident that all studies contributed valuable data on the lived experience of long COVID.

Implications for practice

There is a need for greater understanding and communication about long COVID at a number of levels (public, policy and healthcare professional). Our findings suggest that people with long COVID are well placed to co-create this understanding and communication. Our findings can also be used by those currently developing services for people with long COVID, to ensure that they meet patients' needs.

Implications for Research

Further qualitative research on more culturally diverse samples of people with long COVID is indicated to help understand the impact of long COVID and the healthcare needs of the wider population than is represented by the current review. As models of care and services are developed/adapted for people with long COVID, it is vital that the views and experiences of people with long COVID continue to be explored.

CONCLUSION

We have presented a synthesis of the current qualitative evidence on the experience of living with Long Covid and of accessing healthcare services. People experience Long Covid as a heterogeneous condition, with a variety of physical and emotional consequences. It appears that greater knowledge of Long Covid is required by a number of stakeholders, and that the design of emerging Long Covid services, or adaptation of existing services for Long Covid patients should take account of patients' experiences in their design.

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Contributors

DM, JH, KC, KM and MN developed the protocol. CM conducted the literature searches. JH and DM screened articles for inclusion. KM, DM, JH and MN extracted data, appraised studies, and, including KC, were involved with synthesising the qualitative data, interpreting the findings and writing the first draft of the manuscript. Other members of the research teams within Robert Gordon University, Aberdeen, and Healthcare Improvement Scotland provided peer review comments on the draft manuscript.

Competing interests

None declared.

Data sharing statement

All data are available from the reports or authors of the primary research. No additional data are available.

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FIGURES AND TABLES

Figure 1 PRISMA flow diagram of study selection

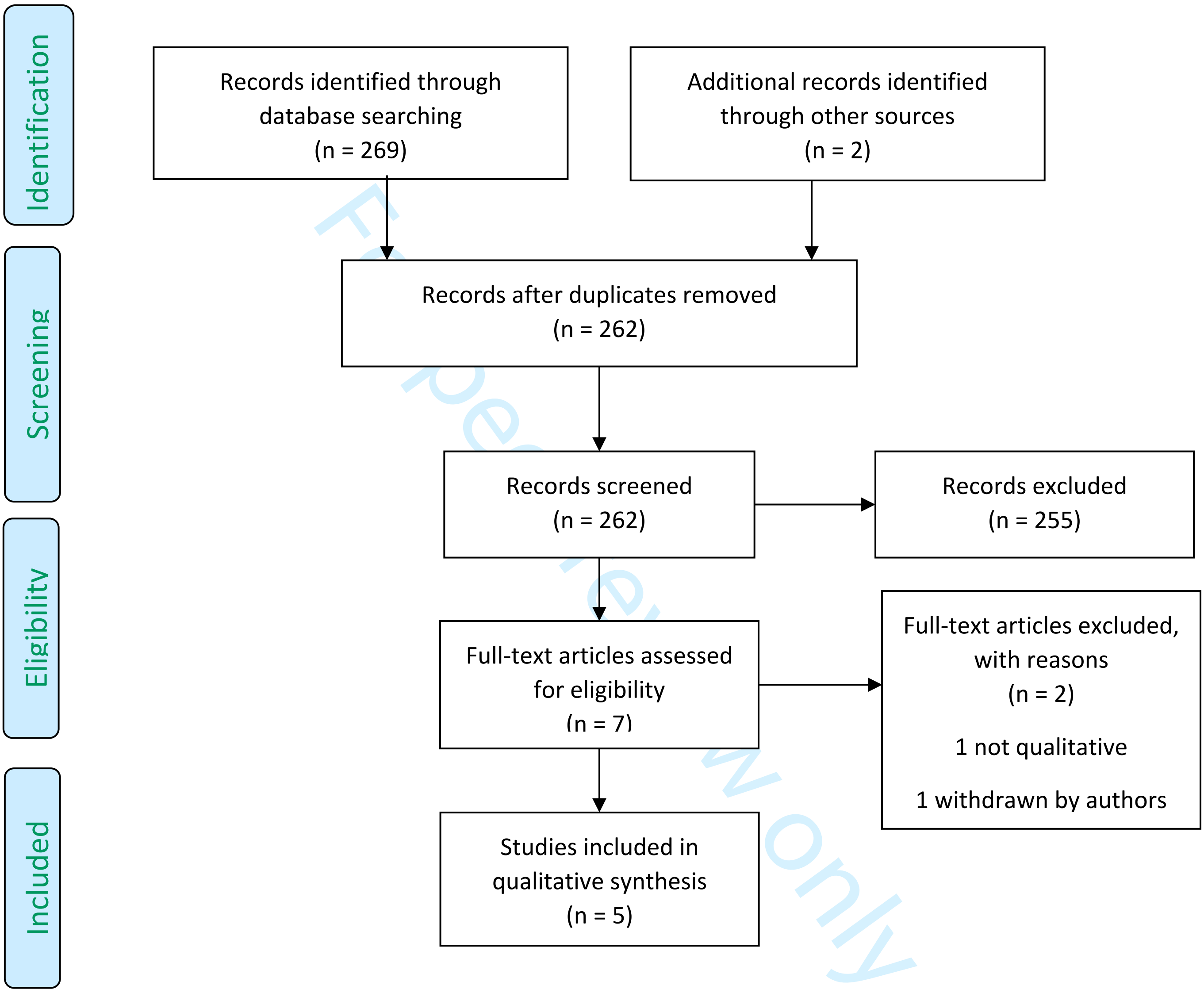

Figure 2 Map of analytical and descriptive themes from the analysis

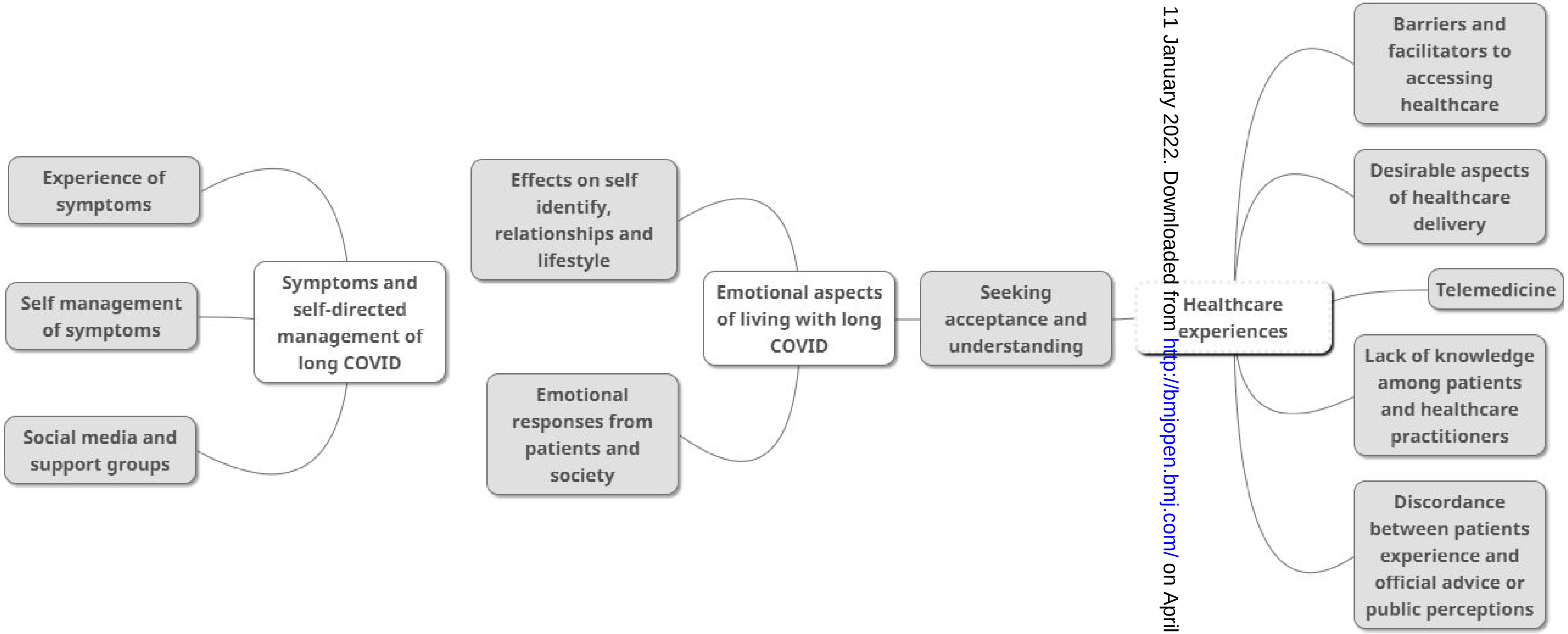

Table 1 Characteristics of included studies

Study [country]	Study methods and setting	Participant characteristics and sample size	Main Results
Assaf *et al*. (2020)[19] [Multinational]	Online survey 21 Apr - 2 May 2020 circulated to long COVID support groups and through social media Quantitative and qualitative data collection	n=640 Patients with symptoms lasting >2 weeks 62.7% aged 30-49; 76.0% white; 76.6% female	Cyclical symptoms experienced unexpectedly for ≥6 weeks Stigma experienced by patients with long-Covid Impacts on lifestyle, including physical activity Dismissed or misdiagnosed by medical professionals Sentiment analysis conducted on satisfaction with medical staff and on sharing experiences.
Davis *et al*. (2020)[16] [Multinational]	Online survey 6 Sept – 25 Nov 2020 circulated to online patients support groups and social media Quantitative and qualitative data collection	n=3,762 Patients with symptoms lasting >28 days 60.8% aged 40-59; 85.3% white; 78.9% female	Patients with Long Covid reported prolonged multisystem involvement and significant disability. The most frequent symptoms reported after 6 months were: fatigue post-exertional malaise cognitive dysfunction.
Kingstone *et al*. (2020)[17] [UK]	Recruitment through social media (Twitter or Facebook) and snowball sampling Jul - Aug 2020 Semi-structured interviews by telephone or video	n=24 Self-reported persistent symptoms following acute COVID-19 illness Age range 20-68; 87.5% white British; 79.2% female	Four key themes reported in results: 'hard and heavy work' of enduring and managing symptoms, trying to find answers, and accessing care living with uncertainty and fear

	call (duration 35-90 minutes) Thematic analysis using principles of constant comparison		importance of finding the 'right' GP recovery and rehabilitation: what would help?
Ladds *et al*. (2020)[18] [UK]	Individual narrative interview (telephone or video) or participation in an online focus group Constant comparison method of data analysis	Total n = 114 55 interviews (40 female/15 male); median age 48 (range 31-68) 59 focus group participants (40 female/19 male); median age 43 (range 27-73)	Five key themes reported in results: the illness experience, accessing care, relationships (or lack of) with clinicians, emotional touchpoints in encounters with health services, ideas for improving services
Maxwell (2020)[1] [UK]	Focus group of COVID-19 Facebook group members	Not reported	Four key themes reported in results: expectations, symptom journey, being doubted, support

Table 2 CASP critical appraisal of using the checklist for qualitative studies

	Assaf *et al.*[19]	**Kingston *et al.*[17]**	**Ladds *et al.*[18]**	**Maxwell[1]**	**Davis *et al.*[16]**
Clear aims statement	Y	Y	Y	N	Y
Appropriate methodology	U	Y	Y	Y	Y
Appropriate research design	U	Y	Y	U	Y
Appropriate recruitment	Y	Y	Y	U	Y
Appropriate data collection	U	Y	Y	U	Y
Researcher-participant relationship considered	N	U	U	U	U
Ethical issues considered	U	Y	Y	U	Y
Rigorous data analysis	U	Y	Y	N	U
Clear statement of findings	U	Y	Y	Y	Y

Y=criterion satisfied; N=criterion not satisfied; U=unclear if criterion satisfied

SUPPLEMENTARY MATERIAL

Supplementary file 1 Inclusion criteria

Criteria	Notes
Population	Adults and children experiencing new or ongoing symptoms: • 4–12 weeks from onset of acute COVID-19 illness • 12 weeks from onset of acute COVID-19 illness
Phenomena of interest	Signs and symptoms of post-COVID-19 syndrome Access to services How symptoms were assessed Management of symptoms and rehabilitation Patient care pathway Information and support provided Communication with healthcare professionals
Comparators	Not applicable
Outcomes	The outcomes will be generated using emergent coding, but are expected to include experiences, views and perceptions of individuals, families or carers on the factors of interest listed (such as Patient Reported Experience Measures)
Settings	Any
Sub-groups	Equality groups, for example, age, gender, ethnicity Diagnosis of COVID-19 (e.g. confirmed or high clinical suspicion) Duration of symptoms
Study types	Systematic reviews of qualitative studies Qualitative studies that collect data from focus groups or interviews Studies that collect qualitative data from questionnaires / surveys Mixed method study designs (including qualitative element)
Countries	Any
Timepoints	Any
Other exclusions	None

Supplementary file 2 Sources searched and MEDLINE search strategy

UK national health service and government websites
Public Health England
Public Health Scotland
Scottish Government
UK Government
National/international policy sources
European Centre for Disease Control
Health Protection Scotland COVID-19 Compendium
Guidelines
National Institute of Health
NICE
SIGN
Evidence summaries and collections
Analytical Collaboration for COVID-19
Cochrane Special Collection
COVID-19 Best Evidence Front Door
COVID-19 Evidence Reviews
Evidence Aid Collection
McMaster rapid review database
Oxford Centre for Evidence-Based Medicine
HTAs
ECRI
Health Technology Wales
National Institute for Health Research
NICE
Specialist Databases
Epistemonikos
EPPI Centre: living systematic map of the evidence
ProQuest
PubMed LitCovid
WHO database of publications
Preprints
bioRxiv
medRxiv
Research centres/organisations
Campbell Collaboration
Centre for Qualitative Research
Health Foundation
King's Fund
Patient issues
Carers UK
Health Talk
Involve
James Lind Alliance

King's Fund Patient Experience Blog
National Association for Patient Participation
National Voices
Our Covid Voices
Patient UK Discussion Forums
Patient Views
Patient Voices
Patients Association
Picker Institute
Primary literature (bibliographic databases)
MEDLINE
PsycINFO
Web of Science

Medline search strategy

1 exp coronavirus/
2 exp Coronavirus Infections/
3 ((corona* or corono*) adj1 (virus* or viral* or virinae*)).ti,ab,kw,kf.
4 (coronavirus* or coronovirus* or coronavirinae* or CoV).ti,ab,kw,kf.
5 ("2019-nCoV" or 2019nCoV or nCoV2019 or "nCoV-2019" or "COVID-19" or COVID19 or "CORVID-19" or CORVID19 or "WN-CoV" or WNCoV or "HCoV-19" or HCoV19 or "2019 novel*" or Ncov or "n-cov" or "SARS-CoV-2" or "SARSCoV-2" or "SARSCoV2" or "SARS-CoV2" or SARSCov19 or "SARS-Cov19" or "SARSCov-19" or "SARS-Cov-19" or Ncovor or Ncorona* or Ncorono* or NcovWuhan* or NcovHubei* or NcovChina* or NcovChinese* or SARS2 or "SARS-2" or SARScoronavirus2 or "SARS-coronavirus-2" or "SARScoronavirus 2" or "SARS coronavirus2" or SARScoronovirus2 or "SARS-coronovirus-2" or "SARScoronovirus 2" or "SARS coronovirus2").ti,ab,kw,kf.
6 (((respiratory* adj2 (symptom* or disease* or illness* or condition*)) or "seafood market*" or "food market*" or pneumonia*) adj10 (Wuhan* or Hubei* or China* or Chinese* or Huanan*)).ti,ab,kw,kf.
7 ((outbreak* or wildlife* or pandemic* or epidemic*) adj1 (China* or Chinese* or Huanan*)).ti,ab,kw,kf.
8 "severe acute respiratory syndrome*".ti,ab,kw,kf.
9 SARS Virus/
10 ("SARSCoV" or "SARS-CoV" or "SARS Cov" or SARScoronavirus or "SARS-coronavirus" or "SARS coronavirus" or SARScoronovirus or "SARS-coronovirus" or "SARS coronovirus").ti,ab,kw,kf.
11 Middle East Respiratory Syndrome Coronavirus/
12 "Middle East* respiratory syndrome".ti,ab,kw,kf.
13 ("MERSCoV" or "MERS-CoV" or "MERS Cov" or MERScoronavirus or "MERS -coronavirus" or "MERS coronavirus" or MERScoronovirus or "MERS-coronovirus" or "MERS Coronovirus" or "camel flu").ti,ab,kw,kf.
14 or/1-13
15 exp Patient Satisfaction/
16 ((patient* or carer* or family) adj2 (experience* or view* or perspective* or preference* or attitude* or expectation* or satisfaction)).tw.

17	15 or 16
18	14 and 17

Supplementary file 3 Summary of key themes relating to the views and experiences of patients, their families and carers

Themes and sub-themes	Summary of sub-themes	Supporting example
Theme: experience of symptoms		
Range of symptoms	Patients described a wide range of symptoms, not all of which were recognised as symptoms of COVID-19.	"The symptoms were like a game of whack-a-mole. Different ones would surge at different times and in different places in my body." (Assaf *et al*)[19] "From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia." (Maxwell)[1]
Severity of symptoms	Symptoms ranged from mild to potentially life-threatening.	"I've been absolutely floored... I've got all sorts of... I've got vasculitis, which I think is a common thing... And I've been left with nerve issues, like really horrible nerve... stabbing pains in my hands and feet and I can't move my toes any more... unfortunately, my journey is far from over." (Ladds *et al*)[18] "From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia." (Maxwell)[1]
Duration and lingering nature of symptoms	Symptoms were experienced for a prolonged but variable length of time.	"He was sleeping for about 20 hours a day, 20 hours out of every 24 and he's still sleeping now, five and half months after, he still sleeps an awful lot, sat up, not lay down, sat up, he's just totally exhausted." (Kingstone *et al*)[17]

Themes and sub-themes	Summary of sub-themes	Supporting example
Fluctuating or cumulative nature of symptoms	Patients described symptoms 'coming and going', and of new symptoms being added to existing ones over time.	"...From week four I started to get chest pains and then breathlessness, gradually other symptoms developed .... The following weeks were frightening as symptoms fluctuated; sometimes thinking that you were improving and then very disheartening when they returned.... After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms...." (Maxwell)[1]
Theme: discordance between patient experiences and official advice or public perceptions		
Disconnect between official advice and lived experience	Patients found official advice on graded exercise and when to come out of isolation unhelpful and contrary to their lived experience of long COVID.	"Well, one of the things that really bugged me about it was the talking about graded exercise and I've learnt from experience that pushing myself even a tiny bit has massive consequences ..." (Kingstone *et al*, p6)[17]
Disconnect between public perception ("labels") and lived experience	The perception that COVID-19 is a binary illness that is either 'mild' or very serious (requiring hospitalisation) was unhelpful and contrasted with patient experience.	"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us." (Kingstone *et al*)[2] "I think the term "mild" should be removed... I know that people who were admitted to the hospital were worse, but we who stayed home did not have MILD cases in all cases" (Maxwell)[1]
Disconnect between expected/official timeframes and lived experience	Patients expected COVID-19 to last approximately 2 weeks, in line with official estimates, and were then confronted by much longer-term illness. Patients experiencing symptoms beyond the 2-week period are often diagnosed with an alternative condition that more neatly fits the timeframe.	"I went back to work too soon and wish I hadn't. Finally had to take a 5 week break in July/ August with the support of my employer. This helped a lot. I have now been back at work for 5 weeks and my symptoms have got worse to a degree." (Davis *et al*)[16]

Themes and sub-themes	Summary of sub-themes	Supporting example
Disconnect between officially recognised symptoms and lived experience	There is discordance between the range of symptoms articulated by patients with long-term illness and those officially recognised by authorities as COVID-19.	"If the message hadn't been [to expect to recover in] around two weeks, I'd have been more cautious at first, … the doctor I saw in A/E described Covid as the gift that keeps on giving and at four weeks I thought that felt like a long time, and now five months on it feels like a very long time" (Maxwell, p11)[1]
Impact of disconnect between officially recognised symptoms and lived experience	As a consequence of the mismatch between officially recognised symptoms and lived experience of long COVID, patients feel ignored, dismissed, and may be misdiagnosed.	"Despite having been diagnosed with suspected Covid by my GP and a doctor in a Covid clinic (swab testing wasn't available to the public at the time) and told I had pleurisy during a visit to A&E two weeks earlier, the doctor on duty didn't take this into account. Instead, he dismissed me with anxiety, advising a course of anti-depressants, and chose not to investigate these concerning symptoms further. Of course I was anxious, but that was a consequence of the physical symptoms, not the cause! I would later learn from a neurologist that what I experienced on that day were clear neurological symptoms that should have been investigated promptly. To be brushed off like this when so little was known at the time of the damage Covid can cause was disheartening and very upsetting." (Maxwell, p15)[1]
Theme: self management of symptoms		
Self care and lifestyle adjustment	Patients attempted various forms of self care, such as taking supplements, and made adjustments to their lifestyle, for example by reducing physical activity, to accommodate long COVID.	"I mean initially I started taking vitamin D. Had a joint vitamin C and zinc thing, which I didn't take every day but I took some multivitamins, but then I was a bit unsure really … my husband's quite anti-vitamin use … So anyway, then I took nothing for a while, and then I more recently started the vitamin D again, and I'm on

Themes and sub-themes	Summary of sub-themes	Supporting example
		B12 just because of all the burning in my feet … and a probiotic and some omega-3.” (Kingstone *et al*)[17]
Pacing and goal setting	The importance of pacing yourself and setting realistic goals was highlighted by patients.	“…I really have to pace myself… I couldn’t do two or three household chores back to back, I have to do a chore, sit down for 15, 20 minutes and then do the next, which frustrates me….” (Kingstone *et al*)[17]
Theme: emotional responses from patients and society		
Helplessness	Long-term symptoms were associated with a feeling of helplessness.	“Most participants continued the discussion after the digital recorder was turned off, emphasising their own feelings of helplessness, but also alluding to the uncertainty and helplessness that GPs had admitted to” (Kingstone *et al*)[17] *[Author quote]*
Anxiety	Patients described anxiety about the prospect of not recovering, uncertainty over the cause of symptoms, not being believed, and some of the content they read on online support groups.	“…. I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not “I’m going to die right now”, but definitely “I’m never going to get better from this” kind of feeling.” (Kingstone *et al*)[17]
Relief	A sense of relief was associated with finding a healthcare professional that believed the patient.	“I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people’s symptoms are real and diverse.” (Maxwell)[1]
Stigma (externally generated)	Employers and others drive a fear of being stigmatised over long COVID.	“Healthcare staff was fearful and I was turned away with no support” (Assaf *et al*)[19] “I had to take two weeks off, had to work from home for four, but had to return for two weeks with fever as my employer would not give me more time […].” (Davis *et al*)[16]

Themes and sub-themes	Summary of sub-themes	Supporting example
Stigma (internally generated)	Patients experienced a sense of shame and blame consistent with stigma.	"Fearful of people around me finding out and overreacting / treating me differently" (Assaf *et al*)[19]
Theme: effects on self-identity, relationships and lifestyle		
Impact on self-identify	Long COVID affected self identity as a healthy, independent individual, and resulted in patients comparing themselves with a pre-COVID version of self.	"I have not had strength to return to physical activity. I did work in my house and 2 days later had a fever again after being 12 days fever free." (Assaf *et al*)[19]
Impact on daily life/work	Patients had to alter their physical activity levels to accommodate long COVID and found cognitive symptoms prevented a return to work.	"I'm trapped, in that I can't park that far away and walk [to the shops] like I normally would because I can't do hills. I can just, in the last couple of weeks, I can do gentle inclines now, but I sort of grind to a halt on a hill. So, it's very limiting." (Ladds *et al*)[18] "I wasn't just fogged. I was confused. I had a very difficult encounter as a result of just being confused about things and that took a long time to resolve. I love words and I enjoy the business of communicating, and I felt that part of my life was lost. Really, I just did admin, I didn't do anything that required clear thinking." (Kingstone *et al*)[17]
Impact on self - reduced confidence	There was a sense of loss of confidence in professional abilities among some patients.	"Doctors and other clinicians …. described how their symptoms and the accompanying prognostic uncertainty …. had also stripped them of confidence in their professional abilities." (Ladds *et al*)[18] *[Author quote]*
Impact on others/relationships	Long COVID had an impact on family members as well as patients.	"I think, at first, they just thought, "Oh, for god's sake, she's napping again." I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted …. I used to enjoy running, and

Themes and sub-themes	Summary of sub-themes	Supporting example
		exercising, and stuff like that. I rarely even go on walks now because I know if I walk to the end of the street, they're [lungs] going to start hurting." (Kingstone *et al*)[17]
Theme: healthcare access – barriers and facilitators		
Barrier - testing	Challenges were experienced with accessing testing (for long-term symptoms or COVID-19 diagnostic testing).	"... My worst and scariest experience with this illness was in week 6, when I was rushed to A&E as I had a sudden relapse of symptoms and found myself gasping for air, with the top of my head numb and tingling and a headache so blinding that I couldn't keep my eyes open. I got worse in the hospital and was shaking visibly, so much so that the nurse couldn't perform an ECG as I just couldn't stay still. Despite having been diagnosed with suspected Covid by my GP and a doctor in a Covid clinic (swab testing wasn't available to the public at the time) and told I had pleurisy during a visit to A&E two weeks earlier, the doctor on duty didn't take this into account. Instead, he dismissed me with anxiety, advising a course of anti-depressants, and chose not to investigate these concerning symptoms further. ... I would later learn from a neurologist that what I experienced on that day were clear neurological symptoms that should have been investigated promptly. To be brushed off like this when so little was known at the time of the damage Covid can cause was disheartening and very upsetting." (Maxwell)[51]

Themes and sub-themes	Summary of sub-themes	Supporting example
Barrier – primary care	Difficulties accessing primary care, particularly face-to-face or through the 'total triage' system were a barrier to healthcare access	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", a.....so I started contacting a different GP, in the same practice, and it's the same outcome, they can't do anything else but he seems to be interested and wants to know what's going on." (Kingstone *et al*)[17]
Barrier – effort involved	Accessing healthcare was complex, difficult and exhausting for patients.	"One day I had blue finger nails and I wasn't cold …. and I phoned the GP and the GP answer phone said if you've got any of the signs of, of Covid please ring 111 and so I rang 111 and, I live in [city with high incidence of Covid-19] I don't know if that makes any difference but I was put on hold and after over an hour, an hour and twenty minutes nobody answered so I just put the phone down ….." (Ladds *et al*)[18]
Barrier – specialist referral	Few patients managed to obtain a referral to a specialist.	"...three of the referrals my GP made (two respiratory and one neurology) were refused by two different hospitals on the grounds that a) they only checked Covid confirmed patients b) that they needed extra tests which weren't done on me at A&E" (Maxwell)[1]
Perceived barrier – healthcare professionals being busy	There was a perception that healthcare professionals are too busy caring for patients with acute COVID-19 to be able to provide care for patients with long-term symptoms.	"At this point, most physicians and researchers are so overwhelmed treating the covid19 patients who are at risk of immediate death, that they don't have the ability to even recognize that people like me exist...." (Assaf *et al*)[19] "I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful,

Themes and sub-themes	Summary of sub-themes	Supporting example
		particularly as I didn't have, and never have had, a cough or fever" (Maxwell)[1]
Perceived barrier – healthcare entitlement	Patients had a perception that they were not entitled to healthcare for long-term symptoms of COVID-19.	"....I guess I felt a bit like I was ineligible for health care now. I felt like I'm just going to have to live with this at home and no one will come and see me and, you know, I'm just, yeah. It was a horrible feeling." (Kingstone *et al*)[17]
Facilitator – follow-ups & check-ins	Regular follow up or check-in with patients with long-term symptoms was viewed as a positive aspect of healthcare.	".... I think for the first five days after I called her she had a daily check in call with me to monitor how I'm doing so it was like a ten minute phone call every day for the first five days" (Ladds *et al*)[18]
Things patients did to access care	Patients engaged in a number of activities to improve their access to healthcare including: • taking the lead in arranging consultations and "circumventing bottlenecks" • deliberately manipulating inflexible algorithm-driven systems to access referrals • accessing private healthcare to prompt NHS follow up, conducting their own research and constructing their own care pathways.	"did the e-consult – I had to do it a couple of times – I kind of learned to answer the questions to get it to send a message to my GP surgery... If you say you've got heart palpitations or breathlessness it's telling you to call 111 which I didn't want to do. And so I had to downplay symptoms [laughs] to get through. I cancelled it and did it again." (Ladds *et al*)[18]
Theme: telemedicine - limitations and benefits		
Limitation – remote consultation	Remote consulting was found to limit access to GPs and to restrict communication of symptoms.	"... reassure me are things where I need my body actually checking which I don't think you could check online, you can't check for blood clots online, you can't check for neurological damage online can you?' (Kingstone *et al*)[17]

Themes and sub-themes	Summary of sub-themes	Supporting example
Limitation – lack of continuity	Loss of continuity of care was particularly impactful on patients with complex presentations.	"The focus when you do get a new GP speaking to you seems to be that they go back to the beginning ….And I think if there was the same GP who we are able to consult regularly they would build a picture of your baseline and I think that's what's lost with digital ways of working." (Ladds *et al*)[18]
Limitation – protocolised care	Strict adherence to protocols in the telemedicine context affected patient safety and led to mismanagement.	"… I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I'm really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don't really sound too out of breath over the phone …. I really felt at that point right if you could see me you would see that I am really like broken" (Ladds *et al*)[18]
Benefits - accessibility	Positive experiences of accessing GPs through telemedicine.	"My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track." (Assaf *et al*)[19]
Theme: lack of knowledge, information and understanding among healthcare professionals and patients		
Lack of knowledge - healthcare professionals	There is a perceived lack of knowledge about long COVID among healthcare professionals.	"…I think all the way through I found doctors that I've come into contact with are just really at a bit of a loss for it. I think at the beginning, particularly when things were going on, and not clearing up it was kind of put on me as just being a strange case ... and my GP was going, "Well, you're just weird, you know".' (Kingstone *et al*)[17]

Themes and sub-themes	Summary of sub-themes	Supporting example
Lack of knowledge – symptoms	The lack of knowledge around long COVID included uncertainty about the expected symptoms, wanting to learn about living with COVID-19, uncertainty about the cause of symptoms, a lack of understanding about the fluctuating nature of symptoms and lack of knowledge about recovery from long-term symptoms.	"None of us knew this [the symptoms] because we're all on our own, in a little bubble, thinking I'm the only one. Why am I the one who has still got it?" (Maxwell)[1]
Lack of knowledge – seeking help	Uncertainty about when patients with long COVID should seek medical help.	"...combined with the UK government message to stay away from health services unless very ill, left many people uncertain about when they should seek help." (Maxwell)[1] *[Author quote]*
Lack of knowledge – employers	Employers need advice on how to manage employees with long COVID.	"Advice on the range of symptoms and duration was also needed by employers who are unclear what to expect of those with ongoing effects." (Maxwell)[1] *[Author quote]* "I have needed more flexible hours (working remotely) post-COVID. That way, I can rest as needed throughout the day. If I had to return to in-person work at this point, it would be severely reduced hours if at all." (Davis *et al*)[26]
Lack of knowledge – management	Lack of knowledge about managing long COVID, resources available locally for patient rehabilitation, and about recovery from prolonged illness.	"I finally had a respiratory appointment three months later, over the phone (not over a video link). I was …. recommended graded exercise. When I then saw a rehabilitation physiotherapist, she said no, we are not going to do graded exercise because that would be counterproductive for you. " (Maxwell)[1]

Themes and sub-themes	Summary of sub-themes	Supporting example
Lack of knowledge – prompts help-seeking from other sources	Lack of widely accessible medical knowledge about long COVID has led to patient reliance on news and social media for information.	"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it. So, you know, sixth sense, I actually think that the support group has given more knowledge than the doctors have." (Ladds *et al*)[18]
Patients prefer healthcare professionals to admit uncertainty	Patients would prefer healthcare professionals to admit to a lack of knowledge about long COVID.	"She just listens a little bit more to what I'm saying and she's much more willing to say, "Of course, we don't really know what's going on because it's a new virus." She doesn't try to pretend that she understands what's going on, which is good." (Kingstone *et al*)[17]
Theme: desirable features of healthcare services/service delivery		
Healthcare structuring – one stop clinics with face-to-face assessment of symptoms by multidisciplinary teams	Patients wanted a 'one-stop' clinic with multidisciplinary teams there to assess symptoms affecting a wide range of body systems.	"What would be most helpful is if all main hospitals could have a Covid clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, We are having such a range of symptoms that GPs are struggling to know what to do with you" (Maxwell)[1]
Healthcare structuring – case management	A case manager or single clinician to co-ordinate investigations and the patient care pathway for each patient with long COVID.	"... there was a view that it would be helpful if people living with Covid19 could have a 'quarter back' or case manager to oversee and coordinate investigations and support services across different medical specialities." (Maxwell)[1]
Healthcare structuring – MDT rehabilitation	Assessment by a multidisciplinary rehabilitation team was proposed.	"... the British Society of Rehabilitation Medicine notes there are people who were never admitted to hospital but who still have ongoing needs for rehabilitation

Themes and sub-themes	Summary of sub-themes	Supporting example
		support after recovering from Covid, or Covid-like symptoms." (Maxwell)[1] *[Author quote]*
Individual - acceptance of patient experiences by healthcare professionals	Empathetic health professionals that accepted patient experiences were desirable to individuals.	"I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people's symptoms are real and diverse." (Maxwell)[1]
Individual - practical coping strategies	Patients wanted practical advice on coping strategies.	"... members understood that there were no magic cures, but were looking for practical advice on coping strategies that go beyond basic advice." (Maxwell)[1] *[Author quote]*
Theme: social media and support groups		
Support through sharing experiences	Online support groups and social media provided opportunities for sharing experiences of long COVID.	"when I found the Long Covid Facebook group that I realised I wasn't alone, thousands of people were in the same situation. Knowing this helped enormously." (Maxwell)[1]
Support through sharing knowledge	Online support groups and social media provided opportunities for sharing knowledge and resource links with others coping with long COVID.	"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have." (Ladds *et al*)[18]
Validation of experiences	Patients found validation of their experiences in communication with others through online support groups.	"many participants – both men and women – found that online peer support groups offered the greatest source of support through shared experiences, knowledge and validation." (Ladds *et al*)[18] *[Author quote]*
Theme: seeking acceptance and understanding		
Perception of being doubted by healthcare professionals	Healthcare professionals were perceived to doubt patient symptoms were related to COVID-19 and to doubt symptom severity.	"There was one GP who just thought it was all anxiety ... she said, "There's nothing wrong with your lungs. This is all anxiety. You must treat your anxiety. There's

Themes and sub-themes	Summary of sub-themes	Supporting example
		nothing wrong with you. How are you going to manage the pandemic if you don't treat your anxiety?" That was really upsetting because I knew I was short of breath..." (Kingstone *et al*)[17]
Perception of being doubted by friends and family	There was a perception that friends and family doubted patients because symptoms were not always obvious.	"... one of my friends did say after quite a while, "I'm not being awful, but do you think a lot of it's in his mind?" and I said "no". I was quite upset about that..." (Kingstone *et al*)[17]
Perception of being ignored	Patients felt that their condition was not given the recognition that it deserved.	"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us." (Kingstone *et al*)[17] "I felt the medical team was dismissive. There were a lot of 'we don't know.' Which is understandable, but difficult." (Assaf *et al*)[19]
Difficulties finding empathetic healthcare professionals	Challenges were described in finding healthcare professionals willing to show empathy and accept patient experiences of symptoms.	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", and that frustrated me because it didn't seem like they were being caring, it felt like I was nagging them and being a hypochondriac..." (Kingstone *et al*)[17] "Because I've spoken to four different GPs throughout this. I've not found them very helpful..." (Kingstone *et al*)[17]
Misdiagnosis or dismissal by healthcare professionals	Dismissal of symptoms or misdiagnoses were associated with a negative perception of healthcare.	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", and that frustrated me because it didn't seem like they were being caring, it

Themes and sub-themes	Summary of sub-themes	Supporting example
		felt like I was nagging them and being a hypochondriac and that's how I was being treated…" (Kingstone *et al*)[17]
When available strong empathetic relationships with healthcare professionals provides strong therapeutic relationships	A minority of patients reported strong therapeutic relationships involving listening, empathy, validation, honesty and arranging tests and follow up.	"… actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful." (Kingstone *et al*)[17]

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Title page
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	2
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	2
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	3
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	3
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	3
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	4
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	4

PRISMA 2009 Checklist

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	4

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	5
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	5 and 15
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	17
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	19
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	17
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	5
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	10
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	11
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	12
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	12

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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Experiences of living with long COVID and of accessing healthcare services: a qualitative systematic review

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Experiences of living with long COVID and of accessing healthcare services: a qualitative systematic review

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ABSTRACT

Objective To explore the experiences of people living with long COVID and how they perceive the healthcare services available to them.

Design Qualitative systematic review

Data sources Electronic literature searches of websites, bibliographic databases and discussion forums, including PubMed LitCovid, Proquest COVID, EPPI Centre living systematic map of evidence, medRxiv, bioRxiv, Medline, Psychinfo and Web of Science Core Collection were conducted to identify qualitative literature published in English up to 13 January 2021.

Inclusion criteria Papers reporting qualitative or mixed-methods studies that focussed on the experiences of long COVID and/or perceptions of accessing healthcare by people with long COVID. Title/abstract and full-text screening were conducted by two reviewers independently, with conflicts resolved by discussion or a third reviewer.

Quality appraisal Two reviewers independently appraised included studies using the qualitative CASP checklist**.** Conflicts were resolved by discussion or a third reviewer.

Data extraction and synthesis Thematic synthesis, involving line-by-line reading, generation of concepts, descriptive and analytical themes, was conducted by the review team with regular discussion.

Results Five studies published in 2020 met the inclusion criteria, two international surveys and three qualitative studies from the UK. Sample sizes varied from 24 (interview study) to 3,762 (survey). Participants were predominantly young white females recruited from social media or online support groups. Three analytical themes were generated: (i) symptoms and self-directed management of long COVID; (ii) emotional aspects of living with long COVID, and (iii) healthcare experiences associated with long COVID.

Conclusions

People experience long COVID as a heterogeneous condition, with a variety of physical and emotional consequences. It appears that greater knowledge of long COVID is required by a number of stakeholders, and that the design of emerging long COVID services, or adaptation of existing services for long COVID patients should take account of patients' experiences in their design.

Strengths and limitations of this study

- This review synthesizes the existing qualitative literature on people's experiences of long COVID and the healthcare services available to them
- The search strategy was comprehensive and sought to find published research, pre-publication articles and grey literature
- The search was limited to the English language, therefore potentially relevant studies may have been excluded

- Only five qualitative studies of variable quality were eligible for inclusion in this review, limiting the extent to which conclusions and practice recommendations can be made
- Participants in the included studies were predominantly younger, female, and users of social media or online support groups, which may also limit the generalisability of the review findings

INTRODUCTION

The long-term effects of COVID-19 are recognised increasingly as being heterogeneous and complex in nature. At the start of the COVID-19 pandemic there was a widespread perception that COVID-19 was an acute infection that resulted in death or recovery after two weeks.[1] However, many people experienced wide-ranging and fluctuating symptoms for weeks or months after confirmed or suspected COVID-19 infection. As these experiences were shared, on social media and other outlets, the term ‘long COVID’ was generated by patients.[2] There remains no internationally agreed definition of long COVID, as COVID-19 is still a relatively new disease, with ongoing research on the long-term effects.[3] Greenhalgh *et al* [4] suggested “post-acute COVID-19” for symptoms lasting beyond 3 weeks after onset, and “chronic COVID-19” for those lasting beyond 12 weeks. Recent UK guidelines defined “ongoing symptomatic COVID-19” as signs and symptoms lasting 4-12 weeks and “post-COVID-19 syndrome” as signs and symptoms developing during or after COVID-19 and continuing beyond 12 weeks.[5 6] As this systematic review is concerned with lived experience, we will use the patient-generated term long COVID to encapsulate all these definitions.

Symptoms of long COVID can affect those hospitalised and ventilated,[3] as well as those with so-called mild COVID-19, during the acute phase.[4] Little is known about long-term sequelae in asymptomatic patients, with this recently highlighted as an important area for future research.[3] Potential long-term effects include central nervous system, psychosocial, cardiovascular, pulmonary, haematologic, renal and gastrointestinal symptoms, as well as widely reported persistent fatigue, dyspnoea, joint and chest pain.[3] Estimates of long COVID rates vary from 10%[4] to 35%[7] with the true rate yet to be determined. Therefore, with over 108,000,000 confirmed COVID-19 cases globally as of 30th January 2021,[8] there are now a large number of people at risk of long COVID.

Healthcare services specifically for long COVID are evolving. For example, some specialist centres have been set up in parts of the UK,[9] and there has been a global call for the development of rehabilitation programmes and services for long COVID patients.[10] In order for healthcare services to meet patients’ needs, it is important to understand the experience of long COVID and of accessing healthcare services from patients’ perspectives. There is a growing body of qualitative research on the lived experience of long COVID, and to date, no published synthesis of this literature. The aim of this qualitative systematic review was therefore to explore the experiences of people living with long COVID and their perceptions of the healthcare services available to them.

METHODS

A qualitative systematic literature review was undertaken based on an *a priori* protocol (available on request) and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.[11] This review updates a review undertaken by the authors to inform the production of the Scottish Intercollegiate Guidelines Network (SIGN), National Institute of Health and Care Excellence (NICE) and Royal College of General Practitioners (RCGP) guideline on the management of long COVID.[5 6]

Inclusion criteria

Full details of the inclusion criteria for the review are given in supplementary file 1.

Participants: Individuals experiencing long COVID whether suspected or confirmed by diagnostic test, with no restriction on duration of symptoms. We excluded studies on the views or experiences of healthcare for conditions other than COVID-19 and those relating to the views of healthcare staff, unless they were patients themselves.

Phenomena of interest: people's views on and experiences of living with and managing long COVID, and on the healthcare services available to them.

Context: studies from any country and any setting.

Types of study: systematic reviews of qualitative studies; primary qualitative studies; qualitative components of mixed method studies.

Information sources and search strategy

An information specialist (CM) carried out a search in October 2020. Sources searched included: PubMed LitCovid, Proquest COVID, EPPI Centre living systematic map of evidence, medRxiv, bioRxiv, Medline, PsychInfo, and Web of Science Core Collection. A full list of resources searched is available in supplementary file 2. Published studies, grey literature and pre-publication articles were sought. In databases not specific to COVID-19, search results were limited to publications in 2020. All searches were limited to the English language due to a lack of translation services and the need for evidence to be synthesised in a timely manner due to the rapidly evolving nature of long COVID research. A search update was conducted on 13 January 2021.

Bibliographic database searches applied adapted versions of the qualitative research filter by DeJean *et al* (2016)[12] and a filter for patient experience literature developed by combining terms from papers by Selva *et al* (2017)[13] and Wessels *et al* (2016)[14]. The search strategy for Medline is available in supplementary file 2. Search strategies for other bibliographic databases are available on request.

Study selection

Citations were uploaded to EndNote software and duplicates removed. Records were screened against the inclusion criteria based on titles and abstracts by two reviewers independently (JH, DM). The same two reviewers then assessed the full text of potentially relevant articles. Disagreements were discussed and referred to a third reviewer where necessary. The two reviewers were in agreement for the majority of the papers and only one study required recourse to the third reviewer. (KM).

Data extraction

Two reviewers independently extracted descriptive data from each study (KC, JH, KM, DM, MN), using a data extraction template designed specifically for this review. Details extracted from the studies included: country in which the study was conducted, method of data collection and analysis, phenomena of interest, setting / context / culture, participant characteristics and sample size, and a description of the main results. As this review was conducted in a short timescale, to provide early evidence on a rapidly evolving subject, we did not contact authors for missing information.

Quality appraisal

Included studies were critically appraised by two reviewers independently (KC, JH, KM, DM, MN, JH) using the CASP qualitative checklist (https://casp-uk.net/casp-tools-checklists/). Discrepancies were discussed and referred to a third reviewer if required. For the reasons described above, authors were not contacted for additional information on methodology of their individual studies.

Data synthesis

Thematic synthesis was undertaken on the findings from included studies.[15] This involved: (i) line-by-line reading of each study by two reviewers independently (JH, KM, MN) to identify initial concepts; (ii) grouping similar concepts into initial descriptive themes and sub-themes, and (iii) generating the final analytical themes. These were discussed and agreed by the review team (KC, JH, KM, DM, MN) throughout the process.

Patient and public involvement

As a systematic review focussed on published and grey literature no primary research involving patients was conducted. The original synthesis that this review updates, was subject to review by an expert group that included several members with lived experience of long COVID, and a targeted public consultation which included groups representing those with experience of this condition. Further details are provided within the NICE long COVID guideline.[5]

RESULTS

Search results

The literature search identified 269 articles. A further two studies were identified from reference lists. After removal of duplicates and title/abstract screening, seven articles were evaluated as full-text. The main reasons for excluding articles were no qualitative element to the research, no patient involvement and not meeting our definition of long COVID (we were interested in studies relating to symptoms over four weeks duration). Out of the seven fully evaluated articles, one study was excluded because it did not use qualitative methods or contain data on direct patient experience. A second study which was initially included was later excluded after it was withdrawn from pre-publication by the authors. A PRISMA flow diagram depicting the study selection process is provided in figure 1.

Characteristics of included studies

Five studies were included in the thematic synthesis (table 1).[1 16-19] Three studies conducted focus groups or interviews with patients from the UK and two studies, from the Patient Led Research group, conducted international surveys with most responses coming from the USA and the UK. Sample sizes varied from 24 interviews to 3,762 survey respondents, and were generally weighted towards white (83.8%), female participants (75%). The number of patients included in the studies in which information was gathered through surveys was much larger than those using interviews and focus groups as data collection methods. However, while representing fewer patients, the latter method offers the opportunity of collecting more in depth data and for interaction among participants and/or with the interviewer. All studies focussed on adults with an age range of 20-68 years in the four studies that reported participants' ages; one study did not report the number of participants or their ages.[1]

Methodological quality

Studies were of variable methodological quality. Three met most of the criteria on the CASP checklist (table 2) and thus were considered of high quality, and two met fewer criteria. No studies were excluded on the basis of quality as all were considered to offer valuable content despite the limitations identified.

All five studies recruited participants through social media and/or online support groups. While this is understandable given the need to quickly access participants for whom no established groups or organisations existed, this convenience sampling may have resulted in bias.[20] 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. Three included studies acknowledged skewed sample characteristics including mainly white ethnicity, over-representation of women, and a generally younger age group.[16 18 19] Limited demographic information was provided on participants, particularly in Maxwell (2020),[1] making it difficult to determine which population groups may have been missed by these studies.

None of the studies discussed potential biases arising from the relationship between researchers and study participants. This is despite people with lived experience of long COVID symptoms being among the study authors, or performing data analysis in some studies.[16 17 19] This participatory research approach can be considered to represent both a strength and a weakness. Having authors and researchers with experience of long COVID analyse data is beneficial in bringing lived experience to the interpretation of data. However, it may also introduce bias for the same reason.

Several other quality issues were noted. In the study by Kingstone *et al* [17], participants received a compensation voucher for their time, which may have influenced decisions on whether to participate. Ladds *et al* [18] only fully transcribed the first 10 out of the 55 interviews (the remaining interviews were partially transcribed). This was due to the urgency of the work and limited resources plus a perceived lack of need to duplicate previously discovered themes. This may have introduced bias. Finally, Maxwell [1] reported very limited methodological details, making it difficult to determine how the research was conducted or the number of people involved in the focus group.

Review findings

The initial stages of thematic analysis resulted in the generation of 138 descriptive themes. These were then refined into 54 sub-themes, which were attributed to 11 higher order themes using an iterative process, with continuous discussion between reviewers. Further review and refinement of themes resulted in three overarching analytical themes: (i) symptoms and self-directed management of long COVID; (ii) emotional aspects of living with long COVID; and (iii) healthcare experiences associated with long COVID. Figure 2 shows the relationship between the final three themes and the initial 11 higher order themes. Full details of descriptive themes and sub-themes are available in supplementary file 3.

Symptoms and self-directed management of long COVID

Evidence from all the included studies[1 16-19] showed that people with long COVID experience a wider range of symptoms than the three symptoms officially recognised as acute COVID-19: high temperature, new continuous cough, and change or loss of sense of smell or taste. One individual stated:

> *"From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia."*[1]

The symptoms experienced by patients with long COVID varied in severity from relatively mild to potentially life-threatening symptoms that required hospital admission. Symptoms also fluctuated over time with new symptoms appearing at different stages of the illness and in different parts of the body. Each symptom was experienced for a prolonged but variable length of time, with a cumulative effect in many cases.

People identified a disconnect between their lived experiences, official advice, and public perception of the illness. It was felt that the public perceived the illness as a binary condition – either mild and easily treated at home or serious and requiring hospitalisation – with no variation or allowances made for ongoing symptoms.

"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us."[17]

The literature showed that people believed they would require a short recovery period and would be back at work in two weeks, a belief mirrored by employers and the public. The lived experience, for some, was quite different:

"After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms..."[1]

"I had to take two weeks off, had to work from home for four, but had to return for two weeks with fever as my employer would not give me more time [...]."[16]

This discordance between expectations and experience seemed to have a direct effect on the mental and emotional state of those experiencing prolonged illness, often leading to uncertainty about what to do about their symptoms. People described needing to adjust their lifestyle, including pacing themselves and setting realistic goals, in order to self-manage their symptoms. A number of patients described attempts at self-care such as taking supplements or trying therapeutic massage.

Many people turned to social media and support groups (online or face-to-face) for support and found them to be a valuable way to share experiences, knowledge and resources with others in a similar situation. This communication helped to validate patient experiences and provided reassurance they were not alone in their struggle with long-term symptoms.

"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have."[18]

However, there were also reports of anxiety and depression triggered by knowledge garnered from these online groups.

" ...Internet support groups, yeah on the Facebook groups that I'm on, I mean to be honest, I try not to read that group too much because it depresses me, makes me a bit anxious."[17]

Emotional aspects of living with long COVID

For many patients there was a feeling that their self-identity was affected by long COVID. People reported an impact on how they viewed themselves, before and after their illness. There was a feeling they had to reconsider who they were and what they could do within the context of family and work. The phrase "compared with how I used to be" was used by multiple participants[17]. Ladds *et al* (2020)[18] commented on the concept of a "spoiled identity" where an identity as previously "healthy, independent and successful" was perceived to be threatened.

Interviews with doctors and other clinicians who had experienced long COVID showed that many were worried about the impact of cognitive deficits on their ability to perform their jobs.

"[T]he medicolegal aspect is huge …. and it's scary to not be able to recognise potentially where you have deficits because if you can't recognise them then that's an unknown unknown in what can you do with that."[18]

There was a sense of stigma associated with long COVID, with people experiencing a sense of shame and blame (internally generated stigma) and expressing fears that employers and others in the community may stigmatise them for having long COVID (externally generated stigma). Family members were considered to be affected by long COVID and were seen as also requiring support. One interview participant described the impact her symptoms had on her family and how she felt they did not believe her:

"I think, at first, they just thought, 'Oh, for god's sake, she's napping again'. I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted …."[17]

Patients described experiencing a range of emotions as part of their illness journey. Anxiety was often related to multiple aspects of the illness including uncertainty about the cause of symptoms, concern that they may never recover completely, and anxiety due to not being believed by healthcare professionals, family and friends.

"…. I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not "I'm going to die right now", but definitely "I'm never going to get better from this" kind of feeling."[17]

Patients also expressed a strong desire to find acceptance and understanding about their experiences of long COVID, both among healthcare professionals and family and friends.

"... one of my friends did say after quite a while, "I'm not being awful, but do you think a lot of it's in his mind?" and I said "no". I was quite upset about that…"[17]

Similarly, there was a widespread perception that healthcare professionals doubted patients' descriptions of long COVID[1], ignored patient concerns[17], misdiagnosed symptoms[19], or were dismissive of patient experiences[19]. This lack of knowledge affected people's feelings around their healthcare experiences[17].

Healthcare experiences

Across all of the studies, participants expressed concerns relating to the lack of knowledge, information and understanding about long COVID among healthcare professionals. While the reason behind this lack of knowledge was understood, there was a general feeling that there needed to be acknowledgement of this gap within the healthcare community.

“Well yeah, I feel like there’s a lack of knowledge. And I really wasn’t able to get any answers, I know, you know this is obviously a novel illness. But just even for one doctor to look into it a bit and come back to me, didn’t happen.”[17]

The absence of knowledge and information about long COVID symptoms was reported to create anxiety and confusion for patients. Ladds *et al* (2020)[18] found that this confusion was intensified by the lack of medical knowledge, understanding and guidance from healthcare professionals. There were also reports of conflicting or inconsistent advice from health professionals.[18]

Some professionals did recognise the limitations of their own knowledge[18] and referred patients to online support groups. Focus group participants suggested they would rather be told that the professional did not have the knowledge required to address their illness, if that was the case. The importance of finding a General Practitioner (GP) who was understanding, empathetic and who provided support to those experiencing long COVID is highlighted in this quote:

“I have to say it was a really powerful experience speaking to the GPs ... the two more recent ones, actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn’t do anything, I just kind of needed to know that I wasn’t losing it really and it was real what I was experiencing, I think so that was really helpful.”[17]

Along with this perceived lack of knowledge, multiple perceived barriers to healthcare access were reported, along with a general perception among participants that health services and doctors were too busy dealing with cases of acute COVID-19 to have capacity to deal with anything else, including patients with long-term symptoms. This perception appeared strengthened by the difficulties people experienced when trying to access primary care, especially if they were seeking a face-to-face consultation.

“I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful, particularly as I didn’t have, and never have had, a cough or fever”[1]

In general, study participants found accessing care to be “complex, difficult and exhausting”.[18] This led to patients describing how they felt they had to manipulate the inflexible algorithm-driven systems in order to receive care, which led to feelings of guilt and anger. Some patients described creative solutions they had come up with to help them access healthcare, while others reported resorting to private healthcare to access tests. Many patients felt they needed to conduct their own research and construct their own care pathways, taking the lead in arranging consultations with specialists and circumventing bottlenecks in the system. This was reported as a route often employed by medical professionals who themselves were suffering from long COVID.

There was also a perceived lack of support within the system. Some individuals described how NHS111 (a national telehealth helpline in the UK) had directed them to their GP who then directed them back to NHS111.[18] There was what appeared to be a lack of guidance for those who did not need to be admitted to hospital but were no longer in the acute phase of the illness.

Patients who felt they had received satisfactory care and access to healthcare were generally those who had been offered follow-up appointments and who felt their healthcare providers gave them ongoing support, even if that was in the form of a video or telephone call.

Telemedicine was widely used to facilitate interactions with healthcare services. However, it was generally perceived by patients to have limitations. Remote consulting with primary care was viewed by some patients as potentially limiting direct access to GPs, disrupting continuity of care (people often could not see the same GP every time), and making the communication of symptoms more challenging. Some patients felt that strict adherence to protocols for telemedicine-delivered care affected patient safety or led to mismanagement of their care.

"... I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I'm really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don't really sound too out of breath over the phone .... I really felt at that point right if you could see me you would see that I am really like broken"[18]

A positive view expressed in relation to telemedicine was that it increased accessibility of primary care during periods of societal restrictions aimed at controlling the spread of COVID-19.

"My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track."[19]

When asked to describe desirable features of healthcare services or service delivery for patients with long COVID, research participants asked for face-to-face assessments and talked about the need for 'one-stop clinics' with multidisciplinary teams (MDT) who could look at their wide-ranging symptoms and treat them holistically. A case manager to oversee individual patients and ensure that all aspects of their care was considered was suggested, along with meaningful referral pathways and criteria.

"What would be most helpful is if all main hospitals could have a COVID clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, we are having such a range of symptoms that GPs are struggling to know what to do with you"[1]

Other participants spoke about wanting to be listened to, to be believed and understood, and to be offered practical advice on coping.

DISCUSSION

To our knowledge, this is the first synthesis of findings from qualitative studies on peoples' experiences of living with long COVID and accessing healthcare services for this condition. Our main findings were threefold. Firstly, that the lived experience of long COVID is highly variable and perceived as being at odds with public perceptions and official guidance on COVID-19. Secondly, that there are significant emotional consequences of living with long COVID that need to be understood by a number of stakeholders. Finally, that people with long COVID report a range of positive and negative healthcare experiences that can be used to inform the development of new, or adaptation of existing, services for this important patient group.

COVID-19 is a new illness, first declared a public health emergency by the World Health Organisation on 30th January 2020.[21] The implications across the globe and stress on healthcare services are unprecedented. It is perhaps unsurprising that knowledge of long COVID is perceived as underdeveloped; there is no agreed definition of long COVID and the long-term sequelae are to a large extent unknown.[3] Many people in the included studies turned to social media and patient-led support groups, due to perceived lack of understanding from family, employers and healthcare professionals.[1 17-19] Social media and support groups are widely used for other health conditions,[22] but are generally considered complementary to healthcare services; part of the "jigsaw" that makes supported self-management successful.[23] Therefore, there appears to be a need for more widespread understanding of and information about long COVID, and people with lived experience are ideally placed to contribute their expert opinion.

Our review highlighted a number of emotional consequences of long COVID including the impact on people's identities, employment, and relationships with family and healthcare providers. Emerging models and recommendations for managing long COVID all highlight the need for psychological inputs.[24-26] It is perhaps more complex to address the wider emotional consequences highlighted by this review; however, understanding and information as described above and targeted at various levels (e.g. healthcare professionals, patients, public, employers) appears to be indicated.

In addition to lack of knowledge, the review found a number of barriers to accessing healthcare, with reports of unhelpful messaging and complex processes to navigate. Healthcare professionals with long COVID were more able to navigate this complex system than non-professionals, suggesting a potential inequality. Telemedicine, rapidly rolled-out in many countries as a way of maintaining healthcare during the pandemic,[27] was not always seen as beneficial. As new models for managing long COVID emerge, these findings may be useful for ensuring that services are patient-centred.[28] The finding that patients want multidisciplinary, holistic services is congruent with the well-documented multi-organ nature of COVID-19, and heterogeneous nature of long COVID symptoms.[3]

Strengths and limitations

Our review has highlighted a range of important issues associated with long COVID and accessing healthcare, from the perspective of people with this condition. The review is limited by the small number of qualitative studies (n=5) that have been published to date, and will benefit from being updated as further research becomes available in this fast-moving field. Nonetheless, it contributes to an early understanding of the lived experience of long COVID and of accessing healthcare services. The majority of studies were conducted in the UK, there was over-representation of younger and female, white, participants, and all studies recruited participants via social media or online support groups. Therefore, the findings apply to this population, and it is possible that other groups of people with long COVID have different experiences and views. Some emerging evidence suggests that long COVID may be more prevalent in younger female individuals[29]; a meta-analysis in pre-print form however reports a linear increase in long COVID from age 20-70[30]. We limited our search to studies published in English; therefore it is possible that we missed studies published in other languages. We did not exclude studies on methodological quality, resulting in the inclusion of one study with limited methodological details resulting in a low CASP score. However, the validity of appraisal of qualitative research is debated in the literature,[31] and we are confident that all studies contributed valuable data on the lived experience of long COVID. We did not contact authors for additional information that may have allowed us to more fully appraise methodological quality of the included studies. However, because we did not exclude any studies based on methodological quality; therefore, the review findings were not affected.

Implications for practice

There is a need for greater understanding and communication about long COVID at a number of levels (public, policy and healthcare professional). Our findings suggest that people with long COVID are well placed to co-create this understanding and communication. Our findings can also be used by those currently developing services for people with long COVID, to ensure that they meet patients' needs. The varied and fluctuating symptoms and emotional consequences experienced by people with long COVID indicate a need for multi-disciplinary services, which provide holistic patient-centred assessment, appropriate management and specialist referral where indicated.

Implications for research

Further qualitative research on more culturally diverse samples of people with long COVID is indicated to help understand the impact of long COVID and the healthcare needs of the wider population than is represented by the current review. As models of care and services are developed/adapted for people with long COVID, it is vital that the views and experiences of people with long COVID continue to be explored.

CONCLUSION

We have presented a synthesis of the current qualitative evidence on the experience of living with long COVID and of accessing healthcare services. People experience long COVID as a heterogeneous condition, with a variety of physical and emotional consequences. It appears that greater knowledge of long COVID is required by a number of stakeholders, and that the design of emerging long COVID services, or adaptation of existing services for long COVID patients should take account of patients' experiences in their design.

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Contributors

DM, JH, KC, KM and MN developed the protocol. CM conducted the literature searches. JH and DM screened articles for inclusion. KM, DM, JH and MN extracted data, appraised studies, and, including KC, were involved with synthesising the qualitative data, interpreting the findings and writing the first draft of the manuscript. Other members of the research teams within Robert Gordon University, Aberdeen, and Healthcare Improvement Scotland provided peer review comments on the draft manuscript.

Competing interests

None declared.

Data sharing statement

Search strategies for databases other than Medline are available by contacting the corresponding author. Full data extraction tables are also available.

Ethics approval statement

Ethics approval was not sought as this study was a systematic review of published evidence.

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FIGURES AND TABLES

Figure legends

Figure 1 PRISMA flow diagram of study selection
Figure 2 Map of analytical and descriptive themes from the analysis

Table 1 Characteristics of included studies

Study [country]	Study methods and setting	Participant characteristics and sample size	Main results
Assaf *et al*. (2020)[19] [Multinational]	Online survey 21 Apr - 2 May 2020 circulated to long COVID support groups and through social media Quantitative and qualitative data collection	n=640 Patients with symptoms lasting >2 weeks 62.7% aged 30-49; 76.0% white; 76.6% female	Cyclical symptoms experienced unexpectedly for ≥6 weeks Stigma experienced by patients with long COVID Impacts on lifestyle, including physical activity Dismissed or misdiagnosed by medical professionals Sentiment analysis conducted on satisfaction with medical staff and on sharing experiences.
Davis *et al*. (2020)[16] [Multinational]	Online survey 6 Sept – 25 Nov 2020 circulated to online patients support groups and social media Quantitative and qualitative data collection	n=3,762 Patients with symptoms lasting >28 days 60.8% aged 40-59; 85.3% white; 78.9% female	Patients with long COVID reported prolonged multisystem involvement and significant disability. The most frequent symptoms reported after 6 months were: fatigue post-exertional malaise cognitive dysfunction.
Kingstone *et al*. (2020)[17] [UK]	Recruitment through social media (Twitter or Facebook) and snowball sampling Jul - Aug 2020 Semi-structured interviews by telephone or video	n=24 Self-reported persistent symptoms following acute COVID-19 illness Age range 20-68; 87.5% white British; 79.2% female	Four key themes reported in results: 'hard and heavy work' of enduring and managing symptoms, trying to find answers, and accessing care living with uncertainty and fear

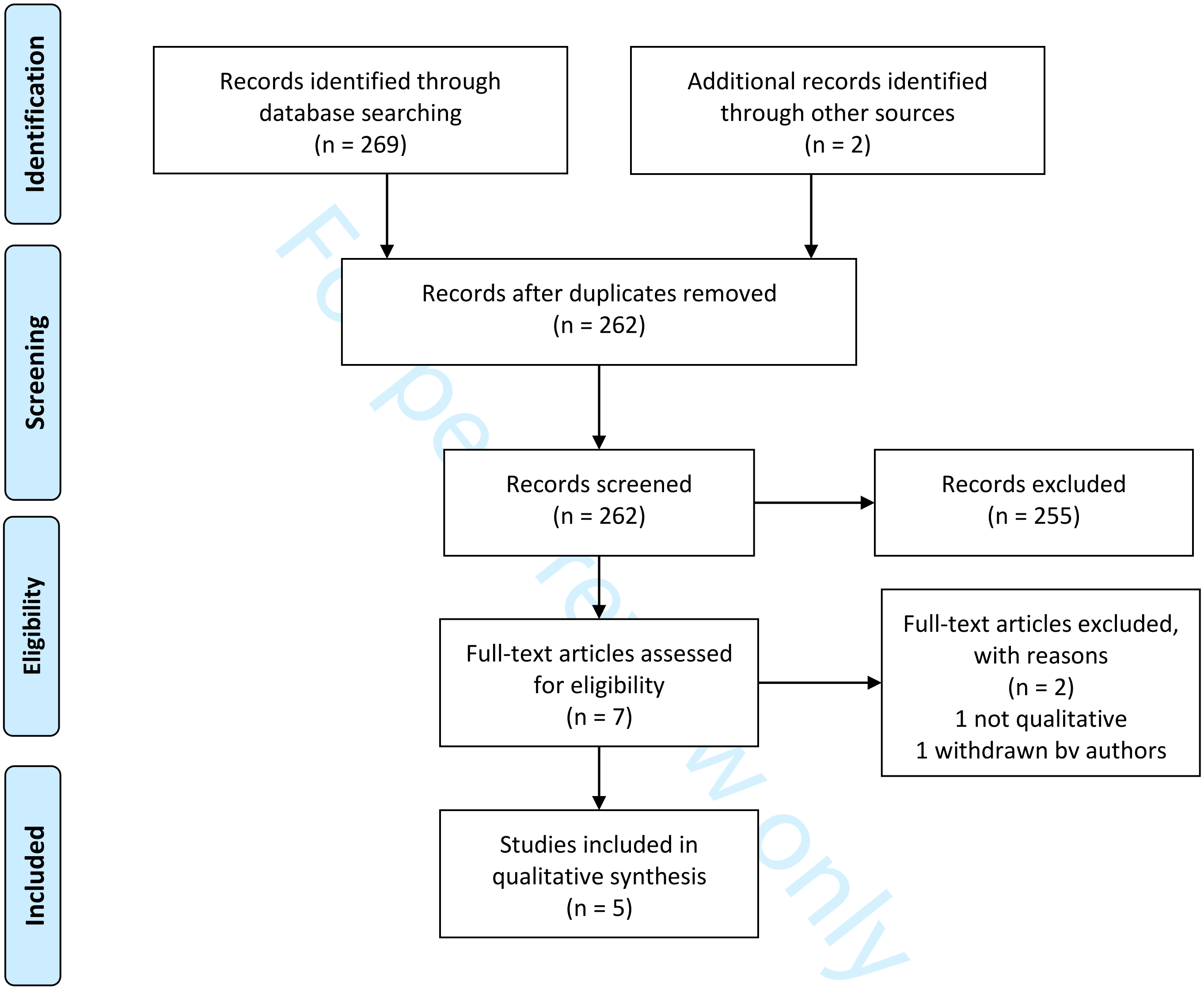
	call (duration 35-90 minutes) Thematic analysis using principles of constant comparison		importance of finding the 'right' GP recovery and rehabilitation: what would help?
Ladds *et al*. (2020)[18] [UK]	Participants recruited from UK-based long COVID patient support groups, social media and snowball sampling Individual narrative interview (telephone or video) or participation in an online focus group Constant comparison method of data analysis	Total n = 114 55 interviews (73% female); median age 48 (range 31-68) 59 focus group participants (68% female); median age 43 (range 27-73)	Five key themes reported in results: the illness experience, accessing care, relationships (or lack of) with clinicians, emotional touchpoints in encounters with health services, ideas for improving services
Maxwell (2020)[1] [UK]	Focus group of COVID-19 Facebook group members	Not reported	Four key themes reported in results: expectations, symptom journey, being doubted, support

Table 2 CASP critical appraisal of using the checklist for qualitative studies

	Assaf *et al.*[19]	**Kingston *et al.*[17]**	**Ladds *et al.*[18]**	**Maxwell[1]**	**Davis *et al.*[16]**
Clear aims statement	Y	Y	Y	N	Y
Appropriate methodology	U	Y	Y	Y	Y
Appropriate research design	U	Y	Y	U	Y
Appropriate recruitment	Y	Y	Y	U	Y
Appropriate data collection	U	Y	Y	U	Y
Researcher-participant relationship considered	N	U	U	U	U
Ethical issues considered	U	Y	Y	U	Y
Rigorous data analysis	U	Y	Y	N	U
Clear statement of findings	U	Y	Y	Y	Y

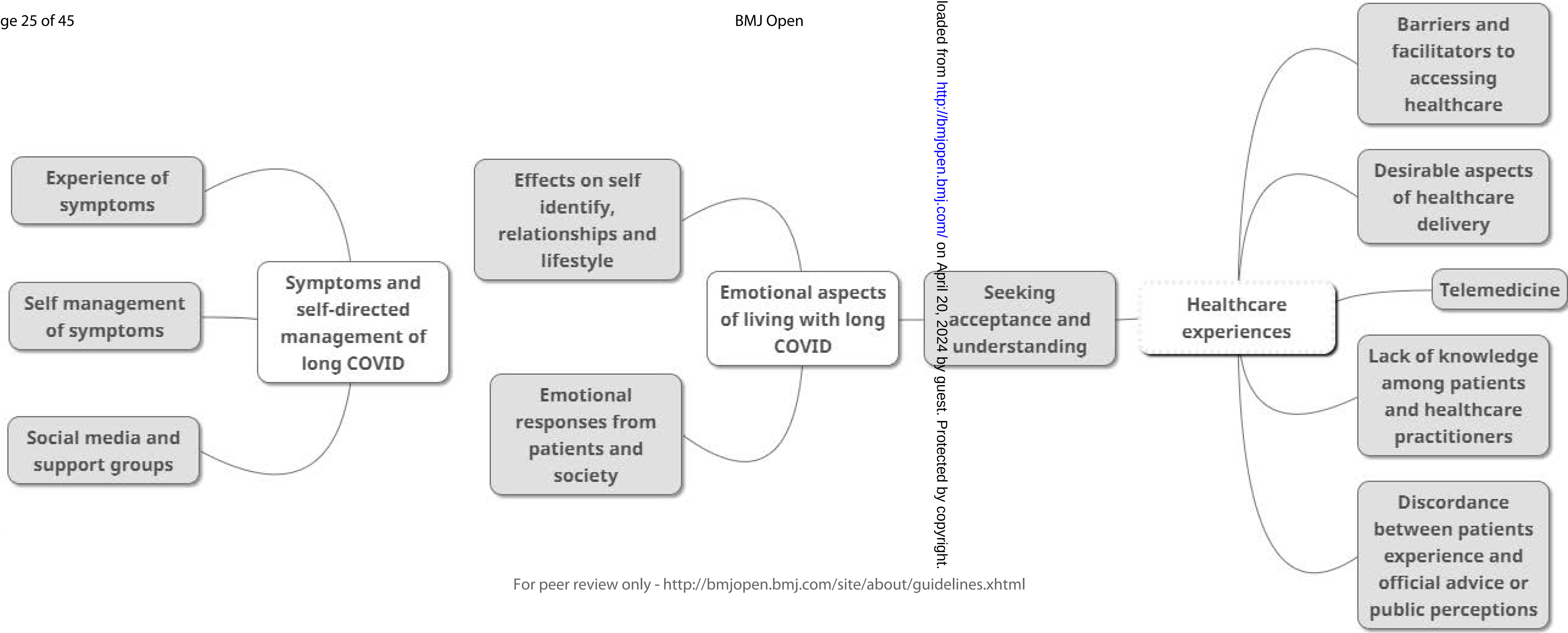
Y=criterion satisfied; N=criterion not satisfied; U=unclear if criterion satisfied

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.


Experience of symptoms
Self management of symptoms
Social media and support groups
Symptoms and self-directed management of long COVID
Effects on self identify, relationships and lifestyle
Emotional responses from patients and society
Emotional aspects of living with long COVID
Seeking acceptance and understanding
Healthcare experiences
Barriers and facilitators to accessing healthcare
Desirable aspects of healthcare delivery
Telemedicine
Lack of knowledge among patients and healthcare practitioners
Discordance between patients experience and official advice or public perceptions

SUPPLEMENTARY MATERIAL

Supplementary file 1 Inclusion criteria

Criteria	Notes
Population	Adults and children experiencing new or ongoing symptoms: • 4–12 weeks from onset of acute COVID-19 illness • 12 weeks from onset of acute COVID-19 illness
Phenomena of interest	Signs and symptoms of post-COVID-19 syndrome Access to services How symptoms were assessed Management of symptoms and rehabilitation Patient care pathway Information and support provided Communication with healthcare professionals
Comparators	Not applicable
Outcomes	The outcomes will be generated using emergent coding, but are expected to include experiences, views and perceptions of individuals, families or carers on the factors of interest listed (such as Patient Reported Experience Measures)
Settings	Any
Sub-groups	Equality groups, for example, age, gender, ethnicity Diagnosis of COVID-19 (e.g. confirmed or high clinical suspicion) Duration of symptoms
Study types	Systematic reviews of qualitative studies Qualitative studies that collect data from focus groups or interviews Studies that collect qualitative data from questionnaires / surveys Mixed method study designs (including qualitative element)
Countries	Any
Timepoints	Any
Other exclusions	None

Supplementary file 2 Sources searched and MEDLINE search strategy

UK national health service and government websites
Public Health England
Public Health Scotland
Scottish Government
UK Government
National/international policy sources
European Centre for Disease Control
Health Protection Scotland COVID-19 Compendium
Guidelines
National Institute of Health
NICE
SIGN
Evidence summaries and collections
Analytical Collaboration for COVID-19
Cochrane Special Collection
COVID-19 Best Evidence Front Door
COVID-19 Evidence Reviews
Evidence Aid Collection
McMaster rapid review database
Oxford Centre for Evidence-Based Medicine
HTAs
ECRI
Health Technology Wales
National Institute for Health Research
NICE
Specialist Databases
Epistemonikos
EPPI Centre: living systematic map of the evidence
ProQuest
PubMed LitCovid
WHO database of publications
Preprints
bioRxiv
medRxiv
Research centres/organisations
Campbell Collaboration
Centre for Qualitative Research
Health Foundation
King’s Fund
Patient issues
Carers UK
Health Talk
Involve
James Lind Alliance

King's Fund Patient Experience Blog
National Association for Patient Participation
National Voices
Our Covid Voices
Patient UK Discussion Forums
Patient Views
Patient Voices
Patients Association
Picker Institute
Primary literature (bibliographic databases)
MEDLINE
PsycINFO
Web of Science

Medline search strategy

1 exp coronavirus/
2 exp Coronavirus Infections/
3 ((corona* or corono*) adj1 (virus* or viral* or virinae*)).ti,ab,kw,kf.
4 (coronavirus* or coronovirus* or coronavirinae* or CoV).ti,ab,kw,kf.
5 ("2019-nCoV" or 2019nCoV or nCoV2019 or "nCoV-2019" or "COVID-19" or COVID19 or "CORVID-19" or CORVID19 or "WN-CoV" or WNCoV or "HCoV-19" or HCoV19 or "2019 novel*" or Ncov or "n-cov" or "SARS-CoV-2" or "SARSCoV-2" or "SARSCoV2" or "SARS-CoV2" or SARSCov19 or "SARS-Cov19" or "SARSCov-19" or "SARS-Cov-19" or Ncovor or Ncorona* or Ncorono* or NcovWuhan* or NcovHubei* or NcovChina* or NcovChinese* or SARS2 or "SARS-2" or SARScoronavirus2 or "SARS-coronavirus-2" or "SARScoronavirus 2" or "SARS coronavirus2" or SARScoronovirus2 or "SARS-coronovirus-2" or "SARScoronovirus 2" or "SARS coronovirus2").ti,ab,kw,kf.
6 (((respiratory* adj2 (symptom* or disease* or illness* or condition*)) or "seafood market*" or "food market*" or pneumonia*) adj10 (Wuhan* or Hubei* or China* or Chinese* or Huanan*)).ti,ab,kw,kf.
7 ((outbreak* or wildlife* or pandemic* or epidemic*) adj1 (China* or Chinese* or Huanan*)).ti,ab,kw,kf.
8 "severe acute respiratory syndrome*".ti,ab,kw,kf.
9 SARS Virus/
10 ("SARSCoV" or "SARS-CoV" or "SARS Cov" or SARScoronavirus or "SARS-coronavirus" or "SARS coronavirus" or SARScoronovirus or "SARS-coronovirus" or "SARS coronovirus").ti,ab,kw,kf.
11 Middle East Respiratory Syndrome Coronavirus/
12 "Middle East* respiratory syndrome".ti,ab,kw,kf.
13 ("MERSCoV" or "MERS-CoV" or "MERS Cov" or MERScoronavirus or "MERS -coronavirus" or "MERS coronavirus" or MERScoronovirus or "MERS-coronovirus" or "MERS Coronovirus" or "camel flu").ti,ab,kw,kf.
14 or/1-13
15 exp Patient Satisfaction/
16 ((patient* or carer* or family) adj2 (experience* or view* or perspective* or preference* or attitude* or expectation* or satisfaction)).tw.

17	15 or 16
18	14 and 17

Supplementary file 3 Summary of key themes relating to the views and experiences of patients, their families and carers

Themes and sub-themes	Summary of sub-themes	Supporting example
Theme: experience of symptoms		
Range of symptoms	Patients described a wide range of symptoms, not all of which were recognised as symptoms of COVID-19.	"The symptoms were like a game of whack-a-mole. Different ones would surge at different times and in different places in my body." (Assaf *et al*)[19] "From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia." (Maxwell)[1]
Severity of symptoms	Symptoms ranged from mild to potentially life-threatening.	"I've been absolutely floored... I've got all sorts of... I've got vasculitis, which I think is a common thing... And I've been left with nerve issues, like really horrible nerve... stabbing pains in my hands and feet and I can't move my toes any more... unfortunately, my journey is far from over." (Ladds *et al*)[18] "From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia." (Maxwell)[1]
Duration and lingering nature of symptoms	Symptoms were experienced for a prolonged but variable length of time.	"He was sleeping for about 20 hours a day, 20 hours out of every 24 and he's still sleeping now, five and half months after, he still sleeps an awful lot, sat up, not lay down, sat up, he's just totally exhausted." (Kingstone *et al*)[17]

Themes and sub-themes	Summary of sub-themes	Supporting example
Fluctuating or cumulative nature of symptoms	Patients described symptoms ‘coming and going’, and of new symptoms being added to existing ones over time.	“...From week four I started to get chest pains and then breathlessness, gradually other symptoms developed .... The following weeks were frightening as symptoms fluctuated; sometimes thinking that you were improving and then very disheartening when they returned.... After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms....” (Maxwell)[1]
Theme: discordance between patient experiences and official advice or public perceptions		
Disconnect between official advice and lived experience	Patients found official advice on graded exercise and when to come out of isolation unhelpful and contrary to their lived experience of long COVID.	“Well, one of the things that really bugged me about it was the talking about graded exercise and I’ve learnt from experience that pushing myself even a tiny bit has massive consequences ...” (Kingstone *et al*, p6)[17]
Disconnect between public perception (“labels”) and lived experience	The perception that COVID-19 is a binary illness that is either ‘mild’ or very serious (requiring hospitalisation) was unhelpful and contrasted with patient experience.	“So, COVID-19, it’s either a mild infection or you die? No. But no one is prepared to think about us.” (Kingstone *et al*)[2] “I think the term "mild" should be removed... I know that people who were admitted to the hospital were worse, but we who stayed home did not have MILD cases in all cases” (Maxwell)[1]
Disconnect between expected/official timeframes and lived experience	Patients expected COVID-19 to last approximately 2 weeks, in line with official estimates, and were then confronted by much longer-term illness. Patients experiencing symptoms beyond the 2-week period are often diagnosed with an alternative condition that more neatly fits the timeframe.	“I went back to work too soon and wish I hadn’t. Finally had to take a 5 week break in July/ August with the support of my employer. This helped a lot. I have now been back at work for 5 weeks and my symptoms have got worse to a degree.” (Davis *et al*)[16]

Themes and sub-themes	Summary of sub-themes	Supporting example
Disconnect between officially recognised symptoms and lived experience	There is discordance between the range of symptoms articulated by patients with long-term illness and those officially recognised by authorities as COVID-19.	"If the message hadn't been [to expect to recover in] around two weeks, I'd have been more cautious at first, … the doctor I saw in A/E described Covid as the gift that keeps on giving and at four weeks I thought that felt like a long time, and now five months on it feels like a very long time" (Maxwell, p11)[1]
Impact of disconnect between officially recognised symptoms and lived experience	As a consequence of the mismatch between officially recognised symptoms and lived experience of long COVID, patients feel ignored, dismissed, and may be misdiagnosed.	"Despite having been diagnosed with suspected Covid by my GP and a doctor in a Covid clinic (swab testing wasn't available to the public at the time) and told I had pleurisy during a visit to A&E two weeks earlier, the doctor on duty didn't take this into account. Instead, he dismissed me with anxiety, advising a course of anti-depressants, and chose not to investigate these concerning symptoms further. Of course I was anxious, but that was a consequence of the physical symptoms, not the cause! I would later learn from a neurologist that what I experienced on that day were clear neurological symptoms that should have been investigated promptly. To be brushed off like this when so little was known at the time of the damage Covid can cause was disheartening and very upsetting." (Maxwell, p15)[1]
Theme: self management of symptoms		
Self care and lifestyle adjustment	Patients attempted various forms of self care, such as taking supplements, and made adjustments to their lifestyle, for example by reducing physical activity, to accommodate long COVID.	"I mean initially I started taking vitamin D. Had a joint vitamin C and zinc thing, which I didn't take every day but I took some multivitamins, but then I was a bit unsure really … my husband's quite anti-vitamin use … So anyway, then I took nothing for a while, and then I more recently started the vitamin D again, and I'm on

Themes and sub-themes	Summary of sub-themes	Supporting example
		B12 just because of all the burning in my feet … and a probiotic and some omega-3." (Kingstone *et al*)[17]
Pacing and goal setting	The importance of pacing yourself and setting realistic goals was highlighted by patients.	"…I really have to pace myself… I couldn't do two or three household chores back to back, I have to do a chore, sit down for 15, 20 minutes and then do the next, which frustrates me…." (Kingstone *et al*)[17]
Theme: emotional responses from patients and society		
Helplessness	Long-term symptoms were associated with a feeling of helplessness.	"Most participants continued the discussion after the digital recorder was turned off, emphasising their own feelings of helplessness, but also alluding to the uncertainty and helplessness that GPs had admitted to" (Kingstone *et al*)[17] *[Author quote]*
Anxiety	Patients described anxiety about the prospect of not recovering, uncertainty over the cause of symptoms, not being believed, and some of the content they read on online support groups.	".... I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not "I'm going to die right now", but definitely "I'm never going to get better from this" kind of feeling." (Kingstone *et al*)[17]
Relief	A sense of relief was associated with finding a healthcare professional that believed the patient.	"I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people's symptoms are real and diverse." (Maxwell)[1]
Stigma (externally generated)	Employers and others drive a fear of being stigmatised over long COVID.	"Healthcare staff was fearful and I was turned away with no support" (Assaf *et al*)[19] "I had to take two weeks off, had to work from home for four, but had to return for two weeks with fever as my employer would not give me more time […]." (Davis *et al*)[16]

Themes and sub-themes	Summary of sub-themes	Supporting example
Stigma (internally generated)	Patients experienced a sense of shame and blame consistent with stigma.	"Fearful of people around me finding out and overreacting / treating me differently" (Assaf *et al*)[19]
Theme: effects on self-identity, relationships and lifestyle		
Impact on self-identify	Long COVID affected self identity as a healthy, independent individual, and resulted in patients comparing themselves with a pre-COVID version of self.	"I have not had strength to return to physical activity. I did work in my house and 2 days later had a fever again after being 12 days fever free." (Assaf *et al*)[19]
Impact on daily life/work	Patients had to alter their physical activity levels to accommodate long COVID and found cognitive symptoms prevented a return to work.	"I'm trapped, in that I can't park that far away and walk [to the shops] like I normally would because I can't do hills. I can just, in the last couple of weeks, I can do gentle inclines now, but I sort of grind to a halt on a hill. So, it's very limiting." (Ladds *et al*)[18] "I wasn't just fogged. I was confused. I had a very difficult encounter as a result of just being confused about things and that took a long time to resolve. I love words and I enjoy the business of communicating, and I felt that part of my life was lost. Really, I just did admin, I didn't do anything that required clear thinking." (Kingstone *et al*)[17]
Impact on self - reduced confidence	There was a sense of loss of confidence in professional abilities among some patients.	"Doctors and other clinicians …. described how their symptoms and the accompanying prognostic uncertainty …. had also stripped them of confidence in their professional abilities." (Ladds *et al*)[18] *[Author quote]*
Impact on others/relationships	Long COVID had an impact on family members as well as patients.	"I think, at first, they just thought, "Oh, for god's sake, she's napping again." I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted …. I used to enjoy running, and

Themes and sub-themes	Summary of sub-themes	Supporting example
		exercising, and stuff like that. I rarely even go on walks now because I know if I walk to the end of the street, they're [lungs] going to start hurting." (Kingstone *et al*)[17]
Theme: healthcare access – barriers and facilitators		
Barrier - testing	Challenges were experienced with accessing testing (for long-term symptoms or COVID-19 diagnostic testing).	"... My worst and scariest experience with this illness was in week 6, when I was rushed to A&E as I had a sudden relapse of symptoms and found myself gasping for air, with the top of my head numb and tingling and a headache so blinding that I couldn't keep my eyes open. I got worse in the hospital and was shaking visibly, so much so that the nurse couldn't perform an ECG as I just couldn't stay still. Despite having been diagnosed with suspected Covid by my GP and a doctor in a Covid clinic (swab testing wasn't available to the public at the time) and told I had pleurisy during a visit to A&E two weeks earlier, the doctor on duty didn't take this into account. Instead, he dismissed me with anxiety, advising a course of anti-depressants, and chose not to investigate these concerning symptoms further. ... I would later learn from a neurologist that what I experienced on that day were clear neurological symptoms that should have been investigated promptly. To be brushed off like this when so little was known at the time of the damage Covid can cause was disheartening and very upsetting." (Maxwell)[1]

Themes and sub-themes	Summary of sub-themes	Supporting example
Barrier – primary care	Difficulties accessing primary care, particularly face-to-face or through the 'total triage' system were a barrier to healthcare access	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", a.....so I started contacting a different GP, in the same practice, and it's the same outcome, they can't do anything else but he seems to be interested and wants to know what's going on." (Kingstone *et al*)[17]
Barrier – effort involved	Accessing healthcare was complex, difficult and exhausting for patients.	"One day I had blue finger nails and I wasn't cold …. and I phoned the GP and the GP answer phone said if you've got any of the signs of, of Covid please ring 111 and so I rang 111 and, I live in [city with high incidence of Covid-19] I don't know if that makes any difference but I was put on hold and after over an hour, an hour and twenty minutes nobody answered so I just put the phone down ….." (Ladds *et al*)[18]
Barrier – specialist referral	Few patients managed to obtain a referral to a specialist.	"…three of the referrals my GP made (two respiratory and one neurology) were refused by two different hospitals on the grounds that a) they only checked Covid confirmed patients b) that they needed extra tests which weren't done on me at A&E" (Maxwell)[1]
Perceived barrier – healthcare professionals being busy	There was a perception that healthcare professionals are too busy caring for patients with acute COVID-19 to be able to provide care for patients with long-term symptoms.	"At this point, most physicians and researchers are so overwhelmed treating the covid19 patients who are at risk of immediate death, that they don't have the ability to even recognize that people like me exist…." (Assaf *et al*)[19] "I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful,

Themes and sub-themes	**Summary of sub-themes**	**Supporting example**
		particularly as I didn't have, and never have had, a cough or fever” (Maxwell)[1]
Perceived barrier – healthcare entitlement	Patients had a perception that they were not entitled to healthcare for long-term symptoms of COVID-19.	“....I guess I felt a bit like I was ineligible for health care now. I felt like I’m just going to have to live with this at home and no one will come and see me and, you know, I’m just, yeah, it was a horrible feeling.” (Kingstone *et al*)[17]
Facilitator – follow-ups & check-ins	Regular follow up or check-in with patients with long-term symptoms was viewed as a positive aspect of healthcare.	“.... I think for the first five days after I called her she had a daily check in call with me to monitor how I’m doing so it was like a ten minute phone call every day for the first five days” (Ladds *et al*)[18]
Things patients did to access care	Patients engaged in a number of activities to improve their access to healthcare including: - taking the lead in arranging consultations and "circumventing bottlenecks” - deliberately manipulating inflexible algorithm-driven systems to access referrals - accessing private healthcare to prompt NHS follow up, conducting their own research and constructing their own care pathways.	“did the e-consult – I had to do it a couple of times – I kind of learned to answer the questions to get it to send a message to my GP surgery… If you say you’ve got heart palpitations or breathlessness it’s telling you to call 111 which I didn’t want to do. And so I had to downplay symptoms [laughs] to get through. I cancelled it and did it again." (Ladds *et al*)[18]
Theme: telemedicine - limitations and benefits		
Limitation – remote consultation	Remote consulting was found to limit access to GPs and to restrict communication of symptoms.	“... reassure me are things where I need my body actually checking which I don’t think you could check online, you can’t check for blood clots online, you can’t check for neurological damage online can you?’ (Kingstone *et al*)[17]

Themes and sub-themes	**Summary of sub-themes**	**Supporting example**
Limitation – lack of continuity	Loss of continuity of care was particularly impactful on patients with complex presentations.	"The focus when you do get a new GP speaking to you seems to be that they go back to the beginning ….And I think if there was the same GP who we are able to consult regularly they would build a picture of your baseline and I think that's what's lost with digital ways of working." (Ladds *et al*)[18]
Limitation – protocolised care	Strict adherence to protocols in the telemedicine context affected patient safety and led to mismanagement.	"… I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I'm really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don't really sound too out of breath over the phone …. I really felt at that point right if you could see me you would see that I am really like broken" (Ladds *et al*)[18]
Benefits - accessibility	Positive experiences of accessing GPs through telemedicine.	"My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track." (Assaf *et al*)[19]
Theme: lack of knowledge, information and understanding among healthcare professionals and patients		
Lack of knowledge - healthcare professionals	There is a perceived lack of knowledge about long COVID among healthcare professionals.	"…I think all the way through I found doctors that I've come into contact with are just really at a bit of a loss for it. I think at the beginning, particularly when things were going on, and not clearing up it was kind of put on me as just being a strange case ... and my GP was going, "Well, you're just weird, you know".' (Kingstone *et al*)[17]

Themes and sub-themes	Summary of sub-themes	Supporting example
Lack of knowledge – symptoms	The lack of knowledge around long COVID included uncertainty about the expected symptoms, wanting to learn about living with COVID-19, uncertainty about the cause of symptoms, a lack of understanding about the fluctuating nature of symptoms and lack of knowledge about recovery from long-term symptoms.	"None of us knew this [the symptoms] because we're all on our own, in a little bubble, thinking I'm the only one. Why am I the one who has still got it?" (Maxwell)[1]
Lack of knowledge – seeking help	Uncertainty about when patients with long COVID should seek medical help.	"...combined with the UK government message to stay away from health services unless very ill, left many people uncertain about when they should seek help." (Maxwell)[1] *[Author quote]*
Lack of knowledge – employers	Employers need advice on how to manage employees with long COVID.	"Advice on the range of symptoms and duration was also needed by employers who are unclear what to expect of those with ongoing effects." (Maxwell)[1] *[Author quote]* "I have needed more flexible hours (working remotely) post-COVID. That way, I can rest as needed throughout the day. If I had to return to in-person work at this point, it would be severely reduced hours if at all." (Davis *et al*)[26]
Lack of knowledge – management	Lack of knowledge about managing long COVID, resources available locally for patient rehabilitation, and about recovery from prolonged illness.	"I finally had a respiratory appointment three months later, over the phone (not over a video link). I was …. recommended graded exercise. When I then saw a rehabilitation physiotherapist, she said no, we are not going to do graded exercise because that would be counterproductive for you. " (Maxwell)[1]

Themes and sub-themes	Summary of sub-themes	Supporting example
Lack of knowledge – prompts help-seeking from other sources	Lack of widely accessible medical knowledge about long COVID has led to patient reliance on news and social media for information.	"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it. So, you know, sixth sense, I actually think that the support group has given more knowledge than the doctors have." (Ladds *et al*)[18]
Patients prefer healthcare professionals to admit uncertainty	Patients would prefer healthcare professionals to admit to a lack of knowledge about long COVID.	"She just listens a little bit more to what I'm saying and she's much more willing to say, "Of course, we don't really know what's going on because it's a new virus." She doesn't try to pretend that she understands what's going on, which is good." (Kingstone *et al*)[17]
Theme: desirable features of healthcare services/service delivery		
Healthcare structuring – one stop clinics with face-to-face assessment of symptoms by multidisciplinary teams	Patients wanted a 'one-stop' clinic with multidisciplinary teams there to assess symptoms affecting a wide range of body systems.	"What would be most helpful is if all main hospitals could have a Covid clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, We are having such a range of symptoms that GPs are struggling to know what to do with you" (Maxwell)[1]
Healthcare structuring – case management	A case manager or single clinician to co-ordinate investigations and the patient care pathway for each patient with long COVID.	"... there was a view that it would be helpful if people living with Covid19 could have a 'quarter back' or case manager to oversee and coordinate investigations and support services across different medical specialities." (Maxwell)[1]
Healthcare structuring – MDT rehabilitation	Assessment by a multidisciplinary rehabilitation team was proposed.	"... the British Society of Rehabilitation Medicine notes there are people who were never admitted to hospital but who still have ongoing needs for rehabilitation

Themes and sub-themes	Summary of sub-themes	Supporting example
		support after recovering from Covid, or Covid-like symptoms." (Maxwell)[1] *[Author quote]*
Individual - acceptance of patient experiences by healthcare professionals	Empathetic health professionals that accepted patient experiences were desirable to individuals.	"I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people's symptoms are real and diverse." (Maxwell)[1]
Individual - practical coping strategies	Patients wanted practical advice on coping strategies.	"... members understood that there were no magic cures, but were looking for practical advice on coping strategies that go beyond basic advice." (Maxwell)[1] *[Author quote]*
Theme: social media and support groups		
Support through sharing experiences	Online support groups and social media provided opportunities for sharing experiences of long COVID.	"when I found the Long Covid Facebook group that I realised I wasn't alone, thousands of people were in the same situation. Knowing this helped enormously." (Maxwell)[1]
Support through sharing knowledge	Online support groups and social media provided opportunities for sharing knowledge and resource links with others coping with long COVID.	"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have." (Ladds *et al*)[18]
Validation of experiences	Patients found validation of their experiences in communication with others through online support groups.	"many participants – both men and women – found that online peer support groups offered the greatest source of support through shared experiences, knowledge and validation." (Ladds *et al*)[18] *[Author quote]*
Theme: seeking acceptance and understanding		
Perception of being doubted by healthcare professionals	Healthcare professionals were perceived to doubt patient symptoms were related to COVID-19 and to doubt symptom severity.	"There was one GP who just thought it was all anxiety ... she said, "There's nothing wrong with your lungs. This is all anxiety. You must treat your anxiety. There's

Themes and sub-themes	Summary of sub-themes	Supporting example
		nothing wrong with you. How are you going to manage the pandemic if you don't treat your anxiety?" That was really upsetting because I knew I was short of breath..." (Kingstone *et al*)[17]
Perception of being doubted by friends and family	There was a perception that friends and family doubted patients because symptoms were not always obvious.	"... one of my friends did say after quite a while, "I'm not being awful, but do you think a lot of it's in his mind?" and I said "no". I was quite upset about that..." (Kingstone *et al*)[17]
Perception of being ignored	Patients felt that their condition was not given the recognition that it deserved.	"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us." (Kingstone *et al*)[17] "I felt the medical team was dismissive. There were a lot of 'we don't know.' Which is understandable, but difficult." (Assaf *et al*)[19]
Difficulties finding empathetic healthcare professionals	Challenges were described in finding healthcare professionals willing to show empathy and accept patient experiences of symptoms.	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", and that frustrated me because it didn't seem like they were being caring, it felt like I was nagging them and being a hypochondriac..." (Kingstone *et al*)[17] "Because I've spoken to four different GPs throughout this. I've not found them very helpful..." (Kingstone *et al*)[17]
Misdiagnosis or dismissal by healthcare professionals	Dismissal of symptoms or misdiagnoses were associated with a negative perception of healthcare.	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", and that frustrated me because it didn't seem like they were being caring, it

Themes and sub-themes	Summary of sub-themes	Supporting example
		felt like I was nagging them and being a hypochondriac and that's how I was being treated…" (Kingstone *et al*)[17]
When available strong empathetic relationships with healthcare professionals provides strong therapeutic relationships	A minority of patients reported strong therapeutic relationships involving listening, empathy, validation, honesty and arranging tests and follow up.	"… actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful." (Kingstone *et al*)[17]

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary file 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	5
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	5

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	6
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6 and PRISMA diagram
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	19
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	21
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	6
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	12
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	12
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	13
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	14

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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Experiences of living with long COVID and of accessing healthcare services: a qualitative systematic review

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Experiences of living with long COVID and of accessing healthcare services: a qualitative systematic review

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ABSTRACT

Objective To explore the experiences of people living with long COVID and how they perceive the healthcare services available to them.

Design Qualitative systematic review

Data sources Electronic literature searches of websites, bibliographic databases and discussion forums, including PubMed LitCovid, Proquest COVID, EPPI Centre living systematic map of evidence, medRxiv, bioRxiv, Medline, Psychinfo and Web of Science Core Collection were conducted to identify qualitative literature published in English up to 13 January 2021.

Inclusion criteria Papers reporting qualitative or mixed-methods studies that focussed on the experiences of long COVID and/or perceptions of accessing healthcare by people with long COVID. Title/abstract and full-text screening were conducted by two reviewers independently, with conflicts resolved by discussion or a third reviewer.

Quality appraisal Two reviewers independently appraised included studies using the qualitative CASP checklist**.** Conflicts were resolved by discussion or a third reviewer.

Data extraction and synthesis Thematic synthesis, involving line-by-line reading, generation of concepts, descriptive and analytical themes, was conducted by the review team with regular discussion.

Results Five studies published in 2020 met the inclusion criteria, two international surveys and three qualitative studies from the UK. Sample sizes varied from 24 (interview study) to 3,762 (survey). Participants were predominantly young white females recruited from social media or online support groups. Three analytical themes were generated: (i) symptoms and self-directed management of long COVID; (ii) emotional aspects of living with long COVID, and (iii) healthcare experiences associated with long COVID.

Conclusions

People experience long COVID as a heterogeneous condition, with a variety of physical and emotional consequences. It appears that greater knowledge of long COVID is required by a number of stakeholders, and that the design of emerging long COVID services, or adaptation of existing services for long COVID patients should take account of patients' experiences in their design.

Strengths and limitations of this study

- This review synthesizes the existing qualitative literature on people's experiences of long COVID and the healthcare services available to them
- The search strategy was comprehensive and sought to find published research, pre-publication articles and grey literature
- The search was limited to the English language, therefore potentially relevant studies may have been excluded

- Only five qualitative studies of variable quality were eligible for inclusion in this review, limiting the extent to which conclusions and practice recommendations can be made
- Participants in the included studies were predominantly younger, female, and users of social media or online support groups, which may also limit the generalisability of the review findings

INTRODUCTION

The long-term effects of COVID-19 are recognised increasingly as being heterogeneous and complex in nature. At the start of the COVID-19 pandemic there was a widespread perception that COVID-19 was an acute infection that resulted in death or recovery after two weeks.[1] However, many people experienced wide-ranging and fluctuating symptoms for weeks or months after confirmed or suspected COVID-19 infection. As these experiences were shared, on social media and other outlets, the term 'long COVID' was generated by patients.[2] There remains no internationally agreed definition of long COVID, as COVID-19 is still a relatively new disease, with ongoing research on the long-term effects.[3] Greenhalgh *et al* [4] suggested "post-acute COVID-19" for symptoms lasting beyond 3 weeks after onset, and "chronic COVID-19" for those lasting beyond 12 weeks. Recent UK guidelines defined "ongoing symptomatic COVID-19" as signs and symptoms lasting 4-12 weeks and "post-COVID-19 syndrome" as signs and symptoms developing during or after COVID-19 and continuing beyond 12 weeks.[5 6] As this systematic review is concerned with lived experience, we will use the patient-generated term long COVID to encapsulate all these definitions.

Symptoms of long COVID can affect those hospitalised and ventilated,[3] as well as those with so-called mild COVID-19, during the acute phase.[4] Little is known about long-term sequelae in asymptomatic patients, with this recently highlighted as an important area for future research.[3] Potential long-term effects include central nervous system, psychosocial, cardiovascular, pulmonary, haematologic, renal and gastrointestinal symptoms, as well as widely reported persistent fatigue, dyspnoea, joint and chest pain.[3] Estimates of long COVID rates vary from 10%[4] to 35%[7] with the true rate yet to be determined. Therefore, with over 108,000,000 confirmed COVID-19 cases globally as of 30th January 2021,[8] there are now a large number of people at risk of long COVID.

Healthcare services specifically for long COVID are evolving. For example, some specialist centres have been set up in parts of the UK,[9] and there has been a global call for the development of rehabilitation programmes and services for long COVID patients.[10] In order for healthcare services to meet patients' needs, it is important to understand the experience of long COVID and of accessing healthcare services from patients' perspectives. There is a growing body of qualitative research on the lived experience of long COVID, and to date, no published synthesis of this literature. The aim of this qualitative systematic review was therefore to explore the experiences of people living with long COVID and their perceptions of the healthcare services available to them.

METHODS

A qualitative systematic literature review was undertaken based on an *a priori* protocol (available on request) and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.[11] This review updates a review undertaken by the authors to inform the production of the Scottish Intercollegiate Guidelines Network (SIGN), National Institute of Health and Care Excellence (NICE) and Royal College of General Practitioners (RCGP) guideline on the management of long COVID.[5 6]

Inclusion criteria

Full details of the inclusion criteria for the review are given in supplementary file 1.

Participants: Individuals experiencing long COVID whether suspected or confirmed by diagnostic test, with no restriction on duration of symptoms. We excluded studies on the views or experiences of healthcare for conditions other than COVID-19 and those relating to the views of healthcare staff, unless they were patients themselves.

Phenomena of interest: people's views on and experiences of living with and managing long COVID, and on the healthcare services available to them.

Context: studies from any country and any setting.

Types of study: systematic reviews of qualitative studies; primary qualitative studies; qualitative components of mixed method studies.

Information sources and search strategy

An information specialist (CM) carried out a search in October 2020. Sources searched included: PubMed LitCovid, Proquest COVID, EPPI Centre living systematic map of evidence, medRxiv, bioRxiv, Medline, PsychInfo, and Web of Science Core Collection. A full list of resources searched is available in supplementary file 2. Published studies, grey literature and pre-publication articles were sought. In databases not specific to COVID-19, search results were limited to publications in 2020. All searches were limited to the English language due to a lack of translation services and the need for evidence to be synthesised in a timely manner due to the rapidly evolving nature of long COVID research. A search update was conducted on 13 January 2021.

Bibliographic database searches applied adapted versions of the qualitative research filter by DeJean *et al* (2016)[12] and a filter for patient experience literature developed by combining terms from papers by Selva *et al* (2017)[13] and Wessels *et al* (2016)[14]. The search strategy for Medline is available in supplementary file 2. Search strategies for other bibliographic databases are available on request.

Study selection

Citations were uploaded to EndNote software and duplicates removed. Records were screened against the inclusion criteria based on titles and abstracts by two reviewers independently (JH, DM). The same two reviewers then assessed the full text of potentially relevant articles. Disagreements were discussed and referred to a third reviewer where necessary. The two reviewers were in agreement for the majority of the papers and only one study required recourse to the third reviewer. (KM).

Data extraction

Two reviewers independently extracted descriptive data from each study (KC, JH, KM, DM, MN), using a data extraction template designed specifically for this review. The reviewers then compared templates and resolved any discrepancies, which were few in number, by discussion. Details extracted from the studies included: country in which the study was conducted, method of data collection and analysis, phenomena of interest, setting / context / culture, participant characteristics and sample size, and a description of the main results. As this review was conducted in a short timescale, to provide early evidence on a rapidly evolving subject, we did not contact authors for missing information.

Quality appraisal

Included studies were critically appraised by two reviewers independently (KC, JH, KM, DM, MN, JH) using the CASP qualitative checklist (https://casp-uk.net/casp-tools-checklists/). Discrepancies, which were minimal, were discussed and referred to a third reviewer if required. For the reasons described above, authors were not contacted for additional information on methodology of their individual studies.

Data synthesis

Thematic synthesis was undertaken on the findings from included studies.[15] This involved: (i) line-by-line reading of each study by two reviewers independently (JH, KM, MN) to identify initial concepts; (ii) grouping similar concepts into initial descriptive themes and sub-themes, and (iii) generating the final analytical themes. These were discussed and agreed by the review team (KC, JH, KM, DM, MN) throughout the process, and any disagreements resolved by discussion within the team.

Patient and public involvement

As a systematic review focussed on published and grey literature no primary research involving patients was conducted. The original synthesis that this review updates, was subject to review by an expert group that included several members with lived experience of long COVID, and a targeted public consultation which included groups representing those with experience of this condition. Further details are provided within the NICE long COVID guideline.[5]

RESULTS

Search results

The literature search identified 269 articles. A further two studies were identified from reference lists. After removal of duplicates and title/abstract screening, seven articles were evaluated as full-text. The main reasons for excluding articles were no qualitative element to the research, no patient involvement and not meeting our definition of long COVID (we were interested in studies relating to symptoms over four weeks duration). Out of the seven fully evaluated articles, one study was excluded because it did not use qualitative methods or contain data on direct patient experience. A second study which was initially included was later excluded after it was withdrawn from pre-publication by the authors. A PRISMA flow diagram depicting the study selection process is provided in figure 1.

Characteristics of included studies

Five studies were included in the thematic synthesis (table 1).[1 16-19] Three studies conducted focus groups or interviews with patients from the UK and two studies, from the Patient Led Research group, conducted international surveys with most responses coming from the USA and the UK. Sample sizes varied from 24 interviews to 3,762 survey respondents, and were generally weighted towards white (83.8%), female participants (75%). The number of patients included in the studies in which information was gathered through surveys was much larger than those using interviews and focus groups as data collection methods. However, while representing fewer patients, the latter method offers the opportunity of collecting more in depth data and for interaction among participants and/or with the interviewer. All studies focussed on adults with an age range of 20-68 years in the four studies that reported participants' ages; one study did not report the number of participants or their ages.[1]

Methodological quality

Studies were of variable methodological quality. Three met most of the criteria on the CASP checklist (table 2) and thus were considered of high quality, and two met fewer criteria. No studies were excluded on the basis of quality as all were considered to offer valuable content despite the limitations identified.

All five studies recruited participants through social media and/or online support groups. While this is understandable given the need to quickly access participants for whom no established groups or organisations existed, this convenience sampling may have resulted in bias.[20] 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. Three included studies acknowledged skewed sample characteristics including mainly white ethnicity, over-representation of women, and a generally younger age group.[16 18 19] Limited demographic information was provided on participants, particularly in Maxwell (2020),[1] making it difficult to determine which population groups may have been missed by these studies.

None of the studies discussed potential biases arising from the relationship between researchers and study participants. This is despite people with lived experience of long COVID symptoms being among the study authors, or performing data analysis in some studies.[16 17 19] This participatory research approach can be considered to represent both a strength and a weakness. Having authors and researchers with experience of long COVID analyse data is beneficial in bringing lived experience to the interpretation of data. However, it may also introduce bias for the same reason.

Several other quality issues were noted. In the study by Kingstone *et al* [17], participants received a compensation voucher for their time, which may have influenced decisions on whether to participate. Ladds *et al* [18] only fully transcribed the first 10 out of the 55 interviews (the remaining interviews were partially transcribed). This was due to the urgency of the work and limited resources plus a perceived lack of need to duplicate previously discovered themes. This may have introduced bias. Finally, Maxwell [1] reported very limited methodological details, making it difficult to determine how the research was conducted or the number of people involved in the focus group.

Review findings

The initial stages of thematic analysis resulted in the generation of 138 descriptive themes. These were then refined into 54 sub-themes, which were attributed to 11 higher order themes using an iterative process, with continuous discussion between reviewers. Further review and refinement of themes resulted in three overarching analytical themes: (i) symptoms and self-directed management of long COVID; (ii) emotional aspects of living with long COVID; and (iii) healthcare experiences associated with long COVID. Figure 2 shows the relationship between the final three themes and the initial 11 higher order themes. Full details of descriptive themes and sub-themes are available in supplementary file 3.

Symptoms and self-directed management of long COVID

Evidence from all the included studies[1 16-19] showed that people with long COVID experience a wider range of symptoms than the three symptoms officially recognised as acute COVID-19: high temperature, new continuous cough, and change or loss of sense of smell or taste. One individual stated:

"From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia."[1]

The symptoms experienced by patients with long COVID varied in severity from relatively mild to potentially life-threatening symptoms that required hospital admission[16-19]. Symptoms also fluctuated over time with new symptoms appearing at different stages of the illness and in different parts of the body[1,17-19]. Each symptom was experienced for a prolonged but variable length of time, with a cumulative effect in many cases [1,16,18].

People identified a disconnect between their lived experiences, official advice, and public perception of the illness. It was felt that the public perceived the illness as a binary condition[1,17] – either mild and easily treated at home or serious and requiring hospitalisation – with no variation or allowances made for ongoing symptoms.

"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us."[17]

The literature showed that people believed they would require a short recovery period and would be back at work in two weeks, a belief mirrored by employers and the public [1,16-19]. The lived experience, for some, was quite different:

"After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms..."[1]

"I had to take two weeks off, had to work from home for four, but had to return for two weeks with fever as my employer would not give me more time [...]."[16]

This discordance between expectations and experience seemed to have a direct effect on the mental and emotional state of those experiencing prolonged illness[1,18,19], often leading to uncertainty about what to do about their symptoms [1,17,18]. People described needing to adjust their lifestyle, including pacing themselves and setting realistic goals, in order to self-manage their symptoms [1,17,18]. One study highlighted specific methods used by anumber of patients attempting to self-care, such as taking supplements or trying therapeutic massage[17].

Many people turned to social media and support groups (online or face-to-face) for support and found them to be a valuable way to share experiences, knowledge and resources with others in a similar situation[17,18,19]. This communication helped to validate patient experiences and provided reassurance they were not alone in their struggle with long-term symptoms.

"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have."[18]

However, there were also reports of stigma, anxiety and depression[17,19] triggered by knowledge garnered from these online groups.

" ...Internet support groups, yeah on the Facebook groups that I'm on, I mean to be honest, I try not to read that group too much because it depresses me, makes me a bit anxious."[17]

Emotional aspects of living with long COVID

For many patients there was a feeling that their self-identity was affected by long COVID. People reported an impact on how they viewed themselves, before and after their illness [16,18]. There was a feeling they had to reconsider who they were and what they could do within the context of family and work[16-18]. The phrase "compared with how I used to be" was used by multiple participants in Kingstone et al's (2020) study,[17] whilst Ladds *et al* (2020)[18] commented on the concept of a "spoiled identity" where an identity as previously "healthy, independent and successful" was perceived to be threatened.

Interviews by Ladds et al[18] with doctors and other clinicians who had experienced long COVID showed that many were worried about the impact of cognitive deficits on their ability to perform their jobs.

"[T]he medicolegal aspect is huge …. and it's scary to not be able to recognise potentially where you have deficits because if you can't recognise them then that's an unknown unknown in what can you do with that."[18]

There was a sense of stigma associated with long COVID, with people experiencing a sense of shame and blame (internally generated stigma) and expressing fears that employers and others in the community may stigmatise them for having long COVID (externally generated stigma)[1,18,19]. Family members were considered to be affected by long COVID and were seen as also requiring support[1,17]. One interview participant described the impact her symptoms had on her family and how she felt they did not believe her:

"I think, at first, they just thought, 'Oh, for god's sake, she's napping again'. I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted …."[17]

Patients described experiencing a range of emotions as part of their illness journey[1,16-18]. Anxiety was often related to multiple aspects of the illness including uncertainty about the cause of symptoms, concern that they may never recover completely, and anxiety due to not being believed by healthcare professionals, family and friends.

".... I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not "I'm going to die right now", but definitely "I'm never going to get better from this" kind of feeling."[17]

Patients also expressed a strong desire to find acceptance and understanding about their experiences of long COVID, both among healthcare professionals and family and friends.

"... one of my friends did say after quite a while, "I'm not being awful, but do you think a lot of it's in his mind?" and I said "no". I was quite upset about that…"[17]

Similarly, there was a widespread perception that healthcare professionals doubted patients' descriptions of long COVID[1], ignored patient concerns[17], misdiagnosed symptoms[19], or were dismissive of patient experiences[19]. This lack of knowledge affected people's feelings around their healthcare experiences[17].

Healthcare experiences

Across most of the studies, participants expressed concerns relating to the lack of knowledge, information and understanding about long COVID among healthcare professionals[1,17-19]. While the reason behind this lack of knowledge was understood, there was a general feeling that there needed to be acknowledgement of this gap within the healthcare community.

"Well yeah, I feel like there's a lack of knowledge. And I really wasn't able to get any answers, I know, you know this is obviously a novel illness. But just even for one doctor to look into it a bit and come back to me, didn't happen."[17]

The absence of knowledge and information about long COVID symptoms was reported to create anxiety and confusion for patients[1,17-19]. Ladds *et al* (2020)[18] found that this confusion was intensified by the lack of medical knowledge, understanding and guidance from healthcare professionals. There were also reports of conflicting or inconsistent advice from health professionals.[18]

Some professionals did recognise the limitations of their own knowledge[17, 18] and referred patients to online support groups. Focus group participants suggested they would rather be told that the professional did not have the knowledge required to address their illness, if that was the case[17]. The importance of finding a General Practitioner (GP) who was understanding, empathetic and who provided support to those experiencing long COVID is highlighted in this quote:

"I have to say it was a really powerful experience speaking to the GPs ... the two more recent ones, actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful."[17]

Along with this perceived lack of knowledge, multiple perceived barriers to healthcare access were reported[1,17,18], along with a perception among participants that health services and doctors were too busy dealing with cases of acute COVID-19 to have capacity to deal with anything else, including patients with long-term symptoms[1,18]. This perception appeared strengthened by the difficulties people experienced when trying to access primary care, especially if they were seeking a face-to-face consultation.

"I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful, particularly as I didn't have, and never have had, a cough or fever"[1]

In general, study participants found accessing care to be "complex, difficult and exhausting".[18] This led to patients describing how they felt they had to manipulate the inflexible algorithm-driven systems in order to receive care, which led to feelings of guilt and anger[18]. Some patients described creative solutions they had come up with to help them access healthcare, while others reported resorting to private healthcare to access tests[18]. Many patients felt they needed to conduct their own research and construct their own care pathways, taking the lead in arranging consultations with specialists and circumventing bottlenecks in the system[18]. This was reported as a route often employed by medical professionals who themselves were suffering from long COVID[18].

There was also a perceived lack of support within the system[1,17,18]. Some individuals described how NHS111 (a national telehealth helpline in the UK) had directed them to their GP who then directed them back to NHS111.[18] There was what appeared to be a lack of guidance for those who did not need to be admitted to hospital but were no longer in the acute phase of the illness [1,18,19].

Patients who felt they had received satisfactory care and access to healthcare were generally those who had been offered follow-up appointments and who felt their healthcare providers listened to them and gave them ongoing support, even if that was in the form of a video or telephone call [17-19].

Telemedicine was widely used to facilitate interactions with healthcare services[1,17-19]. However, it was generally perceived by patients to have limitations[1,17]. Remote consulting with primary care was viewed by some patients as potentially limiting direct access to GPs, disrupting continuity of care (people often could not see the same GP every time), and making the communication of symptoms more challenging[1,17,18]. Some patients felt that strict adherence to protocols for telemedicine-delivered care affected patient safety or led to mismanagement of their care.

"... I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I'm really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don't really sound too out of breath over the phone …. I really felt at that point right if you could see me you would see that I am really like broken"[18]

A positive view expressed in relation to telemedicine was that it increased accessibility of primary care during periods of societal restrictions aimed at controlling the spread of COVID-19.

"My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track."[19]

When asked to describe desirable features of healthcare services or service delivery for patients with long COVID, research participants asked for face-to-face assessments[1,17] and talked about the need for 'one-stop clinics' with multidisciplinary teams (MDT) who could look at their wide-ranging symptoms and treat them holistically[1,17,18]. A case manager to oversee individual patients and ensure that all aspects of their care was considered was suggested, along with meaningful referral pathways and criteria[1].

"What would be most helpful is if all main hospitals could have a COVID clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can

refer you for tests and you can get a plan in place, we are having such a range of symptoms that GPs are struggling to know what to do with you"[1]

Other participants spoke about wanting to be listened to, to be believed and understood, and to be offered practical advice on coping[1].

DISCUSSION

To our knowledge, this is the first synthesis of findings from qualitative studies on peoples' experiences of living with long COVID and accessing healthcare services for this condition. Our main findings were threefold. Firstly, that the lived experience of long COVID is highly variable and perceived as being at odds with public perceptions and official guidance on COVID-19. Secondly, that there are significant emotional consequences of living with long COVID that need to be understood by a number of stakeholders. Finally, that people with long COVID report a range of positive and negative healthcare experiences that can be used to inform the development of new, or adaptation of existing, services for this important patient group.

COVID-19 is a new illness, first declared a public health emergency by the World Health Organisation on 30th January 2020.[21] The implications across the globe and stress on healthcare services are unprecedented. It is perhaps unsurprising that knowledge of long COVID is perceived as underdeveloped; there is no agreed definition of long COVID and the long-term sequelae are to a large extent unknown.[3] Many people in the included studies turned to social media and patient-led support groups, due to perceived lack of understanding from family, employers and healthcare professionals.[1 17-19] Social media and support groups are widely used for other health conditions,[22] but are generally considered complementary to healthcare services; part of the "jigsaw" that makes supported self-management successful.[23] Therefore, there appears to be a need for more widespread understanding of and information about long COVID, and people with lived experience are ideally placed to contribute their expert opinion.

Our review highlighted a number of emotional consequences of long COVID including the impact on people's identities, employment, and relationships with family and healthcare providers. Emerging models and recommendations for managing long COVID all highlight the need for psychological inputs.[24-26] It is perhaps more complex to address the wider emotional consequences highlighted by this review; however, understanding and information as described above and targeted at various levels (e.g. healthcare professionals, patients, public, employers) appears to be indicated.

In addition to lack of knowledge, the review found a number of barriers to accessing healthcare, with reports of unhelpful messaging and complex processes to navigate. Healthcare professionals with long COVID were more able to navigate this complex system than non-professionals, suggesting a potential inequality. Telemedicine, rapidly rolled-out in many countries as a way of maintaining healthcare during the pandemic,[27] was not always seen as beneficial. As new models for managing long COVID emerge, these findings may be useful for ensuring that services are patient-centred.[28] The finding that patients want multidisciplinary, holistic services is congruent with the well-documented multi-organ nature of COVID-19, and heterogeneous nature of long COVID symptoms.[3]

Strengths and limitations

Our review has highlighted a range of important issues associated with long COVID and accessing healthcare, from the perspective of people with this condition. The review is limited by the small number of qualitative studies (n=5) that have been published to date, and will benefit from being updated as further research becomes available in this fast-moving field. Nonetheless, it contributes to an early understanding of the lived experience of long COVID and of accessing healthcare services. The majority of studies were conducted in the UK, there was over-representation of younger and female, white, participants, and all studies recruited participants via social media or online support groups. Therefore, the findings apply to this population, and it is possible that other groups of people with long COVID have different experiences and views. Some emerging evidence suggests that long COVID may be more prevalent in younger female individuals[29]; a meta-analysis in pre-print form however reports a linear increase in long COVID from age 20-70[30]. We limited our search to studies published in English; therefore it is possible that we missed studies published in other languages. We did not exclude studies on methodological quality, resulting in the inclusion of one study with limited methodological details resulting in a low CASP score. However, the validity of appraisal of qualitative research is debated in the literature,[31] and we are confident that all studies contributed valuable data on the lived experience of long COVID. We did not formally calculate agreement between pairs of reviewers at data extraction, critical appraisal or data synthesis stages. However, given the small number of included studies, and frequent communication within the review team, there were very few instances of disagreement, all of which were resolved by discussion. We did not contact authors for additional information that may have allowed us to more fully appraise methodological quality of the included studies. However, because we did not exclude any studies based on methodological quality; therefore, the review findings were not affected.

Implications for practice

There is a need for greater understanding and communication about long COVID at a number of levels (public, policy and healthcare professional). Our findings suggest that people with long COVID are well placed to co-create this understanding and communication. Our findings can also be used by those currently developing services for people with long COVID, to ensure that they meet patients' needs. The varied and fluctuating symptoms and emotional consequences experienced by people with long COVID indicate a need for multi-disciplinary services, which provide holistic patient-centred assessment, appropriate management and specialist referral where indicated.

Implications for research

Further qualitative research on more culturally diverse samples of people with long COVID is indicated to help understand the impact of long COVID and the healthcare needs of the wider population than is represented by the current review. As models of care and services are developed/adapted for people with long COVID, it is vital that the views and experiences of people with long COVID continue to be explored.

CONCLUSION

We have presented a synthesis of the current qualitative evidence on the experience of living with long COVID and of accessing healthcare services. People experience long COVID as a heterogeneous condition, with a variety of physical and emotional consequences. It appears that greater knowledge of long COVID is required by a number of stakeholders, and that the design of emerging long COVID services, or adaptation of existing services for long COVID patients should take account of patients' experiences in their design.

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Contributors

DM, JH, KC, KM and MN developed the protocol. CM conducted the literature searches. JH and DM screened articles for inclusion. KM, DM, JH and MN extracted data, appraised studies, and, including KC, were involved with synthesising the qualitative data, interpreting the findings and writing the first draft of the manuscript. Other members of the research teams within Robert Gordon University, Aberdeen, and Healthcare Improvement Scotland provided peer review comments on the draft manuscript.

Competing interests

None declared.

Data sharing statement

Search strategies for databases other than Medline are available by contacting the corresponding author. Full data extraction tables are also available.

Ethics approval statement

Ethics approval was not sought as this study was a systematic review of published evidence.

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FIGURES AND TABLES

Figure legends

Figure 1 PRISMA flow diagram of study selection
Figure 2 Map of analytical and descriptive themes from the analysis

Table 1 Characteristics of included studies

Study [country]	**Study methods and setting**	**Participant characteristics and sample size**	**Main results**
Assaf *et al*. (2020)[19] [Multinational]	Online survey 21 Apr - 2 May 2020 circulated to long COVID support groups and through social media Quantitative and qualitative data collection	n=640 Patients with symptoms lasting >2 weeks 62.7% aged 30-49; 76.0% white; 76.6% female	Cyclical symptoms experienced unexpectedly for ≥6 weeks Stigma experienced by patients with long COVID Impacts on lifestyle, including physical activity Dismissed or misdiagnosed by medical professionals Sentiment analysis conducted on satisfaction with medical staff and on sharing experiences.
Davis *et al*. (2020)[16] [Multinational]	Online survey 6 Sept – 25 Nov 2020 circulated to online patients support groups and social media Quantitative and qualitative data collection	n=3,762 Patients with symptoms lasting >28 days 60.8% aged 40-59; 85.3% white; 78.9% female	Patients with long COVID reported prolonged multisystem involvement and significant disability. The most frequent symptoms reported after 6 months were: fatigue post-exertional malaise cognitive dysfunction.
Kingstone *et al*. (2020)[17] [UK]	Recruitment through social media (Twitter or Facebook) and snowball sampling Jul - Aug 2020 Semi-structured interviews by telephone or video	n=24 Self-reported persistent symptoms following acute COVID-19 illness Age range 20-68; 87.5% white British; 79.2% female	Four key themes reported in results: 'hard and heavy work' of enduring and managing symptoms, trying to find answers, and accessing care living with uncertainty and fear

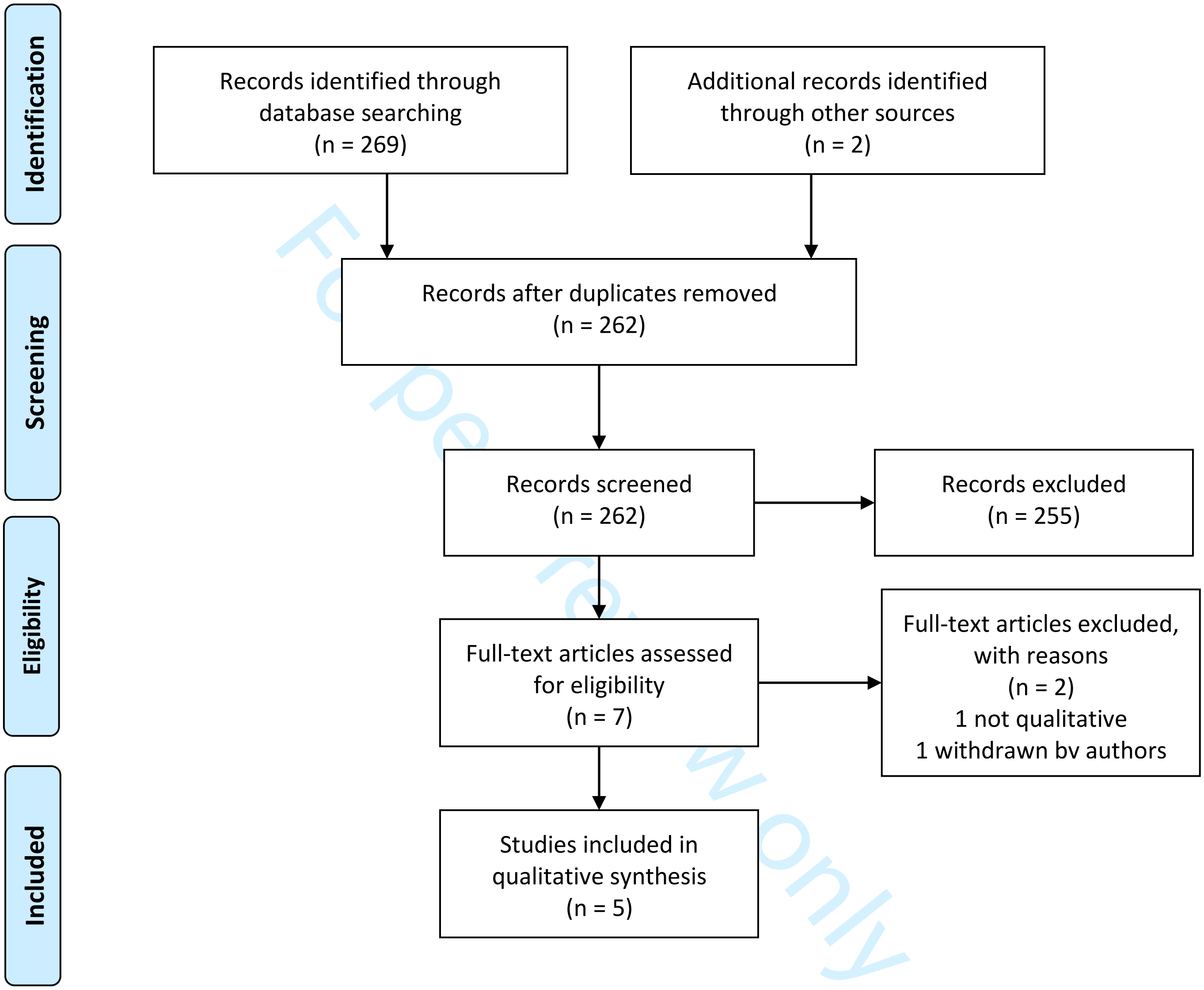
	call (duration 35-90 minutes) Thematic analysis using principles of constant comparison		importance of finding the 'right' GP recovery and rehabilitation: what would help?
Ladds *et al*. (2020)[18] [UK]	Participants recruited from UK-based long COVID patient support groups, social media and snowball sampling Individual narrative interview (telephone or video) or participation in an online focus group Constant comparison method of data analysis	Total n = 114 55 interviews (73% female); median age 48 (range 31-68) 59 focus group participants (68% female); median age 43 (range 27-73)	Five key themes reported in results: the illness experience, accessing care, relationships (or lack of) with clinicians, emotional touchpoints in encounters with health services, ideas for improving services
Maxwell (2020)[1] [UK]	Focus group of COVID-19 Facebook group members	Not reported	Four key themes reported in results: expectations, symptom journey, being doubted, support

Table 2 CASP critical appraisal of using the checklist for qualitative studies

	Assaf *et al.*[19]	Kingston *et al.*[17]	Ladds *et al.*[18]	Maxwell[1]	Davis *et al.*[16]
Clear aims statement	Y	Y	Y	N	Y
Appropriate methodology	U	Y	Y	Y	Y
Appropriate research design	U	Y	Y	U	Y
Appropriate recruitment	Y	Y	Y	U	Y
Appropriate data collection	U	Y	Y	U	Y
Researcher-participant relationship considered	N	U	U	U	U
Ethical issues considered	U	Y	Y	U	Y
Rigorous data analysis	U	Y	Y	N	U
Clear statement of findings	U	Y	Y	Y	Y

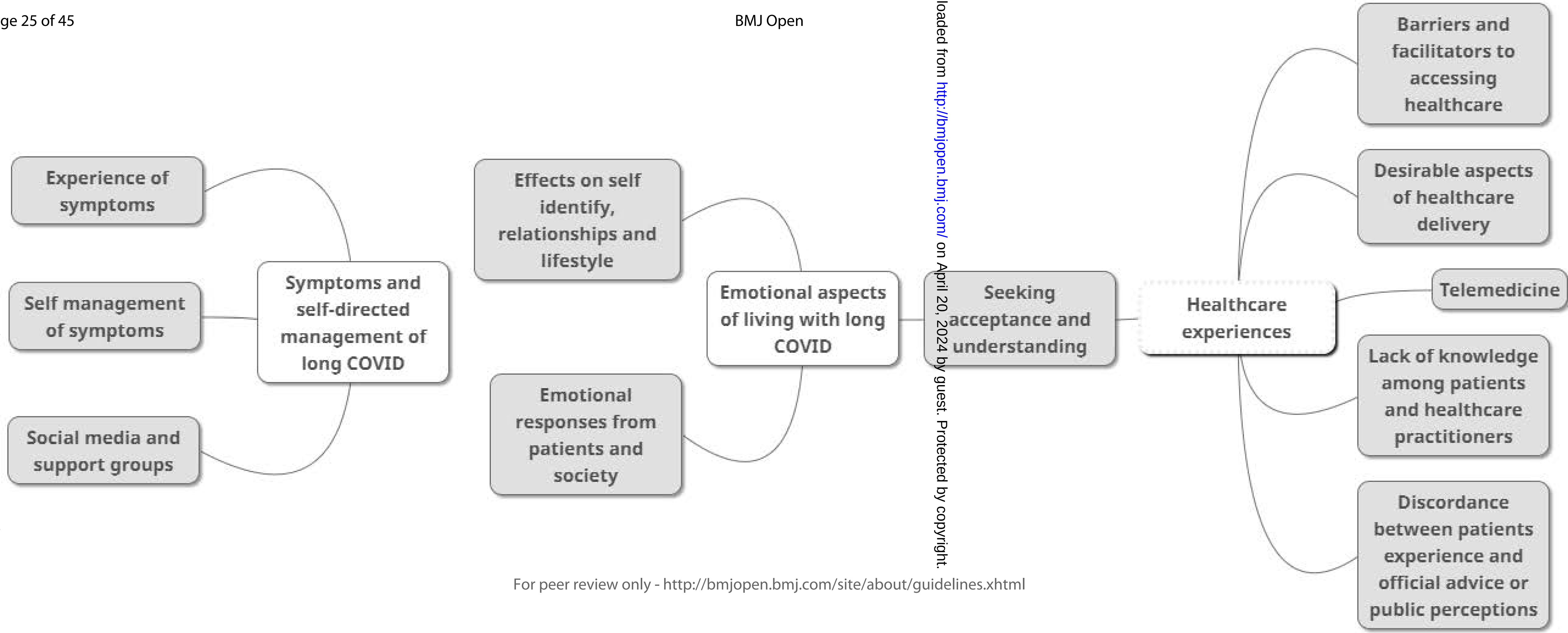
Y=criterion satisfied; N=criterion not satisfied; U=unclear if criterion satisfied

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.


Experience of symptoms
Self management of symptoms
Social media and support groups
Symptoms and self-directed management of long COVID
Effects on self identify, relationships and lifestyle
Emotional responses from patients and society
Emotional aspects of living with long COVID
Seeking acceptance and understanding
Healthcare experiences
Barriers and facilitators to accessing healthcare
Desirable aspects of healthcare delivery
Telemedicine
Lack of knowledge among patients and healthcare practitioners
Discordance between patients experience and official advice or public perceptions

SUPPLEMENTARY MATERIAL

Supplementary file 1 Inclusion criteria

Criteria	**Notes**
Population	Adults and children experiencing new or ongoing symptoms: • 4–12 weeks from onset of acute COVID-19 illness • 12 weeks from onset of acute COVID-19 illness
Phenomena of interest	Signs and symptoms of post-COVID-19 syndrome Access to services How symptoms were assessed Management of symptoms and rehabilitation Patient care pathway Information and support provided Communication with healthcare professionals
Comparators	Not applicable
Outcomes	The outcomes will be generated using emergent coding, but are expected to include experiences, views and perceptions of individuals, families or carers on the factors of interest listed (such as Patient Reported Experience Measures)
Settings	Any
Sub-groups	Equality groups, for example, age, gender, ethnicity Diagnosis of COVID-19 (e.g. confirmed or high clinical suspicion) Duration of symptoms
Study types	Systematic reviews of qualitative studies Qualitative studies that collect data from focus groups or interviews Studies that collect qualitative data from questionnaires / surveys Mixed method study designs (including qualitative element)
Countries	Any
Timepoints	Any
Other exclusions	None

Supplementary file 2 Sources searched and MEDLINE search strategy

UK national health service and government websites
Public Health England
Public Health Scotland
Scottish Government
UK Government
National/international policy sources
European Centre for Disease Control
Health Protection Scotland COVID-19 Compendium
Guidelines
National Institute of Health
NICE
SIGN
Evidence summaries and collections
Analytical Collaboration for COVID-19
Cochrane Special Collection
COVID-19 Best Evidence Front Door
COVID-19 Evidence Reviews
Evidence Aid Collection
McMaster rapid review database
Oxford Centre for Evidence-Based Medicine
HTAs
ECRI
Health Technology Wales
National Institute for Health Research
NICE
Specialist Databases
Epistemonikos
EPPI Centre: living systematic map of the evidence
ProQuest
PubMed LitCovid
WHO database of publications
Preprints
bioRxiv
medRxiv
Research centres/organisations
Campbell Collaboration
Centre for Qualitative Research
Health Foundation
King’s Fund
Patient issues
Carers UK
Health Talk
Involve
James Lind Alliance

King's Fund Patient Experience Blog
National Association for Patient Participation
National Voices
Our Covid Voices
Patient UK Discussion Forums
Patient Views
Patient Voices
Patients Association
Picker Institute
Primary literature (bibliographic databases)
MEDLINE
PsycINFO
Web of Science

Medline search strategy

1 exp coronavirus/
2 exp Coronavirus Infections/
3 ((corona* or corono*) adj1 (virus* or viral* or virinae*)).ti,ab,kw,kf.
4 (coronavirus* or coronovirus* or coronavirinae* or CoV).ti,ab,kw,kf.
5 ("2019-nCoV" or 2019nCoV or nCoV2019 or "nCoV-2019" or "COVID-19" or COVID19 or "CORVID-19" or CORVID19 or "WN-CoV" or WNCoV or "HCoV-19" or HCoV19 or "2019 novel*" or Ncov or "n-cov" or "SARS-CoV-2" or "SARSCoV-2" or "SARSCoV2" or "SARS-CoV2" or SARSCov19 or "SARS-Cov19" or "SARSCov-19" or "SARS-Cov-19" or Ncovor or Ncorona* or Ncorono* or NcovWuhan* or NcovHubei* or NcovChina* or NcovChinese* or SARS2 or "SARS-2" or SARScoronavirus2 or "SARS-coronavirus-2" or "SARScoronavirus 2" or "SARS coronavirus2" or SARScoronovirus2 or "SARS-coronovirus-2" or "SARScoronovirus 2" or "SARS coronovirus2").ti,ab,kw,kf.
6 (((respiratory* adj2 (symptom* or disease* or illness* or condition*)) or "seafood market*" or "food market*" or pneumonia*) adj10 (Wuhan* or Hubei* or China* or Chinese* or Huanan*)).ti,ab,kw,kf.
7 ((outbreak* or wildlife* or pandemic* or epidemic*) adj1 (China* or Chinese* or Huanan*)).ti,ab,kw,kf.
8 "severe acute respiratory syndrome*".ti,ab,kw,kf.
9 SARS Virus/
10 ("SARSCoV" or "SARS-CoV" or "SARS Cov" or SARScoronavirus or "SARS-coronavirus" or "SARS coronavirus" or SARScoronovirus or "SARS-coronovirus" or "SARS coronovirus").ti,ab,kw,kf.
11 Middle East Respiratory Syndrome Coronavirus/
12 "Middle East* respiratory syndrome".ti,ab,kw,kf.
13 ("MERSCoV" or "MERS-CoV" or "MERS Cov" or MERScoronavirus or "MERS -coronavirus" or "MERS coronavirus" or MERScoronovirus or "MERS-coronovirus" or "MERS Coronovirus" or "camel flu").ti,ab,kw,kf.
14 or/1-13
15 exp Patient Satisfaction/
16 ((patient* or carer* or family) adj2 (experience* or view* or perspective* or preference* or attitude* or expectation* or satisfaction)).tw.

17	15 or 16
18	14 and 17

Supplementary file 3 Summary of key themes relating to the views and experiences of patients, their families and carers

Themes and sub-themes	Summary of sub-themes	Supporting example
Theme: experience of symptoms		
Range of symptoms	Patients described a wide range of symptoms, not all of which were recognised as symptoms of COVID-19.	"The symptoms were like a game of whack-a-mole. Different ones would surge at different times and in different places in my body." (Assaf *et al*)[19] "From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia." (Maxwell)[1]
Severity of symptoms	Symptoms ranged from mild to potentially life-threatening.	"I've been absolutely floored... I've got all sorts of... I've got vasculitis, which I think is a common thing... And I've been left with nerve issues, like really horrible nerve... stabbing pains in my hands and feet and I can't move my toes any more... unfortunately, my journey is far from over." (Ladds *et al*)[18] "From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia." (Maxwell)[1]
Duration and lingering nature of symptoms	Symptoms were experienced for a prolonged but variable length of time.	"He was sleeping for about 20 hours a day, 20 hours out of every 24 and he's still sleeping now, five and half months after, he still sleeps an awful lot, sat up, not lay down, sat up, he's just totally exhausted." (Kingstone *et al*)[17]

Themes and sub-themes	Summary of sub-themes	Supporting example
Fluctuating or cumulative nature of symptoms	Patients described symptoms 'coming and going', and of new symptoms being added to existing ones over time.	"...From week four I started to get chest pains and then breathlessness, gradually other symptoms developed .... The following weeks were frightening as symptoms fluctuated; sometimes thinking that you were improving and then very disheartening when they returned.... After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms...." (Maxwell)[1]
Theme: discordance between patient experiences and official advice or public perceptions		
Disconnect between official advice and lived experience	Patients found official advice on graded exercise and when to come out of isolation unhelpful and contrary to their lived experience of long COVID.	"Well, one of the things that really bugged me about it was the talking about graded exercise and I've learnt from experience that pushing myself even a tiny bit has massive consequences ..." (Kingstone *et al*, p6)[17]
Disconnect between public perception ("labels") and lived experience	The perception that COVID-19 is a binary illness that is either 'mild' or very serious (requiring hospitalisation) was unhelpful and contrasted with patient experience.	"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us." (Kingstone *et al*)[2] "I think the term "mild" should be removed... I know that people who were admitted to the hospital were worse, but we who stayed home did not have MILD cases in all cases" (Maxwell)[1]
Disconnect between expected/official timeframes and lived experience	Patients expected COVID-19 to last approximately 2 weeks, in line with official estimates, and were then confronted by much longer-term illness. Patients experiencing symptoms beyond the 2-week period are often diagnosed with an alternative condition that more neatly fits the timeframe.	"I went back to work too soon and wish I hadn't. Finally had to take a 5 week break in July/ August with the support of my employer. This helped a lot. I have now been back at work for 5 weeks and my symptoms have got worse to a degree." (Davis *et al*)[16]

Themes and sub-themes	Summary of sub-themes	Supporting example
Disconnect between officially recognised symptoms and lived experience	There is discordance between the range of symptoms articulated by patients with long-term illness and those officially recognised by authorities as COVID-19.	“If the message hadn’t been [to expect to recover in] around two weeks, I’d have been more cautious at first, … the doctor I saw in A/E described Covid as the gift that keeps on giving and at four weeks I thought that felt like a long time, and now five months on it feels like a very long time” (Maxwell, p11)[1]
Impact of disconnect between officially recognised symptoms and lived experience	As a consequence of the mismatch between officially recognised symptoms and lived experience of long COVID, patients feel ignored, dismissed, and may be misdiagnosed.	“Despite having been diagnosed with suspected Covid by my GP and a doctor in a Covid clinic (swab testing wasn’t available to the public at the time) and told I had pleurisy during a visit to A&E two weeks earlier, the doctor on duty didn’t take this into account. Instead, he dismissed me with anxiety, advising a course of anti-depressants, and chose not to investigate these concerning symptoms further. Of course I was anxious, but that was a consequence of the physical symptoms, not the cause! I would later learn from a neurologist that what I experienced on that day were clear neurological symptoms that should have been investigated promptly. To be brushed off like this when so little was known at the time of the damage Covid can cause was disheartening and very upsetting.“ (Maxwell, p15)[1]
Theme: self management of symptoms		
Self care and lifestyle adjustment	Patients attempted various forms of self care, such as taking supplements, and made adjustments to their lifestyle, for example by reducing physical activity, to accommodate long COVID.	“I mean initially I started taking vitamin D. Had a joint vitamin C and zinc thing, which I didn’t take every day but I took some multivitamins, but then I was a bit unsure really … my husband’s quite anti-vitamin use … So anyway, then I took nothing for a while, and then I more recently started the vitamin D again, and I’m on

Themes and sub-themes	Summary of sub-themes	Supporting example
		B12 just because of all the burning in my feet … and a probiotic and some omega-3." (Kingstone *et al*)[17]
Pacing and goal setting	The importance of pacing yourself and setting realistic goals was highlighted by patients.	"…I really have to pace myself… I couldn't do two or three household chores back to back, I have to do a chore, sit down for 15, 20 minutes and then do the next, which frustrates me…." (Kingstone *et al*)[17]
Theme: emotional responses from patients and society		
Helplessness	Long-term symptoms were associated with a feeling of helplessness.	"Most participants continued the discussion after the digital recorder was turned off, emphasising their own feelings of helplessness, but also alluding to the uncertainty and helplessness that GPs had admitted to" (Kingstone *et al*)[17] *[Author quote]*
Anxiety	Patients described anxiety about the prospect of not recovering, uncertainty over the cause of symptoms, not being believed, and some of the content they read on online support groups.	".... I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not "I'm going to die right now", but definitely "I'm never going to get better from this" kind of feeling." (Kingstone *et al*)[17]
Relief	A sense of relief was associated with finding a healthcare professional that believed the patient.	"I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people's symptoms are real and diverse." (Maxwell)[1]
Stigma (externally generated)	Employers and others drive a fear of being stigmatised over long COVID.	"Healthcare staff was fearful and I was turned away with no support" (Assaf *et al*)[19] "I had to take two weeks off, had to work from home for four, but had to return for two weeks with fever as my employer would not give me more time […]." (Davis *et al*)[16]

Themes and sub-themes	**Summary of sub-themes**	**Supporting example**
Stigma (internally generated)	Patients experienced a sense of shame and blame consistent with stigma.	"Fearful of people around me finding out and overreacting / treating me differently" (Assaf *et al*)[19]
Theme: effects on self-identity, relationships and lifestyle		
Impact on self-identify	Long COVID affected self identity as a healthy, independent individual, and resulted in patients comparing themselves with a pre-COVID version of self.	"I have not had strength to return to physical activity. I did work in my house and 2 days later had a fever again after being 12 days fever free." (Assaf *et al*)[19]
Impact on daily life/work	Patients had to alter their physical activity levels to accommodate long COVID and found cognitive symptoms prevented a return to work.	"I'm trapped, in that I can't park that far away and walk [to the shops] like I normally would because I can't do hills. I can just, in the last couple of weeks, I can do gentle inclines now, but I sort of grind to a halt on a hill. So, it's very limiting." (Ladds *et al*)[18] "I wasn't just fogged; I was confused. I had a very difficult encounter as a result of just being confused about things and that took a long time to resolve. I love words and I enjoy the business of communicating, and I felt that part of my life was lost. Really, I just did admin, I didn't do anything that required clear thinking." (Kingstone *et al*)[17]
Impact on self - reduced confidence	There was a sense of loss of confidence in professional abilities among some patients.	"Doctors and other clinicians …. described how their symptoms and the accompanying prognostic uncertainty …. had also stripped them of confidence in their professional abilities." (Ladds *et al*)[18] *[Author quote]*
Impact on others/relationships	Long COVID had an impact on family members as well as patients.	"I think, at first, they just thought, "Oh, for god's sake, she's napping again." I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted …. I used to enjoy running, and

Themes and sub-themes	Summary of sub-themes	Supporting example
		exercising, and stuff like that. I rarely even go on walks now because I know if I walk to the end of the street, they're [lungs] going to start hurting." (Kingstone *et al*)[17]
Theme: healthcare access – barriers and facilitators		
Barrier - testing	Challenges were experienced with accessing testing (for long-term symptoms or COVID-19 diagnostic testing).	"... My worst and scariest experience with this illness was in week 6, when I was rushed to A&E as I had a sudden relapse of symptoms and found myself gasping for air, with the top of my head numb and tingling and a headache so blinding that I couldn't keep my eyes open. I got worse in the hospital and was shaking visibly, so much so that the nurse couldn't perform an ECG as I just couldn't stay still. Despite having been diagnosed with suspected Covid by my GP and a doctor in a Covid clinic (swab testing wasn't available to the public at the time) and told I had pleurisy during a visit to A&E two weeks earlier, the doctor on duty didn't take this into account. Instead, he dismissed me with anxiety, advising a course of anti-depressants, and chose not to investigate these concerning symptoms further. ... I would later learn from a neurologist that what I experienced on that day were clear neurological symptoms that should have been investigated promptly. To be brushed off like this when so little was known at the time of the damage Covid can cause was disheartening and very upsetting." (Maxwell)[1]

Themes and sub-themes	Summary of sub-themes	Supporting example
Barrier – primary care	Difficulties accessing primary care, particularly face-to-face or through the ‘total triage’ system were a barrier to healthcare access	“I was initially contacting a certain GP, and that GP literally just went “you need to stay at home and rest, there’s nothing we can do”, a.....so I started contacting a different GP, in the same practice, and it’s the same outcome, they can’t do anything else but he seems to be interested and wants to know what’s going on.” (Kingstone *et al*)[17]
Barrier – effort involved	Accessing healthcare was complex, difficult and exhausting for patients.	“One day I had blue finger nails and I wasn’t cold .... and I phoned the GP and the GP answer phone said if you’ve got any of the signs of, of Covid please ring 111 and so I rang 111 and, I live in [city with high incidence of Covid-19] I don’t know if that makes any difference but I was put on hold and after over an hour, an hour and twenty minutes nobody answered so I just put the phone down .....” (Ladds *et al*)[18]
Barrier – specialist referral	Few patients managed to obtain a referral to a specialist.	“...three of the referrals my GP made (two respiratory and one neurology) were refused by two different hospitals on the grounds that a) they only checked Covid confirmed patients b) that they needed extra tests which weren’t done on me at A&E” (Maxwell)[1]
Perceived barrier – healthcare professionals being busy	There was a perception that healthcare professionals are too busy caring for patients with acute COVID-19 to be able to provide care for patients with long-term symptoms.	“At this point, most physicians and researchers are so overwhelmed treating the covid19 patients who are at risk of immediate death, that they don’t have the ability to even recognize that people like me exist....” (Assaf *et al*)[19] “I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful,

Themes and sub-themes	Summary of sub-themes	Supporting example
		particularly as I didn't have, and never have had, a cough or fever" (Maxwell)[1]
Perceived barrier – healthcare entitlement	Patients had a perception that they were not entitled to healthcare for long-term symptoms of COVID-19.	"....I guess I felt a bit like I was ineligible for health care now. I felt like I'm just going to have to live with this at home and no one will come and see me and, you know, I'm just, yeah. It was a horrible feeling." (Kingstone *et al*)[17]
Facilitator – follow-ups & check-ins	Regular follow up or check-in with patients with long-term symptoms was viewed as a positive aspect of healthcare.	".... I think for the first five days after I called her she had a daily check in call with me to monitor how I'm doing so it was like a ten minute phone call every day for the first five days" (Ladds *et al*)[18]
Things patients did to access care	Patients engaged in a number of activities to improve their access to healthcare including: • taking the lead in arranging consultations and "circumventing bottlenecks" • deliberately manipulating inflexible algorithm-driven systems to access referrals • accessing private healthcare to prompt NHS follow up, conducting their own research and constructing their own care pathways.	"did the e-consult – I had to do it a couple of times – I kind of learned to answer the questions to get it to send a message to my GP surgery… If you say you've got heart palpitations or breathlessness it's telling you to call 111 which I didn't want to do. And so I had to downplay symptoms [laughs] to get through. I cancelled it and did it again." (Ladds *et al*)[18]
Theme: telemedicine - limitations and benefits		
Limitation – remote consultation	Remote consulting was found to limit access to GPs and to restrict communication of symptoms.	"… reassure me are things where I need my body actually checking which I don't think you could check online, you can't check for blood clots online, you can't check for neurological damage online can you?' (Kingstone *et al*)[17]

Themes and sub-themes	**Summary of sub-themes**	**Supporting example**
Limitation – lack of continuity	Loss of continuity of care was particularly impactful on patients with complex presentations.	“The focus when you do get a new GP speaking to you seems to be that they go back to the beginning ….And I think if there was the same GP who we are able to consult regularly they would build a picture of your baseline and I think that’s what’s lost with digital ways of working.” (Ladds *et al*)[18]
Limitation – protocolised care	Strict adherence to protocols in the telemedicine context affected patient safety and led to mismanagement.	“… I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I’m really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don’t really sound too out of breath over the phone …. I really felt at that point right if you could see me you would see that I am really like broken” (Ladds *et al*)[18]
Benefits - accessibility	Positive experiences of accessing GPs through telemedicine.	“My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track.” (Assaf *et al*)[19]
Theme: lack of knowledge, information and understanding among healthcare professionals and patients		
Lack of knowledge - healthcare professionals	There is a perceived lack of knowledge about long COVID among healthcare professionals.	“…I think all the way through I found doctors that I've come into contact with are just really at a bit of a loss for it. I think at the beginning, particularly when things were going on, and not clearing up it was kind of put on me as just being a strange case ... and my GP was going, “Well, you're just weird, you know”.’ (Kingstone *et al*)[17]

Themes and sub-themes	Summary of sub-themes	Supporting example
Lack of knowledge – symptoms	The lack of knowledge around long COVID included uncertainty about the expected symptoms, wanting to learn about living with COVID-19, uncertainty about the cause of symptoms, a lack of understanding about the fluctuating nature of symptoms and lack of knowledge about recovery from long-term symptoms.	"None of us knew this [the symptoms] because we're all on our own, in a little bubble, thinking I'm the only one. Why am I the one who has still got it?" (Maxwell)[1]
Lack of knowledge – seeking help	Uncertainty about when patients with long COVID should seek medical help.	"...combined with the UK government message to stay away from health services unless very ill, left many people uncertain about when they should seek help." (Maxwell)[1] *[Author quote]*
Lack of knowledge – employers	Employers need advice on how to manage employees with long COVID.	"Advice on the range of symptoms and duration was also needed by employers who are unclear what to expect of those with ongoing effects." (Maxwell)[1] *[Author quote]* "I have needed more flexible hours (working remotely) post-COVID. That way, I can rest as needed throughout the day. If I had to return to in-person work at this point, it would be severely reduced hours if at all." (Davis *et al*)[26]
Lack of knowledge – management	Lack of knowledge about managing long COVID, resources available locally for patient rehabilitation, and about recovery from prolonged illness.	"I finally had a respiratory appointment three months later, over the phone (not over a video link). I was …. recommended graded exercise. When I then saw a rehabilitation physiotherapist, she said no, we are not going to do graded exercise because that would be counterproductive for you. " (Maxwell)[1]

Themes and sub-themes	**Summary of sub-themes**	**Supporting example**
Lack of knowledge – prompts help-seeking from other sources	Lack of widely accessible medical knowledge about long COVID has led to patient reliance on news and social media for information.	"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it. So, you know, sixth sense, I actually think that the support group has given more knowledge than the doctors have." (Ladds *et al*)[18]
Patients prefer healthcare professionals to admit uncertainty	Patients would prefer healthcare professionals to admit to a lack of knowledge about long COVID.	"She just listens a little bit more to what I'm saying and she's much more willing to say, "Of course, we don't really know what's going on because it's a new virus." She doesn't try to pretend that she understands what's going on, which is good." (Kingstone *et al*)[17]
Theme: desirable features of healthcare services/service delivery		
Healthcare structuring – one stop clinics with face-to-face assessment of symptoms by multidisciplinary teams	Patients wanted a 'one-stop' clinic with multidisciplinary teams there to assess symptoms affecting a wide range of body systems.	"What would be most helpful is if all main hospitals could have a Covid clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, We are having such a range of symptoms that GPs are struggling to know what to do with you" (Maxwell)[1]
Healthcare structuring – case management	A case manager or single clinician to co-ordinate investigations and the patient care pathway for each patient with long COVID.	"... there was a view that it would be helpful if people living with Covid19 could have a 'quarter back' or case manager to oversee and coordinate investigations and support services across different medical specialities." (Maxwell)[1]
Healthcare structuring – MDT rehabilitation	Assessment by a multidisciplinary rehabilitation team was proposed.	"... the British Society of Rehabilitation Medicine notes there are people who were never admitted to hospital but who still have ongoing needs for rehabilitation

Themes and sub-themes	Summary of sub-themes	Supporting example
		support after recovering from Covid, or Covid-like symptoms." (Maxwell)[1] *[Author quote]*
Individual - acceptance of patient experiences by healthcare professionals	Empathetic health professionals that accepted patient experiences were desirable to individuals.	"I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people's symptoms are real and diverse." (Maxwell)[1]
Individual - practical coping strategies	Patients wanted practical advice on coping strategies.	"... members understood that there were no magic cures, but were looking for practical advice on coping strategies that go beyond basic advice." (Maxwell)[1] *[Author quote]*
Theme: social media and support groups		
Support through sharing experiences	Online support groups and social media provided opportunities for sharing experiences of long COVID.	"when I found the Long Covid Facebook group that I realised I wasn't alone, thousands of people were in the same situation. Knowing this helped enormously." (Maxwell)[1]
Support through sharing knowledge	Online support groups and social media provided opportunities for sharing knowledge and resource links with others coping with long COVID.	"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have." (Ladds *et al*)[18]
Validation of experiences	Patients found validation of their experiences in communication with others through online support groups.	"many participants – both men and women – found that online peer support groups offered the greatest source of support through shared experiences, knowledge and validation." (Ladds *et al*)[18] *[Author quote]*
Theme: seeking acceptance and understanding		
Perception of being doubted by healthcare professionals	Healthcare professionals were perceived to doubt patient symptoms were related to COVID-19 and to doubt symptom severity.	"There was one GP who just thought it was all anxiety ... she said, "There's nothing wrong with your lungs. This is all anxiety. You must treat your anxiety. There's

Themes and sub-themes	Summary of sub-themes	Supporting example
		nothing wrong with you. How are you going to manage the pandemic if you don't treat your anxiety?" That was really upsetting because I knew I was short of breath..." (Kingstone *et al*)[17]
Perception of being doubted by friends and family	There was a perception that friends and family doubted patients because symptoms were not always obvious.	"... one of my friends did say after quite a while, "I'm not being awful, but do you think a lot of it's in his mind?" and I said "no". I was quite upset about that..." (Kingstone *et al*)[17]
Perception of being ignored	Patients felt that their condition was not given the recognition that it deserved.	"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us." (Kingstone *et al*)[17] "I felt the medical team was dismissive. There were a lot of 'we don't know.' Which is understandable, but difficult." (Assaf *et al*)[19]
Difficulties finding empathetic healthcare professionals	Challenges were described in finding healthcare professionals willing to show empathy and accept patient experiences of symptoms.	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", and that frustrated me because it didn't seem like they were being caring, it felt like I was nagging them and being a hypochondriac..." (Kingstone *et al*)[17] "Because I've spoken to four different GPs throughout this. I've not found them very helpful..." (Kingstone *et al*)[17]
Misdiagnosis or dismissal by healthcare professionals	Dismissal of symptoms or misdiagnoses were associated with a negative perception of healthcare.	"I was initially contacting a certain GP, and that GP literally just went "you need to stay at home and rest, there's nothing we can do", and that frustrated me because it didn't seem like they were being caring, it

Themes and sub-themes	Summary of sub-themes	Supporting example
		felt like I was nagging them and being a hypochondriac and that's how I was being treated…" (Kingstone *et al*)[17]
When available strong empathetic relationships with healthcare professionals provides strong therapeutic relationships	A minority of patients reported strong therapeutic relationships involving listening, empathy, validation, honesty and arranging tests and follow up.	"... actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful." (Kingstone *et al*)[17]

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary file 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	5
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	5

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	6
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6 and PRISMA diagram
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	19
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	21
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	6
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	12
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	12
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	13
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	14

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