Developing services for long COVID: lessons from a study of wounded healers

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ABSTRACT

Persistent symptoms lasting longer than 3 weeks are thought to affect 10–2 0% of patients following SARS-CoV-2 infection. No formal guidelines exist in the UK for treating patients with long COVID and services are sporadic and variable, although additional funding is promised for their development.

In this study, narrative interviews and focus groups are used to explore the lived experience of 43 healthcare professionals with long COVID. These individuals see the healthcare system from both professional and patient perspectives, thus represent an important wealth of expertise to inform service design.

We present a set of co-designed quality standards, highlighting equity and ease of access, minimal patient care burden, clinical responsibility, a multidisciplinary and evidence-based approach, and patient involvement; and we apply these to propose a potential care pathway model that could be adapted and translated to improve care of patients long COVID.

KEYWORDS: quality standards, new service model, qualitative study, long COVID, post-acute COVID-19

Introduction

In the UK, COVID-19 has struck a healthcare system already under considerable strain. The number of general practitioners (GPs) per 100,000 is at its lowest since 2003, there is a nursing shortage of 40,000 and 40.3% of NHS workers reported feeling unwell as result of work-related stress in the last year.[1–3] For healthcare workers, the moral injury of caring for patients in the context of a near-incurable virus alongside personal danger, fear of placing loved ones at risk, extended shifts, disrupted processes, rota gaps and wider social restrictions have only compounded pressures.[4]

The number of individuals who suffer persistent sequelae following SARS-CoV-2 infection is highly contested. While ongoing fatigue and dyspnoea are common among those who were hospitalised, cohort studies suggest that even among non-hospitalised individuals, 10–20% exhibit ongoing sequelae, with patient self-surveys reporting a higher prevalence.[5,6] Although hospitalisation, comorbidities and acute symptom burden seem to be associated with increased probability of persistence, all individuals are susceptible, including those who were previously fit and healthy.[5] This long COVID may manifest as discreet sequelae relating to organ damage, but frequently causes a range of multisystem symptoms.[7] While specific stratifications have been suggested, the epidemiology and natural course for individuals remain largely unclear.[8]

Preliminary guidance exists to support management and the National Institute for Health and Care Excellence, Scottish Intercollegiate Guidelines Network and Royal College of General Practitioners are collaborating on a definitive guideline.[9] However, while NHS England has allocated funding for a new long COVID service, the details remain unconfirmed.

Healthcare workers with long COVID are ideally placed to contribute to organisational sensemaking required to respond to a new disease and become partners in service development. Alongside the unique perspective of being both within ('emic') and external ('etic') to the system, many have also taken on key advocate and leadership roles within the long COVID community.[10,11] In this study, we sought to explore the experiences of healthcare workers with long COVID to develop a set of quality standards and potential care pathway model for management of long COVID.

Methods

Details of study set-up, governance and methods are published elsewhere.[12] The study was conducted between May 2020 and September 2020, and received ethical approval from the East

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Midlands – Leicester Central Research Ethics Committee (IRAS project ID 283196; REC ref 20/EM0128). The dataset comprised 114 participants who contributed through online focus groups, individual narrative interviews or symptom diaries and statements. This analysis focused on 43 respondents who were healthcare workers. Individuals were recruited through online long COVID support groups and social media, followed by a snowballing strategy and consented by email or verbally. Participants were invited to tell their stories uninterrupted. Audio and video recordings and contemporaneous notes were transcribed in full, deidentified and entered onto NVIVO software version 12. Text were grouped into broad categories and subsequently refined using the theoretical lenses described in the discussion. One theme captured suggestions for service improvement. These were integrated into a model of one potential clinical pathway and a number of quality standards, which were then discussed with the two physician–patient co-authors and refined in an iterative process. All participants were then sent a summary of findings and invited to correct any errors or misinterpretations.

Results

Description of dataset

Participant demographic details are shown in Table 1. Despite our efforts to balance for gender and ethnicity, the final sample was skewed to 81% to female and 84% to white; in line with the gender representation in long COVID support groups but less ethnically diverse than the UK population.[13] In total, around 500 pages of transcripts were produced. Our broad coding produced six overarching themes: uncertainty; use of mindlines; support groups and communities of practice; therapeutic relationships and roles; professional identity and practice; and suggestions for service improvement.

Uncertainty

Participants reported a constellation of persisting, atypical symptoms that did not fit an expected pattern based on their pre-existing professional knowledge. Both participants and the

Table 1. Participant characteristics

	Individual interviews	Focus group participants	Total
Total participants	11	32	43
Female	6	29	35
Male	5	3	8
Age, years, median (range)[a]			40 (32–58)
Ethnicity			
White	6	30	36
Asian	4	2	6
Black	1	0	1
Health profession			
Emergency medicine specialist	2	0	
Consultant gastroenterologist	1	0	
Consultant obstetrician/gynaecologist	0	1	
Consultant psychiatrist	0	1	
Consultant anaesthetist	1	1	
Doctor, unspecified	0	8	
General practitioner	1	6	
Specialty trainees	0	3	
Specialist nurse	3	1	
Research nurse	0	2	
Physiotherapist	0	4	
Occupational therapist	0	1	
Paramedic	1	0	
Midwife	0	1	
Dietician	1	1	
Dental hygienist	0	0	
Pharmacist	1	0	
Management/administration	0	2	
Recruited from			
Online patient group	1	32	33
Social media	10	0	10
Hospitalised with acute COVID-19			
Yes	3	4	7
No	8	28	36

[a] = based on 18 participants as 25 participants were not happy to share their age.

healthcare professionals caring for them found this challenging and attempted to mitigate the uncertainty by placing symptoms within a framework of pathologies or conditions they *did* understand (ie negotiating referrals for familiar investigations or specialist reviews). However, many recognised the limitations of this approach, emphasising the need for further research and knowledge development. Participant from doctors, FG1:

> She went and did computed tomography pulmonary angiography and I said, 'What are we doing with these tests?' because I had the tachycardia as well and there was flattening all over my electrocardiography and she said, 'Well we don't know what to do with long COVID. What we're doing at the moment is what we always do in these situations, we're ruling out other things but if the answer ends up being long COVID we don't know …' I just guard a bit against this. We have the tests and reassurance but we've still got crushing central chest pain, we still get breathless eating soup, we're no better for the investigations, the investigations aren't a treatment.

Use of mindlines

The absence of evidence frequently turned participants towards other sufferers, professional contacts and online communities to make sense of their experience and navigate the best way forward without formalised protocols. Alongside practical benefits (such as the use of contacts or colleagues to navigate the system and access investigations or specialist reviews), a deeper generation of mindlines emerged (ie internalised and collectively reinforced tacit guidelines), which are frequently used by professionals in preference to formal guidance.[14] Individual interview, AP:

> I was fortunate enough to have colleagues working in the hospitals local to me … Basically, as they were trying to put in central lines and realising blood was like glue they would be ringing me up and saying: 'Have you thought about doing this, that and the other?' as we started to understand the full plethora of systems that were affected by the virus.

Alongside professional contacts, many participants reported the support offered by patient-developed mindlines developed from the experiences of unwell colleagues or through social media communities. This was particularly relevant where experiences ran counter to 'official' guidance. For example, many participants emphasised the physical and psychological impact of the lag before persistent symptoms were incorporated in a wider folk understanding of long COVID, in the face of government advice detailing an expected time course of 2–3 weeks. Individual interview, RM:

> At week 7, I was offered an antibody test at work, which came back negative. That day was really bad. I thought I was going mad; I didn't know of anyone else who was taking this long to get better and I couldn't understand why. Did I have something else? Unlikely for an emergency department consultant during a pandemic, but not impossible. Why didn't I have antibodies, would anyone believe that I had COVID? A few days later, colleagues and articles on social media started to describe people with symptoms like mine and I began to feel like I wasn't alone.

Support groups and communities of practice

Participants frequently expressed how helpful they found the long COVID social media support groups. These offered a means of sharing health-related information and enabled the development

of patient, and professional, mindlines. Alongside these practical benefits, groups offered a sense of shared identity and belonging, enabling retrospection of experiences, development of narratives and in many ways becoming 'communities of practice'.[15] Participant from doctors, FG2:

> I was struggling with work as well because one of my colleagues had said, 'Well isn't post-COVID just anxiety?' and I think after my GP had that conversation, she actually suggested that I set up a Facebook group for other doctors. And then XX set one up that weekend, and that's kind of how that happened and it's been really helpful; kind of shared experiences and realising that you're not alone and kind of being [in] a safe space.

Therapeutic relationships and roles

Similar to online communities, positive interactions with healthcare workers were perceived as those that enabled listening and sharing of experiences with an honest acknowledgement of the uncertainties, acceptance of the evidence gap and openness to draw on other resources (eg colleagues or patient experience). Participant from doctors, FG2:

> I think if someone can acknowledge uncertainty then I think that really helps because I think we all know that nobody knows what to do with us but I think where it can become frightening is if they're kind of claiming unwarranted certainty. So, I think actually just saying, 'Well actually, we don't really know what's going on but yes stick with us we'll try and work it out.'

Bearing witness to and sharing suffering (not necessarily 'fixing' it) was hugely significant. Participants had mixed feelings about the appropriateness of remote consultations in doing this. While recognising their necessity in the pandemic context, many emphasised the value and reassurance of face-to-face assessment, particularly given the disease's impact on their ability to make clinical judgments and communicate this remotely. Participant from doctors, FG1:

> I've not actually physically seen my GP face-to-face on any of these occasions … when I phone up, it's very much: 'What are you thinking it might be?' Which, when you're not feeling well, it's very difficult. And then I always come off the phone quite dissatisfied. I've actually spent this morning in [the emergency department] because I thought I've never had a positive diagnosis of [COVID-19]. I've been unwell for, what, 10 weeks now, I need to make sure it's nothing else and I've not actually been examined at any point.

Clinician attitudes also impacted encounters, with confirmatory or personal biases resulting in clinician denial. This compounded the uncertainty participants felt governed many GPs, particularly when faced with well-read, expert patients, occasionally resulting in a dilemma of authority that impeded the quality of therapeutic relationships and outcomes. Participant from allied healthcare professionals, FG3:

> My last interaction with my GP was in June. I asked about my lungs, and he said, 'What do you want me to do about it? You tell me. I have no idea.' It felt very dismissive and it felt like I know GPs don't want patients to look up things on the internet and come and say this is what I think's wrong with me because in the normal world that's definitely not what you want but that's what every person with [COVID-19 has] been driven to because the

response from GPs is 'I don't know what to do. Nothing's got any evidence so, yeah sorry, I can't help.' I went back to work after 5 weeks still very unwell because nobody believed in long COVID in May, they just didn't believe it.

Some participants found attempts at 'shared decision making' in the acute illness challenging, simply preferring the 'patient' role, while others welcomed this transparency. However, the clinical uncertainties later experienced around persistent symptoms and unknown prognosis were frightening for many, regardless of which 'role' was adopted and especially if compounded by a lack of therapeutic continuity or follow-up.

Professional identity and practice

The uncertainty around symptom duration and personal impact of the disease compounded professional tensions. Participants emphasised their strong work ethic and teamworking role and feared colleagues would perceive them as 'shirkers'. However, individuals also had good insight into their physical and mental limitations and expressed fear of coming back to work too soon, risking reputational damage or medico-legal ramifications. Participant from doctors, FG1:

The medical legal aspect is huge and I think certainly feels that way as a GP 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.

There was also much anger and frustration, particularly around accessing care or responses they had received from an unkind, uncompassionate 'system'. This was particularly salient when experienced from 'the other side' as a patient. Participant from allied healthcare professionals, FG3:

I know quite a few of the people at the health centre personally, and I think they're all really good people and really caring people but the experience from my end has not been one of care, particularly.

Suggestions for service improvement

Participants emphasised the duty they felt as eloquent, informed 'expert patients' with knowledge of 'the system' and personal experience of its limitations to advocate for service improvements. Participant from doctors, FG2:

I mean not to sort of self-grandiose our group but there's a certain responsibility to put down our experiences so they can be opened up to other people who don't have the language and the access that we potentially have to communicate it to primary healthcare to access the services that need to be put in place for them.

Difficulty accessing investigations for persisting symptoms and the siloed, single-organ and unintegrated nature of the system led participants to propose holistic, 'one-stop shop' services integrating multiple specialties. A co-designed potential structure is presented in Fig 1.[16]

Such services should be designed to exclude red flag conditions, detect and treat comorbidities or complications, and support symptomatic management. They must be multidisciplinary, run by generalists rather than a single specialty and ideally be situated in primary care to enable continuity in follow-up and rehabilitation, with appropriate links for secondary care referral. However, it was

recognised that they must not fall on GPs and must be appropriately resourced. Participant from allied healthcare professionals, FG1

My expectation of such a clinic would be to rule out treatable causes or complications, based on our symptoms. And then active involvement with physiotherapies and occupational therapies maybe a psychologist […] we now know that COVID is a multi-system disease so the fact that you don't display signs of respiratory infection doesn't mean that you don't have a problem.

The importance of consistent, equitable, and inclusive access criteria was clear – specifically with no prerequisite for a positive PCR or antibody COVID-19 test result, merely referral from a healthcare professional. Linked to this, participants advocated further training of GPs, raising the possibility of a long COVID practice lead. Integration and education of allied healthcare professionals, psychologists and occupational health teams were also emphasised, given the acknowledgement that 'treatment' would frequently be time, and personalised rehabilitation will depend on deficits and organ complications in the context of a caring therapeutic relationship.

Reflexivity and improvement, sharing of knowledge and experiences, and an encouragement of further research and subsequent evidence-based service refinement and clinician education were also essential. Despite these ideals, participants remained sceptical about the likely translation of their proposals due to financial restraints, personnel shortages and the nature of change within the NHS. Participant from doctors, FG2:

I don't know how anyone is [going to] create this sort of a clinic. It just seems, I mean, we know how the NHS works and it just seems like a far-flung reality.

Discussion

Summary of key findings

This qualitative study of 43 UK healthcare workers with long COVID highlights the great uncertainty experienced by patients and healthcare professionals around a novel condition, compounded by pre-existing confirmatory biases and an absence of guidelines or care pathways. Applying existing disease frameworks, utilising professional networks, and the development of professional and patient mindlines and communities of practice were all attempts to minimise this uncertainty, while therapeutic relationships providing supportive continuity and follow-up best enabled individuals to cope with the tension of the unknown.[17]

The personal and professional challenges of long COVID were exacerbated by frustrations and callousness that participants experienced in their encounters with the healthcare system. Given their status of both professionals and patients, they felt a responsibility to aid service improvements and advocated for holistic, multidisciplinary and multisystem services and research initiatives.

Comparison with theoretical literature

Sociological theories of the clinician as patient abound. Hahn and Klitzman highlighted the concept of the 'medical self' where clinicians behave like a doctor even when being a patient.[18,19] This is borne out within our data and compounds and exacerbates the uncertainty. Role ambiguity, reversal or vacillation along a spectrum between the doctor's and patient's roles heightens anxiety and may heighten a clinician's personal sense of frailty,

creating a tension which could result in minimisation of a patient's issues as a protective coping mechanism.[20]

Wounded healers (ie professionals with experience of patient-hood) are frequently said to have developed deeper understanding and wisdom. In ethnomedicine, healers are often chosen *because* they have experienced severe illnesses.[18] In this case, despite exacerbating role confusion, 'medical patients' felt a duty to advocate for future patients through experience-based co-design (EBCD) of long COVID services. The duality of their 'emic' and 'etic' selves with dual vantage points of the healthcare system situated them particularly well to do so.[10]

EBCD was developed to ensure health services were designed around the patient experience. Grounded in the perceptions and reactions of individual patients, this collective sensemaking process produces new understandings that can be pragmatically applied to frontline services; a process enjoyed by participants in this study through participation in focus groups, online communities and authorship groups advocating further action.[11,21]

Implications for services

Alongside a potential multidisciplinary care pathway structure (Fig 1), this study provides supportive evidence for a set of quality principles: Long COVID ABCDE (Box 1), many of which accord strongly with a manifesto written by a group of doctors with long COVID.[11,12] As well as minimising patient suffering, it is hoped
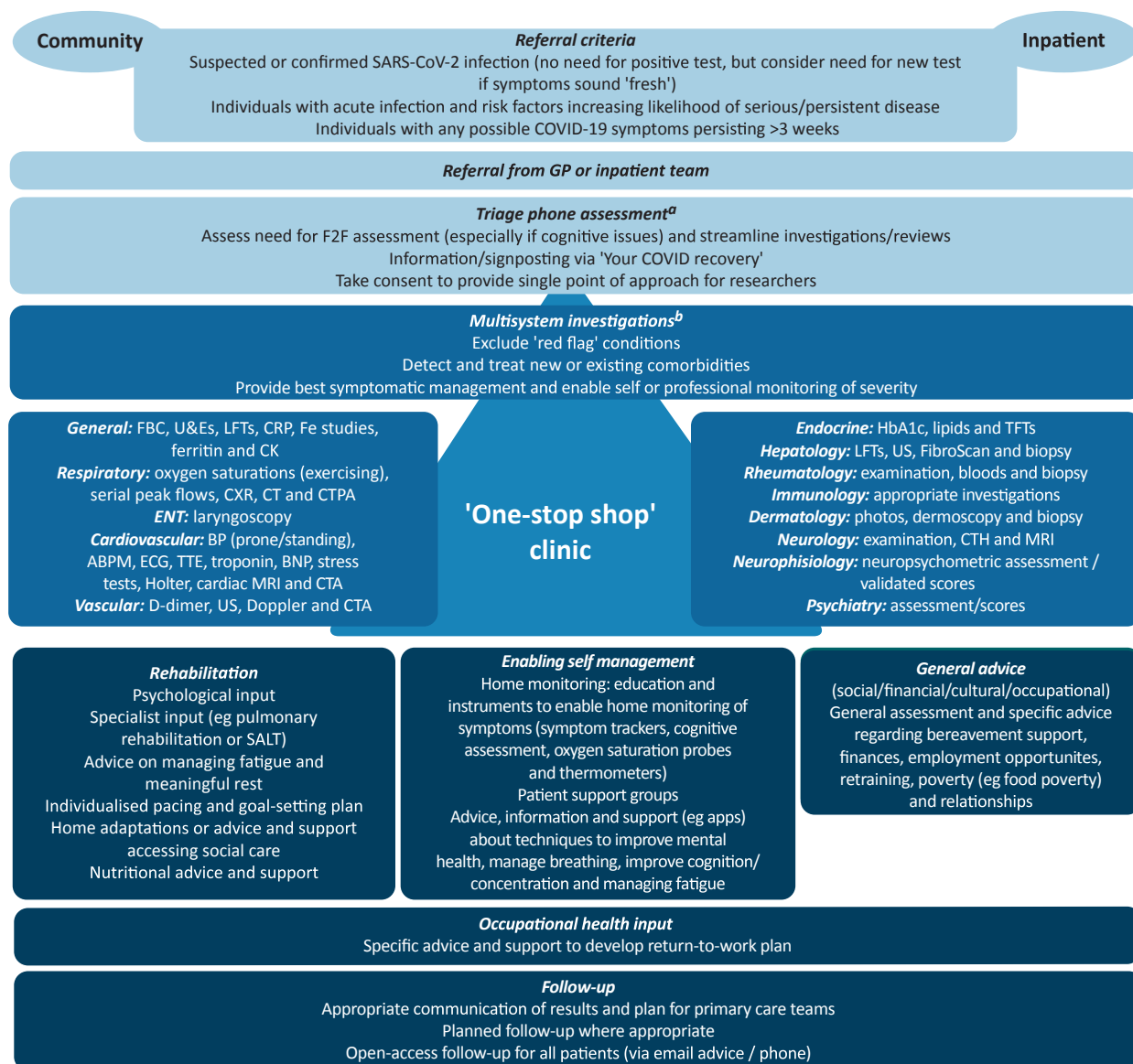
Fig 1. Potential long COVID care pathway co-designed by study participants. [a] = for example, the COVID-19 Yorkshire Screening Tool or post-COVID-19 syndrome functional assessment scale;[16] [b] = possible specialist investigations (not a definitive list); ABPM = ambulatory blood pressure monitoring; BNP = brain-natriuretic peptide; BP = blood pressure; CK = creatinine kinase; CRP = C-reactive protein; CT = computed tomography; CTA = computed tomography angiography; CTH = computed tomography of the head; CTPA = computed tomography pulmonary angiography; CXR = chest X-ray; ECG = electrocardiography; ENT = ear, nose and throat; FBC = full blood count; Fe studies = iron studies; F2F = face-to-face; GP = general practitioner; LFTs = liver function tests; MRI = magnetic resonance imaging; SALT = speech and language therapy; TFTs = thyroid function tests; TTE = transthoracic echocardiography; U&Es = urea and electrolytes; US = ultrasound.

Box 1. ABCDEF of long COVID clinical quality standards

A: Access

Services should be accessible to everyone with long COVID regardless of COVID positive PCR, antibody test or hospitalisation status. However, as the evidence base and diagnostic criteria develop, referral criteria to specialist services may need refinement to ensure optimal resource utilisation. A range of contact and consultation approaches including telephone, video and face-to-face should be considered as appropriate and adjustments make to ensure those with new or chronic disabilities are not disadvantaged.

B: Burden of illness

The burden of treatment needs to be minimised. A 'one-stop shop' model could facilitate this, such as those developed for other complex conditions (eg memory impairment). Alternatively, a shared care model, with clearly defined care pathways disseminated between the community and secondary care is likely to be more achievable for many localities and accords with the Department of Health's long-term conditions model. Such approaches have been applied for over 10 years to multisystem conditions including inflammatory arthritides and diabetes or mental health problems. Outcomes are non-inferior to those achieved through secondary care management and may benefit from enhancing patients' self-efficacy, confidence and satisfaction, and cost-efficacy.[22,23] Successful integration relies on coordination between commissioners and providers, adequate financial resources and appropriate governance structures.

C: Clinical responsibility and continuity of care

A named clinician must be responsible for the patient at every stage. Management and relationship continuity combined with clinical responsibility are essential in any multisystem or chronic condition. They are associated with patient and physician satisfaction; reduced clinician collusion of anonymity; physician trust; and, therefore, treatment adherence, problem recognition and quality of management, and reduced healthcare utilisation and associated costs.[22] Such continuity has also been shown to improve outcomes in rehabilitation care settings; of particular relevance for long COVID.[23]

D: MultiDisciplinary rehabilitation services

Services must be multidisciplinary. Integrated care requires professionals and practitioners from different backgrounds to work together to improve patient outcomes. Multidisciplinary team structures provide a shared identity and purpose encouraging trust; a more holistic and person-centred practice; minimising errors and associated harms; improving efficiency of resource utilisation; and reducing professional isolation and stress.[24] From cancer care to rehabilitation, such approaches have been widely implemented within the NHS to improve clinical outcomes, patient and family experience, and professional satisfaction.[25]

E: Evidence-based standards

Evidence-based standards must be developed to guide consistent symptom management. These should guide the exclusion of potentially serious complications, management of new or existing comorbidities, and holistically address symptoms and should acknowledge the best available evidence or consensus of best practice in the context of a rapid, dynamic context, rather than holding out for randomised controlled trials. Importantly, while consideration of psychosocial factors is crucial, symptoms (such as fatigue or 'brain fog') should not be ascribed to these issues without consideration of, and research into, other causes.

F: Further development of the knowledge base and clinical services

Patients must be offered the opportunity for involvement in further research and service development, which should be enabled by the development of registries of patient data and facilitated through long COVID services. This reflects the key principles of patient-centred medicine and such experience-based co-design also improves alignment of research and service aims with patient priorities; development of meaningful and useful studies and services, in which patients are keen to participate; identification and minimisation of barriers to access or utilisation; enhanced patient education, information dissemination, and application of research findings; and improved patient experience and cost efficiency.

that implementation would reduce mortality, improve patient outcomes, and optimise a return to employment. These proposals align strongly with proposed multidisciplinary pathways for patients with medically unexplained symptoms and there may be significant overlap according to local availability.[26] However, it is essential to note that implementation of any changes should be subject to rigorous, iterative review and refinements in line with emergent evidence and evaluation of service impact.

Strengths and limitations of the study

To our knowledge, this is the largest and most in-depth qualitative study of healthcare workers with long COVID published in the academic literature with a focus on the under-researched majority who were never hospitalised. However, the population sample was drawn exclusively from the UK and may have inadequately captured the perspectives of ethnic minority groups. Further strengths and limitations are discussed elsewhere.[12]

Comparison with previous empirical studies

Our findings affirm the experience of healthcare professionals with long COVID published in narrative reviews, commentaries and manifestos.[11,27,28] Like our own dataset, these emphasise the disorienting uncertainties of this new illness, the stigma of not being believed, frustration of scientific and medical ignorance, and problems accessing services.

Wounded healers are extensively represented throughout the illness experience literature. Our population did not reflect the ethos of invulnerability reported in other narrative accounts.[29] However, the challenges of the patient role; importance of therapeutic relationships and compassionate care; inhumanity of 'the system' and use of professional status to manipulate it; workforce culture and guilt that promote a return to work; and impact on professional understanding and practice all emerged here.[30] Interestingly, as with long COVID, many wounded healers describe their experiences in non-academic forums such as blogs,

memoirs or media outlets, particularly in times of illness that challenges or changes life or identity (eg burnout or palliative care), reflecting a need to attempt a narrative sense-and-meaning-making process.[31,32]

Conclusion

This study of healthcare professionals with long COVID provides further evidence of approaches to minimise and live with the great uncertainty surrounding the condition, capitalising on their dual status as professionals and patients to support quality standards and suggest improvements for long COVID services within the NHS. ∎

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Conflicts of interest

Trisha Greenhalgh is currently sitting on the oversight group for the long COVID guideline at the National Institute for Health and Care Excellence. Trisha Greenhalgh and Emma Ladds provided evidence to the House of Lords select committee on long COVID. Sharon Taylor and Clare Rayner are members of long COVID support groups.

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