

The hidden pandemic: a qualitative study on how middle-aged women make sense of managing their long COVID symptoms

BACKGROUND

A relapsing and remitting illness, long COVID can be challenging and debilitating. A person living with long COVID can feel like they are getting better and recovering only to relapse again. The aim of the research was to explore how non-hospitalized middle-aged women who contracted COVID in the first wave of the pandemic, from March 2020, are managing their long COVID symptoms.

PARTICIPANTS AND PROCEDURE

A qualitative research study with an interpretative phenomenological analysis approach was used to explore how the women made sense of managing their condition and health seeking behaviours. Participants were recruited from long COVID Facebook groups and semi-structured interviews were conducted remotely by Teams audio; these were digitally recorded and transcribed by hand with prior informed consent. Nine women were interviewed and four themes and eight sub-themes emerged from the data.

RESULTS

The four emerging themes were: inequality and inconsistent medical treatment; uncertainty and ambiguity of

managing long COVID symptoms; managing other people's expectations and perceptions of long COVID; and the changing identity. Overall, these results indicated a general mistrust in health care services to provide adequate support and individualized treatment plans leading women to self-advocacy and to seek alternative support and treatment.

CONCLUSIONS

This study raised questions about the possible unfair treatment of women seeking medical attention for their long COVID symptoms; how ambiguous symptoms are misattributed to anxiety and discrimination from health care professionals contributes towards stigma. The study concludes with recommendations for service improvement such as the compassionate validation of patients' pain and the use of evidence-based therapeutic practices such as mindfulness.

KEY WORDS

qualitative research; lived experience; illness experience; health seeking behaviours; misogyny

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AUTHORS' CONTRIBUTIONS – A: Study design · B: Data collection · C: Statistical analysis · D: Data interpretation · E: Manuscript preparation · F: Literature search · G: Funds collection

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BACKGROUND

COVID-19 is an infectious disease caused by the SARS-CoV-2 virus (severe acute respiratory syndrome) and an outbreak of COVID emerged in Wuhan, China in late December 2019. The outbreak reached a pandemic scale, resulting in thousands of deaths worldwide. This led the World Health Organisation (WHO) to declare SARS-CoV-2 a pandemic on March 12th 2020 (Ciotti et al., 2020). The pandemic brought a wave of psychological uncertainty to the global stage which continues to ripple throughout the world in 2023.

Disa Collier,
Gulcan Garip

In the UK, there is an estimated, self-reported, 1.9 million people in private households who have been living with long COVID for more than 4 weeks after the initial COVID infection, 'not explained by something else' (Office for National Statistics, 2023). Long COVID continues to generate psychological and medical uncertainty and research is crucial in finding a treatment pathway. This study explored the lived experience of non-hospitalised, middle aged-women (aged 42-59) who are self-managing an ambiguous and rapidly growing contested illness (Ballard, 2021). Long COVID is medically and psychologically associated with treatment ambiguity, and despite medical intervention pathways, there is no specific treatment or vaccine to assist recovery (Parkin et al., 2021). COVID-19 has been said to 'cast a long shadow' over patients' lives in the non-hospitalised population, and there is evidence that background disability causes persistent fatigue over the lifespan of a patient, contributing to the COVID burden on health (Briggs & Vassall, 2021, p. 5).

Patient support groups on social media began using the term 'long COVID' in 2020 in an attempt to explain why patients were still experiencing long-term symptoms of COVID (Callard & Perego, 2021). The authors have retained the patient-derived term 'long COVID' throughout this study. Long COVID has been defined as not recovering from COVID for weeks or months after the initial COVID infection, with or without a positive test (Nabavi, 2020). It is a heterogeneous and multi-systemic infectious disease which impacts the cardiovascular, pulmonary and neurologic systems and research suggests there are over 200 long COVID symptoms which span across 10 organ systems (Sivan et al., 2022). In the first week after acute COVID infection researchers found that an individual is more susceptible to long COVID if they have 5 COVID symptoms or more (Sudre et al., 2021). However, this susceptibility is contested, because there is no correlation between acute COVID severity (whether hospitalized) and the likelihood of developing long COVID (Shah et al., 2021).

Some of the most persistent symptoms are breathing pattern disorder, dyspnoea, chronic brain fog and cognitive problems, chronic fatigue, fever, neuropathic pain, allergic reactions, dizziness, dissociation,

tachycardia, body and muscular aches (Sivan et al., 2022). These symptoms are frequently exacerbated after physical and mental activity (Phillips & Williams, 2021). Health inequality factors which contribute to higher long COVID prevalence were self-reported as living in deprived areas, aged 35-69, white ethnicity and having a pre-existing health condition (Finch & Tinson, 2022). Women are twice as likely as men to develop long COVID (Nabavi, 2020). A possible explanation could be an elevated immune response (Sylvester et al., 2022). There are known long COVID symptom differences between the sexes, and it is suggested that females are more likely to be at a higher risk due to increasing age and body mass index (Bai et al., 2022; Sudre et al., 2021). Women under 50 are significantly more likely to experience fatigue than men (Sigfrid et al., 2021). Research recognises that long term COVID fatigue is more prevalent in females with a diagnosis of anxiety or depression (Raveendran et al., 2021) and this is consistent with previous studies on chronic fatigue syndrome (Faro et al., 2016). This poses an emerging issue for healthcare, employers and individuals as prolonged post-infection fatigue could cause a health burden (Townsend et al., 2020). The incidence rates of endocrinal and renal complications were significantly higher in males with long COVID and women were more likely to develop GI, psychiatric, fatigue, ENT, neurological, rheumatological and dermatological symptoms (Sylvester et al., 2022).

To the authors' knowledge, there is little published qualitative research that specifically focuses on the subjective and nuanced experiences of middle-aged women managing long COVID symptoms and well-being. There are similar qualitative studies that have researched the lived experience of long COVID in different populations (Duan et al., 2022; Humphreys et al., 2021; Jackes et al., 2022; Kingstone et al., 2020; Ladds et al., 2021; Taylor et al., 2021; Wurz et al., 2022). 134 patients, 81 males and 53 females with diverse ethnicities who were hospitalised with severe COVID symptoms, were surveyed at a 1-month and 6-month post-hospital discharge. Grounded theory was used to analyse the responses of the participants regarding their recovery from long COVID. The study confirmed a need for further awareness of the psychological impact of long COVID recovery and to provide physical and mental health rehabilitation (Duan et al., 2022).

A qualitative study made the recommendation for individualized guidance around physical activity for participants whilst managing long COVID symptoms so they may resume sports that improved their well-being (Humphreys et al., 2021). Although this study focused on the lived experience of managing physical activities of 9 men and 9 women, aged 18-74, this study differs from the current research as the epistemology was an inductive thematic analysis and male

participants were included in the study (Humphreys et al., 2021).

Two focus groups and a secondary qualitative data analysis from a larger research project were explored in the study of 8 Scottish women presenting with long COVID symptoms. A thematic analysis using a phenomenological stance generated five themes which resulted in considering the holistic impact of this debilitating health condition (Jackes et al., 2022).

Another study examined the patients' perspectives on health care professionals after COVID infection (Kingstone et al., 2020). The self-reported experiences of the continued long COVID symptoms of 19 females and 5 men, aged 20-68, recruited from social media, were obtained through a semi-structured interview (Kingstone et al., 2020). A thematic analysis was used and the patients contributed to the overall design and analysis of the study (Kingstone et al., 2020). The results exposed the profile of long COVID in the primary care system and indicated that rehabilitation and support were necessary for patients' recovery (Kingstone et al., 2020).

A further study established the need for 'continuity of care' and a call for an multisystemic evidence-based rehabilitation approach (Ladds et al., 2021). The research recommended quality principles for developing services to treat long COVID (Ladds et al., 2021). Patients initiated this research and asked for their ongoing symptoms to be studied (Ladds et al., 2021). Patients helped in the recruitment process and the main findings of the research were disseminated amongst the participations for feedback (Ladds et al., 2021). The study oversampled men and people from different ethnicities and out of 114 participants, 32 were doctors and 19 were other health care professionals (Ladds et al., 2021).

In a qualitative observational study, 213 participants responded to an online survey of medical and socio-demographic questionnaire focusing on physical activity, post-exertional malaise (PEM), fatigue, breathing issues and quality of life (Wurz et al., 2022). 169 participants identified as female and were aged 40-49, having long COVID symptoms for more than 6 months (Wurz et al., 2022). The study used a reflective thematic analysis and concluded that further support is required to help people adjust to their symptoms (Wurz et al., 2022). Much uncertainty still exists about the relationship between individuals who primarily contracted the wild type variant at the start of the pandemic and who are still living with long COVID (Canas et al., 2023). This is a problem as further research across non-hospitalised populations is required as there are an estimated 762,000 people still living with long COVID symptoms over 2 years after acute infection (Office for National Statistics, 2023).

People living with long COVID are frequently met with discrimination and there is a call for people's

lived experience to be placed at the heart of research development as their insight is valuable to ensure underrepresented voices are heard in order to address this power imbalance (Alwan, 2021). This is a problem for those who live with contested illnesses and the female voice is often underrepresented in medical and psychological care (Ballard, 2021).

This research aimed to explore how middle-aged women who contracted COVID during the first wave of the pandemic were managing and treating their long COVID symptoms and how they perceived their long COVID prognosis.

PARTICIPANTS AND PROCEDURE

STUDY DESIGN

Interpretative phenomenological analysis (IPA) was the chosen study design (Smith et al., 2009). IPA is a research method created to understand how people make sense of their lived experience in relation to their personal and social environments and is widely used in different research contexts such as living with a chronic health condition, medical diagnosis or in this study the lived experience of long COVID (Smith et al., 2009). As an experiential method, IPA is grounded in three theoretical frameworks: phenomenology, hermeneutics and idiography (Smith et al., 2009). This approach was particularly influenced by the work of the German philosopher Martin Heidegger, who developed Edmund Husserl's phenomenological ideas. Taking an interpretative or hermeneutic approach was central to Heidegger's philosophy (Smith et al., 2009). As a researcher, you are trying to understand what is happening to the participant, whilst also trying to make sense of what the participant is experiencing (this is the double hermeneutic) (Smith et al., 2009, p. 35). As part of the hermeneutic process, the researcher actively engages in acknowledging and reflecting their fore-structures (previous experiences and preconceived notions). As the first author has long COVID, they bracketed their lived experience so they could attempt to make sense of the participant's sense making. Since IPA is an idiographic method, transcripts were analysed case by case and within the context of the participant's narrative prior to comparing it with the lived experiences of others. IPA was chosen as it clearly aligns with the epistemological position of the study question and aims, which explored the participant's lived illness experience (Smith et al., 2009). In addition to its psychological impact, COVID-19 had an impact on people's health and their lived experience which unfolded as the pandemic progressed (Teti et al., 2020). As new psychological narratives are being created qualitative inquiry is the preferred method to collect pandemic data and social responses enabling

research to make sense of the lived experience of health and illness as it unfolds (Teti et al., 2020).

PARTICIPANTS

Purposive sampling taking into account age and gender was used to recruit women who met the selection criteria. This sampling strategy was chosen because eligible women who matched the selection criteria were identified as sharing a meaningful, homogeneous long COVID experience (Smith et al., 2009). Women were invited to participate in the research study from the 'Long COVID after infection in March 2020' and 'Long COVID support' Facebook groups. Prior consent from the group admins was obtained to post the participant invitation. See Table 1 for participant characteristics.

RECRUITMENT

Initially, 19 responses were received from the Facebook groups to participate in the study. However, 9 women were interviewed. Eight women were based in the UK and one in Poland. Seven women were White British, 1 was European mixed and 1 was South American with various genetic influences. Their ages ranged from 42 to 59 years. Women who met the key inclusion selection criteria – who contracted COVID from March 2020 (the first wave of the pandemic), who had a self-diagnosis or clinical diagnosis or a positive COVID test, were treated at home and no hospital admission for COVID and had

long COVID symptoms lasting for more than 28 days – were interviewed for this study.

Eligibility and study participation were confirmed by informed consent and the participant's signature was sought in Qualtrics. A brief outline of the study aims was emailed to each participant and there was an opportunity to ask questions prior to the interview. No payments, rewards or incentives were made to the participants.

DATA COLLECTION

Semi-structured interviews were conducted, and the participants were invited to a Teams audio and these remote interviews were held over a 4-week period in February/March 2022. Researchers are increasingly using remote interviews, particularly audio interviews, to collect qualitative data and this method was selected because the participants were located in different locations in the UK and Europe (Ryan et al., 2009).

All participants were briefed on the interview schedule and were able to have a break or finish the interview early should they want to manage their symptoms. After each interview, they were debriefed in Qualtrics and had a 14-day withdrawal period from the study.

Data was generated using an interview schedule and open-ended and prompt questions were used during the interview process. This guided the outline of the study aims and provided relevant questions to the study (Ryan et al., 2009). Interview questions were planned based on IPA guidelines (Smith et al., 2009).

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Table 1

Sociodemographic characteristics

Participant	Age	Ethnicity	Sexual orientation	Education	Job sector	Spiritual or religious beliefs
Luria	49	White British	Heterosexual	–	Civil Service	No
Kelley	59	White British	Heterosexual	Degree	Accountancy	No
Aella	50	White British	–	Masters	Education	No
Kerta	48	European Mixed	–	Masters	Freelance	Yes
Zelda	50	South American	Heterosexual	Undergraduate	Self-employed	Yes
Alala	42	White British	Heterosexual	Masters	Research	No
Ragna	50	White	Heterosexual	GCSE	Management	Spiritualism
Beda	56	White British	Heterosexual	Undergraduate	Education	Roman Catholic
Cahira	51	White British	Heterosexual	Post-graduate diploma	Not working	Agnostic

An example of an interview question: “How have you changed the ways you manage the long COVID symptoms over time?”. Prompt questions were used where appropriate: “Can you tell me a bit more about that? What did you notice?”. This included topics on symptom management, personal control over illness and prognosis. Initially, ten questions were generated and as the interviews progressed, an additional 5 questions were added to the schedule as a direct result of previous interviews and the iterative process. In addition to predetermined topics, a semi-structured interview allows for unanticipated themes to emerge and enables more flexibility (Ryan et al., 2009).

DATA ANALYSIS

The data was transcribed by hand, working with one transcript at a time. Using the ‘analysing the data’ chapter, the first transcript was analysed into exploratory notes containing descriptive, linguistic and conceptual notes before formulating the experiential statements (Smith & Nizza, 2022). This was followed by finding connections between the experiential statements, reviewing, and then clustering into six statements and compiling a table of personal experiential themes (PETS) (Smith & Nizza, 2022). This process continued with each transcript until a table of group experiential themes was compiled (GETS) (Smith & Nizza, 2022). The data analysis process was iterative and stopped when sufficient themes emerged that were common across all transcript cases. Initially five themes and 12 sub-themes emerged from the data. However, the data was iteratively revised to four themes and 8 sub-themes.

REFLEXIVITY

During the research process the first author’s positionality ran on a continuum, from Etic (outsider) to Emic (insider) and a hybrid position (Lahlou, 2011). The author shared sociodemographic similarities with the participants, being a white, middle-class woman living with long COVID from the first wave of the pandemic, and this initiated an emic position. At the recruitment stage, there were many challenges from the long COVID community enquiring about the author’s position, which was initially perceived as an outsider. There was strong negativity towards psychological studies as individuals perceived research to align long COVID with psychological illness. The first author was transparent about her long COVID diagnosis and shared this in a group posting. This congruent information helped to level the power dynamic between the group, author, and research study. This offered an emic position which supported the data collection as the author compassionately

identified with the long COVID narratives and offered appropriate empathy (Gair, 2012).

A hybrid position was shaped during the interview process as there was an empathic curiosity to capture the nuances of the individuals’ lived experience and to respect that whilst there were some shared similarities with the author’s journey there were many differences to comprehend (Acker, 2001; Breen, 2007; Dwyer & Buckle, 2009; Paechter, 2013).

Having prior knowledge and lived experience helped to shape and identify an appropriate research question. During the interview process, having an emic position gave space and openness for the participants to reflect on the real perspectives of their long COVID journey (Acker, 2001; Breen, 2007; Dwyer & Buckle, 2009; Paechter, 2013). Research verifies that an emic position can produce richer data that are more reflective of the participant community culture (Paechter, 2013). During the interviews, there was a shared understanding of long COVID terminology between the participants and author that perhaps would need to be explained to an outsider (Breen, 2007; Dwyer & Buckle, 2009; Paechter, 2013).

ETHICAL APPROVAL

The study was approved by the University of Derby Health, Psychology and Social Care Ethics Committee. During the interview process, several participants were upset due to the sensitive nature of long COVID. Emotions were acknowledged and validated, and the individual’s autonomy was respected to continue with the interview. As the study was sensitive, information about health and wellbeing services was offered to the participants during debriefing.

Each participant was given a pseudonym to maintain their confidentiality throughout the research and this can be seen in their verbatim quotes in the results section.

The transcripts and all data relating to the research were stored safely on a password-protected, external USB and the audio interviews were deleted from Teams within the agreed time frame. The data was reviewed and verified at the independent audit stage, creating robust data collection and analysis (Yardley, 2015).

RESULTS

Four themes and eight sub-themes emerged from the group experiential theme table, which are representative of the sample’s subjective experience (Smith & Nizza, 2022). The four themes presented in the findings are: inequality and inconsistent medical treatment; uncertainty and ambiguity of managing long COVID symptoms; managing other people’s ex-

How middle-aged women make sense of managing their long COVID symptoms

pectations and perceptions of long COVID; and the changing identity. Collectively these provided an insight into how the women made sense of managing their long COVID symptoms.

INEQUALITY AND INCONSISTENT MEDICAL TREATMENT

Mistrust of medical professionals. Inconsistent medical treatment resulting in medical and psychological gaslighting was commonly experienced, leaving most of the women to feel judged, unsupported, and invalidated. The medical interactions would frequently cause distrust and leave the women feeling disempowered and uncertain where to access treatment, leading them to avoid seeking medical support.

Several women found doctor appointments to be unhelpful and invalidating, being left with no explanation, diagnosis, or referral for tests/treatment.

The doctors cannot help you. They actually make you worse because they, they make your stress worse by saying it's in your head (Zelda).

Kelley was distressed after a doctor's appointment and intrinsically knew the guidance was not clinically appropriate. As reported by Accident and Emergency (A&E) staff after a scan, her shaking wasn't caused by anxiety, but rather by the aftereffects of COVID and swollen veins in her brain.

GPs weren't helpful at all, not at all and said, are you sure it's not anxiety? I've never suffered from anxiety and I still don't (Kelley).

After the last appointment, Kelley contacted her own GP, who sent a link about mental health problems, causing further distress. There is a collective awareness in the long COVID community that many patients have experienced medical and psychological gaslighting and Kelley refers to this after the GP signposted for mental health.

I actually sat down and cried. I don't get the shakes because I've got mental health problems [...] and even on that COVID app, that's what people are being told all time. Oh no, I think it it's mental health. You're imagining it (Kelley).

The frustration and distress caused by accessing support was evident across the women's lived experiences. Kerta was told to go to hospital as her pulse was very high. She experienced an unpleasant reaction from medical staff who appeared to lack compassion and understanding.

So I went to hospital, hospital again was, why are you here? And you shouldn't be here, you know? Don't take up our time. Um, so it is really uncomfortable [...] It makes you want to avoid this, those places and avoid seeking help (Kerta).

Stigmatising, judgemental and discriminating comments were experienced by Luria, who was referred to a physiotherapist who recommended sit up

exercises. Having an undiagnosed hernia which exacerbated symptoms made the exercises challenging. Expressing fury, she told the physiotherapist that she could not do the exercises and his reaction was, *that's why you lot have got long COVID, because you're in bed all day*. Considering it was an inappropriate comment from a medical professional, Luria stated, *shouldn't be saying things like that about something he clearly didn't know about*.

Similarly, Kerta was met with generalisations due to her age from a doctor when dismissed from the long COVID clinic. She reflected on being a woman over 40, *but that assumption that if you're female, it must be the menopause*. Kerta noticed the use of language in scientific research, *you have some people who are studying long COVID, usually, unfortunately from the psychological side, will start talking about things like neurasthenia or hysteria. This very misogynist language*.

As an advocate for long COVID, Kerta perceived the medical treatment of women as misogynistic, ageist, and sexist. Kerta reflected on when she was recovering from pneumonia and attended a follow-up hospital appointment. She was wearing a face mask and was accosted by two men at the hospital entrance, berating her about the mask and talking about *stupid conspiracy theories about CoV-2*. Kerta felt threatened as she observed there were men walking past wearing masks, but these men felt enabled to harass her. Kerta shared that this happened more than once.

This theme emphasized the distress and frustration caused by inconsistent medical treatment and stigmatization from medical and psychological gaslighting, resulting in negative interactions.

Validation, support and accessing medical treatment. Three women reported seeking medical attention to be validating and supportive. They felt heard, believed and this contributed to an overall positive medical treatment experience. Aella described the experience as transformative.

[...] my GP rang [...] she believed me, she didn't doubt me for a start. Erm, she was the one who said I think you got long COVID (Aella).

Aella's doctors' surgery was badly impacted by COVID, and during the interview Aella mentioned that a receptionist had passed away from COVID. Aella felt this loss may have contributed to the surgery's understanding of COVID.

Ragna could not fault the NHS support and felt compassion towards the doctor at the long COVID clinic. She was the 5th patient at the clinic and described the doctor as looking at her, *almost forlornly*; she felt he was *helpless* in the face of the long COVID phenomenon. Ragna had many chronic allergies and she wanted to be informed about the safety and impact of the vaccines prior to having them. The immunology team reassured her in the decision-making process, which resulted in not receiving the vaccine.

She felt this team made a difference as they *really listened and, and yeah, heard what I had to say.*

Beda had a positive medical experience as an outpatient compared to many of the participants and felt validated after the hospital consultation resulted in a referral to cardiology, *and when I said to him, thank you for taking me seriously, after speaking to the consultant, he said, why on Earth wouldn't I?* (Beda).

In summary, this theme highlights how three women's experiences of seeking support for long COVID were validated by medical practitioners. This validation contributed to the women feeling heard and supported, leading to positive medical interactions.

UNCERTAINTY AND AMBIGUITY OF MANAGING LONG COVID SYMPTOMS

The factors that increase long COVID symptoms. Participants described precipitating factors that perpetuate long COVID symptoms. Factors such as stress, fear and guilt contributed to relapses and the women felt stuck in a cycle of minor improvements then massive physical and emotional crashes. According to Aella, relapses were associated with work stress. Aella's symptoms seemed to be improving over the last 3-6 months and she felt this was a sustainable improvement. Aella described the maintenance and relapse cycle as a rollercoaster and attributed this to stress.

I'd have this massive crash that would put me back in bed. Um, and I could be back in bed for a few weeks. [...] I seemed to kind of start to get, to improve and then just completely wipe out... (Aella).

Alala shared a similar experience of constantly worrying about symptoms and researched or watched YouTube videos to understand long COVID, which only exacerbated her fears.

[...] I've got to stop focusing on the symptoms. [...] Or allowing myself to get kind of drawn into worrying too much about what was going on (Alala).

Fear of contracting COVID has been integral to the reporting of the virus and Ragna felt the media *put a spin on things*, feeling that generally the public had been told a version of the truth.

It's been quite important to try not to buy into that fear. [...] I've had it twice and I've survived (Ragna).

This theme exemplifies a variety of precipitating factors such as stress, fear and guilt which contributed to the relapsing nature of long COVID. Participants highlighted the importance of removing the fear cycle that exacerbates recovery.

Managing long COVID symptoms. There was a sense of urgency amongst the women to find a way of managing the multiple, and often confusing, debilitating symptoms. Some women turned to alternative methods to promote their health, such as taking supplements, dietary changes, and holistic treatments. In the long COVID community, the low histamine diet

is promoted, and it is a diet which Zelda stated had positively influenced her symptoms.

I'm having a restricted diet, only fruits or vegetables, mostly everything antioxidants. I've been trying for two years [laughs] to try to find the formula (Zelda).

Alala and Aella focused on changing their mindset to manage their symptoms. Alala was distressed about an increased heart rate when cleaning her teeth and decided to try the lightning process.

I think it helped me to learn how to pace a bit and helped me to calm things down a bit (Alala).

Aella tried brain training, which supported the recovery process by shifting thought processes away from the negative and catastrophic to focus on finding solutions and promoting an empowering attitude.

It took some of the fear of relapsing away, cause I think I was going to a negative spiral; you just catastrophize (Aella).

With fluctuating symptoms and learning how to manage them, Alala and Aella learned new skills to adjust and change their mindsets so they could focus on recovery.

For Ragna, mindfulness and being present in the moment helped her to enjoy life. Long COVID had robbed her physically and she did not want to live in fear of another relapse.

I'm just trying to ground myself into that moment just because that's all I can deal with in that time. Everything else, I've got no control over, all I've got control over is my breath at that moment (Ragna).

Ragna had an awareness of focussing on what was within her personal control as she talked about the grounding process.

Summarising this theme, the women found different strategies to manage their relapses and long COVID symptoms. Alternative support such as the low histamine diet, brain training and the lightning process were employed whilst evidence-based practice therapies such as mindfulness gave some relief from symptoms and enhanced the women's coping skills.

MANAGING OTHER PEOPLE'S EXPECTATIONS AND PERCEPTIONS OF LONG COVID

Feeling judged and misunderstood. Family and friends' expectations about the illness contributed to a significant part of the women's lived experience of long COVID. Sometimes this was negatively influenced by a lack of misunderstandings about their loved one's health, and this could lead to a decrease in the women's well-being and mood.

Kelley was supported by her family but received judgements from some friends.

So, I've had friends who have said, mm, I think you just need to get a grip (Kelley).

Aella shared a similar experience losing friends and shared that the relationship with her parents is now

How middle-aged women make sense of managing their long COVID symptoms

very strained as a result of living with long COVID. Aella's father's reaction was quite harsh, *Just get, you know, on, on up and get on with it*. There was a hint of sadness in her voice when talking about her father.

There was a sense of exhaustion and exasperation for Alala as she observed that friends made a lot of assumptions about long COVID and how she should be feeling better. This left Alala feeling a little resentful that her friends did not want to understand the illness, leaving her isolated in a polarizing state of pushing people away but wanting to have company and a conversation.

I have to do such a lot so I can have this conversation with you and not spend a week in in a hell of a lot of pain (Alala).

Ragna stopped talking about long COVID as she found that friends' eyes were glazing over and felt like it was a *token* gesture when they asked how she felt. When attending a funeral, Ragna felt judged as a lady thanked and hugged her for attending the funeral and then explained not to worry as she was fully vaccinated. Ragna responded with, *I'm not vaccinated, oh my God, she repelled from me like I was dirty and unclean [...] it's quite an experience to have*.

Within this theme, the women shared how close relationships affected their long COVID journey as their loved ones' expectations negatively influenced their well-being. The women felt judged by their loved ones' harsh comments and felt this had an isolating impact on their recovery.

Positive and meaningful interactions. For Cahira, meaningful interactions were bittersweet as sometimes seeing a friend reminded her of what she had lost living with long COVID. Although interactions improved her mood, she found that being well enough to do voluntary work made her feel useful again.

Er, so yeah, the more interactions I have, the better (Cahira).

As Ragna described how her life had changed and her ability to conduct daily chores was diminished, she acknowledged the significant impact this had on her husband as their roles had changed. There is a sense of comradery, 'we are in this together', as Ragna shared that her husband gives moral and emotional encouragement.

[...] if I'm having a particularly bad day, he will say to me, come on [...] this is not forever. This is just where we are right now (Ragna).

This theme identified how meaningful interactions positively influenced the women's mood and supported them with making changes to their roles.

THE CHANGING IDENTITY

Mourning the old self. Across the dataset, all women shared narratives about how their lived experience with long COVID had changed their lives. For some

it had helped them to make sense of their health condition by mourning the loss of their old self. Most women shared a loss of identity that correlated with their core role(s) as a parent, partner, employee, and sports enthusiast.

Cahira relied on her husband to take care of her and their children, which made her feel dependent and a burden.

Uh, so as a mother. As an individual, as an independent person. Uhm. I just feel like a like I'm a burden, and I am a burden, but I can't. I can't do my fair share (Cahira).

There was almost a lamenting tone in her voice for everything she had lost, leaving Cahira feeling like a burden to her family.

Alala found that the journey with long COVID had pushed her away from enjoying mountain biking and this was a motivating factor for her to resume the activity.

I just wanna get fit again, cause I was feeling awful. Uh, and I was a mountain biker before all this (Alala).

However, doing something that she loved jeopardised her health.

It didn't really clock for a few months. I'd go for ride and then about 2 hours after the ride, I'd like I just have this complete breakdown. [...] It's like everything, just shut down in me and then I'd have this week of, of hell (Alala).

Like Alala, Kelley was keenly into sport activities, having a home gym where she attempted to do a spinning session, but this resulted in a flare up of symptoms. Kelley was emotional about losing her fitness identity.

[...] but I miss [breaks down crying] I've missed the old me, sometimes. I miss. I miss going to the gym, going swimming. I miss running. Sorry [crying], I don't normally get upset. so, I miss, I miss the old me (Kelley).

Kelley experienced changes to her physical appearance, she lost some hair and this caused much distress when the doctor told her there was nothing that could be done and hopefully it would stop falling out.

[...] I've got a bald patch here and I've got another one here (Kelley).

Aella made a connection to body awareness when reading an Instagram post. The post expressed what it felt like to lose confidence in what your body can do. Aella knew that before long COVID she could push herself hard for a couple of days and then rest over the weekend but now, *I don't feel I've got that resilience anymore*. Her physical and emotional resilience was limited.

This theme provides a brief insight into the loss of identity and how the women navigated their changing roles. The women described how these changes not only affected them emotionally and behaviourally but also prevented them from returning to fitness or engaging in social interactions, often resulting in a loss of confidence.

Hope and gratitude. The women shared a sense of hopefulness about the future and a gentle acceptance of symptoms which was slightly blighted by an underlying uncertainty about the prognosis. Collectively, the women felt deep gratitude for their lives and acknowledged they had so much to be grateful for, including the smallest of improvements.

Cahira felt thankful for the anti-depressant (mirzapine) which helped to settle her into sleep and function more daily. There was a tone of determination in her voice *...for all of this depressing stuff. I have got to keep trying*, and an affirmation of wanting to turn her health around.

Beda had a practical approach to recovery and reflected on how better she felt after a year and aligned this to getting *on with the real world*. She attributed this to not dwelling on the illness all the time and was surprised during the interview how positive she sounded, remarking that it was a *good day today*.

Zelda and Ragna perceived their journey of recovery as a gift from long COVID. For Zelda, there was a chance for a deeper healing, working on past trauma and learning how to take care of herself. There was a sense of a nurturing journey for Zelda as she was *always serving everyone* and through long COVID she had learned to focus attention and energy on herself, *and now my body forced me to say, look, take care of this*.

Luria noticed an improvement in symptoms from how she was feeling a year ago and she felt confident that *once the science catches up* there will be treatment for those who experience long COVID.

Ragna summarised that even though long COVID brings an uncertain future, *it's quite cathartic and quite reassuring that people actually do wanna know what's going on, particularly for research purposes*.

Collectively, the women all shared uncertainty about the future prognosis of long COVID and Ragna echoed this collective consciousness with her poignant words, *What does the future hold for us?*

This theme demonstrates the ambiguity between the long COVID prognosis and the deeply held gratitude and hopefulness the women shared for recovery. The women learned how to navigate their long COVID journey through a lens of gratitude, adopting a practical attitude, perceiving recovery as a gift, interest in research and medication. Although the prognosis and the future are uncertain, the women were flourishing in their newly found skills to manage their long COVID symptoms.

DISCUSSION

Collectively, the women found understanding their long COVID symptoms an ambiguous and often confusing process. Navigating their symptoms daily, the women encountered a health journey of uncertainty.

This led to a loss of confidence in health and body ability, and there was a noticeable change in identity for many of the women (Wurz et al., 2022). Whilst every woman's lived experience of long COVID was unique, there were shared similarities with seeking support along this journey of uncertainty. Inconsistent and invalidating medical interactions disempowered the women, leading them to avoid seeking treatment. This avoidance led some women to an alternative health journey of finding support from long COVID forums and to try holistic treatments such as supplements, dietary changes, and therapy. This health journey, even though it is not clearly defined, empowered the women to make different choices around their health. It created a compassionate space of reflection where the women could mourn their pre-long COVID identity and find some peace and acceptance in their changing roles.

All women gained an insight into the perception of long COVID through the judgements of others. Women often felt stigmatized by the NHS, their families, and friends because there is a lack of awareness about long COVID. Many women have lost friendships, family relationships are strained and some feel less capable as parents, struggling to complete daily tasks. Whilst some women were supported with their fluctuating and persistent symptoms, others encountered indifference, disbelief or discrimination from health care professionals and family members (Rushforth et al., 2021).

Navigating the health care system frequently placed the women in unsupportive consultations which added to the mistrust of medical practitioners, leaving them in a diagnostic limbo (Roth & Gadebusch-Bondio, 2022). In dialogue with clinical health psychologists, Dr Andy Siddaway (2021) confirmed that there is an awareness, information, and bias disparity amongst medical professionals towards those who experience long COVID. Stigma, disbelief and discrimination still prevail in the health care system as many are informed 'it's all in their heads' (Siddaway, 2021). Several women used the term, 'psychological and medical gaslighting' to emphasize this lack of understanding, care, and treatment from medical professionals. Most women were informed by a doctor that they had anxiety, and this finding is consistent with that of Kingstone et al. (2020), whose qualitative research on the long COVID patient's experience of primary care support and treatment corroborates a lack of understanding from medical professionals. These results are in agreement with the findings of Gowda (2022), which identified that long COVID is often described as 'the hidden pandemic,' and in an attempt to understand her own long COVID process, Doctor Gowda explained how ambiguous symptoms were misattributed to anxiety by doctors and this called for the patient's pain to be validated (Gowda, 2022). These findings suggest that best practice is called for

from the medical community to validate the women's pain and symptomology.

Often women would resort to researching and communicating with the long COVID community on social media platforms to find alternative ways to manage their symptoms and have their experiences validated. Community guidance revolves around taking supplements and antihistamines, dietary changes such as the low histamine diet, having spiritual beliefs, mindfulness and cognitive behavioural therapy or counselling. Long COVID can be perceived as an invisible illness and for the women who were disbelieved by family, friends, or doctors, it is comforting that peer support groups can offer hope and validation (Gowda, 2022).

It is encouraging to compare the current results with those of Kingstone et al. (2020), who similarly report in their theme of 'managing symptoms' that participants often managed their symptoms alone without consulting a doctor. The findings of this study identified that a few women praised the NHS and were relieved when their doctor believed them. These results confirm the association with positive doctor treatment as participants in a previous study confirmed that they were listened to by their doctor (Kingstone et al., 2020).

Contemplating recovery brought ambiguity about the future as the women felt a range of emotions from uncertainty to optimism and gratitude. There was a sense of acceptance around the prognosis and for two women, who had started to make peace with their long COVID diagnosis, one conceded that this *could be as good as it gets*. Siddaway (2021) suggests that whilst recovery 'cannot be done to or for someone' with long COVID, some people find their own way of adjusting and others may draw on psychological support to help them cope with the illness. Whilst not all women have fully recovered, they reflected on their journey and celebrated the small improvements. There is a paucity of published data about the prognosis of long COVID and prolonged symptomology, and yet research does indicate a prognosis without further health complications for some long COVID patients (Pavli et al., 2021).

Chronic health conditions can significantly impact an individual's quality of life and place a substantial strain on it (Petrie et al., 2007). As a result of long COVID, the women had to adapt their daily routines and learn new skills to cope with the symptoms. Many women have adapted their lives by using spoon theory, pacing, and resting to manage their energy levels, swapped parenting and daily chore roles with their significant other, reduced work and sports, and integrated mindfulness and therapeutic coping skills into their daily routines.

The common-sense model of self-regulation (CSM) demonstrates how individuals are motivated to problem solve their illness in an attempt to return

to an optimal state of health (Leventhal et al., 2016). The findings identify how the women are motivated to resolve their symptoms by seeking a blended approach of medical intervention and self-managing by adopting a multitude of coping strategies which give some control over the illness. Research suggests that how symptoms are presented in a consultation can affect how individuals are treated by medical professionals (Farquharson et al., 2011). If there is a collaborative understanding of the presenting symptoms between health care professionals and individuals this can influence the care received (Farquharson et al., 2011). Healthcare professionals can provide a more helpful service by collaborating, navigating, and validating the long COVID patients' health care journey.

Some of the women who held negative illness representations (e.g. many symptoms, severe consequences, lack of control and longer timeline beliefs) have a higher probability of future disability and a slower recovery regardless of the severity of the illness initially diagnosed (Petrie et al., 2007). As a result of illness representations, the women who adopted coping strategies and illness seeking behaviours such as attending medical appointments were better equipped to cope with long COVID (Petrie et al., 2007).

STRENGTHS AND LIMITATIONS

The data suggests that many of the women were mistreated and invalidated during medical interactions. A particular novel contribution from one participant highlighted the misogyny of long COVID. IPA as a research methodology can result in an opposition between 'theme' and 'idiography' whereby unique themes seem to be hard to represent unless the research is limited to a single case study (Wagstaff et al., 2014). This finding has implications for health care providers to develop compassionate and validating health care for all women. Long COVID is frequent in younger women, who find it difficult to have their symptoms taken seriously, and this is attributed to misogyny (Gowda, 2022). The findings highlighted how most of the participants, as middle-aged women, did not have their symptoms taken seriously.

A further strength of the research is that it validates the subjective illness experience and health seeking behaviours of women living with long COVID. The research methodology was successful in engaging symptomatic individuals whilst maintaining a robust data collection (Yardley, 2015). Through the use of IPA, the interviews were conducted with a naturalistic approach and degree of flexibility that helped to highlight and interpret the lived experience through careful exploration of every participant's words (Wagstaff et al., 2014). This exploration leads to an emerging

strength of the IPA methodology where the careful engagement of the researcher with the small sample size produces a richly interpreted phenomenological account of participant data (Wagstaff et al., 2014).

As the participants were predominantly educated, English speaking women aged 42-59, the study was limited in racial diversity and socially marginalised underrepresented female voices. The data produced an incomplete representation of the demographic profile of individuals experiencing long COVID due to sampling bias, and this sampling bias in qualitative research can limit a study's generalisability (Oppong, 2013). A possible explanation for this might be the recruitment process of using online forums; therefore this may have excluded some women who may not have had access to the internet. It is possible that these results do not represent all female voices, and to address this bias future research could identify the barriers to access participation so that opportunities are provided for underrepresented females to have their voices validated.

FUTURE RESEARCH

Future research might focus on a longitudinal inquiry to explore the middle-aged women's lived experiences of long COVID as they adapt to physical and psychological changes over a longer period of time. This inquiry could develop further targeted health interventions aimed at supporting the women and the long COVID community. From the analysis, acceptance of the diagnosis by significant others was highlighted as integral to validation and recovery and ongoing support and psychoeducation is required for others to care for those living with long COVID.

As long COVID is heterogenous, a key policy priority should therefore be to plan for the longer-term psychological and medical care of those living with long COVID (Evans et al., 2021). This would lead to providing evidence-based practice and individualised health and mental health treatment pathways if a collaborative approach is taken to develop care in partnership with those living with this illness (Evans et al., 2021). By understanding the holistic experiences of women living with long COVID we may be able to improve the management of illness and the provision of medical intervention.

CONCLUSIONS

A significant question this study has raised is the possible mistreatment of women when seeking medical support and the effect of gender on the treatment of patients. This inequality can lead to stigmatisation and discrimination, which can prevent women from accessing the support they need. The research pro-

vides a way forward for those individuals who live with long COVID, and by activating illness representations they may be able to recover through self-management or a combination of medical, holistic, and psychological treatment.

DISCLOSURE

The authors declare no conflict of interest.

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How middle-aged women make sense of managing their long COVID symptoms

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How middle-aged women make sense of managing their long COVID symptoms