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Experiences of stigma and access to care among long COVID patients: A Qualitative Study in a multi-ethnic population in The Netherlands

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Title: Experiences of stigma and access to care among long COVID patients: A Qualitative Study in a multi-ethnic population in The Netherlands

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Abstract

Long COVID is a post COVID-19 related complication with an undefined aetiology and a diverse symptomatology, which complicates access to healthcare. This qualitative study explored the experience of stigma and access to healthcare by persons with long COVID from the majority Dutch and ethnic minority populations living in The Netherlands.

Between October 2022 and January 2023, 23 semi-structured interviews were conducted with participants of Dutch, Berber/Moroccan Arabic, and Turkish ethnic origins with long COVID living in The Netherlands. Participants were men and women aged 30 years and above. An inductive thematic approach was applied to data analysis using MAXQDA.

Guided by the concepts of stigma and candidacy, the findings are structured according to the broader themes of stigma and access to care. Under stigma, the findings are structured under the subthemes experience of self and public stigma, stigma within the context of healthcare, the role of informal care/support and ethnic differences in the experience or stigma. The findings revealed that people with long COVID suffer self and public stigma resulting from the debilitating illness and symptoms, especially among ethnic minority groups. This experience of stigma persisted within healthcare where lack of information and appropriate care pathways led to feelings of frustration and abandonment. Under the access to healthcare theme, the findings are structured by identification of candidacy and navigation to care, permeability, appearances, and adjudications, and offers and resistance to care. The findings show general difficulties in accessing healthcare for long COVID due to several multifaceted factors related to candidacy. For participants with ethnic minority backgrounds, limited resources and support networks, and language and/or digital literacy barriers further hindered access to care.

The findings call for urgent attention and research to identify and coordinate healthcare for long COVID persons to inform policy makers and practitioners.

Keywords: Long COVID; post COVID complication; lived experiences; Ethnic minority; Migrants; Host population; Access to care; Stigma; Candidacy.

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Key message

What is already known on this topic

Long COVID is a post COVID-19 complication with varied symptoms and scant literature on stigma and access to care from people's lived experiences of long COVID.

What this study adds

Persons with long COVID face universal challenges in accessing healthcare. Ethnic minority populations face additional difficulties due to limited access to information, inadequate resourceful and supportive networks, and pre-existing challenges and inequities in access to health information and care.

How this study might affect research, practice, or policy

Health policy makers and practitioners need to provide accessible, informative, and tailored support systems to facilitate patients' access to information and care pathways for long COVID. Providing tailored information and support and on leveraging social influence and networks is crucial for addressing stigma and facilitating access to appropriate information and healthcare, particularly for persons from ethnic minority backgrounds.

Introduction

The Coronavirus Disease 2019 (COVID-19) pandemic had multiple impacts on people’s health, particularly for persons experiencing long-term post COVID-19 complications (1,2). Literature on COVID-19 and its impact is growing (3–6), but qualitative literature on post COVID complications such as long COVID is limited. Long COVID can affect anyone and at any age regardless of health status (7). Moreover, evidence shows that ethnic minority populations have higher rates of SARS-CoV-2 infection and subsequent hospitalizations in Europe and the United States of America (USA) with a higher risk of long-term health consequences following COVID-19 hospitalizations compared to the majority population (8–14). Recent studies conducted in Canada and the USA further show that non-hospitalized persons who tested positive for SARS-CoV-2 infection were significantly less likely to self-reported long COVID symptoms compared with previously hospitalized persons (15,16). Out-of-hospital populations especially from ethnic minority populations generally have less access to care and rehabilitation programs with scant literature on the role of ethnicity as a risk factor. Addressing the healthcare needs of people with long COVID therefore calls for a comprehensive understanding of the lived experiences of people with long COVID, especially among ethnic minority populations to inform tailored interventions to address their healthcare needs.

Long COVID is a term commonly used to describe symptoms of COVID-19 that persist beyond the acute illness (17). The World Health Organisation (WHO) reports that it occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, who continue to experience symptoms three months after the onset of COVID-19 with symptoms lasting a minimal duration of at least two months, which cannot be explained by an alternative diagnosis (18). Although symptoms greatly differ between individuals, with over 200 reported symptoms with wide prevalence; common symptoms include weakness, general malaise, post-exertional malaise, fatigue and concentration impairment (19–21). Symptoms may be new onset following initial recovery from the acute phase of COVID-19 or persist from the initial illness, fluctuate or relapse over time, and generally impact a person’s everyday functioning and reducing their quality of life (18,20).

Previous studies show that 13.7% of people who had not been hospitalized continued to report complaints three months after testing positive for SARS-CoV-2 and 33-87% of patients who had been hospitalized reported persistent complaints in the United Kingdom (UK) (22–25). For ethnic minority populations living in high-income countries, studies show COVID-19 hospitalised patients with ethnic minority backgrounds are more likely than those of Dutch

origin to report having long COVID; with significant differences in occurrence, nature of symptoms, and duration of long COVID by migration background (8). Another study reported an increased risk of long COVID among ethnic minority populations compared with native Danes in a nationwide register-based cohort study with both hospitalised and non-hospitalised individuals (26). They called for further research to understand long COVID drivers and address care strategies among ethnic minority populations.

Several attributes of long COVID such as its extended duration, the lack of a valid and uniform diagnostic test and effective treatment, renders it a stigma-prone condition (27–30). Research on lived experiences in Italy reinforces the notion that long COVID is stigmatised (31) and a UK study found that 75% of participants with suspected or confirmed long COVID reported often experiencing stigma (32). This experience of stigma can lead to poor health seeking behaviour, which may exacerbate illness particularly for minority ethnic groups, due to aspects related to their identity such as race or ethnicity which can lead to the experience of ‘*double stigma*’ (27,31–33). *Stigma* is a discrediting quality, which diminishes the status of an individual (34) and occurs in social interactions. It is therefore an entirely socially constructed with multiple manifestations such as public stigma, self-stigma, and structural/institutional stigma (*Section A of Box 1*) (34–36). The fear of stigma is worsened by implicit biases within healthcare and social systems, which place minority ethnic groups at a disadvantage in accessing and receiving quality care (37).

Box 1: The concepts of Stigma and Candidacy	
Concept/Stage	Definition
A. The concept of Stigma	
Public stigma	Refers to the social and psychological reactions towards individuals with a stigmatised condition or attribute.
Self-stigma	Refers to the social and psychological impact of having a stigma and encompasses both the experience and anticipation of encountering stigmatizing behaviour (felt stigma) and the diminished self-worth and feelings of shame that often accompany a stigmatizing condition (internalized stigma)
Structural/institutional stigma	‘Legitimization and perpetuation of a stigmatized status by society’s institutions and ideological systems (39).
B. The Candidacy concept	

Stage	Description
1) Identification of candidacy	How individuals decide their symptoms require medical attention
2) Navigation	knowledge of and ability to gain entry to appropriate services
3) Permeability of services	ease of entry into the health system determined by factors within this system, such as cultural alignment or the availability of care pathways for specific conditions
4) Appearances at health services	Process of asserting candidacy during interactions with health professionals
5) Adjudications	Professional judgement about an individual's candidacy, influencing subsequent treatment
6) Offers and resistance	follow-up services may be accepted or rejected by the patient depending on their appropriateness
7. Operating conditions and the local production of candidacy	Locally specific factors that influence interactions between patient and healthcare professional and develop over time
Sources: References 34-41	

Moreover, access to care influences an individual's ability to effectively utilise health services or informal care and encompasses both supply and demand factors (38). It is influenced by the concept of *Candidacy* which is a dynamic process of seven stages (Section B. Box 1) by which people determine their eligibility for health services, through continuous negotiations with their healthcare professionals (39–41). The candidacy model is particularly useful for exploring and understanding how vulnerabilities arise in relation to healthcare access, and how these are influenced at multiple levels and differ between groups and across multiple intersections (40,41). The situation may be compounded for persons less familiar with health services, especially among ethnic minority populations where health literacy is generally lower (39).

This qualitative study therefore draws on the concepts of *stigma* and *candidacy* (33,38) to explore people's lived experiences on long COVID particularly focusing on the experiences of stigma and access to care. It further aims to provide insights into the experiences of ethnic minority populations in comparison with the majority (Dutch) population living in The Netherlands.

Methods

The study utilized a qualitative approach to conduct semi-structured interviews using questions and prompts originating from the theoretical framework on stigma and candidacy (41,42) to guide participants in narrating their illness and patient journeys. This was useful to enable participants share their illness experiences and touch on sensitive illness experiences while allowing the researcher to explore known and unexpected outcomes (43,44).

Study population

Persons with confirmed initial SARS CoV-2 infection by means of Polymerase Chain Reaction (PCR) or antigen testing (self-testing), who continued to experience more than one symptom three months after the onset of COVID-19, lasting for at least 2 months (39), and for whom such symptoms had an impact on their daily lives were included. Persons with differential diagnosis (not SARS CoV-2 infection) or symptoms were purposively excluded. Persons with Dutch, Moroccan and Turkish ethnic origins were purposively included, as they were among the most affected groups, by SARS CoV-2 infection in the Netherlands (8). Identification of ethnic origin was done based on the classification system of Statistics Netherlands, i.e., persons are considered of Dutch origin when they and both their parents are born in The Netherlands while persons are considered to have a Turkish or Moroccan origin if they, or at least one of their parents, is born in Türkiye or Morocco (45). In, qualitative research, sample sizes are guided by the principle of saturation (43,44,46). As such, to ensure variation in ethnic origin, gender, educational level, migration status, and Dutch language proficiency towards reaching data saturation, a purposive sampling approach was used to include a minimum of twenty (20) participants.

Setting and Recruitment

Study participants were recruited using two approaches. First, they were recruited from among persons with long COVID registered with the C-support foundation in the Netherlands. C-Support is a state-financed organization that provides free information, guidance, and advice to patients with long COVID, across the Netherlands (47). Persons with long COVID registered with C-support were approached by C-support via email containing study information and asking their interest in participating in a scientific study. For interested persons, C-support, requested permission to share their contact details with the research team. The shared first author (MT), contacted potential participants (n=20) by phone to check eligibility criteria (Box 2), introduce the research and research procedures, and answer questions from potential

1
2
3 participants. Once eligibility and willingness to participate were established, a date, time, and
4 place were scheduled for semi-structured interviews to be conducted (n=20). Secondly, two
5 Research Assistants (RAs) with
6 Turkish, and Berber, Moroccan
7 Arabic language proficiency who
8 had access to Turkish and
9 Moroccan communities
10 approached nine persons with
11 long COVID with limited Dutch
12 language proficiency who were
13 not registered with C-support.
14 These persons had previously
15 attended community education
16 sessions on COVID-19 at two
17 Mosques. Seven of the nine
18 persons were then included after
19 establishing eligibility and
20 willingness to participate. Out of the total of 27 participants eligible
21 and willing to participate, four persons withdrew due to increased burden of their long COVID
22 symptoms (n=2); family circumstances (n=1); and concerns regarding audio recording of the
23 interview (n=1), resulting in a study sample of 23.

24
25 To facilitate participants,' recall efforts during the interview (48), participants were asked to
26 develop a timeline, marking the onset of their symptoms, interactions with the healthcare
27 system, meaningful experiences, etc prior to the interview. All participants were sent a text
28 message via mobile phone the day before the interview to confirm the appointment and ensure
29 their health allowed for the interview to take place. Post-interview, all participants again
30 received phone text messages to check-up on any health impacts experienced following their
31 interviews. No concerns were reported by participants. Subsequently, all participants received
32 a reimbursement (€15, - gift card) for their participation.

33
34 **Data collection**
35 Interviews were conducted between October 2022 and January 2023. Out of the total of 23
36 individual interviews conducted, 20 interviews were conducted face to face (at participants'
37 homes), while three interviews were conducted online using video conferencing software. MT

Box 2: Inclusion criteria		
Question	Response	Action
When was your initial COVID infection?	Date	
Do you continue to have any symptoms?	Yes/No	If No - exclude If yes- ask next question
Do your symptoms bring about a significant change in your daily functioning with regards to housekeeping, care, studies, or work, and/or affect interpersonal relationships?	Yes/No	If No - exclude If yes- include

conducted seventeen interviews in Dutch, while RAs conducted three online interviews each in Berber, Moroccan Arabic, and Turkish. A semi-structured interview guide, which included questions on access to care and the experience of stigma originating from the theoretical framework on stigma and candidacy (35,38,40) (Supplementary File 1) was used for all interviews. RAs translated the interview guide into Berber, Moroccan Arabic, and Turkish.

Interviews lasted between 45-90 minutes, were audio recorded with participants' consent and transcribed verbatim into Dutch. Interviews conducted in Turkish, Berber, Moroccan or Arabic were transcribed and translated into Dutch by the RAs. A 1–2-page summary of the transcript was shared with each participant, accompanied by a follow-up phone call to discuss the summary with participants. Given the considerable amount of heterogeneity within the sample, twenty-three interviews enabled us reach saturation with no repeat interviews conducted.

Data analysis

Transcripts were coded and analysed using a thematic approach in phases to create meaningful patterns (49). These phases were familiarization with the data, generating initial codes, searching for themes, reviewing themes to explore commonalities and differences, defining, and naming themes, and producing the manuscript (49).

Transcripts were coded using MAXQDA 12 (maxqda.com/help-max20/welcome), a qualitative data analysis software. MT developed the initial coding framework based on the research question and theoretical framework. MT and Nazli Lale-Kahraman (a junior researcher) both coded, compared, and discussed eight transcripts using the initial coding framework, which was revised to include inductive codes emerging from the transcripts. The final coding framework was then used by MT and NH to code all remaining transcripts. MT inductively generated initial themes from the coded data and discussed and revised them with EB to explore commonalities and differences between ethnic minority groups and the majority (Dutch) population.

Patient and public involvement (PPI) in research

Box 3 provides a description of PPI activities.

Box 3: Patient and public involvement (PPI) in research	
Activity	Response

Stage in the research process were patients/the public first involved in the research.	Patients were contacted by C-support on behalf of the research team and study participants who consented to participated and were eligible to participate where involved in the data collection and member checking of transcripts.
Research question(s) and outcome measures developed and informed by their priorities, experience, and preferences.	The research question was developed and informed by the scant literature that existed on long COVID as an emerging public and global health challenge. Team members' discussions (both formal and informal), surrounding peoples' experiences with long COVID, informed and prompted the need to further explore the issues surrounding stigma and access to care for long COVID from the perspectives of persons living with long COVID.
Patients/the public involvement in in study design.	While patients and the public were not implicitly involved in the design of the study, it was the experienced difficulties of known people living with long COVID that aided the design of the study. The study aimed to give voice to persons/people with long COVID, to share their experiences accessing healthcare for a novel condition to inform health policy and practice.
Involvement in the recruitment to and conduct of the study.	Persons with long COVID were contacted by C-support and based on their response, their details were shared with the research team who contacted them to establish eligibility and willingness to participate.
Patient assessment of the burden of the intervention and time required to participate in the research.	All study participants received a participant information sheet containing details of the research including how much time was anticipated that they would spend in the interviews. A member of the research team also phone called each participant to further discuss their concerns and answer any questions arising from the participant information sheet and participation in the research.

Patient/public involvement in dissemination of study results.	C-support is a Dutch Ministry of Health, Welfare, and Sports commissioned foundation, which functions as an informal national registry of persons with long COVID in the Netherlands providing support and advice to persons with long COVID and sharing emerging knowledge on long COVID with other (healthcare) professionals will disseminate the findings with and to long COVID patients)
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Ethics approval and consent to participate.

The medical ethical committee of the Amsterdam University Medical Centres /University of Amsterdam declared this study as nWMO, according to the Dutch Medical Research Involving Human Subjects Act W22_198 # 22.246 (<https://wetten.overheid.nl/BWBR0009408/2022-07-01>).

Conducted in accordance with the CONSORT criteria for Reporting Qualitative research (COREQ) Checklist (Supplementary File 3), this study also obtained written and/or oral (recorded) informed consent from all participants.

Results

Participant characteristics are presented in Table 1. The results are presented under two main themes arising from the conceptual framework with sub-themes and emerging codes. Selected are embedded in the results and additional participant supporting quotes labelled Tu (Turkish), Mo (Moroccan) and Du (Dutch) are also presented as Supplementary File 2.

Table 1: Participant Characteristics	
Characteristics	Number
<i>(Ethnic) Background (1st)</i>	
Turkish (Tu)	9 (7 (first generation))
Moroccan (Mo)	7 (5 (first generation))
Dutch (Du)	7
<i>Gender</i>	
F	18
M	5
<i>Age category</i>	
30-39	4
40-49	5
50-59	10
60-69	3
70-79	1
<i>Educational level</i>	
Higher educational level (HBO/WO:)	9
Mid educational level (MBO2 t/m MBO4)	8

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Low educational level (MBO1, VMBO, onderbouw HAVO/VWO (CBS categories))	6
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Stigma

Participants from both the majority (Dutch) population and ethnic minority groups reported that the initial understanding and empathy for their illness atrophied over time as they relapsed or continued to experience long COVID symptoms.

The experience of public and self-stigma

Participants experienced public stigma mostly in the questioning of their long COVID symptoms during social interactions with other people, often feeling and being referred to as a 'poser' (Dutch: aansteller) and receiving unsolicited advice on the causes and solutions for their symptoms.

"I notice that in the beginning everyone was understanding, but as it takes longer the understanding diminishes. And then, yes, the understanding diminishes, and then maybe they think you are doing it on purpose, or there's something else going on... Among colleagues, or friends, then one says maybe you have burnout, maybe you are depressed, then you get that kind of thing. I feel like everyone just says things." **Participant 6 -TU**

Regarding self-stigma, participants reported experiencing a loss of identity and purpose that contributed to lower self-worth and feelings of depression. Only a few participants, reported finding meaning in their illness through their contribution to research or perceiving their illness as a test of their faith, which protected them from feelings of low self-worth. While most participants reported this self/internalised stigma, they did not report any anticipation of encountering stigmatizing behaviour (felt stigma).

Participants reported variations in the severity and variety of debilitating long COVID symptoms they experienced, which caused them to feel low self-worth. They explained that their symptoms caused prolonged absences from work and family life, causing them to experience feelings of guilt and shame and at times, fear of being seen as using their ill-health as an excuse to not work or contribute to the family. An ethnic minority participant shared that such feelings were worsened by the experience of strong socio-cultural norms regarding family responsibility within their communities.

"I think you have..., lost your dignity, your independence, but also that at some point you can no longer take care of your family. And I'm not talking about the financial stuff, but the attention to your kids, a little bit of homework, the worry, reading letters to them ... Yes you have lost your pride. You are a man.... you are just talking about the Moroccan community, and the Turkish community, but I don't want to say that it is very different from the Dutch community. I think that every head of the house, whether it is a man or a woman, that it is the same for a woman who is single with the children." **Participant 4 -MO**

Stigma within the context of healthcare

Among most participants, lack of information on long COVID generally and from healthcare professionals, attitudes of healthcare professionals, and lack of available care pathways and treatments for long COVID contributed to feelings of abandonment by the healthcare system.

"The frustrating thing was that I was already struggling with word-finding problems. I already had a haze in my head, ... with my last bit of energy, I drag myself over there [GP] to go and sort something out and then it felt like the door is then slammed in front of your face..." **Participant 7 - DU**

Some participants reported that the multiple and severe symptoms, they experienced, without a clear cause resulted in some healthcare professionals assuming a psychological origin/cause for their symptoms. Others, who (already) experienced other health problems, did not feel their long COVID complaints were taken seriously by healthcare professionals, making them feel frustrated.

The role of informal care/support

Participants reported that contact with other persons with long COVID, for example, via (online) support groups made them feel recognized and reassured as persons in those groups recognised their symptoms and challenges which helped alleviate their experience of stigma. They mentioned that they also received information on long COVID healthcare pathways and options available..

"I was really in a dip about myself, is this really corona or something else? But by reading the messages and the stories of those people, that's where I had the most support, this whole long period. Because there were similarities of what you have and them. Then you think "oh, it's real," and several people have the same symptoms, like mine then." **Participant 14 -MO**

Ethnic differences in experiences of stigma

While the experience of stigma did not differ greatly between ethnic minority participants and Dutch participants, two ethnic minority participants reported difficulties accessing care which they related to their ethnicity. A participant explained that whilst proficient in the Dutch language, a speech impediment was one of his/her long COVID symptoms, which resulted in her/him sounding 'like a migrant' and hindered his/her ability to efficiently communicate in Dutch verbally. Another participant felt that the care s/he received from C-support made her/him feel heard, understood, and cared for in comparison with the care received from the general practitioner (GP). When explicitly asked about the experience of double stigma, however, most ethnic minority participants rejected the notion of being stigmatised because of their ethnicity.

"I'm not going to say it's because of my background, you'll never know. ... the first time I got sick, and I had gone to the hospital, then I did feel it... it was just a quick fever reading.... But after that, by C-Support, for example, you're by phone, you did feel understood and that you were listened to.... I really don't dare say it... I don't want to think about them knowing that I'm 'Mocro' ... I'm wearing a headscarf outside.... you can't do anything about it."

Participant 14- MO

Access to care

Identification of candidacy and navigation to care

Participants generally identified their complaints as requiring medical attention and consulted their GP early on (within two to four weeks) after their initial COVID-19 illness. For many participants, the identification of candidacy halted with the GP services, where they were advised to wait out the progression of their symptoms, often, because little or nothing was known about appropriate care pathways for their illness. As a result, some participants reported that when they were eventually referred for specialist services which were not covered by health insurance after the maximum number of consultations eligible for reimbursement, they incurred significant financial costs to access healthcare.

After repeated, and often frustratingly fruitless visits to the GP, some participants reported refraining from seeking care. Some ethnic minority participants expressed frustration with the bureaucratic nature of the healthcare system, compounded by limited Dutch language proficiency which further complicated their navigation to healthcare. Non-Dutch speaking participants shared that they depended on their children to schedule their GP appointments

and to serve as translators during their GP appointments. Several participants reported that they experienced social isolation, exacerbated by their debilitating long COVID symptoms, which further complicated their access to healthcare services. They reportedly succumbing to inadequate care, accepting symptoms, and experiencing little control over their situation.

"After 2 months I was still not the same, I had no strength in my legs, I couldn't concentrate for a very long time after that either and became forgetful... I don't have the strength anymore and no desire to do anything, I get tired easily... I don't know why the symptoms last so long...I go to the family doctor, but she can't give me anything, so I didn't go back."

Participant 25 - TU

Having to find information on their illness themselves exposed participants to potential misinformation and disinformation, mostly electronically and via social media. While most participants found access to the appropriate information for their illness difficult regardless of Dutch language proficiency, some ethnic minority participants further expressed concerns for other members of their communities who had little or no Dutch language proficiency. They explained that for such community members who are challenged by language barriers, access to information on long COVID is limited during encounters with their GPs, resulting in gaps in information received from GPs. They added that even when information is available digitally (such as by C-Support), access to that information is further obstructed for migrants such as older migrants who might not be literate or digitally literate.

"The way they had it set up, you have to log in.... you have to be fairly self-reliant, if you want to know the system and log in and then make an appointment, you have to do all that yourself...they have one of those digital systems that you can only register with your DigiD. So, I think my mother-in-law can't do all that. ... because she's just not digitally savvy, if you're not self-reliant, or you're not digitally savvy... But suppose I hadn't known the way well either, then you do find yourself in a sort of 'loop' with each other, of how to find the right care." **Participant 11 - TU**

All participants expressed disappointment that GPs could not provide more direction to finding the cause or treatment for their illness. While participants were primarily responsible for navigation to appropriate care, there were great variations in the action's participants were able to undertake themselves, which related strongly to their social networks. Most participants regardless of ethnicity reported relying on their social networks to identify and access

information and care for their illness and symptoms. Most participants requested organised support in coordinating and navigating to care to improve care for long COVID. Dutch speaking participants also shared that C-support helped direct them towards care, informing them on specific requests for referrals, or available care within the vicinity of their homes. They mentioned various ways that enabled them access C-Support as they relied on social networks and digital literacy skills to be directed to C-support. Ethnic minority participants who could not sufficiently communicate in Dutch or had limited digital skills reported not being aware of C-Support.

"And then someone in my network who had contact with his physio practice with a number of physio practices in other countries ... And his friend is a good friend of mine, and she said "hey, go talk to my friend." His is very similar to that.. I did google, what could this [long COVID] be? ... I don't know if my own GP had that knowledge at that time.... It was all so vague. So, I made an appointment with him [friend referral/health professional], sat down, explained my symptoms. And then he told me of well this is what we see, when people try to build up [recover], relapse ... I think, "yes, this is it," I recognize myself in this." **Participant 7 - DU**

Only four participants (P3,8,15,18) reported having had access to a clear care pathway early on, i.e., timely referral to long COVID rehabilitation for primarily physical therapy and occupational therapy from their GPs or company doctors. They explained that this was mainly dependent on their GPs' awareness of current COVID related issues and pro-activeness in accessing information to support them.

Permeability

In The Netherlands, GPs function as the main gateway to care with most participants identifying several factors that complicated their ease of entry to accessing healthcare via the GP [see (50) for a description of Dutch system].

For several participants, employment provided an opportunity to enter the healthcare system. They explained that after a few weeks of absence from work due to illness, a company doctor (who looks specifically at the work environment, potential reintegration and is in contact with the GP only with the consent of the employee) attended to them which provided an opportunity to be heard and hear about long COVID, diagnosed and referred for rehabilitative care. They noted that company doctors were more influential and could direct them to healthcare and

advocate for longer recovery time from employers. While some participants added that the company doctor's diagnosis of long COVID immensely relieved them, a few others reported that ill-informed company doctors hampered their access to care and recovery time.

"I'm still very happy with my company doctor... I started seeing the occupational therapist, which has done me very well. And I was able to take myself seriously and I finally I thought that I can just be sick... the GP can't do very much for you... he doesn't have that much influence on you, on your work situation but the company doctor does.... my second company doctor did take me seriously, and confirmed that whole long COVID 100%, she said no doubt about it, you just have long COVID... I remember sitting there with her, I think I used up a whole box of tissues... she also knew a lot about long COVID, and that was also very nice." **Participant 18 - TU**

While participants expected their GPs to be the connecting and coordinating link in all their treatments and care appointments, substitute GPs were regarded as being less informed regarding long COVID and less responsive to addressing their long COVID symptoms. Participants felt this affected the quality of healthcare they received. They indicated that they sometimes felt less confident to speak up or demand care because of a lack of familiarity with substitute GPs which, added to limited consultation time, did not allow for familiarity and a comprehensive discussion of their multiple and varied symptoms.

"Unfortunately, my own family doctor was not there. So, another GP explained what was there. And he also started telling me things about long COVID, all of which I already knew. Because by then I had already started at [name rehab centre], June 20 (or July) I had this feeling that he had just learned something about long COVID... I just didn't think it was good care...." **Participant 17 - MO**

Most participants mentioned that double GP appointment slots did not provide sufficient time for consulting on their multiple symptoms with some of them suggesting that their symptoms may not have been taken seriously resulting in fewer referrals for specialist healthcare. Particularly for ethnic minority participants, although they expressed understanding of this set-up, this characteristic of the Dutch health system frustrated them, prompting them to contemplate seeking healthcare in their home countries or other less restrictive countries. An ethnic minority participant added that the restrictive nature of the Dutch health system meant longer waiting times despite the high cost of health insurance.

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3 *" The Netherlands is a good country, all tightly regulated, we pay VAT for it*
4 *too, all that insurance. But bureaucratic as hell... I sometimes go to a doctor*
5 *in Morocco, because if I have something, yes, it's not top notch, but when I*
6 *go, they can check right away. And here you have to be referred three times*
7 *then you have to wait 6 months if you're lucky. But you do pay every month,*
8 *my wife and I, €400.00 a month for the insurance. And then you have to*
9 *beg for a CT scan, ... Because in Belgium you're faster in that respect too,*
10 *in France too, in Spain too. It's only here."* **Participant -4 - MA**

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17 Another ethnic minority participant explained that because the demography of a
18 neighbourhood determines the expertise that is available at the GP, at GP
19 appointments, some health professionals presume that they cannot communicate in
20 Dutch, or they are not born in the Netherlands, which influences how they behave
21 and act towards them. The participants therefore felt such care was not tailored to
22 suit their health needs. Especially for participants who got ill early in the pandemic,
23 knowledge of their GPs and other healthcare professionals on long COVID was key to
24 facilitating access to care.
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31 *"The treatment towards patients did change, yes.... migrant background,*
32 *they may also be, say, 3^d or 4th generation. not everyone who comes in here*
33 *was born abroad or speaks poor Dutch... You feel that in the treatment, how*
34 *people talk to you, the behaviour of the people who work there. ... things*
35 *like that are signals of I need to change GPs...maybe I don't fit into the*
36 *target group of that general practice anymore."* **Participant 6 - TU**

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42 Most participants reportedly organized care for long COVID themselves by exploring
43 possibilities for care electronically prior to visiting their GPs to ask for a referral. Participants
44 referred for long COVID rehabilitation therapies such as physical therapy, occupational
45 therapy, and speech therapy experienced challenges with coordination of their healthcare. A
46 few participants who had been referred to various healthcare specialists reported feeling
47 discouraged by the lack of follow-up appointments from healthcare professionals or specialists.
48 While Dutch-speaking participants reported been referred for different therapies, most
49 participants with limited Dutch communication proficiency reported less contact with the
50 healthcare system. This implies entry barriers, as most of the non-Dutch speaking participants
51 had only seen their GP with only a few of them been referred for the physical therapy
52 trajectory.
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Appearances and adjudications

When interacting with healthcare professionals, many participants shared having to advocate for themselves to get healthcare but often felt uncomfortable/unable to do so. Consequently, participants' views regarding healthcare professionals' judgement about their candidacy, influencing subsequent treatment for their illness, differed considerably. Ethnic minority participants with limited Dutch proficiency, reported being less able to clearly describe their symptoms, and access referrals to healthcare, and depending on informal translations. They reported self-medicating to manage their symptoms while depending on family members with Dutch proficiency to advocate for them to access healthcare for their symptoms.

Similarly, Dutch-speaking participants also shared experiencing difficulties with asserting candidacy, especially when they were not equipped with information and sought direction from healthcare professionals on how to manage their symptoms. They reported that their symptoms limited their physical abilities and capacity to assert themselves during interactions with healthcare professionals.

"I was not taken seriously. Because long COVID that was nonsense, the family doctor said that was nonsense, he referred me to the physio and the ergo, well they didn't do anything either. He was very negative... I didn't know it myself, my surroundings didn't know it, and I thought myself am I posturing?... No, and I didn't have the knowledge, I didn't have the energy."

Participant 18 - TU

Some participants explained that they were not referred for any therapies by their GPs because of limited evidence-based solutions at the time and/or did not have adequate knowledge about long COVID symptoms and care pathways. Some participants who received referrals mentioned that these therapies did not often significantly address their symptoms. Adjudications did not differ by ethnicity or ability to communicate in Dutch.

For participants who faced such challenges and were aware of C-Support, C-support equipped them with information on specific requests for referrals they could make.

"And then I got to C-Support ...I called them, I had an application there, and this lady who called and she knew exactly... I said, what I was going through, and she had looked up a report, she said show this report to the GP."

Participant 12 - TU

Offers and resistance.

Some participants reported incurring additional healthcare costs when they had exceeded the deductible allocated for their health insurance. Other participants explained that despite having health insurance, they had incurred additional costs for specific referral treatments for their symptoms, which had not been reimbursed. Other participants reported inadequate information about continuing treatment options covered by their health insurance which resulted in them incurring additional costs due to gaps in treatment.

"When I joined C-Support, I had already passed half a year. Because I was not reimbursed for physiotherapy. ..., I went to the doctor, who then didn't think maybe physiotherapy would be useful, and nothing else was followed up...they said at C-Support, well it might be possible if you write a letter."

Participant 11 - TU

Some participants felt that the care they received did not appropriately address their symptoms and needs as they did not feel strong enough to return to their normal duties when they were discharged and often experienced a flare-up of their long COVID symptoms. This resulted in them seeking healthcare all over again. Some participants expressed frustration with the limited healthcare professionals' expertise regarding their illness and the inadequate coordination of care strategies to manage their symptoms. While some participants reported being misdiagnosed, others reported counterproductive effects of some of the therapies they received. These experiences were reported among all ethnic groups.

Discussion

This study draws on the concepts of *stigma* and *candidacy* (30, 32) to provide insights into the lived experiences of people with long COVID with a focus on stigma and access to care from the experiences of both the ethnic minority populations and the majority (Dutch) population in The Netherlands. The study findings show that participants suffer self and public stigma resulting from the prolonged experience of debilitating symptoms. This experience persists in the context of healthcare where lack of information and appropriate care pathways led to feelings of frustration and abandonment. Moreover, participants experienced general difficulties in accessing healthcare resulting from several multifaceted factors related to candidacy. For ethnic minority populations, these challenges were further complicated by limited Dutch language proficiency and digital and/or health literacy.

The findings show the varied symptoms of long COVID and the challenges managing these symptoms made the participants feel misunderstood and afraid of being perceived as

pretending. Although they did initially attract public empathy, this atrophied over time contributing to the experience of public stigma when symptoms persisted or reoccurred. These challenges lead to feelings of isolation and depression, which can facilitate self or internalised stigma, particularly among ethnic minority populations where cultural norms surrounding responsibility led to feelings of shame and guilt. Similar findings have been reported in other studies where the perceived inability of people affected by long COVID to effectively manage their symptoms or reduce severity of their symptoms resulted in all forms of stigma (27,31,32,51).

In the candidacy framework, the process of determining eligibility for health services is for individuals to decide if their symptoms require medical attention followed by navigating to care, which requires the knowledge and ability to enter appropriate services (30). Given the strong relationship between health-seeking behaviour and confidence in self-diagnosis (40), individuals' identification of candidacy for long COVID may be impaired due to the lack of a clear illness trajectory and definition of the condition (52). When study participants identified that their complaints required medical attention, their first point of care was their GPs or in some instances, the company/work healthcare professionals (identification). Subsequently, the lack of a proven treatment method (30) and well-defined care pathways (28,29,52) halted the process of establishing candidacy for care (navigation). The ease of entry into the health system was further complicated by alternating GPs and limited time for consultations (a general practice of the Dutch healthcare system), which hindered familiarity and strong patient-provider relationship to address the varied and multiple symptoms (permeability). In addition, symptoms such as 'brain fog', a common symptom of long COVID and characterised by difficulties with executive function, memory, and communication (52) impinged on individual's ability to accurately portray their symptoms and illness experience during encounters with health professionals thereby reducing their ability to assert candidacy (appearances) and have this validated (adjudications). This has crucial implications for long COVID care access and acceptance of follow-up services or referrals to appropriate care (offers and resistance). Especially for ethnic minority participants who could not communicate in Dutch, "brain fog" and the novelty of their symptoms exacerbated difficulties to clearly describing their symptoms, request for or get referred to care pathways, requiring them to depend on family members to advocate for their care with implications for patient privacy. This challenge in communication particularly in limited or no national language proficiency was highlighted in a review on vulnerable groups and their access to healthcare in the UK (53). This situation is potentially worsened when people are less familiar with health services and

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3 have lower health literacy rates such as among some ethnic minority populations (39). This
4 dynamic process by which participants determined their eligibility for healthcare services,
5 through continuous negotiations with their healthcare providers highlights how vulnerabilities
6 in accessing healthcare arise, are influenced at multiple stages, and differ between
7 populations. This emphasises the crucial need for accessible, informative, and tailored support
8 systems to enhance access to information and care pathways for persons with long COVID
9 and inform the public about current iterative evidence on long COVID and care.
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16 Within the conceptual framework, upon entry, access is affected by the process of asserting
17 candidacy during interactions with health professionals (appearances) and professional's
18 judgement about candidacy, influencing subsequent treatment (adjudications) (39). While
19 there were few reported overt experiences of double stigma and or differential treatment
20 based on ethnic minority background in this study, a general awareness of their minority
21 position caused some ethnic minority participants to voice suspicions of differential treatment
22 when they were not met with appropriate care. Validations of candidacy by healthcare
23 professionals are partially influenced by socially constructed notions about which patients are
24 most likely to respond well and thus 'deserve' treatment as 'ideal candidates' (38,41). This ties
25 into the concept of stigma, as stigmatised individuals are less likely to be perceived as the
26 'ideal candidate' due to public stigma surrounding their identity. Thus, healthcare professionals
27 need to recognise and address biases and inequities, especially among ethnic minority
28 populations who may face implicit healthcare and other social biases in accessing and receiving
29 quality care (37,39). Such implicit biases could adversely facilitate the experience of stigma
30 particularly for long COVID participants from ethnic minority populations (54). In addition,
31 while the findings show general difficulties in accessing care due to the lack of well-defined
32 care pathways for long COVID, ethnic minority participants mostly appear to face additional
33 difficulties such as limited access to information and resourceful and supportive networks,
34 which compound existing inequities (55).
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49 Personal relations or acquaintance with healthcare professionals were found to be key sources
50 of information, access, and referral to appropriate care sources outside of formal care
51 pathways for long COVID participants. While the influence of social networks on peoples'
52 access to health information and navigation to care is commonly reported among ethnic
53 minority populations (55), in this study, both ethnic minority and the majority populations
54 utilised their social networks to facilitate candidacy and navigate access to care for their long
55 COVID symptoms. Studies highlight the role of social networks and connections on health and
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social identity, which can potentially influence peoples’ beliefs and health-seeking behaviour (27,42), which can shape candidacy and access to care. While the complexity, and limited evidence on long COVID, resulted in both healthcare professionals and participants being poorly informed on long COVID, other resourceful and informal networks provided an avenue to access information and care pathways for long COVID symptoms. This placed an immense burden on participants particularly in the face of their long COVID illness and potentially led participants to access inappropriate information and care strategies to manage their symptoms with critical impacts on their current and future health conditions. The importance of social connections and networks was particularly more obvious as non-Dutch speaking, and more socially isolated participants experienced greater difficulties in navigating care within the Dutch health system. Consequently, social networks facilitated access to information sources such as C-support, which provided support and advice for long COVID. Some study participants were thus informed about C-support, which was helpful in equipping them with long COVID related information such as specific referral requests to make from their GPs. This enabled participants better advocate for appropriate care and support for their illness. This emphasises the role strong social or professional networks can play on participants’ ability to assert candidacy in encounters with healthcare professionals in navigating access to care.

Furthermore, other factors surrounding the organisation of GP practices in the Netherlands, such as frustration with limited time of GP consultation, feeling misunderstood, perceived inadequate capacity of health professionals, and the lack of familiarity with their replacement GPs further influence permeability. In the Dutch healthcare system GPs are the gatekeepers to healthcare (50), functioning as key entry points, which requires, time, trust, and building strong relationships with participants to ease entry into the healthcare system. Consequently, GPs can also facilitate social support for long COVID through sensitisation programs to mitigate potential related stigma within the healthcare system and society. Other studies have also highlighted the importance of time, trust, and building relationships between patients and GP services within the context of complex interventions to improve healthcare access (56,57). Health professionals therefore need to be abreast with evidence-based long COVID related information as it emerges, to provide the right direction to appropriate care and better support persons with long COVID. Particularly for ethnic and minority study participants, these challenges are further complicated by Dutch insurance costs and comparisons of the Dutch health system with other less bureaucratic health systems in neighbouring countries or their home countries and pre-existing barriers to accessing healthcare services such as language, literacy, and digital literacy barriers. Specific healthcare professionals such as nurse

practitioners could be trained as case support managers for long COVID, providing longer consultation times and building relationships with them to provide practical support to navigate and access appropriate care.

Moreover, the findings highlight the need to leverage on social connections and networks to prevent and address stigma surrounding long COVID towards improving healthcare access to information and care through community sensitisation to facilitate patients' candidacy in accessing care. Next, like other studies (58,59), centrally structured multidisciplinary medical care could provide support in navigation and coordination of care to improve clinical outcomes. While organisations such as C-support support patients navigate to care, providing a central care point of contact for long COVID linked to the GP system could address inequities in access to long COVID information and care.

In addition, although C-support provided information and directions to care, the findings show that most non-Dutch speaking participants recruited outside of C-support were not familiar with C-Support. This shows the critical role that communication particularly in the host country's language and digital literacy play on access to health information. Patient organizations (both formal and informal) could be leveraged to reach and support sub-population groups by offering language and culturally concordant long COVID information and support which may incrementally improve access to information and care among ethnic minority groups. In addition to growing calls for establishing nationwide registers of people with long COVID (53), collecting data on the lived experiences of various sub-populations could inform health policy and tailored implementation to improve access to long COVID care especially for ethnic minority populations.

Strengths & limitations of the study

The study population might not be representative for the larger population with long COVID, due to debilitating illness and language barriers. However, a key strength of this study was that, using multiple modes of recruitment such as through C-support, mosques and previous attendance at community sessions, the research team was able to identify and reach study participants and follow up on the health of participants during and after study participation. The inclusion of both majority and minority participants i.e., Dutch, and non-Dutch, further strengthened the study although inclusion was restricted to two minority populations in the Netherlands.

Second, most study participants were recruited from C-support foundation, which is state-financed organization that provides free information, guidance, and advice to patients with long COVID, across the Netherlands. This requires some language and digital literacy skills, which can be challenging for persons from low SES and with low literate and/or digital skills such as older ethnic minority populations, which limit the generalizability of the findings. However, to minimize this, we additionally recruited more study participants from persons who had attended previous COVID-19 community education sessions and through two Mosques.

Additionally, although the sample was sufficient for reaching data saturation, it may not capture the full range of ethnic minority perspectives (e.g. African) on long COVID. Participants may also have experienced recall bias or might have omit details, resulting from the symptoms associated with long COVID such as “brain fog” which could lead to inaccuracies in the data. However, to facilitate participants’ recall efforts during the interview (48), participants were asked, before the interview, to develop a timeline, marking the onset of their symptoms, interactions with the healthcare system, meaningful experiences, etc.

Conclusions

This study findings show self and public stigma resulting from the debilitating illness and symptoms that persons with long COVID face highlighting the need for public sensitisation. They also show that people with long COVID experience difficulties in accessing information and healthcare resulting from several multifaceted factors related to candidacy. Leveraging on social and community networks could potentially reach the diverse subpopulations with relevant long COVID related information and care pathways in an iterative manner that improves access to information and care for long COVID.

List of abbreviations

DU	Dutch
GP	General Practitioner
MO	Moroccan
PCR	Polymerase Chain Reaction
RA	Research Assistants
TU	Turkish
UK	United Kingdom

USA

United States of America

WHO

World Health Organisation

Declarations

Ethics approval and consent to participate: The medical ethical committee of the Amsterdam University Medical Centres /University of Amsterdam declared this study as nWMO, according to the Dutch Medical Research Involving Human Subjects Act W22_198 # 22.246 (<https://wetten.overheid.nl/BWBR0009408/2022-07-01>).

Consent for publication: Written or oral informed consent was obtained from all participants and participants were assured anonymity in the presentation and publication of the data.

Availability of data and materials: The datasets generated and/or analysed during the current study are not publicly available due confidentiality concerns related to identifying information in the transcripts but can be accessed in a de-identified form from the last authors on reasonable request.

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Authors' contributions:

The study was conceptualised by MT, EB, MN, and CA. MT and EB were responsible for data collection and analysis. GNN and MT contributed equally to the manuscript preparation, and thus shared the first authorship equally. MT is a female researcher who at the time of data collection was a PhD fellow with at least 4 years of qualitative health research experience. EB and CA supervised the manuscript development and revised the manuscript and thus shared the first last authorship. MIG, MN.EM, BA. MR, PT, SBR, MR and KS contributed to revising the manuscript. All authors provided intellectual content and approved the manuscript for publication.

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Supplementary File 1: Interview guide

1. Can you tell me how the story of your COVID / long COVID illness started?
- When were you first ill with corona?
 - When and how did you realize your symptoms were persisting?
 - Did you relate this to that first corona infection?
2. What did you do when you realized your symptoms were persisting?
- When and where did you seek support? (assertion of candidacy)
 - Informal (e.g., friends, family, internet)
 - Formal (e.g., general practitioner, physiotherapists, psychologist)
 - For what symptoms did you seek support? Why these?
 - Was/is it clear to you where you could seek support? And what kind of support and care options were available?
3. How has long COVID affected your life and the way you see yourself?
- Has there been a change in your daily functioning? How has this change affected your self-image? (identity threat)
 - Has there been a change in your interpersonal relationships? How has this change affected your self-image? (identity threat)
 - Have you felt different or of other value than before / than others because of long covid? Have you felt embarrassed because of long covid? (internalized stigma)
 - What brought about these feelings? What situations, what interactions (with whom) brought about these feelings? (enacted stigma)
4. How has the way you see yourself with long COVID affected when and where you sought support? (self-efficacy, assertion of candidacy)
- Is there a kind of public image of long covid in your community? in society? Can you describe it for me?

- How did this affect where you sought support? (anticipated stigma)
 - Did anything else affect when and where you sought support? E.g. aspects of social identity, previous experiences? (double stigma)
5. What was your experience with [healthcare professional] when telling them your symptoms?
- Did you feel heard? If so, what contributed to this? If no, why not? (testimonial (in)justice) (enacted stigma)
 - Did [healthcare professional] link your symptoms to (long) COVID? (adjudications)
 - Did they explain to you what long COVID is? Did they explain to you what to expect? (Can you describe the conversation?) Was it easy or difficult to understand the information? Why?
 - Did they refer you or follow-up? (adjudications)
 - Did you feel like something was missing? What?
6. What happened next? Can you describe other/subsequent contacts? (permeability, offers/resistance)
- What was your experience of these contacts?
 - DK context: How did you get to know of the long COVID clinics?
 - NL context: How did you get to know about C-Support?
7. How have your experiences with **long COVID care** affected the way you see yourself? And how you see your illness?
- How does this compare to other / previous experiences with care? (double stigma)
8. If you were to write our lessons learnt, in what ways would you say access to care for people with long COVID can be improved? In what ways can care for people with long COVID be improved?
- how can C-support be improved for people of ethnic minority background?
9. We are getting to the end of the interview. Thank you for sharing your experience with me. I will ask you to go through some basic characteristics with me. But before we check these I want to ask if you have anything to add?
- Is there anything important you feel I missed to ask you?

10. Demographics

Sex	Male, female, other
Age	≥18-29, 30-39, 40-49, 50-59, 60-69, ≥ 70
Country of birth	Morocco, Türkiye, The Netherlands
Country of birth mother	Morocco, Türkiye, The Netherlands
Country of birth father	Morocco, Türkiye, The Netherlands
Religion	Religious, not religious, prefer not to say
Educational level (highest obtained)	Primary school, high school, MBO, HBO, WO
Work/study load prior to long covid.	Fulltime, part-time, no (paid) work
Household composition	Living alone, living with partner or other adults, living with children (number/age)
Living conditions (type of housing)	Student housing or flat share, studio, flat or apartment, bungalow, semi-detached housing, detached housing.
Comorbid conditions	Diabetes, heart condition, previous stroke/apoplexy, hypertension, COPD/asthma, cancer, depressive or anxiety disorder, other?

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Supplementary File 2: Participant quotes

Theme	Sub-theme	Participant quotes
Stigma	The experience of public and self-stigma	<p>"No, not so much my self-image. No. I do have a lot of support in my faith. I see things, trying things as a test so to speak." Participant 17 – MO</p> <p>"Yes, was it corona then? Because you are positive, you were really sick. I was ashamed to prove that, how can you be sick for so long... Then it got better...then I had that recognition." Participant 5 -MA</p>
	Stigma within the context of healthcare	<p>"I was accused by the family doctor.... because suddenly, I was going through all these things.... I suddenly had asthma, and everybody said you're getting demented or something... I went there because I also had problems with my back and peeing ... because I had been going to the GP not lately, and they didn't have anything, then they said, wrote that down that, sir it's not real." Participant 12 - TU</p> <p>"The GP also waits for you to come back there.... I assume they are looking hard for something because a lot of people suffer from that. So I assume that at some point there will be a solution, but.... I 'don't always feel it's taken seriously, no.." Participant 1– Du</p> <p>"Yes, you feel kind of abandoned, really abandoned. Because nobody understands you. Sometimes people around you at a certain point start thinking, "Yeah, 'don't be silly." Participant 4 - MO</p>
	Ethnic differences in experiences of stigma	<p>"I even have a speech impediment... normally, I speak fluent Dutch.... now I don't manage quite well, but I have moments when I am searching. And then I say for fun I talk Turkish and Dutch, that's more street language with the boys." Participant 4 – TU</p> <p>"I had contact with C-Support a few times...really good conversations... with the occupational therapist, they also told me that I should apply for this. But that all has to go through the family doctor, who has to make the referral letters." Participant 4 – MA</p>
Access to care	Identification of candidacy and navigation to care	<p>"Those fatigue symptoms that have actually remained until now.... then after six months, I went to see the doctor again, because I had already done that a few times, but everyone said wait and see. And after six months I was sent to physical therapy...just outside the guideline. Because if you did it within so many months then it was covered by health insurance and now it wasn't, because it was again just too late." Participant 1 – Du</p> <p>"It was more about what is happening, and I think the doctor should have seen me in any case, if you are so sick with that. And he said, just looked at all the symptoms, and said, in principle we assume that you will recover, you are young and healthy.... he said, "Yes, usually if something lasts longer than 6 weeks you can</p>

	<p><i>... speak of something chronic." He said, "Come back then." So, I did. And then he said, "Well, okay, the symptoms you still have, you could say you suffer from long COVID." Participant 3 - DU</i></p> <p><i>"So, people who don't speak the language fill in the gaps themselves or start asking and then get the wrong information, so wrong views. ... because where do you have to go to get the information? They usually have contact with a family doctor, not that he or she can speak Arabic or Turkish or whatever. But he or she can give the basic information but no more than that..." like "gosh, this is the medicine or not the medicine or go exercise or go for a walk. But no more than that." Participant 5 – MA</i></p> <p><i>"Uhm, the advice I would give, particularly to general practitioners, deviate from that 5-minute consultation hour. Take somebody seriously. Someone who has a complaint, they don't just come in...there are people who just need to be taken seriously...you have to make a double appointment. I find that with many things in the Netherlands, if I come on time and I have complaints, and you just give me time to only talk about one complaint, when I'm just really sitting with other complaints." Participant 14 – MA</i></p> <p><i>"So I was like, I think I should also just go and investigate myself what exactly is the reason why my back is bothering me so much then...but after I went to see the pulmonologist, she looked, there was nothing wrong actually, I should function. And yet I still feel it.... We were also a little further along in time, so there were more people trying to recover in different ways...Well we started searching on the Internet. But also talking to people who were also already suffering. And fortunately, I know a lot of people who suffer from it...I do know a lot of people, and the people who are then suffering from that, still, I did ask them specifically.... most of the people I've spoken to are women, who all work." Participant 11 - TU</i></p>
Permeability	<p><i>"If that family doctor, or that there's somebody.... that that just that binding just, of all those diseases, there should just be someone or an organization, that should just say hey these are just.... we're looking at what's missing, what the problem is, and we just need to address that... But I just had to convince the GP of my things...I get that too, because that GP who gets only 10 minutes of time from the care facility and he writes a tablet very quickly, painkiller." Participant 12 – TU</i></p> <p><i>"In April, I went back to the doctor again because I kept coughing. And I had painful joints, in addition to the symptoms I already had. And then I asked for a lung picture and an examination, whether I might have rheumatic complaints, inflammatory complaints ... I was like if that GP doesn't look it up then I'm not getting the total picture, or nobody is getting that picture.... I had asked for a double interview...I had the idea that I could tell my story there... then she also said I don't really know...I didn't really know how to proceed." Participant 22 – Du</i></p> <p><i>"At that moment, my family doctor was on vacation and there was a substitute family doctor. And he said I think you are just overworked, and there you have the number of the psychologist, go talk to a psychologist. ...I</i></p>

		<p>tell him that may be, but I want a referral from him that I can use to do more than just go to a psychologist. So for example, I want to be able to go to a physio who specializes in this area and who can guide me through this... yes difficult, difficult. I said "well fine, but then I'll wait until my own family doctor is back and then I'll talk to him" ... So then I got a kind of general referral letter." Participant 7 - Du</p>
Appearances and adjudications		<p>"I think the very first point of entry is the family doctor.... because I think my condition didn't have to be so severe.... And if I have long COVID it's not called so for nothing huh, that means long-term COVID... initially I had recovered, I had absolutely no idea that this could come back this way. And the first few weeks that I went to the doctor, in February I had no idea that I had long COVID. And I don't think they did either." Participant 22 - DU</p> <p>"I have a lot of back pain. It stayed after corona. I went to the doctor. [Because he] speaks Dutch I showed [on] the doctor's back with my hand: I have pain all here. [Pointing to lower back and middle back]. The doctor did nothing for me. Didn't give a painkiller... Also because I don't speak Dutch. My daughter-in-law went to call the doctor and he said he prescribed vitamins and no painkillers... .. after a few months my back pain didn't go away.... I talked to my family first and then went to the family doctor. The family doctor did nothing... a few weeks ago he referred me for an X-ray... I did go but was never referred to the hospital. I couldn't even go to my appointment that day... I had gone alone. Then the GP called my daughter-in-law to translate... There was no diagnosis." Participant 25 - TU</p> <p>"That cardiologist.... I also had sleep apnea before that.... I had already done a test once with one of those devices... that cardiologist said that's not their area of expertise.... So nobody listens to it. Then you have to be with your family doctor." Participant 12 - TU</p>
Offers and resistance		<p>"At that time, I went back to work I couldn't do anything at all again, because I just felt very miserable. And when you have those relapses, it seems like you're sick again. So, then it looks like you're dying again. And that's really, bad. So, in the end the doctor then referred me to that COVID ward in the [ZKHS]. And then I had to go all the way back to square one. So, then I really couldn't do anything anymore... it was really very little what I was allowed to do in a day. That was really difficult... I had already lost that a few times [the deductible/own risk], I also have two children who I have to pay tuition fees for." Participant 1 - Du</p> <p>"I was disoriented, I didn't know what to do. Then I contacted my GP again, and they sent me a referral for physio. And then I started at physio, and I also tried to walk outside every day... Then I went a few more times and then I thought no this is not good, I'm going to stop. Then I contacted the company doctor again and then I told them I stopped the physio, it's still not going so well, and then the company doctor said to me, but that's not good at all that... you just have to recover quietly and actually walk alone. So, build up slowly [recovery]. So, I was hearing different things everywhere, from all sides." Participant 6 - TU</p>

	<p>"I don't know how to do that because we don't get reimbursed for that [therapy]...I came to an occupational therapist... I think I'll do everything once to see what's going to help me, then I'll make choices. And at the occupational therapist I thought what am I doing here? Then I went to that man, I said listen, this is not working, it doesn't give me energy, I can't get any further I want you to think of something else...He said I don't know if we will get reimbursed. When I told him, let me try it once so see if it's something for me, if that's feasible. I'd rather be walking outside than those rotten devices that drive me crazy." Participant 8_Du</p> <p>"The occupational therapy was offered in February, ... she said next time after the last time. I said oh no, no you can't. She said yes, but it's okay. I said yes, it's going well and I am in a better place now and I've learned schedules, but I have to go back to work later, and I think it's important to talk to someone who understands that occupational therapy part. I say you are the one for me who can help me create a different balance in my life and get back into a working mode. And then she said we have to apply for an extension, so you have to go back to that GP. I did that by phone. And that was ready for me again, and then there was that extension again. And I was very happy with that... I'm articulate right, and I think I know what I need...because I had used up my first piece and had not asked for an extension within a certain period. That's not good for the patients, because you don't know it's there, and you really need it." Participant 22 - DU</p> <p>"The neurologist said do an MRI. I did that.... he gave me medication that I totally disagreed with.... I felt totally misunderstood by that neurologist. And I also had the feeling that he was just trying something out... it was very intense medication; I didn't like the side effects. It made me completely drowsy, the headache got even weirder or something...at that moment I didn't feel heard or anything." Participant 17 – MA</p> <p>"I didn't feel like it anymore, I was tired, and then I didn't go. I couldn't handle it. It seemed like it was becoming chronic. Then the GP sent me to a sports doctor... especially with my lung infection the other day... I went to the doctor, and he said I don't hear anything crazy. ... I looked at him, I said is that normal? He looked critically, it was a substitute, said it doesn't really look... he came to me, very shocked and says, I misjudged... there is no one from an agency [GP] who knows what or says I will coach you, I will take you all the way through that... no one takes responsibility, neither the GP nor the occupational therapist, nor the physio." Participant 4 - MA</p>
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COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Experiences of stigma and access to care among long COVID patients: A Qualitative Study in a multi-ethnic population in The Netherlands

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Primary Subject Heading:	Public health

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Secondary Subject Heading:	Qualitative research, Global health, Health services research, Health policy
Keywords:	QUALITATIVE RESEARCH, COVID-19, Public health < INFECTIOUS DISEASES, Delivery of Health Care, Integrated, Health Services, Health Equity





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Title: Experiences of stigma and access to care among long COVID patients: A Qualitative Study in a multi-ethnic population in the Netherlands

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Abstract

Objective: This study explored the experience of stigma and access to healthcare by persons with long COVID from the majority Dutch and two ethnic minority populations (Turkish and Moroccan) living in the Netherlands.

Design: This was a cross-sectional qualitative study that employed inductive and deductive thematic approaches to data analysis using MAXQDA.

Setting and participants: Between October 2022 and January 2023, 23 semi-structured interviews were conducted with participants of Dutch, Moroccan, and Turkish ethnic origins with long COVID living in the Netherlands. Participants were men and women aged 30 years and above.

Results: Guided by the concepts of stigma and candidacy, the findings are structured according to the broader themes of stigma and access to care. The findings show that people with long COVID suffer self and public stigma resulting from the debilitating illness and symptoms. Especially among Turkish and Moroccan ethnic minority participants, strong filial obligations and gendered expectations of responsibility and support within their communities further worsen self-stigma. This experience of stigma persisted within healthcare where lack of information and appropriate care pathways led to feelings of frustration and abandonment especially for participants with pre-existing health conditions which further complicate candidacy. Under the access to healthcare theme, the findings show multiple challenges in accessing healthcare for long COVID due to several multifaceted factors related to the various stages of candidacy which impacted access to care. Particularly for Turkish and Moroccan ethnic minority participants, additional challenges resulting from limited access to information, pre-existing structural challenges and experience of stereotyping based on ethnicity or assumed migrant identity by health professionals further complicate access to health information and long COVID care.

Conclusions: The findings call for urgent attention and research to identify and coordinate healthcare for long COVID. There is also a need for accessible, informative, and tailored support systems to facilitate patients' access to information and care pathways for long COVID. Providing tailored information and support, addressing the various barriers that hinder optimal operating conditions in healthcare and leveraging on social networks is crucial for addressing stigma and facilitating candidacy for persons with long COVID towards improving access to care.

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Keywords: Long COVID; post COVID complication; lived experiences; Ethnic minority; Migrants; Host population; Access to care; Stigma; Candidacy.

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Strengths & limitations of the study

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- A key strength of the study is that it included vulnerable and hard to reach populations that are often overlooked in health care and research.
 - The study population might not fully capture the range of perspectives of ethnic minority perspectives (e.g. sub-Saharan African, South and Northern Asian) on long COVID and the larger study population with long COVID as debilitating illness and language barriers hindered some eligible persons from participating in the study. As such, study findings may not apply to other ethnic Dutch, Turkish or Moroccan persons with experiences of debilitating long COVID symptoms living in the Netherlands.
 - Although most study participants were recruited from C-support foundation which requires some language and digital literacy skills which can be challenging for older populations or persons from low socio-economic status (SES), a key strength of this study was the use of multiple modes of recruitment to identify and recruit additional study participants from previous COVID-19 community education sessions via two Mosques. This sampling strategy ensured variation in ethnic origin, gender, educational level, migration status, and Dutch language proficiency.
 - Some participants may also have experienced recall bias or might have omitted details, resulting from the symptoms associated with long COVID so, to facilitate all participants' recall efforts during the interview ¹, participants were asked, before the interview, to develop a timeline, marking the onset of their symptoms, interactions with the healthcare system, meaningful experiences, etc. These were used together with the topic guide the interviews.
 - Lastly, the use of member checking of summaries of transcripts via phone call ensured that participants who could not speak Dutch were included.

Introduction

The Coronavirus Disease 2019 (COVID-19) pandemic had multiple impacts on people's health, particularly for persons experiencing long-term post COVID-19 complications^{2,3}. Literature on COVID-19 and its impact is growing⁴⁻⁷, but qualitative literature on post COVID complications such as long COVID is limited. Long COVID can affect anyone and at any age regardless of health status⁸. Evidence also shows that ethnic minority populations have higher rates of SARS-CoV-2 infection and subsequent hospitalizations in Europe and the United States of America (USA) with a higher risk of long-term health consequences following COVID-19 hospitalizations compared to the majority population⁹⁻¹⁵. Recent studies conducted in Canada and the USA further show that non-hospitalized persons who tested positive for SARS-CoV-2 infection were significantly less likely to self-report long COVID symptoms compared with previously hospitalized persons^{16,17}. Non-hospitalised populations especially from ethnic minority populations generally have less access to care and rehabilitation programs with limited literature on the role of ethnicity as a risk factor for long COVID and how it shapes access to care. Addressing the healthcare needs of people with long COVID therefore calls for a comprehensive understanding of the lived experiences of people with long COVID, especially among ethnic minority populations to inform tailored interventions to address their healthcare needs.

Long COVID is a term commonly used to describe symptoms of COVID-19 that persist beyond the acute illness¹⁸. The World Health Organisation (WHO) reports that it occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, who continue to experience symptoms three months after the onset of COVID-19 with symptoms lasting a minimal duration of at least two months, which cannot be explained by an alternative diagnosis¹⁹. Although symptoms greatly differ between individuals, with over 200 reported symptoms with wide prevalence; common symptoms include weakness, general malaise, post-exertional malaise, fatigue and concentration impairment²⁰⁻²². Symptoms may be new onset following initial recovery from the acute phase of COVID-19 or persist from the initial illness, fluctuate or relapse over time, and generally impact a person's everyday functioning and reducing their quality of life^{19,21}.

Previous studies show that 13.7% of non-hospitalised people continued to report complaints three months after testing positive for SARS-CoV-2 and 33-87% of patients who had been hospitalized reported persistent complaints in the United Kingdom (UK)²³⁻²⁶. For ethnic minority populations living in high-income countries, studies show COVID-19 hospitalised

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3 patients with ethnic minority backgrounds are more likely than those of Dutch origin to report
4 having long COVID; with significant differences in occurrence, nature of symptoms, and
5 duration of long COVID by migration background ⁹. Another study reported an increased risk
6 of long COVID among ethnic minority populations compared with native Danes in a nationwide
7 register-based cohort study with both hospitalised and non-hospitalised individuals ²⁷. They
8 called for further research to understand long COVID drivers and address care strategies
9 among ethnic minority populations.
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16 Several attributes of long COVID such as its extended duration, the lack of a valid and uniform
17 diagnostic test and effective treatment, renders it a stigma-prone condition ^{28–31}. Research on
18 lived experiences in Italy shows that long COVID is stigmatised ³² with a UK study reporting
19 that 75% of participants with suspected or confirmed long COVID reported often experiencing
20 stigma ³³. This experience of stigma can lead to poor health seeking behaviour, which may
21 exacerbate illness particularly for minority ethnic groups, due to aspects related to their identity
22 such as race or ethnicity which can lead to the experience of ‘double stigma’ ^{28,32–34}. *Stigma* is
23 a discrediting quality, which diminishes the status of an individual ³⁵ and occurs in social
24 interactions. It is therefore an entirely socially constructed with multiple manifestations such
25 as public stigma, self-stigma, and structural/institutional stigma (*Section A, Box 1*) ^{35–37}. The
26 fear of stigma is worsened by implicit biases within healthcare and social systems, which place
27 minority ethnic groups at a disadvantage in accessing and receiving quality care ³⁸.
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38 Moreover, access to care influences an individual’s ability to effectively utilise health services
39 or informal care which encompasses both supply and demand factors ³⁹. It is influenced by
40 the concept of *Candidacy* which is a dynamic seven staged process (*Section B, Box 1*) by which
41 people determine their eligibility for health services, through continuous negotiations with
42 healthcare professionals ^{40–42}. The candidacy model is particularly useful for exploring and
43 understanding how vulnerabilities arise in relation to healthcare access, and how these are
44 influenced at multiple levels and differ between groups and across multiple intersections ^{41,42}.
45 The situation may be compounded for persons less familiar with health services, especially
46 among ethnic minority populations where health literacy is generally lower ⁴⁰.
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Box 1: The concepts of Stigma and Candidacy	
Concept/Stage	Definition
A. The concept of Stigma	
Self-stigma	Refers to the social and psychological impact of having a stigma and encompasses both the experience and

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	anticipation of encountering stigmatizing behaviour (felt stigma) and the diminished self-worth and feelings of shame that often accompany a stigmatizing condition (internalized stigma)
Public stigma	Refers to the social and psychological reactions towards individuals with a stigmatised condition or attribute.
Structural/institutional stigma	'Legitimization and perpetuation of a stigmatized status by society's institutions and ideological systems (39).
B. The Candidacy concept	
Stage	Description
1) Identification of candidacy	How individuals decide their symptoms require medical attention
2) Navigation	Knowledge of and ability to gain entry to appropriate services
3) Permeability of services	Ease of entry into the health system determined by factors within this system, such as cultural alignment or the availability of care pathways for specific conditions
4) Appearances at health services	Process of asserting candidacy during interactions with health professionals
5) Adjudications	Professional judgement about an individual's candidacy, influencing subsequent treatment
6) Offers and resistance	Follow-up services may be accepted or rejected by the patient depending on their appropriateness
7. Operating conditions and the local production of candidacy	Locally specific factors that influence interactions between patient and health care professional and develop over time
Sources: References 34-41	

This study therefore draws on the concepts of *stigma* and *candidacy*^{34,39} to explore people's lived experiences of long COVID focusing on the experiences of stigma and access to care of ethnic minority populations in comparison with the majority (Dutch) population in the Netherlands.

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Methods

A qualitative approach was used to conduct semi-structured interviews using questions and prompts originating from the theoretical framework on stigma and candidacy ^{42,43} to guide participants in narrating their illness and patient journeys. As a phenomenological study, this enabled participants share their illness experiences and touch on sensitive illness experiences while allowing the researcher to explore known and unexpected outcomes ^{44–47}.

Study population

Persons with confirmed initial SARS CoV-2 infection by means of Polymerase Chain Reaction (PCR) or antigen testing (self-testing), who continued to experience more than one symptom three months after the onset of COVID-19, lasting for at least 2 months (39), and for whom such symptoms had an impact on their daily lives were included. Persons with differential diagnosis (not SARS CoV-2 infection) or symptoms were purposively excluded. Persons with Dutch, Moroccan and Turkish ethnic origins were purposively included, as they were among the most affected groups, by SARS CoV-2 infection in the Netherlands ^{9,48,49}. Identification of ethnic origin was done based on the classification system of Statistics Netherlands, i.e., persons are considered of Dutch origin when they and both their parents are born in the Netherlands while persons are considered to have a Turkish or Moroccan origin if they, or at least one of their parents, is born in Türkiye or Morocco ⁵⁰. In, qualitative research, sample sizes are guided by the principle of saturation ^{44,45,51}. Hennink & Kaiser (2022) established that saturation of in-depth interviews was reached at 9-17 interviews ⁵². Since there is a considerable amount of heterogeneity in this study sample and the informational richness of the interviews depended on cognitive functioning of participants, we anticipated that a sample size higher than the established number of interviews was needed to reach saturation. Consequently, and to ensure variation in ethnic origin, gender, educational level, migration status, and Dutch language proficiency towards reaching data saturation, a purposive sampling approach was used to include a minimum of twenty (20) participants.

Setting and Recruitment

Study participants were recruited using two approaches. First, they were recruited from among persons with long COVID registered with the C-support foundation in the Netherlands. C-Support is a state-financed organization that provides free information, guidance, and advice to patients with long COVID, across the Netherlands ⁵³. Persons with long COVID registered with C-support were approached by C-support via email containing study information and asking their interest in participating in a scientific study. For interested persons, C-support,

requested permission to share their contact details with the research team. The shared first author (MT), contacted potential participants (n=20) by phone to check eligibility criteria (Box 2), introduce the research and research procedures, and answer questions from potential participants. Once eligibility and willingness to participate were established, a date, time, and place were scheduled for semi-structured interviews to be conducted (n=20). Secondly, two

Research Assistants (RAs) with Turkish, and Moroccan, Berber and Arabic language proficiency who had access to Turkish and Moroccan communities, approached nine persons with long COVID with limited Dutch language proficiency who were not registered with C-support. These persons had previously attended community education sessions on COVID-19 at two Mosques. Seven of the nine persons were then included after establishing eligibility and

willingness to participate. Out of the total of 27 persons eligible and willing to participate, four persons withdrew due to increased burden of their long COVID symptoms (n=2); family circumstances (n=1); and concerns regarding audio recording of the interview (n=1), resulting in a study sample of 23.

To facilitate participants' recall efforts during the interview¹, participants were asked to develop a timeline, marking the onset of their symptoms, interactions with the healthcare system, meaningful experiences, etc prior to the interview. These individual timelines were used together with the topic guide to facilitate the interviews. All participants were sent a text message via mobile phone the day before the interview to confirm the appointment and ensure their health allowed for the interview to take place. Post-interview, in line with good research practice, all participants again received phone text messages to check-up on any health impacts experienced following their interviews to provide some guidance and signpost to appropriate health care for further support. Participants however reported no concerns.

Box 2: Inclusion criteria

Question	Response	Action
When was your initial COVID infection?	Date	
Do you continue to have any symptoms?	Yes/No	If No - exclude If yes- ask next question
Do your symptoms bring about a significant change in your daily functioning with regards to housekeeping, care, studies, or work, and/or affect interpersonal relationships?	Yes/No	If No - exclude If yes- include

Subsequently, all participants received a reimbursement (€15, - gift card) for their participation.

Data collection

Interviews were conducted between October 2022 and January 2023. Out of the total of 23 individual interviews conducted, 20 interviews were conducted face to face (in private at participants’ homes), while three interviews were conducted by MT online using video conferencing software. MT conducted 17 interviews in Dutch, while each of the two RAs conducted three interviews in Berber, Moroccan Arabic, and Turkish. A semi-structured interview guide, which included questions on access to care and the experience of stigma originating from the theoretical framework on stigma and candidacy ^{36,39,41} (Supplementary File 1) was used for all interviews. RAs translated the interview guide into Berber, Moroccan Arabic, and Turkish.

Interviews lasted between 45-90 minutes, were audio recorded with participants’ consent and transcribed verbatim into Dutch. Interviews conducted in Turkish, Berber, Moroccan or Arabic were transcribed and translated into Dutch by the RAs. A 1–2-page summary of the transcript was shared with each participant, accompanied by a follow-up phone call to discuss the summary with participants. Given the considerable amount of heterogeneity within the sample, twenty-three interviews enabled us reach saturation with no repeat interviews conducted. Participant characteristics are presented in Table 1 below.

Table 1: Participant Characteristics	
Characteristics	Number
<i>(Ethnic) Background (1st)</i>	
Turkish (Tu)	9 (7 (first generation))
Moroccan (Mo)	7 (5 (first generation))
Dutch (Du)	7
<i>Gender</i>	
F	18
M	5

<i>Age category</i>	
30-39	4
40-49	5
50-59	10
60-69	3
70-79	1
<i>Educational level</i>	
Higher educational level (HBO/WO:)	9
Mid educational level (MBO2 t/m MBO4)	8
Low educational level (MBO1, VMBO, onderbouw HAVO/VWO (CBS categories))	6

Data analysis

Transcripts were thematically coded using MAXQDA 12 (maxqda.com/help-max20/welcome), a qualitative data analysis software. Data analysis was done in phases composed of: familiarization with the data; generating initial codes; searching for themes; reviewing themes to explore commonalities and differences; defining, and naming themes; and producing the manuscript⁵⁴.

MT deductively developed the initial coding framework based on the research question and theoretical framework. MT and Nazli Lale-Kahraman (a junior researcher) both coded, compared, and discussed eight transcripts using the initial coding framework, which was revised to include inductive codes emerging from the transcripts. The final coding framework was then used by MT and Nikita Hensen (a junior researcher) to code all remaining transcripts. MT inductively generated initial themes from the coded data, discussed and revised them with EB to explore commonalities and differences between ethnic minority groups and the majority (Dutch) population. Relevant participant quotes were then translated (with www.DeepL.com/Translator (free version)) from Dutch to English for the development of the manuscript.

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Patient and public involvement (PPI) in research

Patients and the public were not explicitly involved in the design of the study but contributed to the research study as participants giving voice to persons/people with long COVID, to share their experiences on stigma and accessing healthcare for long COVID to inform health policy and practice. In addition, C-support is a Dutch Ministry of Health, Welfare, and Sports commissioned foundation, which functions as an informal national registry of persons with long COVID in the Netherland providing support and advice to persons with long COVID and sharing emerging knowledge on long COVID with other (healthcare) professionals will contribute to dissemination of the findings with and to long COVID patients.

Ethics approval and consent to participate.

The medical ethical committee of the Amsterdam University Medical Centres /University of Amsterdam declared this study declared this study as nWMO, according to the Dutch Medical Research Involving Human Subjects Act W22_198 # 22.246 (<https://wetten.overheid.nl/BWBR0009408/2022-07-01>).

Conducted in accordance with the COnsolidated criteria for REporting Qualitative research (COREQ) Checklist (Supplementary File 3), this study also obtained written and/or oral (recorded) informed consent from all participants.

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.
Erasmus Hogeschool

Results

The results are presented under the two main themes arising from the conceptual framework with sub-themes and emerging codes. As shown in Table 1 above, majority of study participants were female (n= 16/23). Several were within the age range of 50-59 (n= 10) and had higher education (HBO/WO) (n= 9). For ethnic minority participants, the majority were first generation migrants (n= 12 out of 16). Selected quotes are embedded in the results and additional participant supporting quotes labelled Tu (Turkish), Mo (Moroccan) and Du (Dutch) are also presented as Supplementary File 2.

Stigma

Participants from both the majority (Dutch) population and Turkish and Moroccan ethnic minority populations reported that the initial understanding and empathy for their illness atrophied over time as they relapsed or continued to experience long COVID symptoms.

The experience of public and self-stigma

Participants experienced public stigma mostly in the questioning of their long COVID symptoms during social interactions with other people, often feeling and being referred to as "aansteller" (Dutch for 'poser') and receiving unsolicited advice on the causes and solutions for their symptoms.

"I notice that in the beginning everyone was understanding, but as it takes longer the understanding diminishes. And then, yes, the understanding diminishes, and then maybe they think you are doing it on purpose, or there's something else going on... Among colleagues, or friends, then one says maybe you have burnout, maybe you are depressed, then you get that kind of thing. I feel like everyone just says things." **Participant 6 -TU**

Regarding self-stigma, participants reported experiencing a loss of identity and purpose that contributed to lower self-worth and feelings of depression. Only a few participants, reported finding meaning in their illness through their contribution to research or perceiving their illness as a test of their faith, which protected them from feelings of low self-worth. While most participants reported this self/internalised stigma, they did not report any anticipation of encountering stigmatizing behaviour (felt stigma).

Participants reported variations in the severity and variety of debilitating long COVID symptoms they experienced, which caused them to feel low self-worth. They explained that their symptoms caused prolonged absences from work and family life, causing them to experience

feelings of guilt and shame and at times, fear of being seen as using their ill-health as an excuse to not work or contribute to the family. An ethnic minority participant shared that such feelings were worsened by strong filial obligations and gendered expectations of responsibility and support within their communities. The participant acknowledged that such expectations potentially occur in other cultures and across genders.

"I think you have..., lost your dignity, your independence, but also that at some point you can no longer take care of your family. And I'm not talking about the financial stuff, but the attention to your kids, a little bit of homework, the worry, reading letters to them ...Yes you have lost your pride. You are a man... if you can't take your responsibility, carry it, execute it, yes then that is not nice..... you are just talking about the Moroccan community, and the Turkish community, but I don't want to say that it is very different from the Dutch community. I think that every head of the house, whether it is a man or a woman, that it is the same for a woman who is single with the children...because are you positive, or were you really sick too.... I was ashamed to prove that, how can you be sick for so long?"

I: And what helped in it to stop feeling that shame?

R: Nothing... I'm glad I was better.... Then it got better [after contact with company doctor]. Then I had that recognition." **Participant 4-MO**

Stigma within the context of healthcare

Among most participants, lack of information on long COVID generally and from healthcare professionals, and lack of available care pathways and treatments for long COVID contributed to feelings of abandonment by the healthcare system. In addition, insecurities caused by long COVID symptoms particularly for patients who (already) experienced an array of health problems affected their health care encounters as they felt that their long COVID complaints are not taken seriously by healthcare professionals making them feel frustrated.

"The frustrating thing was that I was already struggling with word-finding problems. I already had a haze in my head, ... with my last bit of energy, I drag myself over there [GP] to go and sort something out and then it felt like the door is then slammed in front of your face..." **Participant 7 - DU**

Some participants reported that the multiple and severe symptoms, they experienced, without a clear cause resulted in some healthcare professionals assuming a psychological origin/cause for their symptoms.

The role of informal care/support

Participants reported that contact with other persons with long COVID, for example, via (online) support groups made them feel recognized and reassured as persons in those groups recognised their symptoms and challenges which helped alleviate their experience of stigma. They mentioned that they also received information on long COVID healthcare pathways and options available.

"I was really in a dip about myself, is this really corona or something else? But by reading the messages and the stories of those people, that's where I had the most support, this whole long period. Because there were similarities of what you have and them. Then you think "oh, it's real," and several people have the same symptoms, like mine then." Participant 14 -MO

Ethnic differences in experiences of stigma

While the experiences of stigma did not differ greatly between Turkish and Moroccan ethnic minority participants and Dutch participants, two ethnic minority participants reported difficulties accessing care which they related to their ethnicity. A participant explained that whilst proficient in the Dutch language, a speech impediment was one of his/her long COVID symptoms, which resulted in him/her sounding 'like a migrant' and hindered his/her ability to efficiently communicate in Dutch verbally. Another participant felt that the care s/he received from C-support made her/him feel heard, understood, and cared for in comparison with the care received from the general practitioner (GP). When explicitly asked about the experience of double stigma, however, most Turkish and Moroccan ethnic minority participants rejected the notion of being stigmatised or discriminated against because of their ethnicity.

"I'm not going to say it's because of my background, [but] you'll never know. ... the first time I got sick, and I had gone to the hospital, then I did feel it [stigmatised]... But after that, C-Support, for example, you're by phone, you did feel understood and that you were listened to.... I really don't dare say it... I think you're just either lucky or a little unlucky, that's it. I don't want to think about them knowing that I'm mocro and that I'm not.... No. I do have that sometimes... because I'm wearing a headscarf outside... you can't do anything about it." Participant 14- MO

Access to care

Identification of candidacy and navigation to care

Participants generally identified their complaints as requiring medical attention and consulted their GP early on (within two to four weeks) after their initial COVID-19 illness. For many participants, the identification of candidacy halted with the GP services, where they were advised to wait out the progression of their symptoms, often, because little or nothing was known about appropriate care pathways for their illness. As a result, some participants reported that when they were eventually referred for specialist services which were not covered by health insurance after the maximum number of consultations eligible for reimbursement, they incurred significant financial costs to access healthcare.

After repeated, and often frustratingly fruitless visits to the GP, some participants reported refraining from seeking care. Some Turkish and Moroccan ethnic minority participants expressed frustration with the bureaucratic nature of the Dutch healthcare system and in some instances, this was compounded by limited Dutch language proficiency which further complicated this first step in navigating healthcare. Non-Dutch speaking participants shared that they depended on their children to schedule their GP appointments and to serve as translators during their GP appointments. Several participants reported that they experienced social isolation, exacerbated by their debilitating long COVID symptoms, which further complicated their access to healthcare services. They reportedly succumbed to inadequate care, accepting symptoms, and experiencing little control over their situation.

"After 2 months I was still not the same, I had no strength in my legs, I couldn't concentrate for a very long time after that either and became forgetful... I don't have the strength anymore and no desire to do anything, I get tired easily... I don't know why the symptoms last so long...I go to the family doctor, but she can't give me anything, so I didn't go back... I'm fed up with it all, that's why I don't want to go. Who will go with me? I have no one [patient becomes sad]. When my son got sick, he also felt alone and said we are so lonely, there is no one to take us to the doctor. ... I wish I could speak something Dutch and not bother him. Then I would handle my own problems myself, but I don't speak Dutch at all. I always depend on other people, and I find that difficult, I'm ashamed of it, I don't know if they want to do it or not." **Participant 25 - TU**

Having to find information on their illness themselves exposed participants to potential misinformation and disinformation, mostly electronically and via social media. While most participants found access to the appropriate information for their illness difficult regardless of Dutch language proficiency, some Turkish and Moroccan ethnic minority participants further expressed concerns for other members of their communities who had little or no Dutch language proficiency. They explained that for such community members who are challenged by language barriers, access to information on long COVID is limited during encounters with their GPs, resulting in gaps in information received from GPs. They added that even when information is available digitally (such as by C-Support), access to that information is further obstructed for migrants such as older migrants who might not be literate or digitally literate.

"The way they had it set up, you have to log in.... you have to be fairly self-reliant, if you want to know the system and log in and then make an appointment, you have to do all that yourself...they have one of those digital systems that you can only register with your DigiD. So, I think my mother-in-law can't do all that. ... because she's just not digitally savvy, if you're not self-reliant, or you're not digitally savvy... But suppose I hadn't known the way well either, then you do find yourself in a sort of 'loop' with each other, of how to find the right care." **Participant 11 – TU**

"I: There is a site on the Internet called C-Support, have you ever heard of it?"

R: No I'm illiterate and don't know how to find this on my phone, I didn't study...I can ask my son or..." **Participant 19 -- MO**

All participants expressed disappointment that GPs could not provide more direction to finding the cause or treatment for their illness. While participants were primarily responsible for navigation to appropriate care, there were great variations in the actions participants were able to undertake themselves, which related strongly to their ability to rely on and utilise social networks. Most participants regardless of ethnicity reported relying on their social networks to identify and access information and care for their illness and symptoms. Most participants requested organised support in coordinating and navigating to care to improve care for long COVID. Dutch speaking participants also shared that C-support helped direct them towards care, informing them on specific requests for referrals, or available care within the vicinity of their homes. They mentioned various ways that enabled them access C-Support as they relied on social networks and digital literacy skills to be directed to C-support. Although there was no uniformity in access to C-support, Turkish and Moroccan ethnic minority participants who

could not sufficiently communicate in Dutch or had limited digital skills reported not being aware of C-Support.

"And then someone in my network who had contact with his physio practice with a number of physio practices in other countries ... And his friend is a good friend of mine, and she said "hey, go talk to my friend." His is very similar to that... I did google, what could this [long COVID] be? ... I don't know if my own GP had that knowledge at that time.... It was all so vague. So, I made an appointment with him [friend referral/health professional], sat down, explained my symptoms. And then he told me of well this is what we see, when people try to build up [recover], relapse ... I think, "yes, this is it," I recognize myself in this." **Participant 7 - DU**

Only four participants (3 (DU), 8 (DU), 15 (TU), 18 (TU) reported having had access to a clear care pathway early on, i.e., timely referral to long COVID rehabilitation for primarily physical therapy and occupational therapy from their GPs or company doctors. They explained that this was mainly dependent on their GPs' awareness of current COVID related issues and pro-activeness in accessing information to support them.

Permeability

In the Netherlands, GPs function as the main gateway to care with most participants identifying several factors that complicated their ease of entry to accessing healthcare via the GP [see ⁵⁵ for a description of Dutch system].

For several participants, employment provided an opportunity to enter the healthcare system. They explained that after a few weeks of absence from work due to illness, a company doctor (*who looks specifically at the work environment, potential reintegration and is in contact with the GP only with the consent of the employee*) attended to them which provided an opportunity to be heard and hear about long COVID, diagnosed and referred for rehabilitative care. They noted that company doctors were more influential in their employment and could direct them to healthcare and advocate for longer recovery time from employers. While some participants added that the company doctor's diagnosis of long COVID immensely relieved them, a few others reported that ill-informed company doctors hampered their access to care and recovery time.

"I'm still very happy with my company doctor... I started seeing the occupational therapist, which has done me very well. And I was able to take myself seriously and I finally I thought that I can just be sick... the GP can't do very much for you... he doesn't have that much influence on you, on your work situation but the company doctor does.... my second company doctor did take me seriously, and confirmed that whole long COVID 100%, she said no doubt about it, you just have long COVID... I remember sitting there with her, I think I used up a whole box of tissues... she also knew a lot about long COVID, and that was also very nice." **Participant 18 - TU**

While participants expected their GPs to be the connecting and coordinating link in their care appointments, because of the organization of GP practices, where usually, several GPs work in one practice, participants had to explain their complaints repeatedly in case of replacement GPs who they regarded as less informed and less responsive to addressing their long COVID symptoms. Participants felt this affected the quality of healthcare they received as they sometimes felt less confident to speak up or demand care because of a lack of familiarity with replacement GPs which, added to limited consultation time, did not allow for familiarity and a comprehensive discussion of their multiple and varied symptoms.

"Unfortunately, my own family doctor was not there. So, another GP explained what was there. And he also started telling me things about long COVID, all of which I already knew. Because by then I had already started at [name rehab centre], June 20 (or July) I had this feeling that he had just learned something about long COVID... I just didn't think it was good care...." **Participant 17 - MO**

"My family doctor was on vacation and there was a substitute family doctor. And he said I think you are just overworked, and here, you have the number of the psychologist, go talk to a psychologist. I said, I think it's super sweet that you think of me so much, but I know myself, it's not in that corner, this is different... I said well fine, but then I'll wait until my own family doctor is back." **Participant 7 -DU**

Most participants mentioned that double GP appointment slots did not provide sufficient time for consulting on their multiple symptoms with some of them suggesting that their symptoms may not have been taken seriously resulting in fewer referrals for specialist healthcare. Particularly for Turkish and Moroccan ethnic minority participants, although they expressed

understanding of this set-up, this characteristic of the Dutch health system frustrated them, prompting them to contemplate seeking healthcare in their home countries or other less restrictive countries. An ethnic minority participant added that the restrictive nature of the Dutch health system meant longer waiting times despite the excessive cost of health insurance.

"The Netherlands is a good country, all tightly regulated, we pay VAT for it too, all that insurance. But bureaucratic as hell... I sometimes go to a doctor in Morocco, because if I have something, yes, it's not top notch, but when I go, they can check right away. And here you have to be referred three times then you have to wait 6 months if you're lucky. But you do pay every month, my wife and I, €400.00 a month for the insurance. And then you have to beg for a CT scan, ... Because in Belgium you're faster in that respect too, in France too, in Spain too... the advice I would give, particularly to general practitioners, deviate from that 5-minute consultation hour. Take somebody seriously. Someone who has a complaint... If I have complaints, and you just give me time to only talk about one complaint, when I'm just really sitting with other complaints." **Participant -4 - MA**

Another ethnic minority participant explained that because the demography of a neighbourhood determines the expertise that is available at the GP, at GP appointments, some health professionals presume that they cannot communicate in Dutch, or they are not born in the Netherlands, which influences how they behave and act towards them. The participants therefore felt such care was not tailored to suit their health needs. Especially for participants who got ill early in the pandemic, knowledge of their GPs and other healthcare professionals on long COVID was key to facilitating access to care.

"The treatment towards patients did change, yes.... migrant background, they may also be, say, 3^d or 4th generation. not everyone who comes in here was born abroad or speaks poor Dutch... You feel that in the treatment, how people talk to you, the behaviour of the people who work there. ... things like that are signals of I need to change GPs... maybe I don't fit into the target group of that general practice anymore." **Participant 6 - TU**

Most participants reportedly organized care for long COVID themselves by exploring possibilities for care electronically (online) prior to visiting their GPs to ask for a referral. Participants referred for long COVID rehabilitation therapies such as physical therapy,

occupational therapy, and speech therapy experienced challenges with coordination of their healthcare. A few participants who had been referred to various healthcare specialists reported feeling discouraged by the lack of follow-up appointments from healthcare professionals or specialists. While Dutch-speaking participants reported been referred for different therapies, most participants with limited Dutch communication proficiency reported less contact with the healthcare system. This implies entry barriers, as most of the non-Dutch speaking participants had only seen their GP with only a few of them been referred for the physical therapy trajectory.

Appearances and adjudications

When interacting with healthcare professionals, many participants shared having to advocate for themselves to get healthcare but often felt uncomfortable/unable to do so. Consequently, participants' views regarding healthcare professionals' judgement about their candidacy, influencing subsequent treatment for their illness, considerably differed (adjudications). Turkish and Moroccan ethnic minority participants with limited Dutch proficiency, reported being less able to clearly describe their symptoms, and access referrals to healthcare, and depending on informal translations. They reported self-medicating to manage their symptoms while depending on family members with Dutch proficiency to advocate for them to access healthcare for their symptoms.

Similarly, Dutch-speaking participants also shared experiencing difficulties with asserting candidacy, especially when they were not equipped with information and sought direction from healthcare professionals on how to manage their symptoms. They reported that their symptoms limited their physical abilities and capacity to assert themselves during interactions with healthcare professionals.

"I was not taken seriously. Because long COVID that was nonsense, the family doctor said that was nonsense, he referred me to the physio and the ergo, well they didn't do anything either. He was very negative... I didn't know it myself, my surroundings didn't know it, and I thought myself am I posturing?... No, and I didn't have the knowledge, I didn't have the energy."

Participant 18 - TU

Some participants explained that they were not referred for any therapies by their GPs because of limited evidence-based solutions at the time and/or did not have adequate knowledge about long COVID symptoms and care pathways. Some participants who received referrals

mentioned that these therapies did not often significantly address their symptoms. Adjudications did not differ by ethnicity or ability to communicate in Dutch.

For participants who faced such challenges and were aware of C-Support, C-support equipped them with information on specific requests for referrals they could make.

"And then I got to C-Support ...I called them, I had an application there, and this lady who called and she knew exactly.... I said, what I was going through, and she had looked up a report, she said show this report to the GP." **Participant 12 - TU**

Offers and resistance.

Some participants reported incurring additional healthcare costs when they had exceeded the deductible allocated for their health insurance. Other participants explained that despite having health insurance, they had incurred additional costs for specific referral treatments for their long COVID symptoms, which had not been reimbursed. Other participants reported inadequate information about continuing treatment options covered by their health insurance which resulted in them incurring additional costs due to gaps in treatment.

" When I joined C-Support, I had already passed half a year. Because I was not reimbursed for physiotherapy. ..., I went to the doctor, who then didn't think maybe physiotherapy would be useful, and nothing else was followed up...they said at C-Support, well it might be possible if you write a letter."

Participant 11 - TU

Some participants felt that the care they received did not appropriately address their symptoms and needs as they did not feel strong enough to return to their normal duties when they were discharged and often experienced a flare-up of their long COVID symptoms. This resulted in them seeking healthcare all over again. Some participants expressed frustration with the limited healthcare professionals' expertise regarding their illness and the inadequate coordination of care strategies to manage their symptoms. While some participants reported being misdiagnosed, others reported counterproductive effects of some of the therapies they received. These experiences were reported among all ethnic groups with key implications for access to and acceptability of follow up services for participants.

Discussion

This study draws on the concepts of *stigma* and *candidacy* (30, 32) to provide insights into the lived experiences of people with long COVID with a focus on stigma and access to care

from the experiences of two ethnic minority populations (Turkish and Moroccan) and the majority (ethnic Dutch) population in the Netherlands. The key study findings show that participants suffer self and public stigma resulting from the prolonged experience of debilitating symptoms and the lack of information and appropriate care pathways within the context of healthcare which led to feelings of frustration and abandonment. In addition, all participants experienced general difficulties in accessing healthcare for long COVID resulting from several multifaceted factors related to candidacy. The lack of information, appropriate care pathways and care coordination from health professionals as key operating conditions for health care adversely impacted participants' health encounters resulting in participants acceptance of long COVID symptoms and refraining from seeking or accepting follow up care services. However, social networks were strong sources of information which enabled participants to build collective and individual candidacy. For some ethnic minority participants, candidacy was further complicated by limited Dutch language proficiency, digital and/or health literacy and experience of stereotyping based on ethnicity or assumed migrant identity by health professionals.

The findings show that the varied symptoms of long COVID and the challenges managing these symptoms made participants feel misunderstood and afraid of being perceived as pretending. Although they did initially attract public empathy, this atrophied over time contributing to the experience of public stigma when symptoms persisted or reoccurred. These challenges lead to feelings of isolation and depression, which can facilitate self or internalised stigma. This was more evident among ethnic minority participants where collective and gendered norms surrounding family responsibility led to feelings of shame, guilt and a loss of identity as illness challenges made it difficult to engage in social and/or economic obligations, leading to identity disruptions. Similar findings have been reported in other studies where the perceived inability of people affected by long COVID to effectively manage their symptoms or reduce severity of their symptoms resulted in all forms of stigma and identity dilemmas^{28,32,33,56,57}.

Within the candidacy framework, the process of determining eligibility for health services is for individuals to decide if their symptoms require medical attention followed by navigation to care, which requires the knowledge and ability to enter appropriate services³¹. Given the strong relationship between health-seeking behaviour and confidence in self-diagnosis⁴¹, individuals' identification of candidacy for long COVID may be impaired due to the lack of a clear illness trajectory and definition of the condition⁵⁸. When participants identified that their complaints required medical attention, they first contacted their GPs or in some instances, the

company/work healthcare professionals (identification). Subsequently, the lack of a proven treatment method ³¹ and well-defined care pathways ^{29,30,58} halted the process of establishing candidacy for care (navigation). The ease of entry into the health system was further complicated by alternating GPs and limited time for consultations (a general practice of the Dutch healthcare system), which hindered familiarity and effective patient-provider relationship to address the varied and multiple symptoms (permeability). In addition, symptoms such as 'brain fog', a common symptom of long COVID and characterised by difficulties with executive function, memory, and communication ⁵⁸ impinged on individual's ability to accurately portray their symptoms and illness experience during encounters with health professionals thereby reducing their ability to assert candidacy (appearances) and have this validated (adjudications). This has crucial implications for long COVID care access and acceptance of follow-up services or referrals to appropriate care (offers and resistance). Especially for Turkish and Moroccan ethnic minority participants who could not communicate in Dutch, "brain fog" and the novelty of their symptoms exacerbated difficulties to clearly describe their symptoms, request for or get referred to care pathways, requiring them to depend on family members and children to advocate for their care. The use of family members and children to facilitate access to care has implications for patient privacy and their understanding and translating of medical concepts and information could potentially lead to miscommunication and or misinformation. Perhaps, this challenge is more evident because the majority of Turkish and Moroccan ethnic minority study participants were first generation migrants who might have low Dutch language proficiency and digital literacy. The challenge to effective communication, particularly regarding limited or no national language proficiency, and the dependency on children to serve as translators in facilitating patients' access to healthcare has been reported in several studies ⁵⁹⁻⁶⁶. This is potentially worse when people are less familiar with health services or have lower health literacy rates such as among some ethnic minority populations ⁴⁰. This dynamic process by which participants determined their eligibility for healthcare services, through continuous negotiations with their healthcare providers highlights how vulnerabilities in accessing healthcare arise, are influenced at multiple stages, and differ between populations. This emphasises the crucial need for accessible, informative, and tailored support systems to enhance access to information and care pathways for persons with long COVID and inform the public about current iterative evidence on long COVID and care.

Within the conceptual framework, upon entry, access is affected by the process of asserting candidacy during interactions with health professionals (appearances) and professional's

judgement about candidacy, influencing subsequent treatment (adjudications) ⁴⁰. While there were few reported overt experiences of double stigma and or differential treatment based on ethnic minority background in this study, a general awareness of their minority position caused some Turkish and Moroccan ethnic minority participants to voice suspicions of differential treatment when they were not met with appropriate care. Layered on is the experience of stereotyping based on ethnicity or assumed migrant identity by health professionals which further facilitated participants' perception of differential treatment which impacted participants' assertion of candidacy during their interactions with health professionals. Validations of candidacy by healthcare professionals are partially influenced by socially constructed notions about which patients are most likely to respond well and thus 'deserve' treatment as 'ideal candidates' ^{39,42}. These tie into the concept of stigma, as stigmatised individuals are less likely to be perceived as the 'ideal candidate' due to public stigma surrounding their identity. Thus, healthcare professionals need to recognise and address biases and inequities, especially towards ethnic minority populations who may face implicit healthcare and other social biases in accessing and receiving care ^{38,40,67}. Such implicit biases could legitimise or adversely facilitate public stigma especially for long COVID participants from ethnic minority populations with further impacts on patients' candidacy ⁶⁷⁻⁶⁹. In addition, while the findings show general difficulties in accessing care due to the lack of well-defined care pathways for long COVID, some Turkish and Moroccan ethnic minority participants faced additional difficulties such as limited access to information and resourceful and supportive networks, which compound existing health inequities ⁶⁰.

Personal relations and acquaintance with healthcare professionals with knowledge of long COVID were found to be key sources of information, access, and referral to appropriate care sources outside of formal care pathways for long COVID participants. While the influence of social networks on peoples' access to health information and navigation to care is more commonly reported among ethnic minority populations ⁶⁰, in this study, both ethnic minority and the majority population utilised their social networks to facilitate candidacy and navigate access to care for their long COVID symptoms. Studies highlight the role of social networks and connections on health and social identity, which potentially influence peoples' beliefs and health-seeking behaviour ^{28,43}, and shape candidacy. While the complexity, and limited evidence on long COVID, resulted in both healthcare professionals and participants being poorly informed on long COVID, other resourceful and informal networks provided an avenue to access information and care pathways for long COVID symptoms. This placed an immense burden on participants particularly in the face of their long COVID illness and potentially led

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3 them to access inappropriate information and care strategies to manage their symptoms with
4 critical impacts on their current and future health conditions. For digitally literate participants,
5 like findings from other studies,^{70–72} social networks particularly online technologies and
6 media allowed long COVID patients to share and discuss symptoms, search for diagnosis and
7 attempt to resolve identity dilemmas which built a “*collective candidacy*” that facilitated their
8 individual candidacy. For less digitally literate participants such as older or first-generation
9 migrants, there is a need to harness localised and existing initiatives such as through the
10 “*buurthuizen*” (neighbourhood houses) which are accessible community centres fostering
11 social interaction, engagement and connections for residents including vulnerable persons.
12 The importance of social connections and networks was more evident as non-Dutch speaking,
13 and more socially isolated participants experienced greater difficulties in navigating care within
14 the Dutch health system. Consequently, social networks facilitated access to information
15 sources such as C-support, which provided support and advice for long COVID. C-support was
16 helpful in equipping participants with long COVID related information such as specific referral
17 requests to make from their GPs which enabled them better advocate for appropriate care and
18 support for their illness. This emphasises the role strong social or professional networks can
19 play on participants’ ability to assert candidacy in encounters with healthcare professionals in
20 navigating access to care.
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24 Furthermore, operating conditions surrounding the organisation and delivery of GP practices
25 in the Netherlands, limited GP consultation time of, bureaucracy of the health system,
26 alternating/replacement GPs and participants’ perceptions of being misunderstood and the
27 inadequate capacity of health professionals on long COVID, influenced permeability and local
28 production of candidacy. Consequently, Turkish and Moroccan ethnic minority persons,
29 contemplated seeking health care in their home countries where evidence shows they are
30 known to often assess healthcare for referrals to specialist care and diagnostic assessments
31 due to challenges in the operation conditions of the Dutch health care system which court
32 dissatisfaction with Dutch primary care^{73–76}. In the Dutch healthcare system GPs are the
33 gatekeepers to healthcare⁵⁵, functioning as key entry points, which requires, time, trust, and
34 building strong relationships with participants to ease entry into the healthcare system. Several
35 studies have also highlighted the importance of time, trust, and building relationships between
36 patients and GP services within the context of complex interventions to improve healthcare
37 access^{77,78}. Participants felt that most GPs were uninformed about their illness with some
38 healthcare professionals assuming a psychological origin/cause for participants’ symptoms and
39 thus contributing to their insecurities and self-stigma particularly for patients with pre-existing
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health problems. Even with a diagnosis, access to referral and appropriate care was limited due the novel nature (at the time) of long COVID and the subsequent paucity of literature and evidence on effective care and treatment pathways for long COVID. This greatly affected operating conditions for health professionals in establishing treatment and care plans for participants. Several studies have established the lack of well-defined care pathways or proven treatment methods that can be prescribed to all patients^{30,31,79} which emphasises the need for clear operating conditions such as clinical and policy directions for novel and emergent conditions like long COVID. These would profoundly impact health professionals' capacities through the availability of care pathways (permeability), their professional judgement about an individual's candidacy which influences subsequent treatments (adjudications) and influence patient and healthcare professional interactions and developments over time (local production of candidacy). While there is a need for health policy direction to enhance current operating conditions for treatment and care for long COVID, health professionals need to be equipped with evidence-based long COVID related information as it emerges, to facilitate local production of candidacy towards improving access to appropriate care and support for persons with long COVID. GPs could also facilitate social support for long COVID patients through sensitisation programs to mitigate potential related stigma within the healthcare system and public if they are well informed. A recent qualitative study in the UK reported that ethnic minorities with long COVID experienced negative healthcare encounters at the primary health care which complicated access to secondary or specialist care with further access challenges and dissatisfaction with specialist care for long COVID⁶⁷. Particularly for ethnic and minority study participants, these challenges are further complicated by Dutch insurance costs and comparisons of the Dutch health system with other less bureaucratic health systems in other countries or their home countries. These potentially impact on patient and health professional interactions and participants' acceptance or rejection of the follow up services suggested for them by their GPs that require them to incur additional costs for the referral service or wait a longer period to access referral health services despite having health insurance (Offers and resistance). Added on, as similarly reported in other studies are pre-existing barriers to accessing healthcare services such as language difficulties, low literacy and digital literacy barriers which further compound access to care⁸⁰⁻⁸³. Training healthcare professionals such as nurse practitioners as case support managers for long COVID and building relationships with patients to provide practical support to navigate and access appropriate care could potentially reduce these structural barriers There is also a need to sensitize the public on the feasibility of requesting longer consultation times for long COVID symptoms at GP services.

Moreover, the findings highlight the need to leverage on social connections and networks to prevent and address stigma surrounding long COVID towards improving healthcare access to information and care through community sensitisation to facilitate patients’ candidacy in accessing care. Like findings of other studies ^{84,85}, centrally structured multidisciplinary medical care could provide support in navigation and coordination of care to improve clinical outcomes. While organisations such as C-support support patients navigate to care, providing a central care point of contact for long COVID linked to the GP system could reduce inequities in access to long COVID information and care. In addition, although C-support provided information and directions to care, the findings show that most non-Dutch speaking participants recruited outside of C-support were not familiar with C-Support. This shows the critical role that communication particularly in the host country’s language and digital literacy play on access to health information. Patient organizations (both formal and informal) could be leveraged to reach and support sub-population groups by offering language and culturally concordant long COVID information and support which may incrementally improve access to information and care among ethnic minority groups. In addition to growing calls for establishing nationwide registers of people with long COVID ⁸⁶, collecting data on the lived experiences of various sub-populations could inform health policy and tailored implementation to improve access to long COVID care especially for ethnic minority populations.

Conclusions

This study findings show self and public stigma resulting from the debilitating illness and symptoms that persons with long COVID face highlighting the need for public sensitisation. They also show that people with long COVID experience difficulties in accessing reliable information and healthcare resulting from several multifaceted factors related to candidacy. Social and pre-existing challenges and inequities such as communication (including digital) barriers and stereotyping by health professionals further compound ethnic minorities with long COVID candidacy and experience of stigma. Leveraging on social and community networks could potentially reach the diverse subpopulations with relevant long COVID related information and care pathways in an iterative manner that improves access to information and care for long COVID.

List of abbreviations

DU	Dutch
GP	General Practitioner

MO	Moroccan
PCR	Polymerase Chain Reaction
RA	Research Assistants
TU	Turkish
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Declarations

Ethics approval and consent to participate: The medical ethical committee of the Amsterdam University Medical Centres /University of Amsterdam declared this study as nWMO, according to the Dutch Medical Research Involving Human Subjects Act W22_198 # 22.246 (<https://wetten.overheid.nl/BWBR0009408/2022-07-01>).

Consent for publication: Written or oral informed consent was obtained from all participants and participants were assured anonymity in the presentation and publication of the data.

A data sharing statement: The datasets generated and/or analysed during the current study are not publicly available due confidentiality concerns related to identifying information in the transcripts but can be accessed in a de-identified form from the last authors on reasonable request. *Funding statement:* This work was supported by the Novo Nordisk Foundation (<https://novonordiskfonden.dk/en/>) with the grant number 0067528. The funder played no role in the design of the study and the collection, analysis, and interpretation of data and in writing the manuscript.

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Authors' contributions:

The study was conceptualised and designed by Marieke Torensma (MT), Erik Beune (EB), Marie Norredam (MN), and Charles Agyemang (CA). MT was responsible for data acquisition and together with EB and Gertrude Nsorma Nyaaba (GNN), were responsible for analysis and interpretation of the study data. GNN and MT conceptualised, designed and drafted the initial manuscript and thus share the first authorship. MT is a female researcher who at the time of data collection was a PhD fellow with at least 4 years of qualitative health research

experience. EB and CA supervised the manuscript development and revised it critically for important intellectual content and thus share the last authorship. CA is responsible for the overall content as guarantor. Maria Ingeborg Goldschmidt (MIG), Marie Norredam (MN), Ellen Moseholm (EM), Brent Appelman (BA), Mikael Rostila (MR), Peter Tieleman (PT), Sara Biere-Rafi (SBR) and Maria Prins (MP) contributed to the initial interpretation of data and critically revised the manuscript drafts for intellectual content. All authors read, revised and approved the final manuscript and are thus accountable for all aspects of the work.

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Supplementary File 1: Interview guide

1. Can you tell me how the story of your COVID / long COVID illness started?
 - When were you first ill with corona?
 - When and how did you realize your symptoms were persisting?
 - Did you relate this to that first corona infection?
2. What did you do when you realized your symptoms were persisting?
 - When and where did you seek support? (assertion of candidacy)
 - Informal (e.g., friends, family, internet)
 - Formal (e.g., general practitioner, physiotherapists, psychologist)
 - For what symptoms did you seek support? Why these?
 - Was/is it clear to you where you could seek support? And what kind of support and care options were available?
3. How has long COVID affected your life and the way you see yourself?
 - Has there been a change in your daily functioning? How has this change affected your self-image? (identity threat)
 - Has there been a change in your interpersonal relationships? How has this change affected your self-image? (identity threat)
 - Have you felt different or of other value than before / than others because of long covid? Have you felt embarrassed because of long covid? (internalized stigma)
 - What brought about these feelings? What situations, what interactions (with whom) brought about these feelings? (enacted stigma)
4. How has the way you see yourself with long COVID affected when and where you sought support? (self-efficacy, assertion of candidacy)
 - Is there a kind of public image of long covid in your community? in society? Can you describe it for me?

- How did this affect where you sought support? (anticipated stigma)
 - Did anything else affect when and where you sought support? E.g. aspects of social identity, previous experiences? (double stigma)
5. What was your experience with [healthcare professional] when telling them your symptoms?
- Did you feel heard? If so, what contributed to this? If no, why not? (testimonial (in)justice) (enacted stigma)
 - Did [healthcare professional] link your symptoms to (long) COVID? (adjudications)
 - Did they explain to you what long COVID is? Did they explain to you what to expect? (Can you describe the conversation?) Was it easy or difficult to understand the information? Why?
 - Did they refer you or follow-up? (adjudications)
 - Did you feel like something was missing? What?
6. What happened next? Can you describe other/subsequent contacts? (permeability, offers/resistance)
- What was your experience of these contacts?
 - DK context: How did you get to know of the long COVID clinics?
 - NL context: How did you get to know about C-Support?
7. How have your experiences with **long COVID care** affected the way you see yourself? And how you see your illness?
- How does this compare to other / previous experiences with care? (double stigma)
8. If you were to write our lessons learnt, in what ways would you say access to care for people with long COVID can be improved? In what ways can care for people with long COVID be improved?
- how can C-support be improved for people of ethnic minority background?
9. We are getting to the end of the interview. Thank you for sharing your experience with me. I will ask you to go through some basic characteristics with me. But before we check these I want to ask if you have anything to add?
- Is there anything important you feel I missed to ask you?

10. Demographics

Sex	Male, female, other
Age	≥18-29, 30-39, 40-49, 50-59, 60-69, ≥ 70
Country of birth	Morocco, Türkiye, The Netherlands
Country of birth mother	Morocco, Türkiye, The Netherlands
Country of birth father	Morocco, Türkiye, The Netherlands
Religion	Religious, not religious, prefer not to say
Educational level (highest obtained)	Primary school, high school, MBO, HBO, WO
Work/study load prior to long covid.	Fulltime, part-time, no (paid) work
Household composition	Living alone, living with partner or other adults, living with children (number/age)
Living conditions (type of housing)	Student housing or flat share, studio, flat or apartment, bungalow, semi-detached housing, detached housing.
Comorbid conditions	Diabetes, heart condition, previous stroke/apoplexy, hypertension, COPD/asthma, cancer, depressive or anxiety disorder, other?

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Supplementary File 2: Participant quotes

Theme	Sub-theme	Participant quotes
Stigma	The experience of public and self-stigma	<p>"No, not so much my self-image. No. I do have a lot of support in my faith. I see things, trying things as a test so to speak." Participant 17 – MO</p> <p>"Yes, was it corona then? Because you are positive, you were really sick. I was ashamed to prove that, how can you be sick for so long... Then it got better...then I had that recognition." Participant 5 -MA</p>
	Stigma within the context of healthcare	<p>"I was accused by the family doctor.... because suddenly, I was going through all these things.... I suddenly had asthma, and everybody said you're getting demented or something... I went there because I also had problems with my back and peeing ... because I had been going to the GP a lot lately, and they didn't have anything, then they said, wrote that down that, sir it's not real." Participant 12 - TU</p> <p>"The GP also waits for you to come back there.... I assume they are looking hard for something because a lot of people suffer from that. So I assume that at some point there will be a solution, but.... I 'don't always feel it's taken seriously, no.." Participant 1– Du</p> <p>"Yes, you feel kind of abandoned, really abandoned. Because nobody understands you. Sometimes people around you at a certain point start thinking, "Yeah, 'don't be silly." Participant 4 - MO</p>
	Ethnic differences in experiences of stigma	<p>"I even have a speech impediment... normally, I speak fluent Dutch.... now I don't manage quite well, but I have moments when I am searching. And then I say for fun I talk Turkish and Dutch, that's more street language with the boys." Participant 4 – TU</p> <p>"I had contact with C-Support a few times...really good conversations... with the occupational therapist, they also told me that I should apply for this. But that all has to go through the family doctor, who has to make the referral letters." Participant 4 – MA</p>
Access to care	Identification of candidacy and navigation to care	<p>"Those fatigue symptoms that have actually remained until now.... then after six months, I went to see the doctor again, because I had already done that a few times, but everyone said wait and see. And after six months I was sent to physical therapy...just outside the guideline. Because if you did it within so many months then it was covered by health insurance and now it wasn't, because it was again just too late." Participant 1 – Du</p> <p>"It was more about what is happening, and I think the doctor should have seen me in any case, if you are so sick with that. And he said, just looked at all the symptoms, and said, in principle we assume that you will recover, you are young and healthy.... he said, "Yes, usually if something lasts longer than 6 weeks you can</p>

	<p><i>... speak of something chronic." He said, "Come back then." So, I did. And then he said, "Well, okay, the symptoms you still have, you could say you suffer from long COVID." Participant 3 - DU</i></p> <p><i>"So, people who don't speak the language fill in the gaps themselves or start asking and then get the wrong information, so wrong views. ... because where do you have to go to get the information? They usually have contact with a family doctor, not that he or she can speak Arabic or Turkish or whatever. But he or she can give the basic information but no more than that..." like "gosh, this is the medicine or not the medicine or go exercise or go for a walk. But no more than that." Participant 5 – MA</i></p> <p><i>"Uhm, the advice I would give, particularly to general practitioners, deviate from that 5-minute consultation hour. Take somebody seriously. Someone who has a complaint, they don't just come in...there are people who just need to be taken seriously...you have to make a double appointment. I find that with many things in the Netherlands, if I come on time and I have complaints, and you just give me time to only talk about one complaint, when I'm just really sitting with other complaints." Participant 14 – MA</i></p> <p><i>"So I was like, I think I should also just go and investigate myself what exactly is the reason why my back is bothering me so much then...but after I went to see the pulmonologist, she looked, there was nothing wrong actually, I should function. And yet I still feel it.... We were also a little further along in time, so there were more people trying to recover in different ways...Well we started searching on the Internet. But also talking to people who were also already suffering. And fortunately, I know a lot of people who suffer from it...I do know a lot of people, and the people who are then suffering from that, still, I did ask them specifically.... most of the people I've spoken to are women, who all work." Participant 11 - TU</i></p>
Permeability	<p><i>"If that family doctor, or that there's somebody.... that that just that binding just, of all those diseases, there should just be someone or an organization, that should just say hey these are just.... we're looking at what's missing, what the problem is, and we just need to address that... But I just had to convince the GP of my things...I get that too, because that GP who gets only 10 minutes of time from the care facility and he writes a tablet very quickly, painkiller." Participant 12 – TU</i></p> <p><i>"In April, I went back to the doctor again because I kept coughing. And I had painful joints, in addition to the symptoms I already had. And then I asked for a lung picture and an examination, whether I might have rheumatic complaints, inflammatory complaints ... I was like if that GP doesn't look it up then I'm not getting the total picture, or nobody is getting that picture.... I had asked for a double interview...I had the idea that I could tell my story there... then she also said I don't really know...I didn't really know how to proceed." Participant 22 – Du</i></p> <p><i>"At that moment, my family doctor was on vacation and there was a substitute family doctor. And he said I think you are just overworked, and there you have the number of the psychologist, go talk to a psychologist. ...I</i></p>

		<p>tell him that may be, but I want a referral from him that I can use to do more than just go to a psychologist. So for example, I want to be able to go to a physio who specializes in this area and who can guide me through this... yes difficult, difficult. I said "well fine, but then I'll wait until my own family doctor is back and then I'll talk to him" ... So then I got a kind of general referral letter." Participant 7 - Du</p>
Appearances and adjudications		<p>"I think the very first point of entry is the family doctor.... because I think my condition didn't have to be so severe.... And if I have long COVID it's not called so for nothing huh, that means long-term COVID... initially I had recovered, I had absolutely no idea that this could come back this way. And the first few weeks that I went to the doctor, in February I had no idea that I had long COVID. And I don't think they did either." Participant 22 - DU</p> <p>"I have a lot of back pain. It stayed after corona. I went to the doctor. [Because he] speaks Dutch I showed [on] the doctor's back with my hand: I have pain all here. [Pointing to lower back and middle back]. The doctor did nothing for me. Didn't give a painkiller... Also because I don't speak Dutch. My daughter-in-law went to call the doctor and he said he prescribed vitamins and no painkillers... .. after a few months my back pain didn't go away.... I talked to my family first and then went to the family doctor. The family doctor did nothing... a few weeks ago he referred me for an X-ray... I did go but was never referred to the hospital. I couldn't even go to my appointment that day... I had gone alone. Then the GP called my daughter-in-law to translate... There was no diagnosis." Participant 25 - TU</p> <p>"That cardiologist.... I also had sleep apnea before that.... I had already done a test once with one of those devices... that cardiologist said that's not their area of expertise.... So nobody listens to it. Then you have to be with your family doctor." Participant 12 - TU</p>
Offers and resistance		<p>"At that time, I went back to work I couldn't do anything at all again, because I just felt very miserable. And when you have those relapses, it seems like you're sick again. So, then it looks like you're dying again. And that's really, bad. So, in the end the doctor then referred me to that COVID ward in the [ZKHS]. And then I had to go all the way back to square one. So, then I really couldn't do anything anymore... it was really very little what I was allowed to do in a day. That was really difficult... I had already lost that a few times [the deductible/own risk], I also have two children who I have to pay tuition fees for." Participant 1 - Du</p> <p>"I was disoriented, I didn't know what to do. Then I contacted my GP again, and they sent me a referral for physio. And then I started at physio, and I also tried to walk outside every day... Then I went a few more times and then I thought no this is not good, I'm going to stop. Then I contacted the company doctor again and then I told them I stopped the physio, it's still not going so well, and then the company doctor said to me, but that's not good at all that... you just have to recover quietly and actually walk alone. So, build up slowly [recovery]. So, I was hearing different things everywhere, from all sides." Participant 6 - TU</p>

	<p>"I don't know how to do that because we don't get reimbursed for that [therapy]...I came to an occupational therapist... I think I'll do everything once to see what's going to help me, then I'll make choices. And at the occupational therapist I thought what am I doing here? Then I went to that man, I said listen, this is not working, it doesn't give me energy, I can't get any further I want you to think of something else...He said I don't know if we will get reimbursed. When I told him, let me try it once so see if it's something for me, if that's feasible. I'd rather be walking outside than those rotten devices that drive me crazy." Participant 8_Du</p> <p>"The occupational therapy was offered in February, ... she said next time after the last time. I said oh no, no you can't. She said yes, but it's okay. I said yes, it's going well and I am in a better place now and I've learned schedules, but I have to go back to work later, and I think it's important to talk to someone who understands that occupational therapy part. I say you are the one for me who can help me create a different balance in my life and get back into a working mode. And then she said we have to apply for an extension, so you have to go back to that GP. I did that by phone. And that was ready for me again, and then there was that extension again. And I was very happy with that... I'm articulate right, and I think I know what I need...because I had used up my first piece and had not asked for an extension within a certain period. That's not good for the patients, because you don't know it's there, and you really need it." Participant 22 - DU</p> <p>"The neurologist said do an MRI. I did that.... he gave me medication that I totally disagreed with.... I felt totally misunderstood by that neurologist. And I also had the feeling that he was just trying something out... it was very intense medication; I didn't like the side effects. It made me completely drowsy, the headache got even weirder or something...at that moment I didn't feel heard or anything." Participant 17 – MA</p> <p>"I didn't feel like it anymore, I was tired, and then I didn't go. I couldn't handle it. It seemed like it was becoming chronic. Then the GP sent me to a sports doctor... especially with my lung infection the other day... I went to the doctor, and he said I don't hear anything crazy. ... I looked at him, I said is that normal? He looked critically, it was a substitute, said it doesn't really look... he came to me, very shocked and says, I misjudged... there is no one from an agency [GP] who knows what or says I will coach you, I will take you all the way through that... no one takes responsibility, neither the GP nor the occupational therapist, nor the physio." Participant 4 - MA</p>
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COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.