

Dealing with uncertainty. A qualitative study on the illness' experience in patients with long-COVID in Italy

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Abstract. *Background and goals:* An unknown proportion of people who had COVID-19 infection continue to experience symptoms such as fatigue, breathlessness, joint or muscle pain, difficulty sleeping, and brain fog. These symptoms have a significant impact on the quality of life. Long-COVID is a new multisystem disease still under investigation. This research aims to explore the illness experienced by patients suffering from Long-COVID in Italy. *Research Design and Methods:* Qualitative methodology with semi-structured interviews. Participants were recruited on the Facebook patient group between October 2021 and January 2022. Participants had been experiencing symptoms for at least three months following confirmed COVID-19 infection. Interviews were conducted by video call, recorded and transcribed with consent. The thematic analysis method has been chosen to infer data from textual material. *Results:* 17 interviews with women with Long-COVID have been analysed. The main themes include: a total change of life due to the symptomatology, loss of autonomy that affects social, family and professional life; social isolation, a sense of abandonment often increased by stigma, the difficulty of being believed and achieving diagnosis; difficulty in managing symptoms and accessing to care services; living with uncertainty caused by the lack of institutional, social, professional, familial and medical support. *Conclusions:* Intervention programs, both institutional and social-health policies should be developed for patients with Long-COVID. The impact of symptoms could be reduced by developing standards and protocols, and by ensuring access to care and to multi-disciplinary rehabilitation. Further development of knowledge on Long-COVID is essential.

Key words: Long-COVID, Post-covid-19 syndrome, Post-Covid-19 Condition, medically unexplained syndromes, illness experience; uncertainty

Introduction

The Covid-19 pandemic has destabilised entire social structures by dramatically impacting worldwide health organisations. It has had a devastating effect by infecting millions of people and by causing, to date, 6,596,542 deaths globally (1). In the Italian context, 181,733 deaths and 24,488,080 cases of contagion have been counted so far (1). Although compared to

2020 and 2021 many steps forward have been taken for the prevention and treatment of the virus, today it is not always possible to recover completely from Covid-19. Indeed, it seems increasingly evident that in a significant percentage of cases, the virus can develop into a long-term disease, Long-COVID, by leading to complex symptoms that have a significant impact on the quality of life. Patients affected by this disease indeed continue to feel sick for months, even

testing negative for Covid-19 tests. Long-COVID is an emerging disease about which little is medically known; its incidence is unspecified, although it has been estimated 50 million cases worldwide (2, 3) with a clear prevalence in the female population (4-6). Long-COVID involves most of the body systems (7) but the aetiology is not entirely understood as many symptoms do not have clear physiological/organic causes that can be traced through medical examinations and investigations. Symptoms are numerous and heterogeneous, debilitating and can affect subjects of any age. A study on 100 non-hospitalised Covid-19 patients showed that the 10 most persistent symptoms are cognitive dysfunction, headaches, tingling, taste and smell disturbances, muscle pain, dizziness, and blurred vision (8). According to other studies, patients experience prevalent and persistent asthenia and brain fog (9-11). Other symptoms are depression or anxiety, shortness of breath, chest pain, insomnia, changes in blood pressure, gastrointestinal complaints (12), joint pain, fever, sore throat and difficulty swallowing, the onset of diabetes and hypertension, and hives (13). Patients report recovering from symptoms after 2 months in 90% of cases, or after 9 months in 10% of cases (10, 11). Although the diagnostic criteria are not fully defined or unequivocally used by the biomedical community, currently the diagnosis of Long-COVID is clinical and involves an assessment that should be one-stop (day-hospital) with individualised follow-up depending on the patient's characteristics (7). Although antibody testing for Covid-19 or molecular/antigenic swab positivity is helpful, these are not a prerequisite for diagnosis (7). The literature shows that the approach to the patient must be multidisciplinary, aimed at responding to the various clinical, functional, cognitive and psychological manifestations; it should also be personalised, considering the variety of symptoms that may arise (7) since SARS-COV-2 has a multi-organ and multi-systemic impact (14). At present, however, no effective treatment which can simultaneously act on all the symptoms that characterise Long-COVID has been identified. For many patients it is difficult to access linear treatment pathways and to benefit from healthcare services; in particular, it is very complex to obtain a diagnosis because the assistance they receive is often disjointed and isolated, with specialised care

mostly inaccessible and inconstant (10). In the Italian context, there are currently few medical centres dedicated to the treatment of Long-COVID and almost everywhere these services are neither universally accessible (e.g. they have often been limited to patients already hospitalised for acute Covid-19) nor multidisciplinary (capable of handling the diversity of symptoms that may arise from time to time). The difficulties experienced by patients are also caused by the fact that Long-COVID is not a well-defined disease and therefore it is not recognised at an institutional level; this also causes a lack of information or clear indications on how to proceed or whom to turn to for medical support (10,11).

Very often, patients can obtain information on specialists or Long-COVID medical centres by exchanging with other patients through online support groups or platforms and social media. These platforms also allow them to exchange tips on how better manage chronic and debilitating symptoms; this, in a way, helps patients to cope with the uncertainty (15-17). However, organised national surveillance systems would be essential to provide answers and to establish functional intervention plans capable of monitoring disease trends. Such surveillance does not take place routinely in most countries (European and non-European) also because the *conditio sine qua non* for the implementation of a surveillance system is the definition and classification of the problem (18), which in the case of Long-COVID has not yet happened. To support this process, the WHO introduced ICD codes to be used in the post-Covid emergency, laying the basis for a codification of the Long-COVID problem worldwide (18). However, this has not produced essential effects. In the Italian context, patients complain that they suffer from a pathology that is not classified as a condition for the recognition of health codes. For this reason, patients cannot benefit from allowances or invalidity certificates, reimbursements, protection or sick leaves with all that this can determine on an employment protection level and on an economic level, considering that healthcare and medical costs are charged to the patient (18). The scientific literature reveals an absence of a univocal definition of Long-COVID, a lack of certainty regarding its aetiology and difficulty in identifying effective treatments. This research aimed to investigate the illness

experienced by people suffering from Long-COVID in Italy, by analysing, in particular, the impact that the symptomatology has on the quality of life.

Patients and methods

Study design

The study involved a phenomenological approach with semi-structured interviews with patients with Long-COVID. The phenomenological approach allows one to analyse the phenomena starting from individual and subjective representations, by considering the sense and the significance given to particular events or facts that have to be examined. It is thus a paradigm that permits one to understand the meaningfulness of the lived experience and to analyse human phenomena not in its “measurable” aspects, but rather as they are lived by real people (19), by seeking to capture the experience in its primordial origin or essence (20). In this study, the phenomenological paradigm allowed to integrate of the patient’s clinical history with the illness’ experience (21) and to analyse, from the different interviewees’ perspectives, ideas and conceptions about the origin of the illness, the impact of the symptoms on the quality of life and the patients’ experience with medical professionals.

Participants

People who met five inclusion criteria will be included in the study:

1. Experiencing Long-COVID symptoms for at least three months following confirmed COVID-19 infection;
2. Having perceived a significant impact of Long-COVID symptoms on quality of life;
3. Having consulted multiple healthcare professionals in order to receive a diagnosis;
4. Being between 30 and 60 years of age;
5. Being willing to conduct a semi-structured interview

The exclusion criterion will be the refusal to participate in the research.

Participants will be recruited via the Facebook group *Noi che il Covid lo abbiamo sconfitto Sindrome Post Covid #LongCovid* (“We who have beaten Covid #LongCovid Syndrome”) after formal approval by e-mail from the group administrator and through the publication of a post. These people will be then invited to get in touch with the research team by email, who will inform them of the details of the study and agree on when/how the interview would take place. When they will do it, the researcher will send an information sheet and consent form. Participants will be asked to sign the consent form and return it to the research team. The sample will be obtained by convenience sampling and completed by snowball sampling (22).

Instrument

Semi-structured interviews were conducted for this study. The interview is framed as a relationship between two people, which is started by one of the two individuals involved with the intention of reconstructing the social and representational world of the other for knowledge purposes (23). The subjects are not an interviewer and a respondent but are two interpreters, two persons who interpret, each in their own terms, the experience of the other (23, 24). The use of the interview guide (see Table 1) has allowed us to deepen elements and issues that emerged during the interviews, by giving space to each patient’s experience. The questions included 3 sections aimed to explore: 1) the origin of the illness: aimed at investigating when the syndrome appeared; 2) the biomedical response: aimed at investigating the clinical and therapeutic management, and the effectiveness or ineffectiveness of the biomedical interventions; 3) the illness experience: aimed at investigating the impact of the symptoms on the quality of life (private, relational, affective, professional) and on the management of daily life. During the interviews, personal data have also been collected.

Data analysis

Each interview was recorded, transcribed verbatim and then analysed with respect to thematic

Table 1. Interview guide.

Thematic area	Questions
The origin of the illness	What was the progression of Covid-19? What symptoms remained or appeared following the negative Covid-19 test? When and how did you realise that this symptomatology was then related to a Long-COVID?
The biomedical response	Which doctors have you seen so far? What explanation did they give you concerning the symptoms you describe and experience? Have you received a diagnosis of Long-COVID? What kind of treatment did you undergo and what effect did they have on the symptomatology? What kind of therapeutic support and treatments would you like to receive from healthcare professionals?
The illness experience	How was your life before getting sick with Covid-19? What is the impact of the symptomatology on your quality of life and on your everyday activities? What are today your expectations about the future? Have they changed because of Long-COVID? What kind of support have you received so far (family, friends, institutions, associations, informal groups, social networks)?

content. Transcriptions have been read several times by the research team, in order to overall meaning of the interviews. The thematic analysis method has been chosen to infer data from textual material (25). The first analysis step implied an accurate reading of verbatim transcripts. From the textual material have been identified meaning units, such as common statements that participants used frequently to describe relevant issues. These have been summarized while maintaining the expressions of the participants as much as possible, before being coded by the research team and shared. The meaning units have been grouped into common themes. This allowed the identification of sub-themes which were then grouped into more inclusive themes.

Rigour

The research team guaranteed rigour by adopting accurate data collection and regular inter-analysis meetings to share findings. Five researchers (CM, CC, GC, MRC, CT) compared the data obtained and sought agreement. Two external researchers (GA and LS) analysed and supervised any disagreements. All researchers were PhD, MD, RN and MSN, and professionals from medical anthropology, medicine and nursing fields with experience in qualitative research methods and leading interviews. The writing of the article followed the COREQ checklist for qualitative research (26).

Ethical considerations

Participants received a clear informative document explaining the design, aim, and procedure of the study and were informed of the purpose of the study. The informed consent has been approved by the Data Protection Service (DPO) of the University of Parma. The patients who signed the consent have been informed that participation in the study was voluntary and that they could withdraw their consent to participate at any time. The document also stated that the interview would have been audio-recorded if carried out by phone, or video-recorded. The data collected has been reserved and used in compliance with the current legislation on the protection of sensitive data and privacy regulations.

Results

In November and December 2021, 17 people were interviewed, all female and aged between 31 and 59 years. 22 participants were initially recruited but 5 of them dropped out of the study after expressing explicit interest due to health problems. The interviews lasted between 30 and 80 minutes; besides the participant and the researcher, no one else was present during the interview and there was no relationship established with participants prior to the study commencement.

Five researchers (CM, CC, GC, MRC, CT) drew up the interview guide and conducted the interviews. 12 interviews were conducted online, using video conference platforms while 5 interviews were conducted by telephone. Data participants are shown in Table 2.

Three macro themes emerged from the interviews collected: 1) a radical change of life caused by the impact of the symptoms; 2) a profound uncertainty caused by the difficulties in accessing linear treatment pathways and the sensation of feeling stigmatised and disbelieved; 3) the impact of the disease on the psycho-emotional experience.

1. CHANGE OF LIFE

Long-COVID is particularly elusive and insidious. Interviewees refer to an optimal and healthy state, where Covid-19 manifests immediately as a mild-flu syndrome, a cold, or even asymptotically, but then everything suddenly changes. Following the acute phase and the negative covid test, a number of debilitating symptoms occur and become chronic. Dyspnoea, asthma, widespread pain, tachycardia, difficulty

in walking, and myalgias: are just some of the symptoms that have been reported as debilitating to the point of limiting personal autonomy and forcing patients to walk with auxiliary aids, or seeking support. Over time, these symptoms are associated with new and different ones such as brain fog, decreased eyesight and concentration, memory problems, dizziness, cognitive deficits, and asthenia. Interviews show that the most debilitating symptoms are the neurological ones; however, the most commonly reported debilitating symptom is chronic fatigue. Some interviewees state:

My biggest problem is this debilitating tiredness that at certain times is so exhausting that I cannot do normal things during the day (Code 11.05).

At first, what I felt was this hallucinatory feeling of tiredness and fatigue, but my eyesight was also blurred from drowsiness. Even at work my eyes would close, while people might be talking to me (Code 02.09).

The symptomatology changes the self-image, the relationship with others, and the “normal” course of

Table 2 – Participants’ data.

INTERVIEW	AGE	SEX	PROVENECE	WORK ACTIVITY	INTERVIEW MODALITY
01	44	F	Emilia Romagna	Employee (private sector)	Audio call
02	38	F	Lombardia	Employee (private sector)	Video call
03	55	F	Toscana	Healthcare professional (public sector)	Audio call
04	45	F	Lombardia	Self-employed	Video call
05	42	F	Lombardia	Employee (private sector)	Video call
06	57	F	Lombardia	Healthcare professional (public sector)	Video call
07	31	F	Veneto	Employee (public sector)	Video call
08	55	F	Lombardia	Employee (public sector)	Video call
09	48	F	Sicilia	Self-employed	Audio call
10	50	F	Lombardia	Employee (private sector)	Audio call
11	51	F	Piemonte	Employee (public sector)	Video call
12	51	F	Trentino Alto Adige	Employee (private sector)	Audio call
13	56	F	Emilia Romagna	Self-employed	Video call
14	48	F	Lombardia	Self-employed	Video call
15	45	F	Lombardia	Self-employed	Video call
16	49	F	Veneto	Employee (public sector)	Video call
17	55	F	Piemonte	Employee (public sector)	Video call

daily activities. Patients perceive a change in their body which also impacts the emotional sphere:

Now I feel 15 years older on my shoulders, I look at myself in the mirror and I don't even recognise myself ... I call [my body] the carcass because really, I don't recognise myself (Code 06.67).

I have aged so much both physically and in appearance... I have lost my hair... there has been a complete metamorphosis of what my personality was, you don't recognize yourself anymore! [...] because your body doesn't follow you, you don't recognise yourself anymore because when you look at the mirror you look like shit... because if you used to run now you can't even walk (Code 08.25).

Long-COVID – this “monster”, “alien”, “housemate”, “this thing that eats you up inside”, “that has taken over my body” as defined during the interviews (Code 06.22; Code 06.45; Code 06.56; Code 01.28; Code 02.12) – determines a reorganisation of social life. The symptoms cause isolation that leads to withdrawing from others. As several interviewees stated:

I no longer have a life because I go to the doctors and I go back home, also because whatever I do for me is really very complicated because I am very tired” (Code 08.22).

Most people maybe get together and have a pizza in the evening ... from 6 p.m. onwards I start my fever and I literally fall asleep between 9 and 10 p.m. Now it becomes really difficult for me to sustain an evening in the company, also because I can't even stand the confusion, the noise [...] So in the very normal social relationships I had before, I'm scaling everything down according to my strengths, my possibilities, when I succeed (Code 07.42).

Another interviewee states:

If there was a sociality before [...] [now it has disappeared] and it's difficult to metabolise [...] I'm not so young but I'm not so old yet that I'm from a bed to a couch, I didn't expect that (Code 08.27).

Symptoms also have an impact on family and domestic life: *Before, in the morning with my husband we*

used to say: “Let's go to the seaside with the motorbike!”, or we used to decide overnight to do something ... or: “Tonight we are all eating at my house and I will cook something” [...] Now I feel like a burden because I have prevented my husband from doing things because of Long-COVID (Code 06.71, Code 06.69). From the interviews it emerges how the professional life is also compromised since, due to the symptoms, patients not only find it difficult to physically reach the workplace but also because they perceive severe limitations caused by cognitive/memory troubles or brain fog; they feel less “performing”:

I can't do it anymore and I find myself having problems, like... I read something I don't understand, I read it wrong, or I write something instead of something else, so it causes me problems at work (Code 17.31).

Now I don't even know what I'm doing, I mean, I talk to my boss and two minutes later I don't remember what we agreed to do; I read a name on the computer, I raise my head, I don't know that name anymore [...] My boss [...] had a very good and healthy person and now he has me that... today I called him by a name that is not his name (Code 02.22; Code 02.29).

Long-COVID causes a loss of autonomy; patients are no longer able to provide for their own needs, and they depend on family members, relatives, or friends. Interviewees state:

It was devastating, I am no longer able to be an autonomous person... even to go for visits I need to be accompanied by my husband who has never accompanied me anywhere because I have always been independent (Code 08.44).

For me to walk 200 meters means arriving with my tongue hanging out, I can't do it... now for everything, I have to be accompanied and this is no longer a life (Code 10.28).

2. UNCERTAINTY

Patients have undergone several examinations and consulted multiple specialists in order to reach a diagnosis. On different occasions, they encountered

poor medical knowledge among doctors about Long-COVID, which has been often perceived as a lack of attention to their suffering. Specialists prescribed a multitude of diagnostic examinations, which in most cases yielded negative results. As two interviewees state:

I went to the pulmonologist who actually told me: "You fit as a fiddle", then of course he did a lot of blood tests, and looked up a lot of values... maybe they would tell me: "You're deficient in vitamin B, B12, D" ... but everything was perfect! I also grew a bit angry because at a certain point you hope that some values will come up (Code 07.13).

Long-COVID doesn't leave a trace [...] the MRI doesn't detect anything, I've had a chest CT scan and found nothing at all, electromyography nothing at all... but I have muscle weakness, I hold myself up with crutches to walk because otherwise, I fall down since I also have vertigo (Code 03.18).

Living with an undiagnosed illness for a long time is difficult; receiving a diagnosis allows a person to give a name to his/her condition but also to follow a specific therapeutic program. Even when no effective treatments are available, as in the case of Long-COVID, obtaining a diagnosis increases the chances of being able to deal, in some ways, with the disease. As one interviewee states: *I need help from medicine because... otherwise I can't do it alone... that is, my fear is to stay like this... like this not only physically but also like this without a diagnosis... in a sanitary, medical limbo (Code 10.38).* The situation becomes even more complex since most of the Long-COVID symptoms (such as brain fog, pain, and fatigue) are not objectifiable through instrumental examinations and are, in a certain sense, unjustified because "inexplicable" i.e., *sine causa*. Patients state that this lack of objective "data" generates an attitude in doctors that often tend to underestimate and minimise their symptomatology. For this reason, they were frequently confronted with scepticism and often felt stigmatised by doctors. Patients state that on several occasions they have been told: *Yes, but you don't have anything anyway (Code 16.17)*, or that they felt treated with condescension, or that they have been confronted with doctors who have psychologised their suffering:

The explanation always given is: "You are crazy!" (Code 15.45).

A neurologist who didn't know me, who had never seen me before, didn't even look at my face, saying: "But that's not possible! You only have anxiety!" (Code 02.27).

[I received] a diagnosis of Covid-related chronic fatigue syndrome. Other neurologists told me that I'm simply anxious. One neurologist commented that Long-COVID is psychological, so he prescribed me several psychotropic drugs (Code 03.25).

A significant consequence of not receiving a diagnosis or feeling disbelieved is the sense of isolation: *The support I would like to receive, says one interviewee, is definitely that of a doctor who believes that I'm sick (Code 09.08).* Due to the lack of medical attention, some patients turned to other healthcare professionals on their own initiative and privately:

So I decided to go to a rheumatologist and see if at least she could understand something (Code 08.21).

I tried to find a place where I could do physiotherapy because I thought that maybe I need some rehabilitation... after so many months of being immobile, it physically debilitated my muscles... I don't know, it was my idea (Code 01.19).

3. PSYCHO-EMOTIONAL EXPERIENCE

The uncertainty that characterises the medical approach to Long-COVID has a negative impact on the illness and the psycho-emotional patients' experience. The interviewees referred to having difficulties in accessing healthcare services and receiving a linear clinical-therapeutic treatment mainly because they got the virus while remaining in isolation at home and therefore without having been hospitalised for acute Covid-19. This, in their opinion, has led them to manage their symptoms autonomously, to be unsupervised, to be unable to undertake specific treatment and to not be allowed to benefit from ad hoc exemptions or support. All this makes them feel abandoned:

I have symptoms that have never even been considered [...] I feel abandoned (Code 02.08), or: I feel neither frustrated nor angry, but abandoned. Abandoned at the medical level, both with regard to general practitioners and also

with regard to the public healthcare system (Code 16.40). The absence of support is not only medical but also employment-related because any facilitation reserved for vulnerable workers is lacking. Long-COVID patients risk job replacement, demotion and, in some cases, the loss of their job. Two interviewees state:

I realise that we are abandoned at work, because... if there is no possibility of smart working, you have to take a lot of sick leave (Code 17.21).

There should also be an interchange with occupational medicine which then has to define the person's capacity to work because Long-COVID has a disabling impact... in the sense that... I certainly want to think that [the disease] is temporary, but the problem is... as it happened to me... I was not allowed to have smart work and I had to leave my job (Code 01.40).

Patients also complain about the lack of family and social support, not only because Long-COVID causes isolation from others but also because the absence of an official diagnosis has repercussions in daily life and on the patients' relational sphere. Very often, they are not believed by family members, relatives or friends. Moreover, Long-COVID is an emerging disease, it is barely mentioned in the public debate, and not everyone knows what it is.

Some interviewees reported that they hardly speak with others about their illness:

Actually, I've almost stopped talking about Long-COVID, because we don't talk about it that much anyway at the public level and there are still people who don't understand it [...] I'm really disappointed by the fact that they don't know anything about Long-COVID or that I'm living with Long-COVID (Code 04.31).

At home, they understand only now what Long-COVID is, not because of me, but because they hear talking about it on television... just to tell you... my mum [...] comes in one day and says: 'Ah look! They're talking about Long-COVID on television, they're talking about you', 'I've been telling you for a long time, now you're telling me!'... I mean, do you understand? Even making people understand it is not easy (Code 06.32).

Feeling abandoned by doctors, by the healthcare system, at work and by family members can generate feelings of anger, discouragement, loneliness, fear, frustration and worry. This impacts the psycho-emotional experience:

The problem is that the situation doesn't improve and obviously if before there was the hope of getting better [...] now there isn't anymore because something else always comes up and I feel worse and worse. It also becomes emotionally heavy, I've always dealt with problems, I've always seen the glass as half full and even there I'm no longer me... I start to see the glass as half empty (Code 08.25).

I've always been a sociable person [...] I've always been a person who entertained willingly [...] this situation of the pandemic and then also the disease and everything, it weighs me down, yes... because social relations have... have really frayed (17.34).

The fear of abandonment involves the fear of being left alone, of losing "pieces" of one's existence. Patients who experience abandonment perceive that they have lost parts of themselves and therefore feel that their existence is, from this point on, meaningless. As one interviewee states: *I got to the point of saying with my husband that I would rather die (Code 17.44).*

Discussion

From this study emerges that patients experience everyday complex and multifaceted symptomatology which has a considerable impact on life. The process by which it was possible to name this symptomatology with the label of "Long-COVID" (9, 27) enabled patients to transform their subjective experience into a collective one, to give a name to their suffering and to spread information about their individual conditions (28). The name "Long-COVID" has thus been able to establish itself as the widespread designation for a syndrome, even in public health discourses (28). However, this switch has not been sufficient and successful because several aspects of Long-COVID likely contribute to uncertainty, including unpredictable symptoms and prognosis, ineffective treatments, and

limited information about the diagnosis. For these reasons, there is no univocal definition of Long-COVID within the international scientific community, nor there is a clear and recognised classification that allows patients to be included in effective clinical pathways. The “ignorance” (29) that characterises the medical approach to Long-COVID has a negative impact on the illness experience because it causes profound uncertainty in patients: uncertainty about the origin and causes of symptoms, how symptoms may progress, and how an effective remedy may be found. This causes uncertainty about the present and the future. Women interviewed for this study refer to difficulties in accessing healthcare services and obtaining medical support; they have received only partial clinical care and, in addition, they suffer from a disease that is still little known and where even receiving a diagnosis is very complicated. Delays in diagnosis emerge as one of the many issues that have repercussions in daily life and on the relational dimension. Hence also the difficulties felt by family members, friends and colleagues to really perceive the patients’ discomfort. The uncontrollable nature of symptoms, most of which are refractory to treatment and pharmacological interventions, represents an ontological attack that profoundly changes the patients’ experience of life, that causes a loss of control by altering, also, one’s body image and affecting one’s psycho-emotional experience. The physical limitation leads to a total or partial loss of one’s autonomy, by causing major changes that impact all aspects of life. Interviews show how independence and self-confidence are strongly reduced. Women suddenly find themselves confronted with a very different kind of lifestyle than before, without receiving adequate medical, social, family, work and institutional support, this has emerged also in other qualitative research focused on the illness experience in Long-COVID developed with patients coming from other national contexts (10, 30-35). The absence of knowledge and information about Long-COVID symptoms can cause worry and confusion in patients. From the interview analysis, it emerges how the difficulty of being believed – since, despite the fact that patients show important symptoms, diagnostic and instrumental examinations give negative results – causes deep suffering. Patients are unable to obtain any evidence or medical confirmation

of their somatic symptoms. The impossibility of finding objective data that can clarify the cause of symptoms exposes patients to the risk of seeing their suffering constantly underestimated, inadequately treated and delegitimized. This risk is one of the elements, among many that have already been analysed (36, 37), that connects Long-COVID with “medically unexplained syndromes” – MUS – or some contested diseases (38, 39) for example chronic fatigue syndrome (40, 41), migraines (42), fibromyalgia (38, 43, 44). Furthermore, several studies (45-47) have shown that physicians (often male) frequently dismiss the knowledge and experiences of their (frequently) female patients even in the case of chronic pain: pain is also underestimated and underreported because medical professionals tend to frame it as a psychosomatic phenomenon or, in any case, amplified by emotional and behavioural factors (as also happens with CFS, FS and other medically unexplained symptoms). Long-COVID patients interviewed for this study also reported that their illness experience has been often interpreted according to psychosomatic if not psychiatric categories. This factor leads to a deep rupture between two different “explicative models” (48), namely that of the doctor and that of the patient; patients resist the hypothesis that their illnesses may have a psychological or psychosomatic component because they consider the disease as physical and real. Living with a state of the generalised, highly debilitating but undiagnosed illness generates in patients a deep sense of abandonment, by increasing feelings of isolation. Women interviewed state that they feel stigmatised because their illness is not recognized. They denounce institutional discrimination (49) that in fact hinders access to care by keeping them away from health services. Discriminatory experiences can also lead to the development of internalised stigma (49), which occurs when people suffering from a certain health condition interiorise damaging public perceptions and accept them as being applicable to themselves. Internalised stigma is characterised by feelings of guilt, shame, worthlessness and, in some cases, suicidal tendencies. For all these reasons, for patients obtaining a diagnosis of a medically recognised disease would be crucial. This would not only allow them to see their suffering legitimised and to be included in effective and multidisciplinary care pathways

but also to benefit from a form of protection by the NHS (such as co-participation in healthcare costs and medication reimbursement), to receive exemptions or certificates of disability/disability or sick leave. We believe that offering answers are also crucial considering the extension of the Long-COVID phenomenon. Due to the increasing number of patients or people affected by Covid-19, and thus at risk of developing Long-COVID, the recognition issue acquires great relevance in terms of public health policy (7).

Strengths and limitations

Only women participated in this study. This was not due to a methodological choice but to the fact that only female patients have expressed their interest in taking part in the research. This is an element that has not been explored in depth in this first stage of the study but it shows some of the gender dynamics that seem to shape Long-COVID as a phenomenon. A further research phase could foresee the recruitment of only male patients in order to compare data. From the interviews conducted, important changes in the management of daily life emerged, which involved not only the patients but also family members and caregivers. This aspect was not investigated. Another limitation might be the generalisability of our sample. Study limitations can be given by the fact that the total population of the study was composed of only 17 respondents; this number, while deepening the study phenomenon in detail, could make it difficult to generalize the results. Therefore, it is suggested to implement future research aiming at exploring the illness experienced by patients suffering from Long-COVID in Italy.

Conclusion

The present study contributes to the literature by providing an account of the subjective experiences of Italian women with Long COVID, including their understanding of illness. The aim was to portray a snapshot of the experience of those who experience a debilitating and challenging Long-COVID, by experiencing a significant reduction in quality of life. We

hope that the findings will provide important contributions to the development of flexible, person-centred interventions for people recovering and rehabilitating from Long-COVID. In addition, we hope that medical knowledge about this emerging disease will be developed and increased in order to make Long-COVID a less stigmatised condition, to promote the development of an integrated approach to patients, and thereby improve the doctor-patient relationship.

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