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Research Article

Exploring perceived social support in Spanish patients with Long COVID through online discussion forums: A qualitative analysis.

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Short Title: Social Support in Long COVID: Forum-Based Analysis

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Keywords: Long COVID; Social support; qualitative analysis; online forums; peer-based support.

Abstract

Introduction: Long COVID syndrome has significant psychological impacts, compounded by feelings of insufficient support. This study aims to analyze individuals' experiences with Long COVID regarding their perceived social support through a qualitative analysis of online discussion forums.

Methods: A qualitative substudy was conducted as part of a randomized clinical trial (RCT) evaluating the effectiveness of an online group rehabilitation program. A total of 330 posts from the program's discussion forums were analyzed using inductive thematic analysis, with data processed via NVivo11 software.

Results: Three main themes emerged related to different types of social support: formal, informal, and peer support. Concerning formal support, patients reported insufficient empathy and support from medical professionals, perceiving themselves as neglected. Regarding informal support, many experienced isolation and social judgment from family and friends, who lacked understanding of their condition. In contrast, they deeply appreciated the support and empathy shared with others experiencing similar struggles (peer support), which fostered a sense of collective resilience in their recovery.

Discussion and conclusion: The study underscores the need for improved support strategies, both through enhanced healthcare assistance and strengthened personal and peer-based networks for Long COVID patients.

Introduction

After hundreds of millions of cases of coronavirus disease (COVID-19) that have emerged worldwide, understanding the consequences of this disease has become crucial [Li et al., 2023]. Indeed, health care systems are currently facing unprecedented challenges in addressing the long-term complications [Siddiqua, and Hossain, 2021].

Among these consequences is a newly recognized condition: Long COVID [Ostrowska et al., 2023], characterized by a broad range of symptoms [Hayes et al., 2021] This condition leads to functional limitations, and has been acknowledged as—at least temporarily— a potentially disabling condition that substantially reduces the quality of life [Samper-Pardo et al., 2023a].

To date, research on Long COVID syndrome has primarily been conducted from a medical perspective, with studies focusing on the disease's onset, progression, or symptomatology. However, less attention has been paid to the examination of psychosocial factors, including social support [Lüscher et al., 2023]. This area of research is crucial for designing interventions aimed at promoting the well-being of these patients [Seighali et al., 2024].

For instance, the deterioration of health, awareness of deficits, and associated occupational and personal repercussions can give rise to significant psychological challenges for Long COVID patients [Espinar-Herranz et al., 2023]. The psychological impact of this illness is also intensified by a frequently reported perception of insufficient support in managing persistent symptoms [Bota et al., 2024], leading these patients to express a need to feel heard and understood [Tíscar-González et al., 2023]. To address this need, support communities began to emerge early in the pandemic, primarily through social media platforms [Al-Jabr et al., 2023]. These groups facilitated the exchange of information about the disease, reduced the social isolation of their members, and consequently improved their well-being. Over time, more specialized support communities have been established and developed [Mullard et al., 2023]. These communities — in addition to providing emotional support— allow users to share their symptoms with others, giving meaning to their experiences. They also instill hope among those most affected by showcasing successful recovery stories, which may foster a greater willingness to continue fighting the disease [Day, 2022].

Numerous quantitative studies on patients diagnosed with Long COVID report on the extensive range of symptoms experienced. However, to better identify these symptoms and their impact on daily life, a deeper exploration of the individual recovery experience is necessary. In this regard, patient-centered qualitative studies provide valuable insights and serve as a useful resource for guiding interventions and treatments [Zheng et al., 2024; Duan et al., 2023]. Although this methodology is rarely used, some qualitative studies have been conducted, which primarily underscore the negative impact on the emotional well-being of patients suffering from this illness [Samper-Pardo et al., 2023b]. To date, most of these studies have explored participants' experiences through interviews and focus group methodologies. While these approaches allow for an in-depth examination of patients' lived experiences, they may be particularly demanding emotionally and socially for some patients in the context of a condition like Long COVID, which could potentially exclude those who are severely affected [Wurz et al., 2022].

The inclusion of the Internet in the research process has transformed data collection by offering new tools and contexts for gathering, storing, and analyzing information. Online discussion forums are one such tool, where the absence of a researcher encourages more spontaneous sharing of experiences, enabling participants to express themselves freely without the constraints of face-to-face interaction [Roldán Tovar et al., 2021].

Compared to traditional methodologies like interviews and focus groups, online forums provide a more flexible, less resource-intensive alternative. Interviews may exclude individuals who are unable to participate due to health constraints, while focus groups can be emotionally taxing. Forums allow participants to engage at their own pace, reducing the emotional burden and fostering candid discussions, especially on sensitive topics like health struggles. Additionally, forums overcome barriers such as physical, geographical, or time-related limitations, making them more accessible for participants with severe conditions [Stetten et al., 2019; Roldán Tovar et al., 2021; Tanis, 2008].

Qualitative analysis of online forums is particularly suited to studying social support in Long COVID. These forums provide a natural and less intrusive environment where individuals can share their experiences of the disease. In addition, this tool not only facilitates the collection of diverse perspectives but also offers valuable insights into peer support and community-building, which may not emerge in traditional interview-based studies. This makes online forums a particularly effective tool for understanding the social dynamics and collective resilience of Long COVID patients [Mills et al., 2024; Day, 2022].

Nonetheless, it is important to note that the use of self-reported data from online forums presents certain limitations. While these platforms allow for honest and spontaneous expression, the absence of professional oversight means that participants' narratives may be shaped by personal interpretations or emotional states, potentially leading to an overestimation of symptoms or subjective distortions, as observed in similar contexts such as pain-related forums [Collins, and Semino, 2024]. Moreover, professional evaluations—such as those conducted in clinical settings—may diverge significantly from patient perceptions, particularly among individuals affected by fatigue or cognitive impairments associated with Long COVID [Ceban et al., 2022]. These aspects should be considered when interpreting the external validity of the findings presented here.

The aim of this study was to understand and analyze, through qualitative data reported and collected from online discussion forums, the experiences of individuals with Long COVID regarding perceived social support in managing their disease. This research is a substudy, utilizing a sample of patients who constitute the intervention group of a randomized controlled trial (RCT). The primary objective of the RCT was to evaluate the effectiveness of an online multimodal group rehabilitation program in improving symptoms and quality of life for patients with Long COVID, along with additional secondary variables.

Methods

Study design

A qualitative embedded study was designed, as previously mentioned, within a larger randomized controlled trial (RCT). In this trial, patients in the control group received their usual treatment from their general practitioners and specialists, while patients in the intervention group, in addition to their usual treatment, had access to a group-based multimodal online rehabilitation program. A total of eight sessions were conducted via videoconference using the Google Meet application. Each one focused on managing various types of symptoms (physical, cognitive, respiratory, etc.) and their impact on quality of life. This RCT was registered with ISRCTN (registration number: ISRCTN15414370), and detailed information on its methodology can be found in its protocol article [León-Herrera et al., 2023].

Qualitative methods, optimal for exploring human experiences in depth, were chosen for the purpose of gathering subjective data and gaining insight into the perceptions and experiences of Long COVID patients regarding perceived social support [Morgan, 1997]. The research team adhered to the checklist of the Consolidated Criteria for Reporting Qualitative Research (COREQ) (**Supplementary Material**) [Tong et al., 2007].

Sampling and sample size

The participant inclusion criteria were as follows: being aged between 18 and 80 years, experiencing Long COVID symptoms for at least three months since acute infection that were not explained by an alternative diagnosis, and being members of Spanish associations for Long COVID. Exclusion criteria included: having an uncontrolled serious medical condition that could interfere with adherence to the rehabilitation program; receiving structured rehabilitation or psychotherapeutic treatment from health care professionals; participating in another clinical trial in the past six months; pregnancy or breastfeeding; significant suicide risk; and having medical, psychological, or social issues that could seriously affect the participation in the study.

An intentional sampling strategy [Miles et al., 2019] was employed among Long COVID patients who were members of Spanish patient associations and collectives. The research team informed the presidents of these associations about the project and its objectives through an invitation letter. Interested individuals were asked to contact the project researchers. An evaluating researcher (SL-H) contacted them to determine if they met the study's inclusion criteria. Recruitment took place during a two-month period, from November 2022 to January 2023.

The study population for this qualitative analysis consisted of 67 patients who were part of the clinical trial intervention group, as they were the only ones with access to the online platform and thus able to respond to the discussion forums contained therein.

Data collection

To collect data, discussion forums within a Modular Object-Oriented Dynamic Learning Environment (Moodle) platform were utilized. This platform served as a supportive element in the telerehabilitation program, divided into nine modules (**Supplementary Material**) and acting as a repository for all the information, recommendations, and therapeutic exercises supplied by the team professionals [León-Herrera et al., 2023].

Each module comprised various asynchronous discussion forums moderated by team members with clinical expertise in Psychology, Physical Therapy, and Occupational Therapy. The role of the moderators was to facilitate discussion by occasionally posting guiding questions or thematic prompts related to the content of each module (e.g., "How have you experienced support from others while dealing with fatigue?" or "What strategies have helped you feel heard or understood during recovery?"). These prompts aimed to encourage reflection and interaction among participants without leading their responses or interfering with the natural flow of conversation. Moderators ensured control over discussions by overseeing the tone and content of posts, stepping in only when necessary to maintain a respectful environment and to avoid misinformation or health-related claims that contradicted established clinical evidence. No personal feedback, therapeutic guidance, or clinical interventions were provided by moderators. This approach was designed to safeguard scientific rigor while preserving the authenticity of participants' voices.

Two female members of the research team (BO-B and RM-B), both healthcare professionals with previous experience and specific training in qualitative methodology, were responsible for the collection and analysis of a total of 330 posts published between February 1 and March 31, 2023. All posts were anonymized to protect the participants' identity. The researchers had no prior relationship with the participants, and the participants were unaware of their identities. This approach helped minimize potential biases and ensure greater objectivity in the analysis.

The data collected from the discussion forums underwent qualitative thematic analysis, following the approach outlined by Braun and Clarke [Braun, and Clarke, 2012]. This method was specifically chosen to explore and interpret the perceptions of Long COVID patients regarding social support.

Initially, the research team engaged in an intensive reading and note-taking exercise of the forums posts to gain familiarity with the data set. This process aimed to attain a comprehensive understanding of the content and context of the discussions among participants.

After becoming familiar with the initial material, the first author (SL-H) conducted a preliminary exploration of the forum content to identify relevant segments for the study's focus. This exploration phase helped determine initial codes and potential topics.

Using NVivo 11 software (QSR International), the two experienced researchers (BO-B and RM-B) independently conducted open coding. They systematically assigned labels and codes to text segments capturing significant ideas or themes related to perceived social support. This phase involved breaking down the data into smaller units for detailed analysis.

Through iterative discussions and comparisons, the research team identified patterns and relationships among the codes to develop main themes. These topics represented key aspects of participants' experiences and perceptions regarding social support in managing Long COVID.

Once the initial themes were identified, the team refined them in accordance with the research objectives. This ensured that the themes accurately reflected the data and provided meaningful insights into participants' perspectives.

During the data interpretation phase, representative quotes were selected to illustrate each identified theme. The selected quotes were carefully chosen to capture the essence of the main ideas and reinforce the evidence supporting the study's findings. On occasion, some of these quotes were edited for clarity and readability, while always maintaining their original meaning.

Throughout the analysis process, the research team adhered to rigorous principles of qualitative research to ensure validity and reliability of the findings. Techniques such as peer debriefing and the maintenance of a detailed decision record were used to this end.

Ethical considerations

The Clinical Research Ethics Committee of Aragón approved the conducting of the Randomized Clinical Trial (PI22/482). The procedures carried out to produce this research were adjusted to the ethical standards of the aforementioned committee and to the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Study participants received written information about the voluntary participation, the study conditions, the right to quit at any time, the data security, and the publication of anonymized results. All subjects signed a written informed consent form; their data were anonymized and used only for research purposes. The protocol was followed as approved by the Ethics Committee, and no modifications were required to be reported.

Results

Participant characteristics

Of the 67 patients who had access to the Moodle Platform, 37 (55.20%) actively participated in the discussion forums. **Table 1** presents key demographic data for participants who engaged in the forums and those who did not. Participation was predominantly female, with a mean age of 48 years, married or in a relationship, residing in urban areas, having secondary or higher education, and being employed or on Temporary Work Disability (TWD), with an average of 18 symptoms. Analyses showed no significant differences in most sociodemographic variables between both groups, indicating that the sample was broadly representative of the general population under study. The only exception was educational level, in which a significant difference was observed, as all forum participants had secondary or higher education.

A total of 330 posts were identified in the discussion forums of the platform. Out of these, 82 posts were selected based on their relevance to the study's objectives. After a more thorough review, 71 posts were ultimately included in the detailed qualitative analysis, as they provided significant information regarding the perception of social support among Long COVID patients (shown in Fig. 1).

The remaining posts (n = 259) were excluded because they addressed topics unrelated to social support, such as participants' individual progress in physical or cognitive exercises, technical issues with the platform, or general expressions of gratitude toward the program. While valuable for evaluating other aspects of the intervention, these posts did not contribute meaningfully to the thematic analysis focused on perceived social support.

From the extracted data, three main topics were identified, each with their respective subthemes. The three main themes were related to three types of social support [Taylor, 2011]:

1. Formal Social Support: Including 28 posts, it encompasses support and resources supplied by institutions, organizations, and/or professionals.
2. Informal Social Support: Including 18 posts, it refers to support offered spontaneously and non-structurally by personal and social relationships of the patients.
3. Peer Social Support: Including 25 posts, it focuses on support given among individuals with similar experiences.

Although there was some overlap among these themes, particularly between peer support and informal support (since peer support could be considered a specific type within informal support), they represented a useful framework for interpreting the results.

The variation in the number of posts across themes may reflect differing levels of discussion rather than their relative importance. Given the qualitative nature of the analysis, we did not use frequency as a proxy for significance, but rather focused on the depth, richness, and relevance of the content to determine thematic importance.

Table 2 provides a summary of the three main themes identified in the study, along with their respective subthemes.

Theme 1: Formal Social Support

The analyses revealed a widespread perception of neglect and rejection by the health care system towards these patients. Most participants expressed a lack of empathy from general practitioners and specialists, who often delayed referrals to other specialists and attributed symptoms to psychological disorders without sufficient basis. This attitude caused frustration and discomfort among the patients. Additionally, a significant disparity between autonomous communities in Spain was perceived, as some patients appreciated greater multidisciplinary care in certain regions compared to others less developed in this regard.

Perception of neglect and rejection by the health care system. Participants felt neglected, rejected, and disrespected by their health care professionals, expressing dissatisfaction with decisions attributing symptoms to a psychological disorder.

"Many of us have felt rejected by some physicians. Referrals to specialists are delayed, and medical appointments often lack empathy and respect." (Woman, 41 years old)

"After ruling out known illnesses, we are often referred to mental health. They initially thought I was suffering from depression, and my psychiatrist diagnosed me with a somatic symptom disorder. " (Woman, 51 years old)

Perceived disparity between autonomous communities. Participants noted a perceived disparity in Long COVID care among different autonomous communities, with some areas believed to be providing more effective and comprehensive treatments than others.

"In my autonomous community, we are light years away from having this disease treated with a multidisciplinary team and receiving the best possible care compared to other communities." (Woman, 41 years old)

Theme 2: Informal Social Support

The theme of informal support from family and friends revealed a profound isolation and social stigma experienced by many Long COVID patients. Many participants felt lonely and judged during their recovery, as their loved ones often lacked an accurate awareness of the severity of their condition. This led them to a significant social isolation, with some patients feeling excluded from activities that brought them happiness due to a lack of acknowledgment of their limitations. Personal relationships were negatively affected, as patients felt misunderstood and disbelieved by those around them, further exacerbating their sense of disconnection and loneliness.

Social isolation and stigma. The results highlighted a profound impact on Long COVID patients' social lives. Many experienced the loss of personal relationships due to a lack of understanding of their situation. They felt judged for being unable to work and for the negative effect their illness had on those around them. Furthermore, they expressed frustration over friends and family not understanding the changes in their lives, feeling disconnected and often not believed. This social isolation was exacerbated by the difficulty in keeping up with usual social activities, contributing to a gradual sense of detachment from active social life.

"Some people have disappeared from my life. Not everyone understands your situation. Sometimes I feel judged, as if I didn't have the right to do something that brings me happiness just because I can't work. It's also tough to see how my situation negatively affects those around me." (Woman, 38 years old)

"It's a total life change, you feel like you've aged 10 to 15 years at least. People around you who continue with their lives don't understand that." (Man, 51 years old)

"Socially, you can't keep up with the pace of others, so in the end, you gradually drift away and stay where you're comfortable." (Man, 29 years old)

Theme 3: Peer Social Support

Participants greatly valued peer support through forums. They stressed the usefulness of sharing experiences and resources among individuals facing similar symptoms, feeling accompanied and supported by this mutual exchange. For many, this support network was crucial in their recovery process, providing them with hope.

Acknowledgment of the worth of other participants' recommendations and perception of these as a source of mutual support. Participants emphasized the importance of exchanging feedback and recommendations on efficacious treatments and experiences. They found the ideas and advice shared by peers to be useful and comforting, highlighting the role of this mutual support in their recovery.

"Since it's a new and unknown disease, it's very useful for the group to share their advice. I believe this mutual support is key to our recovery." (Woman, 35 years old)

"Communicating with other affected individuals is positive because of the feedback we can offer on experiences that have led to improvement."(Woman, 41 years old)

Sense of understanding, network, and group support. Forums provided participants with a sense of community and significant support. Discovering others in similar situations brought comfort and a feeling of not being alone, crucial for coping with the illness and seeking collective solutions.

"Seeing that there are others going through the same thing is incredible, things I thought were just unique to me... We have a great opportunity to form a network, to try to achieve something more, especially in terms of treatment..." (Woman, 51 years old)

"Talking to other people with the same condition has helped me a lot, as well as seeing that we are not alone in this." (Man, 41 years old)

Shared hope. Despite the challenges and duration of symptoms, many maintained a positive attitude towards recovery. Reading about others' improvements gave them hope and strengthened their belief in the possibility of recovery, fostering determination and confidence in finding effective treatments.

"I feel so much hope reading that you have improved so much, because I want to believe that the same can happen to me too." (Woman, 51 years old)

"Even though I have had these symptoms for almost three years, I do not lose hope that a treatment will come along that will improve them somewhat." (Woman, 53 years old)

Sense of collective struggle in recovery. Patients shared a feeling of collective struggle in their recovery process. The group program motivated them to persevere and establish a dedicated routine for their recovery.

"Even though some exercises are challenging for me, I enjoy doing them because I feel like I'm fighting to recover." (Woman, 47 years old)

"The sessions have helped me to be patient and push myself a little harder each day. Taking small steps in the right direction." (Woman, 48 years old)

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Discussion

This study examined how Long COVID patients perceive social support through the analysis of moderated forum discussions. 55.20% of patients engaged in these forums, sharing diverse experiences that reveal deficiencies in social support within this population, as well as differing perceptions based on the type of support received (formal, informal, or peer).

Regarding formal social support, the results reflect a concerning perception of neglect and rejection on the part of the healthcare system towards patients with Long COVID. Our findings are consistent with previous research indicating that navigating the healthcare system is complex and challenging for this population [Miller et al., 2024; Brehon et al., 2023]. A shared concern among these patients is the lack of knowledge about Long COVID among healthcare professionals [Macpherson et al., 2022]. Given that this is a recent condition, the current state of limited knowledge is accepted by some patients, while others are awaiting answers, which gives rise to feelings of anxiety and frustration due to the uncertainty [Ireson et al., 2022].

In the present study, negative attitudes from some healthcare professionals not only caused emotional distress but also highlighted significant disparities in care across different regions. This phenomenon aligns with findings documented in the existing literature, indicating that such disparities are not only evident between different regions but also among specialists [Maclean et al., 2023; Clutterbuck et al., 2024b]. Addressing these disparities requires a multifaceted approach. First, healthcare providers must receive comprehensive, continuous training on Long COVID to ensure they can recognize and manage this complex condition [Grant et al., 2024; Dempsey et al., 2024]. Standardizing care protocols could also mitigate some of the regional disparities observed [Décary et al., 2021]. Furthermore, telemedicine could be leveraged to bridge gaps in access to healthcare, particularly in underserved areas. Collaborative care models, where specialists work in tandem with primary care providers, could also ensure more consistent care for Long COVID patients across regions [Décary et al., 2021]. These interventions, if implemented, would ensure that all patients, regardless of their geographical location or access to specialists, receive the necessary care [Taghrir et al., 2023].

The study reveals that, in addition to facing medical challenges, patients with Long COVID experience significant lack of understanding and support from their family and friends, contributing to noticeable emotional isolation. These findings are consistent with previous research, which highlights how persistent physical pain, fatigue, or limited energy impede this population’s ability to maintain and develop social relationships, resulting in a decreased contact with family and friends [Chasco et al., 2022; Van de Vyver et al., 2021].

In our study sample, a predominance of female participants was observed. Although the posts did not reveal differences in social support by gender, according to Aghaei et al., women may face more significant impacts due to their social roles and existing structural inequalities. Role conflict, especially between work and family responsibilities, emerges as one of the main challenges for women with Long COVID. These findings underscore the need for providing more personalized counseling and social support to address the complexities of these women's social lives [Aghaei et al., 2022].

Another crucial aspect is the stigma associated with Long COVID, which plays a significant role in the social interactions of these patients. They are often perceived as "carriers of contagious viruses" and face discrimination both socially and in the workplace [Wang et al., 2022]. This stigmatized perception not only imposes sanctions of isolation and social exclusion but also negatively affects the patients' self-image, making them feel guilty or doubt the legitimacy of their symptoms. Negative reactions and lack of empathy from others can trivialize their condition, exacerbating their isolation and impacting their emotional well-being [Wang et al., 2022].

Insufficient awareness and understanding of Long COVID both in the community and within the healthcare system exacerbate these experiences of social isolation [Clutterbuck et al., 2024b].

The lack of an official diagnosis and adequate attention to the sequelae of COVID-19 in public discourse contribute to patients feeling lonelier and more abandoned by the healthcare system, in their work, and with their family and social environment [Moretti et al., 2024].

On the other hand, our study sheds light on the importance of peer support through forums and groups of people sharing similar experiences. Participants largely valued the opportunity to establish connections and share experiences and resources with others who had been similarly affected, finding comfort and hope in this network of mutual support. This exchange not only provided practical strategies for symptom management but also strengthened their sense of community and solidarity in battling the disease. Since the early stages of the pandemic, this type of social support has been crucial, especially as patients grappled with understanding their persistent symptoms. This process of awareness began to unfold as they connected with others experiencing similar situations. The use of technology and online platforms accelerated this process by enabling patients to share stories, symptoms information, and treatment strategies [Maclean et al., 2023]. Through these collective interactions, they were able to identify and define their illness as Long COVID. These online communities not only helped patients recognize the seriousness of their condition and the need for medical attention but also gave a sense of relief knowing they were not alone [Rushforth et al., 2021]. By sharing their experiences and naming their suffering, patients transformed their subjective individual experiences into a collective one, thus solidifying their identity as individuals affected by Long COVID and fostering a sense of belonging and mutual validation [Roth, and Gadebusch-Bondio, 2022].

Despite the challenges they faced, participants in this study demonstrated a resilient and optimistic attitude toward their recovery process. The hope of finding effective treatments and improving their quality of life remains a powerful motivation. However, to enhance long-term care and support, it is crucial to address disparities in medical attention, increase awareness and education about Long COVID among healthcare professionals, and reinforce both formal and informal social support networks. Furthermore, implementing a more robust system for integrating peer support into formal healthcare settings could be beneficial. Involving peer support specialists in care teams may help bridge the emotional and informational gaps that are often left unmet by traditional healthcare providers [Mulvale et al., 2019; Slater et al., 2023].

Given the widespread impact of Long COVID, this study’s results could inform healthcare practices and policies across different countries. Despite regional and cultural differences, patients with Long COVID face common issues, including inadequate medical attention, lack of social support, and stigma. These shared challenges suggest that global healthcare systems must be better prepared to address the needs of this population. Additionally, policies must be adapted to recognize the disease as a chronic condition and ensure equitable care across regions and specialties [Ladds et al., 2020; McNabb et al., 2023; Clutterbuck et al., 2024a].

The study's key strengths include the identification of significant gaps in formal and informal support. In particular, it draws attention to the neglect and rejection from the healthcare system, as well as the profound emotional impact due to stigma and lack of social understanding. However, this study also highlights peer support through online communities as a valuable resource for sharing experiences, symptoms management strategies, and enhancing a sense of belonging and solidarity.

However, the study presents significant limitations. First, participation bias may have influenced the results, as only a subset of participants had access to the online forums, limiting the diversity of the sample. Additionally, the study focused on individuals affiliated with Spanish Long COVID patient associations, which may not fully represent the broader population of Long COVID patients. This selection could have led to a sample that is more engaged in seeking support and information, which may differ from those who are not part of such networks. Consequently, the findings may not be fully generalizable to individuals who are not connected to support communities.

In addition, the research is geographically and culturally specific. This sample's cultural specificity may limit the generalizability of the findings to non-Spanish populations or individuals from different cultural contexts.

There was also a gender imbalance among participants, with 86.48% female respondents and only 13.51% male respondents. This gender bias is consistent with the higher prevalence of Long COVID among women, as has been consistently documented in previous research [Pelà et al., 2022], and reflects the gender distribution of the original RCT cohort from which participants were drawn.

In future research, it would be beneficial to expand the sample size and include a broader geographical and cultural diversity. Additionally, exploring how cultural differences influence the experiences and perceptions of social support among Long COVID patients would provide further insight into the challenges faced by diverse groups.

Moreover, while the content analysis of discussion forums is valuable for exploring deep perceptions and experiences, it does not provide an empathetic view of patient experiences outside the digital environment. There are aspects of social support that may not be adequately captured in a virtual setting or may differ in face-to-face interactions. To address this limitation in future research studies, it would be beneficial to adopt a holistic approach that combines digital methods with traditional qualitative techniques such as interviews and in-person focus groups is recommended. Additionally, conducting longitudinal follow-ups would better elucidate the evolving social support needs of these patients. Integrating qualitative and quantitative approaches would facilitate a holistic understanding of the dynamics of social support in the Long COVID-affected community.

In conclusion, the findings of this study underscore the urgent need to enhance understanding, improve care, and facilitate access to both formal and informal social support for Long COVID patients. It is crucial to implement effective measures that address the multifaceted needs of these patients, thereby ensuring comprehensive treatment and adequate support to enhance their quality of life.

Statements

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Statement of Ethics

The Clinical Research Ethics Committee of Aragón approved the conducting of the Randomized Clinical Trial (PI22/482). The procedures carried out to produce this research were adjusted to the ethical standards of the aforementioned committee and to the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Study participants received written information about the voluntary participation, the study conditions, the right to quit at any time, the data security, and the publication of anonymized results. All subjects signed a written informed consent form; their data were anonymized and used only for research purposes. The protocol was followed as approved by the Ethics Committee, and this no modifications were required to be reported.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

SL-H: Conceptualization, participant recruitment, methodology, thematic analysis, and manuscript writing; RM-B: Supervision of the study, data collection, thematic analysis, review, and editing of the manuscript; BO-B: Conceptualization, methodology, project administration, data collection, thematic analysis, review and editing of the manuscript; SA-L: review, and editing of the manuscript; AA-L: Literature review and manuscript revision; RS-A: Interpretation of results and manuscript revision.

Data Availability Statement

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

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Figure Legends

Fig. 1. Posts selection and analysis

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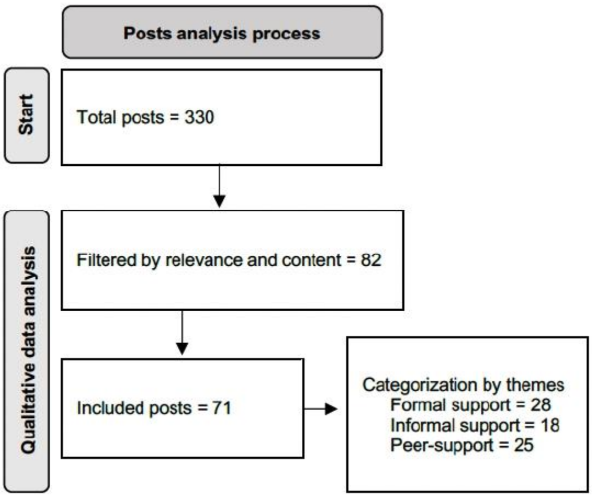

Table 1. Characteristics of engaged and disengaged participants in the online platform discussion forums.

Variables	Engaged participants (n=37)	Disengaged participants (n=30)	p-value
Gender, N (%)			
Female	32 (86.48%)	24 (80%)	0.476
Male	5 (13.51%)	6 (20%)	
***Age,** Mean (SD)	47.68 (7.46)	49 (8.64)	0.503
Marital Status, N (%)			
Single, divorce, or widowed	12 (32.43%)	9 (30%)	0.831
Married or living as a couple	25 (67.57%)	21 (70%)	
Living area, N (%)			
Rural area	10 (27.03%)	6 (20%)	0.502
Urban area	27 (72.97%)	24 (80%)	
Educational level, N (%)			
No studies, or primary studies	0 (0%)	3 (10%)	0.049
Secondary or university studies	37 (100%)	27 (90%)	
Employment status, N (%)			
Employee	13 (35.14%)	16 (53.33%)	0.724
Employee with TWD	15 (40.52%)	9 (30%)	
PWD	3 (8.11%)	2 (6.67%)	
Unemployed	2 (5.41%)	3 (10%)	
Retired	1 (2.70%)	0 (0%)	
Another situation	3 (8.11%)	2 (6.67%)	
***Number of symptoms**, Mean (SD)	18.46 (6.62)	18.20 (5.92)	0.868

Notes: Statistics used: Frequencies and percentages except for variables with *, for which mean and standard deviation have been used. For comparison, Chi-squared was used except for the variables with *, for which Student's t test has been used. **Abbreviations**: TWD: Temporary work disability; PWD: Permanent work disability

Table 2. Summary of the themes and subthemes

Themes	Subthemes
Formal Social Support	Perception of abandonment and rejection by the healthcare system. Disparity in treatment options among communities.
Informal Social Support	Social isolation and stigma
Peer Social Support	Acknowledgment of the worth of other participant's recommendations and perception of these as a source of mutual support. Sense of understanding, network, and group support. Shared hope. Feeling of collective struggle in recovery.