

COMMUNICATION BETWEEN LONG COVID PATIENTS WITH EXCELLENT RESULTS IN THE NEW DISEASE VISIBILITY

COMUNICACIÓN ENTRE PERSONAS AFECTADAS POR COVID-19 PERSISTENTE CON EXCELENTES RESULTADOS EN LA VISIBILIDAD DE LA NUEVA ENFERMEDAD

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RESUMEN

La COVID-19 persistente es una enfermedad aún muy desconocida. Sólo cuando la Organización Mundial de la Salud (OMS) la define a finales del año 2021, es cuando empieza a tener entidad propia. Sin embargo, desde mayo de 2020 se empezaron a crear colectivos de afectados por esta nueva patología buscando soluciones y explicaciones a sus síntomas persistentes. Iniciaron una colaboración con la Sociedad Española de Médicos Generales y de Familia (SEMG) para crear material didáctico y participar en una encuesta a nivel nacional. El objetivo de este trabajo observacional descriptivo es demostrar como la comunicación entre diferentes colectivos afectados de ámbito autonómico y una sociedad científica (SEMG) que aportó valor, a través de las redes sociales y los medios de comunicación, ha facilitado su unión y conseguido el objetivo de poner el foco en el problema de salud de la COVID-19 persistente. Su mejor ejemplo es la plataforma de colectivos de pacientes LONG COVID ACTS (LCA), que ha conseguido ofrecer a los pacientes un espacio digital accesible en el que encontrar información de calidad sobre Long Covid (LC) y compartir su experiencia. El reconocimiento de la COVID-19 persistente empezó a llegar por la exposición mediática de los propios afectados y el eco que se generó en las redes sociales, incrementando el impacto de las noticias hasta llegar a un mayor número de actores sociales. Los medios de comunicación fueron una herramienta fundamental que sirvió de altavoz a los pacientes para llegar a la comunidad médica, científica, y a la sociedad en general, para luchar por el reconocimiento, la investigación y el correcto tratamiento de su enfermedad.

Palabras clave:

COVID-19 persistente Sociedades Científicas, Redes Sociales, Medios de Comunicación, Pacientes, Investigación.,

ABSTRACT

Long COVID is still a largely unknown disease. Only when the World Health Organization (WHO) defines it at the end of 2021, is when it begins to have its own entity. However, since May 2020, there have been groups of people affected by this new pathology who seek solutions and explanations for their persistent symptoms. They began a



collaboration with the Spanish Society of General and Family Physicians (SEMG by its acronym in Spanish) to create teaching material and participate in a national survey. The objective of this descriptive observational work is to demonstrate how communication between different affected groups in the autonomous communities and a scientific society (SEMG) that provided value, through social networks and the media, has facilitated their union and achieved the objective to put the focus on the health problem of long COVID. Its best example is the LONG COVID ACTS (LCA) patient group platform, which has managed to offer patients an accessible digital space in which to find quality information about Long Covid (LC) and share their experiences. The recognition of long COVID began to arrive due to the media exposure of those affected and the echo that was generated on social networks, increasing the impact of the news until it reached a greater number of social actors. The media were a fundamental tool that served as a loudspeaker for patients to reach the medical and scientific community, and society in general, to fight for the recognition, research, and correct treatment of their disease.

Keywords: Long COVID, Scientific Societies, Social Networks, Media, Patients, Research.

Translation by **Paula González** (Universidad Católica Andrés Bello, Venezuela)

1. INTRODUCTION

The Chinese city of Wuhan became, in December 2019, the epicenter of a pandemic whose consequences – some of them irreversible – increase as the hours go by. The illness is believed to have started in a local wildlife and seafood market, suggesting that the virus had been transmitted from animal to person. However, the rapid spread of COVID-19 indicates that it is also a person-to-person transmission (Barrientos-Báez *et al.*, 2021).

A few months later, in May 2020, cases began to appear of people who, once they had overcome acute COVID-19, manifested and maintained various symptoms, such as: anosmia, muscle pain, dyspnea, and extreme fatigue. In other cases, they reported neurocognitive disorders, such as lack of memory or concentration. In all of them, the absence of detectable organic damage that justified it coincided, and the fluctuation of symptoms persisted over time. This set of symptoms began to be called Long COVID (LC). In Spain, the denomination of *COVID-19 persistente* (PC), coined by those affected, gradually prevailed.

Long COVID has been an unknown and unrecognized disease for a long time. The beginnings were very hard and it had different definitions, but only when the World Health Organization (Soriano *et al.*, 2021) defined it at the end of 2021 is when it truly began to have its own entity and greater recognition by the scientific community.

The post-COVID-19 condition occurs in individuals with a history of confirmed or probable SARS-Cov-2 infection, usually three months after the onset of COVID-19 with symptoms lasting at least two months, and cannot be explained by an alternative diagnosis. The most common symptoms are fatigue, shortness of breath, and cognitive dysfunction, but other symptoms can also occur that usually affect the daily functioning of the patient. The symptoms can be of new appearance, after the disease. Symptoms may also fluctuate or relapse over time. For children, another definition may apply. (Soriano *et al.*, 2021)

For over a year and a half, this lack of recognition has meant that those affected do not receive adequate health care for their illness, and even today they still do not receive it. Many aspects have influenced this, among them, that those affected could not confirm the disease with positive tests because they could not access a diagnostic test due to the saturation of the health system during the first wave of the pandemic (Rodríguez *et al.*, 2021a). Besides not being able to prove that they have passed the disease, there are also no specific tests to confirm that they continue to have the symptoms of the disease.

The search for solutions led those affected to create, at the beginning of the pandemic, a network of groups that used social media and traditional media as a loudspeaker to stop being invisible and draw the attention of the authorities. At that time, the groups requested help from the medical community, without receiving a response. In May 2020, only the Spanish Society of General and Family Physicians (SEMG by its acronym in Spanish) became aware of this problem and contacted the groups, initiating a collaborative work, called *Proyecto Marco-19*, to develop care protocols appropriate to their needs.

1.1. Groups and associations of affected people

1.1.1. Number of members

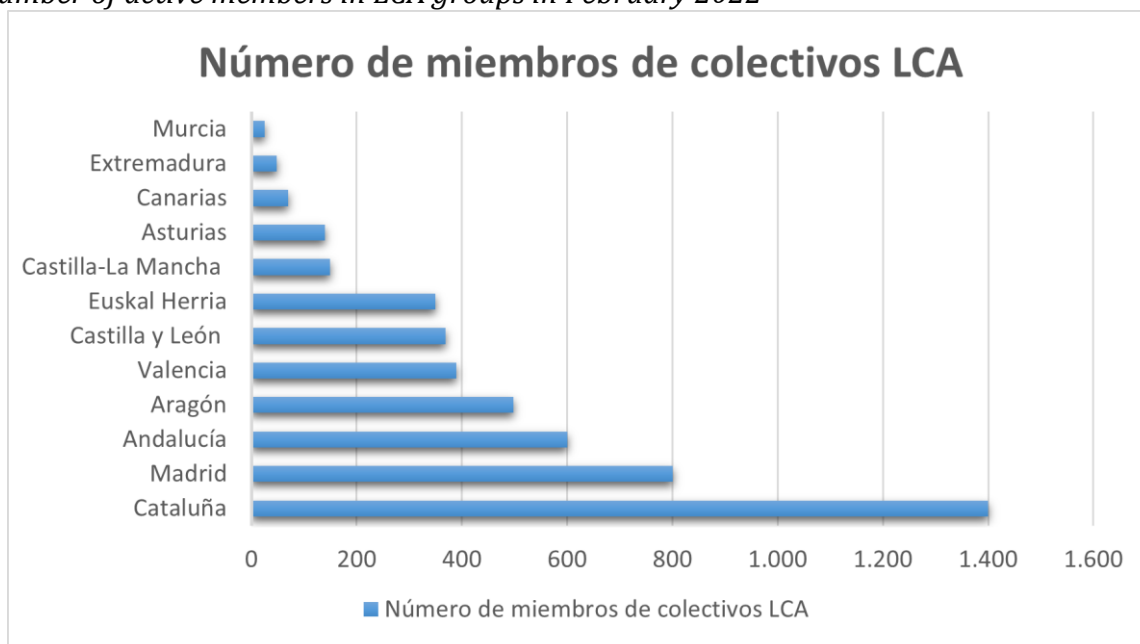
It all started at the beginning of May 2020, when, after weeks of being infected by the SARS-CoV-2 virus and not recovering, Silvia Soler read, at her home in Castelldefels, the case of Lara Toro in an article in *Diario Ara* (Marc-Toro, 2020). This resident of the Eixample neighborhood in Barcelona explained that she had had symptoms of COVID-19 for more than 50 days and that they had not disappeared. Silvia identified with most of the symptoms described in the article and began searching social networks for more cases like hers. There she met other women from Catalonia who were going through the same thing and had even appealed on Twitter to find others affected. It was then that eight patients from Catalonia got together and decided to create the first group of patients affected by Long COVID. At the same time, and on the same dates, the same thing was happening in the Community of Madrid.

Specifically, the group of people affected by Long COVID in Madrid was born in the last week of May 2020, when five people from Madrid, including Beatriz Fernández, contacted the group of affected people in Catalonia, created some weeks before. After a first meeting, they realized that they had a common denominator: they had all started to have symptoms of Covid-19 since the end of February and the beginning of March, which, far from having disappeared in two weeks, continued to manifest themselves constantly or cyclically, greatly limiting their quality of life.

The first two to form a group were Catalonia and Madrid from May 2020, until reaching the twelve autonomous communities that formed Long COVID ACTS in February 2022: Andalusia, Aragon, Asturias, Castilla-La Mancha, Castilla y León, Catalonia, Basque Country, Extremadura, Canary Islands, Madrid, Murcia, and Valencia, with a total of 4,840 active members in total (Figure 1). Groups that work day by day with patients from the Long COVID community, answering their questions on social networks, supporting them in their process, giving them a voice in media interviews, and involving them in all communication actions to always give them more visibility in search of official recognition of the disease.

Figure 1.

Number of active members in LCA groups in February 2022



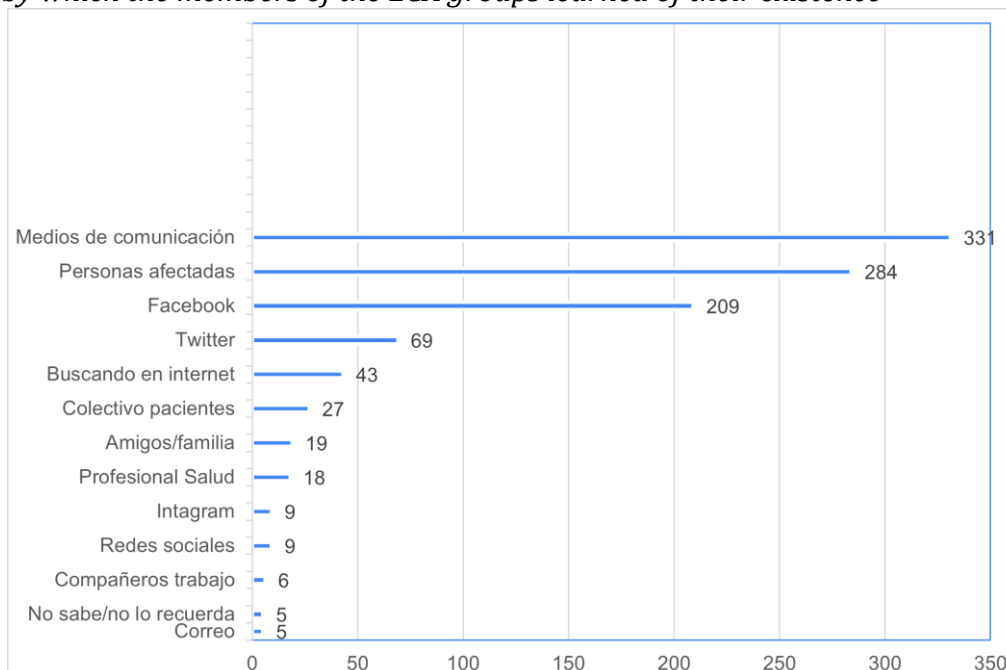
Source: Own elaboration - LCA.

1.1.2. How they found out about the Long COVID ACTS

In September 2021, Long COVID ACTS carried out an internal survey among those affected in all the autonomous communities in which 1,034 people participated. One of the objectives of the survey was to know the way or means by which its members learned of their existence. The results of this survey indicate that 64.7% of those 1,034 respondents met them through the media, social networks, or the Internet.

Figure 2.

Means by which the members of the LCA groups learned of their existence



Source: Own elaboration - LCA internal survey.

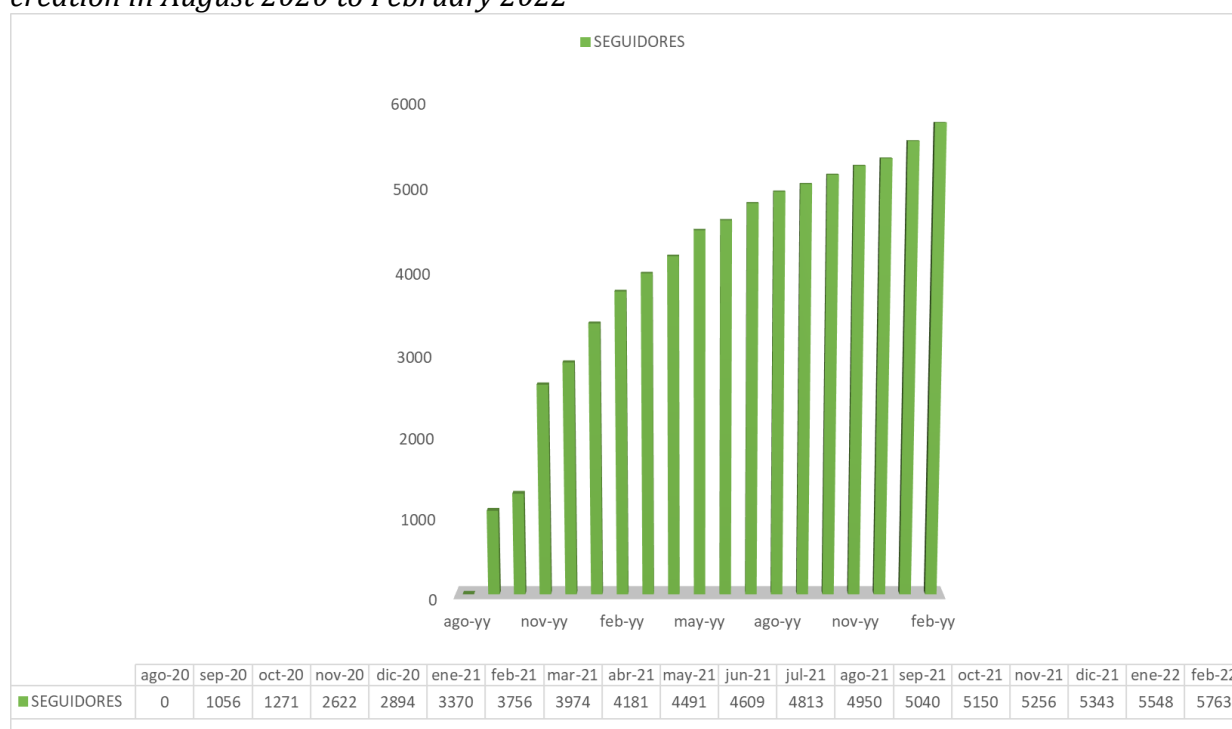
1.2. Number of followers on social networks

1.2.1. Twitter

Long COVID ACTS has a central Twitter account (@longcovidspain), which is responsible for publishing the institutional information of the state group and collaborating scientific societies, such as the SEMG, retweeting relevant information from regional accounts or patient testimonials, as well as content from other accounts of Long COVID patients abroad and scientific advances on the disease. This central account has experienced progressive growth in followers since it was created in August 2020, reaching more than 5,700 followers in February 2022 (figure 2).

Figure 3.

Increase in followers of the LONG COVID ACTS Twitter account (@longcovidspain), from its creation in August 2020 to February 2022



Source: *Own elaboration – Twitter.*

Each autonomous community has also created its own Twitter account (Table 1), so powerful joint information campaigns can be planned on this network, disseminating surveys to patients, informing of important advances from the organization and the scientific community, or even citizen awareness videos.

Table 1.

Twitter accounts and followers that the regional LCA groups had in February 2022.

COVID persistent Catalunya: @covid19persist1	5.312 seguidores
COVID persistente Madrid: @covid_madrid	3.757 seguidores
Long COVID Andalucía: @andaluciacovid	2.170 seguidores
COVID persistente Valencia: @Covid19Valencia	1.697 seguidores
Long COVID Euskal Herria: @covideuskal	1.484 seguidores
Long COVID Aragón: @longcovidaragon	1.266 seguidores
Long COVID Castilla La Mancha @covidpersistent4	598 seguidores
Long COVID Castilla y León: @longcovidcyl	506 seguidores
Long COVID Asturias @covidasturias	425 seguidores
Long COVID Islas Canarias: @canaryLongCovid	391 seguidores
Long COVID Extremadura: @covidextremadur	323 seguidores
Long COVID Murcia: @longcovidactsmu	191 seguidores
TOTAL	18.120

Source: *Own elaboration – LCA.*

1.2.2. Facebook

The LCA-affected groups are also present on Facebook under the name LONG COVID ACTS. Being a closed group, to preserve the privacy of Long COVID patients and allow entry only to people who suffer from it, the statistics are not as complete as those of a public page. However, we can highlight a continuous increase in members since the group's creation on June 2nd, 2020, as the group in Madrid, reaching 3,500 members in February 2022, already consolidated as LCA. In this group, the high participation of the affected people who are members stands out, acting above all as a support group and for the dissemination of relevant news.

A very revealing fact is that the profile of most of the members of the Facebook group is very similar to the result of the Survey of symptoms and disability produced by them, in those affected by Long COVID (SEMG, 2020b) in terms of distribution of Long COVID patients by gender, with 78% women compared to 79% detected by SEMG. Similarly, the average age of the members of the group is 45 years, an age very similar to that obtained in the aforementioned survey carried out by the SEMG (43 years). This denotes a greater impact of Long COVID among young women, as local and international studies have shown.

Figure 4.
Gender of followers in the LONG COVID ACTS Facebook Group



Source: Own elaboration – Facebook.

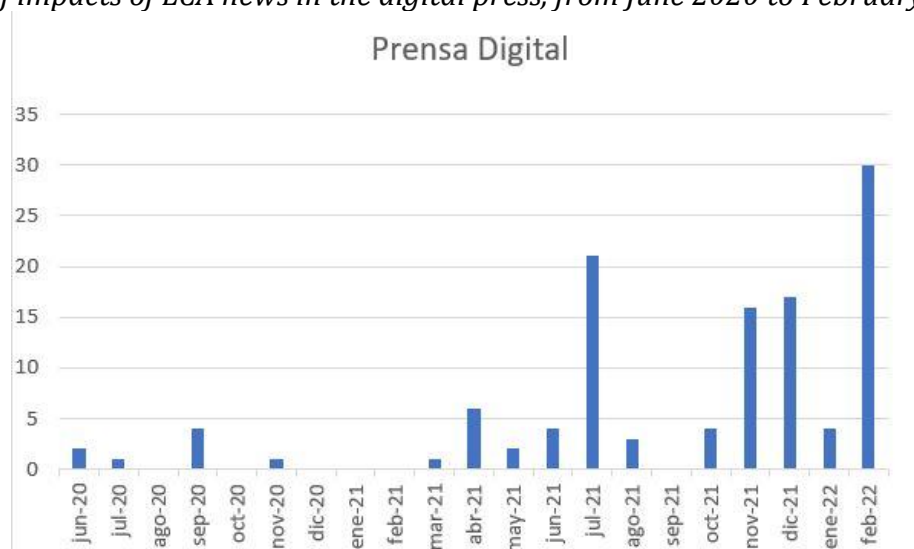
1.3. Number and type of press appearances

The media have been a fundamental tool for the Long COVID ACTS groups, not only as a loudspeaker for those affected by Long COVID when describing their many symptoms, but also to reach the medical and scientific communities and society in general.

The appearances of the affected groups in the national media have been progressively growing throughout the pandemic. Specifically, since October 2020, the Long COVID ACTS group managed an average of two interviews per day. The news stories about Long COVID were picked up by national, regional, and local media.

1.3.1. Digital media

Figure 5.
Number of impacts of LCA news in the digital press, from June 2020 to February 2022

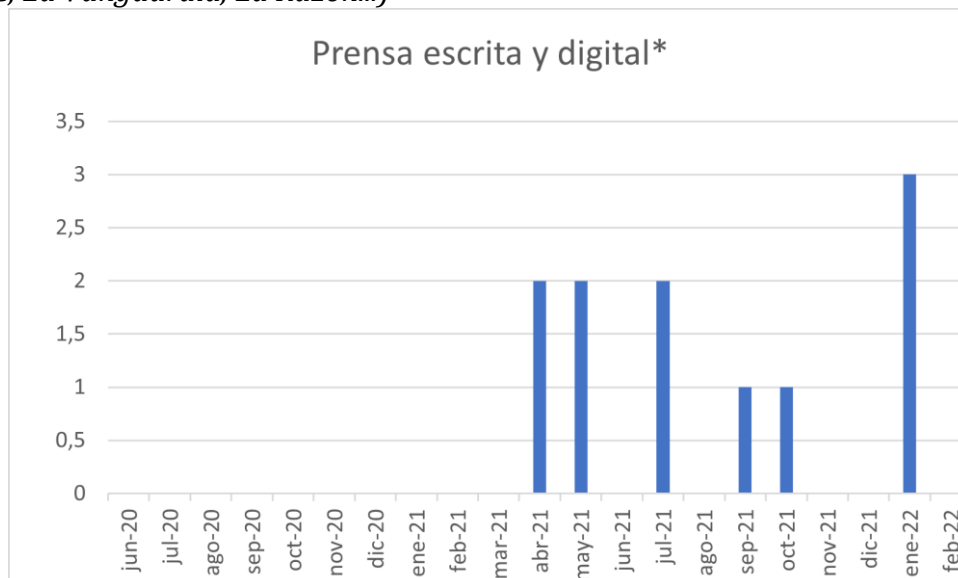


Source: Own elaboration – LCA.

1.3.2. Printed press

Figure 6.

*The number of impacts of LCA news in the printed and digital press, including the *national media that publish the news in their printed edition and digital format (for example, El País, ABC, La Vanguardia, La Razón...)*

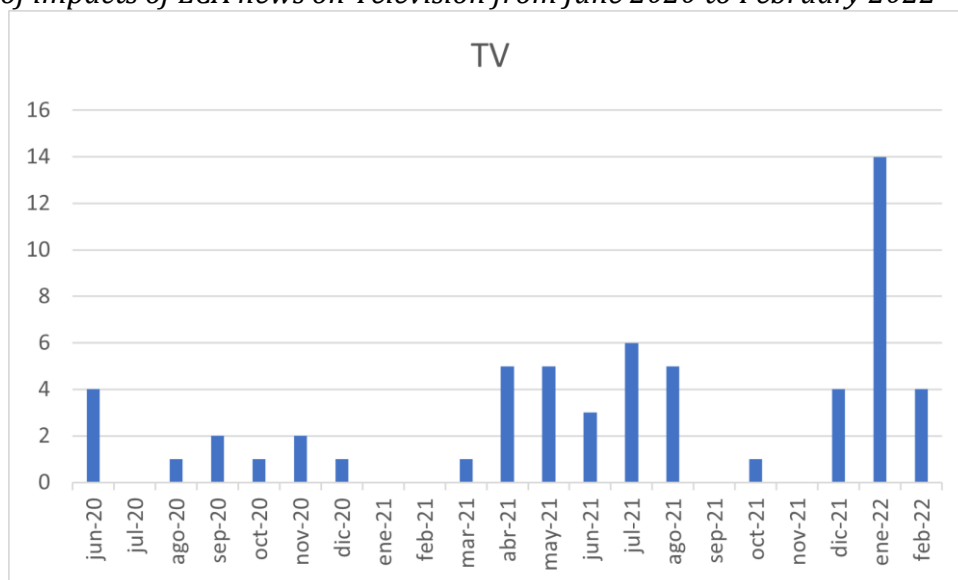


Source: Own elaboration – LCA.

1.3.3. Television

Figure 7.

Number of impacts of LCA news on Television from June 2020 to February 2022

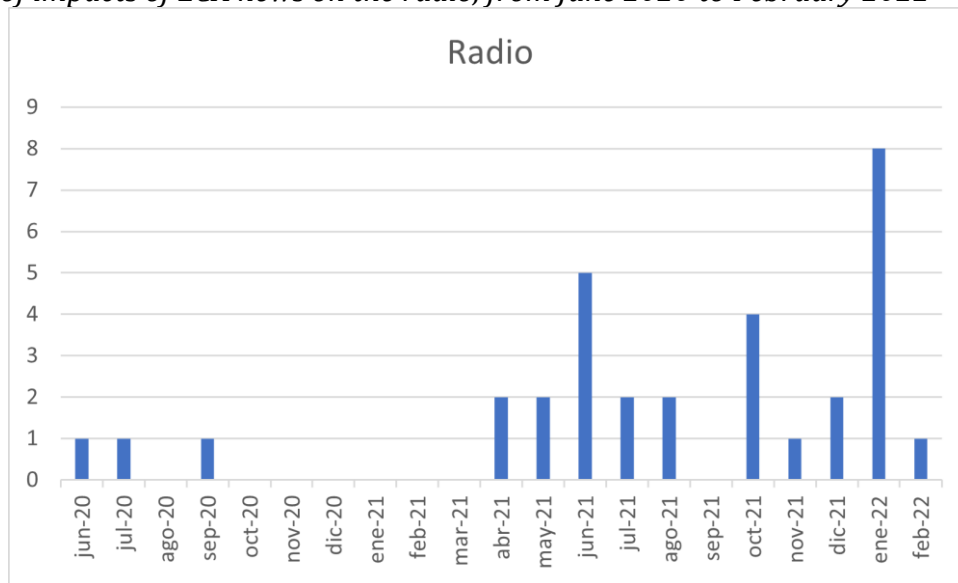


Source: Own elaboration – LCA.

1.3.4. Radio

Figure 8.

Number of impacts of LCA news on the radio, from June 2020 to February 2022

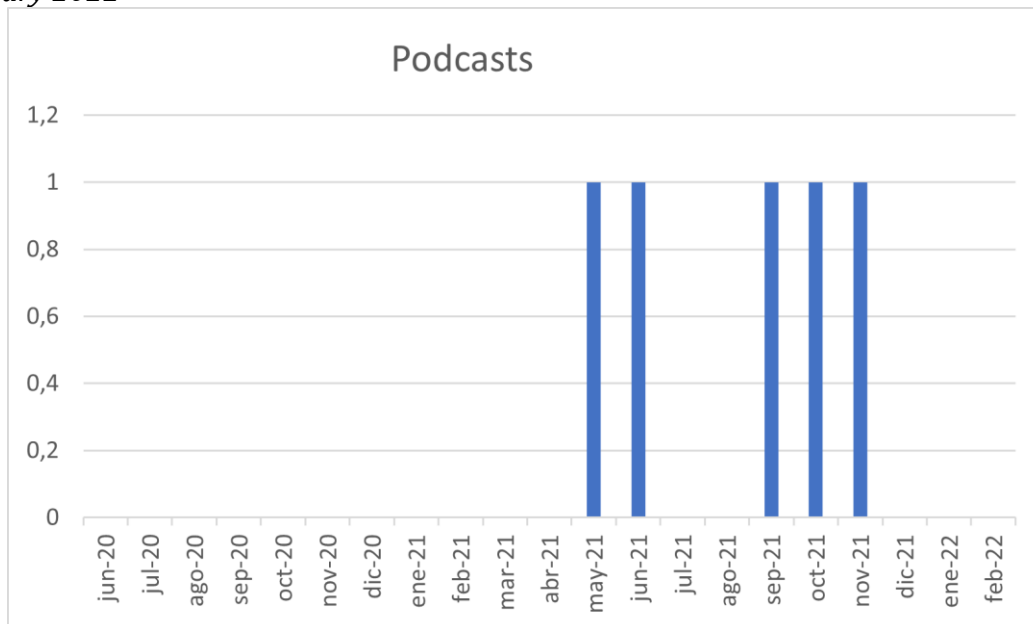


Source: Own elaboration – LCA.

1.3.5. Podcasts

Figure 9.

Number of impacts of LCA news and interviews in podcast format, from June 2020 to February 2022

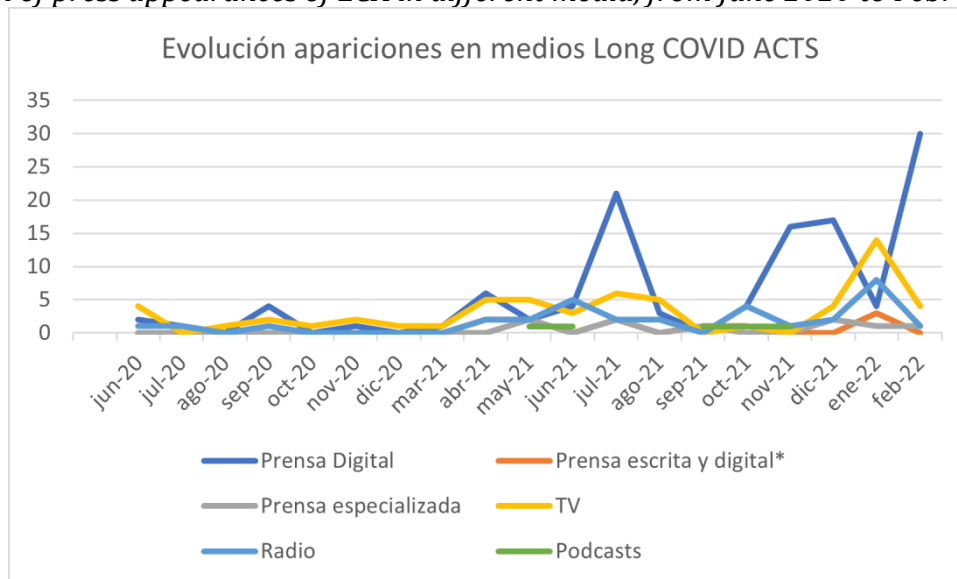


Source: Own elaboration – LCA.

1.3.6. Evolution and total media appearances

Figure 10.

Evolution of press appearances of LCA in different media, from June 2020 to February 2022



Source: Own elaboration – LCA.

Table 2.

Total media appearances from June 2020 to February 2022

Impacts on the media	2020	2021	Until Feb. 2022	
Total	22	144	66	232

Source: Own elaboration – LCA.

2. OBJECTIVES

Demonstrate how communication between different affected groups in the autonomous communities and a scientific society (SEMG) that added value, through social networks and the media, has facilitated their union and achieved the objective of focusing on the health problem of Long COVID. Its best example is the LONG COVID ACTS (LCA) patient group platform, which has managed to offer patients an accessible digital space in which to find quality information about LC and share their experiences.

LCA's use of online communication tools, whose use considerably increased due to the pandemic itself, has increased the visibility of the disease and has led to joint work to achieve its goals. Besides the search for a solution to their health problems, its purpose was to give visibility to the disease in the health and political sphere, for its subsequent recognition; provide doctors with tools to work with patients with this disease; as well as the creation of specific units for monitoring and treatment, etc.

Among the achievements made is the creation of documents, such as: the Basic Care Kit for Patients with Long COVID disease (Spanish Society of General and Family Physicians [SEMG], 2020a), protocols and consensus, such as the I Document of Consensus for the approach of patients with mild symptoms of Long COVID (Association for Self-Care of Health, 2022), or the studies carried out by the SEMG to find out the most frequent symptoms and the profile of most of those affected (Rodríguez *et al.*, 2021b). The largest

project is the Long-COVID-Patient Care Guide (Spanish Society of General and Family Physicians (SEMG) *et al.*, 2021) promoted by the SEMG and LCA, with the endorsement of fifty scientific societies and patient associations. Outside the clinical field, the reception of LCA-affected groups by political representatives stands out, to the point of getting a motion to reach the Senate urging the Government to adopt certain measures to address the problems suffered by those affected by Long COVID in our country (Senate of Spain, 2022).

3. METHODOLOGY

The research method is descriptive observational since the objective of this work is the description of variables during a period, specifically, focused on the monitoring of social networks and impacts in the media generated by the groups of people affected by Long COVID.

The objectives are the following:

Primary: Demonstrate that, through the media and social networks, an unknown disease can be made visible and recognized by health agencies, the medical community, political authorities, and society in general.

Secondaries:

Know the number of groups and associations of affected people and how they know of their existence.

To quantify the number of their followers on social networks since the LONG COVID ACTS groups were created until February 2022, as well as their majority profile (gender and age).

Quantify the number and type of their press appearances, from the beginning of the pandemic to the present, by compiling the media impact of the interviews with Long COVID ACTS patients in an Excel table.

4. DISCUSSION

The health sector is beginning to understand that patients have changed: they search for information on the Internet and consult search engines before choosing a pharmacy, the specialist who is going to treat them, or, when they do not know what is happening to them, they even look for people who are going through the same thing.

The affected people felt very isolated and confused about their situation and medical care was not being offered in the chaotic situation that occurred during March, April, and May 2020. As a result of that first contact, they discharged their own profiles on social networks and created a group of people affected by Long COVID in Madrid. Since then, they receive daily numerous contacts from people who are in the same situation. After the experience of Catalonia and the Community of Madrid, the network grew as affected people from other autonomous communities contacted them.

In a moment of absolute uncertainty, patients come together and create a digital platform in which to share their experiences and seek solutions to the lack of initial medical recognition of the disease. Long COVID ACTS is a project designed by and for patients that has transcended borders -even uniting with other European patient groups- and continues every day, adding support, achievements, and recognition. A chain of empowered and active patients, twinned in Spain under the name of Long

COVID ACTS, an alliance of people struggling to regain health by equitably accessing treatments and advances. Social networks, in this sense, play a fundamental role in keeping up to date with pertinent and relevant information for patients, which is why the increase in members (Table 1) and followers in the accounts of the LCA groups (Figures 1 and 3) has been progressive throughout the pandemic, as has been confirmed in this article.

Similarly, the media, as a result of the progressive increase in press appearances throughout the pandemic (Figure 10 and Table 2), have been a fundamental tool for the Long COVID ACTS groups, not only as a loudspeaker for those affected by Long COVID when describing their numerous symptoms, but also to reach the medical and scientific communities, and society in general.

As with numerous rare or unknown diseases, recognition also comes -thanks to the advocacy and drive of patients- through media exposure and the echo generated on social networks, sharing publications (articles, radio or television interviews, podcasts, etc.), and increasing the impact of the news until it reaches a greater number of social actors. In this sense, the immediacy of social networks does not exist in any other medium and has served as a communication link between people and institutions, between patients themselves, between patients and the scientific community, and society. For this reason, social networks have been and are an essential axis in the communication strategy of the Long COVID ACTS groups.

In the same way, social media users have gone from being mere consumers of information to actively participating in it, in the preparation and management of content, developing group intelligence. It should not be forgotten that 50% of those affected by Long COVID registered in the Survey of symptoms and disability caused by Long COVID (SEMG, 2020) were between 35 and 50 years old, an age in which social networks and the digital world are part of daily life. The patient, therefore, is also on social networks and used the Internet to search for information about Long COVID and to learn about the existence of the LCA patients' alliance (Figure 2).

5. CONCLUSIONS

Long COVID ACTS has made the patients themselves the protagonists of the news and the interviews, thus conveying their message and demands to the medical community, the political authorities, and society in general. If they didn't listen to them in consultations, if they didn't believe them because it was a new and unknown disease, they were going to help formulate the questions and send them to the experts, looking for answers.

The numerous press, television, and radio impacts of Long COVID ACTS compiled in this article (Figures 5-10) have created solid contacts with local and national journalists, explaining their pathology, and providing them with up-to-date information and patient testimonials. To such an extent that these communication professionals have had them as references and call them every time new information comes out to compare it and find out their opinion on it.

Articles and interviews that have been disseminated through the social networks of the groups, which have registered a progressive increase in followers throughout the health crisis (Figures 1 and 3), which has made it possible to amplify their message and reach

others affected, isolated at home, so that they would know that they were not alone and that other people, with the same disease and with the support of a medical society, such as the SEMG, were fighting for the recognition of the disease. To achieve their goal; a goal that they repeat like a mantra: "I want to be me again".

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