Hand in hand towards a better care: an experience of patient-professional collaboration during COVID-19 pandemia.

Key words: primary care, covid19, patient participation

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Annex:
Annex 1: Symptoms diari
Annex 2: Figure My Abdomen
Annex 3: Management of people with covid-19 and long-lasting symptoms in primary care

Summary:

The individual experience of people affected with Long covid (some of them professionals in the health system) has allowed us to understand the variability of symptoms that persist months after the initial contagion and to have a glimpse of how it affects the function of the body. The difficulties that the health system has had in providing an adequate response and care for these people, united by the uncertainty of facing an unknown disease, has led them to share their experiences through social networks and to organize themselves in groups.

Some primary care (PC) professionals have collaborated with these groups in order to expose the situation and advise them on their process of recognition and care.

The perseverance of citizen participation in defense of first hand knowledge experienced as a source of knowledge against the imposition of protocols elaborated by experts, and its organization in groups has led to the achievement of both local (working with the territorial government) and international political incidence (managing to contact institutions such as the WHO).

The coordinated work of professionals and patients has made it possible to develop a joint care proposal for people affected with Long covid in PC that facilitates the construction of joint knowledge through observation, monitoring and the study of all of those involved.

From individual experience ...

My infection of SARS-COV-2 and the narrative of my illness

My contagion occurred the week of March 9, 2020. During that time, I treated five people without protective measures in my PC center and also in their homes. They were later confirmed cases and hospitalized.

The symptoms began after eight days of isolation. I debuted with febrile and respiratory symptoms that ended in bilateral pneumonia. Subsequently, for 21 days I presented dyspnea at rest with desaturations of 88% at minimal effort and tachypnea, without tolerance to sitting.

Given the importance of the symptoms, I repeatedly went to the emergency services of PC and hospitals in my city. However, my previous physical conditions (no pathological antecedents of interest), my age (45 years old) and the moderate severity of my symptoms, together with the phase of overwhelmed hospitals at the beginning of the pandemic prevented me from being hospitalized, despite finding a bilateral lung involvement.

I overcame bilateral pneumonia without any health support (neither pharmacological nor care) in the context of initial uncertainty and confusion in the health system. From that moment on, the fear caused by the magnitude of the symptoms and the ignorance about their possible evolution would not leave me until many months later.

I organized my respiratory rehabilitation with bibliographic resources[1] and some contacts with physiotherapist colleagues when verifying that there were no protocolized recovery alternatives at that time for patients like me. After a few days of progressive rehabilitation, I decided to return to work 6 weeks after the onset of symptoms, despite persisting fatigue and dyspnea on exertion, which I attributed at that time to the usual convalescence process in this type of illness.

Seven days after going back to work, the fever, diarrhea and a disconcerting abdominal symptoms returned, which forced me to leave my job again.

*I then started a symptom diary to be able to record all the changes that were taking place in my body and that seemed to have no clear pathophysiological explanation (****Annex 1****). I had symptoms that corresponded to almost all systems: polyuria, paresthesia, chest pain, hypotension, erythema, diarrhea, abdominal pain, menstrual disturbances, ageusia, headache, loss of concentration, anomia.*

*And I was functionally disabled: I could not walk, nor shower or do the usual activities of my life without help. I also began to photograph the changes my abdomen was undergoing (****Annex 2****). My abdominal distention magnitude reminded me of those caused by my three previous pregnancies.*

My family doctor could not find a convincing explanation for what was happening to me and tried to coordinate my care with hospital specialists. However, referrals were not attended to because care for hospitalized people was prioritized over patients who had not been admitted for months, ignoring the interconsultations requested from PC.

The first week of May I was affected with abdominal distension, intolerance to eating, disabling abdominal pain and more than ten mucus stools a day. After 20 days without being able to eat anything, I was admitted to the hospital for study. After 24 hours of observation, I was discharged without being able to explain or solve any of the symptoms I presented. My disconcerting clinical symptoms were attributed to a situation of anxiety, intervening the gender bias in the interpretation of the narrative that I made of my own symptoms in my case (as in that of many other affected people)[2]*. I returned home with the certainty that the treatment and cure for what happened to me was not going to be provided by the health system. People like me who presented persistent symptoms had not been observed or studied by the hospitals nor by the primary care centers. I was then convinced that the experiences of the people who were suffering from the disease should be integrated into the response to face it, as had already happened with other diseases in the past.*[3]

Thereafter, and for 3 months I tried all the empirical measures and treatments that I was reading from other affected people, as well as from colleagues who suggested treatments based on the similarity of the new virus with known previous infections. Thus, I took paracetamol, metamizole and ibuprofen for pain, montelukast[4], azithromycin, corticosteroids and salbutamol for respiratory symptoms, probiotics for diarrhea, famotidine for abdominal symptoms, anxiolytics for paresthesias….

The pressure of the groups of affected people[5] (which we will describe later) led to the creation of some specific study units for this type of patients in the infectious services of the hospitals in the area[6] These units began caring exclusively for people who had been hospitalized at the beginning of the pandemic, including later care (in some cases) for patients who had not been hospitalized. However, the skepticism and ignorance of the majority of health professionals assigned to these units has so far provoked a cascade of interventionist actions in the people who have been treated in them, mainly aimed at objectifying each symptom referred individually without taking into account the holistic view.

In my case, between the months of July and August I had an abdominal ultrasound, gastroscopy, colonoscopy, digestive biopsies, radiographs, abdominal and thoracic tomography, arterial blood gas, blood and urine tests, blood cultures, serologies of different viral agents, stool cultures, different studies of intestinal malabsorptive syndromes, blood transfusions and intravenous treatments.

The results of most of the complementary examinations were normal. Only residual pulmonary fibrosis and iron deficiency anemia (probably a side effect from my difficulty in swallowing) could be observed.

All this time, my body was still affected and without any other treatment to relieve it than the constant support of the people who took care of me (my family and the entire support network that was woven around me between friends and professional colleagues). I began to discover some actions that improved my physical and emotional state. For example, *regulating my physical activity, avoiding intellectual effort, controlling stress or adapting my intake to the tolerance that my abdomen marked.*

I learned that the illness, despite involving a disability in many of the facets of my life at that time, evolved in the form of flares. These crises, which I called "storms", were unleashed without warning, but when they came I was able to clearly identify them. The start of the "storm" was always in the morning: I woke up with discomfort and with an inexplicable sensation in my body. First it was the headache (which was unlike any previous headache I had ever had), and then came the tingling in the arms and legs. At the same time, a low-grade fever and a disabling fatigue appeared that prevented me from getting out of bed, eating, reading, speaking ... I could only lie supine waiting for the crisis to end. The "storms" lasted between 3 to 9 days, and later they disappeared just as they had arrived, without me being able to identify what had caused their resolution.

Four months after the infection, I observed that the symptoms in the inter-crisis periods were increasingly tolerable and that the disability during the crisis also improved. My last "storm" was at the end of July.

In August I started to improve. The bloating subsided and I was able to reintroduce many foods into my diet. Gradually, I regained capacity and tolerance to exercise and established a recovery plan that I adapted according to the improvement that my body was experiencing.

... to the collective experience.

Co-creation of a protocol with the group of patients affected by Long covid:

The confusion when faced with unknown symptoms, together with the difficulty of the health system to respond to these situations, prompted affected people to organize ourselves into groups of[7-12]. Working groups were created in order to use the media to make the problem visible and politically influence the specialized commissions of the government of our territory.

At the same time, health system professionals observed cases in our PC consultations of people who had been infected in the month of March-April who had been classified as mild or moderate, who presented persistence in some symptoms and were unable to perform daily activities prior to infection. Thus, through social networks we came into contact with groups and began to collaborate.

The collective work has made it possible to promote proposals that can improve the care received from the health system, forming a political advocacy group that has been in contact with the Secretary of Health Care and Participation of the Department of Health since June, 2020. Among the achievements of this collaboration is the public recognition by the Council of the existence of this type of persistent affectation of COVID19, the creation of an informative memo on persistent symptoms sent out to all PC professionals of the Institut Català de la Salut[13], the creation of a clinical care protocol for PC and the commitment to support the research being carried out by PC on the persistent involvement of the disease.

The collaboration of different groups from different parts of the world has permitted contact with the WHO and the recognition of the persistence of symptoms as a distinct entity from the acute picture of SARS-COV-2, with the commitment to promote research on this material[14-15].

Discussion:

The appearance of SARS-COV2-19 in PC consultations has transformed the relationship between patients and professionals in Spain.

Since the end of March, 2020, governments have taken measures to prevent infection within PC centers by limiting the presence of people requesting care, prioritizing contact by phone or online and increasing individual protection for people who work in the health system.

However, before the implementation of these measures, many professionals in the health system[16] had already been infected. Also, among the population there were people affected with persistent symptoms more than 3 weeks after contagion (Long covid[17]).

In all these people, the impediments of accessing face-to-face care in health centers, the lack of knowledge of the persistence of symptoms and the majority of health system professionals' lack of credibility in the symptoms of the patients have contacted them have prompted the search for other resources that can provide a response and support for their situation.

This incapacity of the health system, perceived and experienced by affected people, has led many of them with persistent symptoms (some also health professionals) to organize into groups that expose the problem in order to achieve adequate health care and generate knowledge collaboratively[18]. Thus, in many cases, individualized symptomatology records have been made to systematically detail the physical, functional and emotional affectations that they were suffering (Annex 1).

The coordination and collaboration between the group of affected people and some health professionals in our territory has crystallized into the joint creation of an protocol of action that allows a better approach to the symptoms presented and contributes to the simultaneous generation of knowledge in the framework of a co-creative process of citizen participation (Annex 3).

Conclusions:

- The pandemic has highlighted that a positivist view alone on the disease and its evolution is insufficient to create knowledge, and that it is inevitably interwoven with the experience of the disease in affected people who, in the face of any disease, and especially if it is unknown, are an asset as source of knowledge[19].

- Faced with the inefficiencies of the system, the affected groups have been the best source of pressure on the administrations by highlighting these inefficiencies and demanding a solution for them. Behind the claim for health care, there is a political claim.

- Present in the claims of those affected is the defense and support of the public health system, and specifically PC, which has been reflected in the joint implementation of protocols that prioritize listening, observation, longitudinality, an integral vision of the person and the role of coordinating care between the different levels of care, the values of PC against fragmentation and technification, which the groups of affected patients have experienced in other levels of care.

- The groups of people affected and affected by persistent COVID call into question the current framework for the generation of scientific knowledge. On one hand, they cast doubt on the growing obstinacy of the system on the need for tests to define diseases (most of them do not have a PCR test that confirms their diagnosis, as required by the case definition[20], given that in the first months of the pandemic in the Spanish State, only PCR was performed on hospitalized patients) and they remind clinicians, in an exercise of epistemic justice[21] that there is no definition of disease without a patient who suffers and narrates it[22]. On the other hand, they question the current classification of the disease, based solely on the severity of the acute period, which classifies them as mild or moderate, despite having functional limitations beyond the usual recovery period from the acute disease.

- The clinical spectrum of covid19 disease with persistent symptoms appears to be very broad. It is necessary to promote studies in the primary care setting in order to describe all the variability it contains. A study is currently being run on the clinical manifestations and their evolution in persistent COVID, with a protocol and questionnaire carried out in collaboration with health professionals and a group of affected people.

- Health professionals affected by COVID19 represent a fundamental source of knowledge, as they have suffered from the deficiencies in the care received from the health system in which they usually work. The biologist and hospital-centric orientation of said system has been questioned, as it is not able to address the uncertainty that has accompanied these people throughout their process of becoming ill.

- The physical and emotional consequences that these professionals present in the future will condition the care they can give their patients. Monitoring will allow us to understand the variety and scope of the possible effects of the disease and will contribute to formulate mechanistic hypotheses (biologists) that permit finding ways of treatment and rehabilitation.

- The experience of the clinical descriptions of the patients and the fact that they are being shared is very valuable, not only for the understanding of the biological aspects of the disease, but also for the understanding of how patients experience symptoms and how the health system must learn from them in order to treat COVID (and other diseases) in a more holistic way.

- Sharing the experience of acquiring knowledge on the persistent symptoms of COVID-19 with affected people has enormous potential, not only to improve their care, but to raise awareness among medical societies, professional groups, health organizations and governments of the existence of this entity (long COVID19).

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References

1. Colegio de Fisioterapeutas de la Comunidad de Madrid (2020): Recomendaciones de fisioterapia y ejercicio terapéutico para personas confinadas en fase de recuperación por COVID-19. Version 1:0 March 31, 2020. https://www.cfisiomad.org/pdf/noticia_1978.pdf
2. Kirsti M. Symptoms as a source of medical knowledge: understanding medically unexplained disorders in women. Fam Med. 2000;32:603-11.
3. PWA Movement (1983).The Denver Princip https://www.poz.com/pdfs/denver_principles.pdf
4. Sanghai, N., & Tranmer, G. K. (2020). Taming the cytokine storm: repurposing montelukast for the attenuation and prophylaxis of severe COVID-19 symptoms. Drug Discovery Today, Advance online publication. https://doi.org/10.1016/j.drudis.2020.09.013
5. Col·lectiu d'Afectades i Afectats persistents per la Covid-19. El nostre segon manifest (02/06/2020): Exclosos de la Sanitat Pública!! Retrieved September 23, 2020. Home
6. Hospital de Bellvitge. El Hospital de Bellvitge crea una unidad específica para atender las secuelas del Covid-19. Retrieved May 22, 2020. https://bellvitgehospital.cat/es/actualidad/noticia/el-hospital-de-bellvitge-crea-una-unidad-especifica-para-atender-las-secuelas
7. Col·lectiu d'afectades i afectats persistents per la COVID-19 [@COVID19persist1]. Retrieved September 23, 2020 de: https://twitter.com/COVID19persist1
8. Long Covid ACTS. Autonomous Communities Together Spain [@longcovidspain]. Retrieved September 22, 2020: https://twitter.com/longcovidspain
9. Covid Persistente Euskal Herria. [@covideuskal] September 24, 2020 de: https://twitter.com/covideuskal
10. Coronavirus Persistente Andalucía. [@AndaluciaCovid]. September 23, 2020 de: https://twitter.com/AndaluciaCovid
11. Afectats per la Covid19 València. [@Covid19Valencia] Retrieved September 24, 2020: https://twitter.com/Covid19Valencia
12. Covid-19 persistente Madrid [@covid_madrid] Retrieved September 24, 2020. https://twitter.com/covid_madrid
13. Generalitat de Catalunya (). Coronavirus Sars-Cov 2. Atenció als pacients pot-covid. June 23, 2020. Available at: https://canalsalut.gencat.cat/web/.content/_A-Z/C/coronavirus-2019-ncov/material-divulgatiu/nota-informativa-pacient-post-covid-19.pdf
14. Adhanom Ghebreyesus T. WHO (21 August 2020). Media briefing on COVID19 with Dr.Tedros. Adhanom Ghebreyesus. (Presidency) Conference at World Health Organization (WHO). Switzerland. https://www.pscp.tv/w/1LyxBaBOjWbJN
15. Lokugamage A, Rayner C, Simpson F, Carayon L. We have heard your message about long covid and we will act, says WHO. 3 september 2020. BMJ . : https://blogs.bmj.com/bmj/2020/09/03/we-have-heard-your-message-about-long-covid-and-we-will-act-says-who/

16. Moreno-Casbas MT. Factores relacionados con el contagio por SARS-CoV-2 en profesionales de la salud en España. Proyecto SANICOVI. Enferm Clin. 2020. https://doi.org/10.1016/j.enfcli.2020.05.021
17. Greenhalgh T.,Knight M, A'Court C, Buxton M, Husain L. Management of post-acute covid-19 in primary care. BMJ 2020;370:m3026.
18. Sácristan JA, Aguarón A, Avedaño-Solá C, Garrido P, Carrión J, Gutiérrez A, et al. Participación del paciente en la investigación clínica: por qué, cuándo y cómo. El paciente prefiere la adherencia. 2016; 10 : 631–640. doi: 10.2147 / PPA.S104259. [Artículo gratuito de PMC] [PubMed] [CrossRef] [Google Scholar]
19. Jacques-Aviñó C, Pons-Vigués M, Mcghie JE, Rodriguez Giralt I, Medina-Perucha L, Mahtani-Chugani V, et al. Participación pública en los proyectos de investigación. Formas de crear conocimiento colectivo en salud. Gac Sanit. 2020;34:200-203.
20. Ministerio de Sanidad. Instituto de Salud Carlos III. Estrategia de detección precoz, vigilancia y control de COVID-19. Aupdated September 10, 2020. https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/COVID19_Estrategia_vigilancia_y_control_e_indicadores.pdf
21. Fricker M. La injusticia epistémica. Barcelona: Herder; 2017.
22. Epstein S. The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. Science, Technology & Human Values. 1995;20:408-37