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

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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
[Annex 4 is English translation of Annex 3]

Key words: primary care, covid19, patient participation

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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Tabla 1. Symptoms diary corresponding to a Long COVID patient from May 17th to July 1st of 2020

		MAY																	JUNE													
	Date	14	17	19	20	21	22	25	30	31	1	3	7	8	9	10	11	12	14	15	16	17	20	21	22	23	24	25	26	27	28	29	30	1
Symptoms																																		
	Fever	37,8	no	37,7	no	37,7	no	no	no	no	no	no	no	37,4	no	37,7	no	no	37,7	no	no	no	no	no	no	37,7	no	no	no	no	37,8	no	no	37,8
	Paresthesia	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
General	Headache	yes	no	yes	no	yes	no	no	no	no	no	no	no	yes	no	no	no	no	yes	no	no	no	no	no	no	no	no	no	no	no	no	yes	yes	yes
	Abdominal pain	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	not	no	yes	yes	yes	yes	yes
	Abdominal distension	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yesy	yes	yes
	Loss of appetite	no	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	no	no	no	yes	no	no	no	no	no	no	yes	no	no	no	yes	yes	yes	yes	yes
	Sickness	yes	yes	yes	no	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	yes	no	no	no	yes	yes	yes	yes	yes
	Esophagus pain	no	no	yes	yes	yes	yes	yes	yes	yes	no	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	yes	yes	yes	yes
	Ageusia	yes	yes	yes	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
		yes			yes						yes	yes	no	yes					yes		yes	yes	yes	yes	yes	yes		yes						
Gastrointestinal	Diarrhea	10	no	no	12	no	no	no	no	no	13	10	8	10	no	no	no	no	6	no	4	6	3	6	4	8	no	9	no	no	no	yes	no	no
Urinary/reproductive	Polyuria	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	yes	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
	Menstrual disorders	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
	Chest pain	8/10	8/10	8/10	8/10	8/10	8/10	8/10	8/10	8/10	5/10	6/10	6/10	7/10	7/10	7/10	7/10	5/10	8/10	8/10	6/10	6/10	no	no	3/10	7/10	3/10	no	NO	7/10	7/10	7/10	7/10	6/10
	Chest tigthness	yes	yes	no	no	yes	no	no	yes	yes	no	no	no	no	yes	yes	yes	yes	yes	yes	no	no	no	no	no	no	yes	yes	yes	yes	yes	yes	yes	yes
	Dyspnea	yes	yes	no	yes	yes	no	no	yes	yes	no	no	no	no	no	no	no	no	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
Respiratory	Dyssynchrony between rib cage and abdomen while breathing	yes	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
	Macula	no	no	no	no	no	yes	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
	Vesicle	yes	yes	no	no	no	no	no	no	no	no	no	no	no	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no
Dermatology	Pruritus	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	no	yes	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	no	no
Neurological	Cognitive blunting	yes	yes	yes	yes	yes	no	no	no	no	no	no	no	no	no	no	no	no	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
	Not able to leave the bed for few hours a day	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	no	yes	no	no	no	no	yes	no	no	no	no	no	no	yes	yes	no	no	yes	yes	yes	yes	yes
	Able to sit in a chair	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no	no	yes	no	no	no	no	yes	no	no	no	no	no	yes	yes	no	no	no	yes	yes	yes	yes	yes
	Able to exercise at home	no	no	no	no	no	no	no	no	no	yes	yes	yes	no	no	yes	yes	yes	no	no	yes	yes	yes	yes	yes	no	yes	no	yes	no	no	no	no	no
Functionality	Able to walk outside the house	no	no	no	no	no	no	no	no	no	no	yes	no	no	yes	yes	no	yes	yes	yes	yes	yes	yes	yes	yes	no	yes	yes	yes	yes	no	yes	yes	yes
	Paracetamol 650mg	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	2	2	3	1	3	1	1	1	1	1	1	1	1	1	1	1	1	1
	Ibuprofen 400mg	2	0	1	1	0	0	0	0	0	0	1	0	0	1	0	0	0	0	1	1	1	1	1	0	0	0	0	0	0	0	0	1	0
	Metamizole 575mg	2	2	2	2	2	2	2	2	2	2	1	2	2	1	2	2	1	1	1	1	1	1	0	0	0	1	0	1	2	3	2	3	2
	Salbutamol inhalaat	2	2	2	2	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Montelukast 10mg	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
	Prednisone mg	15	15	10	10	10	10	10	10	10	5	5	5	5	5	5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	2,5	0
	Famotidine 20mg	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
	Azithromycine 500mg	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Hydroxochloroquine	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Treatments	Probiotics	0	0	0	0	0	0	0	1	1	1	1	1	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

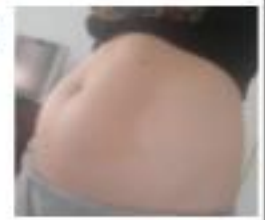
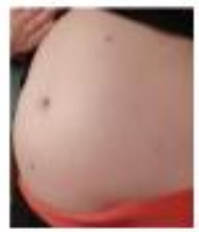
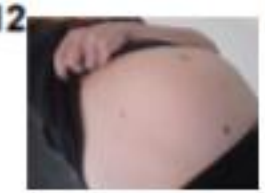
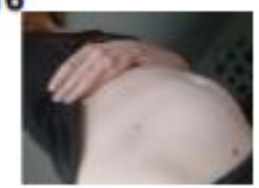
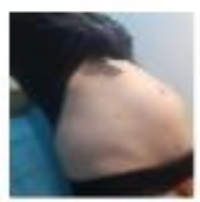
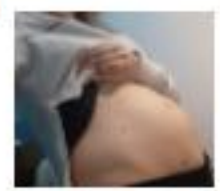
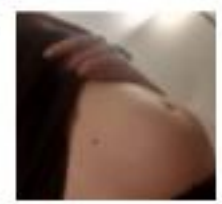
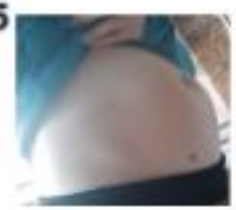
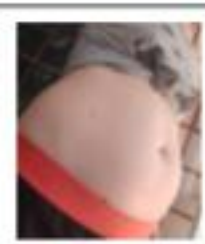
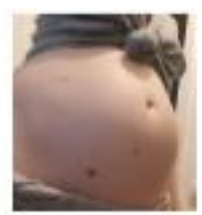
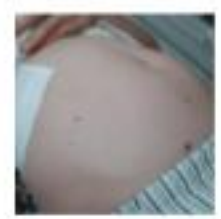
Fever is shown in degrees Celsius

When diarrhea occurred, number of stools /(per) day are specified in the table

In the chest pain section, pain score is shown on a scale from 0 to 10

The red column corresponds to those labelled by the patient as "Stormy days"

May 2020

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
					1	2
3	4 	5 	6 	7 	8 	9 
10 	11 	12 	13 	14 	15 	16 
17 	18 	19 	20 	21 	22 	23 
24 	25 	26 	27 	28 	29 	30 

Protocol de seguiment a les persones amb símptomes persistents COVID19 a l'Atenció Primària

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Introducció

Els pacients amb símptomes persistents COVID19 representen un problema de salut emergent derivat de la infecció per SARS-COV-2.[1] La persistència de símptomes invalidants en aproximadament el 10% de les persones que han patit la COVID19 molts mesos després de l'inici de la clínica condiciona la necessitat de fer un seguiment i una atenció acurada des de les consultes d'Atenció Primària.[2] Actualment ja s'ha observat, per exemple, la persistència de complicacions respiratòries a llarg termini.[3]

Cal tenir en compte que les dades existents sobre persistència de símptomes en COVID19 han estat realitzades en un entorn hospitalari i en pacients greus que van requerir ingrés a planta o a UCI. Els pacients greus representen el 14 % dels infectats.[4] No tenim dades de detecció actuals que estimin el nombre de persones afectades per símptomes persistents que no van complir criteris d'ingrés en el seu moment, que van ser classificats com a lleus o moderats, que van constituir el gruix de la primera onada de la pandèmia (81%) i que van ser atesos per l'Atenció Primària.

Les persones afectades ingressades a l'hospital tenen un diagnòstic de confirmació amb PCR, mentre que les persones afectades amb quadres lleus i moderats que no complien criteris d'ingrés no tenen prova confirmatòria, ja que la PCR no va estar disponible a l'Atenció Primària fins a mitjan mes de maig, moment en què moltes d'aquestes persones ja portaven més de 30 dies d'evolució de la malaltia.

[1] Carfì A., Bernabei R., Landi F. for the Gemelli Against COVID-19 Post-Acute Care Study Group: "Persistent Symptoms in Patients After Acute COVID-19". JAMA. 2020; 324 (6): 603-605. doi: 10.1001 .
[2] Trisha Greenhalgh T., Knight M., A'Court C., Buxton M., Husain L.: "Management of post-acute covid-19 in primary care." BMJ 2020; 370: m3026.
[3] Fraser, E.: "Long term respiratory complications of covid-19".BMJ 2020; 370: m3001.
[4] Wu Z., MD, McGoogan JM.: "Characteristics of and Important Lessons From the Coronavirus Disease 2019 (COVID-19) Outbreak in China"; summary of a report of 72.314 cases from the Chinese Center for Disease Control and Prevention. JAMA. 2020; 323(13):1239-124.
Disponible a: https://jamanetwork.com/journals/jama/fullarticle/2762130

En el context epidemiològic actual, sense un tractament curatiu conegut fins ara, l'observació i l'abordatge de la simptomatologia invalidant en aquestes persones representa una oportunitat per a generar coneixement des de l'Atenció Primària juntament amb les persones afectades. L'acompanyament d'aquestes persones ha de tenir com objectiu alleugerir-ne el malestar i facilitar la seva reincorporació a l'activitat que desenvolupaven abans d'haver estat infectats.

L'existència d'un protocol d'actuació que fomenti la observació i l'acompanyament d'aquests casos es fa imprescindible donada la situació de pandèmia actual, que fa preveure un augment de casos de COVID19 en els pròxims mesos, molts dels quals patiran símptomes persistents.

El protocol d'actuació per al seguiment de persones amb símptomes persistents de COVID19 en l'Atenció Primària tindrà com a finalitat:

- Garantir una homogeneïtat en el tractament de la persona amb símptomes persistents, amb independència del territori o CAP al qual pertanyi.
- Posicionar el metge de capçalera com a figura de referència en el seguiment i tractament integral dels diversos sistemes afectats per la malaltia.
- Millorar l'eficiència de recursos emprats i facilitar l'accés de l'Atenció Primària a proves complementàries en base a la clínica particular de cada pacient.
- Aprofitar les sinèrgies creades a partir del coneixement generat per part de les unitats postcovid hospitalàries, l'Atenció Primària i el col·lectiu de pacients afectats per símptomes persistents.

Definició

Persones amb símptomes compatibles amb la COVID19 diagnosticades clínicament durant la primera onada de la pandèmia (11 de març 2020-actualitat) amb o sense PCR positiva, amb o sense serologia positiva, que presentin símptomes de més de 3 setmanes d'evolució. [5-6]

La manca de disponibilitat de tests durant l'inici de la pandèmia i les seves limitacions fan que molts dels i de les pacients que presenten actualment símptomes persistents tinguin els seus símptomes desenvolupats en un context de pandèmia com a única prova que avali la seva malaltia.

Les limitacions de les PCR —falsos negatius més enllà del vuitè dia d'inici de símptomes— i de les serologies — s'ha descrit que casos lleus i moderats poden generar menys anticossos o no generar-ne — fan que no sigui prudent usar-les com a úniques eines diagnòstiques ni tampoc com a definitòries de la curació de la malaltia.[7] En aquest cas, com en molts d'altres en la nostra pràctica clínica, el diagnòstic s'ha de recolzar principalment en la clínica que presenten i han presentat els pacients, en un context de plausibilitat epidemiològica del diagnòstic.

[5] Welsh Government, NHS Wales, the Scottish Government and NHS Scotland: "COVID Symptom Study". United Kingdom Publishing (2020); http://covid.joinzoe.com

[6] Gemelli Against COVID-19 Post-Acute Care Study Group: "Post-COVID-19 global health strategies: the need for an interdisciplinary approach"; Aging Clin Exp. Res 2020; doi:10.1007/s40520-020-01616-x. pmid:32529595

[7] Bastos ML., Tavaziva G., Kunal Avidi S., et col.: "Diagnostic accuracy of serological tests for covid-19: systematic review and meta-analysis." BMJ 2020; 370:m2516Banda.
J M., Viguruji Singh G, Alser O, Prieto-Alhambra D.: "Long-term patient-reported symptoms of COVID-19: an analysis of social media data"; medRxiv 2020.07.29.20164418; doi: https://doi.org/10.1101/2020.07.29.20164418

Seguiment a Atenció Primària

Els símptomes en les persones amb COVID-19 persistent es caracteritzen per la seva variabilitat i l'evolució fluctuant. És per això que el seguiment ha de ser acurat i sistemàtic, amb l'objectiu de poder abordar els canvis (i la invalidesa que condicionen en cada pacient) a mesura que aquests vagin apareixent.

- Anamnesi:

Actualment s'han detallat símptomes en pràcticament tots els sistemes de l'organisme. Caldrà orientar l'entrevista clínica recollint els aspectes següents:

- Data d'inici dels símptomes.
- Símptomes actuals [8+9]:
  - ✓ Símptomes generals; sensació distèrmica, calfreds, anorèxia, mareig
  - ✓ Símptomes respiratoris; dispnea, tos seca o productiva, sibilàncies
  - ✓ Símptomes musculoesquelètics; fatiga, miàlgies, artràlgies
  - ✓ Símptomes neurològics; cefalea, parestèsies, debilitat, manca de concentració i memòria, anòsmia, disgèusia
  - ✓ Símptomes gastrointestinals; disfàgia, pirosi, nàusees, síndrome diarreica
  - ✓ Símptomes cutanis [10]; fotosensibilitat, exantemes, sequedat cutània
  - ✓ Símptomes otorrinolaringològics; dolor a sinus, disfonia, vertigen, rinorrea, otàlgia
  - ✓ Símptomes cardiovasculars; canvis en la pressió arterial habitual, palpitacions, taquicàrdia
  - ✓ Símptomes oculars: conjuntivitis
  - ✓ Símptomes miccionals
- Diari de símptomes (des de l'inici dels símptomes, si és possible, o des del moment de la visita): La realització d'un diari dels símptomes permet una observació més acurada de l'evolució de la malaltia i pot ajudar aquestes persones a percebre les millores en el temps. En els casos ja establerts i que van iniciar símptomes al mes de març és més difícil recollir aquestes dades, ja que hi haurà un biaix de memòria (annex 1).
- Evolució dels relapses o brots: freqüència d'aparició, intensitat (proposem escala Likert 0 a 5), símptomes que el constitueixen i ordre d'aparició, situacions que l'empitjoren o el milloren, durada del brot, situació postbrot respecte a situació prèvia.

[8] Body Politic COVID-19 support group: "What does COVID recovery actually look like? An analysis of the prolonged COVID-19 symptoms survey by Patient-Led research team." Disponible a: https://docs.google.com/document/d/1KmLkOArlJem-PArnBMbSp-S_E3OozD47UzvRG4qM5Yk/edit#heading=h.tl7frov254ll

[9] Generalitat de Catalunya (23 de juny 2020); "Coronavirus Sars-Cov 2. Atenció als pacients pot-covid." Disponible a: https://canalsalut.gencat.cat/web/.content/_A-Z/C/coronavirus-2019-ncov/material-divulgatiu/nota-informativa-pacient-post-covid-19.pdf

[10] Galván Casas C., Català A., Carretero Hernández G., et al.: "Classification of the cutaneous manifestations of COVID-19: a rapid prospective nationwide consensus study in Spain with 375 cases."; Br. J. Dermatol 2020;183:71-7. doi: 10.1111/bjd.19163 pmid: 32348545

- Escales (annex 2), es proposen les següents escales, aplicables en el diari de símptomes que pot realitzar la persona afectada al domicili i en les visites successives de seguiment per a poder valorar canvis en el seu estat general.

    - ✓ *EVA:* escala usada per a la valoració del dolor, autoadministrada de forma diària.
    - ✓ *Daniels:* escala usada per a avaluar la força muscular, professional, en períodes intercrisi (cada mes, p.ex.).
    - ✓ *Likert:* proposada per a valorar la intensitat dels brots o relapses, autoadministrada, en cada brot.
    - ✓ *Euroqol-5D:* escala de valoració de la qualitat de vida, autoadministrada. Es podria utilitzar cada 2 mesos.
    - ✓ *Escala Borg modificada:* percepció de l'esforç. Determinar amb la persona afectada activitats diàries habituals i valorar la percepció de l'esforç en finalitzar-les (p.ex. baixar les escombraries, pujar un pis d'escales). Autoadministrada. Repetir cada mes.
    - ✓ *Escala d'Afectació Activitats Vida Diària (AVD):* administrada pel o per la professional a consulta. Es proposa realitzar-la cada 2 mesos per tal d'objectivar-ne diferències.

- Exploració física:

Inicialment cal descartar signes de gravetat que obliguin a fer una derivació al servei d'urgències hospitalàries: [2]

- Saturació d'oxigen a l'aire <96%.
- Dolor toràcic de característiques inexplicables.
- Empitjorament sensació respiratòria.
- Focalitat neurològica (pèrdua de força en una extremitat, p.ex.).

Cal una exploració física inicial acurada de tots els i les pacients afectats per COVID19 a consulta (o al domicili) que inclogui:

- Presa de constants: temperatura corporal, saturació d'oxigen, tensió arterial, freqüència cardíaca.
- Auscultació cardiopulmonar
- Exploració abdominal
- Observació de la pell
- Exploració neurològica
- Valoració de la capacitat funcional i de la qualitat de vida (veure annex 1)

Posteriorment:

- Es recomana nova exploració física davant de nous símptomes, variacions en els símptomes presents i davant de sospita de gravetat.

- Observació acurada dels símptomes i evolució (veure annex 3).

- Exploracions complementàries:

Malgrat que no sempre seran necessàries, en cas de detecció d'empitjorament o persistència de clínica invalidant cal tenir accés des d'Atenció Primària a:

- Analítica. Valorar segons sospita: dímer-D, LDH, hemograma, ferritina, funció renal, electròlits i aquells paràmetres que ens permetin descartar altres processos dins del diagnòstic diferencial dels símptomes que presenta la persona que atenem.
- Radiologia de tòrax
- ECG
- Espirometria
- Ecografia pulmonar i abdominal
- Altres proves complementàries en les mateixes condicions d'accés que abans de la pandèmia per a aquells casos específics en què estigui indicat un estudi més acurat (per exemple: proves d'imatge o endoscòpiques per a valoració de clínica respiratòria o digestiva persistent i invalidant, ergometria per a valoració capacitat aeròbica).

Cal fer èmfasi en l'objectiu de les proves complementàries. Per una banda, poden ajudar a descartar gravetat; per altra banda, poden ajudar a objectivar (i, per tant, a reconèixer) allò que la persona està experimentant, poden ajudar a reduir la incertesa en el/la pacient i en el/la professional (davant d'un resultat dins dels paràmetres de la normalitat) i poden ser útils per a descartar altres patologies que es puguin incloure en el diagnòstic diferencial.

El curs en brots pot fer que sigui útil la realització d'algunes proves durant el brot i durant el període intercrisi (en què poden ser normals).

Cal adequar-les a l'objectiu que perseguim i conversar amb el/la pacient sobre la seva utilitat, possibles resultats, etc. per no ser maleficents.

- Coordinació amb segon nivell assistencial:

És imprescindible la possibilitat de contacte àgil i bidireccional entre professionals (telemàtica, telefònica, via interconsulta habitual). Segons els símptomes pot ser necessari realitzar interconsulta amb:

- Cardiologia
- Pneumologia
- Neurologia
- Digestologia
- Dermatologia
- Rehabilitació física
- Otorrinolaringologia

- Reumatologia
- Endocrinologia
- Salut mental

- Coordinació amb treball social:

L'existència de símptomes persistents limitadors o invalidants pot abocar la persona a noves dificultats, sobretot les relacionades amb la cura d'altres persones al seu càrrec, amb la seva situació laboral i aquelles que en puguin comprometre la subsistència econòmica (alimentària, d'habitatge). Aquesta situació derivada de la malaltia no pot recaure únicament sobre l'individu que la pateix, sinó que ha d'entendre's en el context d'una responsabilitat social i comunitària, que repari i contribueixi a pal·liar les conseqüències que comporta emmalaltir.[11]

Tractament

En absència d'un tractament curatiu actual, cal oferir a les persones afectades un tractament pal·liatiu i simptomàtic amb l'objectiu d'alleugerir el seu malestar.

El tractament cal que valori les seves necessitats en totes les esferes en les quals hagi impactat la malaltia, tal i com es realitza en d'altres afeccions. Les decisions sobre l'abordatge d'aquest impacte, s'hauran d'individualitzar i consensuar amb cada pacient.

- Fàrmacs:

Davant la falta d'evidència sòlida sobre l'eficàcia d'alguns fàrmacs en la millora de símptomes de COVID19 però coneixent-la en altres malalties amb símptomes similars, es podrien tractar alguns símptomes de forma empírica (com es fa amb altres malalties). Aquest procés caldrà fer-lo mitjançant una conversa amb el/la pacient sobre els riscos i beneficis de l'ús de cada fàrmac i la incertesa sobre la seva utilització en aquests casos concrets.

Es pot plantejar l'ús de [12]:

- Corticoides orals en tandes curtes per a símptomes respiratoris
- Corticoides tòpics per a alteracions cutànies
- Probiòtics per a afectació intestinal
- Anti-H2 per a afectació gàstrica
- Analgèsics i AINES per a cefalea, dolor muscular, altres dolors

Pel què fa a l'ús d'antidepressius i benzodiazepines, igual que amb la resta de fàrmacs, cal ser prudents i consensuar-ne l'ús i l'objectiu amb les persones afectades. L'ansietat generada per la incertesa i per la persistència dels símptomes, per la diferent relació amb el propi cos canviant i limitat cal poder-la abordar amb la paraula i l'acompanyament.

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[11] Castelló M, Fernández de Sanmamed MJ, García J, Mazo MV, Mendive JM, Rico M, Rovira A, Serrano. E, Zapater F. Atenció a les persones amb malestar relacionat amb condicionants socials a l'Atenció Primària de salut. Barcelona: Fòrum Català d'Atenció Primària, 2016.

[12] BMJ; "Best Practice. Coronavirus Disease 2019 (COVID-19). Approach." Disponible a: http://newbp.bmj.com/topics/es-es/3000168/management-approach

- Rehabilitació:

Cal poder coordinar-se amb l'equip de rehabilitació de zona des de l'inici del diagnòstic per poder oferir rehabilitació respiratòria i física, així com mesures d'adaptació progressiva a l'exercici a aquests/es pacients per tal de millorar-ne la funcionalitat de forma gradual.[13]

- Abordatge del malestar emocional:

Els efectes que provoquen la persistència perllongada de símptomes en els/les pacients que han patit la infecció per COVID19 afecten l'esfera emocional i en condicionen la recuperació. El seguiment des d'Atenció Primària ha de garantir el vincle assistencial [13] (coneixement mutu entre professional i pacient) que permetrà una escolta activa i empàtica per part del professional i evitarà la medicalització innecessària.

Es podrà valorar de forma individualitzada la prescripció social amb l'objectiu d'utilitzar els recursos de suport comunitari en el procés de convalescència, així com la informació sobre l'existència d'associacions i col·lectius integrats per persones afectades per símptomes persistents de COVID19.

Finalment, poden ser un recurs adient els grups d'ajuda mútua com espais d'autocura i de suport mutu.

Gestió de la incapacitat laboral

Donat que actualment no hi ha una definició de "curació" de la malaltia i basant-nos en el que coneixem com a "curació" en altres malalties (absència de símptomes), les persones afectades per COVID19 amb símptomes persistents no es poden considerar curades en tant que presenten símptomes de forma intermitent i una limitació funcional secundària als mateixos, que impedeix que es reincorporin a la seva activitat laboral.[14]
Cal avaluar l'adequació del manteniment de la baixa en les visites successives de seguiment i en tant que continuïn amb símptomes.

[13] Royal College of Occupational Therapists; "How to manage post-viral fatigue after COVID-19? Practical advice for people who have recovered at home."; Disponible a: https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0
[14] Alwan, Nisreen A.: "Surveillance is underestimating the burden of the COVID19 pandemics."; Correspondence; The Lancet. Disponible a: DOI: https://doi.org/10.1016/S0140-6736(20)31823-7

ANNEX 1

Diari d'evolució dels símptomes amb ús d'escales per valorar-ne intensitat:

DIES i EVOLUCIÓ (durant un mes)

SÍMPTOMES I ESCALES	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	18	20	21	22	23	24	25	26	27	28	29	30	31
Tos																															
Fatiga																															
Febreta																															
altres																															
.../...																															
.../...																															
E. EVA (dolor)																															
E. Daniels (força)																															
Likert (brot)																															
Euroqol-5D (qualitat de vida)																															

E. Borg (esforç percebut)																														
E. AVD																														

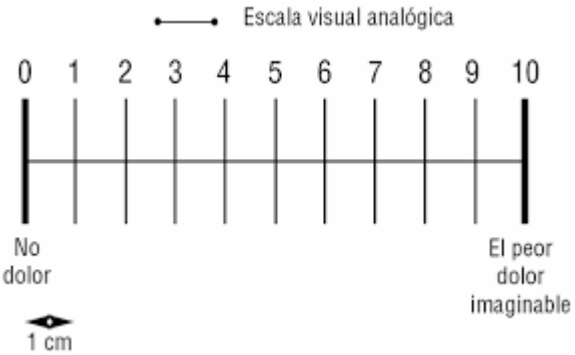
ANNEX 2

Proposta d'escales d'avaluació:

Se suggereix l'ús d'algunes escales per poder avaluar el seguiment d'una forma que permeti comparar l'evolució dels símptomes.

- EVA

Escala visual analògica per la valoració del dolor:



-Escala Likert

Avaluació de la intensitat dels brots:

1 Molt suportable

2 Poc suportable

3 Suportable

4 Força insuportable

5 Insuportable

- Escala Daniels

Avaluació de la força muscular:

0 - Absència de contracció

1 - Contracció sense moviments

2 - Moviment que no venç la gravetat

3 - Moviment complet que venç la gravetat

4 - Moviment amb resistència parcial

5 - Moviment amb resistència màxima

- Escala Borg modificada d'esforç percebut

Escala senzilla que permet avaluar la progressió en l'esforç percebut per part del/la pacient, aplicable a la realització de tasques diàries. Usada en rehabilitació cardiovascular, pulmonar i en entrenaments:

0 - Repòs

1 - Molt, molt lleuger

2 - Molt lleuger

3 - Lleuger

4 - Una mica pesat

5 - Pesat

6 - Més pesat

7 - Molt pesat

8 - Molt molt pesat

9 - Màxim

10 - Extrem

- Taula d'Afectació d'Activitats de la Vida Diària (AVD) [15]**:**

Categories d'Afectació de les Activitats de la Vida Diària (AVD)	**Grau d'Afectació d'Activitats de la Vida Diària (AVD)**
Sense afectació	Les funcions són normals
Afectació lleu	Presenta dificultats en activitats específiques, però pot realitzar-les

[15] ídem nota 13: Royal College of Occupational Therapists; "How to manage post-viral fatigue after COVID-19? Practical advice for people who have recovered at home."; Disponible a: https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0

Afectació moderada	Pot realitzar activitats específiques amb esforç i malestar
Afectació severa	Necessita ajuda per a la realització d'activitats
Afectació molt severa	Impossibilitat per a realitzar les activitats

- EUROQOL-5D (requereix credencials per usar-la):

Marcar amb una creu la resposta de cada apartat que descrigui millor el seu estat de salut a dia d'avui:

Mobilitat

No tinc problemes per caminar ☐

Tinc alguns problemes per caminar ☐

Haig d'estar al llit ☐

Cura personal:

No tinc problemes per a la cura personal ☐

Tinc alguns problemes per dutxar-me o vestir-me ☐

Soc incapaç de dutxar-me o vestir-me ☐

Activitats quotidianes (p.ex. treballar, estudiar, fer les tasques de la casa, activitats familiars o activitats en el temps de lleure):

No tinc problemes per a realitzar les meves activitats quotidianes ☐

Tinc alguns problemes per a realitzar les meves activitats quotidianes ☐

Soc incapaç de realitzar les meves activitats quotidianes ☐

Dolor/malestar:

No tinc dolor ni malestar ☐

Tinc dolor o malestar moderat ☐

Tinc molt de dolor o malestar ☐

Ansietat/depressió:

No estic ansiós/osa ni deprimit/da ☐

Estic moderadament ansiós/osa i deprimit/da ☐

Estic molt ansiós/osa i deprimit/da ☐

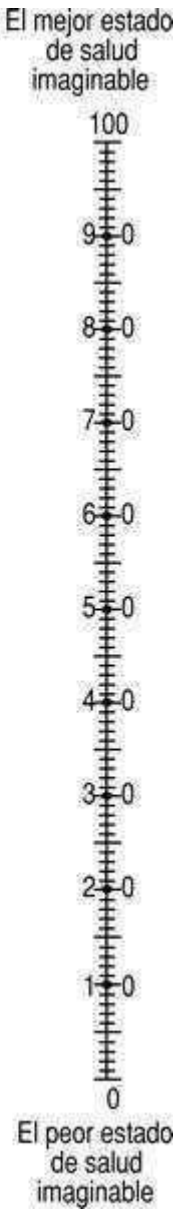
- Termòmetre EUROQOL d'autoavaluació de l'estat de salut:

TERMÓMETRO EUROQOL DE AUTOVALORACIÓN DEL ESTADO DE SALUD

Para ayudar a la gente a describir lo bueno o malo que es su estado de salud hemos dibujado una escala parecida a un termómetro en el cual se marca con un 100 el mejor estado de salud que pueda imaginarse y con un 0 el peor estado de salud que pueda imaginarse

Nos gustaría que nos indicara en esta escala, en su opinión, lo bueno o malo que es su estado de salud en el día de HOY. Por favor, dibuje una línea desde el casillero donde dice «Su estadode salud hoy» hasta el punto del termómetro que en su opinión indique lo bueno o malo que es su estado de salud en el día de HOY.

Su estado de salud hoy



ANNEX 3:

Taula 1: Símptomes observats en pacients amb símptomes persistents COVID19

A fi de facilitar l'anamnesi i la recollida de dades, i donada l'enorme variabilitat, es presenten els símptomes agrupats per sistemes tot i que en el moment actual es desconeix si els símptomes referits poden ser atribuïbles o no al sistema assignat.

Símptomes generals	Malestar i fatiga	R53
	Febre o febreta	R50.9
	Dolor a les articulacions	M25.5
	Tinnitus	H93.1
	Pèrdua de pes	
Símptomes respiratoris	Dispnea	R06.0
	Tos	R05
	Afonia/ disfonia	R49.1
	Inspiració incompleta	
	Epistaxi	
	Congestió nasal/mucositat	
Diagnòstics respiratoris	Pneumònia viral	J12.9
	Embolisme pulmonar	I26
Símptomes i signes cardíacs	Dolor al pit	R07.4
	Taquicàrdia	R00.0
	Hipotensió	
	Bradicàrdia	R00.1

	Elevació tensió arterial (sense diagnòstic d'HTA)	R03.0
Símptomes neurològics	Insomni	G47
	Mal de cap	R51
	Miàlgies	M79.1
	Anòsmia	R43.0
	Anòmia	
	Amnèsia	R41.3
	Paragèusia	R43.2
	Desorientació	R41.0
	Altres signes i símptomes relacionats amb la funció cognitiva	R94.1
	Parestèsies	
	Trastorn del sistema nerviós autònom	G90.9
Símptomes dermatològics	Prurit	L29.9
	Rash o erupció cutània	R.21
	Caiguda del cabell	
	Aftes bucals, herpes labial	
Símptomes digestius	Nàusees/ vomits	R11
	Anorèxia/ inapetència	
	Diarrea	

	Presència de sang o mucositat en la femta	
	Distensió abdominal	
Altres	Alteracions visuals no especificades	H53.9
	Poliúria	
	Alteracions del cicle menstrual	
	Sinusitis crònica	J32.9

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MANAGEMENT OF PEOPLE WITH COVID-19 AND LONG-LASTING SYMPTOMS IN PRIMARY CARE.

- INTRODUCTION

Patients presenting long-lasting symptoms of COVID-19 represent an emergent Health issue derived from SARS-COV-2[1] infection.

The persistence of invaliding symptoms affects approximately 10%[2] of people who have suffered COVID-19 months after the onset of the acute disease. It determines the need of a caring follow-up from primary care consultations. For example, there have been described long-term respiratory complications[3] .

Data about the long-lasting symptoms of COVID19 has been reported from hospital settings and in severe patients, who had been admitted either to hospital or to an Intensive Care Unit. Severe patients represent 14% of infected patients. Evidence is lacking about estimated data of the number of people affected by long-lasting symptoms who didn't fulfil admission criteria at the moment of acute disease and were classified as a mild or moderate. They constitute the huge of the first wave of the pandemic (81%) and were assisted by primary care centres. People admitted to the hospital have a PCR confirmation test whereas people with mild or moderate disease who didn't fulfil admission criteria don't have, due to the lack of availability of the confirmatory test (PCR) at the primary care Health centres until may 2020. At that moment, many of these people were experimenting symptoms from more than 30 days.

In the actual epidemiologic context, without any curative treatment, observation and management of invalidating symptoms presented by these patients represents an opportunity to generate knowledge from primary care in collaboration with people affected. The objective of accompanying these people has to be alleviate their physical and emotional discomfort and facilitate the reincorporation to their laboral and personal activity which they developed before getting sick.

The existence of a guidance that encourage observation and accompaniment of these people is essential given the actual pandemic situation, with an expected increase of COVID19 cases during next months, some of them will develop long-lasting symptoms as we now have observed.

The object of this guidance aims to be:

- To guarantee a similar treatment of people with long-lasting symptoms, no matter where they live or the Health centre they are related to.
- To position the primary care professional as person of reference for the management, follow-up and integral treatment of people with long-lasting symptoms and their different affected systems.
- To improve the efficiency of the used resources, giving primary care access to any test required based on the particular clinical situation of every patient.

- To take profit of the joint effort created through the generated knowledge of Post-Covid Units at the hospitals with primary care and the group of patients affected with long-lasting symptoms.

- DEFINITION

People with compatible symptoms of COVID19 who have been clinically diagnosed during the first wave of pandemic (11th march 2020- to actuality) with or without a positive PCR, with or without a positive serology, who presents symptoms for more than 3 weeks[5-6] from the onset.

Lack of availability of tests at the beginning of the pandemic and their limitations, implies that the vast majority of people with long-lasting symptoms have as the only aval of their disease, their symptoms, which they developed in the ongoing of a pandemic.

PCR limitations (false-negative results beyond 8th day of symptoms onset) and serologies limitations (mild and moderate cases have been described to generate few or none antibodies[7]) make imprudent using them as the only diagnostic nor defining tool of disease's curation[7].
In this cases, as in many cases we face in our daily practice, diagnosis has to rely on the clinical features that have experienced or that are experiencing patients, in a context of epidemiologic plausibility for that diagnosis.

- FOLLOW-UP AT PRIMARY CARE

Prolonged symptoms in people with COVID19 are characterized by their variability and fluctuant evolution. That is way the following up have to be accurate and systematic with the aim of describing and tackling the changes (and the disability that these symptoms condition in each patient), as they occur.

ANAMNESIS:
Symptoms have been described in practically all systems. Medical record may be oriented to collect the following aspects:

- Day of symptoms 'onset.
- Actual symptoms[8-9]:

    - General symptoms: feeling feverish, chills, anorexia, dizziness
    - Respiratory symptoms: dyspnoea, wheezing, dry or expectorated cough
    - Muscle-skeletal symptoms: fatigue, myalgia, joint paint
    - Neurologic symptoms: headache, paraesthesia, weakness, lack of memory and concentration, anosmia and dysgeusia
    - Gastrointestinal symptoms: dysphagia, heartburn, feeling nauseous, diarrhoea.
    - Cutaneous symptoms[9]; photosensitivity, rashes, dry skin.
    - Otorhinolaryngologic symptoms: sinus pain, dysphonia, vertigo, nasal discharge, earache
    - Cardiovascular symptoms: blood pressure changes, palpitations, tachycardia
    - Ocular symptoms: conjunctivitis
    - Urinary symptoms

- Diary of symptoms (from the onset of symptoms, if it is possible, or from the moment of the first appointment). Creating a symptoms' diary allows an accurate observation of the disease and can help people affected to perceive improvement as time goes by. In people who started symptoms during March, the memory bias can difficult data collection. (annex 1)

- Relapse or flair-up evolution and description: frequency, intensity (we propose using Likert Scale from 0 to 5), which symptoms includes and order of appearance, which situations make them better or worse, duration of the episode, functional situation after the relapse compared to previous situation.

- Scales (annexe 2). The following scales are proposed, as they can be useful to specify the intensity or quality of some of the symptoms in the diary; they can be completed by the affected person at home and discussed at following encounters with the primary care physician, aiming to detect changes in their functional state.
    - EVA : Used to value pain, autocompleted diary.
    - Daniels : Scale used to assess muscle strength. Completed by a physician, during inter-relapses periods (monthly).
    - Likert : A proposal for quantify the intensity of relapses or flair-ups, autocompleted, used at each relapse.
    - Euroqol-5D : Value of quality of life, autocompleted. It could be used each 2 months.
    - Modified Borg scale: It values the effort perception. It needs to previously select with affected person some repeated daily activities and assess the effort of doing them when ending. E.g. to take trash out, to climb one floor by the stairs). AutoCompleted, monthly.
    - Activities of Daily Living (ADL) Scale: Complemented by primary care physician or nurse at the Health centre. It is proposed to completed it each two months, to objectify differences.

PHYSICAL EXAMINATION

Initially, to discard severity signs that implies a referral to an emergency room is needed[2] :

- Oxygen saturation at room air <96%
- Inexplicable causes of chest pain
- Worsening of a respiratory discomfort
- Neurological focus (loss of strength in any upper or lower limbs, e.g)

It is essential to do an accurate initial physical exploration of every patient affected with COVID19 either at the Health centre or at home, including:

- Vital signs: temperature, oxygen saturation, blood pressure, heart rate.
- Cardio-pulmonary auscultation
- Abdominal exploration
- Skin inspection
- Neurological exploration
- To assess functional capacity and quality of life (see annex 1)

Afterwards:

- It is recommended a new physical exploration in front of the appearance of new symptoms, changes or variation in existing symptoms or if severity is suspected.
- A thorough observation of symptoms and their evolution (see annex 3)

ADDITIONAL TESTS

Although they will not always been necessary, in case of worsening or long-lasting disabling symptoms, primary care needs to have a quick access to:

- Blood test: depending on suspicion: LDH, hemogram, CBC, dímer-D, LDH, hemogram, ferritin, kidney function, electrolyte and all those values that helps us to discard other pathologies involved in the differential diagnosis of symptoms presented.
- Chest X-ray
- Electrocardiogram
- Functional respiratory test
- Pulmonary and abdominal sonography
- Other kind of tests easily to access and perform at equal conditions than before pandemic, for those specific cases which need an thorough study (e.g. a tomography or an endoscopy to value respiratory symptoms or persistent and disabling digestive symptoms; cardiac stress test to assess aerobic ability)

It is important to insist on the aim of additional tests. On one hand, they can help to discard severity, on the other hand they can help to objectify (and so, to recognize) what is happening to the affected person, they can also reduce uncertainty both in the patient and professional (in front of a non pathologic result of the test) and can be useful to discard other pathologies included in the differential diagnosis.

The relapsing course of long COVID19 could make the performance of additional test as useful during the flair-up as during the inter-relapses period (when the result is more likely to be normal).

We need to adequate the aim we prosecute with the test and have a conversation with the patient about its usefulness, probable results, interpretations of the results, e.g., just to avoid being maleficient.

OTHER SPECIALIST REFERRAL

An agile and bidirectional contact is essential between primary care professionals and hospital specialists, by phone, by an interconsultation without patient, by videoconference or whatever resource may it possible. It may be needed to refer to:

- Cardiologist
- Pneumologist
- Neurologist
- Gastroenterologist
- Dermatologist

- Physical Therapist or Occupational Therapist
- Ear, nose and throat specialist
- Rheumatologist
- Endocrinologist
- Mental Health specialists

SOCIAL WORKER COORDINATION.

As prolonged symptoms can be disabling, people can experience new difficulties, among them those related with taking care of people at their charge, their Laboral situation and others that can compromise their economic survival (nutritional, housing). This situation caused by the disease can't rely only on individuals who suffer from it, but must be understood in the context of a social and communitarian responsibility, which has to be able to help them and repair the consequences that bring with being sick.

- TREATMENT

There is no curative treatment, but in its absence, we can offer the affected people a palliative and symptomatic treatment with the aim of alleviate their malaise.
Treatment must value their needing's in every sphere where disease might have impacted, as we do in front of other diseases. Decisions about the management of this impact, must be individualized and agreed with each patient.

Drugs:
In front of lacking of evidence of efficacy of some drugs to improve COVID19 symptoms, but, knowing their usefulness in other diseases that develop similar symptoms, some of them can be empirically treated, as we do in other diseases. Prescribing drugs to patients needs to be done in a conversation with patient informing about risks and benefits of using each of the proposed drugs, uncertainty involving their use in particular cases.

Drugs that may be useful can be[11]:

- Oral steroids, for respiratory symptoms.
- Topic steroids for skin conditions
- Probiotics if there is intestinal involvement.
- Anti-H2 if gastric involvement.
- Analgesia and NSAID if headache, muscular pain and other kind of pain.

Use of antidepressants and benzodiazepines ((and the aim we pursued with it), as prescription of other drugs does, must be agreed with the patient and demands to be cautious. Anxiety can be generated by uncertainty, by persistence of symptoms, by a different relationship with oneself and a body that changes uncontrollably and by feeling disabled. This anxiety must be managed principally with words and accompaniment.

Physical Therapy:
A coordination with the Physical Therapy Centres of each area from the beginning of diagnosis in order to offer physical and respiratory therapy, and also progressive exertion adaptation in those patients is needed to improve gradually their funcionality [12].

Management of emotional distress:

Emotional effects of the prolonged symptoms in patients with COVID19 can condition their recovery.

Primary Care follow-up has to be able to guarantee the bond[13] that exists between patient and professional. Its existence will allow an active and empathic listening by the professional and will reduce unnecessary medicalization.

Some patients will need social prescription with the aim to use community support resources during their convalescence and information about the existence of associations and other groups of people affected by prolonged symptoms of COVID19.

Finally, some mutual helping groups as self-cure and mutual support spaces can be an useful resource for some patients.

MANAGING LONG TERM DISABILITY.

As there is not a definition for "curation"[14] of COVID19 and based on what we know about "curation" in other diseases (absence of symptoms), people affected with prolonged symptoms of COVID19 can't be addressed as "cured" because they still experiencing intermittent symptoms and a functional disability secondary to those symptoms that prevent them from going back to their work.

An evaluation of maintenance of the long term disability has to be done in each follow-up encounter and for as long as people still showing symptoms.

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