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Empowering Patient to Co-design Covid-19 Responses: The Role of Online Health Communities

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Empowering Patient to Co-design Covid-19 Responses: The Role of Online Health Communities

Abstract

Covid-19 has paved the way for major disruptions to conventional healthcare systems accelerating participatory health enabled by interactive virtual environments. The role of the ‘patient voice’ as a fundamental resource in an effective Covid-19 response has moved centre stage. In this time of extraordinary crisis and health system disruptions, patient-centred models offer opportunities for embedding shared decision-making to improve health outcomes using digital tools. Through an exploratory case study, this paper examines patient action during Covid-19 and how co-design methods can be adapted to an online environment in response to Covid-19 restrictions to improve the Covid-19 patient and family experience of care. Experienced-based co-design was employed to map the care journey of patients with Covid-19 confined at home in Spain - one of the hardest-hit countries in the pandemic, to identify quality improvements. Main touchpoint needs were explored in online co-design workshops leading to improvement projects including the development of a Covid-19 patient online health community (OHC) to deliver patient-centred care during the outbreak. The Covid-19 patient OHC has become an instrument that facilitates Covid-19 patient’s recovery, especially psychological resilience. OHC participation has clear potential for empowerment and transformative agency as it enables Covid-19 patients to control the content and flow of the information available to them. This paper offers valuable insights on how co-design can be adapted to an online format to enable more meaningful patient input to healthcare design when faced with uncertainty and ambiguity during health crises.

Keywords: Covid-19; participatory health; patient voice; co-design; patient empowerment; Online Health Communities; patient journey map; experienced-based co-design.

1. Introduction

The current Covid-19 pandemic caused by the coronavirus SARS-CoV-2 presents unprecedented challenges to healthcare systems and care services, bringing intense pressure and accelerating the use of innovations and improved approaches (Duek and Fliss, 2020, Brem et al., 2020). Digital technologies are being harnessed to support the public health response to Covid-19 worldwide (Budd et al., 2020), including an accelerated trend towards virtual care to ensure that patients continue to receive convenient medical care without the risk of exposure (Wosik et al., 2020), the use of AI-powered triage systems (e.g., medical chat bots) to ease the burden on healthcare systems by identifying infection severity (Wittbold et al., 2020), and the development at a high rate of healthcare wearable devices to support early detection of Covid-19 related symptoms (Weizman et al., 2020).

The Covid-19 crisis is also shaping an environment for greater patient involvement and engagement in healthcare innovation and delivery (Abrams et al., 2020). Pitts (2020) refers to 'the patient voice' as the most powerful weapon to fight Covid-19. The allocation of scarce resources during the pandemic has caused countless ethical and legal challenges (Rawlings et al., 2020). Hence, managing over-stressed clinical health systems but still providing ethical care highlights the importance of patient's active role as a fundamental resource in the quest towards more equitable, sustainable and resilient health systems (Richards and Scowcroft, 2020). It requires engaging with patients, user groups and communities using models of care that are patient-centred (Turk et al., 2021). These models are built on the underlying premise of active collaboration and shared decision-making between patients, families and healthcare providers to improve quality and care (Richards et al., 2015).

Such a paradigm shift however is challenging and implementing patient-centred models poses multiple challenges (Oliver et al., 2019, Moore et al., 2017). To be truly transformative, there must be a shift of power towards equitable partnerships between healthcare professionals, patients and communities (Gremyr et al., 2021), removing artificial distinctions between 'recipients' and 'providers' of healthcare services, and seeing patients as co-producers of knowledge (Palumbo, 2016).

In this paper, we seek to understand the relevance of co-production under Covid-19 and the conditions that made co-production to emerge as an alternative in the Covid-19 response. Co-production in healthcare means embedding the patient voice in decision-making, from commissioning to co-design and co-delivery (Vennik et al., 2016) and it is flourishing under Covid-19 (Steen and Brandsen, 2020, Marten et al., 2021). Failure to respond to the global Covid-19 pandemic in participatory and inclusive ways has paved the way for different methods of health stakeholder engagement to find flexible and innovative solutions (Beresford et al., 2021a, Beresford et al., 2021b, Turk et al., 2021, Loewenson et al., 2021). Particularly, the increased use of digital platforms has powerfully enhanced patient engagement and enabled greater diversity of voices and ideas in the Covid-19 response (Denegri and Starling, 2021, Mills et al., 2020). Online platforms have also enabled global social responses to Covid-19, such as Frena la Curva (*slow down the curve*) a citizen-driven platform connecting Spanish speaking countries to accelerate coping strategies, especially for the most vulnerable (Lungati, 2020) and The GEO Indigenous Hackathon, an online platform engaging indigenous groups around the globe to co-design culturally appropriate Covid-19 response methods (GEO, 2020).

Applying co-production can be challenging and a gap still remains in the understanding of how to engage patients in co-producing knowledge (Palumbo and Manna, 2018, McCarron et al., 2021). Through an exploratory case study (Yin, 2003), this paper examines patient action during Covid-19 and how Experience-based Co-design (EBCD) can be used to improve the Covid-19 patient and family experience of care. Our discussion aims to contribute to the emerging literature in EBCD as an approach in healthcare service design and its application to drive quality improvements during a health crisis situation. It demonstrates how EBCD can be adapted to an online environment in response to Covid-19 restrictions (Kennedy et al., 2021). EBCD is based on the principles of co-production and engages key stakeholders in a systematic, participatory process of reflection and collaboration leading to the co-design of improvements (Bate and Robert, 2007). EBCD involves patients, families and professional staff exploring the care pathway and the emotional journey patients experience along it, capturing experiences, and then working together to understand these experiences and identify improvement priorities (Boyd et al., 2012). Allowing patients, carers and staff express their lived experience and stories regarding care delivery gives them a voice within the process that can used to improve quality and care (Donetto et al., 2015).

The current qualitative study describes the use of EBCD with Covid-19 patients confined at home in Spain - one of the hardest-hit countries during the first of wave of Covid-19. The dramatic shift towards social distancing measures to curb transmission, protect the vulnerable, and reduce the burden on the healthcare system presents important challenges to the health and wellbeing of Covid-19 patients after being discharged from hospital (Venkatesh and Edirappuli, 2020). To improve the Covid-19 patient and family experience of care, EBCD was used by the Institute for Patient Experience (IEXP) to map the patient journey. Journey maps capture the thoughts, feelings and actions throughout the personal healthcare journey from the perspective of the patient (Trebble et al., 2010, McCarthy et al., 2016). The resulting visual tool helps to identify opportunities for improvement of patient interaction with the service. Main touchpoint needs were explored in online co-design workshops leading to improvement projects, including the need for a Covid-19 patient online health community (OHC) to deliver patient-centred care during the Covid-19 outbreak. An OHC - also known as Virtual Communities of Practice (VCoPs), refers to a group of people (e.g., patients, health professionals or a mixture of both) who interact with each other in online environments about similar health issues (Wang et al., 2017). The onset of the Covid-19 pandemic has led to a renewed engagement with OHCs that offer social and informational support to Covid-19 patients (Jong et al., 2021, Mills et al., 2020, Li et al., 2020).

By combining health information and audio-visual resources (i.e., reports, podcasts and videos alongside personal testimonies of people affected and recovered from Covid-19), the Covid-19 patient OHC offers community members instant messaging, forums and patient geolocation, as well as a chatbot called Patty, based on emotional and motivational intelligence, to track the progress of the virus. The OHC has become an instrument that facilitates Covid-19 patients recovery, especially psychological resilience, since the connection between patients of the same pathology generates encouragement, empathy and esteem (Yan and Tan, 2014, Zhang et al., 2018). Participation in the OHC has influenced Covid-19 patients' perceptions of being empowered as it enables them to control the content and flow of the information available to them.

The paper proceeds as follows. Following, the introduction, Section 2 provides a brief overview of co-production and co-design in healthcare. Section 3 discusses the EBCD approach used to meaningfully engaged Covid-19 patients, family members and healthcare professionals to deliver patient-centred care during the outbreak. Section 4 provides a discussion and conclusions.

2. Theoretical Background

Co-production in healthcare is receiving increasing attention in the literature, public policy debates and civic society responses as the cornerstone of a sustainable healthcare system of the future (for recent systematic reviews refer to Marsilio et al., 2021, Fusco et al., 2020, Palumbo, 2016). The WHO Global Strategy for Integrated People-Centred Health Services 2016-2026 (World Health Organization, 2015) argues that the future of care requires an 'equal and reciprocal relationship' between clinical and non-clinical professionals together with individuals using care services, their families and communities. Covid-19 has renewed interest in and advocacy for adoption of co-production of public responses to the pandemic to tackle health inequalities in societies (Beresford et al., 2021a, Allen et al., 2021).

Co-production in healthcare means that patients actively contribute to the provision of health services as partners of health professionals and service providers (Vennik et al., 2016). The effective participation of patients as key stakeholders in the design and production of healthcare services is seen as an important means to increase satisfaction with the experience of care, reduce complications associated with the treatment, and improve health outcomes (Batalden et al., 2016). Co-production challenges the traditional model of healthcare provision where patients are mostly seen as passive recipients of care from service providers (Laing et al., 2002, Taylor, 2009). Value creation was conceptualised as company centric with the value, defined as the benefit to patients' quality of life resulting from healthcare resources (Lee, 2017), being provided by the company to the consumer (i.e., an approach directed entirely by the doctor) (Rezaei Aghdam et al., 2020).

With a shift towards service-dominant logic in service science supported by digital developments, health care practice and academia have started to recognise that patients are no longer passive recipients of their treatment but actively engaged in its implementation (Joiner and Lusch, 2016, Palumbo, 2017). Patients are increasingly becoming engaged and active consumers who participate in the creation of 'health' value by sharing information, competencies and resources with service providers in order to improve the quality of care – *multi-actor integration of resources* (McColl-Kennedy et al., 2017, Van Oerle et al., 2018, Nordgren, 2008). This perspective allows a focus on the patient as an operant resource in co-production processes (Vargo and Lusch, 2004).

Patient-centred approaches for quality care are designed around the specific needs of the patient – '*the physician tries to enter the patient's world, to see the illness through the patient's eyes*' (McWhinney et al., 1989). Meaningful clinical engagements require building a partnership in the encounter process, sharing detailed information and allowing patients to deliberate and express their preferences and opinions during this process (Elwyn et al., 2010, Pitts, 2019, Bate and Robert, 2007). Patients' active participation is essential in order to enhance treatment options as well as to improve health outcomes and cost efficiencies (McColl-Kennedy et al., 2012, Elg et al., 2012, Cyril et al., 2015). Co-production can facilitate the implementation process as well as the sustainability and scalability of the interventions (Greenhalgh et al., 2016).

A patient-centred approach also offers opportunities for co-production practices that involve a network of actors collaborating to provide a healthcare solution. Sweeney et al. (2015) argue that co-production can be seen as a three part process: within and outside-hospital activities and self-generate activities by the patient. Hence, co-production can be achieved through a range of activities at different levels, including self-management of healthcare and improving communication and shared understanding (Frow et al., 2016). Additionally, a patient-centred model extends the range of collaborative activities to include actions offering both emotional and physical wellbeing (Kuipers et al., 2019).

Co-production is therefore used as a general umbrella term to describe the various activities undertake by co-producers, including co-commissioning, co-design, co-delivery and co-assessment (Bovaird et al., 2019). This paper specifically examines co-design in healthcare defined as '*a method of designing better experiences for patients, carers and staff*' (NHS Institute for Innovation and Improvement, 2017, p.3). It seeks to actively involve all stakeholders (patients, careers and staff) working in partnership in the design and review of services (Donetto et al., 2015). Co-design has been cited as being successful in creating greater staff awareness of patients' experiences, improvements in care and treatment processes, and better health outcomes (Boyd et al., 2012, Goodyear-Smith et al., 2015). Implementing co-design in healthcare is challenging, particularly it can be time consuming, adding to already high clinical workloads (Kirk et al., 2021). Truly equalising power and challenging dominating relationships and practices between servicer users and providers might be an obstacle to true participation (Farr, 2018, Farrington, 2016).

Relatively few insights are available on how co-design can be applied in the healthcare context and the methodology and tools to ensure meaningful participation. This paper offers practical evidence and focuses on experience-based co-design (EBCD), an evidence-based approach based on participatory action research, narrative theory, learning theories and design thinking (Bate and Robert, 2007, Donetto et al., 2015). EBCB enables patients, careers and practitioners to collaborate on the design of solutions (Fucile et al., 2017, Robert et al., 2015). EBCD principles include participants sharing their experiences of care through narrative and story-based approaches to move from an individual to a collective understanding of key touchpoints on the journey of care that can inform health service development or improvements (Robert, 2013, Mulvale et al., 2019, Fylan et al., 2021). Touchpoints are emotional interactions between staff and patients, both positive and negative, that both parties regard as key to the overall experience of receiving or delivering care (Robert et al., 2015, Bate and Robert, 2007). The integration of the lived experience of service users ensures that outcomes are targeted and co-designed with those most likely to be affected by issue, change of process or intervention (Donetto et al., 2015, Palmer et al., 2015). The collaborative nature of EBCD seeks to deeply embed service users' experiences as the primary driver of system change and provides a commitment to shared power arrangements and decision making '*by enabling a voice for people to take part in the conversation*' (Dimopoulos-Bick et al., 2018, p.88).

Due to Covid-19, social distancing and lockdown, researchers have come up with innovative ways to adapt face-to-face co-design methodology to an online environment (Kennedy et al., 2021, Beresford et al., 2021b). Digital platforms, such as WhatsApp and Facebook, have been successfully used for co-design (Brown et al., 2020) and more flexible processes of collaboration have been proposed that respond to the need for low-contact and social distancing as a result of Covid-19 (Davis et al., 2021, Langley et al., 2021). Digital co-design methods can help overcome power imbalances and inequalities (Kennedy et al., 2021), although the type of technology and accessibility are key considerations in digital co-design methods (Hall et al., 2021).

The present work focuses on the application of the EBCD process as a patient, family and healthcare provider engagement method in quality improvements initiatives. EBCD was employed to improve the care experience of Covid-19 patients isolated at home and families.

3. Co-design Quality Improvements for Covid-19 patients

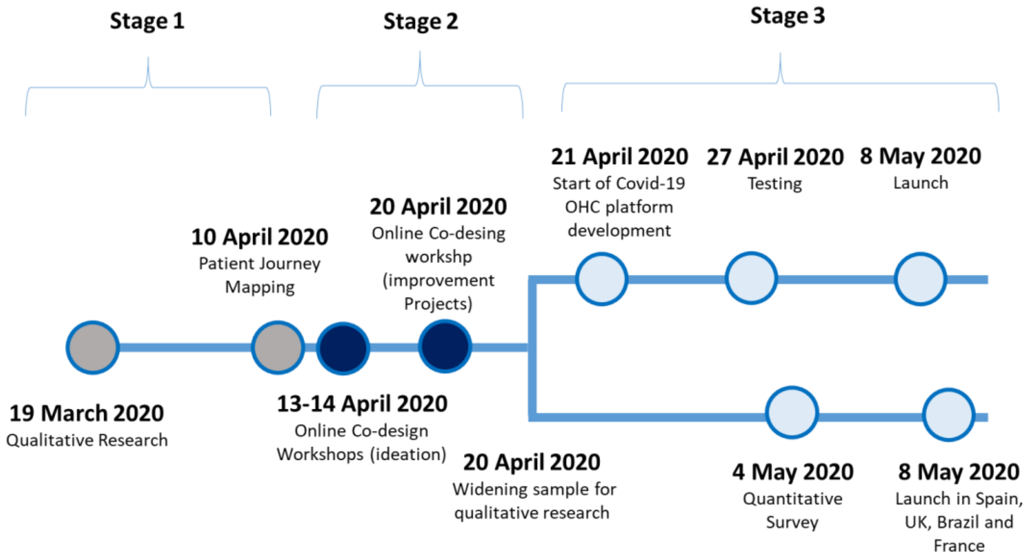
The first wave of Covid-19 spread rapidly in Spain, one of Europe's most affected countries. Official data shows that from 24 February to 31 March of 2020, Spain recorded 102,136 positive cases with 9,053 deaths. Faced with the severity of the situation, the Spanish government declared a state of alarm on 14 March 2020, and subsequently, it paralysed all non-essential economic activity. The national lockdown was later extended until 21 June 2020. Government interventions generated significant psychological and social effects on the population due to the loss of freedom, reduced social contact and constant fear and uncertainty about the advancement of the disease and control measures (Alfonso Viguria and Casamitjana, 2021).

The impact of isolation presents important challenges to the health and wellbeing of patients with Covid-19 after being discharged from hospital (Venkatesh and Edirappuli, 2020, He et al., 2021). Isolation might result in drastic and lasting psychological effects, such as anxiety, depression and post-traumatic stress disorder (PTSD) (Brooks et al., 2020). The impact has been amplified by fearmongering and misinformation; thereby, hampering the response to the outbreak (Barua et al., 2020). As noted by WHO Director General Dr Petros '*Misinformation on the coronavirus might be the most contagious thing about it*' (WHO, 2020).

In Spain, given the urgency of the pandemic and the ferocity of the first wave of Covid-19, the Institute for Patient Experience (IEXP) used EBCD to understand the care needs of Covid-19 patients confined to their flats and houses during the first months of the pandemic. EBCD is a powerful tool for patient involvement where patients, carers and health professionals work together to improve healthcare quality (Gustavsson and Andersson, 2019). The process involves capturing and understanding the patient experience and then implementing solutions with and for those for whom it is designed (Green et al., 2020). EBCD enables embedding more deeply end users' experiences as the primary driver of health system change processes and provides a commitment to shared power arrangement and decision making (Lewis et al., 2021).

To capture and understand patient experiences, a number of tools were employed including patient journey mapping and co-design workshops. A patient journey map is a summary of the service experiences patients have over time (Trebble et al., 2010, McCarthy et al., 2016, Simonse et al., 2019). Based on direct quotes from Covid-19 patients, the patient journey map is a tangible representation of the Covid-19 patient voice. It includes patient journey phases, interactions, emotions and motivations throughout the personal care journey, touchpoints (significant points of contact between the patient and service) and suggested improvement ideas. Co-design workshops involve a wide range of people coming together to discuss issues and make decisions (Bessant and Maher, 2009). Figure 1 depicts the EBCD process followed to improve the home isolation experience of Covid-19 patients.

Figure 1. EBCD to improve the home isolation experience of Covid-19 patients



3.1. Stage 1 – Patient Journey Mapping

The first stage aims at capturing and understanding the Covid-19 patient experience through in-depth interviews. Given the novelty and urgency of the outbreak, participants were selected by the research team through their networks, followed by a snowballing sampling approach (SBA) and consented via email or verbally. This method is preferred to other probabilistic approaches of sampling when the desired sample characteristic is rare (Siddiqui et al., 2016). Initially, key informants for the study population are identified, and based on the information provided by key informants, potential subjects are located (Valerio et al., 2016). Participation in the study included 15 Covid-19 patients isolated at home, living in Madrid, both genders and between 18-64 years old. The sample was increased to 41 patients in the quality improvements stage to improve the accuracy of the study and capture the evolving nature of the Covid-19 outbreak at the pick of the first wave (Spring 2020).

Patient interviews are aimed at helping patients identify and explore emotional 'touchpoints' on the journey of care, with a view to improving these experiences (Robert et al., 2015). Based on patient interview data, the research team generated the Covid-19 home isolation patient journey map (Figure 2). Patient journey maps are utilised to depict the healthcare service from the patient's perspective (Trebble et al., 2010, McCarthy et al., 2016). They are based on mapping a consecutive series of patient touchpoints with a specific healthcare experience. If we understand the patient journey map as a matrix, the horizontal axis shows the stages of the service delivery experience while the vertical axis shows the dimensions of the patient experience (i.e., operational, emotional, interactional, etc.) (Simonse et al., 2019). Thus, for each stage in the service delivery process, the visual tool enables to map the relative position of individual experiences as a high or low point. Similarly, it is possible to follow different aspects of the patient experience along the service delivery path and their evolution.

The design of the patient journey map in this study provides a deep understanding of the home isolation experience of Covid-19 patients from the onset of illness to recovery and enables to uncover unmet needs of patients leading to improvement opportunities. In particular, the patient journey map describes the *service delivery experience*, *emotional journey*, *touchpoints*, *actors* and *patient needs*.

- *Service delivery experience*: maps the patient experience across the stages from an extensive awareness period before testing positive to possible recurrence and discharge The journey for Covid-19 patients infected by the coronavirus during the first wave was full of uncertainties due to the limited knowledge in relation to the pathology and its treatment, and the tremendous strain on healthcare resources. As shown in Figure 2, the Covid-19 patient journey does not start with symptoms but rather the exacerbated need to seek health related information when facing a situation of crisis that creates an unmeasurable anxiety for knowledge. In Spain, it is reported that information consumption increased by 55% (Pérez-Escoda et al., 2020) and the Spanish population were the most social Europeans, with an increase of 48% in the use of social network apps (Gevers, 2020).

- *Emotional journey*: shows how the patient's experience changes as they move through the different touchpoints. The patient journey, starting from unprecedented amounts of Covid-19 information available up to the hospital discharge, was emotionally charged for Covid-19 patients and their families. Patients' emotions related to three factors: (i) the disease itself and its associated effects; (ii) the relationship with family members; and (iii) the relationship with healthcare professionals and healthcare systems – the latter been perceived as a separate entity from those working there. Emotional experiences were not only intense and varied but the state of mind of Covid-19 patients had various highs and lows - the lowest point being the diagnosis when fear and anxiety emerged.
- *Main touchpoint needs* - the needs of isolated Covid-19 patients at home were clustered around five areas:

i) *Communication and information*: patients commonly mentioned the need for accurate, trustworthy and credible sources of news and advice on Covid-19 – anxiety might arise from inadequate information by less reliable media sources heightening confusion and false hope (e.g., hydroxychloroquine) (Brooks et al., 2020).

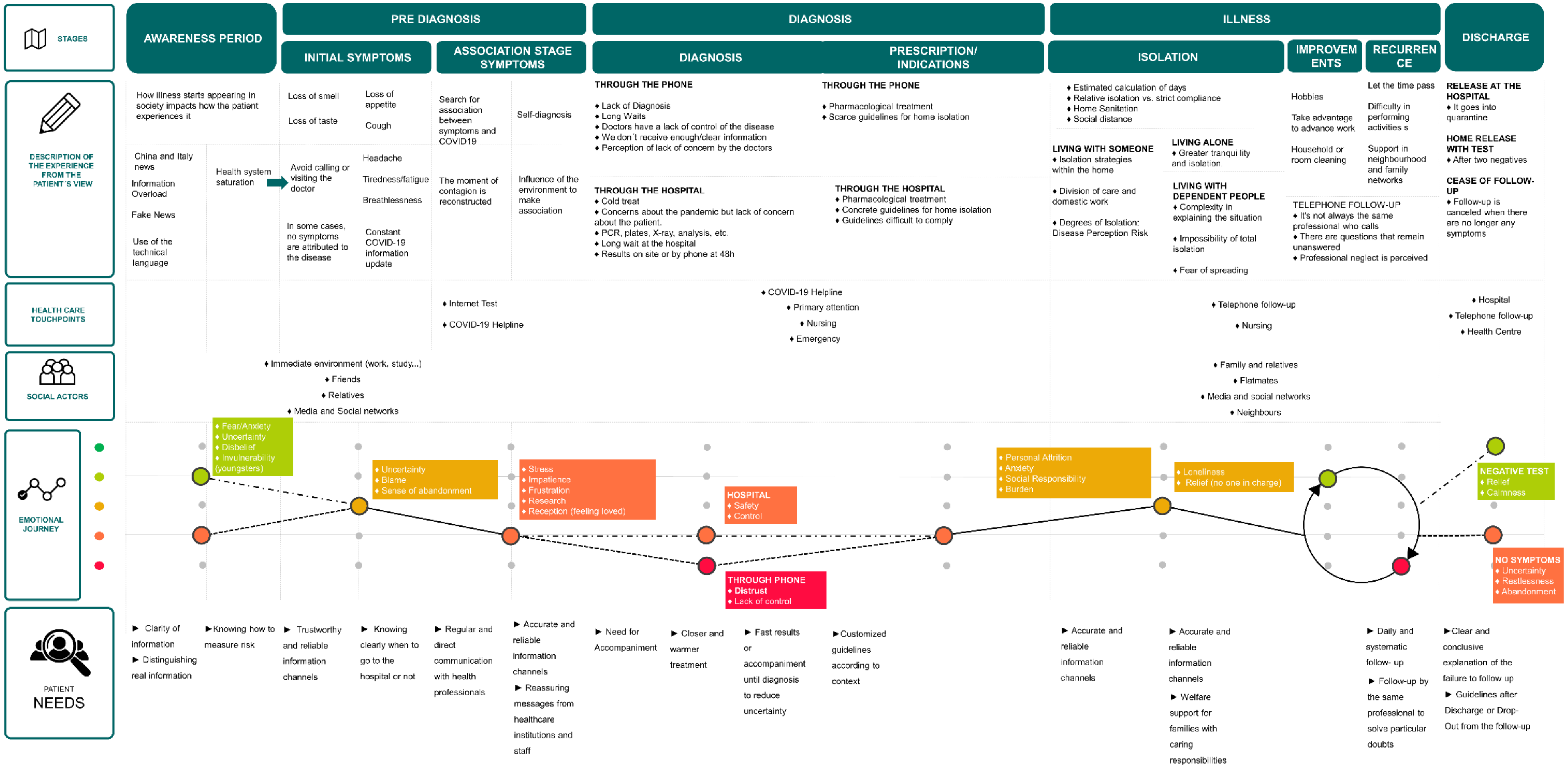
ii) *Healthcare support* – in the case of patients with caring responsibilities

iii) *Emotional support*: to overcome anxiety, panic attacks, depression, guilt and uncertainty, burden, fear or loneliness

iv) *Logistical support* – for patients living alone (shopping) or single parents (child care). Often homes did not have the means for an effective isolation due to lack of resources and spaces.

v) *Treatment and humanization* – at a time when so many people were alone and growing social concern, patients wanted to feel safe and cared for.

Figure 2. Covid-19 Home Isolation Patient Journey Map



STAGES

AWARENESS PERIOD

PRE DIAGNOSIS
- INITIAL SYMPTOMS
- ASSOCIATION STAGE SYMPTOMS

DIAGNOSIS
- DIAGNOSIS
- PRESCRIPTION/ INDICATIONS

ILLNESS
- ISOLATION
- IMPROVEMENTS
- RECURRENCE

DISCHARGE

DESCRIPTION OF THE EXPERIENCE FROM THE PATIENT'S VIEW

How illness starts appearing in society impacts how the patient experiences it

China and Italy news

Information Overload

Fake News

Use of the technical language

Health system saturation ➡ Avoid calling or visiting the doctor

Loss of smell

Loss of taste

Loss of appetite

Cough

Headache

Tiredness/fatigue

Breathlessness

In some cases, no symptoms are attributed to the disease

Constant COVID-19 information update

Search for association between symptoms and COVID19

The moment of contagion is reconstructed

Self-diagnosis

Influence of the environment to make association

THROUGH THE PHONE
- Lack of Diagnosis
- Long Waits
- Doctors have a lack of control of the disease
- We don´t receive enough/clear information
- Perception of lack of concern by the doctors

THROUGH THE HOSPITAL
- Cold treat
- Concerns about the pandemic but lack of concern about the patient.
- PCR, plates, X-ray, analysis, etc.
- Long wait at the hospital
- Results on site or by phone at 48h

THROUGH THE PHONE
- Pharmacological treatment
- Scarce guidelines for home isolation

THROUGH THE HOSPITAL
- Pharmacological treatment
- Concrete guidelines for home isolation
- Guidelines difficult to comply

- Estimated calculation of days
- Relative isolation vs. strict compliance
- Home Sanitation
- Social distance

LIVING WITH SOMEONE
- Isolation strategies within the home
- Division of care and domestic work
- Degrees of Isolation: Disease Perception Risk

LIVING ALONE
- Greater tranqui lity and isolation.

LIVING WITH DEPENDENT PEOPLE
- Complexity in explaining the situation
- Impossibility of total isolation
- Fear of spreading

Hobbies

Take advantage to advance work

Household or room cleaning

Let the time pass

Difficulty in performing activities s

Support in neighbourhood and family networks

TELEPHONE FOLLOW-UP
- It's not always the same professional who calls
- There are questions that remain unanswered
- Professional neglect is perceived

RELEASE AT THE HOSPITAL
- It goes into quarantine

HOME RELEASE WITH TEST
- After two negatives

CEASE OF FOLLOW-UP
- Follow-up is canceled when there are no longer any symptoms

HEALTH CARE TOUCHPOINTS

- Internet Test
- COVID-19 Helpline

- COVID-19 Helpline
- Primary attention
- Nursing
- Emergency

- Telephone follow-up
- Nursing

- Hospital
- Telephone follow-up
- Health Centre

SOCIAL ACTORS

- Immediate environment (work, study...)
- Friends
- Relatives
- Media and Social networks

- Family and relatives
- Flatmates
- Media and social networks
- Neighbours

EMOTIONAL JOURNEY

- Fear/Anxiety
- Uncertainty
- Disbelief
- Invulnerability (youngsters)

- Uncertainty
- Blame
- Sense of abandonment

- Stress
- Impatience
- Frustration
- Research
- Reception (feeling loved)

HOSPITAL
- Safety
- Control

THROUGH PHONE
- **Distrust**
- Lack of control

- Personal Attrition
- Anxiety
- Social Responsibility
- Burden

- Loneliness
- Relief (no one in charge)

NEGATIVE TEST
- Relief
- Calmness

NO SYMPTOMS
- Uncertainty
- Restlessness
- Abandonment

PATIENT **NEEDS**

- ► Clarity of information
- ► Distinguishing real information
- ► Knowing how to measure risk
- ► Trustworthy and reliable information channels
- ► Knowing clearly when to go to the hospital or not
- ► Regular and direct communication with health professionals
- ► Accurate and reliable information channels
- ► Reassuring messages from healthcare institutions and staff
- ► Need for Accompaniment
- ► Closer and warmer treatment
- ► Fast results or accompaniment until diagnosis to reduce uncertainty
- ► Customized guidelines according to context
- ► Accurate and reliable information channels
- ► Accurate and reliable information channels
- ► Welfare support for families with caring responsibilities
- ► Daily and systematic follow- up
- ► Follow-up by the same professional to solve particular doubts
- ► Clear and conclusive explanation of the failure to follow up
- ► Guidelines after Discharge or Drop-Out from the follow-up

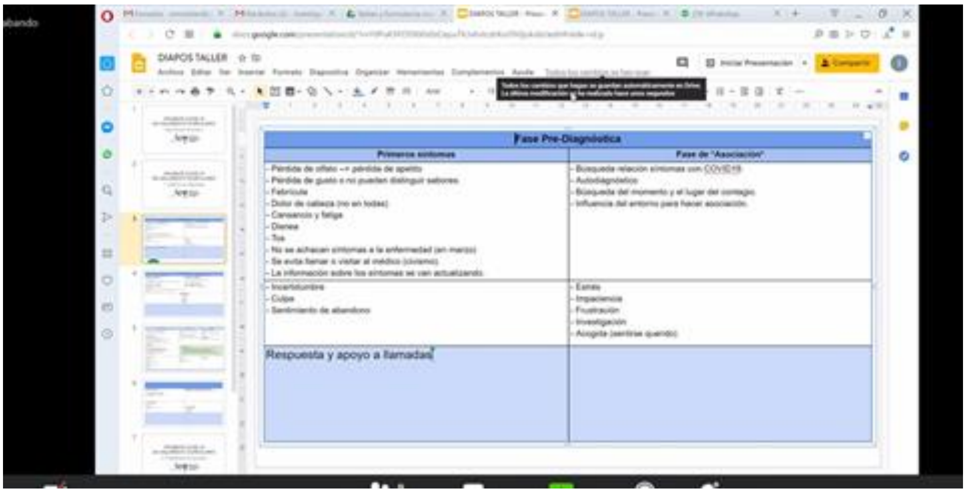
3.2. Stage 2 – Co-design Workshops

After care needs were identified, the project organised three online co-design workshops with Covid-19 patients to jointly develop interventions. Engaging patients in the co-design of public health interventions increases adherence and effectiveness due to the empowerment of patients to develop outcomes tailored to their own needs (Green et al., 1996, Trischler et al., 2019). The first two co-design workshops focused on the ideation stage of the service design process while the third involved concept evaluation and development of ideas into solutions. The co-design methodology, based on participatory action research (Koshy et al., 2011), was adapted to the online environment in response to Covid-19 restrictions, including fewer participants and shorter interaction times.

The online ideation co-design workshops were held on April 13 and 14 2020 involving Covid-19 patients isolated at home, clinicians infected by the virus, physicians from the Spanish Society for Quality Healthcare as well as members of the innovation unit at La Princesa Hospital (Madrid). Online co-design healthcare workshops followed a stage-based methodology to overcome social, power and knowledge gaps across the different groups. Careful moderation was necessary to compete all stages in the online environment (Figure 3).

Online co-design workshops validated the qualitative study results (Stage 1) and generated a number of ideas, including offering psychological support, listening to the ‘friendly voice’ of other Covid-19 patients, providing accurate and trustworthy information, and trusted sources for logistical support. First ideas were further refined leading to improvements, including webinars for psychological support, medical information, physiotherapy, etc. A further improvement was the creation of an accurate and validated list of medical and logistic resources and technological support to enable connectivity among Covid-19 patients.

Figure 3 –Online Covid-19 co-ideation workshop



Fase Pre-Diagnóstica	
Primeros síntomas	Fase de "Asociación"
- Pérdida de olfato → pérdida de apetito - Pérdida de gusto o no pueden distinguir sabores - Febrícula - Dolor de cabeza (no en todos) - Cansancio y fatiga - Disnea - Tos - No se achacan síntomas a la enfermedad (en marzo) - Se evita llamar o visitar al médico (civismo) - La información sobre los síntomas se van actualizando	- Búsqueda relación síntomas con COVID19 - Autodiagnóstico - Búsqueda del momento y el lugar del contagio - Influencia del entorno para hacer asociación
- Incertidumbre - Culpa - Sentimiento de abandono	- Estrés - Impaciencia - Frustración - Investigación - Acogida (sentirse querido)
Respuesta y apoyo a llamadas	

On April 20 2020, the third online co-design workshop took place. Although Covid-19 is not a chronic disease, the co-design workshop involved physicians and biologists who have suffered Covid-19 and had first-hand experience on the care needs of Covid-19 patients isolated at home (*experiential knowledge*) combined with their professional knowledge of the disease (*scientific knowledge*). The co-design workshop was structured into three parts: (i) proposal, (ii) prioritization and selection, and (iii) development of the idea into an action plan. To improve the level of detail, proposals were prepared in advance by participating teams using a detailed template. Specific improvements were prioritised during the co-design workshop, including the development of a Covid-19 OHC since patients need peer-to-peer support. Interacting with other people living with the same health condition has become a key component of health self-management and patient empowerment (Meng et al., 2019, Wu and Bernardi, 2020).

Stage 3 – Covid-19 Online Health Community

Since OHCs are normally organised around social networks, apps or websites, participants agreed to use an existing digital platform (www.pacientalia.com). This platform hosts communities of chronic patients to provide information, solidarity and support. Pharma companies tend to support these communities in exchange for insights and data. The online platform provides a virtual meeting place for the Covid-19 community to exchange information about their ‘lived experience’ of the condition and treatment as well as the opportunity to host webinars, offer psychological support, and organise forums on specific topics (e.g., clinical information, logistics, etc.). Participants agreed that in order to ensure information quality and reliability, the Spanish Society for Healthcare Quality would validate the content.

Figure 4. Covid-19 OHC Interface

First Covid-19 OHC meeting

On May 22 2020, the first virtual meeting of Covid-19 patients was held, including patients in self-isolation, post-patients and family members. 123 Covid-19 patients from 11 countries participated in the online meeting; 102 of whom came from Spain, 16 from Latin America, including Brazil, and 4 from other Western European countries (France, Switzerland and the Netherlands). During 60 minutes, there was a dialogue between patients and health professionals. The meeting was moderated by a Covid-19 patient and health professional. Covid-19 patients asked 50 questions to health professionals: most questions were related to testing and tracking (16%), the possibility of re-infection (14%) and the fear of re-infection (14%) (Figure 5). "*For us patients who have had mild symptoms that have lasted 2 months (...) Aren't we going to be tested to see if we have recovered?*" complained one of the participants. In fact, 36% of Covid-19 patients reported that they have not had any serological testing or PCR tests. A health professional noted that '*the majority of the population do not know their current immunological status*' and '*a problem with testing is that they are not 100% reliable'*.

Clinical, symptomatology and continuation of treatment topics account for 24% of concerns. Mental health was an important discussion topic (10%) along with aspects related to safety and easing of lockdown restriction (10%) (the meeting took place in the weekend leading up to the lifting of some restriction in Madrid). Mental health may not seem like the most urgent topic based on the number of question. However, further analysis of the conversation shows that it is arguably the most important latent topic. The group's main concern focused on the possibility of the virus spreading, being infected, and the anxiety due to insufficient testing and lack of information regarding the type of testing and protocols. In order words, patients are talking about an objective situation of uncertainty that generates specific fears, leading to anxiety. *"... many people are worried about going back to work*," said one patient. In fact, 20% of participants said they felt guilty about spreading the virus.

A significant part of the conversation revolved precisely around terror and fears, in line with a recent study[2] suggesting that 46% of Spaniards have experienced psychological distress. During the meeting, 55% of patients said they suffered anxiety, 45% sadness and 20% guilt for having infected others. Only 1% claimed they had felt nothing in particular.

Another psychological concern discussed was the meaning of being ‘isolated’; in this case, a ‘double whammy’ since in addition to the national lockdown, Covid-19 patients lived in separated rooms, unable to move freely at home and with very little contact with their families. "*This has been the disease of loneliness*," emphasised the psychologists attending the meeting.

Finally, as indicated, the meeting took place two days before the lifting of some restrictions in Madrid, so another significant part of the conversation focused on safety, the proper use of masks and the need remain alert. "*It is up to us to take the necessary prevention measures*."

In summary, the main concerns of Covid-19 patients during this first OHC meeting revolved around infection, reinfection and testing. Patients' main latent (not directly manifested) concerns are related to fear, anxiety, and uncertainty. Also latent are the psychological impacts of isolation and bereavement. Finally, the clinical aspects of Covid-19 generated great interest, but did not raise concerns. Therefore, there is a need for safe, validated and well disseminated information regarding infection, safety and testing. This information, in addition to practically addressing safety issues and avoiding new spikes, would help to reduce the psychological impact that fear and anxiety generate in Covid-19 patients. Second, it is essential to treat the psychological impact of isolation (Brooks et al., 2020), not exclusively through professional care; a friendly voice and talking to other patients are needs highlighted by participants during the meeting. Finally, information on clinical and symptomatic aspects of the disease should also be communicated.

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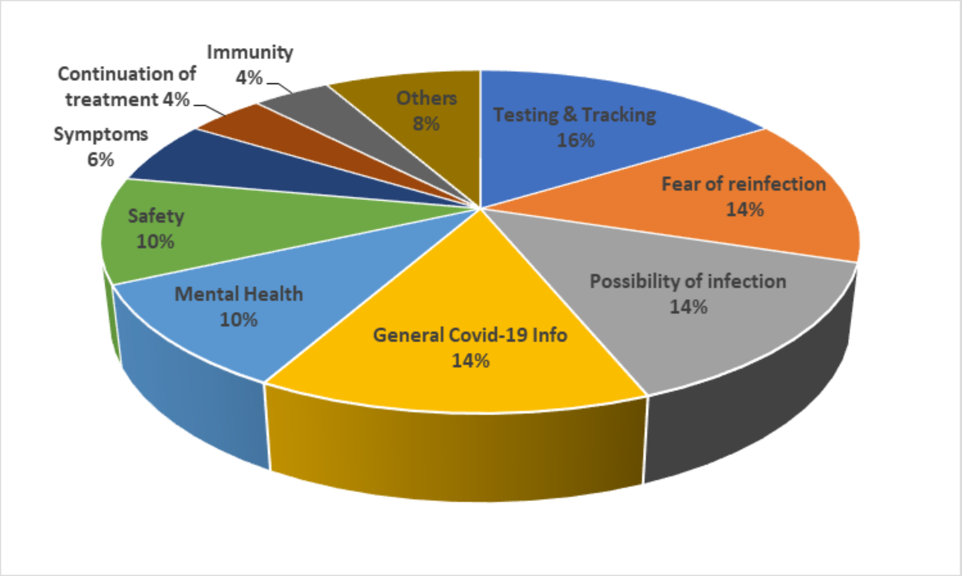
[2] https://www.consalud.es/pacientes/especial-coronavirus/46-espanoles-padecen-malestar-psicologico-confinamiento_80021_102.html

Figure 5. Key discussion points by Covid-19 OHC during the first virtual meeting



Second Covid-19 OHC meeting

On 10 June 2020, the second Covid-19 OHC meeting was held, with the aim of supporting the deconfinement (Spain lifted the national state of emergency in June 20 2020). Discussions highlighted that OHC participation provides for direct benefits in the form of information utility and social support (*main touchpoint needs*). While at the first meeting on 20 May 2020, most questions referred to the fear of reinfection or infection (28% between both categories), and testing (16%); this second meeting showed a shift in interest towards clinical topics with a focus on symptoms and related illnesses (41% of the questions) (Figure 6), suggesting a process of patient empowerment, a key objective of the Covid-19 OHC by acting as a reliable source of information. Patient empowerment enables patients to '*manage their healthcare and advocate for themselves as they use healthcare services*' (Helmer et al., 2011).

Well-informed questions regarding guidelines and treatment (18% between both categories) are also indicative of patient empowerment. Patients are gaining greater control over decisions and actions affecting their health. This perception is further reinforced by the fact that in the area of mental health, questions about fear of reinfections and infections have virtually disappeared.

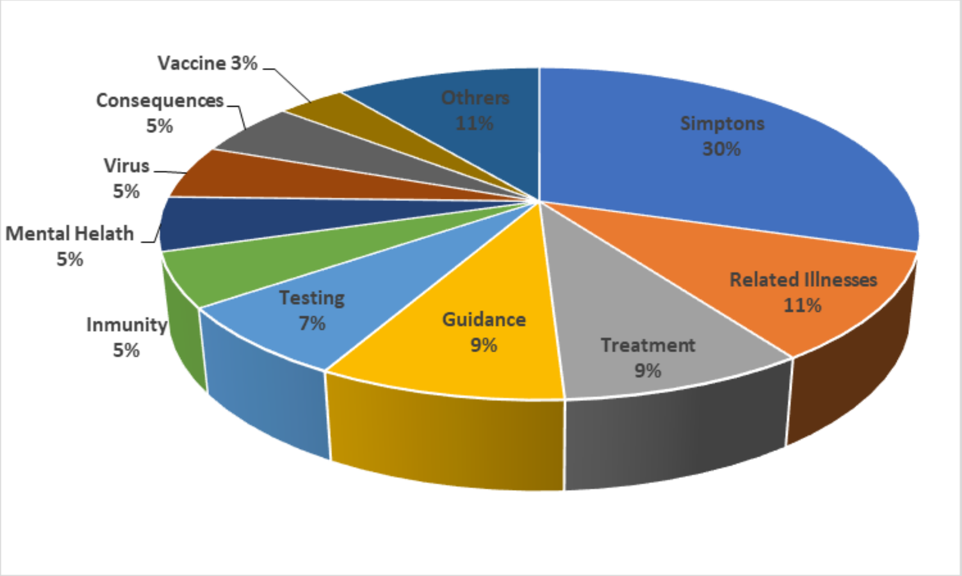
However, mental health remains the most important issue, as in the first meeting. Questions to health experts related to topics of more immediate interest, but the conversation reflects the deepest concerns among Covid-19 patients from the imminent end of social confinement. Health experts explained that deconfinement is an emotionally complex subject, since we are living many situations of post-traumatic stress. ‘*Let's come out stronger [from lockdown] is a social slogan that hides what a lot of people have gone through. We don't come out better*" says one of the experts, "*we come out the way we went in*: *those who were irresponsible before the confinement remain the same now during the deconfinement and those who were responsible, remain so*."

Experts reported that confinement has produced in many Covid-19 Patients ‘*cabin fever’*, a form of agoraphobia that an individual may experience when they are confined to their home of extended periods (Rosenblatt et al., 1984). Psychologists explained that anxiety will remain a residual manifestation of Covid-19. They also highlighted another new psychological factor that is appearing, ‘stigma’: "*many people are reluctant to look up in the subway when they cough, because that cough can be a Covid-19 synthon*."

Physical recovery of Covid-19 patients isolated at home was also an important issue. It is important to take it slow and gradually reintroduce physical activity. Experts recommended caution in the deconfinement but without fear. The conversation ended with the idea that the body must be taken care of, but also the mind and soul.

In summary, Covid-19 OHC’s patients have undergone an empowerment process which is critical to recovery. These patients have agency and as a result are more involved with and follow through with their care plans. The conversation shows that mental health issues remain important, but there is a more practical approach with a focus on seeking guidelines as opposed to manifestations of fear and anxiety, as was the case before. In conclusion, while the positive evolution of the pandemic in Spain (at the end of the first wave) and the increased experience with the disease contribute to this empowerment of psychological knowledge, the Covid-19 OHC seems to have contributed to a positive evolution of Covid-19 patients.

Figure 6. Key discussion points by Covid-19 OHC during the second virtual meeting



4. Conclusion

Covid-19 presents a valuable opportunity for exploring new ways of empowering patients to identify the challenges and co-design the best solutions. Active patient participation in healthcare design can improve patient experiences and services (Richards and Scowcroft, 2020, Majid and Wasim, 2020). Co-production redefines the role of the patient from a passive recipient to a more autonomous, active, collaborative partner in healthcare delivery and research (Gallan et al., 2013, Sweeney et al., 2015). The paper demonstrates how patients, family members and service providers can collaborate to deliver patient-centred care during the Covid-19 outbreak using EBCD methodology adapted to an online environment in response to Covid-19 restrictions. Mapping the patient journey serves to uncover new knowledge and promotes greater learning and shared understanding of the home isolation experience of Covid-19 patients. The process allowed for open discussion and the inclusion of the patient perspective into care service innovation (Simonse et al., 2019). Main touchpoint needs were transformed into quality improvement initiatives to improve the experience of Covid-19 patients, including the development of a Covid-19 patient OHC to address the need for peer-to-peer interaction and information and experience sharing. The trusted relationships that patients value as part of these interactions have the potential to improve healthcare outcomes. One of the strengths of the Covid-19 OHC is that it can provide new ways to reinforce internal motivation during situations of high anxiety. OHC participation has influenced Covid-19 patients' perceptions of being empowered as it enables them to control the content and flow of the information available to them. Empowered patients want and need consistent, high quality communication with service providers and OHCs can act as important enablers of patient empowerment (Johnston et al., 2013).

This paper offers valuable insights on patient-centred service design to improve the quality of care. It provides practical evidence on how EBCD works and therefore it contributes towards the evidence base of quality improvement approaches in healthcare. A limitation of our project is the speed in which it was implemented. EBCD projects take up to one year to complete (Robert et al., 2015). However, an accelerated implementation was followed in this project given the urgency of the pandemic and the ferocity of the first wave; and therefore, the need to understand how Covid-19 patients managed the disease at home. Some of the formal stages (i.e., project set-up) were omitted but the research team had ample experience in EBCD to address any shortcomings. Further, the qualitative research to generate the patient journey map with Covid-19 patient after discharged from hospital included a smaller number of subjects. However, they provided a robust evidence base to support the process of change as evident by the impact of the Covid-19 OHC on patient recovery. Further, because the participants in this study were recruited from a single OHC and in a time of extraordinary crisis, generalisation of any results should be made with caution since OHCs can vary significantly in terms of membership, aims and structure (Panda and Mohapatra, 2021). Results suggest that OHC participation provides for direct benefits in the form of information utility and social support, and indirectly influences their perception of being empowered. However, a range of indicators of patient empowerment should be considered in future studies to demonstrate the empowerment gained through OHCs.

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