

Assessment of the COVID-19 pandemic and its impact on a children's hospital: The point of view of patients and families

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Cover Page Footnote

To the patients' representatives of SJDH who have participated in the study responding to the interviews. To Alejandro and Pablo, members of the Youth Council. To Manar, Marta and Chloe, Members of the Children's Council. To our patients and their families. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

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Abstract

The coronavirus pandemic has affected our health, social behavior, and quality of life. In addition to the deaths and morbidity, the crisis also affects all spheres in society. The objective of this study was to assess the perception of hospital patients and families regarding the pandemic. This is a descriptive study conducted May-July 2020 in the Sant Joan de Déu children's hospital, Barcelona, Spain. We developed a mix-method approach. It included online semi-structured interviews and photo voice. Seventeen patients' representatives were interviewed. In their opinion, the pandemic has affected the health of patients and families at the physical and psychological areas. The pandemic also made them to adapt to the new technologies. Participants expressed the impact the pandemic had at the social level and in the sustainability of patients' associations. Members of the Infant and Youth Councils expressed their feelings about the pandemic through pictures. It is necessary to carry out social research that helps to interpret the impact that the pandemic is having on patients, families and society.

Keywords

COVID-19 pandemic, children's hospital, patients' participation

Background

Society is facing a new and disturbing health situation. The current coronavirus pandemic has abruptly affected our customs, behavior, duties, and quality of life. Throughout history, human beings have been involved in different types of crises and have had to adapt to new situations.¹ As in previous pandemics, the state of uncertainty that this situation generates affects people both, at individual level (from the physical and psychological point of view), and in the relation with the environment. We have been involved in a global health crisis that goes beyond populations health.^{2,3} In addition to the large number of deaths and morbidity associated with the COVID-19 infection,⁴ the crisis also affects all spheres in society.^{5,6}

This is a new situation in our society, and the efforts made by all countries to recover a state of normality as soon as possible mean that, at this time, different vaccines have been created, and numerous studies have been carried out to know the epidemiological, clinical and social impact of the pandemic on population.^{7,8}

The Sant Joan de Déu children's hospital (SJDH) in Barcelona, Spain, tried to respond to the immediate needs

of the population regarding the pandemic. The SJDH is a referral center for rare pediatric diseases and a highly specialized hospital. It also has had to adapt to the new needs of the population due to the pandemic, as well as create new spaces to accommodate patients from other hospitals that could not address the growing number of patients affected by coronavirus.

This hospital is part of the Order of Saint John of God and has 150 years of history, being a reference for pediatric and obstetrical-gynecological assistance. It has 306 beds and its activity is around 25,000 hospital discharges per year; 240,000 outreach visits; 14,000 surgical procedures and around 120,000 emergency visits.⁹

Patient-centered care and hospitality are part of the foundational values of the SJDH's culture and are a hallmark recognized by the population. This strategic role includes the empowerment and participation of patients and their families in healthcare management, as well as their co-responsibility in the development and improvement of health services and the design of physical spaces.

For more than 10 years, patients and families in the hospital have participated in different degrees in the health decision-making process with regard to the management of the disease itself or in the improvement of care processes, as well as representing other patients and families.¹⁰ Therefore, patients and families also participate in the hospital through stable participation bodies. In them, different people, chosen by certain criteria, represent others to make their voice reach the hospital's directorate. Currently, a Children's Council (with children up to 12 years of age), a Youth Council (with boys and girls from 13 to 18 years old) and a Family Council (with parents and relatives of hospital patients) form these participation bodies. Since the pandemic began, these participation bodies have helped to detect the needs of our patients and their families, as well as to develop actions for improvement.

The objective of this study was to assess the perception of hospital patients and families regarding the current coronavirus pandemic and how it affects their health and quality of life.

Methodology

This is a descriptive, cross-sectional study, conducted between May and July 2020 in SJDH. The information to develop the study has been obtained through a mix-method design or a combination of different data collection techniques.^{11,12} These include a literature review, semi-structured interviews and photo voice.

Literature review

First, we conducted a review of the scientific literature on the first data existing in these months regarding the pandemic and its main effects on people and society.

Semi-structured interviews

Based on the literature reviewed and the experience of the research team, we designed a script of open-ended questions about the impact of the pandemic. The thematic areas of the interview were the overall affectation of patients, families, and patient associations; the impact of the pandemic on their health status and health care; the difficulties they were facing to overcome the situation; and the main challenges they have for the future.

The semi-structured interview¹³ was written down and adapted to the online format through the Google forms platform. We followed ethic requirements like confidentiality of the information given by participants. Ten people, experts in this type of methodology, and persons with similar characteristics to whom they had to respond, validated the interview.¹⁴ We conducted 17 online semi-structured interviews with representatives of patient's associations related to our hospital. Participants responded all the interviews between May 15 and 31.

The information obtained from the interviews was processed. We then carried out a content analysis of the information extracted from them.¹⁵ We established categories and subcategories to detect the most important aspects about how the pandemic was affecting participants.

Photo voice

Next, under the photo voice methodology,¹⁶ the members of the Hospital's Youth Committee were asked to take a photograph related to the pandemic and to explain how it had affected their lives. Likewise, the members of the Children's Committee were asked to draw a picture of what they were living at home because of the pandemic and to express how it was affecting them. Parents were asked to help children to understand the task.

Participants were informed about the objectives of the study and the methodology used to obtain the information needed. We guaranteed confidentiality. Participants gave us consent regarding the treatment and publication of the data obtained through the study.

Results

According to the 17 patient representatives who participated in the online semi-structured interviews, the pandemic has meant for patients and families a certain concern for their health status and quality of life. They also expressed the need to adapt to the new technologies in order to communicate with others. In addition, participants said they presented some psychological effects with sleep problems, attention problems, character impairment, anxiety or depression. They also said they have experienced some fatigue and social isolation. Families have also experienced some organizational problems in their daily life activities.

When asked about how the health and health care of the patients they represent has been affected, the participants commented that there have been some complications of the underlying disease and some difficulty in the body movement during quarantine. At the same time, non-urgent visits or treatments have been canceled, and telephone consultations with health professionals have been made instead. Table 1 presents some of the responses expressed by the participants about what the pandemic meant for them.

Concerning how the pandemic has affected patient associations, participants said that they have had to face difficulties such as the closure of the organization's headquarters and the cancellation of meetings or events. Patients' representatives also had to adapt to remote work. Other mentioned aspects were the difficulty of raising funds and maintain economic sustainability, as well as the difficulty of coordinating with professionals and finding

Table 1. Overall impact of the pandemic on patients and families

Area	Participants' Expressions
Patients	
Health status	<i>"There have been some complications of the underlying disease, such as difficulty moving."</i> <i>"The situation did not aggravate patients' illness."</i>
Health services	<i>"Some non-urgent visits have been canceled. Delayed testing."</i> <i>"Some patients have been affected by the inability to go to medical appointments."</i> <i>"Some patients have prolonged going to the emergency room to the extreme for fear of contagion."</i> <i>"It has been impossible to do physical therapy or speech therapy."</i> <i>It has affected all their treatments and visits."</i> <i>"The presence of companions has been restricted."</i> <i>"Everything has been disrupted."</i> <i>"The health system has had to focus all its efforts on the COVID."</i> <i>"Despite this situation, patients who have required urgent assistance have been able to obtain it."</i>
New technologies	<i>"The management of technological tools makes it more difficult for people with disabilities to participate."</i> <i>"Telephone consultations have given peace of mind to resolve doubts but are not as decisive as a face-to-face visit."</i>
Psychological aspects	<i>"Fear of going to the hospital for possible contagion."</i> <i>"Emotionally they have handled the confinement quite well."</i> <i>"Their character and sleep have been affected, and they have more weakness, fear and anxiety."</i> <i>"They have been concerned about whether they were a risk group."</i>
Social aspects	<i>"Home confinement has greatly limited social participation."</i> <i>"Not wanting to leave home."</i> <i>"Not being able to relate to colleagues."</i> <i>"Reduce your circle of friends."</i> <i>"Confinement has exacerbated social isolation."</i>
Families	
Organization	<i>"Having to take on tasks that professionals did until now."</i> <i>"It has greatly affected the functioning of families."</i> <i>"Spaces for family respite and care for the caregiver have been affected."</i> <i>"Families have had to live with a dependent child or relative 24 hours a day."</i> <i>"Fatigue."</i>
Psychological aspects	<i>"It is a very difficult situation to cope with."</i> <i>"The initial uncertainty of the possible contagion of children."</i> <i>"Great fear of contagion, with stress and anxiety due to the concern of living with a child with an underlying disease."</i> <i>"Great family concern."</i> <i>"New fears such as contagion have appeared."</i> <i>"Consultations for anxiety and insomnia have increased."</i>
Social aspects	<i>"Financially, income has been reduced."</i> <i>"The concern of parents of young people of working age about the possibility of contagion and loss of income."</i> <i>"Reconciling family and work life is very complicated with dependent people at home."</i> <i>"Social relationships outside the home have been affected."</i>

reliable information on the pandemic. This situation, on the other hand, has also helped them to adapt and be closer to the families, as well as to see what their needs were (Table 2).

Table 2 also presents some of the ideas expressed by the participants about the future of patients' associations. Regarding how they perceive their future needs, participants said that they will surely have a great economic burden and will have to seek new initiatives, especially for the most vulnerable groups of patients. Although the associations' fee for members is not very high, it varies between associations and some people

cannot afford it. Accessible, rigorous and easily understandable information for the general population will be also needed.

Participants also see the role of patients' associations as crucial for patients and families during the health crisis. They said they will have a main role in protecting the rights of patients, covering the needs unsolved by the administration or being a nexus between patients and professionals, among other roles. As what they think are their strong points, participants stressed their closeness, communication, and support of patients and families, as well as their credibility among them.

Table 2. Impact of the pandemic on patient associations

Aspects	Participants' Expressions
Limitations	<p><i>"We have had to close offices, stop projects and carry out psychosocial care online."</i></p> <p><i>"Cessation of the processes of calls and resolution of aid that put into question the economic sustainability of the association."</i></p> <p><i>"I think everyone has been very understandable and has adapted."</i></p> <p><i>"The difficulty of being able to travel and visit patients at their homes."</i></p> <p><i>"Not being able to carry out training in health centers and hospitals."</i></p> <p><i>"We have stopped carrying out scheduled activities such as attending medical congresses."</i></p> <p><i>"Participate in various research projects that should have already started and we do not know when they can be conducted."</i></p> <p><i>"Having to adapt very quickly to providing care electronically, which in patients or families with whom there is still no link, is a complex contact channel for the first assessment."</i></p> <p><i>"In some cases, not having coordination and indications with professionals on how to proceed with children in specific situations."</i></p> <p><i>"On the one hand, the professionals who treat us have been telling us that we were a population at risk and, on the other hand, the administration does not consider us a vulnerable population, so we have not been able to obtain some benefits such as free masks, home shopping service or telecommuting."</i></p> <p><i>"At the bureaucratic level, everything has come to a standstill."</i></p>
Main challenges	<p><i>"Adapt to online care."</i></p> <p><i>"Having information, although at all times we have had the support of the hospital and professionals."</i></p> <p><i>"Inform families on COVID issues when nobody was clear about anything."</i></p> <p><i>"Check if our children were being affected by the COVID."</i></p> <p><i>"Telephone calls to all members to inquire about their situation."</i></p> <p><i>"Fear of losing staff due to lack of financial resources."</i></p> <p><i>"That we recover from all this together, united and alive"</i></p> <p><i>"Deliver sanitary gowns that we have made to different hospitals and residences for the fight against COVID."</i></p> <p><i>"Find resources to meet the needs that have arisen in the group."</i></p> <p><i>"Staying away from the virus by disinfecting everything that entered the house."</i></p> <p><i>"Maintain contact with families, doctors, and researchers."</i></p> <p><i>"Offer families emotional care and social support."</i></p> <p><i>"Training for professionals regarding the accompaniment of minors in mourning for the loss of a family member due to COVID."</i></p>
Patients' associations role in the future	<p><i>"This situation will generate a greater workload due to the economic bankruptcy."</i></p> <p><i>"It will be difficult to involve companies to continue collaborating in our projects."</i></p> <p><i>"Patient associations will become more important, as there will be more people who will depend on them."</i></p> <p><i>"More or less as before."</i></p> <p><i>"Supporting role and continuing to raise money for research."</i></p> <p><i>"Very important to support families."</i></p> <p><i>"The associations will be very important for the most vulnerable groups, as in rare diseases."</i></p> <p><i>"We are concerned about the sustainability of many associations."</i></p> <p><i>"An important nexus role between patients and professionals."</i></p> <p><i>"It will be a fundamental role, since public organizations will be saturated and it will be the associates who will be able to attend to patients."</i></p> <p><i>"Important covering the needs that are not solved from the administration."</i></p> <p><i>"Important to give greater visibility."</i></p> <p><i>"Leading the protection of the rights of the people we represent."</i></p>
Strong points	<p><i>"Closeness to people to meet their needs."</i></p> <p><i>"The involvement and enthusiasm of families."</i></p> <p><i>"Specialization in specific diseases and issues."</i></p> <p><i>"Support for research."</i></p> <p><i>"The credibility after so many years of work."</i></p> <p><i>"Face-to-face care and the search for solutions."</i></p> <p><i>"Offer good information and services."</i></p> <p><i>"Communication with families."</i></p> <p><i>"The mobilization of resources and the online connection with the families we serve."</i></p>

Table 2. Impact of the pandemic on patient associations (cont'd.)

Aspects	Participants' Expressions
Needs	<p><i>"Of an economic nature due to the reduction of subsidies."</i></p> <p><i>"Members will not be able to pay the fee."</i></p> <p><i>"The cancellation of acts to raise funds will cause more financial needs."</i></p> <p><i>"Get support for research."</i></p> <p><i>"Health care needs, information about the disease, vaccines and treatments."</i></p> <p><i>"Psychological needs, in the management of fear and uncertainty."</i></p> <p><i>"COVID tests to professionals who have to treat our children."</i></p>
Challenges	<p><i>"How to maintain social distancing."</i></p> <p><i>"The way to go financially."</i></p> <p><i>"The increase in virtual services."</i></p> <p><i>"The design of a new work plan."</i></p> <p><i>"More knowledge about the virus and the vaccine."</i></p> <p><i>"Restart the acts to continue fighting for our cause."</i></p> <p><i>"Raise awareness in society."</i></p> <p><i>"How to support families in moments of break or rest."</i></p>

The representatives of the Youth Council presented through their photographs a duality in their personal experience of the pandemic. For some youths, the current situation has been a break, a stone in the road or a sinkhole from which they have to get out to continue their daily life (image 1). For others, it has meant being able to spend more time at home with their families, to play or spend leisure time with friends online and to relax a little compared to their usual days.

The representatives of the Children's Council through their drawings presented the same duality. On the one hand, they expressed fear of the virus ("the bug"), the damage it is doing and the fact that they cannot leave home. On the other hand, they showed that, by all being at home, they have been able to spend more time with the family and do things together such as cooking, playing and applauding the health professionals every day at 8 p.m. (image 2).*

() During the months of confinement, the Spanish population went out to the balcony or window every day at 8 p.m. to applaud health professionals in appreciation for their work during the pandemic.*

Discussion

Patient participation in the health decision-making process is gaining more and more relevance in our environment. The role of patients in society has changed considerably in recent decades, and, today, health care planning cannot be considered without taking into account the patient's viewpoint.¹⁷

As already mentioned, the SJDH has created participation bodies such as the Family Council, the Youth Council and the Children's Council, in addition to the work carried out for more than a decade with the network of patients'

associations. These working groups meet systematically with health professionals and hospital directors to contribute to the improvement of health care, care protocols and procedures, as well as the hospital physical spaces. This way of working allows us to capture what the patients' experience is regarding specific issues of interest and their vision on improvement.

The use of different qualitative data collection techniques, in this case, through a literature review, semi-structured online interviews and photo/picture voice, complements and helps to understand and deepen the subject under study. Thus, semi-structured interviews with representatives of patient associations provided very valuable information on how the pandemic is affecting its members (children and adolescents patients and their families), the association itself and the health system. The information also referred to the vision about how to overcome the limitations that the pandemic is producing and try to adapt and move forward in the fight for the rights of patients.

This methodology can be applied to different areas and organizations. Combining techniques allows us to have a deeper understanding of the situation under study.^{11,12} It also promotes patient-centered practice, as well as system sustainability, effectiveness, and satisfaction, both for patients and professionals.

As a limitation of the study, although from a qualitative point of view, it was not intended to generalize these results to the population to which the participants belonged; these results refer exclusively to the opinion of the people who responded to the interviews. Even so, these are the results of legitimate patients' representatives, aware of the situation their members were going through. These results also coincide with what emerges from other

Image 1. Photographs of members of the Youth Council



Source: Adapted from <https://soymotor.com>. Pablo, 13 years of age

“The photograph is a hole in a road. The road symbolizes the path of our lives and the pit is this interruption we are experiencing, this confinement.”



Source: Own picture. Alejandro, 15 years of age

“This is my computer. It is one of the objects I give the most use to, especially during this confinement. Because with so much free time I was able to keep doing activities I enjoy the most like playing video games. Thanks to the computer, video games, and the internet, I have been able to keep playing alongside my friends, and share experiences with them that make it seem like we have not seen each other in so many months. So, for me, the computer has been a door to be able to feel close to my friends, have fun and, of course, make confinement a great experience.”

similar studies.¹⁸ Likewise, the pictures and the drawings shown in the images do not represent the experience of all members of the Councils but are a reflection of how some of their members felt during the pandemic.

As conclusions of this study, although the pandemic affects the SJDH patients and their relatives, as also happens in other places,¹⁹ the impact that the situation has on this population will depend on different factors, on the one hand, the underlying disease of the child or adolescent. If there is a chronic disease or the patient is in delicate health, the impact of the pandemic will be

reflected in terms of greater vulnerability of the patient, delay in some tests or treatments and less access to health services. In turn, this can lead to a feeling of fear or helplessness, anxiety and isolation.

It is also important to emphasize the importance of the collaboration between professionals and patients in improving the quality of care. Any patient or family member can contribute valuable information and experiences to better understand what their needs are, as well as jointly assess possible ways to improve care.²⁰⁻²² In the case of children and adolescents, we should consider

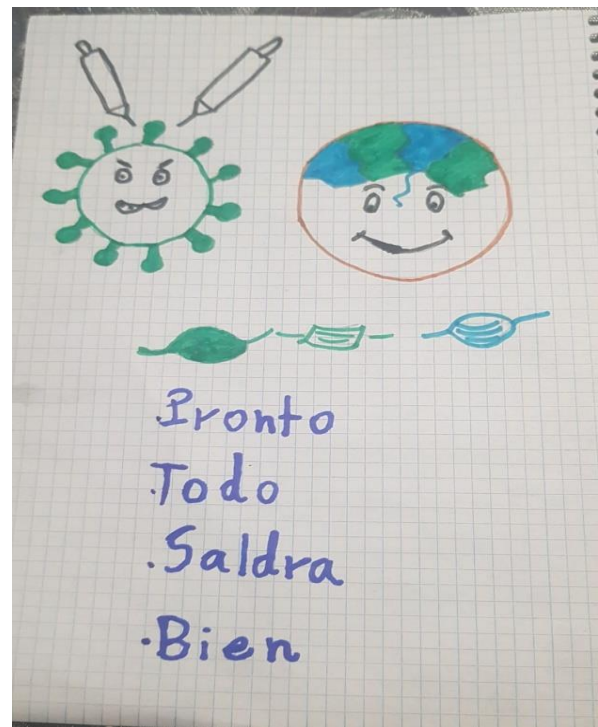
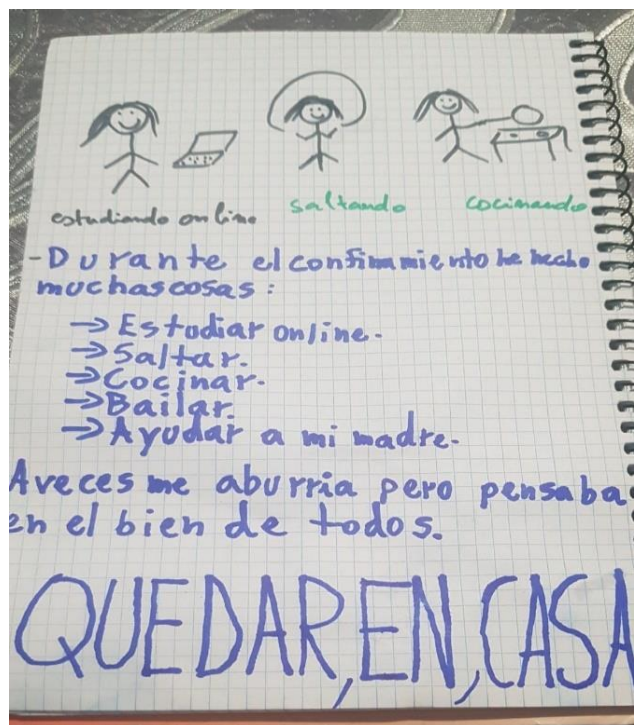
their point of view as well. No one better than them to explain how they are feeling a problem and no one better to think of possible solutions.

In this pandemic situation, it is necessary to continue with the epidemiological investigation of the disease, but it is also necessary to carry out social research that helps to interpret the impact that the disease is having on patients and families, as well as on society.

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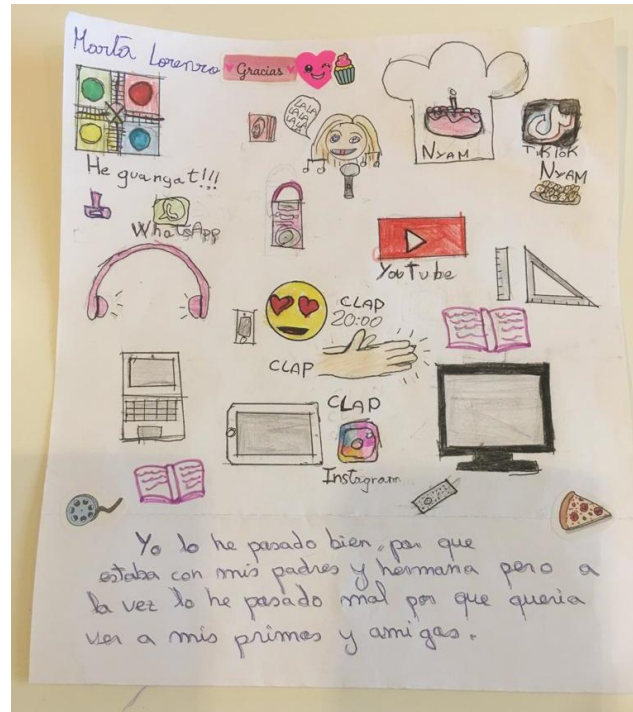
Image 2. Drawings of members of the Children's Council



Source: Own drawing. Manar, 12 years of age

"During the confinement I have done many things: studying online, jumping, cooking, dancing, helping my mother. Sometimes I was bored but I thought of the good of all STAY AT HOME. Soon everything will be alright."

Image 2. Drawings of members of the Children's Council (continued)



Source: Own drawing. Manar, 12 years of age

“During the confinement I have done many things: studying online, jumping, cooking, dancing, helping my mother. Sometimes I was bored but I thought of the good of all STAY AT HOME. Soon everything will be alright.”



Source: Own drawing. Chloe, 6 years of age

“The bug has come into the world to do a lot of damage”

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