

**Autonomy and isolation experienced by patients and primary caregivers during
COVID-19 hospitalization in Barcelona (Spain)**

Running title: Autonomy and Isolation during COVID-19

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AUTONOMY AND ISOLATION EXPERIENCED BY PATIENTS AND PRIMARY CAREGIVERS DURING COVID-19 HOSPITALIZATION IN BARCELONA (SPAIN)

ABSTRACT

This study aims to describe patients' and family caregivers' hospitalization experiences during the COVID-19 pandemic. Using qualitative exploratory descriptive methods, thirteen patients admitted to the largest hospital in Barcelona (Spain) due to COVID-19 were interviewed by telephone once discharged, as were eight primary caregivers. Data were analyzed using the content analysis method proposed by Krippendorff. Two main themes were identified: a) Acceptance of mandatory isolation for patients and family caregivers, which refers to the verbalization of a feeling that justifies the imposed isolation and the need for the use of personal protective equipment by the health team for everyone's safety, and b) Limited autonomy during hospitalization for patients and family caregivers, which describes participants' perceptions of autonomy during hospitalization. Patients and caregivers experienced feelings of loneliness, which negatively affected their emotional health. In addition, they experienced reduced autonomy due to new habits and routines intended to control the pandemic for public and global health.

Keywords: autonomy; family, isolation; SARSCoV-2; qualitative research

Key points:

1. The COVID-19 pandemic aroused feelings of loneliness among patients and caregivers because of the required isolation rules for infection control.
2. Patients and caregivers accepted the isolation policies as they felt they were necessary.

3. In the event of a new pandemic scenario, digital/virtual communication channels must be implemented to reduce feelings of loneliness and loss of autonomy.

INTRODUCTION

The COVID-19 pandemic has necessarily restricted freedom of movement, limited meetings, isolated those diagnosed by COVID-19, and instituted quarantines to reduce the number of infected people (Royal Decree, 2020). However, the common good prevailed over individual good in managing the pandemic (Cetron & Landwirth, 2005; Institute of Medicine Forum on Microbial Threats, 2007), including closing hospitals to relatives. The concept of 'common good' refers to the social strategies implemented to improve a community's health respectfully, contributing to individual benefit (Kalekin-Fishman, 1996). Therefore, patients were left isolated with the physical company of only the health professionals. Little is known about patients' and their families' ability to participate in decision-making during the pandemic (Asghari & Tehrani, 2020). A "family's physical presence" policy could increase the risk of infections during an outbreak and may pose moral dilemmas; hence, the need to minimize isolation requires a reassessment of these policies (Voo et al., 2020).

The ethical principle of autonomy requires patients to be treated as autonomous agents who can control their actions (Beauchamp & Childress, 2009). In Spain, as in most countries, the COVID-19 pandemic has caused a health emergency that has forced the transformation of general hospitals into monographs of this disease and the optimization of material and human resources to ensure every effort was made to address the problem. In Spain, access to healthcare is universal for all citizens. The hospitals are open to relatives 24 hours. Most hospitals have restricted visiting times for relatives in critical units such as Intensive Care or Operation Theater. The covid-19 pandemic meant an essential paradigm shift since many patients and professionals had never worked before within a non-visits policy.

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During the COVID-19 pandemic, patients' loneliness and unfamiliarity with professionals were identified as factors that could put patients' decision-making ability in question, especially among people with mobility or communication problems (Wang et al., 2020). Another aspect that raises ethical challenges during a pandemic is patients' refusal to undergo specific tests or preventive measures (Sprague et al., 2016). In such scenarios, it is crucial to approach the phenomenon from a bioethics perspective to help maintain public confidence (Asghari & Tehrani, 2020). It is also essential to fully understand the phenomenon, which may be beneficial for in situ adaptations or future outbreaks. Therefore, in response to measures to the COVID-19 pandemic, efforts should be made to identify and address patient concerns.

BACKGROUND

Autonomy is often seen only as a right to freedom. In contrast, the common good is a value of sufficient weight to advocate for a limitation of freedom and autonomy. The interests of individuals and communities are inevitably interrelated. Autonomy can be seen as an ethical construct with responsibilities toward other members of society (Jeffrey, 2020).

Clinical practice has evolved more in line with treating the patient's disease. Care ethics, as a moral orientation, imply promoting autonomy (Lindberg et al., 2014). Respect for autonomy is universally recognized as a fundamental principle in bioethics (Beauchamp & Childress, 2009); however, the reference to autonomy concerning patients in a healthcare context could be considered paradoxical. A person's vulnerability with impaired physical or cognitive capacity broadens in the care context, thus increasing the need to promote autonomy (Lindberg et al., 2014). However, the perception of autonomy

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is associated with the absence of limitations and does not consider the notions of relationship, responsibility, and care; it does not provide the best means to improve oneself (Greaney et al., 2012). For example, preventive isolation was implemented for those admitted to hospitals among the safety measures employed during the COVID-19 pandemic to prevent infection. Therefore, patients were no longer allowed to receive visits from their families, friends, or significant others, leading to a sense of loneliness since emotional care and face-to-face support from loved ones are necessary for patients as the central axis of health care (Voo et al., 2020).

Previous studies have addressed patients' experiences in isolation due to infectious diseases reporting feelings of loneliness and ethical dilemmas because of mobility limitations. Older people experience more sadness and loneliness; women in isolation are more concerned about transmission. Although these data suggest a problem exists, there is a gap in what we know about improving the experience of isolation and making it more tolerable for patients and their families (Hereng et al., 2019; Nair et al., 2020; Pursell et al., 2020). In the context of hospital admission during the COVID-19 pandemic, the autonomy and isolation aspects of the patient-professional relationship have, thus far, not been studied. Thus, the experiences of patients and caregivers and how their autonomy and isolation may have been compromised while receiving care remain unknown. This information is key to reviewing and adapting care protocols for future situations. Therefore, this study aimed to describe the hospital care experiences of patients and family caregivers in terms of autonomy and isolation during the COVID-19 pandemic by describing their experiences.

METHODS

This study used qualitative descriptive methods (Sandelowski, 2010), focusing on the experience of caregivers and patients in terms of autonomy and isolation after hospital admission due to COVID-19 during the pandemic. This type of qualitative design helps to illuminate how a particular phenomenon manifests itself and is especially useful for describing little-studied phenomena (Hunter & Howes, 2019; Polit & Beck, 2017; Ward et al., 2018). The consolidated criteria for reporting qualitative research (COREQ) were followed (Tong et al., 2007).

Purposive sampling was used to recruit participants. The inclusion criteria were patients and their direct caregivers over 18 years of age who were discharged to their homes from the XXXXX University Hospital (hidden for blinding purposes) after a diagnosis of COVID-19. This is the biggest hospital in Barcelona, and one of the biggest in Spain; thus, the highest number of COVID-19 patients, both critical and non-critical, were admitted there.

A hospital research nurse assessed the suitability of the candidates for participation and excluded those whose emotional or physical health situation contraindicated participation in the study (e.g., major depression, respiratory problems, speech problems, or psychotic disorders). The sample consisted of 13 patients (7 women, six men) and eight caregivers (3 women, five men), all of whom were family members.

The principal investigator reviewed the discharges made during March–April 2020 and made the first telephone contact with those who could actively participate in the study according to their professional criteria. After describing the study, their participation was purposively requested. The principal investigator telephoned interested parties at least seven days after discharge. Those who agreed to participate provided oral consent; afterward, the interview date and time were set. Data were collected through semi-structured phone interviews, lasting approximately 60 min each. Before beginning the

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interviews, the participants were informed that the conversation would be recorded. Sociodemographic data from the medical history were also collected to describe the characteristics of the sample and help analyze the findings (age, sex, date of onset of symptoms, date of diagnosis, date of admission, date of discharge, level of study, place of residence, comorbidities, marital status, and family structure). The interview script (see Table 1) was developed according to the research aim and the decision of the research team after several meetings to discuss and verify the appropriateness of the questions and their clarity. The script was open to modifications as the study progressed. Field notes were taken during the interviews to promote reflective thinking, answer questions, identify topics, and propose new questions. The interviews were immediately transcribed verbatim after completion. The sample size was determined by data saturation; when the data obtained became redundant (Mandal, 2018). Four participants refused to participate for different reasons (mainly not feeling well or not wanting to participate).

-----TABLE 1-----

Data collection and analysis were simultaneously performed. Data were analyzed following the content analysis method proposed by Krippendorff (2019) with the support of the qualitative analysis software Atlas.ti® v8. Initially, the transcripts were read several times to familiarize researchers with them and identify their first impressions of the meaning(s) therein. Next, the texts were coded according to their content to group these codes into categories based on their similarities. This last step was discussed and agreed on among the research team members to identify meanings and solve doubts and

disagreements regarding meaning(s). Data matrices helped clarify the findings and provide meaning to the entire process.

Once a preliminary version of the results had been obtained, two participants were asked for feedback to confirm the results. During the telephonic communication, participants fully confirmed the results, ensuring they felt represented and adequately identified with this information so that the findings' meaning, and coherence were verified. Finally, verbatim fragments of the interviews (without identifying data) were provided to illustrate and provide evidence for the results (Polit & Beck, 2017).

Various procedures were performed to ensure the validity of the data (Guba & Lincoln, 1994). The interviews were conducted by two highly experienced researchers with no previous relationships with the participants (M.A. and J.L.). Audio files were transcribed by a single researcher (O.M.) to avoid discrepancies. Reflexivity, constant discussion, and verification by team members confirmed the accuracy of the interpretations obtained from the interviews. Since the interviews were all conducted in Spanish, they were translated into English by professional translators and verified by a bilingual team member (J.L.); thus, it was ensured that the translated texts contained not only the syntax but also the essence of the original meaning. Four participants verified the results and suggested that no changes were needed.

Approval was obtained from the Ethics and Research Committee of XX XXXXXX (hidden for blinding purposes). During the interviews, the participants' real names or any personal information that could reveal their identity were not recorded; the interviewees were identified by the letter "P" for "participant" and the number assigned to the interview. Additionally, it was confirmed whether the informant was alone or surrounded by the people to whom they granted permission for the interview. Similarly, the interviewer let the participants know they were in a safe and private location suitable for conducting the

interview. The participation was voluntary and withdrawn if requested. The participants did not receive any financial compensation for their participation. No hierarchical relationships between the interviewer and the interviewee were identified. Throughout the data collection and analysis, the researchers were mindful of the information collected on experiences, agreement or dissonance with their values, onto-epistemological background, and the possible impact on the analysis (Råheim et al., 2016).

RESULTS

Twenty-one participants were interviewed (13 patients and eight family members). The patients' ages ranged from 31 and 74 years, whereas caregivers were 38–52 years old (more details are shown in table 2). The mean duration of hospital stay was 11.92 days. Data analysis identified two themes: a) Acceptance of mandatory isolation for patients and family caregivers, and b) Limited autonomy perceived as necessary during hospitalization for patients and family caregivers (Table 3).

-----TABLE 2-----

-----TABLE 3-----

Theme 1: Acceptance of mandatory isolation for patients and family caregivers

Physical distancing was required to avoid COVID-19 transmission. The admitted patients could not receive visits from their loved ones, and the only contact allowed to them was virtual (e.g., video chat, messaging) and by telephone. Based on this situation, this

category is defined by the circumstances shaped by the isolation patients, and their caregivers underwent during hospitalization.

Health professionals were forced to use IPE to perform the necessary clinical and care procedures. These protective measures were necessary to prevent the spread of the virus. IPE consisted of masks, glasses, gowns, gloves, and caps. Having to wear such clothing and devices made it difficult to identify the healthcare professional treating the patients then. Some participants felt like "weirdos" or stigmatized, feeling they were being treated differently from non-COVID-19 patients. However, most of them understood that health professionals should protect themselves in this way in such a situation.

The depersonalization of care, such as not seeing the person, not feeling skin-to-skin contact, or not seeing a smile, saddened them every day; nevertheless, the acceptance of the situation outweighed the sadness, and they complied with these conditions without any protest. They knew that the situation necessitated the conditions; it was simply "the fairest thing for all." They even valued simple gestures of proximity, such as introducing themselves or a caress, even with a glove. These affectionate actions were experienced as gestures of humanity that dignified them in such complicated circumstances.

I felt very flattered that, even in this situation, those nurses approached me affectionately and touched me, with gloves and without fear. They came up and touched me. That is the part where I said, "wow!" Above all, they made me feel like a person (P12).

Patients and caregivers especially remembered feeling lonely. Priority was given to the common good, that is, to what felt right and fair. Although they accepted, understood, and abided by these restrictions, some negative feelings were generated in the patients and caregivers. Despite understanding the causes and accepting these restrictions, for

many participants, forced isolation was the most challenging part of their admission—the aspect that made them suffer and saddened them the most. The patients could not see or have any physical contact with their surroundings; the caregivers could not experience the hospitalization process in person with their loved ones and offer personal support. Therefore, the most frequently used resources were telephone and virtual communication channels, allowing the participants to see, hear, and encourage each other. Albeit virtually, distances were reduced, encouraging them to draw strength from and motivate themselves to face the situation.

There was no other choice but to do what they (nurses) told us, and I did not see anyone, even though it was very hard. I could not just think of myself but also the rest of the people and not infect anyone (P7-C).

It was hard to get out of your routine all at once, out of your day-to-day, being away from everyone and everything. I saw them by video call (relatives), but of course, it is not the same. You need physical contact (P13).

The worst thing that she [family member] always comments on is loneliness, but it could not be otherwise. One day she even said that she felt awful, not because of the place or the virus, but because she was always alone (P3-C).

Not being able to be there with him was like abandoning him. It was a horrible experience (P4-C).

Theme 2: Limited autonomy perceived as necessary during hospitalization for patients and family caregivers

The hospitalization process includes changing habits, schedules, and routines for admitted patients and their caregivers. This category includes all aspects of the participants' perceptions of autonomy during hospitalization. It comprises two subthemes: the limitation of autonomy and the effort of healthcare staff to maintain patient autonomy.

Patients diagnosed with COVID-19 experienced more significant distress due to two main causes: on the one hand, the virus caused physical limitations, such as breathing difficulties, and on the other hand, strict measures were imposed by hospitals for COVID-19-positive patients and their caregivers. Especially in the second situation, participants sometimes emphasized the restrictions on their autonomy of action and decision. However, they understood that these limitations were widely imposed and were essential for managing hospital work organized and coping with the spread of the virus. On repeated occasions, they lamented that they could not do everything they wanted, but they accepted the situation and were swayed by the health personnel's decisions and the routines they set. Therefore, the health workers set the pace throughout the process, and patients conveyed in various ways that they consciously ceded/delegated their autonomy to the greater good.

Autonomy is basic, the fact of breathing is essential, and we do not think about it when we do it—one breathes, and that is it. However, what about when you cannot breathe? Then I realized the importance of being autonomous (P1).

I entrusted them with my care. When I left the ICU, I could hardly move, and if they had to clean me, they cleaned me. That was what they had to do. However, even if I felt better, I understood what must be done. They [health workers] decide (P7).

Health professionals cared for patients' safety and the safety of their caregivers concerning the care and the information they offered. The participants perceived it this way and praised the health professionals for their confidence in action and willingness to answer any questions. This disposition and constant dedication generated positive feelings in patients and their caregivers. Most interviewees valued the attempts of health workers to maintain their autonomy and decision-making power as much as possible. This was perceived as a way to enhance the capacity of each patient and promote their independence. They also emphasized that the professionals adapted to different recovery rates and gave patients time to fend for themselves.

I felt that doctors and nurses knew what they were doing; they gave me security.

Although I know they faced the unknown, I do not know if they did, but they gave me security and helped me a lot (P3-C).

They counted on me for everything: checking blood pressure, oxygen saturation, everything. They gave us support. When I could not, they (the nurses) were there ... There was no problem; there were so many personnel, and so many came in that they gave you all the options to adapt (P11).

From all this, it can be inferred that the participants felt grateful to the health professionals. The expressions "I appreciate it" and "thank you" were the most repeated phrases in all the interviews. Participants felt grateful to healthcare professionals for taking care of them, for all the efforts made, for always pursuing their wellbeing, and for their constant involvement in the patients' recovery. The group of nurses was the most praised and valued group by the participants. Many agreed on this group's excellent treatment, kindness, and empathy. They remembered particular actions, many of them effortless, such as offering a coffee, a caress, a conversation, providing in-depth information, or always encouraging them. Small gestures made them feel better and

experience the situation differently. In the same way, they emphasized the great professional care offered by the nurses.

I have two beautiful memories from two wonderful nurses—the day I said I am dying for a coffee, and they brought me a coffee, and the day I needed company, and stayed with me, holding my hand. You do not know how much I appreciated it. It was a negative experience due to the disease, but it has allowed me to meet wonderful people who reduced my anguish (P8).

DISCUSSION

This study highlights the feeling of isolation and its relationship with the loneliness experienced by the participants during their COVID-19 hospital stay. Furthermore, it reveals the meaning that the interviewees gave to the concept of autonomy, with particular emphasis on the efforts of health personnel to maintain it and their limitations. Although autonomy is greatly valued, restrictions had to be implemented for the patients' and the general population's wellbeing to provide the best care. Notably, participants considered this limitation to be part of their duties as patients and caregivers or as members of society, and their loss was assumed to be natural, typical of the process they were experiencing, and always in furtherance of the common good (Bellver-Capella, 2020). These themes are repeated in other studies that analyze the experiences of hospitalized persons, especially in areas with strict infection controls or where significant isolation periods are required (Vottero & Rittenmeyer, 2012; Siddiqui et al., 2019; Adams et al., 2020; Shaban et al., 2020). Likewise, ethical issues related to care have emerged among the central pillars of healthcare, and their consideration and analysis are essential in all areas of

health, especially in crises such as those described (Bellver-Capella, 2020; Tyrrell & Williams, 2020; Sun et al., 2021; WHO, 2021).

Owing to the pandemic, patients had to remain in isolation throughout their hospital stay. In addition, the unique circumstances of the COVID-19 pandemic meant that the restrictive measures imposed in various social environments, including the hospital environment, have increased. The decrease in the transmission is based on physical distancing, which leads to social isolation and professionals' use of specific protective measures (Tyrrell & Williams, 2020). This means that patients were admitted alone and faced challenging and complex situations in the absence of their loved ones, which undeniably impacted their emotional health (Ho & Neo, 2020). The participants verbalized feelings of loneliness, sadness, and helplessness in the face of an unforeseen situation, which coincides with other studies (Abad et al., 2010; Siddiqui et al., 2019; Eli et al., 2020; Shaban et al., 2020,). Similarly, according to the studies by Luchetti et al. (2020) and Pursell et al. (2020), loneliness is related to higher mortality and morbidity, is detrimental to emotional health, and has potential consequences for physical health.

The use of IPE was another prominent theme throughout the interviews and contributed directly to the isolation and loneliness experienced by the participants. IPE was related to the depersonalization of care, making it challenging to identify professionals and even generating feelings of stigmatization among patients. Especially in the case of people diagnosed with COVID-19, this stigma is accentuated because they feel excluded from the other patients, making them feel like "strange creatures," a concept that emerged in some of the interviews. Other authors have analyzed this aspect in other hospital care situations and obtained similar conclusions (Gammon et al., 2019).

To fight the feeling of loneliness, using mobile phones and other digital devices helped reduce the sense of distance between participants and their family members and loved

ones, slightly alleviating their need for physical contact and providing them with the strength and motivation to persevere. This idea opens the door to future research in new technologies in times of crisis, which some authors have already launched (Conroy et al., 2020; Shah et al., 2020). For example, new technologies in the public health environment have made it possible to obtain epidemiological information quickly and improve the identification and traceability of cases (Budd et al., 2020; Molina-Mula & Gallo-Estrada, 2020).

This study also described the experiences of family members regarding their relative's hospitalization. The caregivers experienced feelings similar to those of the patients. In addition, family members' concern about being excluded from the care process has been analyzed in the literature (Bartoli et al., 2021). Evidence shows that disease impacts all family members and their relationships, making it necessary for the family to adapt to new demands, such as the distribution of new roles and functions (Canga et al., 2016). Family concerns, fear, and anxiety increase when the disease leads to hospitalization. In Spain, health services are organized around the patients, considering the family as part of the context; they are a resource that provides a solution in caring for their sick relatives (Canga, 2014). During the COVID-19 pandemic, families could not care for their loved ones. However, families suffered alone at home with little or no follow-up from healthcare professionals. Therefore, families must be included as another vital piece in the healing process for future pandemic situations. It is known that interventions that consider the family as a caring unit positively impact health for both patients and family caregivers (Villanueva et al., 2015).

Another interview finding is that patients with COVID-19 had to delegate much of their autonomy to control transmission, even though their health status was stable and not critical (Molina-Mula & Gallo-Estrada, 2020). Preserving autonomy and avoiding

isolation of patients and their families during the pandemic was difficult, although not impossible, as indicated in this study. Therefore, nurses became the reference persons for their care and acted as intermediaries for caregivers and their families (Flagg, 2015; Woo et al., 2017). For this reason, non-verbal communication, such as caresses or gestures, acquired great value in ensuring excellent care. Likewise, the nurse-patient relationship evolved throughout the hospitalization process, passing through the role of professional, confidant, partner, and advisor, preserving as much autonomy as possible and alleviating patient loneliness. Consequently, there was unconditional acceptance of the nursing role, a valuing of professionalism, and the creation of a bridge between trust and nursing leadership (Woo et al., 2017).

The nursing role is directly related to concepts such as the humanization of care and patient-centered care (Flagg, 2015). These aspects are of particular relevance in 2020, which the World Health Organization has declared the year of nursing because of the excellent health work of the nursing profession (Borger, 2020). In addition, COVID-19 has highlighted the importance of this profession's work—its holistic approach sense of responsibility, capacity for sacrifice, professionalism, and dedication and commitment to the patients and families that nurses serve (Fernandez et al., 2020a; Ulrich et al., 2020).

The gratitude of the participants toward the health personnel and the acceptance of the measures they took to protect themselves and other people being treated reveals a controversial issue that arises for healthcare providers in crises: the fine line that separates the care of patients from the self-care of professionals (Bellver-Capella, 2020). Health personnel has been among those most affected by COVID-19, and critical situations have been experienced due to the lack of adequate material to protect themselves from the risk of infection, increased workloads, and psychological and emotional effects of the stress experienced (Braquehais et al., 2020; Gómez-Ibáñez et al., 2020). The interviewees

perceived this dedication, effort, and involvement of the health workers, who wanted to express their gratitude repeatedly to everyone who had collaborated in their recovery.

Facing the complexity of a global pandemic, the ethical issues that arise must be considered: not only those treated in this study, such as the autonomy violation and isolation, but also the scarcity of material and human resources, health system saturation, implementation of experimental therapies, and vaccine distribution that can be encompassed in the principle of equity; the consequences of this will prevail for a long time.

Although the sample may be small, reaching data saturation ensures the rigor and transferability of the results in territories with similar health policies. It should be considered that Spain has a free and universal health system with 24-h open access for family members; therefore, the results cannot be applied to other health contexts. It should also be taken into account that because of the sampling procedure, it is highly probable that only those whose experience with professionals and the system was satisfactory agreed to participate, thus ignoring the experiences of those dissatisfied.

Therefore, patients consciously sacrificed their autonomy for the common good within a dynamic of acceptance and accurate knowledge of the pandemic. In many cases, the patient assumed a passive role with the nursing staff because their relationship focused on trust in decision-making (Molina-Mula & Gallo- Estrada, 2020). Evidence from a prior study highlights the importance of adequate control of patient autonomy in the hands of nursing professionals (Skår, 2010).

CONCLUSION

During the COVID-19 pandemic, feelings of loneliness among patients and caregivers remained latent, affecting their emotional health because of the strict isolation rules for infection control. Therefore, reduced autonomy concerning measures and protocols for the benefit of public health must be added. This fact has been well accepted by all the participants, who have also shown appreciation for the work done by the healthcare staff.

RELEVANCE TO CLINICAL PRACTICE

This study highlights the emotional impact of isolation for patients and caregivers due to the COVID-19 pandemic: feelings of loneliness and loss of autonomy. Appropriate strategies must be created to alleviate these situations. It is confirmed that caregivers should be included in the care process, a positive element for all actors involved.

From the COVID-19 pandemic, it is necessary to potentiate information and communication technologies in a new health scenario as it has hastened the design of new health strategies and catalyzed the rapid implementation of digital-virtual channels in many areas. Telemedicine allows access to health information and professional contacts, as well as the implementation of online procedures and clinical diagnoses, and promotes telephone assistance. In addition, situations and conflicts triggered by the pandemic heighten the need to search for new strategies and resources to deal with patient isolation, loss of autonomy, and stress that impacts the illness evolution and, in time, turns into mental health issues.

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Table 1. Sample questions

-
- How was the nursing care received by you or your family member?
 - What memories are the most intense? Why?
 - Did you have a chance to ask questions? How did you feel?
 - Did you ever feel lonely? Why? What impact did it have on your autonomy?
 - Did you feel that your autonomy or that of your family member was violated?
Why?
 - How would you assess the information and care received from healthcare professionals?
-

Table 2. Sample details

| Participant | Gender | Kinship | Age | Occupation | Level of studies | Total day of admission |
|---------------------|---------------|----------------|------------|-------------------|-------------------------|-------------------------------|
| Patient 1 (P1) | Male | - | 31 | Administration | University | 10 |
| P2 | Female | - | 74 | Retired | Basic | 36 |
| P2-Caregiver (P2-C) | Male | Nephew | 49 | Informatics | University | - |
| P3 | Female | - | 72 | Administration | Basic | N/A |
| P3-C | Female | Daughter | 35 | N/A | N/A | - |
| P4 | Female | - | 58 | School teacher | University | 36 |
| P4-C | Female | Sister | 52 | Event planner | University | - |
| P5 | Male | - | 44 | Administration | Basic | 30 |
| P6 | Female | - | 58 | Retired | Secondary | 9 |
| P7 | Male | - | 38 | Informatics | University | 30 |
| P7-C | Female | Spouse | 39 | Administration | University | - |
| P8 | Male | - | 57 | Lawyer | University | 39 |

| | | | | | | |
|-------|--------|---------|----|-----------------|------------|----|
| P8-C | Female | Friend | 62 | N/A | N/A | - |
| P9 | Male | - | 62 | N/A | N/A | 20 |
| P9-C | Female | Sister | 58 | Concierge | Basic | - |
| P10 | Female | - | 40 | Sales | Basic | 4 |
| P10-C | Male | Friend | 45 | Truck driver | Basic | - |
| P11 | Female | - | 38 | Nurse assistant | Secondary | 6 |
| P11-C | Male | Husband | 38 | Factory | Basic | - |
| P12 | Male | - | 39 | Driver | University | 8 |
| P13 | Female | - | 36 | Housekeeping | Basic | 6 |

Table 3. Themes and subthemes

| Theme | Subtheme | Codes |
|---|---|--|
| Acceptance of mandatory isolation for patients and family caregivers | Use of IPE | Feeling stigmatized |
| | | Depersonalization in care |
| | | Understanding |
| | | Acceptance/abiding by the situation |
| | Feeling alone/ loneliness | Suffering |
| | | Need of physical contact |
| | | Virtual/telephone relationship |
| | | Motivation |
| Limited autonomy perceived as necessary during hospitalization for patients and family caregivers | Limitation of autonomy | Limitations imposed |
| | | Acceptance |
| | | Voluntary assignment/ delegation of autonomy |
| | | Provide security |
| | Effort of healthcare staff to maintain patient autonomy | Enhance capabilities |
| | | Adapt to individual recovery rates |
| | | Gratitude |
| | | Nurse role |