

# Living the hospitalization of a family by COVID-19

**RESUMO** | Objetivo: apreender como os familiares vivenciaram o período de hospitalização do seu ente com a forma grave da Covid-19. Método: trata-se de um estudo qualitativo realizado junto a doze familiares de pacientes que apresentaram a forma grave da Covid-19. Os dados foram coletados, por meio de entrevistas individuais em profundidade, e a análise guiada pelas etapas analíticas da Grounded Theory. Resultados: emergiram-se duas categorias “O impacto da internação hospitalar na família” e “A importância do apoio social ao familiar”. Conclusão: Viver o internamento de um familiar em decorrência da Covid-19, propicia o surgimento de vários sentimentos e emoções, tornando-se um momento difícil, permeado de incertezas e angústias perante o desfecho do internamento do seu familiar. Destaca-se a importância dos profissionais da saúde e da comunidade, destacando-os como importantes fatores de proteção neste período.

**Descritores:** COVID-19; Hospitalização; Família; Pesquisa qualitativa.

**ABSTRACT** | Objective: to learn how family members experienced the period of hospitalization of their loved one with the severe form of Covid-19. Methods: this is a qualitative study carried out with twelve family members of patients who had the severe form of Covid-19. Data were collected through in-depth individual interviews, and the analysis was guided by the analytical steps of the Grounded Theory. Results: two categories emerged “The impact of hospitalization on the family” and “The importance of social support to the family”. Conclusion: Experiencing the hospitalization of a family member as a result of Covid-19, provides the emergence of various feelings and emotions, making it a difficult time, permeated with uncertainties and anguish in the face of the outcome of the hospitalization of your family member. The importance of health professionals and the community is highlighted, highlighting them as important protective factors in this period.

**Keywords:** COVID-19; Hospitalization; Family; Qualitative research.

**RESUMEN** | Objetivo: conocer cómo los familiares vivieron el período de hospitalización de su ser querido con la forma grave de Covid-19. Métodos: se trata de un estudio cualitativo realizado con doce familiares de pacientes que tenían la forma grave de Covid-19. Los datos fueron recolectados a través de entrevistas individuales en profundidad, y el análisis fue guiado por los pasos analíticos de la Grounded Theory. Resultados: surgieron dos categorías “El impacto de la hospitalización en la familia” y “La importancia del apoyo social a la familia”. Conclusión: Vivir la hospitalización de un familiar a consecuencia del Covid-19, propicia el surgimiento de diversos sentimientos y emociones, haciendo que sea un momento difícil, permeado de incertidumbres y angustias ante el desenlace de la hospitalización de su familiar miembro. Se destaca la importancia de los profesionales de la salud y de la comunidad, destacándolos como importantes factores protectores en este período.

**Palabras claves:** COVID-19; Hospitalización; Familia; Investigación cualitativa.

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## INTRODUCTION

The new coronavirus, also called Severe Acute Respiratory Syndrome Coronavirus 2 (Sars-Cov-2), emerged at the end of 2019 and is the etiological agent of the respiratory disease Covid-19. In January 2020, it was declared a major public health emergency, receiving the name of a pandemic in March 2020. <sup>(1)</sup>

Its numbers are expressive: until No-

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verember 20, 2021, 257,168,692 cases of Covid-19 were confirmed in the world, with 5,146,467 deaths. In Brazil, whose first case occurred in February 2020, there were 22,012,150 confirmed cases and 612,587 deaths in the same period. Also noteworthy is the number of hospital admissions due to Covid-19: in 2020, 700,372 hospitalizations occurred in Brazil due to Severe Acute Respiratory Syndrome (SARS), caused by the new coronavirus.<sup>2</sup>

Such data demonstrate the severity and evolution of the disease, which resulted in changes in the way society works and in the personal interactions between the patient, family, community and health professionals. Some families began to experience stressful events in their daily lives, as they experienced the illness of several members, in a short period of time, and were prevented from visiting their loved ones, even in the face of the imminent possibility of death.<sup>3</sup>

In hospitalizations for Covid-19, social distancing was imposed, due to the high degree of transmissibility of the disease, vetoing the presence of the family with the patient, intensifying signs of stress, anxiety and depression in all involved. Also, the hospitalization of a family member is responsible for the disruption and disorganization of the family constitution, causing anguish about the health status of the hospitalized member.<sup>4</sup>

Thus, both patient and family members face difficulties in the face of illness by Covid-19, especially during hospitalizations, facing situations such as fear of the unknown and distress when it is necessary to make decisions related to health.<sup>4</sup> Added to this is the fact that social distancing can cause individuals, families or communities to lose emotional ties with their loved one, leading to a weakening of social support.<sup>5</sup>

It becomes, therefore, important that hospital services seek alternatives that address the needs of the family and allow them to circumvent the lack of their physical presence in these places.<sup>4</sup> In this

context, the use of technology with remote communication has become an ally, making it possible to reduce distances through phone calls and videoconferencing, even during hospitalization. Howe-



Some feelings such as hopelessness, insecurity, helplessness and fears were observed in family members and through them, it is possible to think of humanized care for families of critically ill patients. Technological resources and training for professionals are necessary to rethink care in the future.



ver, the use of these technologies did not fully meet the need for contact, being responsible, at times, for further reducing the support offered to family members, for

unqualified communication and for providing deficient or incomplete information to the family.<sup>6-7</sup>

Thus, by understanding that the family is the core of the assistance provided to the patient, essential and unique in the care process, and considering that their care needs may be related to the experiences arising from their absence in the hospital environment, the study aimed to understand how family members experienced the period of hospitalization of their loved one with the severe form of Covid-19.

#### METHOD

This is a qualitative study that used Symbolic Interactionism (SI) as a theoretical framework. The methodological framework followed Grounded Theory's analytical techniques.

The study was carried out in a municipality in the state of Paraná, located in the Center-South region, with a population of 182,644 people, in a territorial area of 3,163,441 km<sup>2</sup>.<sup>8</sup>

In Paraná, until December 2020, a total of 413,412 cases of Covid-19, 7,912 deaths and 1,588 patients were hospitalized in a public and private hospital environment were confirmed. The study site had 4,868 confirmed cases and 55 deaths from Covid-19 in 2020, with 42% bed occupancy on December 31, 2020, which brings it closer to the reality of other Brazilian cities of the same size, so that its representativeness on the national scene could be used to choose the place of study.<sup>9</sup>

Study participants were 12 family members of patients who were discharged after hospitalization for the severe form of Covid-19, hospitalized from March 21st to October 13th, 2020. Being selected for convenience from the list of hospitalizations for Covid-19, from the Municipal Health Department of the municipality of reference, acquired in line with the Department of Work Management and Health Education - DGTES (Departamento de Gestão do Trabalho e Educação em Saú-

de) and the municipality's Covid-19 Call Center (Call Center). The family members of individuals who generated the Inpatient Hospital Authorization (IHA) and were discharged from the hospital, who lived in the same residence or, at most, were included in the study. 30 minutes away from your family member and aged 18 or over and under 60 years of age.

After applying the inclusion criteria, 42 participants were identified and telephone contact was made with them, according to the progress of the research. None of those contacted withdrew or refused to participate in the study. However, when conducting interview number 12, it was decided to end the inclusion of new participants, as the theoretical saturation of the data occurred 10, identified by the lack of new information in the analysis.

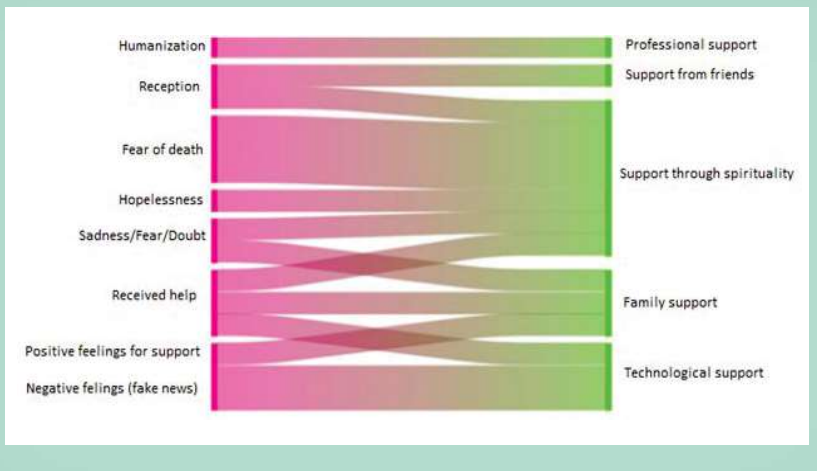
Initially, the contact with the participants took place via telephone, for the presentation of the research and the interviewer, providing the pertinent information about the academic interest of the interviewer. In this contact, data collection was scheduled, carried out from October to December 2020, through individual in-depth interviews, according to the availability of the participants.

Due to the impossibility of face-to-face collection, due to the high spread of the Covid-19 virus, the interviews were carried out through telephone calls and had an average duration of 30 minutes. During the same, a script built by the researchers was used according to the objective of the study, consisting of two parts.

The first addressed sociodemographic characteristics and the second contained the following guiding question: "What was it like for you to experience the period of hospitalization of your family member due to contamination by Covid-19?" and support issues.

Before starting data collection, the participant was asked to consent to the recording of the interview to ensure transcription and a reliable interpretation of the information. It is important to note that right after the end of the characterization

**Figure 1 - Diagram of the intensity of relationships on the experiences of family members of patients who had the severe form of Covid-19. Guarapuava, Paraná, Brazil. 2021.**



Source: the author, 2021.

questions, the participant was asked if he was comfortable to start the open questions. It was requested that, as far as possible, they look for a private place at home, so that they have freedom to express their feelings.

Data collection and analysis took place concurrently. After each interview, the speeches were transcribed and analyzed, which is essential to guide the selection of the next participants. Throughout this process, the criteria of theoretical saturation were respected, a point of qualitative data analysis in which the researcher, resulting from the data analysis, finds that no new facts emerge.<sup>10</sup> With this, data collection ended with interview<sup>12</sup>.

Data were entered into a Microsoft Word 2019 document and submitted to Grounded Theory's analytical techniques. The techniques adopted were open and axial coding, as they provide a technical systematization in the collection and analysis of data, emphasizing how important is the understanding, knowledge and interpretation of the phenomenon of study.<sup>10</sup>

For data organization and material exploration, Atlas.ti: The Qualitative Data

Analysis & Research Software, version 9.0.16 was used. Through the textual corpus constructed from the interviewees' discourse, the association of extracts from the text in relation to quotes and codes was carried out.

The methodological process followed the following phases: (1) Open coding: where data recognition and analysis took place. At this stage, using the ATLAS.ti software, a line-by-line analysis was carried out in order to identify each incident and elaborate possible hypotheses, assigning different Codes to the speeches for the follow-up of the analysis and subsequent grouping for the elaboration of the concepts; (2) Axial Coding: at this stage the data were regrouped in order to obtain an explanation of the phenomenon of study, in which, with the process of building the Codes, the categories and subcategories were associated, through a systematized analytical process of connection and comparison between the data.<sup>10</sup>

In this study, 207 Quotes and 15 Codes emerged from the textual corpus, giving rise to two thematic categories: "Experiencing hospitalization in the family" and "The importance of social and family

support". In addition, it was possible to construct the Sankey Diagram to assist in the visualization of subcategories, categories and their co-occurrences. In the diagram, the width of the arrows between the subcategories is proportional to the flow of relationship between the categories. Each thematic category in the diagram was represented by a color in order to analyze the relationships between them: 1st category color pink and 2nd category color green.

The guidelines of resolutions 466/2012 and 510/2016 of the National Health Council were duly respected during the study, which was authorized by the municipality and approved by the Ethics and Research Committee of the State University of Maringá -UEM, CAEE: 38455620.0.0000.0104, under opinion No. 4,316,211, on 10/02/2020. To maintain the anonymity of the participants, they were identified using "P1; P2.." corresponding to the participant, followed by Arabic numerals, according to the order in which the interviews were carried out.

## RESULTS

Twelve family members were interviewed, aged between 24 and 58 years, of which 11 were female, 10 were children of the patients, nine were of mixed race, eight were Catholic and five had completed higher education. It is noteworthy that of the 12 participants, 11 had already been diagnosed with the disease previously.

As for the sectors and length of stay of the family member, seven patients were hospitalized in the ward with an average of five days of hospitalization, while five patients stayed in the Intensive Care Unit (ICU) with an average of nine days.

With the organization of the Codes, the categories originated: "The impact of hospitalization on the family" (pink) and "The importance of social support to the family (green)". The categories were organized in the Sankey diagram to verify possible relationships between them and their respective Codes.

### Co-occurrence of the Codes

Figure 1 shows the intensity of the co-occurrence of the Codes between the categories, with the width of the lines of each category and subcategory being proportional to the flow of relationship between them and their intensity, allowing us to infer from the interviewees' statements that the relationship between the various events experienced can be a possible source of mutual support, which deserve to be explored.

It is noted that the categories emphasize feelings related to the support received, such as professional support related to humanization; Support from friends with the reception; Spiritual support with fear of death, hopelessness and sadness; Family support with the help received and help to deal with sadness/fear, and finally, Technological support linking positive feelings of support and negative feelings related to fake news.

### Experiencing hospitalization in the family

Through the interviewees' reports, it was possible to observe that during hospitalization the family had to live with the non-existence of a specific treatment for Covid-19, the severity of the disease and the uncertainty of the prognosis, as well as the feelings generated by these.

It was, like, one of the worst phases we've had here. I felt despair, [...] because it's a disease like that, so violent, so evil, my God [...]. (P2)

We noticed that the medical profession did not have a specific treatment for the disease. So we felt extremely vulnerable, isolated and helpless. (P10)

We don't know if the person will be okay or not, it was horrible. (P3)

So many deaths that have occurred with the disease, at the time everything passes in the head. Will they survive or not? (P6)

The hopelessness, vulnerability, helplessness and uncertainty mentioned in the previous speeches were added to other negative feelings, such as concern, agony, anguish, impotence and fear, evidencing that the experience of the interviewees during the hospitalization of their family member was permeated by suffering.

So (hospitalization) was difficult, all the time thinking, worried, afraid... and I had a small child and was expecting another one. (P6)

Feeling of agony, anguish, of not knowing, precisely because it is a new disease. (P3)

The impotence, not knowing what to do, just seeing the agony, like, the anxiety of my wife's illness, and not being able to do much [...]. (P10)

For some interviewees, hospitalization was less painful, as being in hospital treatment and the improvement provided by it brought tranquility to the family members.

I knew he was there in the hospital, being well taken care of. So I didn't even worry too much, he was better there. (P4)

We didn't know what it was about and what could be happening, what could still happen to her, if it really was COVID-19. And then, from the moment she was hospitalized, the tests were done and she started to feel better and we managed to get in touch with her, we started to calm down. (P5)

Then, with the medication, it ea-



sed and he had a good improvement, so, then, we were calmer. (P6)

The isolation of the family member during hospitalization was addressed by the participants and identified as a generator of bad moments by preventing physical contact between them. Reports also demonstrated the understanding that this was necessary to reduce further contamination, and brought up the questioning of those who wanted to be close to their sick family member at this time, regardless of the risks involved in this contact.

Isolation was the worst thing, it was the worst moment. [...] the insecurity of having contact only with the social worker is very great, even more so when he was admitted to the ICU [...]. (P8)

You have to respect isolation. If you're not worried about having the disease, at least you have to have respect for others. I was already infected, thank God I was cured. But I still have respect for that person who, suddenly, hasn't gone yet [...]. (P10)

I didn't care about that, if the worst was to happen to me, let it happen. [...] So I didn't care about anything, I was aware that if they had a disease, I could get it, but I didn't care [...]. (P7)

### The importance of social and family support

In this category, it was possible to identify in the speech of some interviewees that, in order to face the moment of hospitalization of their relative, the reception of friends and family, trust in health professionals and religiosity/spirituality were essential, allowing them to go through this moment more peacefully.

The neighbors left food here at

my door, I ended up feeling very loved in that sense, that even far away I felt a lot of affection from people. (P3)

Faith [...], something I held on to a lot. I tried to forget the fear, I left the fear aside. Everything that was negative, I tried to eliminate, both from thinking and... from everything. But I think that the faith was enough and the trust and support of the professionals. (P8)

[...] it was the family support too, you know, chain of prayers, the family praying and helping in everything, everyone together because it is a very difficult time [...]. (P9)

Through faith, God for sure, a lot of prayer, a lot of friends calling, making a prayer chain, so that's how I got stronger. (P3)

In addition, the support received from health institutions and professionals were equally important for the family member to feel good. A quality, humanized care, focused on providing the best to the patient and his family was verified, and it was reported that the possible and the impossible were carried out in the face of this new pandemic, under the conditions that the health system had.

I think the service was very good. There was a day when I was very emotionally shaken, you get desperate. Then they calm you down, they calm you down, you know [...]. (P9)

I don't have to complain about the treatment, they took care of me very well. What they could do, they did, I think even the impossible [...]. (P7)

From the beginning to the end

of our quarantine we were very well taken care of, [...] they were touched by the moment we were going through, you know, it was really cool. (P11)

For this support to be possible, technology proved to be an important ally of health services. Telephone contact was the best possible means of communication between health teams and family members of hospitalized patients. However, in some reports, the spread of mass news in the media and fake news made the family members anxious and more concerned about the life of their family member.

During Covid, the Call Center staff was very present, they called, sent messages, the nurse and the doctor, they were all like, very good [...]. (P1)

The hospital was a 10, we were very well attended and from the Call Center they called almost every day, to see how we were [...]. (P4)

The news (from the media) were horrible, that mass of news of death and people dying and stuff, shook us psychologically. (P10)

The media that made the people a little more worried, a little more anxious about the information. (P11)

### DISCUSSION

The emergence of Covid-19 and its pandemic consequences brought concern to the population both for its severity and for the lack of a specific treatment. Infected individuals needed to be treated without drugs with proven action against the new coronavirus, as well as in the face of the lack of guidelines and protocols arising from scientific knowledge.<sup>11</sup>

In this scenario, feelings of vulnera-

bility and insecurity affect the population regarding the treatment of infection by the new coronavirus and even question the performance of health professionals. Due to the increase in cases and mortality, it took dedication from the scientific community to learn more about the new coronavirus, how it acts and how it should be faced, which has become a huge challenge.<sup>12</sup>

It should be noted that, even without scientific evidence to support the use of existing drugs in the treatment of Covid-19, they were widely used by the population and in health services. This is because, due to the lack of an effective treatment, based on science, and the need to seek the best possible treatment to keep the patient alive, many health professionals chose to prescribe them, despite the risks, and combine them to identify, empirically, what could work.<sup>11</sup> However, this did not go unnoticed by family members, resulting in negative feelings and doubts about what was being offered to their patients.

Another experience highlighted by the participants was having to deal with the severity of the disease and the uncertainty of the prognosis during hospitalization. This may be based, mainly, on the possibility of worsening the condition, with hospitalization in the ICU, and death. A study carried out in the first semester of the pandemic in Brazil, with data from official information systems, showed that mortality from Covid-19 was 38% of hospitalized patients, increasing with age and oscillating according to the region of the country.<sup>13</sup> The South region was identified as the one with the lowest mortality among those hospitalized, with 12.8% in a southern capital, considerably lower than that found at the national level.<sup>12</sup>

The emotional aspects resulting from the Covid-19 pandemic are ambivalent, being expressed by the participants of this study through the identification of positive feelings of hope and protection, referring to ICU admission, especially in the most severe cases. These feelings reflect confi-

dence in services and professionals trained in their various specialties, due to the experience and knowledge necessary to maintain life.<sup>14</sup>

And on the other hand, negative feelings, such as worry, anguish, impotence, helplessness, fear, among others. Such feelings are intensified by the family's need to reorganize itself without the hospitalized entity and by the conflicts between its members generated by hospitalization<sup>15</sup> and by the severity of the disease and the present uncertainties.<sup>14</sup>

It should be noted that this scenario is not specific to the current pandemic, but to any situation that resembles it in terms of the need for hospitalization and severity. Relatives of patients hospitalized in ICUs before the pandemic due to the new coronavirus, with an indication of palliative care, also pointed out that they live with negative feelings, also highlighting pain, sadness and loneliness.<sup>14</sup>

However, during the pandemic, this condition of uncertainty for family members was aggravated, mainly due to the news published in the media. Access to impactful news, which addressed illness and death, directly interfered with the mental health of individuals, contributing to anxiety, depression, distress and panic, especially in those who commonly sought information on social media.<sup>15</sup>

In view of this, it is essential that health professionals working in intensive care sectors recognize their importance and are trained to welcome family members and their negative feelings, so that they manage to lighten the possibility of the existing loss and promote their comfort and calm.<sup>14</sup> Thus, the quality of communication between the health team and the family will depend on adequate information about the conduct of the patients' treatment and medical decisions, as well as being more accessible in moments of doubts and concerns of the families.<sup>16</sup>

In this sense, technology was a strategy used during the pandemic, which minimized the suffering of family members. With the use of smartphones, computers and

media, family contact was made possible in order to provide an improvement in the elaboration of the illness process and relief of suffering among those involved.<sup>4</sup> Relatives of patients with invasive ventilation in the ICU highlighted the need to receive regular updates related to the clinical condition and treatment developed, through different modes, such as calls, information pages and text messages.<sup>15</sup>

However, not all family members feel comfortable receiving video calls to monitor the evolution of their patient, especially when there are indications that the case is serious, with intubation, unconsciousness and the use of monitors. This contributes to internal conflicts, as they want to see their family member, but the image in the video brings even more suffering.<sup>15</sup>

Thus, it is noted that it is essential that health systems review the total impediment of family presence, especially in cases of patients at risk of death, since with the use of the necessary care, these moments can be a means of taking care of the family and providing them with less suffering with the loss of their loved one, if this occurs.<sup>16</sup>

Another experience highlighted by the participants was the support of community members as a great ally in facing adversity during the hospitalization of their family member by Covid-19. Support from neighbors, community and religious leaders who make up the support network of family members is considered a protective factor against stressful events.<sup>17</sup> A study carried out in Wuhan - China found that psychosocial symptoms had a positive association with factors related to social support, while the absence of this is related to the emergence of depressive symptoms.<sup>17</sup>

In this study, spirituality, religion and faith were widely cited by the participants. Faith is pointed out as a means of strengthening the family in facing the situation experienced, especially when there is a risk of death and a feeling of powerlessness. Spirituality allows for a better understanding of hospitalization and the

adversities encountered in treatment, reducing suffering and providing comfort, hope, peace and tranquility.<sup>14</sup>

Therefore, it is clear that the participants faced many challenges and changes in their lives during the hospitalization of their family member, such as fears, anxieties and insecurities about the health of their loved one in the face of a little-known disease, demonstrating how the technological support, from health, social and spiritual professionals was an important source of support at this time.

## CONCLUSION

The study revealed that even in the face of difficulties and obstacles, the experience of hospitalization of the family member, in the face of Covid-19, is centered on the support conditions offered by family members, professionals and the community during hospitalization.

Some feelings such as hopelessness, insecurity, helplessness and fears were observed in family members and through them, it is possible to think of humanized care for families of critically ill patients.

Technological resources and training for professionals are necessary to rethink care in the future.

This investigation has limitations in data collection, since the interviews were carried out with family members after their loved one was discharged and not during hospitalization, which may influence changes in their perceptions after a certain period of discharge. Thus, it is recommended that future investigations be carried out in contexts favorable to data collection. 🌱

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