# A pandemia dos órfãos: Terminalidade, Morte e Luto nos tempos da COVID-19: Vivências de enfermeiros

The orphans pandemic: Terminality, Death and Grief in the time of COVID-19: Nurses' experiences La pandemia de huérfanos: Terminalidad, Muerte y Duelo en tiempos de COVID-19: Experiencias de enfermeras

#### **RESUMO**

Objetivo: Investigar e descrever sentimentos, atitudes e vivências de enfermeiros perante da terminalidade, finitude, morte/morrer e o luto no contexto da pandemia por COVID-19. Método: Trata-se de um estudo de natureza descritivo-exploratório com abordagem qualitativa, realizada entre janeiro e março de 2022, na qual foi adotado o método de história oral temática. Para a apreciação e avaliação dos dados utilizou-se a análise de conteúdo referenciada por Bardin. Resultado: Emergiram-se três categorias centrais: Principais desafios e sentimentos frente a morte por CO-VID-19. Categoria Central. Fragilidades dos enfermeiros na abordagem das famílias e pacientes; Vivências e inquietações de enfermeiros diante do cuidado no momento da morte. Conclusão: De acordo com essas vivências, lidar com o processo da morte mostrou-se um desafio diário para esses profissionais, em virtude das poucas informações acerca dessa enfermidade, bem como tentar esclarecer aos familiares os protocolos em relação às visitas e proximidade com os internados contaminados.

DESCRITORES: Morte; Luto; Enfermagem; Infecções por Coronavírus; Pandemias.

#### **ABSTRACT**

Objective: To investigate and describe feelings, attitudes and experiences of nurses in the face of terminality, finitude, death/dying and grief in the context of the COVID-19 pandemic. Method: This is a descriptive-exploratory study with a qualitative approach, carried out between January and March 2022, in which the thematic oral history method was adopted. For the appreciation and evaluation of the data, the content analysis referenced by Bardin was used. Result: Three central categories emerged: Main challenges and feelings in the face of death by COVID-19. Central Category. Nurses' weaknesses in approaching families and patients; Experiences and concerns of nurses in the face of care at the time of death. Conclusion: According to these experiences, dealing with the process of death proved to be a daily challenge for these professionals, due to the little information about this disease, as well as trying to clarify the protocols for family members regarding visits and proximity to hospitalized patients. contaminated. **DESCRIPTORS:** Death; Mourning; Nursing; Coronavirus infections; Pandemics.

#### RESUMEN

Objetivo: Investigar y describir sentimientos, actitudes y vivencias de enfermeros frente a la terminalidad, la finitud, la muerte/morir y el duelo en el contexto de la pandemia de la COVID-19. Método: Se trata de un estudio descriptivo-exploratorio con abordaje cualitativo, realizado entre enero y marzo de 2022, en el que se adoptó el método de historia oral temática. Para la apreciación y evaluación de los datos se utilizó el análisis de contenido referenciado por Bardin. Resultado: Emergieron tres categorías centrales: Principales desafíos y sentimientos ante la muerte por COVID-19. Categoría Centro. Debilidades de las enfermeras para acercarse a las familias y los pacientes; Experiencias e inquietudes de los enfermeros frente al cuidado en el momento de la muerte. Conclusión: De acuerdo con estas experiencias, lidiar con el proceso de la muerte resultó ser un desafío diario para estos profesionales, debido a la poca información sobre esta enfermedad, además de tratar de aclarar a los familiares los protocolos sobre visitas y proximidad a los pacientes hospitalizados. .contaminado.

DESCRIPTORES: Muerte; Luto; Enfermería; infecciones por coronavirus; Pandemias.

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#### Guadalupe da Silva Herculano

Nurse graduated from Escola Superior de Cruzeiro-ESC, Cruzeiro-São Paulo - Brazil. ORCID:0000-0002-5573-3960



#### Roberta Villela Serpa

Nurse graduated from Escola Superior de Cruzeiro–ESC, Cruzeiro–São Paulo – Brazil. ORCID:0000-0001-9001-6863

#### Fabiano Fernandes de Oliveira

Nurse, Master and PhD student in Nursing by the Graduate Program, Academic Doctorate Course at the São Paulo State University – "Júlio de Mesquita Filho" – UNESP - Botucatu, São Paulo - Brazil. Professor of the Graduate Course in Nursing at Escola Superior de Cruzeiro – ESC, Cruzeiro, São Paulo - Brazil. ORCID: 0000-0001-6768-4257

# INTRODUÇÃO

tudies have revealed that both the pandemic itself and the measures adopted to contain it seem to impact mental health, increasing the risk of developing symptoms of stress, anxiety and depression, what has been identified in the general population, and in health professionals.

In this sense, COVID-19 can be considered a collapse from an epidemiological and also psychological point of view, given the cognitive, emotional and behavioral changes that tend to be experienced in this period. (2)

In general terms, pandemics are associated with massive losses, both in human lives and in routines, face-to-face social connections and financial stability. Due to COVID-19, many people have experienced drastic changes in their daily lives and have to deal with the unpredictable future. Many others were infected or even lost someone from their socio-affective network as a result of the disease. (3)

In this scenario, nurses were and are key workers in the demand for care during the COVID-19 pandemic, as has been evidenced in the international literature (4), emphasizing its performance in surveillance, prevention and control of transmission of the virus, in patient care, in research and in guidelines for the health of the community, as well as in the reorganization of health services. (5)

In fact, the successive number of deaths correlated to COVID-19 and the impact on health professionals who experience them have been announced in the media of all countries. Although it is known that death is an integral part of the life cycle, in the face of a virus and an unknown disease. (6)

Faced with multiple losses, especially of people with an affective bond, mourning in the pandemic context is expected, given that mourning consists of a normative process of adapting to afflictions, encompassing emotions, cognitions, physical sensations and behavioral changes. (7)

In this perspective, it is known that the coping process is essential for re-signification of mourning, namely: acceptance of the reality of the loss, as the feeling that death did not occur may emerge; acknowledgment of the suffering caused by the loss, without using subterfuges, since avoiding or suppressing the pain tends to prolong it; adaptation to the context of life without the presence of the deceased person, which requires taking on functions that he previously performed in the family; and, emotional repositioning of the deceased person, that is, organization of an emotional space to remember them, so that life can continue. (8)

This is even more emerging among nurses, in view of the length of stay and proximity to patients, which reflected in the following question: "What are the experiences and attitudes of nurses in the face of terminality, finitude, death/dying and mourning and what factors are associated with this process, during the COVID-19 pandemic?".

Thus, this study is justified and becomes relevant, as it presents an unprecedented theme that deals with the recollections and the role of nurses in the pandemic scenario and the ways of coping related to the process of terminality, finitude, death/ dying and mourning.

At the same time, this study brings re-

flections that have the potential to assist nurses in decision-making and action in the face of the death and dying process and directly in the care of patients during and after the Covid-19 pandemic.

Therefore, the objective was to investigate and describe feelings, attitudes and experiences of nurses in the face of terminality, finitude, death/dying and mourning in the context of the COVID-19 pandemic.

#### **METHOD**

"Article "extracted from the Course Completion Work (TCC) entitled: "The orphan pandemic: Terminality, Finitude, Death and Mourning in the Times of CO-VID-19: Oral History and Experiences of Nurses", presented to the Department of Undergraduate Nursing at Escola Superior de Cruzeiro - ESC, Cruzeiro, São Paulo, Brazil in the year 2022.

This is a descriptive-exploratory study with a qualitative approach, in which the thematic oral history method was adopted, which consists of a technique of remembering, rescuing and recovering the past related to a certain subject, as conceived by those who experience it. (9)

The study scenario was virtual, considering that the data and participants were recruited and interviewed remotely via the virtual platform of Google forms, between the months of January to March 2022.

The definition of study participants was based on a "Snowball" sample, considered non-probabilistic, with the intention of apprehending the representativeness and meaning of the interviewee's experience in the face of the death/dying process.

A sample of nurses was reached, who

worked or had worked on the front line during the COVID-19 pandemic and experienced moments and situations of terminality, finitude, death/dying and mourning or until reaching the theoretical saturation of the data either by repetition or similarity of responses as it is a qualitative research.

The following inclusion criteria were adopted: being a nurse who works or has worked on the front line of patient care with COVID-19 who died and who had a significant and memorable experience, facing the process of death, dying and mourning. Professionals who were on leave or on leave during the data collection period and those who did not respond to the invitation to participate in the research in at least three requests by the researchers were excluded.

Data collection followed the recollections of the thematic oral histories technique, experienced by the study participants, in situations of death and dying.

Memories were stimulated by sending a semi-structured questionnaire, prepared by the authors themselves, containing questions to characterize the sociodemographic profile, with the objective of collecting information about the social condition, economic and demographic of the participants, questioning them about gender, age, time and area of expertise in nursing and had questions considered guiding to achieve the objective proposed by the research.

These experiences discussed in the form of oral history formed the sources and content for document analysis, described in the form of reports and thematic oral history telling. (9)

Therefore, the analysis was organized in the phases of pre-analysis, material exploration, treatment of results, inference and interpretation, working on speech, specifically the practice of language, seeking to know what is behind the words they express at a given moment. (10) We then sought to explain the results in light of the existing literature, leading to the identification of central categories.

Before opening the questionnaire, each

participant received the option to accept or not accept the Free and Informed Consent Form (FICF), in which the implications and peculiarities of the study were presented and anonymity was guaranteed

To guarantee the anonymity of the participants, they were referenced using an association of letters and numbers, the acronym "Nur" for Nurse was used, followed by Arabic numerals from 1 to 7 according to the order of the interviews.

The research followed all ethical precepts in accordance with the recommendations established by Resolution 510/16 of the National Health Council for research carried out with human beings, and after approval of the project by the host institution, the project was submitted to the Ethics and Research Committee (CEP ), through Plataforma Brasil, destined for Centro Universitário Teresa D'Ávila (UNIFATEA), having received opinion 5,168,461 and Certificate of Presentation of Ethical Appreciation (CAAE) number 54201621.4.0000.5431 on April 6th, 2022.

### **RESULT**

This study had the voluntary participation of 07 nurses who worked on the front line in different sectors such as the Intensive Care Unit (ICU) for patients with COVID-19, Epidemiological Surveillance and Family Health Strategy, and in sectors of care for patients infected with COVID-19 considered a field hospital.

Below, in Table 1, some information collected and cataloged will be presented in order to facilitate the interpretation of the sociodemographic profile of individu-

Among the participants, there was a predominance of females, six women and one man, the age ranged between 21 and 38 years, as for the training time, it presented an average between 4 months and 05 years of experience in the nursing area, with a predominance of 2 years of experience in different sectors, divided into three participants who worked in a specific Intensive Care Unit for COVID-19, three at the Integrated Health Center (Campaign Hospital), one participant who works in epidemiological surveillance, and one in Family Health Strategy (ESF).

After content analysis, the data obtained were grouped into central categories and their thematic units.

# Core Category 1 - Main challenges and feelings facing death from COVID-19.

In the investigation about the main challenges and feelings to face a death situation, the participants expressed the following answers:

> "... And he said to me like 'I need to talk to my wife, and I need to see my children because I know I won't

Chart 1: Sociodemographic data of study participants. São Paulo, Brazil, 2022.

Participant	Age	Year of formation	Time of experience	Sector	Gender
NUR 01	34	2019	3 years	COVID ICU	M
NUR 02	26	2018	4 years	Integrated Health Center	F
NUR 03	25	2018	4 years	COVID ICU	F
NUR 04	38	2019	3 years	Integrated Health Center	F
NUR 05	21	2021	4 years	EPIDEMIOLOGICAL SURVEILLANCE	F
NUR 06	38	2018	4 years	COVID ICU	F
NUR 07	29	2017	5 years	FAMILY HEALTH STRATEGY	F
(Source: Researchers database, 2022)					

be able to resist, I won't be able to stand it. 'And we told him "don't think like that, let's think positive." He said "I know I won't make it.". And for me it was very shocking, we made a call, he said goodbye to the children, his wife, and he was intubated with us that night..." NUR 01

"... And I remember that I prayed, it was about 4:30 in the morning, I remember that I felt very bad, we create a bond with the patient and family,

and I just asked God not to let me have contact with the wife because the doctor called her to go to the hospital to break the news to her, in fact they already knew that was it, I just prayed and asked God like this "Lord, he was already admitted to the hospital with me, he was intubated with me, so let him not be here when his wife arrives..." NUR 01

".... What shook us a lot, shook us a lot is to see young people die, because we saw many "young" patients die, you know! Like 20 years and get worse, worse and go to death. One of the things that struck me, for example, were some patients who always looked at us and asked "girl, please don't transfer me, because I know that if I go there they will intubate me and I will die".

NUR 02

"...To this day, when I enter Covid isolation, I see the image of him dying in bed,

the body being prepared for burial and the moment when the family was notified of the death and that they would not be able to say goodbye to him, this will undoubtedly be a case that I will remember forever and that still moves me very much. We will never be 100% prepared to deal with the loss, whether of a loved one or not, and even more so under these circumstances." NUR 05

"... Unfortunately he died at the beginning of the same night, as was his fear, and exactly six months before his 40th birthday. Breaking the news to his relatives was extremely difficult as I was his longtime friend. His mother only became aware of what happened after being discharged from the hospital, as she was unable to deal with the situation while she was hospitalized... ' **NUR 06** 

Regarding the challenges faced by nurses, fatigue and mental exhaustion stand out, which was identified as one of the main stressors, since many dealt with patients from hospitalization until the time of death, having to deal not only with the isolated individual but with the family, since one of the restrictions of covid-19 was the impossibility of family members visiting their loved ones, causing many to have only the nursing team to take refuge, overloading these professionals emotionally and psychologically.

## Core Category 2 - Weaknesses of nurses in approaching families and patients.

In the investigation of the main weaknesses in approaching the family and patients, it can be identified in the following statements:

> "... The thing that scared the most about covid was the treatment regimen, because you are prevented from having contact with family members, so this is much more complicated. And we got to know each other over the long days, as the person in charge of the team, I had counted on this patient every day, he had to do some test collections, especially gasometry, which we collected daily at the beginning and end of the shift, so I talked a lot with him..." NUR 01

- "... I suffered to the point where, you look and see that the patient is the same age as you, the same age as the father, the same age as the mother, so we put ourselves in their shoes, as if the patient was me, my father or my mother. It's the empathy thing..." **NUR 02**
- "...I think it's very sad both for the family and for us in the (health) area, because we are human beings too... I didn't know him, I didn't live with him, I didn't have friendship, but we end up feeling it, right..." NUR 04
- "...it was that of a gentleman aged approximately 90, who was positive for covid and already had pulmonary involvement, but whose family did not authorize his transfer for hospitalization in another unit. I followed the entire evolution of the case, and on one of the last visits I made, he held my hand and told me that he could no longer bear to live like this, that he was suffering on earth and that he wanted to rest..." **NUR 05**

About the main feelings and experiences presented, it was the feeling of empathy, of the professional putting himself in the family's place. The patient-nurse bond is also something that motivated them, as patients had strong confidence in professionals, showing their fears and afflictions; holding them in their hands, and making the nurses feel empathetic to those situations.

#### Central Category 3 Nurses' experiences and concerns regarding care at the time of death.

In the question referring to experiences of the care process in the face of death, the participants reported the following answers:

"...I have a family, a small son at

the time, you know! So I was really afraid of bringing something home..." NUR 01

"...There were a lot of remarkable stories that we were able to follow from the beginning to the end of the story, but sometimes they were sad stories, so I think it's worth telling and emphasizing the good development of the story! Because with the grace of God we were able to be there together, even if it was just a minute we were able to see the outcome of these stories." NUR 03

"... in relation to my feeling, that's what I told you, I'm a person who, unfortunately, as I told you, I'm not proud of that, I don't get attached to patients, you know! So what happens is the following, I did suffer, but not to the point of crying for patients, no, that never happened to me..." NUR 02

"... This case marked me a lot not only because it was our first patient, in everything, because it was our first death too, but mainly knowing that the grandson of a scientist who had already formulated so many vaccines had died precisely from a virus that the whole world was waiting for the immunobiological that would save us from experiencing death from this stupid disease. And from there my fear only multiplied, because as I said we did several quick tests and none found the virus, how to live with the doubt of something unknown? I, who live with a person with severe COPD at home, my life and mental health turned upside down, because I lived with the uncertainty of tomorrow." NUR

For most of the interviewees, dealing with the death process is always a challenging situation, especially when an unknown and highly contagious disease

is involved, after all, they had to deal with the insecurity of taking something home and their family on a daily basis, in addition to having to deal with the patients in their entirety, since family visits were prohibited and at that moment the nurses and nursing staff were the people closest to them, having to accompany the whole process and being the ear, the welcoming hand and the voice that calms them down in times of distress and fear.

Some participants considered it a tiring and challenging experience due to the loneliness that these patients felt during their hospitalizations, having them be the family at that moment for them, emphasizing the emotional and psychological distress of these professionals.

#### **DISCUSSION**

Nurses have been the subject of studies, as they have experienced occupational stress due to a workload beyond the normal range, reducing their quality of life. The major concern currently is professional burnout, as we had an outbreak and a considerable increase in cases of CO-VID-19 in a short time. 11

The psychosocial effects of the covid-19 pandemic make nurses vulnerable. The front line is directly related to who acted in the assistance, and as sources of overload and stress, we point out the following parameters: severe evolution of patients, prolonged workload, inadequate conditions for rest, the nature of the infection itself, among other conditions. 12

There is a difficulty for these professionals to recognize that they are exhausted or stressed, because of the sense of commitment to work, or even the fear of asking for help. When looking for support, these factors can interfere with coping with psychological and physical stress, which is why it is important to observe the working professional. The importance of care for those who provide care cannot be unilateral for understanding nurses' exhaustion. 13

Most hospitals had tablets available so that inpatients could call their family members and loved ones and say whatever they wanted in those moments when the patient felt lonely, anxious or afraid. Most of the time, when they were unable to speak or were sedated and/or intubated, the team guided and encouraged the family members to speak so that the patient felt that they were not alone. As nurses, we must be sure that this contact, even through technology, is carried out, as the support of offering care and seeing family members comforted in some way is extraordinary. 14

The professional, despite his quest not to get involved with the pain of the patient and/or family members because he is in a professional environment, conflicting feelings at a personal and professional level can affect both perspectives, emphasizing the importance of hospitals and institutions investing in spaces that allow professionals to experience their emotions repressed by the process of finitude and mourning of these patients. 15

The precariousness of work, such as lack of biosecurity, lack of training for gowning and undressing to which it is submitted, brings out insecurity and instability to the team and/to the nurse responsible for this sector. 16

The mental illness of health professionals, the fear of being infected, the experience with the suffering of patients, and the anguish experienced together with family members were aspects that contributed to the reluctance to return to work. 1

Professionals who worked in the covid-19 sectors were the groups most affected by stress, anxiety and depressive reaction, which are factors favorable to triggering Burnout Syndrome, as the lack of knowledge about the new coronavirus and the sudden change in work style, and the uncertainty of tomorrow caused the professionals' emotions to surface; fear, uncertainty, stress, among other factors, trigger nurses' mental exhaustion. 18

The process of finitude and death was increasingly frequent in the hospital context, and the nurses' attitudes towards this issue can inspire their team not to be discouraged and to act in care in a more empathetic way and defining strategies that aim not only at the well-being of the patient, but also of their team, because those who care also need care. 19

Despite the dual feelings that nurses felt, hope was built and identified in the spiritual realm, projecting that the pandemic would pass soon, encouraging the nursing team to be optimistic and hopeful. Considering that these feelings are a projection of the spiritual well-being that motivated them to elaborate care plans. However, the human and mainly professional condition, hope and faith in better days are essential. 20

#### **CONCLUSION**

During the COVID-19 pandemic, when witnessing terminal patient situations, most nurses reported physical and mental experiences due to emotional pressure and high workload, such as tiredness, mental exhaustion, fear, sadness and stress, as well as feelings of empathy and emotional bond with the sick and their families, due to long periods of hospitalization. A small portion said they managed to separate the emotional and social side of the professional, expressing only regret for the patient's final moments.

According to these experiences, dealing with the death process proved to be a daily challenge for these professionals, due to the lack of information about this disease, as well as trying to explain to family members the protocols regarding visits and proximity to contaminated hospitalized patients, resulting in full responsibility for these clients.

Although taken by so many sometimes discouraging feelings, the confidence that the pandemic was temporary and the hope for better days was described as motivation for nurses to draw up care plans for their patients.

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