

**DEATH IN THE CONTEXT CULTURALLY MODIFIED BY COVID-19 – IMPACTS AND CHALLENGES OF FAMILY CARE**

**MUERTE EN EL CONTEXTO CULTURALMENTE MODIFICADO POR EL COVID-19 – IMPACTOS Y DESAFÍOS DEL CUIDADO FAMILIAR**

**A MORTE NO CONTEXTO CULTURALMENTE MODIFICADO PELA COVID-19 – IMPACTOS E DESAFIOS DO CUIDADO À FAMÍLIA**

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**ABSTRACT**

**Introduction:** Social isolation due to the COVID-19 pandemic dictated a new pattern of coexistence and communication, responsible for new cultural behaviors of personal and social human relationships, being more challenging for families of fatal victims. **Objective.** Understand the impacts and challenges of family care in the context of culturally modified by COVID-19. **Method.** Qualitative study based on Leininger's Transcultural Care. The participants were family members of COVID-19 fatal victims, recruited using the snowball technique. The collection took place between may and august 2022 through narrative interviews, submitted to thematic content analysis with support from the WebQDA software. **Results.** They identified impacts of death from COVID-19 on the family's experience: personal, family, social and team isolation; lonely death; the violated rituals and complicated mourning. In addition to pointing out the challenge of accessibility and empathetic reception in the care of health professionals. **Conclusions.** The restrictive culture imposed by COVID-19 compromises humanized care, so nurses must be encouraged to create empathetic care strategies that consider the cultural needs modified by the pandemic. Nursing can make a difference in the distressing experience triggered by the new coronavirus through professional reinvention, led by transcultural care, in order to overcome distance, safely, but also with dialogue, proximity, bonding and flexibility in face-to-face family access or virtual.

**Keywords:** COVID-19; Empathy; Nursing; Family; Death.

**RESUMEN**

**Introducción:** El aislamiento social por la pandemia de COVID-19 dictó un nuevo patrón de convivencia y comunicación, responsable de nuevos comportamientos culturales de relaciones humanas personales y sociales, siendo más desafiante para los familiares de víctimas fatales. **Objetivo.** Comprender los impactos y desafíos del cuidado familiar en el contexto de muerte culturalmente modificada por COVID-19. **Método.** Estudio cualitativo basado en el Cuidado Transcultural de Leininger. Los participantes eran familiares de víctimas mortales de COVID-19, reclutados mediante la técnica de bola de nieve. La recolección se realizó entre mayo y agosto de 2022 a través de entrevistas narrativas, sometidas a análisis de contenido temático con apoyo del software WebQDA. **Resultados.** Identificaron los impactos de la muerte por COVID-19 en la experiencia de la familia: aislamiento personal, familiar, social y de equipo; muerte solitaria; los rituales violados y el duelo complicado. Además de señalar el desafío de la accesibilidad y la acogida empática en la atención de los profesionales de la salud. **Conclusiones.** La cultura restrictiva impuesta por la COVID-19 compromete el cuidado humanizado, por lo que se debe alentar a los enfermeros a crear estrategias de cuidado empático que consideren las necesidades culturales modificadas por la pandemia. La enfermería puede marcar la diferencia en la angustiada experiencia desencadenada por el nuevo coronavirus a través de la reinención profesional, liderada por el cuidado transcultural, para superar la distancia, con seguridad, pero también con diálogo, proximidad, vinculación y flexibilidad en el acceso familiar cara a cara o virtual.

**Palabras clave:** COVID-19; Empatía; Enfermería Familia; Muerte.

**RESUMO**

**Introdução:** O isolamento social devido a pandemia pela COVID-19, ditou um novo padrão de convivência e comunicação, responsáveis por novos comportamentos culturais de relacionamento humano pessoal, social, sendo mais desafiador para às famílias de vítimas fatais. **Objetivo.** Conhecer os impactos e desafios de cuidado à família na experiência da morte culturalmente modificada pela COVID-19. **Método.** Estudo qualitativo fundamentado no Cuidado Transcultural de Leininger. Os participantes foram familiares de vítimas fatais da COVID-19, recrutados pela técnica *snowball*. A coleta se desenvolveu entre maio e agosto de 2022 através de entrevistas narrativas, submetidas à análise temática de conteúdo com suporte do software WebQDA. **Resultados.** Identificaram impactos da morte por COVID-19 na experiência da família: o isolamento pessoal, familiar, social e da equipe; a morte solitária; os rituais violados e o luto complicado. Além de apontarem para o desafio da acessibilidade e acolhimento empático no cuidado dos profissionais de saúde. **Conclusão.** A restritiva cultura imposta pela COVID-19 compromete o cuidado humanizado, de modo que, os enfermeiros devem ser encorajados a criar estratégias assistenciais empáticas que considerem as necessidades culturais modificadas pela pandemia. A enfermagem pode fazer a diferença na experiência angustiante deflagrada pelo novo coronavírus através da reinvenção profissional, conduzida pela via do cuidado transcultural, no direcionamento de transpor o distanciamento, com segurança, mas também com diálogo, proximidade, vínculo e flexibilidade no acesso familiar presencial ou virtual.

**Palavras-chave:** COVID-19; Empatia; Enfermagem; Família; Morte.



## INTRODUCTION

The COVID-19 pandemic has significantly impacted ways of life, death, and human behavior. Social isolation has invariably dictated a new pattern of coexistence and communication, responsible for undertaking new cultural behaviors in personal and social human relationships, and especially in the context of health care, affecting everything from the family to the hospital, that is, society as a whole. In view of this, this study focuses on the impacts and challenges experienced by families of fatal victims of COVID-19, with a view to reinventing nursing care in the face of death in the scenario culturally changed by the pandemic.

To this end, we will use Leininger's Theory of Cultural Diversity and Universality as a theoretical framework. From the author's perspective, culture is understood as the set of norms, knowledge, habits, or beliefs that govern behaviors assumed as a standard by a given social group. In this sense, the author advocates that Nursing direct its actions in a way that is congruent with the cultural values and lifestyle of each family. Transcultural Care, then, is that which considers the sociocultural context of the person, incorporating creative, individualized and humanized initiatives that are meaningful to them (1).

In this case, the scenario that demands adaptation is defined as a cultural perspective of self-protection against a potentially fatal virus. This involves an intense and sudden population adherence to a previously unimaginable pattern

of social isolation, fueled by strong uncertainty and fear, superimposed as a negative cascade on family mental health. The family, affected by illness and death, in this context, experiences a kind of upheaval in its relationships, overwhelmed by the imperative need to negotiate rituals and routines, while also needing to manage emotional insecurity and the reduction of sources of resilience (2).

Because of this condition, family-centered care is even more important in a pandemic situation. This approach demands that health professionals quickly adapt practices and approaches aimed at families experiencing illness and hospitalization due to COVID-19. It is important to highlight the importance of using communication strategies, whether mediated by telephone or in writing, to ensure family engagement, despite physical distancing. Free internet access is considered a benefit in this process, in addition to sending and delivering messages containing videos, audios or written messages between the patient and their family (3).

This is a unique situation that demands flexibility and competence from health professionals to align their care with current restrictions, without discontinuing the welcoming and empathetic nature of their care. In this sense, professional attitudes that are supportive of strengthening family socio-affective relationships are suggested, including support for spiritual values as essentially opportune resources for a less hostile



confrontation of the pandemic, especially among families affected by the severe form of COVID-19 or by the loss of a loved one due to the disease (2-5).

In this regard, there is a significant gap in the care provided to families facing the process known as end-of-life. Despite being considered an essential component of comprehensive palliative care, this care remains a gap, which is even more evident during the pandemic caused by the new coronavirus. With the increasing number of deaths caused by the agent, this need has become increasingly urgent, in order to gather as much knowledge as possible about how to more assertively care for families facing death due to COVID-19 (6).

Therefore, it is important to invest in research that corroborates with constructive evidence the development of care that makes more sense in view of the demands of families experiencing grief in the current scenario, a context of major cultural changes, especially regarding social interaction. In this sense, this study was guided by the question: what are the impacts and challenges of family care in the context of death culturally modified by COVID-19? And its objective was: to understand the impacts and challenges of family care in the experience of death culturally modified by COVID-19.

## METHOD

This is a qualitative, descriptive, and exploratory research anchored in Leininger's

Transcultural Care theoretical framework (1). It was developed in accordance with resolution 466 of December 12, 2012, approved by the Research Ethics Committee of the School of Nursing of the University of São Paulo under opinion no. 5.381.347/2022. Thus, the participants' consent was signed through the Free and Informed Consent Form - TCLE. The setting consisted of the city of Vitória da Conquista, the main municipality in the southwestern region of Bahia. The participants were family members of fatal victims of COVID-19, recruited by snowball 7, from the researchers' social network of reference. The inclusion criteria were: being a family member of a fatal victim of COVID-19 and having a close relationship with the victim, regardless of the degree of kinship; and the exclusion criteria were: being under 18 years of age. These criteria were observed through the participants' self-declaration and aimed to ensure that the interviewees were directly involved in the experience of hospitalization, loss, mourning, and funeral of their loved one. Thus, 12 participants were interviewed after agreeing to the informed consent form between May and August 2022, when it had been at least 1 year since the loss of their loved one. They were delimited by the theoretical saturation of the data (analyzed simultaneously with the collection) and their anonymity was preserved through codenames. The families, represented in the genogram, were given fictitious names of birds, which were used as the surname of the respective interviewed family member.



The participants were contacted via WhatsApp, informed by the person in the reference network who recommended them. At this first moment, the main researcher introduced himself and also described the research, inviting them to the interview. In total, 17 family members were contacted/invited, of which 05 immediately refused, given their emotional sensitivity in reporting on the loss. The consenting individuals signed their consent form and were interviewed in person (8) or via video call (4), according to their preference. The data collection was developed by two female researchers experienced in conducting the following techniques: family genogram and narrative interview. Regardless of the data collection method, in person or online, the interviews were conducted individually, with audio recording for later transcription and analysis. In the case of in-person interviews, the researcher wore a surgical mask and maintained the recommended distance. The prompt for narration was: tell me about your experience of losing your loved one to COVID-19. The genogram was partially prepared together with the participating family member, given the limitations of information unknown to them. It consists of a family assessment instrument in the form of a diagram, which presents the internal structure of the family, illustrating the generations, health conditions, among other basic information. In this study, the emphasis was to situate the interviewee and the COVID-19 victim in the context of their family, adding the

relational bond between them, through the bond symbols provided in Mitchell's Psychofigure (8).

Data analysis was performed using Leininger's theoretical framework and followed the thematic content technique, which was divided into three stages: pre-analysis, which consisted of skimming, corpus formation and reformulation of hypotheses and objectives; exploration of the material, classification operation that aimed to achieve understanding of the text by directing categories; and treatment of the interpreted results, which involved organizing the information obtained(9). This process was supported by WebQDA software in the second and third stages, providing practicality and security through digital coding and differentiated possibilities for viewing and organizing the data.

## RESULTS

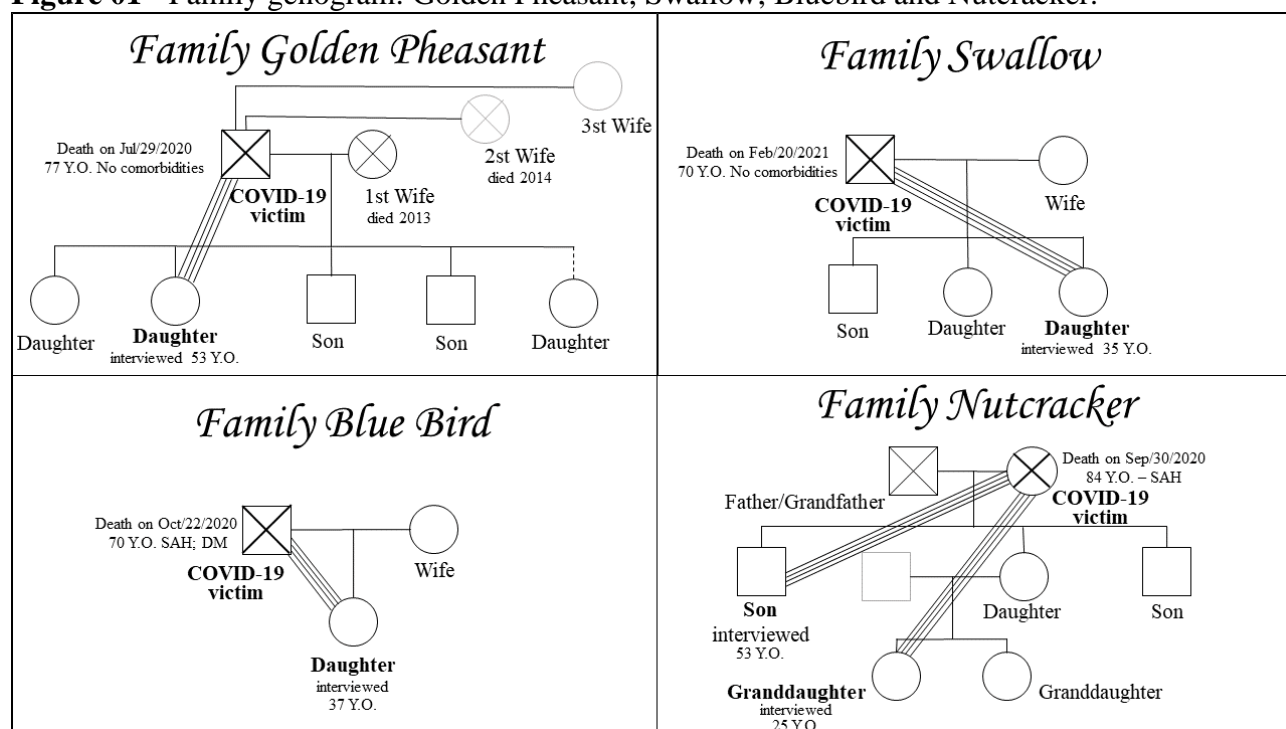
The participants, 12 family members of fatal victims of COVID-19, are presented in Figure 01, Figure 02 and Figure 03 (family genogram, whose caption is in Figure 04). This instrument was adapted to contextualize the interviewee in relation to the victimized relative, with emphasis on the degree of kinship between them, age of both, date of death and presence of comorbidities of the victim (Systemic Arterial Hypertension (SAH) and Diabetes Mellitus (DM), among others) and projection of the type of bond they had with each other, based on Mitchell's Psychofigure (8).



The majority of the interviewees were: aged between 35 and 45 years old (06); female gender (10); nursing as a profession (04); kinship of son/daughter with the fatal victim of COVID-19 (06); strong bond with the deceased loved one (12); choice of in-person interview (08), with an approximate average of 57 minutes.

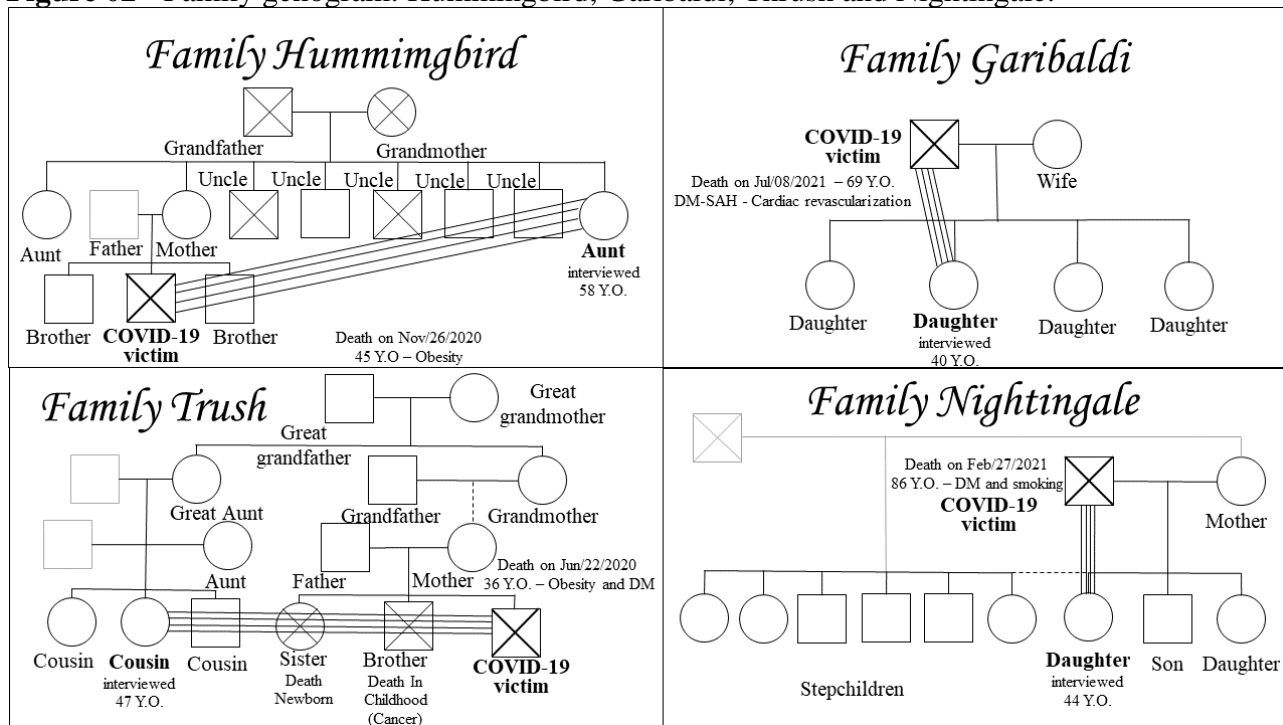
The results grouped 05 categories, 03 referring to the impacts of death by COVID-19 (axis A): lonely death; violated rituals and complex mourning; and 02 referring to the challenges of care (axis B): family accessibility and professional empathy.

**Figure 01** - Family genogram: Golden Pheasant; Swallow; Bluebird and Nutcracker.



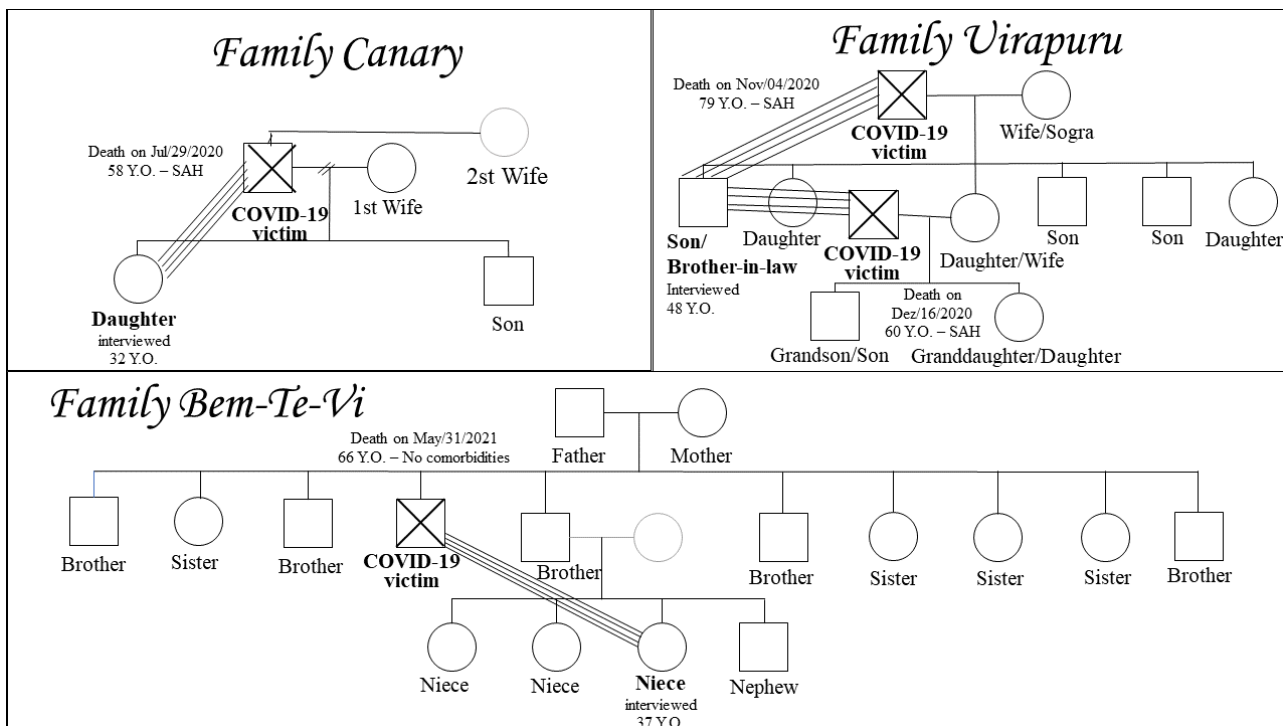
Source: Own elaboration

**Figure 02** - Family genogram: Hummingbird; Garibaldi; Thrush and Nightingale.

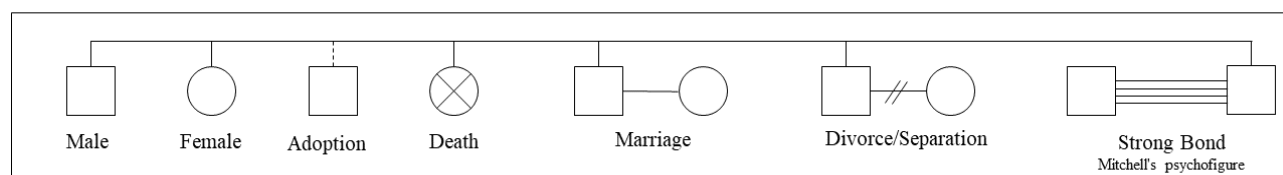


Source: Own elaboration

**Figure 03** - Family genogram: Canary; Uirapuru and Bem-te-vi.



Source: Own elaboration

**Figure 04** - Legend referring to the simplified genogram and ecomap

Source: Own elaboration

### Axis A: The impact of death from COVID-19 on the family experience

(Rosana Garibaldi – Death of a loved one on: 07/08/2021).

#### CATEGORY 1: Lonely death

Subcategory 1a: Family isolation watching the access door close into the ICU

*It wasn't death itself. We had already lost him before we received the news [...] he had already been taken from us [...] since that day he went to the ICU a door closed, we could no longer see [...] that thing that you know is necessary for survival "I'm here with you, we're waiting for you out here, boy your son is here, we love you", hearing a hymn sung, a prayer [...] at that moment there is nothing [...] just total silence, everyone intubated, there was only tum tum tum, you think "what's the point of staying in this tum tum tum? I'm already dead" (Paula Sabiá – Death of a loved one on: 06/22/2020).*

*[...] seeing his family, I think he might have wanted to go back, not seeing anyone and being in that cold environment, maybe he would have given in more easily [...] it's very cold, just one call a day, you spend 24 or 26 hours waiting for the report, it's very difficult and painful (Joyce Dourado – Death of a loved one on: 07/20/2020).*

*COVID took away a lot of things. I think it was a disease that only those who went through it or who had a family member in the situation can understand [...] because just being taken away from seeing the one you love and participating in the care, for me that is already a death, a very painful process*

Subcategory 1b: Isolation from loved one -

knowing that he or she died alone

*[...] a lonely death, and that is painful, knowing that the person was alone, it is different from someone who has cancer, in their final stages and has a family member there by their side, holding their hand... Someone who dies of COVID does not have the right to have that, you know? You do not have the right to say goodbye, you do not have the right to see, to talk, to touch, to be with them when they are about to die, you lose that right, that right is taken away from you (Camila Canário – Death of a loved one on 01/06/2021).*

*My father died alone, abandoned inside a hospital [...] Oh my God, this is the height of it! Having a relative like that and not being able to visit them, [...] my father died there thinking that he was abandoned, he must have thought: "where are my relatives? They're gone!" (Rafaela Andorinha – Death of a loved one on: 02/20/2021).*

Subcategory 1c: Isolation of the healthcare team

- clashing with the coldness of multidisciplinary communications

*[...] I told the doctor, "My father has been here for so many days... Let us see him at least once a week." She replied, "He just arrived yesterday [...] three people who attempted suicide and there's one who won't be gone for 5*

*minutes, he's going to die now [...] that lady at the door is his mother and she wants to go see him and I didn't let her and I won't let her, imagine that" [...]. I thought it was so cold! Where's the oath? You come in so cold, so cold and say something like that (Rafaela Andorinha – Death of a loved one on: 02/20/2021).*

*[...] I even think that the professionals are a bit cold, sometimes they don't think about these issues, they're tired [...], but they are important things, especially for relatives who are away (Max Quebra-nozes – Death of a loved one on: 09/30/2020).*

*[...] sometimes the doctor was a little more aggressive, ruder, colder, [...] they said that we had to prepare for everything. So, I think that sometimes the fact that people don't know how to deal with their family member very well makes the situation, for those on the outside, more painful (Camila Canário – Death of a loved one on 06/01/2021).*

Subcategory 1d: Social isolation – losing human warmth, hugs and the presence of friends

*COVID brought fear, I won't go because I'm afraid, I won't hug you because I'm afraid [...] a scenario of fear that paralyzed us [...] I could say something like "I want to see if it's really him", go, open it and get infected, and be the next one to go to the ICU, who's going? So, the story goes back to [...] fear made it impossible for me to go to the wake, to open it, to pick it up, to choose (long pause). You can see that this thing is kind of crazy, no matter how much you love it, how much you want to, you don't do it. And now I'll go back to my first statement, we are selfish [...], first it's us, it suffers, it hurts, but thank goodness it wasn't me (Paula Sabiá – Death of a loved one on: 06/22/2020).*

*Until the wake [...] there was almost no one there, just us and his wife's family. [...] when you lose someone, you want*

*your loved ones close to you and we realized that there is a fear, even though people say that the coffin is open because it is authorized, that there is no risk of contamination! [...] people are afraid to go (Camila Canário – Death of a loved one on 01/06/2021).*

*[...] we lose that freedom to go out and meet the people we want [...] it really is a change in coexistence (Teodora Azul – Death of a loved one on: 10/22/2020).*

## CATEGORY 2: Violated rituals

Subcategory 2a. Unrecognized body – receiving a sealed coffin

*He came out of there inside a coffin, there was no last goodbye! [...] I kept thinking, "Is it really him? Who can guarantee that it was him?" [...] we don't choose clothes [...] we don't choose how to wear our hair [...] we don't even know if, in fact, he had his limbs neatly arranged, or if they threw them inside the coffin (long pause) [...] My cousin left the hospital straight away, he walked through the city streets and people were saying goodbye from his window (Paula Sabiá – Death of a loved one on: 06/22/2020).*

*[...] people said there was no way to see him and then it was desperate [...] they were already sealing the body [...] that really left a mark on me [...] [...] not being able to see the body, I think that's very, very aggressive towards the family (crying). I waited for about 15 days for the hospital to call and say: "look, we made a mistake and your mother is here in the hospital" (Max the Nutcracker – Death of a loved one on: 09/30/2020).*

*When the doctor gave me the information, I asked if I could see it and he said no [...] it's very painful, you know? [...] I didn't see it, I was given a sealed coffin and that sealed coffin was my father and that was it (Joyce Dourado – Death of a loved one on: 07/20/2020).*





Subcategory 2b. Wake prohibited and burial restricted – missing the opportunity to pay tribute/honor/process farewell

*It was very complicated, because we are used to the wake, saying goodbye to the body and having the ceremony, the funeral service for her life here on earth, and my grandmother didn't have that [...] it was very, very difficult to see her being placed in the grave without anyone being able to get close [...]* (Ana Quebra-nozes – Death of a loved one on: 09/30/2020).

*There would have to be a way for you to be able to watch without being close to the person who died, and I think the family has to be free to say whether they want to see it or not, because the family doesn't want to know if someone died of COVID or another contagious disease, at a time like this you want to see the person. [...] You can only remove the body to take it to the cemetery [...] And at the time of the burial, there are very limited people, a very difficult situation, a trauma that I don't believe we will forget* (Cíntia Beija-flor – Death of a loved one on: 11/16/2020).

*And at the funeral we had a problem because he died in Brasília, the death certificate was made addressing the body here to Bahia, but a municipal decree prevented the transfer. So we had to file a lawsuit [...] the body was not prepared to stay for three days, so we managed to get a chamber to put it in, but instead of cooling it, it heated the body, because it didn't work. It was a huge inconvenience, a despair, it hasn't been easy, pains that don't heal* (Enzo Uirapuru – Death of loved one on 11/04/2020).

### CATEGORY 3: Complex grief

Subcategory 3a. Anticipated grief – losing the other person in life when the voice is silenced by intubation

*Before going to the ICU, we talked, he still had his cell phone there, then he said to me “my daughter, my time has come, I'm not going back home anymore”, [...] he gave me some recommendations [...] he told me to take care of my stepmother's pension, he gave me my brothers [...] and then he stopped talking, I had no more contact, I didn't hear from him anymore [...]* (Joyce Dourado – Death of a loved one on: 07/20/2020).

*He was intubated and from that moment on we knew that the losses were getting more and more painful. So, it wasn't on the day he passed away, it was from the first day in the ICU, the situation got worse, he lost this and that. It was like that, day after day of mourning, we lived, as if we were maturing that mourning, every day a little bit was gone* (Paula Sabiá – Death of a loved one on: 06/22/2020).

*He was hospitalized for about 8 days, he was doing well, but the day he said: he's going to have to be intubated, it was a shock! "If you intubate him, he won't come out"* (Maitê Bem-te-vi – Death of a loved one on 05/31/2021).

Subcategory 3b. Complicated grief – going crazy in a cycle of loss that won't close

*COVID grief is complicated for me because it's as if the cycle never ends [...] I often find myself waiting for my father to arrive. [...] I think psychology will have to work with COVID grief, no one is the same anymore [...] he has been keeping me up at night a lot... I sometimes don't feel like getting out of bed, I keep asking myself "why was it my*



*father?" [...] I've picked up the phone to call my father several times, and then I think I'm going crazy [...] two of my brothers are taking antidepressants to cope and I also need help (Joyce Dourado – Death of a loved one on: 07/20/2020).*

*I couldn't do this final part, it was a nullified part for me and it feels like something was missing to complete the cycle. I know we have to accept death, but we have the right to watch it happen and that right was taken away from me [...] a pain that won't heal [...]. A situation that has been destroying me [...] I feel devastated... I can't be the same person anymore! I pay a very high price because I lost someone without even being able to say goodbye (crying), I think this is irreparable. I'm in therapy, but it's hard to live with this pain, with this loss, with this mourning (Alicia Rouxinol – Death of a loved one on: 02/27/2021).*

*When the body arrived I don't know what happened, I had a crisis [...] today I tell you something "I don't accuse anyone who commits suicide like I did before, who has depression, [...] today I tell you "a person is capable of killing anyone", because our brains are very fragile! [...] When my father died I kept thinking "are the animals already eating his body? Oh my God, I kept trying to imagine [...] it's mind-blowing [...]. It's going to be a year and a half, but it's still so difficult, it's so difficult, we still have crying fits, we scream, there are days when I don't feel like getting out of bed... (Rafaela Andorinha – Death of a loved one on: 02/20/2021).*

## **Axis B: Challenges of care for the bereaved family in the context culturally modified by COVID-19 during the end of life of the loved one in the ICU**

### **CATEGORY 4. Family accessibility**

#### **Subcategory 4a. Allowing the family in-person access to the loved one**

*What I missed most at the time of hospitalization, if I could choose, would be to see my father even if he was intubated or in any way, to see, to be able to touch, and for him, even if he was intubated, I think it would have made a difference for me too, for my emotional and psychological well-being (Camila Canário – Death of a loved one on 06/01/2021).*

*I think there should be a way to study in the future so that we can see, so that the family can recognize the body. [...] health care professionals should have a system that could, I don't know, an urn with glass, something that you could see, at that moment, [...] a possibility of a very safe system for the family to see, to be able to see their relative (Max Quebra-nozes – Death of a loved one on: 09/30/2020).*

#### **Subcategory 4b. Making a video call for family to talk and/or see their loved one**

*I believe that contact with the family, a video call, you know? [...] even if the patient is intubated, but we wanted to see, we wanted to at least see how he was, if he was swollen or not, his expression, but it was all very cold [...] a professional inside an ICU making this bridge between family and patient, I think it would be fantastic (Joyce Dourado – Death of a loved one on: 07/20/2020).*

*I think that a video system is really needed so that the family can follow more closely (Max Quebra-nozes – Death of a loved one on: 09/30/2020).*

*There are tablets that you can see, right? You can follow... I think that if it were something like that, some technological means that you could follow some moments like the patient*



*because he was there and we had no news. [...] it was really complicated, right? Why did we keep wondering if he was okay, if he wasn't, if he was eating, if there was someone there all the time (Teodora Azul – Death of a loved one on: 10/22/2020).*

*not the best person. I think there should be someone, a psychologist, who could speak more calmly, with more empathy, more patience, more love. Who could understand that there is a desperate family member there (Camila Canário – Death of a loved one on 01/06/2021).*

## CATEGORY 05: Professional empathy

Single Subcategory: Treating the family with empathy during virtual and in-person interactions

*When my father was intubated, I went to visit him and there was a nurse [...] she said “I’m going in with you”, she held my hand, said she had lost her father and that she knew what I was feeling [...] she took me to my father’s bedside, holding me, it was something that really left a mark on me! [...] there’s no point in having the best doctor if you don’t have a good nursing team, because they’re the ones at the bedside, they’re the ones who are the eyes, the ones who speak, the ones who listen, they’re everything, there are professionals who make a difference in our lives when we’re on the other side, precisely because they make this difference. So nursing makes a difference, we have to value it (Rosana Garibaldi – Death of a loved one on: 07/08/2021).*

*I received the news from a very humane doctor [...] he called me and asked if I was somewhere I could talk, if I was okay, [...] he said “God chooses the most beautiful flowers in the Garden and today he chose your grandmother to pick [...]”. I thought it was very kind, it even lessened the impact [...] it managed to alleviate it a little [...] I would suggest that professionals have this empathy with the family and provide more emotional support (Ana Quebra-nozes – Death of a loved one on: 09/30/2020).*

*I think that more qualified people should be placed to deal with family members with COVID [...]. Maybe the doctor is*

## DISCUSSION

The pandemic has highlighted the gap that persists in end-of-life care in an unprecedented way. It has changed the way our society functions, including the way we care for the sick and bereaved. Some customary interventions, such as face-to-face meetings with patients and families, in-person visits, and bedside conversations, have been replaced by remote conversations, isolation, and the real possibility that patients will die alone, separated from their loved ones. Likewise, rituals that normally brought comfort to the family and opportunities for access to support after death are no longer possible, predisposing these individuals to develop complicated grief, characterized by feelings of loss, anguish, frustration, guilt, and despair (6).

Thus, the greatest impact experienced by families who have lost loved ones to COVID-19 has been related to the “dehumanization” of professional care during the pandemic. The use of protective equipment, combined with strict isolation measures, had a direct impact on care, compromising touch, identification, dialogue, bonding and warm interaction between nurses and patients and their families (4). This created a sense of urgency, from a public health



perspective, in directing support and care to the families of COVID-19 victims (6).

The term humanization, when used in the context of care, means a relational, welcoming and empathetic professional attitude towards the patient and their family. Thus, humane care is that which values and dignifies the other (10). Its practice arises from ethics, morals and the meaning that nursing acquires in the personal sphere of each professional. This anchoring is better supported by the knowledge and applicability of Nursing theories, which enhance a critical-reflective, mature and adaptive stance in the face of the different demands of these professionals (11).

In the context of COVID-19, the Theory of Transcultural Care is relevant to add adaptations and assertiveness in the face of restrictions resulting from the new cultural perspective imposed by the pandemic. In this, world perspectives and cultural values are suppressed by the rigidity of standardized attitudes provided for by social isolation. In view of this, the transcultural lenses of nursing can corroborate possibilities of adapting care, in order to respect contamination control measures, but also guarantee new ways of demonstrating empathy and acceptance to the patient and family (12).

Leininger's theory seeks to disseminate an individualized understanding of the human being, capable of mobilizing in nursing an adaptive praxis appropriate to the demands modified by new and/or different cultures. Thus,

the caregiver is challenged to plan meaningful care actions for each family within a logic that incorporates specific care needs with the cultural values assumed by the family at a given time (13). In terms of COVID-19, this challenge was marked, above all, by the need to deal with death within new and painful standards. The restrictions compromised the family's experience of loss, by denying them the right to culturally important funeral rituals.

In view of this, the literature on COVID-19 has already contributed recommendations capable of ensuring the humanization of end-of-life care in the pandemic context. Among them are virtual visits for emotional support of the patient and family; welcoming and helping the couple during the death process; dialogue favorable to minimizing complicated mourning;(4,14) in addition to enabling family identification of the body (via cell phone)(15) and, finally, the development of effective communication with the family, ensuring that the patient did not die alone and that he or she was well cared for (4,16).

Such attitudes converge with the Hospice concept developed by Cicely Saunders. Her philosophy is centered on the authentic presence of the health professional with the terminally ill patient and his/her family. For her, both are immersed in an experience full of desolation, helplessness, emptiness, suffering, loneliness and pain. Therefore, this presence transcends the performance of specialized techniques and procedures, reaching the meaning of, essentially,



bringing to those individuals the human warmth that they lack at that moment. End-of-life care therefore implies the empathetic attitude of remaining by their side, showing that one cares, that one is a witness to the entire process and, therefore, represents a safe support that welcomes, shares the pain and is compassionate (17).

In this sense, the pandemic context of the new coronavirus imposes the need for nursing interventions that guarantee humanized care despite the entire protocol for containing the new coronavirus. It therefore implies transpersonal therapeutic management that can guarantee open listening to concerns, loneliness, helplessness or fear; individuality (calling by name); psychological support; relaxation practices; relationship, touch (holding the patient or family member's hand); sensitivity in speaking (using an affectionate and calm tone of voice); music; alternative communication (drawings); valuing beliefs; and, welcoming spiritual and religious needs, beliefs and values about the meaning of life (5).

Other strategies include dialogue via videoconference; allowing the family member to be physically present, even if limited; professional availability to deliver text or audio messages sent by families, even if the patient is unable to communicate; sending written, audio or video messages from the patient to their family members; encouraging the patient to record their memories and feelings during hospitalization; pastoral support for prayer as

desired (via videoconference) and promoting a comfortable and personalized environment through audio, books, music and/or television (18). These forms of care, in times of pandemic, increase the quality of care in the ICU and generate therapeutic benefits for the family by ensuring informational and emotional support during virtual and/or in-person visits (19).

From Leininger's perspective, this creative adaptation involves the professional ability to preserve, negotiate, and restructure care based on dialogue and understanding of each individual's cultural legacy, which is more easily observed in contact with the family and its values. Therefore, the transcultural care model mobilizes nursing skills capable of contributing to family-centered care, developed by professionals who embrace the context of the hospitalized person by directing culturally shared care between nurses and families (20). Thus, this vision assumes physical and psychoemotional care that is culturally congruent with the needs of a person or group in a given context (13).

In the context of the pandemic, the use of technologies such as cell phones, tablets, videoconferencing, among others, has allowed family members to communicate differently with the patient and the team and to virtually monitor their loved one, through the exchange of information and visualization of the loved one. Such possibilities certainly reverberate in greater chances of resilience at the time of loss and mourning, which is often complex in this context. Therefore, it is encouraging to see how



the innovation and creativity of many nurses are making a difference in the care of families affected by death from COVID-19 (16).

To this end, nursing will be more assertive and humane with transcultural support, which requires that these professionals continually learn from their experiences, develop their otherness, and have social, cultural, pedagogical, and communication skills in diverse contexts, such as during the novel coronavirus pandemic. This perspective favors individualized and holistic care based on each person's cultural needs, beliefs, and customs. Therefore, nurses must be sensitive to needs modified by new contexts and willing to constantly assimilate and seek continuing education, in order to be creative and adaptive in the face of demands such as COVID-19 (21).

## FINAL CONSIDERATIONS

The experience of families who have lost a loved one to COVID-19 is full of frustration, pain, and incompleteness. Their reports demonstrate how complicated and sometimes unbearable grief is in this circumstance. However, despite the new cultural behaviors imposed by the pandemic, this study endorsed possibilities for humanization led by professionals who made a difference in the lives of these family members with their empathy, support, willingness, and sensitivity.

Therefore, the relevance of Transcultural Care is reiterated as a subsidy for a

reorganization of patient-family care routines in the context of the pandemic. Creative and technological adjustments that do not impose risks of contamination, but that preserve the bond, closeness, and humanization with these individuals who are so vulnerable and in need of the hospitality and compassion of nurses.

Nursing can make a difference in the distressing experience triggered by the new coronavirus, especially in the context of death. To this end, a process of professional reinvention is encouraged, conducted through transcultural care, with the aim of overcoming distancing safely, but also with dialogue, empathy, connection, availability and in-person or virtual accessibility to family members.

The limitations of this study are related to its methodological approach, which suggests investment in research that can contribute to revealing the phenomenon from other perspectives and through other techniques.

## REFERENCES

1. Leininger MM, Mcfarland MR. Culture care diversity and universality: a worldwide nursing theory. 2 ed. Sudbury. Massachusetts: Jones and Bartlett publishers; 2006.
2. Prime H, Wade M, Browne DT. Risk and resilience in family well-being during the COVID-19 pandemic. *American Psychologist*, [Internet]. 2020 [cited 2022 Jul. 05]; 75(5):631–43. Available from: <https://doi.org/10.1037/amp0000660>
3. Pascarella G, Strumia A, Piliego C, Bruno F, Del Buono R, Costa F et al. COVID-19 diagnosis and management: a comprehensive



- review. *J Intern Med.* [online] 2020 [cited 2022 Jul. 05]; 288(2):192-206. Available from: <https://doi.org/10.1111/joim.13091>
4. Fernández-Castillo RJ, González-Caro MD, Fernández-García E, Porcel-Gálvez AM, Garnacho-Montero J. Intensive care nurses' experiences during the COVID-19 pandemic: A qualitative study. *Nurs Crit Care* [Internet]. 2021 [cited 2022 Jul. 05]; 26(5):397-406. Available from: <https://doi.org/10.1111/nicc.12589>
5. Paula PHA, Pinheiro PNC, Mondragón-Sánchez EJ, Costa MIF, Rodrigues IP, Dourado JVL. The dimensions of the human being and nursing care in the pandemic context of COVID-19. *Esc. Anna. Nery* [online] 2020 [cited 2022 Jul 10]; 24(spe):e20200321. Available from: <https://doi.org/10.1590/2177-9465-EAN-2020-0321>. doi:10.1590/2177-9465-EAN-2020-0321.
6. Morris SE, Moment A, Thomas JL. Caring for Bereaved Family Members During the COVID-19 Pandemic: Before and After the Death of a Patient. *J Pain Symptom Manage* [online] 2020 [cited 2022 Jul. 05]; 60(2):e70-e74. Available from: <https://doi.org/10.1016/j.jpainsymman.2020.05.002>.
7. Handcock MS, Gile KJ. On the Concept of Snowball Sampling. *Sociological Methodology.* 2011; 41(1):367-71.
8. Wright LM, Leahey M. *Enfermeiras e famílias-um guia para avaliação e intervenção na família.* 5 ed. Editora Roca; 2012.
9. Minayo MC. *O desafio do conhecimento: pesquisa qualitativa em saúde.* 14ª ed. São Paulo: Hucitec Editora; 2014.
10. Mega MN, Bueno BC, Menegaço EC, Guilhen MP, Pio DAM, Vernasque JRS. Students' experience with literature in medical education. *Rev. bras. educ. med.* [online]. 2021 [cited 2022 Jan 20]; 45(02):e059. Available from: <https://doi.org/10.1590/1981-5271v45.2-20200226>.
11. Santos BP, Sá FM, Pessan JE, Criveralo LR, Bergamo LN, Gimenez VCA. The training and praxis of the nurse in the light of nursing theories. *Rev Bras Enfermagem* [Internet]. 2018 [Accessed 20 Sep. 2021]; 72(2): 566-70. Available from: <https://doi.org/10.1590/0034-7167-2018-0394>.
12. Almeida GMF, Nascimento TF, Silva RPL, Bello MP, Fontes CMB. Theoretical reflections of Leininger's cross-cultural care in the context of Covid-19. *Rev. Gaúcha Enferm.* [online] 2021 [cited 2022 Jul 10]; 42(spe):e20200209. Available from: <https://doi.org/10.1590/1983-1447.2021.20200209>.
13. McFarland MR, Wehbe-Alamah HB. Leininger's Theory of Culture Care Diversity and Universality: An Overview With a Historical Retrospective and a View Toward the Future. *J Transcult Nurs.* [Internet]. 2019 [cited 2022 Jul. 05]; 30(6):540-557. Available from: <https://doi.org/10.1177/1043659619867134>
14. Moraes CLK, Tavares DC, Freitas GB, Aued GK. A perspectiva dos enfermeiros sobre o acompanhante na UTI em tempos de COVID-19. *Glob Acad Nurs* [Internet] 2021 [cited 2022 Jul 10]; 2(Spe.2):e108. Available from: <https://globalacademicnursing.com/index.php/globalacadnurs/article/view/211>
15. Conz CA, Braga VAS, Vasconcelos R, Machado FHRS, Jesus MCP, Merighi MAB. Experiences of intensive care unit nurses with COVID-19 patients. *Rev Esc Enferm USP* [online]. 2021 [Cited 17 Jun 2022]; (55):e20210194. Available from: <https://doi.org/10.1590/1980-220X-REEUSP-2021-0194>.
16. Luttik MLA, Mahrer-Imhof R, García-Vivar C, Brødsgaard A, Dieperink KB, Imhof L, et al. The COVID-19 Pandemic: A Family Affair. *J Fam Nurs.* [online] 2020 [cited 2022 Jul. 05]; 26(2):87-9. Available from: <https://doi.org/10.1177/1074840720920883>
17. Saunders C. *Velai Comigo, inspiração para uma vida em cuidados paliativos.* Tradução:



Franklin Santana Santos. 1. Ed. Salvador: FSS; 2018. 93p.

18. Hart JL, Turnbull AE, Oppenheim IM, Courtright KR. Family-Centered Care During the COVID-19 Era. *J Pain Symptom Manage.* [Internet]. 2020 [cited 2022 Jul. 05]; 60(2):e93-e97. Available from: <https://doi.org/10.1016/j.jpainsymman.2020.04.017>

19. Rose L, Yu L, Casey J, Casey J, Cook A, Metaxa V, Pattison N, Rafferty AM, et al. Communication and Virtual Visiting for Families of Patients in Intensive Care during the COVID-19 Pandemic: A UK National Survey. *Ann Am Thorac Soc.* [online] 2021 [cited 2022 Jul. 05]; 18(10):1685-92. Available from: <https://doi.org/10.1513/AnnalsATS.202012-1500OC>

20. Nascimento ACST, Morais AC, Amorim RC, Santos DV. The care provided by the family to the premature newborn: analysis under Leininger's Transcultural Theory. *Rev Bras Enferm* [online]. 2020 [cited 2022 Jul. 05]; 73(4): e20190644. Available from: <https://doi.org/10.1590/0034-7167-2019-0644>.

21. Jesus HG, Silva HL, Duarte BAS, Peixoto IVP. A importância da transculturalidade na assistência ao paciente crítico. *Braz. J. Hea. Rev.* [online] 2019 [cited 2022 Jul 10]; 2(6):5731-40. Disponível em: <https://doi.org/10.34119/bjhrv2n6-068>

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**Nothing to declare.**

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