

MEANINGS OF MOURNING FOR PEOPLE WHO FACED THE DEATH OF A FAMILY MEMBER DUE TO COVID-19

SIGNIFICADOS DO LUTO PARA PESSOAS QUE ENFRENTARAM A MORTE DE UM FAMILIAR POR COVID-19

SIGNIFICADOS DEL LUTO PARA PERSONAS QUE ENFRENTARON LA MUERTE DE UN FAMILIAR POR COVID-19

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How to cite this article: Souza JB, Brum CN de, Zuge SS, Zenevicz LT, Maestri E, Lima LJ, Beckert RAT. Meanings of mourning for people who faced the death of a family member due to COVID-19. *Rev baiana enferm.* 2022; 36:e47489.

Objective: to understand the meanings of mourning for people who faced the death of a family member due to COVID-19. **Method:** qualitative study, action-participant type, based on the assumptions of Paulo Freire. Participants were 16 family members living on the coast of Santa Catarina, Brazil. A Culture Circle was held in a virtual way, following the stages of the Freire's Itinerary. **Results:** the participants meant that the experience of mourning the family, due to COVID-19, took them the opportunity to say goodbye to their loved one. The pandemic also took away their jobs, their children's face-to-face classes, meetings, weddings, hugs and smiles. But it also meant that it brought learning, with strengthening of spirituality and family. **Conclusion:** the meaning of mourning permeated countless losses, restricting the experience of the stages of mourning. However, there was a greater search for spirituality and religion, with appreciation of family and life.

Descriptors: Coronavirus. Family health. Death. Bereavement. Spirituality.

Objetivo: compreender os significados do luto para as pessoas que enfrentaram a morte de um familiar devido a COVID-19. *Método:* estudo qualitativo, do tipo ação-participante, fundamentado nos pressupostos de Paulo Freire.

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Participaram 16 familiares, residentes no litoral de Santa Catarina, Brasil. Realizou-se um Círculo de Cultura de modo virtual, seguindo as etapas do Itinerário Freireano. Resultados: os participantes significaram que a vivência do luto do familiar, devido a COVID-19, tirou-lhes a oportunidade de se despedir do ente querido. A pandemia também lhes tirou o emprego, as aulas presenciais dos filhos, encontros, casamentos, abraços e sorrisos. Mas também significaram que trouxe aprendizado, com fortalecimento da espiritualidade e família. Conclusão: o significado do luto permeou inúmeras perdas, restringindo a vivência das etapas do luto. Contudo, houve maior busca pela espiritualidade e religião, com valorização da família e da vida.

Descritores: Coronavírus. Saúde da família. Morte. Luto. Espiritualidade.

Objetivo: comprender los significados del luto para las personas que enfrentaron la muerte de un familiar debido a COVID-19. Método: estudio cualitativo, del tipo acción-participante, fundamentado en los presupuestos de Paulo Freire. Participaron 16 familiares, residentes en el litoral de Santa Catarina, Brasil. Se realizó un Círculo de Cultura de modo virtual, siguiendo las etapas del Itinerario Freireano. Resultados: los participantes significaron que la vivencia del luto del familiar, debido a COVID-19, les quitó la oportunidad de despedirse del ser querido. La pandemia también les quitó el empleo, las clases presenciales de los hijos, encuentros, matrimonios, abrazos y sonrisas. Pero también significaron que trajo aprendizaje, con fortalecimiento de la espiritualidad y familia. Conclusión: el significado del luto ha permeado numerosas pérdidas, restringiendo la vivencia de las etapas del luto. Sin embargo, hubo mayor búsqueda por la espiritualidad y religión, con valoración de la familia y de la vida.

Descriptores: Coronavirus. Salud de la familia. Muerte. Aflicción. Espiritualidad.

Introduction

Coronavirus Disease (COVID-19) has spread worldwide, which affected the need to adopt protocols standardized by the World Health Organization⁽¹⁾, including the closure of schools, universities, social isolation and sanitary hygienic measures to preserve lives⁽²⁾. This reality abruptly imposed the fragility of human life, and, by the beginning of November 2021, about 614 thousand Brazilians died, leaving family members a trail of pain and reflexes in the social, economic and emotional dimensions. After almost two years of pandemic in Brazil, it is evident that there have been significant changes in personal, family and professional orders in society, including the experience of mourning⁽³⁾.

COVID-19 has deprived thousands of Brazilians of experiencing the process of mourning. It is emphasized that mourning is a natural and personal process, in which each individual emits a response to the rupture of bond, to losing someone who loves or is significant in their life⁽⁴⁾. As an individual response, it varies according to the cause of death, beliefs, personal involvement, culture, and this process can potentiate psychic, individual and/or collective suffering⁽⁵⁾. In addition, family members had

stages suppressed in the mourning process, expressing the feeling of powerlessness with the breakdown of wishes expressed in life by the loved one.

The gap in farewell rituals, prevented by health regulations due to the pandemic situation and that once eased pain, can have repercussions on feelings of helplessness, impotence and anxiety. Saying goodbye represents, in the process of death and dying, a unique moment, because it gives opportunity to solve unfinished issues, ask for forgiveness, thank the shared life, embrace and give the last kiss, which are acts that promote quality of life for those who stay and a dignified death for those who leave^(6,7). Thus, it is noteworthy that in the pandemic scenario such rituals should be rethought, because it is understood the relevance to the continuity of those who remained.

Given the above, the research question of this study emerged: what are the meanings of mourning for people who faced the death of a family member due to COVID-19? Therefore, the objective was to understand the meanings of mourning for people who faced the death of a family member due to COVID-19.

Method

This is a qualitative study of the participant action type⁽⁸⁾, based on the theoretical and methodological assumptions of Paulo Freire. Action research is associated with the resolution of a collective problem. For this, both researchers and participants are involved in a cooperative or participatory way. In order to do so, the Freire's Itinerary was followed, which comprises three dialectical and interconnected stages: Thematic Research; Coding and Decoding; Critical Unveiling⁽⁹⁾. The stages of the Freire's Itinerary were developed in the Culture Circle, which is a space that comprises a group of people who dialogue common themes in a horizontal and participatory manner, instigating collective knowledge seeking the transformation of reality⁽¹⁰⁾.

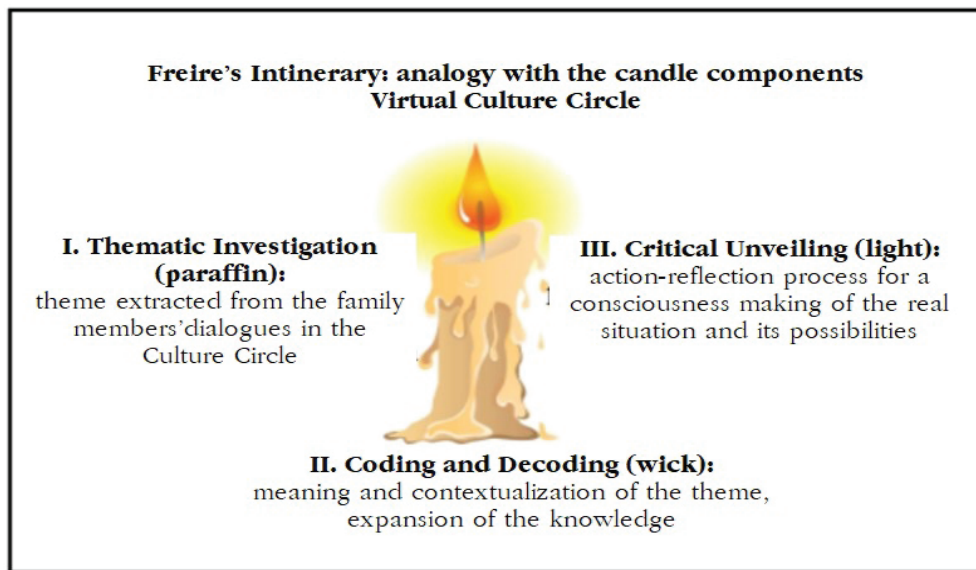
In the face of the pandemic conjuncture, the Culture Circle was developed virtually, using the Zoom® application and support of electronic devices such as smartphone or computer camera, which provided interaction between the participants of the research, even physically distant. Thus, in May 2021 a Virtual Culture Circle (VCC) was held, which lasted approximately two hours. The study included the participation of 16 family members, who faced the mourning of deceased loved ones due to COVID-19, living on the coast of Santa Catarina, Brazil.

Inclusion criteria were: people who were facing the mourning of one or more family members as a result of COVID-19, over 18 years of age. The exclusion criteria were: not having access to the internet and electronic devices to participate in the VCC. To bring together the study participants, two people from the researchers' social network

were first invited, who were facing grief from COVID-19. Subsequently, through the Snowball sampling method⁽¹¹⁾, these people invited other participants who were experiencing grief due to COVID-19 to join the VCC. All invited people accepted to participate in the study, and there were no refusals.

The 16 participants were initially contacted by WhatsApp®, explaining the objective of the study. Firstly, a brief virtual meeting to dialogue with all family members was scheduled, in order to present and read the Informed Consent Form (ICF), inviting participants to sign it and return it by email. Moreover, the possible doubts about the handling of the application Zoom® were solved and the participants were questioned about a possible object that had meaning in the experience of mourning, in which they elected the candle as a symbology of light in facing the darkness of mourning.

Thus, they defined that they would be named in the study by the name of stars, meaning the light of their relatives who died. On the day of the VCC, in order to encourage dialogue and go through the three stages of the Freire's Itinerary in a meaningful and concrete way, an analogy was made with the components of the candle (Figure 1).

Figure 1 – Freire's itinerary: analogy with sail components.

Source: Created by the authors, using the image available from: <https://pt.vecteezy.com/arte-vetorial/1271218-derretendo-vela-isolada-no-branco>.

The Thematic Research, the first phase of the Freire's Itinerary, is guided by dialogical praxis, based on liberating education, in which the generating themes are discussed and shared⁽⁹⁾. To instigate the dialogue, the mediator lit a candle, highlighting the presence of the paraffin and, symbolically, invited the participants to feel illuminated by the candle light and together investigate the experience of mourning, asking the question: what are the meanings of mourning for people who faced the death of a family member due to COVID-19?

To answer this question, family members were asked to write a representative term on a blank sheet. Each family member presented their terms, showing their meanings to the group, while the mediator registered them on the computer's shared screen. After the mediator read all the representative terms, validated them with the participants and urged them to elect the generating themes for discussion. Then, the group elected a single generating theme, meaning the discussions raised in the VCC, which consisted of mourning and spirituality.

To go through the second phase of the Freire's Itinerary, Coding and Decoding⁽⁹⁾, the mediator highlighted that, for the candlelight to be present, it was necessary to have the presence of several

components, such as the wick, pointing out that, although little appears, was necessary and significant. Thus, the mediator invited them to seek meaning and expansion of knowledge on the generating theme, triggering the question: What are the meanings of mourning and spirituality in the face of the death of a family member due to COVID-19?

Family members discussed and reflected on the question, and all participants had the opportunity to speak. Meanwhile, the mediator recorded a term, or phrase, representing the perceptions of each family member, which were encoded and decoded. The mediator's records were read to the group in order to validate them, when it was sought to encourage the continuation of new reflections on the proposed theme.

The last stage of the Freire's Itinerary, the Critical Unveiling, seeks to overcome the magical vision through the development of a critical reality, with a view to transforming action⁽⁹⁾. At this time, the mediator kept the candle burning in their hands, highlighting its light and the significant heat of the fire, opening an embracement space so that family members could (re)mean about their experience in coping with grief. In this context, spirituality emerged, manifested by faith, as a source of support, in a process of awareness

of their real situation, strengthening each other. At the end, the mediator questioned the relatives about the meaning of having participated in the VCC in the experience of mourning in pandemic times.

The Critical Unveiling occurred throughout the development of the VCC, as foreseen in Freire's Research Itinerary, in a continuous analytical process. It should also be noted that the data analysis in the Freire's Itinerary occurred permanently, with the participation of all members of the Circle⁽⁹⁾. The dialogues were recorded with the participants' authorization, and later were transcribed and organized in digital folders, according to the representation of the Coding and Decoding in the dialogical praxis of the VCC.

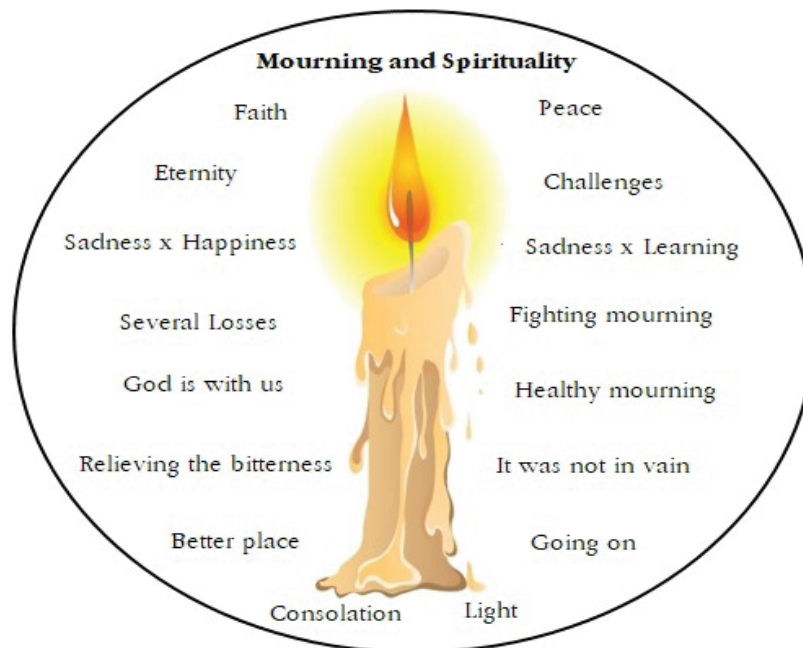
The research followed the ethical precepts of Resolution 466/2012, evaluated by the Research Ethics Committee of a public university in southern Brazil, with opinion number 4.068.387.

Results

The 16 family members participating in the study were aged between 23 and 62 years, seven male and nine female. Four participants self-declared as Spiritists, seven evangelicals and five Catholics. As for the degree of kinship of the study participants with the relative who died from COVID-19, two were mothers, nine were children, two were wives and three were siblings.

Through the dialogues in the VCC, the participants defined Mourning and Spirituality as generating themes for discussion, as shown in Figure 2.

Figure 2 – Representation of the Coding and Decoding of the generating theme Mourning and Spirituality



Source: Created by the authors, using the image available from: <https://pt.vecteezy.com/arte-vetorial/1271218-derretendo-vela-isolada-no-branco>.

The family members revealed that they have experienced several mourning, pointing out that the pandemic has reflected in several losses to society, because, in addition to the pain of the death of their family member, they also lost other

friends due to COVID-19. Moreover, they also missed the opportunity to say goodbye to their family, as well as joy in the family, employment, face-to-face classes, meetings, weddings, hugs and smiles:

The pandemic has brought us many losses. In addition to my father's death, we lost a lot. So many meetings and weddings that stopped happening, in-person classes don't take place and all this is also a mourning for society! (Sirius).

A lot of people lost their jobs, lost the opportunity to hug more and smile more (Vega).

In the experience of mourning, the study participants highlighted that emerged, mainly, the feeling of sadness. But beyond that, such experience also brought them intense learning, in which they could strengthen themselves as a family and give greater value to life, showing that, with pain, they discovered that all people, factually, will one day die:

Living this grief isn't easy, it's very sad (crying). But we have learned a lot. Our family has become much stronger and we have learned together to value life more because when someone close to us dies, that's when we realize that all people will die. (Pollux).

Entwined with the feeling of sadness at losing a family member to COVID-19, the participants also revealed the feeling of joy at having had the opportunity to live with the deceased family member, believing that they are happy and in a better place:

I'm very sad, my family is sad because it's not easy to lose someone like that. But at the same time, we feel happy for having had the opportunity to spend all these years with my mother. [...] She's in a much better place than we are now. I know she's happy, smiling and it makes me happy! (Rigel).

I also think my brother is in a much better place. He's happy and it eases my sadness. (Antares).

For some family members of the study, the family member who was gone was always light while living, spreading love to others. They believe that they will continue to enlighten them on the life journey, and that they need to keep going:

My daughter was always like a ray of sunshine, a light that illuminated everyone around her. She helped everyone and many people cried for her death, but what makes me keep going is knowing that she will continue to enlighten us from where she is. I just know it. (Sun).

[...] we need to keep going. That's what I'm trying to do. (Adhara).

In coping with grief, some family members highlighted the faith meaning that God is present with them and that they feel comforted.

Furthermore, they pointed out the need to ease the bitterness of losing a family member:

I also have a lot of faith in God and that's what has kept me on my feet. We can't do it alone, but God comforts us and strengthens us every day. (Avior).

Every day God finds a way to comfort me. In small details, God is present and renews my strength. (Rigel).

I confess that I need to relieve all this grudge, this sorrow of mine for having lost my sister. [...] It's all difficult. I have faith, I believe in God, my family also has a lot of faith, but I still need to work on all this feeling inside me (Regor).

In this scenario, family members spoke intensively about the challenge of alerting other families and friends that death due to COVID-19 still persists and that can occur to anyone. They also revealed that even in the face of grief, they need to continue their lives and continue fighting:

We have the challenge of alerting other families, our friends that death is here, knocking on everyone's door. That it really is a terrible virus, so small, but that has the power to take the lives of the people we love [...]. (Merak).

Even in mourning, we have to keep fighting for the good of our family and everyone else. [...] (Avior).

The study participants discussed that nothing happens by chance and believe that it was not in vain the death of their families, pointing out that they seek peace and healthy mourning. Moreover, some of them have shown that they believe in eternity and that one day they will be with their relatives in heaven:

I think nothing happens in vain and it was no accident that they died. In everything there is learning and that gives me peace. (Mizar).

Experiencing this grief isn't easy, but my family has sought to be at peace and has tried with serenity to go through this moment of loss. (Izar).

I believe in the eternity of life and I know that one day I will see my father in heaven. (Sirius)

She (mother) died here on earth, but she is alive in heaven. And one day I'll go there and I'll be with her and Jesus. (Castor).

The relatives talked about the relevance of having participated in the VCC, in which they had the opportunity to reflect on the experience of mourning and to discover that they are not alone facing their losses, affecting and empowering each other to understand and transform their reality:

I want to thank you for the opportunity to come here to talk to you. When I accepted to participate, I had no idea that we would talk as much as we did. And there were things that needed to be said and heard and I had no one to talk to about it all. (Pollux).

During our conversations it was good because I realized that there are a lot of people going through exactly what we are going through. It helped me a lot to have participated. Thanks! (Nunki).

Discussion

The COVID-19 pandemic has intensified transformations in different care scenarios, moving actions on treatments, forms of contagion and circumscription, linked emotional aspects, among others. When considering the emotional aspects, the repercussions triggered by social restrictions, changes resulting from the death of family members and the need for adjustments in the different life panoramas arise⁽¹²⁾.

One of the major obstacles to the assimilation of the initial impact of loss is that it occurs abruptly and unexpectedly. Random and chaotic, loss situations give an impression of unreality when faced with the massive experience of death in times of pandemic⁽¹³⁾.

The family cannot say goodbye with traditional rituals, due to the severity of the disease and the greater risk of contagion with agglomerations of funerals and burials^(13,14). These changes in farewell rituals can awaken in the relatives the feeling that they did not pay the condolences that the deceased family member deserved, making the process of mourning more painful⁽¹⁵⁾.

The loss of many people for COVID-19 and the limitation to perform farewell rituals among family members, with restriction in funeral rituals, hinder the experience of mourning. These rituals have intense meaning in the context of losses, which brings up the discussion about the creation of alternative and respectful actions for the ritualization of the death process⁽¹⁶⁾. Funeral rituals mature the experience of the process of death and mourning, because they collaborate so that the relatives identify the loss and publicly demonstrate their grief⁽¹⁷⁾.

In Brazil, farewell rituals make up the cultural habits and, even if justified their cessations, they

cause feelings of disbelief and suffering to family members, who get the feeling of a cycle that has opened and not closed completely, because the farewell ritual allows crying, gathering family and sharing comfort and solidarity. It creates a scenario that amplifies the pain, suffering, loneliness and discouragement of bereaved family members, and stigmas associated with the disease may arise, since the grieving family member is seen as a possible vector of transmission of COVID-19⁽¹³⁾.

The celebration of rituals provides an environment of communion, complicity, attachment to the sacred and the beginning of the process of disconnection between the grieving family member and the deceased family member. Offering the latest tributes allows for repairs and reconciliations. Nevertheless, with the new rules imposed by the pandemic that alter the funeral and burial, farewells tend to be disturbing rather than comfortable⁽¹⁷⁾.

Mourning is composed of biological, psychological and social factors, and its real and symbolic malfunctions arise throughout the development of the human being. The experience is individual and built by the own mourner with the support of the family, religion and the social environment where they are inserted⁽¹⁸⁾.

The experience of mourning requires access to the fact of loss, because there may arise the impression that death did not happen; consideration of the suffering that the loss caused, since preventing pain tends to prolong it; adaptation to the new context of life with the absence of the family member, which leads to adopt roles that the loved one previously exercised and prepare an emotional space to remember them following life⁽¹⁹⁾.

Experiencing the death of a family member is an experience of pain and suffering, which induces the development of strategies that help overcome difficulties in the face of grief. Spirituality, religiosity and religion are a beneficial strategy and need to be respected and optimized by other family members and professionals who perform care at this time.

This study evidenced that the participants chose spirituality and mourning for discussion during the VCC. Nonetheless, very often they considered religion and religiosity to be spirituality. It is worth remembering that spirituality involves the peculiar dimension of people, pushing them in the search for the sacred and giving meaning and response to the fundamental aspects of life. Religion encompasses certain beliefs and rites, such as the institutional and doctrinal concept through a religious experience, while religiosity is understood in the personal dimension. Religiosity is the practice or expression of the believer, being able to relate to a religious institution⁽²⁰⁾.

Faced with the experience of mourning, it is necessary to offer support for understanding, acceptance and pain caused by the death of a family member. Reflection on the finitude of human beings as part of the life cycle rescues the considerations about separation and assists in extrapolating the pain of loss, and religion^(19,21), hope and spirituality appear as an effective strategy during the process and enable resignifications about death⁽²²⁾.

When envisioning death as part of the natural cycle of existence, the anxieties of being an end in itself emanate moderate reflections on religious beliefs about the afterlife, focusing on the continuity of existence and the conviction of the existence of a higher being. Believing in continuity softens the anguish of family members and allows reflection on their own finitude, bringing the reflection that the deceased family member performed their tasks. In this sense, spirituality and religious engagement support the acceptance of death, recover meanings and re-signify different aspects of human life, providing a review of values and the very process of dying⁽²³⁾.

Thus, it is up to nursing professionals to understand the relevance of religion and spirituality during the death process, to embrace grieving relatives, appreciating the essence of the human being in an occasion of emotional pain. Therefore, the professional must appreciate the demands that will arise from the perceptions

of family members and develop strategies that enable the manifestation of pain and affection in farewell. Spirituality brings together different extensions of health care and needs to be focused on promoting well-being, as it is configured as a baseline resource for understanding suffering and strengthening humanity for challenges⁽¹⁶⁾.

The use of the Culture Circle was interesting, because it instigated the dialogue between the participants promoting an important space of exchange of knowledge in the experience of mourning through respect and love. The VCC enabled the interaction of people from different locations, at a time when it was necessary to maintain social distance. As a limitation of the study, the possibility of physical embrace is cited, since it is a sensitive topic, and at times the family members got emotional and showed the desire to embrace each other as a source of mutual support.

Final Considerations

The VCC instigated reflections to the family members who, by meaning the mourning, talked about the losses in their lives, and pointed out that it was not only their loved ones and friends, but also the loss of their jobs, the coexistence with people they love and other relationships. However, they were grateful for the opportunity to live with those who passed away. They meant the moments lived as cherishing moments in this moment of sadness, as a way of coping, and with this, they allied faith in God and placed religion and spirituality as necessary to go on.

During the VCC dialogues, participants turned to their reality, listened and were heard, signifying their experiences and feelings, strengthening each other. Nevertheless, they cited spirituality, religion and religiosity, considering them as something unique and distinct concepts, although interrelated.

Given these findings, it is urgent that the nursing team can establish strategies to address the aspects of grief in care, in order to help people who have lost their family, friends, among other aspects, to re-signify their feelings.

In this sense, it is suggested the continuity of studies that address the experience of mourning as a result of COVID-19, with new views on this social problem, which affected people in Brazil and the world.

Collaborations:

1 – Conception and planning of the project: Jeanne Barros de Souza and Crhis Netto de Brum;

2 – Analysis and interpretation of data: Jeanne Barros de Souza and Crhis Netto de Brum;

3 – Writing and/or critical review: Jeanne Barros de Souza, Crhis Netto de Brum, Samuel Spiegelberg Zuge, Leoni Terezinha Zenevicz, Eleine Maestri, Lélío José Lima and Richard Augusto Thomann Beckert;

4 – Approval of the final version: Jeanne Barros de Souza, Crhis Netto de Brum, Samuel Spiegelberg Zuge, Leoni Terezinha Zenevicz, Eleine Maestri, Lélío José Lima and Richard Augusto Thomann Beckert.

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Received: March 30, 2021

Approved: September 26, 2022

Published: November 21, 2022



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