

# Grief and experienced feelings by COVID-19 diagnosis under the perspective of nursing care

## Luto e sentimentos vivenciados pelo diagnóstico de COVID-19 sob o olhar da enfermagem

## Duelo y sentimientos vividos por el diagnóstico de COVID-19 bajo la perspectiva de enfermeira

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# REVISIA

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### RESUMO

**Objetivo:** Identificar os sentimentos experimentados por indivíduos ao receberem o diagnóstico de COVID-19 durante a pandemia. Discutir o enfrentamento do luto em função das perdas vivenciadas, com ênfase nas implicações emocionais e desafios associados. **Método:** Estudo descritivo de abordagem mista e delineamento transversal, com participação voluntária de pessoas maiores de 18 anos, de ambos os sexos, que consentiram em compartilhar suas vivências. Foram utilizadas análises qualitativas e quantitativas para compreender as experiências relatadas. **Resultados:** O diagnóstico de COVID-19 gerou emoções negativas como medo, tristeza, frustração, culpa e desespero. Participantes relataram o impacto emocional da perda de familiares e amigos próximos, destacando a impotência e a falta de rituais de despedida, intensificando o sofrimento. **Conclusão:** O estudo evidencia a importância do suporte psicológico para diagnosticados com COVID-19 e pessoas que enfrentaram perdas significativas. Ressalta-se a necessidade de estratégias para acolhimento emocional em situações de perdas abruptas e ausência de rituais que promovam o fechamento emocional e o início do luto. **Descritores:** Cuidados de Enfermagem; Pandemia por COVID-19; Sentimentos vivenciados; Perda; Luto.

### ABSTRACT

**Objective:** Identify feelings experienced by individuals diagnosed with COVID-19 during the pandemic. Discuss coping with grief due to losses, emphasizing emotional implications and challenges. **Method:** Descriptive study with a mixed approach and cross-sectional design. Voluntary participants over 18 years old, of both genders, consented to share their experiences. Qualitative and quantitative analyses were used to achieve a comprehensive understanding. **Results:** COVID-19 diagnosis triggered negative emotions such as fear, sadness, frustration, guilt, and despair. Participants reported the emotional impact of losing relatives and close friends, emphasizing helplessness and the lack of farewell rituals, which amplified suffering. **Conclusion:** The study highlights the importance of psychological support for those diagnosed with COVID-19 and those experiencing significant losses. Strategies focusing on emotional care for sudden losses and absent rituals are crucial to promote closure and initiate the grieving process. **Descriptors:** Nursing care; COVID-19 Pandemic; Experienced feelings; Loss; Grief.

### RESUMEN

**Objetivo:** Identificar sentimientos vividos por individuos diagnosticados con COVID-19 durante la pandemia. Discutir el afrontamiento del duelo, destacando implicaciones emocionales y desafíos asociados. **Método:** Estudio descriptivo con enfoque mixto y diseño transversal. Participaron voluntarios mayores de 18 años, de ambos géneros, que aceptaron compartir sus vivencias. Se utilizaron análisis cualitativos y cuantitativos para una comprensión integral. **Resultados:** El diagnóstico de COVID-19 generó emociones negativas como miedo, tristeza, frustración, culpa y desesperación. Los participantes destacaron el impacto emocional de perder familiares y amigos cercanos, señalando impotencia y la falta de rituales de despedida, lo que intensificó su sufrimiento. **Conclusión:** El estudio subraya la importancia del apoyo psicológico para diagnosticados con COVID-19 y personas que enfrentaron pérdidas significativas. Estrategias enfocadas en el apoyo emocional para pérdidas abruptas y ausencia de rituales son esenciales para el cierre emocional y el inicio del duelo. **Descriptores:** Cuidado de Enfermería; Pandemia de COVID-19; Sentimientos vividos; Pérdida; Duelo.

## Introduction

The impacts of the COVID-19 pandemic, since its declaration in 2020, have been devastating in several countries. In Brazil, the disease, caused by SARS-CoV-2, was responsible for more than 700 thousand deaths in 4 years<sup>(1)</sup>.

Health systems were not fully prepared to face the rapid spread of the virus and the worsening health conditions of those infected. The lack of capacity to offer adequate care to those who needed it resulted in complex decisions, challenging fundamental ethical principles in the health area. These difficulties impacted the suspension of surgeries, as well as the discontinuation of prolonged treatments, such as those for neoplasms. New modalities of treatment and health care, such as virtual care, were implemented.<sup>(2-3)</sup>

For health professionals, such as nurses and nursing staff, the COVID-19 pandemic was especially challenging because, in addition to offering specific care to affected patients, there was also the need to move away from their families and, often, from their homes. Nursing was the category most affected by staff losses due to the disease in Brazil<sup>(4-5)</sup>.

The psychological suffering, felt by people who contracted the virus and survived, and by family members and close friends of people who lost their lives to the disease, left sequelae in society in general, because, in addition to the loss of human lives, during the pandemic, we also experienced losses of social interaction, freedom of movement, jobs, expectations and even one's own health<sup>(6)</sup>.

The COVID-19 pandemic has brought grief to the world population in several ways, such as the deprivation of face-to-face socialization with people, even the loss of one's own health or that of family and close friends, or even the frequent coexistence and proximity to death<sup>(7)</sup>.

As it is an intensely contagious disease, with serious health effects, sanitary measures were taken in order to prevent the high spread of the virus during collective events, such as funerals. In Brazil, wakes of people who died contaminated with the virus were allowed, but with a reduced number of people, who did not belong to the risk groups for the disease and who did not have respiratory symptoms associated with the disease. They should be held in ventilated and open places and the coffin should remain closed<sup>(8)</sup>.

Receiving the diagnosis of COVID-19 causes anguish and fear due to the sequelae that the disease can leave and also due to the uncertainty about the future and the risk of imminent death associated with the symptoms<sup>(9)</sup>. These feelings can trigger anticipatory grief, which is developed by feelings that help organize thoughts for the elaboration of pain and adjustment of emotions<sup>(10)</sup>.

Grief can be explained by a whirlwind of alternating and deep feelings, which involve sadness, guilt, anger, loneliness, emotional shock, longing, helplessness, despair, liberation, and even relief. They are represented by physical sensations, such as tightness in the throat, difficulty breathing, muscle weakness, dry mouth, among others<sup>(8,11)</sup>.

Different behaviors are also evidenced during the grieving process, such as social isolation, disturbing dreams, usually associated with loss, avoidance of memories, agitation, easy crying, deep sighs, and hyper or hypoactivity. Cognitive changes may be present, affecting sleep and appetite, as well as the perception of one's own identity<sup>(8,10-11)</sup>.

This article aims to identify the feelings experienced by participants in a study, when they had the diagnosis of COVID-19 confirmed in the midst of the pandemic, and to discuss the development of grief in the face of the losses suffered.

## Method

This study is linked to the research project entitled "Psychic Suffering in the context of the COVID-19 Pandemic", which was approved by the Research Ethics Committee of the University of Brasília - Faculty of Health Sciences and Technologies (CEP-FCTS), registered under CAEE No. 47388821.4.0000.8093.

This is a descriptive, mixed, cross-sectional study with volunteers of both sexes, over 18 years of age. Two instruments were applied in the research, the first being a questionnaire prepared by the researchers to assess the sociodemographic data of the participants and questions about the COVID-19 pandemic, and the second the Self-Reporting Questionnaire (SRQ-20) (SRQ reference - 2023), created by the World Health Organization (WHO), and validated in Brazil, used to assess mental suffering. For this analysis, only the first instrument was used.

The survey was released through social networks, mainly WhatsApp and Instagram, where the link to access the form on Google Forms was made available. Thus, data collection took place between December 2021 and April 2022 and was carried out remotely due to the pandemic scenario in force in the period.

The instruments were released only after the signing of the Informed Consent Form (ICF). The inclusion criteria were: being born or naturalized Brazilian and being 18 years of age or older. Incompletely completed questionnaires were excluded from the survey.

## Results

A total of 154 people aged between 18 and 76 years participated in the study. Among them, 61% were between 18 and 39 years old, 29% between 30 and 49 years old and 10% were over 50 years old. Most participants were female (74.6%).

About 38.4% reported having been diagnosed with COVID-19 at least once during the pandemic. Of these, 44% were diagnosed before vaccination, while 56% reported the diagnosis after receiving two or more doses of the vaccine, which reduces the worsening of symptoms. Regarding vaccination, 98% of the participants reported having completed the initial schedule with two doses, according to the recommendations in force for adults over 18 years of age at the time of data collection.

In addition, 74% of participants reported that family and close friends were diagnosed with COVID-19. Among these, 46% had at least one family member diagnosed, while 18.8% had more than one. About 58.7% said they know someone who has been diagnosed with the disease.

Participants reported several feelings when they received the diagnosis of COVID-19. Fear was the most common (72.8%), followed by sadness (49.1%) and frustration (30.5%). Guilt and despair were mentioned by 22%, surprise by 18.6% and hopelessness by 15.2%. Other reported feelings included confidence

(10.1%), anger and distrust (6.7%), hope (5%), as well as enthusiasm and disgust (3.4%).

Among those who tested positive for COVID-19, 55.9% reported that the result affected both them and close family members, 28.8% said that the diagnosis impacted their daily lives, that of family members and other people, and 15.2% said that it only affected their own daily lives.

Finally, 58.4% of the participants reported having lost a family member or close friend to the disease. Of these, 53.3% reported having lost more than one person.

## Discussion

Experiencing grief and the feelings associated with this process is essential for the person involved to be able to adapt and recover. Significant losses can lead to profound changes. This is an important moment, which allows us to resignify the loss, reorganize the overcoming and understand the natural process of living and dying<sup>(12)</sup>.

Grief arising from the death of a loved one evokes our mortal condition, as well as the inevitability and irreversibility of death. Losing close friends or family members suddenly interferes with social and psychological development, since the bereaved person does not have the opportunity to prepare in advance to face the void left by the loss. This is different from situations where the loss occurs as a result of an illness with continuous and prolonged treatment. In this context, the bereaved have more time to organize themselves emotionally, which favors a more satisfactory adaptation to the absence<sup>(12)</sup>.

In the context of grief, it is also important to understand anticipatory grief, especially considering that it was not possible for several family members and friends of people who died as a result of COVID-19. Anticipatory grief is a period that enables the resolution of conflicts, the treatment of pending issues and a more open communication between those involved, allowing them to deal with important aspects related to illness and death. However, due to the sudden development of COVID-19, there was no time for this planning and conflict resolution, which made coping with grief equally sudden and challenging<sup>(13-14)</sup>.

In addition, in some phases of the grieving process, there may be identification with the deceased person. In this sense, the bereaved may feel uncomfortable or even guilty when performing activities that were to the liking of the departed person. As previously mentioned, feelings such as guilt and hopelessness were widely reported in the interviews, which may be a reflection of a grief that did not allow anticipation and emotional preparation for friends and family<sup>(15)</sup>.

In addition, it is relevant to reflect on the censorship of the expression of feelings, often associating the pain of loss with weakness. In addition to this already existing social censorship, the physical distancing imposed during the pandemic and the difficulty of elaborating and making sense of losses contributed to farewell rituals marked by the concealment of death. This scenario has often deprived mourners of the comfort that these rituals traditionally provide<sup>(12)</sup>.

During the pandemic period, farewells, which could normally happen continuously, with moments of conversation and physical or social contact, were severely impaired. These moments, in which memories are shared and future projects are built, especially for those who say goodbye, were taken away from the people who fell ill and their families. Health authorities prohibited direct and face-to-face contact with SARS-CoV-2 carriers, which made it difficult to carry out collective funeral rituals <sup>(16,18)</sup>.

The absence of these rituals compromises the understanding and elaboration of the pain of loss, depriving people of the opportunity to deal with feelings and emotions that help in the recognition of human finitude. It is essential to experience the loss and occupy the space of farewell, something felt intensely by those who could not participate in these moments. This is essential for the cycle to close and allow adaptation to the new reality of survival <sup>(17-18)</sup>.

Participants in this study reported that, when their diagnosis of COVID-19 was confirmed, they experienced intense feelings associated with the symptoms of the disease, such as the fear of not overcoming the condition and of losing their own life. This fear, while understandable, can paralyze and impair treatment <sup>(19-20)</sup>.

However, fear also played an important role in controlling the pandemic by encouraging preventive behaviors. Among the participants in the study, most consciously adhered to the vaccination offered by the public health system. Other studies conducted during the pandemic corroborate this finding, indicating that, when people became aware of fatalities in their close circles, they tended to modify their perceptions of risk, becoming more favorable to isolation and social distancing <sup>(15, 19)</sup>.

In addition to fear, other feelings, such as sadness and frustration, were reported by the participants. Sadness was mainly related to isolation and social distancing. After the positive diagnosis, the quarantine period became necessary to avoid contamination of other people in the community. During this time, which could last more than 15 days, the patient had to remain isolated in an area of the house, without physical contact with other people. Their belongings were also to be separated, and any biological materials, such as food scraps, needed to be properly sealed and disposed of. Frustration, on the other hand, was associated, above all, with the impossibility of avoiding the disease <sup>(19-21)</sup>.

Sadness and frustration, as well as guilt and shame, are feelings that can lead to the development of depressive symptoms, further aggravating the condition of the disease and making recovery difficult. Despair upon receiving the diagnosis and hopelessness, described by some participants, were directly related to the fear of dying. This fear was exacerbated by the impossibility of sharing the anguish of the disease and the distance imposed from other people <sup>(21, 24)</sup>.

Fear is part of human development, acting as a possible defense and a warning mechanism in the face of security threats. During the COVID-19 pandemic, fear and anguish were felt in a broad and homogeneous way, generating affective confusion and different reactions, ranging from perplexity to denialist behaviors. <sup>(22)</sup>

The feeling of fear does not occupy the beginning in the sequential order of emotional experiences; It is reactive and emerges to deal with the expectation of repeating negative sensations, working as a defense. Fear can be

understood as an existential condition, as it establishes possibilities for the individual to continue existing, while mitigating intolerable anxieties. The fear of death, in particular, is related to other fundamental fears, such as the fear of madness, collapse and panic, since they all express precarious states that correspond to the insecurity generated by the absence of a clear meaning for existence <sup>(23)</sup>.

In the work *Psychoanalytic Explorations*, Winnicott analyzes the case of one of his patients, in which the fear of dying is not necessarily linked to the fear of death itself, but rather to the fear of dying alone, without the presence of another person. This distinction reinforces the importance of considering the data from the personal history of each individual in the grieving process, since each case has particular nuances <sup>(23)</sup>.

In view of the feelings experienced, the nursing care offered to the diagnosed and their families becomes essential to minimize the effects of grief and provide emotional support. The nursing team is directly affected by involvement in care and exposure to the virus in the dynamics of their work <sup>(24)</sup>.

Among the strategies available to nursing are: developing clear and constant communication to reduce anxiety and fear, in addition to stigma related to the disease. Promote emotional well-being by offering verbal comfort and creating a welcoming environment, with video contact between the patient and family and close friends <sup>(25)</sup>.

In addition, nurses must take care of themselves to avoid emotional and physical exhaustion in care and, in this way, promote self-care and support for the health team, with the purpose of preventing stress and accumulated grief.

## Conclusion

This study aimed to analyze the psychological effects of a positive diagnosis of COVID-19 during the pandemic period correlated with the grieving process. The results indicated that most participants experienced intense feelings of fear, sadness and frustration and that the diagnosis affected not only the daily lives of themselves, but also of family and friends, in view of social isolation and uncertainty about the severity of the disease.

In addition, more than half of the study participants experienced the loss of a family member or close friend, evidencing the grieving process developed in the pandemic context, a scenario marked by losses and changes in social paradigms such as social distancing, the impossibility of performing funeral rituals and other types of celebrations in person, which, in turn, compromises the process of coping with and overcoming grief.

Grief over the diagnosis of COVID-19 is a complex phenomenon, involving both patients and health professionals. In the context of nursing, it is essential that professionals know how to deal with emotional challenges, both their own and those of their patients, offering care that integrates physical, emotional and social aspects to support the process of coping with the disease.

These findings underscored the importance of implementing appropriate psychological interventions to support individuals during periods of crisis and isolation, especially in situations of rapid loss and no goodbyes.

Future research could explore the relationship between social support and the development of coping strategies in people affected by COVID-19, as well as assess the long-term psychological impact of this experience.

The findings of the present study should be considered in the light of some limitations. First, this is not a population-based study and, therefore, the results apply only to the selected sample and do not allow generalizations. The sample was mostly female, which affects its representativeness. Data collection through social networks, although facilitating the recruitment of volunteers for the research, may induce a selection bias, from the point of view of sociodemographic variables, such as education and socioeconomic level, and it cannot be excluded that social problems and convenience factors may have influenced the participants' answers to the questionnaire.

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