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End-of-life care and grief: study conducted with family members of COVID-19 victims

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Abstract *This article aims to investigate the implications of grief among family members of COVID-19 victims; verify the prevalence of prolonged grief symptoms; and identify family members' expectations regarding end-of-life care for their loved ones affected by COVID-19. Descriptive, cross-sectional research, with a quantitative-qualitative approach. Data collection was performed using an online questionnaire, guided by the PG-13 instrument. Descriptive and inferential statistics were applied. The results were presented descriptively and with the aid of tables. The study sample included 142 family members, mostly female, who presented emotional, physical, social, and financial implications as a result of grief. A prevalence of prolonged grief symptoms was observed in 11.4% of the mourners with more than six months and 29.6% of those with less than six months. Three thematic categories were identified: transparency in communicating the health situation, access to moments of farewell, and promotion of comfort in care actions. The symptoms of Prolonged Grief Disorder have a significant association with the degree of kinship. In final care, family members' expectations were classified as: permission for a dignified farewell, effective communication, and promotion of comfort and care.*

Key words *Bereavement, COVID-19, Palliative Care, Nursing, Health Communication*

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Introduction

Palliative care is a holistic approach for individuals of all ages suffering from any disease which threatens one's continuity of life or from a condition with a high mortality risk, which can cause suffering that may not be relieved without professional intervention and can compromise the individual's physical aspects, social functioning, and spiritual and/or emotional aspects. Its objective is to improve the patient's, the family's, and the caregivers' quality of life. It applies care strategies for the family and makes use of caregivers during the patient's illness and up to the final stage of life and the grieving process[1].

Palliative care in the final stage of life acknowledges the risk of a rapid deterioration of the patients' conditions and establishes the creation of a predefined care plan, which includes the wishes and preferences of the patients and their families, ensures the protocols for the management of symptoms, and provides psychosocial and grief care.

Grieving is a natural and universal response that most people will endure in face of the loss of a significant other, thus being considered a very stressful event[2]. However, a substantial part of the grieving reactions may be severe, incapacitating. and may extend beyond normal expectations, resulting in the need for proper professional follow-up[3].

Going through the sudden loss of a family member due to a life threatening disease, such as COVID-19, combined with the exposure to several secondary stress factors, such as infection, social isolation, quarantine, and loss of employment, may affect the death rituals and the social support, causing severe grieving situations in people during that pandemic, including prolonged grieving[4,5]. This disorder causes social and occupational involvement of the mourner by generating progressive symptoms of separation anxiety, as well as cognitive, emotional, and behavioral symptoms[3].

The disease caused by the coronavirus (COVID-19) has the SARS-CoV-2 virus as its causal agent and presents a potentially fatal pathology, rendering it a major public health concern worldwide. The first cases were reported in China, in December 2019, when five people were hospitalized with severe respiratory distress syndrome, one of whom died[6].

As COVID-19 affects communities in general, the death experiences become increasingly more personal, and taking into consideration the environment in which they take place, the physical, mental, and social consequences of social distancing may intensify complications to the process of grieving incurred by the families of COVID-19 victims[7]. Data from the World Health Organization (WHO) indicate that, by June 2021, nearly four million deaths by COVID-19 had occurred globally, 540,000 of which in Brazil[8].

An increase is expected in terms of grieving disorders related to the pandemic, which commonly causes a greater need for treatment[9]. Therefore, to inform the approaches in terms of palliative care, studies need to be conducted to offer a continuous investigation of the impacts of the changes in the services for family caregivers, both during treatment and during grieving[10]. This demonstrates the importance of palliative care in the final stage of life and during the process of grieving.

Therefore, the present study aims to investigate implications regarding the grieving process for family members of COVID-19 victims; to verify the prevalence of prolonged grieving symptoms among family members of COVID-19 victims; and to identify the expectations of families regarding care in the final stage of life provided to their loved ones suffering from COVID-19.

Methodology

Study design

This is an exploratory, descriptive, and cross-sectional study, following a quanti-qualitative approach, of a concomitant nature. To guide the study, the following instruments were used: COnsolidated criteria for REporting Qualitative research (COREQ)[11,12] and Strengthening the Reporting of Observational Studies in Epidemiology (STROBE).

Scenario in which data collection was conducted

Since this study dealt with national evidence from the time of the COVID-19 pandemic, it was conducted in the Brazilian virtual reality. This choice was influenced by the public health strategy of social distancing, a measure by the government used to minimize the spread of the virus in the country[13]. It is important to highlight that the institution that proposed this study is located in the city of João Pessoa-PB, Brazil.

The online research modality has often been used as a resource for data collection, especially when expanding the possibilities of access to different groups by the researcher; to reduce costs with in-person stages, such as commuting and staff; and to provide the participants with more privacy and flexibility in terms of the time chosen to answer questionnaires[14].

Population

The study population consisted of Brazilians who went through a grieving process after the passing of a family member due to COVID-19.

Selection criteria

The inclusion criteria was: family members of people who passed away due to COVID-19, with or without hospitalization at a health facility; 18 years of age and older, regardless of sex, who had some kind of digital device with Internet access, and that were literate. The exclusion criteria was: participants who gave up on answering the questionnaire before its conclusion.

Sample definition

The sample was non-probabilistic, following the snowball sampling strategy, and by accessibility. This study counted on the participation of 263 individuals who accessed the questionnaire. Of those participants, three clicked the button to choose not to participate (without explaining the reasons why), and 118 did not meet the eligibility criteria, since their family members hospitalized with COVID-19 had not passed away at the time they answered the questionnaire, thus invalidating the analysis of grieving after death. In the final study sample, 142 individuals met the selection criteria.

Study variables

The present study considered the following variables: socio-demographic characteristics of the participants; feelings and symptoms related to grieving; repercussions of the grieving process on the life of the family members; access/interest of the grieving individual to receive professional follow-up; and expectations of the participants in relation to the care provided to their relative in the end of life.

Instruments used for information collection

To enable data collection, an online questionnaire was applied, structured in five parts: 1 - term of consent; 2 - triage question; 3 - basic socioeconomic characteristics of the participant; 4 - PG-13 instrument; 5 - additional questions (referring to repercussions of the process of disease and grieving in the lives of the mourners, professional follow-up in the grieving process and expectations of family members regarding care in the end of life).

Six experts in palliative care were invited to evaluate the instrument in terms of clarity, importance, and adequation of each of the items in the referred instrument, with the purpose of attaining face and content validity. The questionnaire was pre-tested with three people in grief; adaptations were then made in some questions, after which time the instrument was considered adequate for application.

The questions presented had predetermined answer options, also providing the "other" option, in which the participants had the possibility to include whatever answer they so desired. It is important to emphasize that, with the exception of the term of consent and the triage question, none of the questions were mandatory, allowing the participants the autonomy to choose to abstain from answering a question deemed as inadequate, without having to abandon the entire questionnaire. The questions and the formatting of the research were inserted into Google Forms®.

To evaluate grief, this study used the PG-13 prolonged grief evaluation instrument, validated for the Brazilian context, developed based on the criteria for the diagnosis of prolonged grief disorder[2].

The PG-13 questionnaire contains 13 items, describing a set of symptoms (feelings, thoughts, and actions) related to the loss of a significant other, and are necessarily connected to a social and/or a functional dysfunction. To meet the criteria for the diagnosis of prolonged grief in the previously mentioned instrument, validated for Brazil, the symptoms must be frequent and intense, and must be present for at least six months after the loss. However, according to a researcher and author of instruments aimed at studying prolonged grief, a grief scale may be used with two purposes: to offer a continuous evaluation of the intensity of grief on a dimensional scale and to diagnose prolonged grief syndrome according to defined criteria[3].

In this study, the grief reactions due to COVID-19 were examined, and the participants were divided in two groups: family members in grief for less than six months since the death, and family members with six months of grief or more since the death. Researchers, who are international references in the field of grieving, used this research strategy, taking under consideration the recent character of the pandemic, the divergent diagnosis criteria in relation to time, and the opportunity of gathering data that will serve as an empirical basis for verifying if grieving complications will increase due to the pandemic[9,15-17].

In addition to the aforementioned grief instrument, the researchers also created complementary questions which covered the listed variables and could address the objective of the study, as can be seen in the results section. Moreover, the present study aimed to cooperate in the progress of knowledge by presenting evidence on grief by family members of COVID-19 victims, an issue which deserves attention from researchers and that supports nursing care for the population being studied in the field of Palliative Care.

Data collection

The gathering of data took place between April and June 2021. A Google Forms® link was generated and then advertised by the author in the following media: personal email lists, Facebook® contacts, WhatsApp® groups and Instagram®. Some contacts were obtained by using the hashtags #lutocovid19, #lutocovid, and #vitimascovid in the social networks Facebook® and Instagram®. The link was accompanied by a short presentation text and the content of the study was projected in simple language. Additionally, an explanatory video was produced regarding the research, which was shared together with the link. The participants were invited to take part in the study and to promote it among their contacts. The decision of finishing the research was based on the behavior of the data. It presented constancy after the 10th week of data collection, suggesting a possible saturation of the answers.

Data treatment and analysis

Quantitative data was exported into Google Spreadsheets, charted and organized for analysis in the Statistical Package for the Social Sciences (SPSS), version 22.0, applying descriptive (frequency, percentage, average, median, and standard deviation) and inferential statistics, with the use of the Parson chi-square test; p-values below or equal to 0.05 were considered to be significant. The results were presented in a descriptive manner, with the aid of images and tables to synthesize the findings. Qualitative data was handled by the IRaMuTeQ 0.7 alpha 2 software and was submitted to thematic analysis in three stages: pre-analysis, exploration of the material and treatment of results, and interpretation[18]. Frequencies were produced to indicate common senses, and the main answers within the domains of the questions were presented as discourse.

Ethical aspects

The research project was approved by the Research Ethics Committee of the proposing institution, logged under decision no. 4,584,374, and followed the ethical guidelines set forth in Resolution No. 466/2012, published by the National Health Council. The researchers also followed recommendations of the National Research Ethics Committee to conduct the study in an online format[19]. The use of the PG-13 instrument was authorized by the author, who constructed the version validated for Brazil.

Consent was obtained by the answer to the first question, after reading the free and Informed Term of Consent. All of the surveys were developed anonymously via Google Forms®. When fragments of the family members' testimonies were used, they were identified by the letter P, for participant, followed by a number based on the order of the research.

Results

Characterization of family members

The sample consisted of 132 family members, mostly women (84%; n=119), with a median age of 41 years (average 41.3; SD=12.4), living in the same location where the family member had passed away (52.1%; n=74) or in other towns (47.9%; n=68). As far as the region where the death occurred, the Northeast corresponded to 73.2% (n=104) of the answers, followed by the Southeast (17.6%; n=25), North (4.2%; n=6), Midwest (2.8%; n=4), and South (2.1%; n=3).

Regarding the degree of kinship of the participants, the loss of mother/father was more frequent (27.5%; n=39), followed by uncle/aunt (26.1%; n=37), grandfather/grandmother (9.2%; n=13), cousin (9.2%; n=13), sibling (8.5%; n=12), spouse (3.5%; n=5), son (0.7%; n=1), and other (15.5%; n=22), such as stepfather/stepmother, father/mother-in-law, brother/sister-in-law. It is important to mention that, among the grieving relatives, seven participants were family members of people who died without receiving proper hospitalization in the healthcare system.

The participants were asked if the passing of the relative caused changes in their life. The answers included: Not completely (27.5%; n=39), Physical repercussions (4.2%; n=4.2), Psychological repercussions (47.9%; n=68), Physical and psychological repercussions (10.6%; n=15), Social/financial repercussions (9.2%; n=13), and No answer (0.7%; n=1).

Participants were questioned as well if they had professional follow-up in the process of grieving, and the results were: Yes (21.8%; n=31); No (6.3%; n=9); I believe I do not need it at this moment (47.2%; n=67); I need follow-up for the grieving process, but I do not know which service I should seek (19.0%; n=27); I already have professional follow-up for other reasons (4.2%; n=6); and No answer (1.4%; n=2).

Symptoms of grief among the family members

Table 1 presents the data regarding symptoms affecting family members according to questions approached in the Prolonged Grief instrument. The participants were divided in two groups according to the period of the grief experience: Group 1: Less than 6 months of grieving; Group 2: 6 months of grieving or more.

This study analyzed 98 participants with a period of grieving of less than 6 months and 44 participants with a period of grieving of 6 months or more. In this second group, 5 (11.4% of the sample) were diagnosed with Prolonged Grief Syndrome, and of the remaining 98 participants, 29 (29.6% of the total sample) were classified as people with severe symptoms of Prolonged Grief Disorder, except for the time criteria ≥6 months (Table 2).

As the data shows, in terms of degree of kinship, we were able to identify that there was a higher concentration of people in a state of grief who lost close relatives, such as father/mother/siblings/spouses. In terms of professional follow-up, most of the respondents who had no professional follow-up (46.5%; n=66) are also the majority of those who had no diagnosis of prolonged grief (Table 3).

Grief disorder

The third question is: "If you knew that your relative could become sick to the extent of dying, what would you like to be done for him in terms of healthcare services?". This question approaches the expectations of the participants related to the care provided at the end of life for their hospitalized relatives. Considering the answers obtained, a textual corpus was created and processed through IRaMuTeQ 0.7 alpha 2 software, generating a Descending Hierarchic Classification (DHC), with 85.46% of the use of text segments. In the DHC, three classes of words emerged, as Figure 1 shows.

Class 1 - Permission to bid a dignified farewell

This class referred to 55.32% of the text segments, given that the terms grouped here represent the anguish of the family members for not having had the opportunity to participate in the final moments of life of their beloved ones, and for not being able to say farewell.

[...] they should have allowed the family to say goodbye more calmly (P-100).

[...] not saying goodbye, it's hard to stay away from people that we love, the pain from the loss is much worse when we cannot be with the person (P-163).

[...] So I could say goodbye and kiss his gray head one last time. I feel that we didn't do all that we could, and this is going to haunt me for the rest of my life (P-245).

[...] that there was the possibility of the family saying goodbye, even if just via telephone or social media (P-63).

Families mentioned the desire to accompany the patient and be able to give the affection messages they wished, to give psychological support, to show that the patient is loved by his/her kin.

I wish I could have stayed by his side, not leaving him alone, sometimes I think that being there alone was what led to his death [...] (P-92).

To speak to him, have a chance to tell how much I loved him (P-224).

If I'd only been allowed to give one last hug (P-249).

Especially, to be with him, talking about God's love for everyone (P-115).

Class 2 - Effective communication

In this class, corresponding to 29.79% of the text segments, we can see a concentration of statements related to difficulties in commu-

Table 1. Data distribution according to items covered in the evaluation instrument (n=142). João Pessoa-PB. Brazil. 2022.

Variable	Group 1		Group 2	
	n	**%**	**n**	**%**
Q1 - IN THE LAST MONTH, how often did you miss or feel the absence of the person you lost?				
Almost never	1	0.7%	3	2.1%
At least once	14	9.9%	10	7.0%
At least once a week	12	8.5%	12	8.5%
At least once a day	23	16.2%	9	6.3%
Many times a day	48	33.8%	10	7.0%
Q2 - IN THE LAST MONTH, how often did you feel intense emotional pain, sadness/grief or episodes of anguish related to the lost person?				
Almost never	0	0.0%	6	4.2%
At least once	16	11.3%	11	7.7%
At least once a week	19	13.4%	13	9.2%
At least once a day	27	19.0%	5	3.5%
Many times a day	36	25.4%	9	6.3%
Q3 - In relation to the 2 (two) previous questions, did you experience those symptoms at least once a day, at least six months after the loss?				
Yes	-	-	13	9.2%
No	-	-	31	21.8%
Q4 - IN THE LAST MONTH, how often did you try to avoid contact with things that make you remember the person who passed away?				
Almost never	29	20.4%	27	19.0%
At least once	12	8.5%	7	4.9%
At least once a week	11	7.7%	2	1.4%
At least once a day	24	16.9%	1	0.7%
Many times a day	22	15.5%	7	4.9%
Q5 - IN THE LAST MONTH, how often did you feel shaken, shocked, or confused about your loss?				
Almost never	9	6.3%	10	7.0%
At least once	20	14.1%	14	9.9%
At least once a week	19	13.4%	10	7.0%
At least once a day	24	16.9%	7	4.9%
Many times a day	26	18.3%	3	2.1%
Q6 - Do you feel confused about your place in life or feel that you do not know who you are since the loss (that is, you feel that a part of you died)?				
Absolutely not	25	17.6%	19	13.4%
Slightly	15	10.6%	5	3.5%
Fairly	21	14.8%	6	4.2%
Very	25	17.6%	10	7.0%
Extremely	12	8.5%	4	2.8%
Q7 - Have you had difficulties in accepting the loss?				
Absolutely not	13	9.2%	13	9.2%
Slightly	13	9.2%	9	6.3%
Fairly	24	16.9%	7	4.9%
Very	36	25.4%	7	4.9%
Extremely	12	8.5%	8	5.6%
Q8 - Have you had difficulties trusting others since your loss?				
Absolutely not	44	31.0%	26	18.3%
Slightly	9	6.3%	3	2.1%
Fairly	15	10.6%	9	6.3%
Very	24	16.9%	5	3.5%
Extremely	6	4.2%	1	0.7%

it continues

Table 1. Data distribution according to items covered in the evaluation instrument (n=142). João Pessoa-PB. Brazil. 2022.

Variable	Group 1		Group 2	
	n	%	n	%
Q9 - Do you feel bitter about your loss?				
Absolutely not	18	12.7%	15	10.6%
Slightly	19	13.4%	10	7.0%
Fairly	16	11.3%	6	4.2%
Very	31	21.8%	8	5.6%
Extremely	14	9.9%	5	3.5%
Q10 - Do you feel that moving on with your life (for example, making new friends, having new interests, would be difficult for you at this point?				
Absolutely not	40	28.2%	29	20.4%
Slightly	15	10.6%	6	4.2%
Fairly	20	14.1%	4	2.8%
Very	17	12.0%	3	2.1%
Extremely	6	4.2%	2	1.4%
Q11 - Do you feel emotionally dormant since your loss?				
Absolutely not	29	20.4%	17	12.0%
Slightly	21	14.8%	12	8.5%
Fairly	21	14.8%	7	4.9%
Very	19	13.4%	4	2.8%
Extremely	8	5.6%	4	2.8%
Q12 - Do you feel that life is not satisfactory, empty, or meaningless since your loss?				
Absolutely not	49	34.5%	29	20.4%
Slightly	16	11.3%	3	2.1%
Fairly	11	7.7%	6	4.2%
Very	12	8.5%	4	2.8%
Extremely	10	7.0%	2	1.4%
Q13 - Do you feel a significant decline in your social life, in your professional life, or in other important areas (for example, household duties)?				
Yes	66	46.5%	21	14.8%
No	32	22.5%	23	16.2%
Total	98	69.0%	44	31.0%

Source: Authors.

nication, the interviewees said that there was no clarity in the information, not everyone did video calls and whenever they did do them, they did not follow regular times, increasing even further the family's anxiety.

They should have explained the seriousness of the condition at the time he was hospitalized and should have given him a chance to speak to his daughters. I don't think he ever knew that he was going to die (P-42).

I wished they had made a video call, so that he could see his family and know that he was not alone (P-13).

[...] Every day, we received information from a different doctor, and some were quite cold-hearted. The last one was awful, he left us speechless and bewildered for hours, really anxious, until in the early morning, when we received the worst news (P-219).

[...] I did very little, I was not informed that he would need non-invasive ventilation, and the hospital did not have it. [...] Lack of communication with the family, I could have taken medication that they did not have in stock (P-196).

The desire to grant the patients' last wishes was a recurring answer as well; family members mentioned that they wished they could grant this to their sick relatives:

Fulfill his last wishes (P-30).

Observe the last wishes (P-18).

Fulfill some kind of request by this family member (P-257).

Table 2. Prevalence of grief symptoms according to the PG-13 instrument (n=142). João Pessoa-PB, Brazil, 2022.

Variable	**Group 1**		**Group 2**	
	n	**%**	**n**	**%**
Part I - In relation to the 2 questions (Q1-Q2), did you experience those symptoms at least once a day?				
Yes	57	58.2%	13	29.5%
No	41	41.8%	31	70.5%
Part II - In relation to the 9 questions (Q4-Q12), did you experience at least 5 (five) of those symptoms at least once a day?				
Yes	33	33.7%	7	15.9%
No	65	66.3%	37	84.1%
Part III - Did you feel a significant reduction in your social life, in your professional life, or in other important areas (for instance, household duties)?				
Yes	66	67.3%	21	47.7%
No	32	32.7%	23	52.3%
Total evaluation (positive answer in the three stages of evaluation, simultaneously)				
Yes	**29**	**29.6%**	**5**	**11.4%**
No	69	70.4%	39	88.6%
Total	98	100%	44	100%

Source: Authors.

Table 3. Association table from the Pearson Chi-Square Test (n=142). João Pessoa-PB, Brazil, 2022.

	Prolonged Grief Syndrome		**χ^2**	**gl**	**p-value**
	Yes	**No**			
Kinship			21.681	2	**<0.001**
Parents/sons/daughters/siblings/spouses	**25**	32			
Grandparents/Uncles and Aunts/Cousins	5	58			
Other kin	4	18			
Professional follow-up					
Yes	12	19	11.280	3	**0.010**
No	12	**66**			
I need follow-up, but I do not know where to get it.	10	17			
I already have professional follow-up for other reasons	0	6			
Total	34	108	-	-	-

Source: Authors.

There were also comments from patients who accepted the situation and were aware that the healthcare team could not do much:

In my opinion, I think that they did the best they could, even though they first put my father on a respirator, then they informed the family, so it's hard to tell (P-220).

[...] the hospital was perfect [...] (P-57).

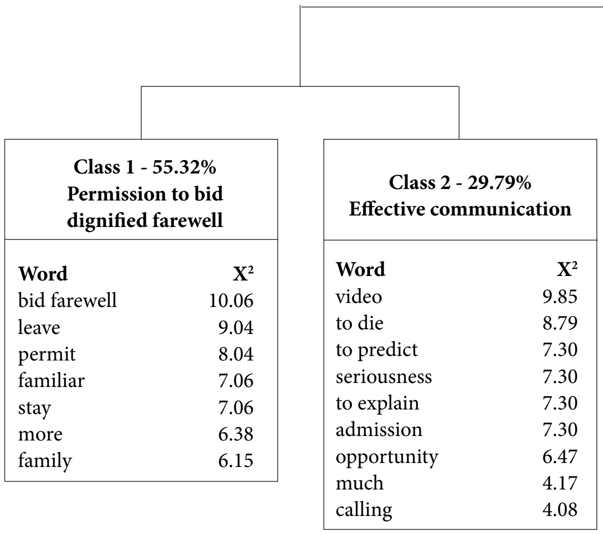
I believe the doctors did what they could, but I wish there had been more transparency in terms of information, at least... (P-188).

[...] Everything was done with excellence, for my father and for me (I was the one with whom the doctors and social assistants communicated) (P-166).

Class 3 - Promotion of comfort and care

Accounting for 14.89% of the text segments, this class showed the wish of the family members for the patients, with the help of the medical professionals, to receive the comfort and care that they would like to provide but were not able to because of restrictions imposed on family members.

To pass away feeling the least amount of pain (P-74).



Class 1 - 55.32%
Permission to bid dignified farewell

Word	X^2
bid farewell	10.06
leave	9.04
permit	8.04
familiar	7.06
stay	7.06
more	6.38
family	6.15

Class 2 - 29.79%
Effective communication

Word	X^2
video	9.85
to die	8.79
to predict	7.30
seriousness	7.30
to explain	7.30
admission	7.30
opportunity	6.47
much	4.17
calling	4.08

Class 3 - 14.89%
Promotion of comfort and care

Word	X^2
possible	36.62
to believe	23.87
pain	23.68
care	8.48
to feel	6.55
doctor	4.67

Figure 1. Decreasing Hierarchic Classification Dendrogram (words with high semantic content and X^2>3.80.

Source: Authors.

That the hospital provided the best possible comfort for easing his pain (P-52).

That they prevented him from feeling pain as much as possible (P-48).

That more attentive care was provided (P-69).

In this context of pain and suffering, but also, of hope, we could notice a wish for the patient to be saved regardless of the seriousness of the disease, and some interviewees hoped to be able to bring their relatives back home:

All available medical and technological services, comforting and humanization of healthcare (P-28).

Everything that was possible to do to save him (P-101).

Had given him the possibility of surviving, of having a proper treatment, he was sent back home twice, being that he was already gravely ill, and when he went back to the hospital, there were no available places for hospitalization, when an opening happened, he did not survive, he did not make it even to a room with oxygen! It is very sad to know that my uncle died from lack of air! (P-29).

It is hard to say what I would have liked. It is an enormous pain to lose someone who we believed was going to come back home (P-238).

Discussion

The results provide evidence of the complexity of the responses regarding grieving by family members of COVID-19 victims, revealing mainly emotional and behavioral characteristics, as well as possible risks of bad adaptation by those in a state of grieving.

The present study found a high level of severe grieving symptoms among people who lost family members to COVID-19 more recently (<6 months), also known as the severe grieving period, since nearly 30% (n=29) fit into the criteria of prolonged grief (Table 2), not including the time element. Such a finding contradicts with results verified by recent studies conducted in the Netherlands, in which people who suffered a recent loss during the pandemic showed higher levels of grief in comparison to people who suffered a recent loss before the pandemic. The authors suggest that expectations of death may explain this effect, considering that people who experience grief related to COVID-19 experience the loss as something unexpected, more often than those who experienced a natural loss. The authors also recommend that palliative care professionals, grief counselors, and policymakers should be aware of this demand[9,15].

On the other hand, among the people who had a grieving period of more than six months, 11.4% (n=5) fully met the comprehensive criteria for the diagnosis of Prolonged Grief Syndrome (Table 2). This result is similar to what was found by the validation study of the PG-13 for the Brazilian population, prior to the pandemic, in which a 10.43 percentage was found of people meeting the criteria of Prolonged Grief[2]. This result, however, diverges from the expectation of increased levels of prolonged grief after death by COVID-19, since the people who effectively fit into all of the criteria corresponded to a percentage similar to that of the pre-pandemic period.

According to the data observed in Table 3, there is a significant relationship between being a family member who meets the criteria of Prolonged Grief Syndrome and the degree of kinship. The study also revealed that most of the respondents who do not have professional follow-up (46.5%; n=66) are also the majority who have no diagnosis of prolonged grief (Table 3). However, this finding does not necessarily mean that people who did not meet all of the diagnostic criteria are not suffering. It is important to mention that some family members (19.0%; n=27) answered that they need follow-up, but they do not know which service could meet their demands.

One study on prolonged grief in China showed that more severe prolonged grief symptoms were associated with the loss of a closer relative due to COVID-19. The study investigated people with grieving periods more than and less than six months, verifying a 29.3% prevalence of prolonged grief symptoms with no considerable difference between the two groups. However, one interesting fact shows that 30% of the participants who suffered grief for more than 6 months believed that their grieving reactions were above what is expected by the local culture. This fact suggests that there is discrepancy between what the people themselves think and feel, and the concept of abnormality of grief from the standpoint of a professional evaluation[17].

Notably, behind the deaths listed as mere statistics, there are social networks of family and friends who are deeply moved by a loss[18], which is often considered to be unexpected due to the possibility of a rapid deterioration of conditions due to severe reactions to the disease.

From the analysis of the results of each question from the PG-13 instrument, we can see considerable frequencies of feelings of longing for or absence of the person who perished, as well as episodes of anguish. Considering cognitive, emotional, and behavioral symptoms, we can see that family members are shocked or confused by the loss, with feelings of bitterness and difficulties in accepting the death (Table 1).

One study, which investigated the development of prolonged grief, anxiety, and depressive symptoms, found that the first anxiety symptoms (in the first month) seem to contribute to the development of subsequent depressive symptoms of grief, which worsen in a later stage[19].

By contrast, some results suggest relevant aspects of the process of dealing with the loss by some of the participants, as it can be noticed in people who stated that they carry on with life, preserving some significance and maintaining interpersonal relationships (Table 1).

Although the grieving experience may be something natural, it is important to consider that the disturbance of the connection resulting from the generalized and persistent longing for the deceased, the loss of significance, and identity disorders are all symptoms that may arise late or last for over a year after death, being distressing and incapacitating. These symptoms, combined with any of the ten additional grieving reactions present in the grief instrument and presumed as indicative of intense emotional pain, indicate the need for specialized treatment for the person in grief[3].

Several participants reported repercussions in their social and professional lives and other activities in part III of the grief instrument (Table 2). This result was complemented by a characterization question, in which respondents stated that the death of the relative caused changes in their lives, in the physical, psychological, social, and financial dimensions.

Economic hardships, uncertainty about the future, as well as approaches required for the containment of the spread of the virus, all play critical roles in the social and psychological impact, in both the short and long terms, of the COVID-19 pandemic. Inequalities based on race and socioeconomic level influence the rates of both infection and death, as well as the steps required for recovery[20]. In Brazil, the high number of infections and deaths by COVID-19 reveals a profile of social impact, since the pandemic, initiated in neighborhoods of high socioeconomic level, gradually spread through the peripheral areas[21].

Regarding the expectations of the participants related to end-of-life care for their hospitalized relatives, if they knew that their relatives could become sick to the point of dying, the themes identified were: Permission for a dignified farewell, Effective communication, and Promotion of comfort and care.

The answers by the family members were mostly concise, something common in Internet communication. However, they did synthesize what really made sense to them in terms of grave situations. The findings indicate that the characteristics of access to patients during the pandemic represented the lack of a closer and more frequent contact (Class 1).

The hospitals became a habitual place for end-of-life situations, but not in the usual conditions, owing to such factors as the restrictive measures, which blocked families from staying with hospitalized relatives. Factors, such as social distancing, unexpected death, and the impossibility to bid farewell, may be predictors of Prolonged Grief Syndrome. Therefore, there is a need to dignify the conditions of end-of-life care in the context of the COVID-19 pandemic[22].

In many instances the bodies were removed after death, identification of the deceased was done at a distance and by means of digital pictures of the face, and the corpses were kept in body bags and were not dressed in the outfit chosen by the family. The coffins were closed and had to be kept closed during the funeral, and the burials were delayed or the family had to watch from a distance, or only a few people were allowed to attend[23]. In the proposed study, similar situations were verified, as can be seen in the statement of a participant regarding her deceased mother: "*I wish they had let the family take the outfit that she loved the most, to dress her with it*" (P-66).

It is interesting to highlight that some family members believe that it is indispensable to have frequent communication and information regarding the seriousness of the conditions (Class 2). In that regard, we understand that families and patients in palliative care want to talk about their preferences if the disease should progress[24], since a lack of transparency can become an additional source of stress. Given the circumstances of the pandemic, professionals need tools and resources to facilitate care planning and quality communication[7].

The data suggests that, in cases of imminent death, the participants mentioned that they wished their relatives had received a Promotion of Comfort and Care (Class 3), with emphasis on pain relief.

Symptom control is essential, and manifestations, such as dyspnea, pain and delirium in severely sick patients, must be properly addressed, considering that lack of comfort causes distress to the patients, families, and members of the healthcare team, leading to exhaustion and compassion fatigue[25].

Considering that participants stated that, "*even in the imminence of death, they assumed that everything possible was done to keep the patient alive*" (P-20). We emphasize that palliative care does not deny the importance of life-saving or life-prolonging care[26]; it rather recognizes the moral imperative of providing therapeutic proportionality in the care and relief of suffering for everyone, even when a cure is impossible.

The management of symptoms and support to grief are essential elements of palliative care[27]. Therefore, grief related to terminal cases in the current context is something that must be reconsidered, including the development of innovative means through which to connect people, and deal with the before and after death, adapting rituals, resorting to physical or virtual alternatives of memorializing and paying respects, and therefore providing comfort to the families while maintaining the rules of infection control[28,29].

The results presented in this study contribute to the improvement of knowledge in the field of palliative care, with emphasis on acknowledging grief and reflecting on end-of-life care. The use of an instrument for the evaluation of people in grief, such as the PG-13, is recommended in the field of palliative nursing care as one of the ways to identify indicators of suffering, providing help in terms of relieving symptoms and eliciting the work of multidisciplinary teams.

Interventions carried out by nurses, such as telephone contacts, follow-up, and emotional support before and after death, may help to reduce grief symptoms among family caregivers, such as anxiety, anguish, and depressed mood. However, these practices require a more in-depth study, with a higher level of evidence[30].

As limitations of this study, we must mention the challenges in conducting a study on such a complex theme, conducted via internet during the pandemic, as can be noted in the many short answers, typical of a social network language, thus complicating a deeper analysis of the testimonies. Other relevant factors included: working with a non-probabilistic sample, a higher number of answers from the Northeast region (which was the author's region of origin), and the fact that only people with electronic devices (computer, smartphones) connected to the internet were able to access the questionnaire, which does not represent the reality of the Brazilian population.

Conclusion

The present study illustrates elements of the evaluation of grief among family members of COVID-19 victims, involving separation anxiety elements, cognitive and behavioral symptoms, and social implications. The symptoms of Prolonged Grief Syndrome have a significant relationship with the degree of kinship, as people who lost a close relative due to COVID-19 generally presented intense grieving reactions.

Grief evaluation instruments, such as the PG-13, may be useful for nurses in identifying elements of suffering in grieving people, in enabling better mental health support, in relieving patients of symptoms, and in referring at-risk individuals to specialized care.

One point that stands out is that in end-of-life situations, when people are so sick that they are about to die, the findings indicate that families expect transparency in communication regarding the health situation, as well as moments to say goodbye and the promotion of comfort for the sick person. The findings provide evidence for nurses and other health professionals that they need to adopt the practice of palliative care for patients and family members in such scenarios. Further studies are warranted in order to investigate relationships between the described findings so as to expand knowledge regarding this complex moment experienced by humanity.

Collaborations

PLC Lucena: conception and planning of the study, methodology, investigation, data curation, original manuscript, critical review of the article, and approval of the final version. AMPM Alves: conception, data curation, critical review of the article, and approval of the final version. PSS Batista: conception, data curation, critical review of the article, and approval of the final version. G Agra: conception, data curation, critical review of the article, and approval of the final version. AV Lordão: methodology, data curation, software, critical review of the article, and approval of the final version. SFG Costa: conception and planning of the study, methodology, data curation, original manuscript, critical review of the article, and approval of the final version.

References

1. Radbruch L, Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, Blanchard C, Bruera E, Buitrago R, Burla C, Callaway M, Munyoro EC, Centeno C, Cleary J, Connor S, Davaasuren O, Downing J, Foley K, Goh C, Gomez-Garcia W, Harding R, Khan QT, Larkin P, Leng M, Luyirika E, Marston J, Moine S, Osman H, Pettus K, Puchalski C, Rajagopal MR, Spence D, Spruijt O, Venkateswaran C, Wee B, Woodruff R, Yong J, Pastrana T. Redefining palliative care – a new consensus-based definition. *J Pain Symptom Manag* 2020; 60(4):754-7646.
2. Delalibera M, Delalibera TA, Franco MHP, Barbosa A, Leal I. Adaptação e validação brasileira do instrumento de avaliação do luto prolongado: PG-13. *Psicol Teoria Pratica* 2017; 19(1):94-106.
3. Prigerson HG, Boelen PA, Xu J, Smith KV, Maciejewski PK. Validation of the new DSM- 5-TR criteria for prolonged grief disorder and the PG-13-Revised (PG-13-R) scale. *World Psychiatry* 2021; 20(1):96-106.
4. Eisma MC, Boelen PA, Lenferink LIM. Prolonged grief disorder following the Coronavirus (COVID-19) pandemic. *Psychiatry Res* 2020; 288:113031.
5. Kokou-Kpolou CK, Fernández-Alacántara M, Cénat JM. Prolonged grief related to COVID-19 deaths: do we have to fear a steep rise in traumatic and disenfranchised griefs? *Psychol Trauma* 2020; 12:S94-S95.
6. Rothan HA, Byrareddy SN. The epidemiology and pathogenesis of coronavirus disease (COVID-19) outbreak. *J Autoimmun* 2020; 109:102433.
7. Wallace CL, Wladkowski SP, Gibson A, White P. Grief during the covid-19 pandemic: considerations for palliative care providers. *J Pain Symptom Manage* 2020; 60(1):e70-e76.
8. World Health Organization (WHO). *Coronavirus (COVID-19) dashboard* [Internet]. 2021 [cited 2023 mar 15]. Available from: https://covid19.who.int/.
9. Eisma MC, Tamminga A, Smid GE, Boelen PA. Acute grief after deaths due to COVID-19, natural causes and unnatural causes: An empirical comparison. *J Affect Disord* 2021; 278:54-56.
10. Walshe C. Perspectives on COVID-19 and palliative care research. *Palliat Med* 2021; 35(1):4-5.
11. Souza VRDS, Marziale MHP, Silva GTR, Nascimento PL. Translation and validation into Brazilian Portuguese and assessment of the COREQ checklist. *Acta Paul Enferm* 2021; 34:eAPE02631.
12. Malta M, Cardoso LO, Bastos FI, Magnanini MMF, Silva CMFPD. STROBE initiative: guidelines on reporting observational studies. *Rev Saude Publica* 2010; 44(3):559-565.
13. World Health Organization (WHO). *Transmission of SARS-CoV-2: implications for infection prevention precautions* [Internet]. 2020 [cited 2023 mar 15]. Available from: https://www.who.int/publications/i/item/modes-of-transmission-of-virus-causing-covid-19-implications-for-ipc-precaution-recommendations.
14. Salvador PTCO, Alves KYA, Rodrigues CCFL, Oliveira LV. Online data collection strategies used in qualitative research of the health field: a scoping review. *Rev Gaucha Enferm* 2020; 41:e20190297.
15. Eisma MC, Tamminga A. Grief Before and during the COVID-19 pandemic: multiple group comparisons. *J Pain Symptom Manage* 2020; 60(6):e1-e4.
16. Boelen PA, Lenferink LI. Symptoms of prolonged grief, posttraumatic stress, and depression in recently bereaved people: symptom profiles, predictive value, and cognitive behavioural correlates. *Soc Psychiatry Psychiatr Epidemiol* 2020; 55:765-777.
17. Tang S, Xiang Z. Who suffered most after deaths due to COVID-19? Prevalence and correlates of prolonged grief disorder in COVID-19 related bereaved adults. *Globalization Health* 2021; 17:19.
18. Minayo MCS. *O desafio do conhecimento: pesquisa qualitativa em saúde*. São Paulo: Hucitec; 2014.
19. Comissão Nacional de Ética em Pesquisa. *Orientações para procedimentos em pesquisas com qualquer etapa em ambiente virtual* [Internet]. Brasília: MS; 2021 [acessado 2023 mar 15]. Disponível em: http://conselho.saude.gov.br/images/Oficio_Circular_2_24fev2021.pdf.%20Acesso%20em:%2002%20mar.2021.
20. Osofsky JD, Osofsky HJ, Mamon LY. Psychological and social impact of COVID-19. *Psychol Trauma Theory Res Pract Policy* 2020; 12(5):468-469.
21. Medeiros EAS. A luta dos profissionais de saúde no enfrentamento da COVID-19. *Acta Paul Enferm* 2020; 33:e-EDT20200003
22. Beneria A, Castell-Panisello E, Sorribes-Puertas M, Forner-Puntonet M, Serrat L, García- González S, Garriga M, Simon C, Raya C, Montes MJ, Rios G, Bosch R, Citoler B, Closa H, Corrales M, Daigre C, Delgado M, Dip ME, Estelrich N, Jacas C, Lara B, Lugo-Marin J, Nieto-Fernández Z, Regales C, Ibáñez P, Blanco E, Ramos-Quiroga JA. End of life intervention program during COVID-19 in Vall d'Hebron University Hospital. *Front Psychiatry* 2021; 3(12):608973.
23. Aguiar A, Pinto M, Duarte R. Grief and mourning during the COVID-19 pandemic in Portugal. *Acta Med Port* 2020; 33(9):543-545.
24. Sharpe TD. You won't die alone: technology and compassion in the covid-19 pandemic. *Enferm Foco* 2020; 11(2 n. esp.):52-54.
25. Fadul N, Elsayem AF, Bruera E. Integration of palliative care into COVID-19 pandemic planning. *BMJ Support Palliat Care* 2021; 11(1):40-44.
26. Chalk D, Robbins S, Kandasamy R, Rush K, Aggarwal A, Sullivan R, Chamberlain C. Modelling palliative and end-of-life resource requirements during COVID-19: implications for quality care. *BMJ Open* 2021; 11(5):e043795.
27. Harrop E, Scott H, Sivell S, Seddon K, Fitzgibbon J, Morgan F, Pickett S, Byrne A, Nelson A, Longo M. Coping and wellbeing in bereavement: two core outcomes for evaluating bereavement support in palliative care. *BMC Palliat Care* 2020; 19(1):29.
28. Helton G, Wolfe J, Snaman JM. Definitely Mixed feelings: the effect of covid-19 on bereavement in parents of children who died of cancer. *J Pain Symptom Manage* 2020; 60(5):e15-e20.

29. Mayland CR, Harding AJE, Preston N, Payne S. Supporting on grief and bereavement adults bereaved through covid-19: a rapid review of the impact of previous pandemics. *J Pain Symptom Manage* 2020; 60(2):e33-e39.
30. Tofthagen CS, Kip K, Witt A, McMillan SC. Complicated grief: risk factors, interventions, and resources for oncology nurses. *Clin J Oncol Nurs* 2017; 21(3):331-337.

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