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The experience of COVID-19 through the eyes of those who had the disease: a qualitative study

A experiência da COVID-19 pelo olhar de quem apresentou a doença: um estudo qualitativo

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ABSTRACT
To know and understand, through the eyes of the person who had COVID-19, what it was like to have gone through this experience. Qualitative exploratory descriptive research. Study population composed of individuals diagnosed with COVID-19 referred for treatment at a Physical Rehabilitation Center. Data collection performed through a questionnaire (characterization) and semi-structured interview. The interview responses were analyzed using Content Analysis (Bardin). Participants reported a bad and difficult experience with an unknown illness. Several feelings were experienced, fear being very emphasized. Respondents had physical and emotional limitations and loss of independence. They started to worry more about their health and value family, friends, and health professionals. Early assistance to this population is important, providing means of information about the disease, psychotherapeutic and rehabilitation care, preventing long-term effects that hinder their recovery.

Keywords: Coronavirus infections. Health-disease process. Psychological distress.

RESUMO
Conhecer e compreender, por meio do olhar da pessoa que apresentou a COVID-19, como foi ter passado por essa experiência. Pesquisa descritiva exploratória qualitativa. População do estudo composta por indivíduos com diagnóstico de COVID-19 encaminhados para tratamento em um centro de reabilitação física. Coleta de dados realizada por meio de um questionário (caracterização) e entrevista semiestruturada. As respostas da entrevista foram analisadas com a Análise do Conteúdo (Bardin). Os participantes relataram uma experiência ruim e difícil, com uma doença desconhecida. Diversos sentimentos foram vivenciados, sendo o medo muito enfatizado. Os entrevistados apresentaram limitações físicas, emocionais e perda da independência. Passaram a se preocupar mais com sua saúde e valorizar mais a família, amigos e profissionais da saúde. É importante a assistência precoce a essa população, disponibilizando meios de informações sobre a doença, atendimento psicoterapêutico e de reabilitação, prevenindo efeitos a longo prazo, que dificultam sua recuperação.

Palavras-chave: Infecções por coronavírus. Processo saúde-doença. Angústia psicológica.

INTRODUCTION

The disease caused by SARS-Cov-2, COVID-19 (Coronavirus Disease), was first recorded in December 2019 in the city of Wuhan, China[1]. The spread of the virus occurred quickly, taking on global proportions, and on March 11, 2020, the World Health Organization (WHO) declared that the COVID-19 outbreak had become a pandemic with a high state of alert [2,3].

Since then, COVID-19 has become a major threat to global health, responsible for 542 million cases and 6 million deaths worldwide according to the WHO. In Brazil, according to official Worldometer statistics, the number of deaths has already surpassed the 670,000 mark and estimates indicate that more than 32 million Brazilians have already been infected with the virus[4,5].

COVID-19 is a disease that presents a wide range of clinical manifestations, mainly affecting the respiratory system, but can compromise other organs and systems[3]. About 80% cases are considered asymptomatic or mild and 20% cause some type of severe respiratory impairment, often evolving to acute respiratory failure, multiple organ failure, and may lead to death[6].

During the acute phase of the disease, the most common clinical manifestations include fever, dry cough, fatigue, dyspnea, sore throat, loss of taste or smell, nasal congestion, muscle and joint pain, chest and head pain, in addition to gastrointestinal symptoms such as nausea, vomiting, and diarrhea[7].

Even after the acute phase of COVID-19, some individuals continue to have residual symptoms, especially those who were affected by the severe or moderate form of the disease[3]. Post-COVID-19 syndrome, as it is called, can be divided into a subacute phase, when symptoms or dysfunctions remain from four to 12 weeks after infection; and a chronic phase, when symptoms remain present after 12 weeks or more and are not associated with other diagnoses[8].

In post-COVID-19 syndrome, commonly reported symptoms and dysfunctions are fatigue, muscle weakness, dyspnea, myalgia, chest pain, cough, dysosmia, dysgeusia, cognitive and mental changes, such as memory and attention problems, in addition to an increase in probability to develop psycho-emotional changes such as stress, depression, irritability, insomnia, confusion or frustration[9,10].

In similar events, such as the Severe Acute Respiratory Syndrome (SARS), in 2003, and the Middle East Respiratory Syndrome (MERS), in 2015, infected individuals presented psychological distress during the acute phase, showing symptoms of extreme anxiety due to the lack of knowledge about the disease, feelings of anger and fear during the period of isolation, in addition to concern about the possible death of a family member or with social issues[11-13].

Long-term follow-up studies after these events have shown that depressive symptoms, anxiety, panic disorder, and post-traumatic stress are present in survivors, even after three years of contagion[13,14]. In studies with the aim of exploring the psychological disorders of COVID-19 survivors, similar results were observed[15-17].

The physical and psychological suffering experienced by individuals who survive COVID-19, both in the acute phase and the late phase of the disease, can negatively influence recovery and return to activities of daily living, directly interfering with the quality of life of these people[14].

Since the beginning of the pandemic, many studies have been conducted in relation to COVID-19. There is a large amount of qualitative research in the literature that addressed the experiences of health professionals in coping with this disease in their daily work. However, there are still few studies that seek to understand the experiences of individuals who were affected by COVID-19 and survived.

The collected data can contribute information that will help the health teams involved in the prevention and treatment of COVID-19, to understand the needs of these individuals during and after their treatment and, in this way, help the planning and execution of more individualized and humanized conducts, seeking assistance that includes these people, given comprehensive care in the health area. In this way, the goal of this study was to know and understand, through the eyes of the person who had COVID-19, what this experience was like.

METHODS

This was a qualitative, exploratory, descriptive study. The study population was individuals who had a diagnosis of COVID-19 and were referred for treatment at the Physical Rehabilitation Center (CRF) of the State University of Western Paraná (Unioeste), located in the city of Cascavel, state of Paraná, in the year 2021. This study was approved by the Human Research Ethics Committee from Unioeste, under opinion 5031987.

Inclusion criteria were: people of all genders; age above 18 years; tested positive for COVID-19; being assisted or having been assisted in one of the sectors of the CRF in the year 2021. The exclusion criteria were: individuals who had cognitive and communication alterations that made it impossible to collect information through the application of a questionnaire and interview.

In the CRF, medical records were analyzed to identify the subjects referred to receive treatment for the post-COVID-19 syndrome during the year 2021. Individuals who met the inclusion criteria were contacted by telephone to be invited to participate in the study. For those who agreed to participate, the date and time were scheduled for data collection, which could be

conducted in three ways: in person, by video call, or by telephone, depending on the participant's availability. In this first contact, the researchers provided clarifications on the justification of the research, its objective, and how it was carried out.

In the face-to-face format, the Informed Consent (IC) was read and signed by the participant. In the format by phone or video call, the researchers read the IC and after obtaining the individual's verbal consent, a copy of the document was sent via email or through a smartphone messaging application.

Data were collected by a questionnaire and a semi-structured interview, in which a guiding question was used. In the face-to-face format, the interview was audio recorded (digital recorder). In the video call format, the image and audio were recorded during the application of the questionnaires and the interview. In the telephone format, the application of the questionnaires and the interview were audio recorded.

The applied questionnaire consisted of questions with variables to characterize the participants: personal data; sociodemographic data; how long have been attending or attended CRF-Unioeste; how many times have been infected with the coronavirus; whether or not were hospitalized; whether or not used oxygen support; whether or not needed any type of ventilatory support. The semi-structured interview was based on the following guiding question: "For you, how was the experience of COVID-19?". Data collection for the study took place from March to April 2022.

Data from the questionnaire characterizing the individuals were entered into Microsoft Excel spreadsheets and analyzed using simple descriptive statistics. The answers to the semi-structured interview question were transcribed verbatim and identified by the letter "E" for "interviewee" followed by numbers, obeying the order in which they were carried out, to be analyzed later.

The data saturation criterion was adopted to determine the number of interviews carried out. Considering this assumption, the number of interviews is related to the recurrence of information, that is, as the interviews were carried out and transcribed and no changes were found in the pattern of responses, the collection was finished[18].

The transcribed texts were analyzed using Content Analysis, following a few steps: (1) pre-analysis, (2) exploration of the material, and (3) organization of results, inference, and interpretation[19].

In the pre-analysis, all the texts of the individuals who agreed to participate were analyzed, obtained in similar ways, using the pre-established guiding question, formulated from the research objective. In this phase, with the floating reading of the texts, some hypotheses and indicators were raised so that the data could be analyzed and interpreted[19].

In the step corresponding to the exploration of the material, the record units (citations) were identified in the transcribed texts, that is, the statements that had some meaning. In the third step, the record units with similar thematic characteristics were grouped into categories, which made their interpretation possible[19].

RESULTS

In 2021, 65 individuals were referred to CRF-Unioeste to undergo treatment for post-COVID-19 syndrome. Of these 65 subjects, 24 were excluded: two for being minors; two because there was no information on confirming the positive diagnosis of COVID-19; 14 for having been referred, being on the waiting list, but not yet having undergone treatment at CRF-Unioeste until the time of data collection; and six for abandoning treatment.

From the list of 41 remaining individuals, a draw was made to establish who would be interviewed until the data saturation criterion was reached. In all, 26 people were contacted, six of whom did not accept to participate in the study and four did not answer the calls; resulting in 16 subjects with an average of 52.5 (± 15.58) years. Table 1 lists the characterization data of the participants.

Table 1 - Characterization data of participants, Cascavel, state of Paraná, 2022, (n=16)

Variables	N (%)
Gender	
Female	8 (50.00)
Male	8 (50.00)
Marital status	
Married	10 (62.50)
Single	2 (12.50)
Divorced	2 (12.50)
Widowed	2 (12.50)
Education	
Elementary education	5 (31.25)
High school	8 (50.00)
Higher education	3 (18.75)
Religion	
Evangelicals	6 (37.50)
Catholics	5 (31.25)
Spiritists	1 (6.25)
Other religions	2 (12.50)
No religion	2 (12.50)
Occupation	
Salaried	8 (50.00)

Self-employed	2 (12.50)
Retired	4 (25.00)
Unemployed	2 (12.50)

None of the participants had attended CRF-Unioeste before having COVID-19 and, on average, they remained in treatment for 3.5 (±3.26) months. All were contaminated only once with the coronavirus, with 15 (93.75%) requiring hospitalization and only one (6.25%) not. Table 2 lists the data related to the period of hospitalization of these 15 people.

Table 2. Data related to the hospitalization period, Cascavel, state of Paraná, 2022 (n=15)

Variables	N (%)	Time/days (mean ± SD)
Hospital admission sector		
Emergency Care Unit - UPA	6 (37.50)	2.5 ±1.04
Intensive Care Unit - ICU	8 (50.00)	19.5 ±11.16
Infirmary	11 (57.89%)	8.4 ±3.93
Need for ventilatory support		
Yes	10 (66.67)	-
No	5 (33.33)	-
Type of ventilatory support		
Invasive Mechanical Ventilation - IMV	4 (26.67)	-
Non-Invasive Mechanical Ventilation - NIMV	6 (40.00)	-
Oxygen therapy during hospitalization		
Yes	14 (93.33)	-
No	1 (6.67)	-
Non-Invasive Mechanical Ventilation		
Yes	6 (40.00)	-
No	9 (60.00)	-

Eight thematic categories emerged from the analysis of the transcribed speeches: 1) the positive/negative perception of COVID-19; 2) the feelings experienced during the acute and late phases of COVID-19; 3) hospitalization due to COVID-19; 4) the recovery process: the difficulties and limitations experienced during the post-COVID-19 syndrome; 5) dependency during the chronic phase of COVID-19; 6) health care adopted after COVID-19; 7) spirituality as a coping strategy; 8) valuing family, health, life, and health professionals: learning after the experience with COVID-19.

The positive/negative perception of COVID-19

Participants, when asked about the experience of having COVID-19, defined this experience as bad and difficult, as they had to deal with an unknown disease. They were

subjected to situations considered unpleasant, such as being forced to wear masks, being hospitalized, dealing with issues related to death and still suffering from the consequences of the disease. Excerpts from the participants' speeches are presented to demonstrate these experiences.

"The bad part is that you have this disease, you have something that you never thought you would have in your life" (E14).

"[...] horrible experience being hospitalized because of a disease that affected a lot of people, killed a lot of people, I saw a lot of people die during the period I was hospitalized" (E11).

"[...] my physical condition is no longer the same, I feel very tired, so it is a bad experience in that sense, having gone through Covid" (E2).

Due to this negative perception, participants reported that this type of situation they would not wish for other people.

"An experience that I would not want anyone to go through" (E7).

"[...] no one deserves that; it is an experience that is harmful and suffocating" (E12).

On the other hand, some individuals classified the experience as "good", because according to them, it allowed them to learn information about health care and life lessons.

"[...] my experience of going through COVID-19 was good because I learned a lot, what we should do, what we shouldn't do, take care, protect ourselves to prevent it" (E9).

"In parts, you can say that my experience was even good, I was able to learn, you have to be very careful, not only with Covid but with everything" (E11).

Feelings experienced during the acute and late phases of COVID-19

Individuals reported that, during the acute phase of COVID-19, fear was the main feeling experienced. Other feelings were present, such as anxiety, irritation, and anger, because they had to remain in social isolation. They mentioned feeling useless, depending on other people to carry out their daily activities, and being traumatized by the COVID-19 experience.

"I had this feeling of fear of dying in there, it's horrible [...] I was afraid of dying, afraid of going to the ICU" (E11).

"[...] I was kind of angry with the existence of Covid, with spoiling the moment, of forcing me to stop my life" (E6).

"Useless because I wanted to do things, let's say, a practical example, I wanted to get out of bed to take a shower, I didn't have the strength to do that, I couldn't do that" (E7).

"You see all the protocol that is used after it happens that you are already there, that there is no way to keep your cell phone, you cannot receive visits, you cannot see anyone, so this is traumatizing, it traumatizes us" (E1).

In the late stage of the disease, in general, feelings such as sadness, seeing so many deaths in the population, misunderstanding why this was happening to them, and fear of the possible sequelae of the disease, were the externalized feelings.

"It's sad, we see so many people dying from this, leaving the family, still little children, it's very sad" (E5).

"I was afraid of being alone at home, of having depression" (E10).

"The experience we have is that people think that they can have sequelae, we think that it will not go back to normal, we have all this fear afterward" (E15).

"And this is because of Covid, I don't understand until I was with the caregiver I was hungry, I even wanted to eat more, and then when I get home, I can't eat anything" (E4).

Hospitalization due to COVID-19

Individuals who remained hospitalized reported experiences they never imagined they would have, such as being dependent on health professionals for basic needs and personal hygiene and witnessing the deaths of other people affected by the disease.

"I never imagined being in a situation like that in the hospital, not being able to hold a glass of water [...]" (E13).

"I went to the nurse, wow, I need to take a shower anyway, someone has to help because I can't do it alone, then she helped me to take a shower [...]" (E7).

"Because there was a lady who died in the same room as me, all the protocol that was adopted, with the body, we see it there, you have to notify the family and such, you take, bag it, place the body in a bag, seal it well the bag, puts medicine on everything, puts a ribbon with her name and age, because no one else will see" (E1).

The recovery process: the difficulties and limitations experienced during the post-COVID-19 syndrome

The research participants reported that the first days at home were difficult, as they had to deal with limiting situations, in which they had constant shortness of breath, difficulties in eating, and limitations in walking and performing their hygiene independently.

"[...] I lay down and I remember that I woke up a few hours at night and I couldn't even get up, I had a shortness of breath that seemed like this, that it was terrible" (E10).

"The first few days I couldn't walk, it was very difficult" (E15).

"Everything I ate, I vomited and everything I was going to put in my mouth made me urge to vomit, if I forced myself, I would vomit everything [...] (E4).

"I spent four months, five months on the oxygen tube, sometimes I had to take a shower with that mask on my face [...]" (E13).

During this period, participants had to recover motor and sensory functions, in addition to facing the traumas experienced due to the disease.

"I held on to the chair and changed my steps, it was like I was a child, learning to walk" (E15).

"I couldn't sleep [...] because of the shortness of breath I had, because I thought that every time I go to sleep it will be like this" (E10).

"The taste of food lasted seven months, now I started to feel the smell after three months" (E15).

Some individuals are still struggling to fully recover, facing difficulties due to the physical and emotional changes caused by COVID-19. In addition, many still suffer from the consequences of the disease.

"Until now I'm still in the fight, I've been trying my best, my best. There is no way to try harder [...]" (E4).

"[...] just like a person with depression who doesn't feel like doing anything, doesn't want anyone to talk, no one, you know, stays in their place like that" (E2).

"It hit my mind a lot, I was very forgetful [...] Today I meet an acquaintance, I keep looking at his face, talking and trying to remember who he is" (E13).

"It lacks a little resistance, but that's fine, with time it comes" (E12).

Dependency during the chronic phase of COVID-19

Due to limitations caused by COVID-19, some individuals needed help from others, especially family members, during the late phase of COVID-19, for activities of daily living and financial matters. This condition, most of the time, caused discomfort, as it left the participants in a situation of vulnerability and loss of independence.

"Until now the financial conditions of people, because like me, I was the head of the house, so I had to depend on the children, I depend until now [...]" (E13).

"[...] an experience that I found out that we are dependent on people, even if you don't want to, that you think you are capable of everything alone, you will always be depending on help, on a favor" (E10).

"The person who is always doing things for everyone, is always serving people, let's say, then suddenly you feel in that situation, I can't do anything else, I wanted to do this, but I can't [...]" (E7).

Health care adopted after COVID-19

Through lived experience, individuals demonstrated to be more concerned with health care in general, using the preventive measures introduced during the COVID-19 pandemic, to prevent contamination with other diseases.

"I think we fought anyway and got this whole experience now, the mask, using alcohol in our hands, going out warm [...] because it's not just Covid that kills" (E9).

"Because it's not just Covid that causes it, a mask helps to avoid a lot of things, it's not only this disease that you have, alcohol protects us against other diseases [...]" (E11).

They reported concern about being contaminated again with the coronavirus, as they fear the possible consequences of new reinfection, thus also seeking to follow preventive measures as a form of protection.

"Health staff are asking you to use alcohol, wear a mask and wash your hands frequently, and look for as many things as possible to make the places airy [...]" (E10).

"[...] I go out on the street, I still wear a mask, I'm always using gel alcohol and everything, I do worry because I still want to live another two years at least" (E5).

"Your lung isn't even healed yet and there's a sequel again, and then it's all over again [...] so I'm careful" (E4).

Spirituality as a coping strategy

Spirituality/religiosity was cited by the participants, many of whom claim to have survived COVID-19 due to the will and presence of a superior being.

"I was very close to death when I had Covid, I was dead, for five days I couldn't even move my fingers, but there was a God up there, and that God freed me once again from the loop of death" (E4).

"Because if it were God's will, maybe I wouldn't even be here anymore" (E10).

"[...] it was a miracle from God that I saved myself, got rid of it" (E5).

The individuals interviewed associated spirituality/religiosity as one of the mechanisms that helped them in the recovery process and report gratitude for health and life.

"[...] every day you open your eyes thank God because it's a gift you get, a new day" (E10).

"I thank God that no organ was affected, only the lung, and thank God that the lung is fine today [...]" (E12).

"The good thing is that I recovered, God gave me thanks, that's the best thing about it" (E15).

"I'm just grateful to God who has helped me so far [...] I'm back, I'm working, which is the thing I love to do most in my life" (E14).

Valuing family, health, life, and health professionals: learning after the experience with COVID-19

Individuals who participated in the study reported having gained a new chance at life. They began to act differently in the face of everyday events, valuing family, friends, and health more, seeking to have a more humanized look at the people around them.

"It was a huge learning experience [...], I learned to value things a lot, time, people, friends" (E3).

"We value life more, we value family more, people around us more, and we try to take better care of ourselves" (E15).

"I think this was one of the experiences that made me look more at the human side of people" (E10).

"[...] I think it's more human, it's no longer material things, I think there is a lack of humanity for everyone who is in this rush, in this crazy life" (E3).

These learnings may be due to the feeling of finitude that the subjects experienced when faced with near-death situations.

"[...] I almost died, so I was like, my God, we have no way of knowing what Covid will cause" (E6).

"[...] everything you see there in the hospital, people coming in and not being able to leave, you see that you have taken one more step towards life, it gives more value" (E1).

Another aspect raised by the individuals was their appreciation of health professionals. They began to realize the importance of the role of these individuals in their treatment and recovery.

"[...] I think these are people who, when they die, go to heaven, because they give their lives, their time, to be there taking care of other people" (E10).

"I also learned to value health professionals [...] especially physical therapy, physical therapy is something essential" (E3).

DISCUSSION

The mean age of participants in this study was 52.5 years. In the study by Son *et al.*[20], the mean age was 54.5 years, while in Schiavi *et al.*[21] e Sun *et al.*[22], the mean was 62.8 years and 32 years, respectively. Most research participants reported being married, having an occupation (being employed), having completed high school, and practicing some religion. The present study presents similar results to previous studies[20-22].

Similarly, Schiavi *et al.*[21] observed that most participants required hospitalization, with severe clinical manifestations of the disease, with the need for oxygen support and IMV, in an average hospital stay of 19.1 days. Individuals who needed ICU care remained hospitalized for an average of 13.7 days. Still regarding hospitalization, Son *et al.*[20] and Sun *et al.*[22] found an average length of stay of 34.1 and 17 days, respectively.

Participants of the present study, when asked about what this experience was like, for the most part, defined the experience of having COVID-19 as bad and difficult, as they had to deal with an unknown disease, be subjected to situations considered unpleasant and still suffer from the consequences left by the disease.

Cava *et al.*[23] investigated the experiences of individuals during the SARS outbreak, and participants reported uncertainties, mainly because they were dealing with an unknown disease, having to interrupt their daily routines, and fearing for their health or that of a loved one. Those affected also reported having to deal with issues that were also considered unpleasant, such as rejection and prejudice by other individuals in society and permanent changes in many aspects of their lives, preventing them from returning to normality[23].

Some individuals in the present study classified the experience as positive, because, according to them, it was possible to learn about health care and have life lessons. In the studies by Sun *et al.*[22] and Sun *et al.*[24], participants reported that, through the experience with the disease, there was learning, demonstrated by personal growth, greater appreciation of their health, and expressions of gratitude for COVID-19.

The interviewees of this study reported that in the acute phase of the disease, that is, during the period of isolation and hospitalization, they experienced different feelings, such as anxiety, irritation, anger, and mainly fear. They reported feeling useless for depending on other people to carry out their daily activities and traumatized by the experiences they had during the disease. In similar studies, individuals stated that, due to concern about the symptoms and the health of family members and the lack of information passed on by the medical team, feelings such as anxiety, sadness, stress, anger, and a feeling of helplessness were triggered[25-26].

Fear is one of the most reported feelings during this period, as it is related to several factors experienced, such as manifestations of symptoms considered severe, hospitalization, isolation, the possibility of infecting other individuals, and even dying[24-26].

Regarding the late phase of COVID-19, the participants externalized feelings such as sadness, misunderstanding, and fear of the possible consequences of the disease. In the study by Schiavi *et al.*[21], which sought to understand the experiences of people who were discharged after hospitalization due to COVID-19, fear was again the most reported feeling, highlighting the dread of remembering the experience and the fear of being contaminated and getting sick again. Anxiety, depressive symptoms, and worry were other feelings experienced in this phase[21].

The interviewees in the present study, who remained in the hospital, reported experiences that they did not imagine they would go through, such as being dependent on health professionals for basic needs and personal hygiene, in addition to witnessing the protocols adopted after the death of other people affected by COVID-19, expressing that this period

brought a negative experience. Participants of the study by Venturas et al.[27], when asked about hospitalization due to COVID-19, reported that they felt safe and confident, as they believed they were receiving good care from health professionals and despite the difficulties experienced, such as social isolation and evolution of symptoms demonstrated positivity in this period.

In the present study, the subjects expressed that the first days at home were difficult, as some still had persistent symptoms that limited their activities of daily living. During the recovery process, they had to deal with changes in their motor and sensory functions, in addition to emotional issues. The study by Pei *et al*.[25] presents reports of individuals who believed that recovery after hospital discharge would be gradual, but the persistence of symptoms such as muscle weakness, loss of appetite, and shortness of breath caused concern due to the possibility of not fully recovering.

In previous studies[25,29], participants stated that fatigue and muscle weakness were marked physical symptoms during the late recovery from COVID-19, making it impossible for them to walk and perform their daily activities. Cognitive alterations, such as forgetfulness and difficulty concentrating, also negatively influenced the quality of life of those affected, and these reports are similar to those found in the present study.

In the study by Schiavi *et al*.[21], based on the analysis of the participants' statements, two different perceptions emerged about recovery after COVID-19. While some individuals reported partial recovery, in which they were not yet able to perform all their activities of daily living, others claimed to have returned to their routine, but not exactly as it was before the illness.

Faced with the stress associated with the experience of COVID-19, some people have persistent psychological symptoms during the recovery process, such as anxiety and depression, which can be identified in reports of loss of enthusiasm for life, because they feel depressed, discouraged, and constant concerns [16,21]. In long-term follow-up studies after similar events, such as SARS, in 2003, and MERS, in 2015, depressive symptoms, anxiety, and post-traumatic stress were present in survivors, even after four years of contagion[13,14].

The study participants reported that the help of others, especially family members, was required during the recovery phase of COVID-19, to help with their activities of daily living and financial matters. This condition caused discomfort, as it left them in a situation of vulnerability and with a change in independence.

In the study by Missel *et al*.[30], participants reported that the care provided by their support network was very important in their lives during the period of isolation. Nevertheless, similar to the reports of the interviewees in this study, this situation also caused discomfort and embarrassment. Individuals put themselves in a condition of inability to repay what they were

receiving and showed concern about becoming a burden to the people who were helping them[30]. In the study by Jesmi *et al*.[26], the affected people were afraid of becoming dependent on family members, due to their fragility and inability to meet their basic needs.

Members of the present study were more concerned about general health-related care after experiencing COVID-19; reported concern about being contaminated with the coronavirus again, as they feared the possible consequences of a new reinfection. In the study by Sun *et al*.[22], individuals also showed greater awareness of the importance of health care after infection with COVID-19. After recovering and returning to their daily routine, they continued to use masks in public places and frequently washed their hands, adopted healthier habits in their lives, and emphasized the importance of health care, including vaccinations and regular physical examinations[22].

Spirituality was mentioned by the interviewees in this study as one of the strategies for coping with the disease and one of the mechanisms that helped them in the recovery process. In similar studies, it is possible to observe the use of spirituality, trust, and gratitude to a superior being, as a coping mechanism to moderate stress, helping to reduce tensions and concerns during COVID-19[16,26].

The people who participated in this study considered that they had gained a new chance at life, started to act differently in the face of everyday events, valued family, friends, and health more, and sought to have a more humanized look at the people around them. Other investigations to understand the experience of individuals who had COVID-19 showed that most people experienced, after this experience, a positive change in their attitudes and values towards life, going through a process of reassessing their priorities. They also demonstrated positive changes in family and friend relationships [22,24]. This process is commonly reported in the case of infectious diseases or events that cause post-traumatic stress[22].

Another aspect raised by individuals in this study was the appreciation of health professionals. The importance of the work of these individuals for their treatment and recovery was reported. In the studies by Sun *et al*.[22] and Sun et al.[24], participants expressed their gratitude to health professionals involved in the treatment of individuals with COVID-19, recognizing the efforts and risks assumed during the care provided to those affected.

According to Sun *et al*.[22], health professionals can benefit from the positive changes reported by patients in their experience with COVID-19, using them as a coping mechanism to help with the emotional and physical difficulties presented during the recovery process.

Given the reports of the individuals in the present study and in line with other results already presented by the literature, the physical and psychological suffering experienced by survivors of COVID-19, both in the acute and late phases of the disease, can negatively affect

recovery and return to activities of daily living, directly interfering with the quality of life of these people[25,29].

When analyzing previous events with repercussions similar to COVID-19, early assistance to individuals is essential. Through strategies applied by health professionals that aim to transmit information to patients and their families during the illness, it is possible to reduce the fear related to the unknown. Introducing psychotherapeutic assistance as soon as possible is important to mitigate the long-term psychological effects triggered by the disease [13,14,16]. Associated with this, health professionals have to provide information about the possible sequelae of the disease and properly refer those affected to rehabilitation programs, as the functional limitations presented cause suffering, as demonstrated in the results obtained.

CONCLUSION

The data collected to know and understand, through the eyes of those who had COVID-19, what this experience was like, evidenced that the participants mostly reported negative experiences lived during COVID-19. Several feelings were externalized during the experience with the disease, majorly fear. Infected individuals were faced with situations they did not imagine they would have to go through, such as becoming dependent on health professionals during hospitalization and the recovery process, dealing with difficulties caused by physical and psycho-emotional limitations, and many continue in the daily struggle to overcome sequels and return to the normal routine.

The people who participated in this study pointed to spirituality as an important coping mechanism during the experience with the disease and in the recovery process, and many reported that having COVID-19 was a great learning experience, leading them to act differently in everyday life, valuing more the family, friends, and health professionals.

Our findings, together with other results found in the literature, demonstrate the importance of early assistance to individuals who had COVID-19, providing means of information about the disease, psychotherapeutic and rehabilitation care, and preventing long-term effects, that make recovery difficult.

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