



# Psychological Impact of the COVID-19 Pandemic on Families of People with Severe Mental Disorders Participating in Community Peer Support Groups in Brazil

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## Abstract

People with severe mental disorders are at increased risk of dying from COVID-19 and more susceptible to the impacts of the pandemic. This study aims to understand how the families of patients with severe mental disorders followed up in community peer support groups experienced the beginning of the pandemic in Brazil and how they fared during the period of restricted physical contact. Family members ( $n=82$ ) and patients ( $n=27$ ) belonging to community groups in Rio de Janeiro responded to an online survey that included assessments of quality of life and well-being along with open-ended questions. Thematic analysis of the answers showed that the majority of remarks were positive, despite the concerns, fears, and feelings common at the time. Positive feelings were also mentioned significantly. These findings demonstrate that this population was adaptive and resilient in coping with the restrictions on physical contact. The main concerns and difficulties of this population are discussed.

**Keywords** Family · Severe mental disorder · Lockdown · Quarantine · COVID-19 · Community groups

## Abbreviations

WHO	World Health Organization
PHEIC	Public Health Emergency of International Concern
CAPS	Psychosocial care centers
IPUB	Institute of Psychiatry of the Federal University of Rio de Janeiro
WHOQOL-BREF	World Health Organization Quality of Life Scale
WEMWBS	Warwick-Edinburgh Mental Well-being Scale

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## Introduction

The COVID-19 pandemic represents the most serious public health crisis worldwide in the last 100 years. In addition, it has caused health concerns and had economic, social, and cultural impacts, the real extent of which cannot yet be measured (Lasco, 2020). In addition to the immediate consequences of infection with the virus and the impacts of quarantine and social distancing, there are concerns about a mental health crisis that adds pressure to an already overloaded health system (Torous et al., 2020). Among the most vulnerable people are those with pre-existing mental disorders, who are susceptible to greater psychological stress due to trauma and who require additional support during quarantine (Brooks et al., 2020; Holmes et al., 2020).

### COVID-19 in the Population with Severe Mental Disorders

The social distancing imposed by the COVID-19 quarantine period may have a disproportionate impact on the population with severe mental disorders, which already has a smaller and qualitatively weaker social network than the general population and whose absence can result in losses of recovery and insertion into the community (Kozloff et al., 2020). Exposure to stressful events, changes in routine and increased anxiety in interpersonal and family relationships due to prolonged quarantine, fear of contracting COVID-19, or difficulty adhering to protective measures may act as triggers of crisis (Fonseca et al., 2020). Financial and community service dependence can compromise the basic needs of this clientele, increasing their risk of relapse and psychosocial suffering, which highlights the importance of developing approaches to help them maintain social connection and instrumental support (Kozloff et al., 2020).

In addition to their vulnerability to the stress of the quarantine, this population is more susceptible to death from the SARS-COV-2 virus. A higher incidence of COVID-19 in people with mental disorders than in the general population was reported in two national cohort studies conducted in the USA (Taquet et al., 2021; Wang et al., 2021). A third retrospective cohort study conducted in New York found that the diagnosis of schizophrenia was associated with a 2.7-fold higher risk of mortality from COVID-19 (Nemani et al., 2021).

The greater susceptibility to transmission and death by COVID-19 is due to several factors: (1) cognitive impairment, such as lack of insight and risk perception; (2) higher prevalence of chronic medical comorbidities and inadequately treated health conditions; (3) worse access to health services that can lead to decompensation of diseases due to lack of follow-up and treatment; (4) worse adherence to preventive measures, such as hygiene and social isolation; (5) higher rates of substance abuse and smoking; (6) smaller social and family support network; (7) more precarious housing conditions, including homelessness and living in shelters and prisons, which are more common in this population; (8) prejudice and discrimination, with greater difficulty in accessing public policies such as health, education, culture,

and social assistance; (9) increased risk of psychiatric relapse due to the pandemic, requiring hospitalization (Kozloff et al., 2020; Zhand & Joobar, 2021).

Patients with severe mental disorders are four times more likely to develop high levels of pandemic-related stress and are three times more likely to experience anxiety and depression symptoms than healthy individuals. Higher levels of anxiety and depression in this population may in turn increase the risk of suicide (González-Blanco et al., 2020; Iasevoli et al., 2021).

The main concerns of family members of patients with severe mental disorders include who would care for the patients if their family members became infected with COVID-19, whether the patients would be refused appropriate medical services because of their mental illness and concerns regarding restrictions on the use of community services and the deterioration of family relationships due to the longer stay at home during the lockdown (Yasuma et al., 2021). Lebow (2020) warned that the COVID-19 pandemic could introduce additional difficulties to families with troubled family members when help from others is not possible and the frequency of contact between family members is already a problem (Lebow, 2020).

### **COVID-19 in Brazil**

The COVID-19 pandemic officially started in Brazil in February 2020. Given the indifference and negligence of government authorities, which allowed Carnival festivities (February 22nd to 25th) to occur as normal, the spread of COVID-19 in Brazil accelerated, with a daily increase rate of 45.4% in the week of March 4th to 10th, 2020, with the worst situation in the Southeast in cities such as Rio de Janeiro and São Paulo (Cavalcante et al., 2020; Szwarcwald et al., 2020).

Because of the seriousness of the situation, in March 2020, sudden restrictive measures were enacted in Brazil, including the closure of schools, churches, and nonessential commercial establishments; limitations on the use of intermunicipal public transport; and the banning of concert halls, parties, parks, and beaches. A nationwide study conducted between April 24th and May 24th, 2020, that included 45,161 Brazilians found that 74.3% of the population complied with physical contact restrictions. A quarter of the population did not limit social contact or made minimal changes; this group predominantly was male, aged 30 to 49 years, had a low education level, and continued working during the COVID-19 pandemic (Szwarcwald et al., 2020).

These restrictions lasted until early July, when they were relaxed. During this period, a nationwide online study of 13,584 people found that 88.8% of the population had experienced new psychological symptoms after the onset of restrictions, including a high prevalence of stress (50.8%), anxiety (44.2%), and depression (61.3%). Among people with mental disorders, 96.2% reported new symptoms, demonstrating the severe psychological impact on Brazilians at the beginning of the pandemic (Campos et al., 2020).

In the health system, the COVID-19 pandemic brought both the challenge and the opportunity to develop and adapt digital health tools to be used when face-to-face consultations are not recommended; thus, access and continuity of care could be

ensured through telemedicine (Torous et al., 2020). In Brazil, the lack of regulation and operationalization of telemedicine led the Ministry of Health to issue ordinance 467 of March 20, 2020, authorizing the use of information and communication technology in both the public health system (SUS) and in private institutions. The social and digital inequality of the Brazilian population was a major obstacle. Data from the Information and Communication Technologies Households-2019 survey conducted by the Regional Center for Studies for the Development of the Information Society (2019) revealed that 83% of individuals in urban areas have access to the Internet, whereas in rural areas, this proportion is only 61%. For Internet users, the most commonly used device in any area is the cell phone because only 75% and 51% of urban and rural households, respectively, have access to the Internet. Among the population who did not use the Internet, 41.6% said that they did not know how to use it (Caetano et al., 2020; Cardoso, 2020). Thus, the country had to confront the COVID-19 pandemic without a telemedicine structure that would ensure continuity of care for all when in-person access to health services was restricted.

In the field of mental health, community care services in Brazil, known as psychosocial care centers (CAPS), are responsible for caring for the population with severe mental disorders. During the pandemic, CAPS offered only medical prescription refills and crisis treatment, suspending psychosocial and group activities. Mental healthcare professionals began to offer remote support, initially through telephone contact, to ensure the continuity of drug treatment, provide referrals to primary care services, and support families in situations of conflict and social suffering. However, these professionals encountered outdated telephone records due to the high turnover of telephone contracts among service users. Thus, telemedicine initiatives were spontaneously created by health professionals and users through social media platforms, such as WhatsApp, and videoconferencing applications, such as Zoom and Google Meet; these initiatives became the main tool for monitoring and supporting the population with severe mental health disorders and served as important sources of mutual aid for managing stress and mental health problems during the pandemic (Cruz et al., 2020; Ricci et al., 2021).

## Present Study

In the city of Rio de Janeiro, autonomous and community peer support groups have been meeting since 2013 in various neighborhoods to offer support to individuals living with severe mental disorders such as schizophrenia and bipolar disorder, establishing a care network parallel to mental health services (Palmeira et al., 2020). As COVID-19 quarantine commenced, these groups decided to continue their meetings online.

The objective of this study is to understand how patients and their families participating in these community support groups faced the first months of the COVID-19 pandemic. How did the measures adopted by the government, the alarming news of the COVID-19 pandemic, and the inevitable changes in our daily lives and relationships emotionally impact patients and their relatives? To what extent would their

perceptions and experiences contribute to a deeper understanding of the social reality this clientele is experiencing?

The restriction measures were in effect in the city of Rio de Janeiro from March 13 to the beginning of July. When we administered the first study questionnaire (on May 27, 2020), Brazil had reached a total of 24,512 deaths by COVID-19 and was adding more than 1,000 deaths daily; within 2 weeks, it had become the second-largest epicenter of the pandemic in the world, behind only the USA (Martins & Mariz, 2020).

## Methods

A qualitative study was conducted with patients with severe mental disorder and their families during the first peak of the COVID-19 pandemic in the city of Rio de Janeiro.

The study sought to assess the multiplicity of subjective, interrelated, and opposite experiences that are being constructed by the subjects as social actors in constant negotiation with the pandemic and with the difficulties and experiences that the pandemic imposes at different moments. Realities are therefore viewed as constructions, and truth is viewed as multiple and subjective (Berger & Luckmann, 2016; Gergen, 1999).

## Study Sample

The study included patients with severe mental disorders (schizophrenia and bipolar disorder) and their family members from the city of Rio de Janeiro who participated in peer support groups based on the recovery model and the problem-solving method through the “Entrelaços Program” of the Institute of Psychiatry of the Federal University of Rio de Janeiro (IPUB). Nine community peer support groups were operating at the time of this study and were already accustomed to using social media platforms, such as WhatsApp and Facebook, before the pandemic. During the pandemic, they began meeting through the Internet using videoconferencing applications, such as Zoom and Google Meet, thus ensuring the continuity of support.

The sample population was chosen by monitoring these peer support groups and maintaining permanent contact with their members during the pandemic through videoconferencing. The population was initially selected by convenience sampling via calls to the peer group coordinators and later by snowball sampling, with each coordinator inviting participants within each group (Moser & Korstjens, 2018). The groups consisted of both patients and their family members.

## Procedures

Questionnaires containing objective and open-ended questions and two scales, i.e., the World Health Organization Quality of Life Scale (WHOQOL-BREF) and the Warwick-Edinburgh Mental Well-being Scale (WEMWBS), were administered through the

Google Forms platform. The questionnaires were applied to the studied entire population for the purpose of future comparison and are not presented here. The open-ended questions gathered information about the feelings, the moments, and the environment in the context of the pandemic that the participants were experiencing and how they handled them, i.e., What feelings are prominent for you during this moment?; How is this moment for you?; How is the environment where you spend this moment? The questions were sufficiently broad to capture feelings and attitudes that the participants wanted to report spontaneously, without prior concern with specific themes for this population. The participants were encouraged to write freely and provide as much detailed information as possible. The questionnaire and scales were sent via WhatsApp and email on May 27, 2020, and collected until June 11, 2020.

### Qualitative Analysis

The qualitative data were thematically analyzed according to the methodology proposed by Braun and Clarke (2006) using ATLAS.ti software. Thematic analysis was selected due to its epistemological flexibility and compatibility with the constructivist paradigm, which allows the extraction of a complex network of data that reveals the reality of the participants' experiences with the pandemic and reveals the deepest layers of the social context and how it collides with the meanings produced by the study subjects (Braun & Clarke, 2006).

Initially, the feelings identified in the data corpus were counted separately to analyze their occurrence in the patient and family groups. The researchers classified the feelings as negative or positive according to the social meaning they revealed. If the feeling indicated a social context of resilience or positive coping, they were classified as positive, otherwise as negative. Then, an inductive and semantic approach, as described by Sundler et al. (2019), was used to identify the themes according to the explicit meanings present in the dataset without the theoretical or thematic biases of the researchers. The data were coded and grouped by themes and subthemes into different categories. The analysis process was cyclical. As new topics emerged, we returned to the questionnaires to investigate new codes. Finally, categories were grouped into larger thematic groups (Sundler et al., 2019). Meetings were held among researchers during different phases of the analysis, always with access to prior data. After the thematic categories were defined, they were presented for validation and refinement to the other researchers and to the participants through four focus group meetings via Zoom videoconferencing: two groups comprised patients, and two groups comprised their family members.

The study was approved by the National Research Ethics Committee of the Ministry of Health of Brazil. All participants signed the Free and Informed Consent Form electronically through Google Forms and received a copy by email.

## Results

A total of 109 individuals answered the questionnaire (27 patients and 82 family members). The mean age of the patients was 35 years, and that of the family members was 59 years. Most patients were male (70.4%), while most family members were female (76.8%). Both groups had a high level of education (high school/undergraduate), and the majority belonged to socioeconomic classes C/D, according to the classification of the Brazilian Institute of Geostatistics (IBGE), which categorizes families according to income into classes A, B, C, D, and E. Classes C/D have monthly earnings of two to eight minimum wages (\$350–1,400 USD). Most participants attended peer support group meetings via the Internet (81% of patients and 60% of family members).

Regarding the COVID-19 pandemic, only 18% of the patients and family members said they were afraid of dying from COVID-19; 8% of the family members had already had the disease, and none of the patients had been infected with the virus at the time of the study. Regarding deaths of relatives or close friends, 11% of the patients and 36% of the family members reported that someone close to them had died from COVID-19. Most patients (52%) and family members (78%) evaluated themselves as “concerned” or “emotionally unwell” at the beginning of the pandemic. Regarding the current environment, 68% of the patients and 73% of the family members rated the situation as good.

### Feelings During the Pandemic

Patients reported 17 feelings at the onset of the COVID-19 pandemic, which were cited 42 times. Of the total number of citations, 32 (76%) corresponded to negative feelings. Family members mentioned 40 different feelings, with 145 citations, of which 107 (74%) were related to negative feelings. The most common negative feelings were similar among patients and family members. Anxiety, fear, anguish, and sadness were most frequently reported. Among the positive feelings, both groups reported feeling hope, compassion, and happiness. All the feelings are listed in Table 1.

### Thematic Groups

Three main thematic categories that emerged from the qualitative data obtained from the open-ended questions were fears of COVID-19, experiences with physical contact restriction measures, and concerns about that point in the pandemic. Table 2 summarizes the frequency of quotes for each category for family members and patients.

**Table 1** Frequency of negative and positive feelings for family members and patients

	<b>Patients, frequency</b>	<b>Family members, frequency</b>
Negative	Anxiety (9), fear (7), anguish (4), sadness (3), tiredness (2), restlessness (2), doubt (1), nervousness (1), impatience (1), loneliness (1), longing (1)	Anxiety (21), fear (20), anguish (10), sadness (9), concern (8), insecurity (8), impotence (6), apprehension (3), perplexity (3), anger (2), discouragement (2), longing (2), hopelessness (2), mistrust (2), uncertainty (2), disappointment (1), ermpiness (1), impatience (1), indignation (1), rebellion (1), tension (1), tiredness (1)
Positive	Compassion (2), hope (2), happiness (2), balance (1), patience (1), love (1)	Hope (9), tranquility (6), solidarity (4), compassion (3), happiness (2), readiness (2), balance (1), determination (1), enthusiasm (1), faith (1), forgiveness (1), gratitude (1), growth (1), peace (1), protection (1), resilience (1), resistance (1), unity (1)



**Table 2** Frequency of quotes for each category for family members and patients

	<b>Patients quotes (n = 48), frequency (%)</b>	<b>Family members quotes (n = 186), frequency (%)</b>
Fears of COVID-19	-	11 (6)
Experiences with physical contact restrictions		
Advantages	31 (65)	85 (46)
Disadvantages	14 (29)	34 (18)
Concerns about the impacts of the pandemic		
About the patient	-	19 (10)
About work and finances	2 (4)	16 (9)
About the government	1 (2)	21 (11)

### Fears of COVID-19

In addition to the fear of dying from COVID-19, which was expressed by both groups, the family members also reported a fear of becoming ill and a fear of transmitting COVID-19 to other relatives. Their fears extended to all other family members and were not limited to those with mental disorders.

“I’m very confused. Sometimes I worry about transmitting the disease to my husband and family as I care for a brother with HIV who is bedridden and a mother who has depression and diabetes.” (F23)

“I’m afraid of dying without being able to get my child to accept treatment. I’m afraid of leaving him because he depends on me.” (F52)

“I am concerned about getting sick and transmitting the disease to someone in my family because I’m still working and can have contact with confirmed COVID cases.” (F12)

### Experiences with Physical Contact Restriction Measures

Regarding experiences with the restriction of physical contact, two subthemes emerged: one presented the restrictions as advantageous, highlighting responses such as adaptation and changes in routine, and the other presented the restrictions as disadvantageous, highlighting the effects of confinement, problems in family life, and the impact of news of deaths.

**Advantages of Physical Contact Restriction** Reports of adaptation/changes in routine during physical contact restriction reflect the participants’ efforts to seek out activities and practices that alleviate suffering and monotony, such as dedication to household chores, exercise and meditation practices, reading, leisure activities at home, spiritual practices, and virtual family meetings. The absence of old routines and daily activities was also noted.

“This moment has been one of internalization and reflection on everything I am experiencing. Although I have to be confined, I try to take advantage of it, practicing meditation and prayer, seeking balance.” (P16)

“I realize that it is a lost year, mainly without routine. I used to see people on the streets going to work and children coming back from school” (P10)

Many family gatherings that had previously occurred in person were moved online through videoconferences, and the attempt to maintain these practices was beneficial during this moment.

“I’m finding that I can still cook! I do gymnastics when I get up and a 25-minute walk late in the afternoon. The literature class continues online, and the Nar-Anon group continues online. My children, grandchildren and I have had weekly videoconference meetings.” (F78)

Some participants described the period of restricted physical contact as an opportunity to improve their self-knowledge, focus on personal growth, and review old practices with the goal of facing challenges positively, with hope and pride.

“It has been a time of inner growth and immersion within me, of reflection. However, there are several moments of boredom, and sometimes, I feel I’m going at a slow pace, very sluggish. At other times, I feel alternately happy and excited; I think about what I want to do when this is all over.” (P24)

“It is challenging; it has changed my routine and brought a new way of life. I am more careful in my attitudes and taking better care of my personal hygiene because we have to be vigilant all the time.” (P3)

“We seek to renew our strengths and increase our confidence together. We try to maintain a new routine, reframing our goals; we continue studying, reading, listening to music, participating in lives, calling family members, watching religious services online, celebrating birthdays online - in short, taking care of the body in all spheres.” (F62)

**Disadvantages of Physical Contact Restriction** Confinement, difficulties in family life, and news of deaths were highlighted as the greatest disadvantages of physical contact restrictions. The inability to maintain activities outside the house and the separation from family members and people in their social circle generated feelings of anxiety, sadness, and loneliness.

“I feel a little empty. I miss the people, hugging, looking in their eyes while we talk, drinking that coffee that every Brazilian likes.” (F11)

“I feel helpless. I lack freedom.” (F41)

“Loneliness sometimes hits hard, being in isolation. I try to talk to my cousins, my aunt, my father, but even so, it is very difficult to not feel alone.” (P9)

The intensity of family life led to moments of tension and conflict and the need to exercise daily tolerance and take care of family relationships.

“My husband and my son are having a lot of conflict, confronting each other. He doesn’t accept that his son has the disease. I am afraid that my son needs hospitalization at this time and can’t have visitations. I feel alone, afraid; sometimes I find myself without strength.” (F25)

“Most of the time I am calm, but the confinement has increased conflicts with my mother.” (P2)

The news of deaths from COVID-19 had a great emotional impact on the participants, and their responses reflected the severity of the situation and their feeling of impotence in the face of the pandemic.

“I am saddened by the death of so many people, and social inequalities affect everyone in a way that makes us feel helpless. The pandemic affects the global structure.” (F78)

“At first, it was a little terrifying because we didn’t know what was going to happen, and seeing and hearing all kinds of news, we came to our senses and realized that the situation was serious. (...) The saddest part is to see the number of dead....” (F12)

### **Concerns About the Impacts of the Pandemic**

In addition to the immediate concerns focusing on the patient, the family members were also concerned about work and finances and the national government’s approach to the pandemic. Only three patients mentioned this topic.

**Concerns about the Patient** Family members reported increased concerns about the health status of the patients during the pandemic, including fears about how they would adapt to the physical contact restrictions, whether they would be able to adhere to care and protection measures and whether continuity of treatment and support would be available in the face of the health services crisis.

“My son has bipolar disorder and is living with friends. This week, he fought with me over the phone and resumed his resistance and accusations about the hospitalizations; the fight took my peace away, and I am very distressed about this.” (F31)

“I try to reinforce with my son the hygiene measures at home, to remember to carry a mask and to apply these measures outside the house.” (F11)

“My son has schizophrenia; he has been oscillating, and with the pandemic, he is very afraid of getting sick. We have difficult days at home. His doctor is not attending, and my son does not accept looking for another professional.” (F14)

**Concerns About Work and Finances** Concerns regarding work were related to the increased workload arising from working remotely, the adaptation to new schedules, the overlap of work with household chores, and infection concerns among those who continued to work in person. Wage reductions, unemployment, and the

sectors of the economy that suffered heavily from the pandemic contributed to financial concerns and insecurity about maintaining the family's income.

"I have more work working from home, putting in even more hours than at the office. In addition, I have household chores I didn't used to do before." (F49)

"I am tense. I have been at home for three months without working because of this pandemic. My husband and I are self-employed; it is difficult to bear." (F62)

"Sad for those who were unemployed, including my husband." (F58)

"At the moment I am dedicating myself to the group of 15 of us, I resigned at work, and I am looking for a replacement". (P15)

**Concerns About the Government** Concerns about the neglect of the federal government and cases of corruption in the purchase of health materials and the establishment of field hospitals were mentioned by family members in a tone of revulsion, indignation, and disapproval. The political situation in the country affected the family members' feelings regarding the pandemic; however, the patients did not mention the topic.

"Tired of the lack of clarity in collective conduct." (F29)

"Indignation when I hear that politicians are taking advantage of the situation." (F72)

"Anger toward the leaders who show total unpreparedness and insensitivity to caring for the welfare of the population." (F67)

"I am very sorry that the political situation has gotten where it is." (P7)

## Discussion

This study aims to elucidate the experience of patients with severe mental disorders and their families who participate in community peer support groups in Rio de Janeiro with regard to the COVID-19 pandemic and the physical contact restriction measures adopted by the government. The groups began to meet through videoconferencing applications over the Internet and were monitored by the researchers throughout the quarantine period.

Most patients with severe mental disorders and their family members sought to cope with the onset of the COVID-19 pandemic in Brazil by adapting their routines, using healthy practices and seeking social connection with family and peers during the period of physical contact restriction. Even while concerned regarding the pandemic and reporting more negative than positive feelings, the participants mentioned more beneficial experiences than disadvantageous experiences in their attempt to fill the time and mitigate isolation.

The qualitative results of the study allowed us to broaden our understanding of the social reality and the subjective experiences of the participants regarding their adaptability. The fact that the open-ended questions were broad allowed for more

diverse and spontaneous answers less influenced by the researchers' prior concern with the specific difficulties or symptomatology of the studied group. The objective was to capture the experiences of the participants during this period.

### **Fears and Concerns About the Pandemic**

Although most patients and family members answered the objective questions with "concerned" or "emotionally unwell" at the beginning of the pandemic, with approximately one-quarter of the respondents fearing death from COVID-19, the qualitative data reveal that the environment and routines helped them cultivate a positive atmosphere of optimism and hope with respect to coping with the pandemic and the difficulties imposed by the physical contact restriction measures. The patients spontaneously showed less concern about the pandemic than their family members, while family members reported greater concerns about the patients' health and well-being, whether they would be able to adhere to the protective measures, and how they would react to the restrictions imposed on health services, including whether these restrictions would lead to risks of relapse.

The patients' answers, in addition to being more succinct, were also more positive with respect to showing their adaptability and resilience during the quarantine period. This finding may reflect certain clinical and social aspects specific to this population, such as a lower propensity to express one's concerns spontaneously, less exposure to the media and other communications outlets (leading them to be less informed than their family members), less social demands (such as work and financial demands), and greater participation in online support groups. The latter phenomenon may have had a protective effect, as the patients identified online meetings as a strategy to mitigate the negative effects of quarantine. Incidentally, the patient group was one of those that grew the most during the pandemic (adhesion above 80%) and eventually had to be split in two to accommodate new members.

Other studies have shown differences in patients with mental disorders with regard to the COVID-19 pandemic. In a study that assessed the level of general knowledge regarding the COVID-19 pandemic and how to prevent it, patients with a severe mental disorder scored 19.2% lower than the control group on rating scales (Matei et al., 2020). On the other hand, compared to the control group without mental disorders, 85% of patients were able to make better use of their free time, with relaxation and meditation activities (González-Blanco et al., 2020).

The concerns of family members regarding the ill individual in their group are common and natural, and mentioning them during the pandemic is expected. However, the results did not demonstrate an excess of concern on the part of family members in this regard, with proportions well distributed between patient, work/finances, and government.

Concerns about employment and finances are understandable given the high unemployment rates in Brazil, a country that was facing a serious economic crisis before the pandemic and saw unemployment increases by 33.1% during the first 6 months of the pandemic, resulting in an unemployment rate of 14% (Silveira, 2020). Wage cuts, high unemployment rates, concerns about job loss, and the

difficulty of finding new jobs during the COVID-19 pandemic have had a negative impact on the well-being of the population and constitute an additional risk factor for anxiety and depression (Holmes et al., 2020; Pacheco et al., 2020; Wilson et al., 2020).

Concerns about politics were among the concerns most frequently cited in the study. The participating family members expressed a mixture of revolt and indignation and feelings of sadness, anxiety, anger, and hopelessness, with concerns focused on the most vulnerable populations.

In Brazil, the president's response has been polarizing, characterized by opposition to science and to state governments, which have assumed responsibility for public health governance in the wake of the president's abdication of responsibility and refusal to support health measures and social distancing, dissemination of false news, underestimation of the severity of the virus, questioning of official data, promotion of treatments that are not supported by evidence, and ridiculing of the vaccine. The president's position has had a strong impact, particularly among the most marginalized classes and those with less access to information, and has compromised adherence to health measures and, consequently, the control of the pandemic in the country (Ortega & Orsini, 2020; Ricard & Medeiros, 2020).

Communication between political leaders and scientific authorities is considered crucial during a pandemic. The interference of background noise with this communication can have negative consequences for individuals and the entire community, generating disunity, disengagement from public health measures, confusion and distrust in the government, and affecting mental health, increasing fear and anxiety in the population. The quarantine functioned as an amplifier, increasing the population's exposure to social media in the absence of debate and exposure to ideas in the real world. Adequate communication should favor the most vulnerable and marginalized populations and should consider differences in literacy (and health literacy) by using simple, objective, and nondiscriminatory language (Fagherazzi et al., 2020).

### **Adaptability to the Pandemic**

Most quotes from patients (65%) and nearly half of the quotes from family members (46%) emphasized efforts to seek a healthy way to relate to measures of physical contact restriction while seeking to adapt routines and modify behaviors to enable them to pass the onset of the pandemic with greater resilience. In addition, approximately 70% of the patients and family members rated their living environment positively during the quarantine period.

One of the main resources reported by patients and family members used to mitigate the isolation of quarantine was videoconference meetings. Most of the respondents also participated in online peer support groups. Most families that have members with severe mental disorders in Brazil have a weak social support network and do not participate in community support groups (Presotto et al., 2013). They may have felt more isolated because they had to address problems related to mental disorders. The longer time of family contact during the pandemic and the interruption

of community services due to physical distancing measures can contribute to an increase in domestic conflicts. Studies have shown that participation in a network of contacts, whether by phone, messaging, or videoconferencing, reduces psychological distress (Brooks et al., 2020; Sher, 2020; Xiao et al., 2020). Along these lines, initiatives that promote peer communication have been proposed as a way to optimize social capital in the workplace (Pacheco et al., 2020), in healthcare teams (Rubin & Rassman, 2021), and in the general population, with the aim of sharing information and support and reducing isolation (Carvalho et al., 2020).

However, the emphasis on advantageous behaviors and experiences should not be interpreted as the absence of specific difficulties in this population, nor should they be overlooked, since many of them may still be present in the daily lives of these individuals as obstacles to achieving quality of life and well-being. The difficulties and concerns identified in this study were reinforced in the focus groups as important and relevant for an understanding of the overall picture of the initial period of the pandemic, which is why we believe that it is important to highlight them here.

The greater intensity in family relationships due to confinement was cited by both family members and patients as a disadvantage of the pandemic. In families with high expressed emotion (e.g., presence of criticism and emotional overinvolvement), excessive contact time between family members and patients has been associated with more family conflicts and patient relapses (Butzlaff & Hooley, 1998; Leff, 1976). The COVID-19 pandemic may have created additional difficulties for family members, who no longer had the help of people outside the family nucleus, and for patients, who lost the scarce social contact they had, which is important for the creation of new social ties, for expanding relationships beyond the family, and for reducing contact time at home.

Study participants also reported difficulties in the face of confinement imposed by government measures and the widespread practice of the media counting the daily number of COVID-19 deaths and presenting news stories on families who had lost several relatives. Meta-analyses have shown that higher media exposure during the COVID-19 pandemic was associated with higher risk of emotional distress (anxiety and depression), while greater social and family support, including through electronic means, was found to be protective for the population in general (Salari et al., 2020; Wang et al., 2020).

## **Feelings Related to the Pandemic**

The pandemic and the restriction of physical contact have caused a variety of psychological and psychiatric problems worldwide. Disorders such as anxiety, depression, substance abuse, and posttraumatic stress disorder have been reported in different countries (Brooks et al., 2020; Holmes et al., 2020; Qiu et al., 2020). A study conducted in South Brazil with 2,321 participants found 6.6- and 7.4-fold increases in moderate to severe symptoms of anxiety and depression during the pandemic, respectively; these increases were associated with decreases in monthly income, the presence of chronic diseases, and lack of physical activity (Feter et al., 2021). Feelings such as irritability, anger, sadness, insomnia, stress, nervousness, fear,

anguish, frustration, and loneliness have been found to be highly prevalent during the COVID-19 pandemic. Positive feelings, such as joy and relief, were reported less frequently (5%) (Brooks et al., 2020; Campos et al., 2020; Sher, 2020; Xiao et al., 2020).

In this study, patients and family members also reported more feelings such as distress, sadness, nervousness, fear, and anger. The higher prevalence of negative feelings was expected given the pandemic and the impact of news reports about the deaths and, more generally, the massive media coverage. However, the frequency of positive feelings in the midst of the difficulties at such time must be highlighted. Both groups (i.e., family members and patients) reported positive feelings such as hope, compassion, joy, and tranquility, corresponding to a quarter of the citations.

These results, combined with the answers that reflect adaptability to the pandemic and the physical contact restriction measures, reinforce the resilience of the patients and family members. A study that assessed feelings and resilience in 2,000 individuals in the USA and the UK during the first wave of the COVID-19 pandemic showed that positive feelings, even when the most prevalent feelings were negative (as expected in periods of heightened stress), are strong predictors of resilience, suggesting that positive feelings play a key role in fostering a resilient mindset and in transforming suffering to reduce the negative impact of collective crises (Israelashvili, 2021).

## Limitations

A limitation of the study is its ability to generalize the findings to other Brazilian families. Brazil is a continental country with deep social inequalities. Study participants belong to social classes C/D, which correspond to 55.7% of the population in the Southeast, where the state of Rio de Janeiro is located. Our participants also have a higher educational level than the average population. This higher educational level may have simplified access to online tools and helped the groups remain cohesive during the pandemic (IBGE/DPE/Departamento de População e Indicadores Sociais et al., 1998).

The city of Rio de Janeiro has communities whose income distribution and other social markers are similar to those in the poorest regions of Brazil, where the poorest classes (class E and the no income class) can constitute more than half of the population. These communities also face serious problems, such as violence and a lack of basic sanitation, health, and education services. These factors alone are known to represent a greater risk of mental illness (Ludermir, 2008). The COVID-19 pandemic deepened these inequalities; 80% of residents in these communities survived on less than half the income they had before, and 41% received no government assistance until June 2020 (Cardoso, 2020; Gurgel et al., 2020).

The fact that most of the participants in the study participated in peer support groups in person prior to the pandemic and virtually during periods of physical contact restrictions, is another bias of the study. However, it could have also been a protective factor for the mental health of these individuals.



## Future Research

The COVID-19 pandemic has imposed the development and adaptation of face-to-face social and health services and equipment to online services, including peer support initiatives. In the postpandemic period, there will be a readjustment with the return to face-to-face activities. However, we believe that many activities can take place in a hybrid manner (online and in person), incorporating the technological advances and social achievements of this period. In the near future, we intend to study how the participants of community groups organized themselves to return to face-to-face activities, what changes to the dynamics and functioning of such groups the pandemic period has brought, and what the impact of this process is for family members and patients.

## Conclusions

To our knowledge, this is the first study conducted in Brazil to examine how patients with severe mental disorders and their families are facing the COVID-19 pandemic. The responses to the open-ended questions and their feelings showed that they were coping with the pandemic in positive ways. The fact that the majority participated in peer support groups through the Internet must be better studied to assess its potential protective effect on mental health during the pandemic.

The COVID-19 pandemic struck in an era of massive technological advances. This study may thus provide a starting point for discussions of how digital health solutions can be used to address this crisis and mitigate the social and emotional impacts of the pandemic on the population, especially its most vulnerable members, such as people with mental disorders and their families.

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**Data Availability** The data that support the findings of this study are openly available in Zenodo at <https://doi.org/10.5281/zenodo.5027420>.

**Code Availability** The authors declare that for the analysis they used Atlas.ti software, licensed by the Laboratory for Assessment of Services and Quality of Life in Mental Health of the Psychiatry Institute of the Federal University of Rio de Janeiro.

## Declarations

**Ethics Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by

the National Research Ethics Committee of the Ministry of Health of Brazil (No. 30853520.8.0000.5263; at 05/29/2020).

**Consent to Participate** All participants gave full informed consent to participate.

**Consent for Publication** All participants gave consent for their data to be used in publication.

**Conflict of Interest** The authors declare no competing interests.

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