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Original Article

Influences of COVID-19 on the everyday lives and mental health of caregivers of family members with schizophrenia

Influências da covid-19 no cotidiano e na saúde mental de cuidadoras de familiares com esquizofrenia

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Abstract

Introduction: Individuals with schizophrenia require continuous follow-up by mental health services and by a caregiver, a role commonly assumed by a family member. The coronavirus (COVID-19) pandemic disrupted service provision, overburdening caregivers and causing significant changes in their everyday lives. **Objective:** To identify and describe, from the perspective of caregivers of family members with schizophrenia, the changes in their everyday lives resulting from the social distancing imposed by COVID-19. **Method:** A qualitative, descriptive, cross-sectional study conducted in a specialized outpatient clinic with 10 female participants. Data were collected through semi-structured interviews and examined using thematic content analysis. **Results:** Two analytical categories were identified: (1) Altered daily life (participants reported difficulties in occupations such as work, activities of daily living, leisure, and instrumental activities of daily living); (2) Perceptions of mental health (depressed mood and feelings such as anxiety, worry, and fear). Participants described new challenges during the pandemic both in their relationships with ill relatives and in relation to themselves. COVID-19 impacted caregivers' occupations and mental health, requiring new ways of being and coping with difficulties. The social marker of gender proved essential for understanding these women's lived experiences. **Conclusion:** Caregivers' everyday lives underwent multiple changes during social distancing, and their vulnerabilities were exacerbated, resulting in multidimensional suffering. It is essential that caregivers receive attention from occupational therapists and interprofessional teams, and that public policies supporting this group be strengthened, especially during health crises.

Keywords: COVID-19, Caregivers, Schizophrenia, Mental Health, Occupational Therapy.

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Resumo

Introdução: Pessoas com esquizofrenia necessitam de acompanhamento contínuo pelos serviços de saúde mental e por uma cuidadora, papel assumido comumente por um familiar. A pandemia de coronavírus (covid-19) provocou descontinuidade na assistência oferecida pelos serviços, sobrecarregando a cuidadora e gerando mudanças significativas em seu cotidiano. **Objetivo:** Identificar e descrever, sob a ótica de cuidadoras de familiares com esquizofrenia, as mudanças em seus cotidianos decorrentes do distanciamento social imposto pela covid-19. **Método:** Pesquisa qualitativa, descritiva e transversal, realizada em um ambulatório especializado com 10 participantes do sexo feminino. Os dados foram coletados por meio de entrevista semiestruturada e tratados por meio da análise temática de conteúdo. **Resultados:** Duas categorias analíticas foram identificadas: 1) Cotidiano alterado (as participantes explicitaram dificuldades em ocupações como trabalho, atividades da vida diária, lazer e atividades instrumentais da vida diária); 2) Percepções sobre a saúde mental (humor deprimido e sentimentos como ansiedade, preocupação e medo). As participantes apontaram novos desafios durante a pandemia, tanto na relação com parentes adoecidos quanto consigo mesmas. A covid-19 impactou as ocupações e a saúde mental das cuidadoras, exigindo novas formas de existir e de lidar com dificuldades. O marcador social de gênero mostrou-se essencial para a compreensão das experiências vividas no cotidiano dessas mulheres. **Conclusão:** O cotidiano das cuidadoras sofreu diversas mudanças diversas durante o distanciamento social e suas vulnerabilidades foram exacerbadas, provocando sofrimento multidimensional. É fundamental que cuidadoras recebam atenção de terapeutas ocupacionais e equipes interprofissionais, considerando a necessidade de fortalecimento das políticas públicas voltadas a esse grupo, especialmente em contextos de crise sanitária.

Palavras-chave: Covid-19, Cuidadores, Esquizofrenia, Saúde Mental, Terapia Ocupacional.

Introduction

Schizophrenia is a chronic disorder with marked functional decline, with a prevalence of approximately 1% in the global population. It is one of the leading causes of disability worldwide, with a high morbidity rate and a shorter life expectancy compared with the general population. Symptoms may develop insidiously or abruptly, usually in early adulthood, and manifest differently in everyone. In general, they affect emotional, behavioral, and cognitive dimensions (Hasan et al., 2020).

With a predominantly clinical diagnosis, the disease presents heterogeneously and requires treatments such as pharmacotherapy and psychosocial interventions. Pharmacotherapy aims to support the person's adherence to medication, relieve symptoms, and prevent relapses, but does not necessarily promote the recovery of autonomy, which falls under the responsibility of non-physician professionals. It is a disorder that requires continuous follow-up by mental health services and by a caregiver, usually a member of the person's own family (Faden & Citrome, 2023).

The diagnosis of a chronic illness in an individual significantly affects the family circle, as it is expected to provide care support. Since schizophrenia is a chronic illness, it often demands a high level of vigilance because of the patient's functional impairments. It is common for care to be assumed by one of the parents, usually the mothers. This information is consistent with the study by Kantorski et al. (2019), according to which, in terms of gender, women are the ones who most often assume caregiving, including mothers, sisters, grandmothers, and spouses. These authors emphasize that such responsibilities place caregivers in a domestic and private context, despite the numerous achievements and transformations experienced by women in various social contexts. They also point out that gender should be understood from a relational perspective between women and men, to assign social and cultural meaning to relationships, revealing power relations and, therefore, transcending differences based solely on the biological characteristics of the sexes.

The primary caregiver of the ill family member becomes subject to higher levels of mental distress. Given the responsibility of caregiving, which can last for years, the caregiver abandons personal projects and relationships, which affects their quality of life and the care provided to the family member (Rahmani et al., 2022).

In 2020, the global outbreak of coronavirus (COVID-19) caused a crisis in global public health. To reduce the spread of the disease and its consequences for the population, efforts were made to decrease overcrowding in health services, and measures such as social distancing, quarantine, and isolation were adopted. These measures affected various lifestyles, including those of individuals with schizophrenia and their caregivers, since the need for continuous follow-up required their presence in health services. With reduced assistance, caregivers and individuals with schizophrenia, already in a situation of vulnerability, began to experience higher levels of mental distress (Nooraeen et al., 2023).

As a result, there were important changes in the everyday lives of patients and caregivers. In Brazilian occupational therapy, in the field of mental health, everyday life is considered the core of the profession (Constantinidis et al., 2025). "Everyday life" is understood as the real circumstances of a person's and their collective's existence, in which actions and expressions occur instantly and often unconsciously. Everyday life is changeable, constructed in a complex and heterogeneous manner regarding its content and meaning. To understand everyone, it is necessary to consider their singular and socio-historical aspects and, from the analysis of their everyday life, to grasp their ways of existing in the world (Galheigo, 2020).

Throughout the history of occupational therapy, there has been a critical stance among professionals in the field regarding the concept of occupation, with the aim of deconstructing reductionist, functionalist, normative, and status quo-preserving theoretical and methodological bases (which heightened social inequalities), supported by Anglo-Saxon models grounded in arbitrary and individualistic ideals of physical, mental, and social independence. The choice of an occupation requires a critical understanding that it arises from socio-historical interrelations and is interrelated with people and contexts. This contributes to overcoming the ideals, fostering a more consistent historical and political perspective on professional practices (Drummond & Costa, 2023).

The sociology of everyday life entered the field of occupational therapy by enabling the critical review reductive aspects of social processes by investigating "[…] the visible and apparent aspects of everyday actions and relationships in the mediation between social structures and historical processes" (Drummond & Costa, 2023, p. 20). For the purposes of this study, the theoretical-conceptual framework on everyday life developed by Brazilian social occupational therapy is considered. This framework is tied to human experience and to the inseparability between person and collective, whose social practices allow for the transformation of time and space (Galheigo, 2020). Occupations and everyday life are inseparable, since the latter, being constructed in space, time, history, and culture, involves human experiences in which occupations are lived (Drummond & Costa, 2023).

This study agrees with Drummond & Costa's (2023) observations concerning occupational therapy's commitment to understanding people's relationships with occupations in diverse contexts, immersed in their everyday lives, with such occupational relationships being dynamic and not based on rigid categories. Considering this theoretical affinity, it is important to note that, although this study used the document Occupational Therapy Practice Framework: Domain & Process of the American Occupational Therapy Association (Gomes et al., 2021), this was done solely to characterize part of the occupations mentioned.

The understanding of the everyday life of caregivers of family members with schizophrenia constitutes the focus of this study, with the aim of understanding the changes that occurred during the COVID-19 pandemic period.

Objectives

To identify and describe, from the perspective of caregivers of family members diagnosed with schizophrenia, the perceived changes in their everyday lives, especially in relation to their occupations and mental health, based on their experiences during the COVID-19 pandemic.

Method

This is a qualitative, descriptive, cross-sectional study that explores and discusses the changes that occurred in the occupations and mental health of caregivers of individuals with schizophrenia during the COVID-19 pandemic. The qualitative approach focuses on subjective data and allows for the interpretation of an individual's experiences in their social environment, describing perceptions, thoughts, and emotions (Minayo, 2015). According to Cesário et al. (2020), the descriptive aspect of research lies in its central purpose of describing the characteristics of a population or specific phenomenon (in this case, the caregivers and their experiences in providing care during the COVID-19 pandemic); the cross-sectional aspect is characterized by the fact that the data were collected only once, over a defined period, to portray the subject studied at a specific point in time.

This study was approved by the Research Ethics Committee (CEP) – CAAE: 69884923.4.0000.5440.

The study was conducted in a mental health outpatient clinic of a general hospital, located in a municipality in the interior of the state of São Paulo, where weekly therapeutic groups are held for patients with schizophrenia and their family caregivers. Coordinated by an occupational therapist and a psychologist, the groups aim to promote greater adherence to treatment, provide guidance on care management for family members, and encourage patients' autonomy.

The following inclusion criteria were adopted: being the primary caregiver of a family member diagnosed with schizophrenia; being over 21 years of age, of either sex; having the family member receiving care in the outpatient clinic's occupational therapy service; having regular attendance by both caregiver and family member to the therapeutic groups since before COVID-19. Ten female participants met these criteria, constituting a sufficiently large sample for the qualitative research approach, which focuses on the depth of content rather than on the operationalization of quantitative variables (Minayo, 2015).

The caregivers were invited to participate in the study after the conclusion of the therapeutic groups. At the end of each group session, the study was briefly presented to the caregivers, and those meeting the study criteria were invited. Ten invitations were extended at the outpatient clinic over the course of five sessions. For those who expressed interest, the study was explained in greater detail, the forms of participation (semi-structured interview) were presented, and any questions were answered. An Informed Consent Form (ICF) was distributed to formalize the caregivers' agreement to participate through their signature. Subsequently, a telephone contact was requested to schedule data collection in a private room at the outpatient clinic, to ensure participants' privacy.

The data were collected through semi-structured interviews prepared by the researchers. The script addressed topics such as the sociodemographic profile of participants, their knowledge of the family member's illness, their perception of the care provided during the COVID-19 pandemic, and questions concerning their occupations and mental health during the critical period of the pandemic.

The data were collected individually in 13 in-person meetings between the researcher and the participant, with an average duration of 50 minutes. This process occurred between August and December 2023.

All interviews were recorded using a digital audio recorder, transcribed, and stored on an institutional server (Google Drive), with access restricted to the researcher and the study advisor.

The participants' names were replaced by acronyms to ensure anonymity. C1, for example, refers to caregiver 1, and so forth.

The data were examined using Bardin's (2016) thematic content analysis, which comprises three stages: pre-analysis, consisting of an exhaustive reading of the interview transcripts to establish initial familiarity with the data and first impressions regarding the content; material exploration, allowing the identification of recording units, codes, and categories; data interpretation, highlighting the content of the interviews and interpreting them according to the study's guiding concept (everyday life). All stages were discussed between' the researcher, the advisor, and the co-advisor to jointly analyze the data and develop analytical categories and thematic units.

Results

The participants were characterized according to some sociodemographic aspects: All 10 participants in the study were female. The age range varied from 42 to 82 years. Regarding education, one caregiver completed higher education and three completed elementary school; two had incomplete elementary school, one completed high school, one did not finish high school, one did not complete higher education, and one had not attended school. Regarding marital status, three participants were married, one divorced, three widowed, two single, and one in a stable union (Table 1).

Table 1. Sociodemographic profile of the participants.

Participant	Sex	Age	Education*	Marital status	Occupation	Average monthly income	Kinship with family member	Duration of care
C1	F	42	E.S.I.	Single	Supermarket cashier	BRL 1,700	Mother	10 years
C2	F	82	E.S.C.	Widow	Retired (Teacher)	BRL 8,000	Mother	31 years
C3	F	75	No formal education	Married	Retired (Rural work)	BRL 4,000	Mother	13 years
C4	F	68	E.F.C.	Married	Retired (Seamstress)	BRL 5,000	Mother	17 years
C5	F	68	E.M.C.	Divorced	Retired (Factory assistant)	BRL 3,000	Mother	15 years
C6	F	63	E.M.I.	Widow	Retired (Rural work)	BRL 2,000	Mother	26 years
C7	F	67	E.F.I.	Married	Retired (Homemade appetizer caterer)	BRL 5,000	Mother	10 years
C8	F	72	E.F.C.	Single	Retired (Seamstress)	BRL 2,900	Mother	24 years
C9	F	45	E.F.C.	Cohabiting	Cleaning worker	BRL 1,800	Mother	7 years
C10	F	59	E.F.I.	Widow	Cleaning worker	BRL 1,300	Mother	10 years

*__Legend:__ Higher Education, Incomplete (E.S.I.); Higher Education (E.S.C.); Elementary School (E.F.C.); High School (E.M.C.); High School, Incomplete (E.M.I.); Elementary School, Incomplete (E.F.I.). **Source:** Prepared by the authors, 2025.

The caregivers' occupations were: two retired rural workers, two retired seamstresses, two housekeepers, one retired teacher, one retired homemade appetizer caterer, one retired factory assistant, and one supermarket cashier. The monthly family income ranged from BRL 1,300 to 8,000.

Regarding degree of kinship, the 10 caregivers were mothers (100% of the sample). Among the participants, all were aware of their children's diagnoses. The time dedicated to caring for their children ranged from seven to 31 years.

From the procedures of content analysis of the interviews, the following categories and thematic units emerged, presented in Table 2.

Table 2. Analytical categories and thematic units.

Analytical Categories	Thematic Units
1) Altered everyday life	● Work
	● Activities of Daily Living (ADL)
	● Leisure
	● Instrumental Activities of Daily Living (IADL – Caring for others)
2) Perceptions of mental health	● Depressed mood
	● Age of caregiver
	● Anxiety, worry, and fear

Source: Prepared by the authors, 2025.

Altered everyday life

Work

The participants reported that the period of social distancing during the pandemic generated concerns that interfered with important occupations, such as work. Some mentioned the cessation of work activities, while others expressed concern about being infected by the virus because of the need to continue working. Their statements were as follows:

> *During the pandemic. I think I only did one cleaning job, which was for my neighbor. The rest stopped completely* (C9).

> *At the time, I was very afraid because I continued working as usual. But I kept wearing masks and sanitizing my hands properly. Thank God, I never got it, nor did he* [son]. *So, I believe I managed, but the concern was always there.* [...] *I was really worried, you know? Because I was exposing myself to other people. I believe it had a big impact. I believe that if I could, I would have stayed home* (C1).

Activities of Daily Living (ADL)

According to the caregivers interviewed, the most critical period of the pandemic also caused impairments in performing some ADL because of lack of motivation, a situation that could later be redefined with the availability of vaccines in Brazil and the control of the pandemic. In Brazil, according to Maciel et al. (2022), the lack of political support from the Federal Government delayed the start of vaccination compared with other countries, prolonging citizens' social isolation and harming their mental health, causing or exacerbating pre-existing psychiatric conditions, especially anxiety and depression (Ancelmo et al., 2024).

> *I did not, I did not take a shower, I did not want to change clothes... you know, it was chaos in my life. I even felt a noise inside my head. You know when you freeze and do not feel like doing anything?* (C6).

> *I no longer felt like putting on lipstick, makeup, or doing anything. I believe it changed, disrupted, and demotivated me a little. My mind was already so anxious, maybe it kept me from doing anything. So, I think today I do more for myself than I did during the pandemic* (C1).

Leisure

Although distancing was strongly recommended by the World Health Organization (WHO) as a protective measure against coronavirus infection (Maciel et al., 2022), there were reports that made explicit the caregivers' mental exhaustion because they felt overwhelmed from having no one to share the care of their sick children with. In this sense, the following statement highlights leisure as a need to relieve fatigue, even in a vulnerable moment experienced on a global scale.

> *There was a time when I needed to leave him and travel, go to my sister's house, to clear my mind a little because everything was on me, you know? At some point, you feel like your mind is tired, right?* (C8).

Instrumental Activities of Daily Living (IADL – Caring for others)

There were significant rearrangements in health and mental health services, with teams of professionals being reassigned to prioritize care for people infected with coronavirus. These changes also affected the outpatient clinic where this study was conducted, which adopted as an eligibility criterion the care of persons with schizophrenia with active psychotic symptoms. Other patients were monitored remotely through telephone contact and teleconsultations, and their caregivers could no longer attend family group sessions, since these were suspended. The aim was to protect patients and family members from contagion. The impacts of these changes are reflected in the following accounts, which indicate the re-aggravation of crises in relatives with schizophrenia:

> *He had a crisis like... wanting, thinking that people were speaking ill of him. He had a relapse, right?* [...] *He had to seek medical help, and his medication had to be increased* (C8).

> *Look, that crisis... a little fear that he has had for a long time. Fear that he does not know where it comes from, panic, almost every day* [...] *during COVID this increased* (C7).

Considering this, there were changes in some IADL – Caring for others, as caregivers could not have their needs promptly addressed by the mental health service and had to cope with new crises of their relatives in a predominantly domestic context. Still considering the IADL – Caring for others, the fact that the caregivers studied attended a mental health outpatient clinic suggests a better adaptation of these women to domestic life with relatives more stabilized in relation to symptoms; however, this study pointed out aspects that require attention.

The following excerpts indicate that caregivers assumed full responsibility for the care of their children with schizophrenia, suggesting difficulties faced by them in terms of sharing caregiving tasks with other people:

> *We must be aware that the patient wears a person out, but that is normal. You have to take care of your son, there is no one better than you to take care of him, so we have to be patient* (C5).

> *No, no difficulty at all, we have been learning to deal with it for so many years, right?* (C8).

> *I have my husband, someone who... spends a lot of time at home, only goes out... to church and so on. But at home he helps me. Yes, but the one who really takes care of J.G.* [son] *is me* (C7).

> *It is me all the time, even before COVID. And now I am even more concerned* (C4).

The caregivers studied made explicit in their accounts the existence of a scarce support network. They reported not receiving help from others in caregiving tasks:

> *In fact, no one wants, you know... to care, so... And I am the mother; it is my role* (C1).

> *No, it is just me, you know?* (C4).

> *Look, there is his father, but in practice... in everyday life, it is mostly me, taking him, picking up medication, keeping an eye on everything, it is me* (C1).

> *Oh, I have my husband, but it mostly depends on me. I cannot rely too much on him* (C8).

> *I have my married son and daughter-in-law, but they do not understand much. My granddaughter also, she does not understand his problem, I have explained many times. And she does not want to understand, she wants him to be like us... like her, but he is not, what can we do?* (C3).

Considering the set of perceptions regarding the occupations performed during the pandemic revealed by the participants in their interviews, and associated with an insufficient and ineffective support network, the following category explores the impacts of these everyday life experiences on the caregivers' mental health.

Perceptions of mentel health

Depressed mood

Some of the respondents manifested depressed mood and avolition during social distancing. Some women reported the need to receive support from other people to perform their caregiving tasks:

> *It is taking him to the doctor, doing blood tests, getting medication, I always have to be with him... And so, one feels at times that the head is somewhat tired, right? So, I needed...* [help] (C8).

One respondent mentioned that one of her sons (not the one affected by schizophrenia) was dismissed from his job during the pandemic, which allowed him to assume the care of his brother given the depressed mood of the mother.

> *I got up without any will. My son lost his job and then started helping with the care because I became very weak. I spent two months in bed without eating and bathing properly, nothing, it was all A.* [son] *who took care of me. I really felt like disappearing* (C6).

Age of the caregivers

Another aspect that emerged as a concern for the caregivers was advanced age. The mean age of the participants was 64 years, and they expressed fear of no longer being able to provide adequate care for their children because of fatigue and the proximity of death.

> *Because of my age one becomes tired, right? So, I think that sooner or later I will not remain, as I grow older, I worry that perhaps I can… ah, the real problem is age* (C3).

> *I don't know whether it's because I was younger, now I am approaching 65 years. One becomes tired… I don't know, because before I didn't have this* (C6).

Anxiety, worry, and fear

The issues related to the consequences of the pandemic were multiple, generating or exacerbating anxiety, worry, and fear. The uncertainties about contagion and the lack of knowledge about the pandemic in its initial phase, as well as its future impacts on the participants' lives, combined with restrictions on their own and their children's access to mental health services, are potential causes of psychological suffering, as the following testimonies indicate:

> *I was really anxious* [...] *what most affected me was the anxiety itself.* [...] *One ends up becoming afraid, right? It is not something known, it makes one afraid of catching it* (C1).

> *Then I felt uncertain because... I was afraid of catching it. I was afraid, but more because of him* [son]. *I was even afraid of catching covid because of him* (C10).

> *Ah, the worry seemed to have increased somewhat* (C3).

> *Me too, because of the problem he* [son] *experienced and the problems that were happening during the pandemic, I also needed to take medication to sleep, and today I still use medication, I needed to take Diazepam, I needed to take sertraline, you know? And I still take them because I also had a disorder, you understand?* [...] *At times I think I won't manage, this takes away my sleep… I keep thinking a lot, you know?* (C6).

The essential problem that pervades the life of the caregiver of a person with a chronic illness such as schizophrenia, who has no one to share caregiving tasks with, often lies in the perception that they care less for themself and more for the sick family member. This aspect emerged as one of the findings of this study and appears in the following account:

> *The real care I had was with W.* [son]*, you know? I forgot myself, I thought I was fine. But in the end, I was not, right?* (C6).

The mental suffering of the participants also resulted from problematic conditions and events related to their children's illness, as indicated below:

> *Then the anxiety increased… so much so that with the course of his* [illness] *problem, by being like that I also become like that* (C5).

> *During the pandemic he stayed in bed a lot, right? That was when he even attempted... suicide. He needed to come here, to be hospitalized, right? So, for me it was very difficult. Very much so. I can imagine for him, right? And until today I am afraid, I fear that one day this will happen again* (C6).

These situations are not uncommon in people with schizophrenia and may compromise the caregiver's mental health. This aspect will be addressed in the discussion of the results.

Discussion

During the COVID-19 emergency, several changes affected the everyday lives of millions of people worldwide. This previously unknown and rapidly spreading disease reached high mortality levels among those infected, suddenly compelled individuals to restructure their life patterns, and directly affected the population's mental health (Dubey et al., 2020). Among those affected by these changes were caregivers of people with schizophrenia, who commonly experience significant levels of exhaustion (Issac et al., 2022). In this study, composed exclusively of mothers as caregivers, it was possible to highlight that their individual experiences were complex.

These mothers were the main providers of care to their children, which might not have been performed only by them. Assuming the entirety of care is common among women in Western societies, according to Badinter (1985). Motherhood, in the sense of giving birth, is exclusive to women. However, caregiving can be performed by both men and women, as it is a social and historical construct. The repetition of caregiving tasks by women results in the naturalization of the act and leads to the social recognition of care as an essentially feminine responsibility (Badinter, 1985). Thus, this naturalization may restrict men's participation in caregiving tasks, reflecting a way of living everyday life in which the relationship between those involved in these tasks fosters the overload and vulnerability of women.

In addition to the usual demands related to care, many participants tried to reconcile this responsibility with other roles, such as those associated with marriage, work, family, and social life. According to Galheigo (2020, p. 13):

> Everyday life encompasses the set of human activities, heterogeneous in content and meaning. Therefore, everyday life unfolds from birth to death; it is traversed and modified according to historical time, culture, social class, gender, and age.

Immersed in an ordinarily challenging everyday life in which many reconciliations are made, the caregivers were surprised by a new reality, marked by an unknown virus and the demand for new ways of existing (use of masks, distancing, hand, food, and object hygiene, etc.). From these abrupt modifications in everyday life, significant issues in their occupations and mental health were generated or intensified. The results of this study show that, during the pandemic period, there were changes in the performance of occupations related to work and difficulties in some ADL. Even with isolation measures and the uncertainty regarding the outcomes of the worsening pandemic, visiting relatives became a form of leisure for relieving the everyday tension of one caregiver. The participants' accounts indicated greater overload in an IADL central to the lives of these women: caring for others.

In conceptual terms, work may be related to the development and production of services with financial benefits; ADL are characterized as individual practices oriented toward caring for one's own body, aimed at maintaining one's quality of life; leisure refers to motivating, non-mandatory activities, unrelated to occupations such as work and performed during free time; IADL are activities that support everyday life in the home and community context, and include caring for others (Gomes et al., 2021). It is noteworthy that these occupations were briefly characterized, considering the content made explicit by the caregivers in their accounts. It was not necessary to define them in their entirety, as that would go beyond the scope and limits of this study.

Although it is expected that the family group serves as a source of care and affection for relatives with mental illness, individuals who assume the position of primary caregiver in the family are more likely to experience a high level of everyday stress (Janah & Hargiana, 2021). In this study, seven participants were retired by age. However, three caregivers remained working during distancing and expressed difficulties in maintaining income and feelings of concern because of the high exposure

to virus contagion. Because of social distancing measures, many work activities were suspended indefinitely, remaining only those considered essential. Considering this, the provision of care does not exempt women from accumulating tasks in the public and private spheres, which generates double and triple workdays (Kantorski et al., 2019), because of women's massive entry into the labor market (Guimarães & Vieira, 2020).

In this study, the participants were the main reference in caring for their children, and their reports evidenced stress related to caregiving tasks, accentuated during the pandemic. Even in situations of suffering and vulnerability, these caregiving mothers strove to adapt their difficulties to the reality modified by COVID-19. This highlights the changeable nature of everyday life, in which adaptations are possible. However, for the women studied, this adaptation is dangerous, as it reflects socially engendered and disseminated ideas that women are obliged to take on caregiving for relatives and the domestic context, even under adverse conditions. This adaptation may generate mental suffering if caregiving tasks are not negotiated, shared, and transformed within the family microcosm.

From a gender perspective, care provided predominantly by women reveals moral and cultural values that use female biological nature to justify and socially reinforce that caregiving tasks are assigned exclusively to women. This implies the notion of a sexual division of labor, which emphasizes differences between public and private work, the latter being strongly devalued and delegated to women (Kantorski et al., 2019). In this sense, caregiving tasks directed toward family members, and the domestic sphere are rendered invisible and placed as "obligation," deprived of remuneration and performed regularly. They are disregarded as work. These tasks occur through a social construction whose meaning refers to "love" and "family responsibility," reinforcing this behavior and contributing to its repetition (Guimarães & Vieira, 2020).

Thus, with the changes brought by the pandemic, the performance and maintenance of work activities became yet another stressor for caregivers to deal with in their everyday lives. Added to this is the fact that only three participants were married, which did not prevent them from fully taking on the tasks of caring for their children. This suggests yet another aggravating factor to the overload experienced, given the impossibility of relying on partners and other family members to share care and expenses. In this regard, and according to the data presented, the relationships established between caregivers and their partners suggest the absence of negotiation of caregiving tasks between the couple, nor do they indicate a spontaneous willingness on the part of the partners to share them with the women. This situation is interwoven with gender relations, in which men are granted the possibility of choice, which does not necessarily occur with women.

ADL were not effectively performed by some caregivers, who reported feeling unmotivated to conduct basic care and hygiene activities, which may be related to the feelings expressed in their accounts, such as concern and anxiety. In contrast, there were interviewees for whom, even in a worrying pandemic period, marked by fear of interpersonal contact, meeting with relatives was a form of coping through leisure, aiming to reduce the prevalent mental exhaustion and fatigue. Studies report that many caregivers seek social support to relieve their stress levels (Janah & Hargiana, 2021).

Because of home confinement and the restrictive scenario resulting from the health crisis, it is possible to suggest that the participants' everyday life was restructured in a

heterogeneous way, since some of them were able to cope with problematic situations (seeking their existing support network), while this did not occur for others. This fact refers to the unique ways that permeate the relationships established between the caregivers studied and their relatives, an aspect that aligns with the idea that everyday life is constituted by the real circumstances of a person's existence and their collective (Galheigo, 2020).

Many global health systems were not prepared to deal with the COVID-19 emergency. Changes in the organization of health services were essential to ensure care for people affected by the coronavirus, along with the continuity of treatment for those with other critical health conditions. With various deficits arising from these changes, countless groups were affected (Druss, 2020). In this scenario, the interviewees reported having experienced new crisis episodes in their children, resulting from the interruption of outpatient care, especially after the implementation of quarantine, which intensified their suffering. In this everyday life pervaded by challenges and uncertainties, the caregivers had to manage their children's psychotic re-exacerbation in the domestic environment without the immediate support of specialized services, which may have contributed to greater overload among the participants who went through these experiences. In this sense, the literature points out that the ideal follow-up of people with mental disorders involves various types of treatment: pharmacological, psychosocial, and rehabilitation when necessary. The interruption of these care services that meet the needs of these patients usually culminates in negative consequences, such as new crises or relapses (Kopelovich et al., 2021).

Still considering care tasks, the mothers in this study reported having become responsible for the totality of their children's care, given the scarcity of a support network. The analysis of the interviews shows that when caregivers spend years looking after a person with a chronic illness, such as schizophrenia, they often develop health problems themselves, particularly if they lack social support. As previously mentioned, the mechanisms that naturalize the idea that only the maternal figure must provide adequate care may lead, consciously or not, to a vulnerable way of existence, as they generate health and mental health problems in these caregivers, sometimes through an imperceptible process. The participants presented a fragile support network, and it was common for this network to exempt itself from the responsibility of sharing care when one member proved sufficient to perform such tasks, which occurs because of the caregiver's impossibility or difficulty in negotiating the division of care of the ill person with her family group. Situations like this reinforce the trivialization of overload (predominantly in women) and the naturalization of women as the only ones responsible for providing care, with no external support (Cohen et al., 2021).

Studies indicate that, during the pandemic, caregivers felt prepared to assume the care of the ill relative, since they were already accustomed to performing such tasks. However, they felt less prepared to delegate their daily functions to others during this period (Turner et al., 2023). This study suggests that the reduction of healthcare services strengthened in the participants the feeling of greater responsibility in managing care. Thus, it is reiterated that family caregivers must recognize that the lack of clarity in situations such as this can result in suffering and psychological illness, which will be discussed below.

The results of this study show that the participants experienced everyday realities characterized by exhaustion in periods prior to COVID-19. As mentioned, the pandemic brought new challenges to their lives, which may have aggravated or caused changes in their mental health. The caregivers reported a significant presence of depressed mood during the isolation period. They expressed demotivation to perform their ADL, needing external care and support to stabilize and return to their routine. The need for anxiolytics and sleep inducers was pointed out during and after the critical stage of the pandemic, showing that the mental health impairments did not cease after COVID-19 was controlled. Caregivers compromise their occupations, especially those linked to self-care, to meet the demands of ill relatives, which takes up a considerable part of their everyday lives (Rôse et al., 2023). Thus, it is possible that the pandemic caused greater impacts on occupations already previously compromised. With the decrease in professional and family support, associated with the greater overload reported by caregivers during that period, negative effects on their mental health became evident.

The results of this study corroborate those reported by Kantorski et al. (2019), who found a prevalence of minor psychiatric disorders (stress, anxiety, and mild depression) in women who assumed full care of relatives with mental illness. They point out the process of illness as resulting from the plurality of roles performed by women in society, as workers, mothers, wives, and caregivers. In this sense, the social marker of gender in the suffering experience of the caregivers studied is reiterated.

The characterization of the sociodemographic aspects of the participants revealed an average age of 64 years and an average of 16 years of care for their children with schizophrenia. Among these caregivers, four lived with partners and six did not. Most of them had low educational levels. Four participants had an average monthly income of less than twice the minimum wage. These results are important, since previous studies pointed out higher levels of overload in female caregivers with advanced age, low educational attainment and family income, divorced and widowed. It is worth noting that, in this research, in addition to having low income, participants also had their work affected by the pandemic, which was either interrupted or performed with psychological suffering because of fear of contagion. Relatives who care for male patients with schizophrenia, who spend more hours of the day with the ill family member, and who provide care for longer periods are also considered a vulnerable population (Hajebi et al., 2019; Hsiao et al., 2020).

The sociodemographic aspects mentioned, combined with the emergence of COVID-19, may have intensified the caregivers' suffering, leading them to identify and worry about their own frailties and the end of life. The perception of these frailties translated into fear of losing control over their children's care, of not being able to provide the necessary help because of age, as well as difficulties in dealing with their own health conditions and concerns related to COVID-19. As most participants were of advanced age, they were considered part of the risk groups for COVID-19. Nevertheless, and despite their fear of death and other feelings, as reported, they prioritized the ill family member, reinforcing the idea of the mother's exclusive dedication to her child.

Studies indicate that caregivers feel prepared to meet the usual demands of care but have difficulties in delegating the role of primary caregiver (Soysal et al., 2023). It is possible that this difficulty was intensified during the pandemic, considering what was

presented regarding the increase in caregivers' suffering in the face of care demands. It is important that the family member who assumes the responsibilities of care, as well as other family members, receive professional guidance to address the challenges inherent in this task, which may involve a gradual transfer of primary care to others. This guidance can be provided by occupational therapists together with other mental health professionals, with the purpose of offering caregivers a multidimensional approach to health and mental health care. In this way, it is expected that the responsibilities linked to care, which demand a significant part of the caregivers' everyday lives, can be shared, allowing them to devote more attention to self-care, including their physical and mental health (Cruz et al., 2024).

In this study, the impacts on participants' mental health were made explicit. The caregivers attributed to the pandemic the intensification of feelings such as anxiety, worry, and fear. They exposed anxiety and fear as the main feelings during the initial critical phase of COVID-19, as they considered the disease a threat to their lives and to those of their children, which generated intense worry. It is reiterated that, with social distancing measures, participants had reduced access to healthcare services and support networks, which aggravated the already challenging situation of dealing with the pandemic. This is corroborated by other studies that indicate an association between social distancing measures and the consequent reduction of mental health support for caregivers (Altieri & Santangelo, 2021).

In addition to the psychological suffering arising from the threat of coronavirus, some caregivers expressed psychic frailty because of relapses and increased anxiety of the relatives under their care, who also went through a transformation in their everyday lives, experiencing greater isolation and interruption of regular mental healthcare. This discontinuity of care during the pandemic affected people with mental disorders differently when compared with other populations, since they were more affected by the negative emotional responses brought by the pandemic, aggravating their psychological suffering (Yao et al., 2020).

The pandemic imposed new challenges on the population in general, requiring daily transformations for people to adapt to a reality until then unknown. This study shows that such changes altered the ways of existing in the participants' everyday lives, whether in their efforts to understand the pandemic and its impacts, in managing adverse situations experienced in occupations of both individual and collective nature, in their relationships with children and other relatives, or in their interaction with mental healthcare services. The COVID-19 pandemic marks a historic and transformative moment in everyday life, which had to be re-signified, requiring new adaptation strategies and new ways of thinking about care relations.

Conclusion

This study identified and described, from the perspective of mothers who are caregivers of children with schizophrenia treated in an outpatient setting, significant changes in their everyday lives, with emphasis on aspects related to their occupations and perceptions of their own mental health in the context of the COVID-19 pandemic.

According to the study participants, the main occupations that were altered during the pandemic were work (interrupted or performed with concern because of

fear of contamination); some ADL, mainly self-care and hygiene activities; leisure with family members, undertaken in a non-recommended situation to reduce fatigue and stress; and IADL – Caring for others, since the participants were mothers of persons with schizophrenia, in which care was permeated by feelings of concern and not necessarily shared with other family members, resulting in greater fatigue and burden. In this situation, gender was strongly intertwined as a social marker. The experience of living in a gendered everyday life emphasized ideas and reproduced behaviors of holding the studied women responsible for caregiving tasks, with important consequences for their mental health.

The perceptions elaborated by the caregivers regarding their own mental health included depressed mood, concerns with age and with their own death, and increased anxiety, concerns, and fear, considering the more critical and little-known context of the pandemic.

The vulnerability of caregivers of relatives with schizophrenia requires the attention of occupational therapists, since taking care alone, without sharing tasks with others, increases the likelihood of their health deteriorating. It was notable that the participants dedicated themselves entirely to the care of their children, to the detriment of self-care. In this sense, the provision of interprofessional care is suggested for those who assume responsibility for caring for a relative with a mental disorder, from a multidimensional perspective.

It is also suggested that more robust public policies be developed that address the health and mental health of caregivers through interprofessional and intersectoral actions that go beyond family groups.

This study is considered relevant because it (re)confirmed, with the advent of COVID-19, the insufficiency of actions aimed at caregivers' health, even though the pandemic initially modified the care structures of mental health services. Considering the methodological option of this study, 10 participants receiving care at a mental health outpatient clinic were selected, which produced a segment of reality that cannot be generalized. It is possible that in other contexts and services of the Psychosocial Care Network (RAPS), with the inclusion of more participants, the findings will prove more robust and optimistic. What has been presented here is noted as a limitation of the present study, but other studies can be conducted to investigate the mental health conditions of caregivers in the current post-pandemic phase, that is, with greater control of the disease after access to vaccines.

Thus, after the initial phase of COVID-19, future studies may portray the realities of caregivers in a modified and re-signified everyday life.

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Author's Contributions

Beatriz Carneiro Alves de Lima: literature review and update, drafting of the research project, submission of the project to the Research Ethics Committee, data collection and analysis, writing of the manuscript. Regina Yoneko Dakuzaku Carretta (co-supervisor of the study): support in the stages of content analysis of the transcribed data, collaboration in the development of analytical categories and thematic units. Elke Tiegui Baldo: support in the process of submitting the research project to the Research Ethics Committee, collaboration in the discussion of the results, and revision of the final text. Leonardo Martins Kebbe (supervisor of the study): design of the research project and participation in all stages related to the development of the study. All authors approved the final version of the text.

Data Availability

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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