

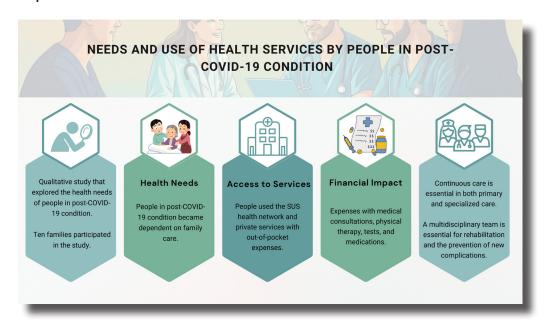
# Needs and access to health services by people in post-COVID-19 Condition in Brazil: a qualitative study

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#### Highlights

- Persistent symptoms impact the quality of life and autonomy of people in post-COVID-19 condition.
- Delays in accessing specialized care within the SUS led to increased costs for patients.
- Fragmentation of services hinders comprehensive access to treatment and recovery for people in post-COVID-19 condition.
- It is necessary to strengthen strategies to ensure free and comprehensive care for this population.

# **Graphical Abstract**



#### **Abstract**

Post-COVID-19 condition involves persistent symptoms that impact quality of life and require ongoing care. This study aimed to identify the health needs and health care services used by individuals in post-COVID-19 condition, as well as to describe the costs borne by the users. This is a qualitative study conducted at the post-COVID outpatient clinic of a teaching hospital in the city of Pelotas, Rio Grande do Sul, Brazil. Ten families participated, comprising ten individuals in post-COVID-19 condition and ten family members, totaling twenty participants. The sample was intentional, and data collection took place between March and August 2022 through semi-structured interviews. Data were organized using the IRAMUTEQ software and analyzed through content analysis. Individuals in post-COVID-19 condition presented health needs that made them dependent on family care and required multidisciplinary care. They accessed different services within the SUS care network, as well as private services paid for out-of-pocket, such as medical consultations, physical therapy, tests, and medication purchases. People in post-COVID-19 condition require continuous care, both in primary and specialized care, with a multidisciplinary team for rehabilitation, prevention of functional dependency progression, and new complications.

Keywords: COVID-19. Rehabilitation. Accessibility to Health Services. Health Expenditures. Qualitative Research.

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# INTRODUCTION

Post-COVID-19 condition is described as a set of symptoms that generally emerge three months after the onset of coronavirus infection, persist for at least two months, and are not explained by other diagnoses<sup>1</sup>. Based on a conservative estimate of 10%, the global prevalence of post-COVID-19 condition would reach approximately 75 million people, with around 4 million cases in Brazil<sup>2</sup>. This figure highlights the need to develop public policies and management strategies aimed at both the prevention and effective treatment of complications resulting from COVID-19.

These prolonged symptoms can affect the respiratory, neurological, cardiovascular, gastrointestinal, musculoskeletal, rheumatological, dermatological, and immune systems, in addition to impacting mental health<sup>3,4</sup>. They can range from mild to disabling conditions, potentially affecting health-related quality of life, increasing demand for health services, resulting in absenteeism, and raising both direct and indirect health care costs<sup>2</sup>.

Given these persistent impacts, post-discharge rehabilitation has been recommended for individuals with complications associated with COVID-19, aiming to improve the course and prognosis of the disease<sup>5</sup>. This requires long-term follow-up, individualized according to the patient's clinical profile, and conducted in rehabilitation services with a multidisciplinary team<sup>6</sup>.

In Brazil, the Unified Health System (SUS), established by the 1988 Federal Constitution, recognized health as a right of all citizens and a duty of the State. Based on the principles of universality, comprehensiveness, equity, decentralization, regionalization, hierarchy, and social participation, it aims to ensure universal, comprehensive, and equal access to health for the entire Brazilian population. One of the challenges faced by the system is providing effective responses to chronic conditions affecting a significant portion of the adult population, especially considering the fragmentation of actions and health services in light of changes in the population's epidemiological profile.

It is important to highlight the relevance of the SUS since its implementation, and especially during the COVID-19 pandemic, as it addressed a growing demand from individuals requiring care, including diagnosis, treatment, and high-complexity services. The COVID-19 pandemic challenged the resilience of health systems globally, particularly in Brazil, which was among the countries most affected by

the disease. To mobilize resources in response to the pandemic, several programs and services had to be suspended, while hospital beds initially intended for other treatments were reassigned to care for patients with severe COVID-19 cases<sup>8</sup>.

Caring for individuals infected with the coronavirus who continue to experience the consequences of the disease represents a new demand for the SUS. The initial assessment and management of people in post-COVID-19 condition should be carried out in primary health care (PHC), considered the main point of entry into the SUS. PHC is characterized by longitudinal and comprehensive care, coordination of services, person- and family-centered attention, community-oriented actions, and the presence of human resources with a cultural attitude aligned with primary health care9. According to the Guiding Note for primary health care in post-COVID-19 cases, published by the State Government of Rio Grande do Sul in 2021, PHC is responsible for continuously providing care for other health conditions and illnesses in the population, in parallel with care for those requiring post-COVID-19 rehabilitation<sup>10</sup>.

A cohort study conducted in Wuhan, China, showed that individuals in post-COVID-19 condition continue to require care six months after the acute phase of the disease, emphasizing the importance of continuous follow-up to reduce morbidity and mortality<sup>3</sup>. In the United Kingdom, clinical guidelines recommend a multidisciplinary approach and active follow-up for rehabilitation, but reports indicate difficulties in accessing health services and lack of care coordination. As a result, many patients turn to self-management of symptoms and informal support networks<sup>11</sup>.

The Brazilian literature includes studies describing the use of health services by individuals in post-COVID-19 condition for both treatment and rehabilitation<sup>12,13</sup>. Other studies indicate that these individuals seek care in basic health units or private services through in-person or telehealth consultations, bearing the costs of treating complications out-of-pocket<sup>12,14,15</sup>.

Given the magnitude of the pandemic and the resulting post-COVID-19 condition, further studies are needed to better understand this phenomenon. Therefore, this research aimed to identify the health needs and health care services used by individuals in post-COVID-19 condition, as well as to describe the costs borne by the users.



#### METHODOLOGY

This is a qualitative study conducted between March and August 2022. Its development followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

The study was carried out in Pelotas, a municipality in the southern region of Rio Grande do Sul, Brazil, with an estimated population of 325,685 inhabitants<sup>16</sup>, at the post-COVID outpatient clinic of a teaching hospital linked to the SUS network through the Municipal Health Department.

During the pandemic, the municipality organized an extensive COVID-19 response network, which included the creation of a municipal committee, the reorganization of Basic Health Units (UBSs), the designation of Sentinel Units for respiratory cases, and the establishment of the so-called "COVID Area," with specific beds for hospitalizations at various levels of complexity. At the time of the study, Pelotas had 91 beds dedicated to patients diagnosed with COVID-19 and had recorded over 46,000 recovered individuals, with a recovery rate exceeding 93%<sup>17</sup>.

Primary care in the municipality consists of 51 UBSs, one Specialty Center, and nine Psychosocial Care Centers, which are coordinated with the emergency and urgent care network comprising one Emergency Care Unit (UPA), one Immediate Care Basic Unit (UBAI), the Municipal Emergency Room, and the Mobile Emergency Care Service (SAMU)<sup>18</sup>. In terms of hospital care, Pelotas has five hospitals that serve the SUS, one of which provides only psychiatric services. The other hospitals offer high-complexity care for Pelotas and the surrounding region in specialties such as nephrology, neurology/neurosurgery, radiotherapy, hematology, cardiovascular surgery, interventional cardiology, and traumatology, in addition to three private hospitals<sup>18</sup>.

The post-COVID outpatient clinic, implemented in the first half of 2021, aims to assist individuals with sequelae from the disease and is staffed by a multidisciplinary team composed of pulmonologists and physiatrists, physical therapists, occupational therapists, psychologists, and physical education professionals.

The study included 10 families, consisting of 10 individuals in post-COVID-19 condition and 10 family members, totaling 20 participants. Family selection was followed by the choice of the dyad composed of the individual in post-COVID-19 condition and one family member. The sample was intentional. The following inclusion criteria were applied to select individuals in post-COVID-19 condition: having received care at the outpatient clinic in 2022; being male or female aged between 18 and 59 years; having received

a COVID-19 diagnosis at least three months prior; presenting at least two symptoms of post-COVID-19 condition; being immunized with the COVID-19 vaccine; and being able to communicate verbally. For selecting family members, the inclusion criteria were: being the family member most involved in the care of a person with this condition; being 18 years of age or older; being immunized against the virus; and being able to communicate verbally.

The researcher reviewed the medical records and patient charts of those registered at the outpatient clinic. In cases where the inclusion criteria were met, the researcher approached potential participants at the clinic, explained the study, and invited them to participate. Subsequently, contact was made via messaging app or phone call with 18 identified patients. Of these, nine agreed to participate, while the other nine declined due to reasons such as the need for hospital readmission, withdrawal, unavailability of their family member, or lack of response to contact attempts. After accepting the invitation, their family member was also invited, and interviews were scheduled according to their availability, either at their homes or online. One individual who declined to participate referred the researcher to a coworker who also experienced complications from the disease; this person contacted the researcher and, after confirming the inclusion criteria, the interview was conducted.

Data were collected through semi-structured interviews with the family, consisting of the person in post-COVID-19 condition and a caregiving family member, following the presentation of the study and the signing of the Informed Consent Form. A guide was used with questions related to the individual's experience with COVID-19 illness, self-care practices, support network, feelings and perceptions resulting from the illness, expenses related to treatment and rehabilitation, as well as questions aimed at understanding, from the family's perspective, the care and practices involved in the recovery and rehabilitation process.

Eight in-person interviews and two online interviews were conducted using the Webconf virtual platform of the university, as requested by the participants. The interviews were conducted by the first author of this article, who at the time was a master's student and a nurse at a teaching hospital with experience in qualitative research. Transcription was carried out by the primary researcher with the assistance of an undergraduate nursing student who had received proper training.



Data processing was conducted using the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ), version 0.7 Alpha 2, developed by French researcher Pierre Ratinaud, and anchored in the R statistical software and Python programming language. This tool allows for various statistical analyses and processing of textual corpora and individual/word tables<sup>19</sup>.

The textual corpus of this study comprised ten interviews, generating 2,563 text segments, of which 2,345 were utilized, representing 91.49% of the total corpus. The Descending Hierarchical Classification (DHC) method was used. Based on the interview set and corpus preparation, the DHC method segmented the elementary context units (ECUs) or text segments (TS), classifying them according to the most frequent vocabulary, which was interpreted as significant for the qualitative analysis of the data, following the content analysis approach proposed by Bardin (2016)<sup>20</sup>.

The analyses, conducted through lexical statistics and the construction of classes using the IRAMUTEQ software, provided indicators for the emergence of categories discussed in the study.

Following data processing, the data analysis phase was initiated and developed in six stages: Stage 1: organization and preparation of the data for analysis, including transcription and its revision, carried out based on guidelines for corpus construction; Stage

2: conducted through an initial reading of the full material, followed by successive re-readings to evaluate the transcribed content; Stage 3: the actual analysis phase, with coding performed in IRAMUTEQ, which generated the word list presented in dendrogram form; Stage 4: use of the coding and categorization process for analysis, with assessment of the classes presented in the dendrogram and new re-readings of the interviews; Stage 5: description of the categories, supported by the conceptual framework consulted after the category analysis; and Stage 6: interpretation of the data and, after analysis, presentation of the results by the researcher through her personal interpretation, grounded in the scientific literature. This article presents one of the categories constructed, entitled "Use of the Biomedical Subsystem in the Post-COVID-19 Condition", along with its three subcategories.

The study was approved by the Research Ethics Committee of a Brazilian Federal University under CAAE 54365421.2.0000.5317. The Free and Informed Consent Form was applied, and to ensure anonymity, participants were identified using the abbreviation 'P' for participant and 'F' for family member, followed by a cardinal number, the letter 'M' for women or 'H' for men, and age, for example: 'P01M59years' and 'F01M40years'. Participants were invited to remain in contact for feedback on the study.

# **RESULTS**

Among the individuals in post-COVID-19 condition, there were five men and five women. Regarding age, five participants were between 50 and 59 years old, three were between 40 and 49 years old, one was 37 years old, and one was a 24-year-old male. Concerning marital status, six individuals reported not having a partner.

With respect to occupation, participants reported working as a public transportation driver, app-based driver, recently graduated agronomist, shopkeeper, cleaning assistant, school monitor, and homemaker.

Regarding the need for hospitalization, eight individuals were admitted to the hospital; of these, six required care in an Intensive Care Unit (ICU), and five underwent Mechanical Ventilation. The length of hospital stay ranged from 18 to 96 days. At the time of data collection, all individuals had been undergoing rehabilitation for complications related to COVID-19 for more than nine months.

Among the family members, nine were female. The degree of kinship included daughter, mother, wife, husband, stepmother, and cousin, with the majority of family members (seven) being over 40 years old.

#### Health needs of people in post-COVID-19 condition

The complications reported by participants included: fatigue, dyspnea, cough, chest pain, muscle pain, loss of physical conditioning, lack of appetite, heart failure, difficulty concentrating, memory loss, dizziness, anxiety, and depression. All individuals in post-COVID-19 condition were receiving care from a multidisciplinary team. These findings are illustrated in the excerpts below:

Sometimes I get tired. If I walk too fast, that staircase I go up, I get a bit tired. (P01F59years)

He had 100% lung involvement. And now he has fibrosis. [...] he still has those respiratory sequelae, because he developed fibrosis and PE [pulmonary embolism]. So now he uses [oxygen] for exertion and to sleep. (F02F27years)

I cook when he's [husband] about to arrive, or I sit next to the stove and wait until the food is ready so I don't forget. I forget things. (P04F-59years)



There are days when I see that he's really down, he doesn't talk, he sleeps or he cries, and I say 'calm down, it will pass, there's no point in rushing things'. Today, for example, I found him looking dejected. (F06F49years)

Post-COVID-19 condition led individuals to become dependent on family care following hospital discharge and return to their homes. This care included personal hygiene, feeding, assistance with ambulation, transportation to medical appointments and physical therapy, wound care, medication administration, intermittent bladder catheterization, and support for leisure activities, as illustrated below:

[Diaper] I still use it at night. During the day, thank God, I stopped. I managed. But I still have to be protected because sometimes there's not enough time to get to the bathroom. At night I have to wear it, sometimes I have to change two or three times during the night. (P04F59years)

So, let's say, for the first 3 months after I had COVID, if I walked three blocks I would already feel sick, I couldn't go on. I couldn't even walk three blocks. (P02M53years)

I'm taking the medications, I was on insulin, when I came home I still needed it. My sister-in-law administered it for me, the Melhor em Casa staff taught her how to do it, all the right times. So we had a list, a paper posted on the wall, already written out with everything, the medications, the times, everything. And they [my brothers] adapted the house for me. Upstairs there are two bedrooms, but they set up a bed here, they cleared everything, they changed it all, there wasn't even this [cabinet with the TV], and they set up a counter for the medications. (P09F37years)

#### Access to and use of health services

This study identified the need for specialized care in areas such as pulmonology, gastroenterology, endocrinology, neurology, rheumatology, and nephrology. Other professionals, such as psychologists, occupational therapists, and physical therapists, were also mentioned. To address the complications, study participants used more than one health service for the rehabilitation of their post-COVID-19 condition. Figure 1 illustrates these services, with the size of the icons representing the relevance attributed to each of them in the participants' narratives.

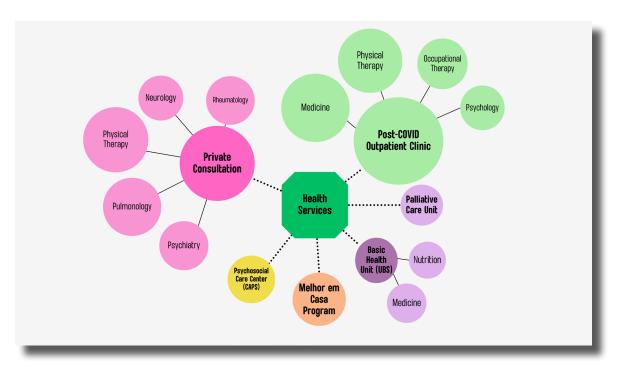


Figure 1 - Health services used by participants.

Participants used services within the SUS health care network, such as basic health units, outpatient clinics, the Home Care Service – *Melhor em Casa* Program, and the Psychosocial Care Center (CAPS), in addition to accessing specialized care in both public and private sectors.

Some participants reported that upon hospital discharge, they were referred with a scheduled appointment at the post-COVID outpatient clinic and to the *Melhor em Casa* Program of the Teaching Hospital's Hospital Care Service. Others were referred by basic health units for care and rehabilitation. According to participants' accounts, the waiting time for care at the outpatient clinic did not exceed 20 days.

I was discharged from the hospital on August 10 with a scheduled appointment, referred



to the university's post-COVID clinic. So that post-COVID care was essential to my recovery. (P03M56years)

I was discharged from the hospital with a referral to the outpatient clinic, and it was quick. I think it was about a week later. It was so fast that I was even surprised. (P04F59years)

I left the hospital with a referral to the outpatient clinic. Soon after, they called for consultations, follow-up, and medication. (P07M43years)

The post-COVID outpatient clinic was described as an essential service for providing care and access to specialized medical attention. It also enabled referrals to other areas requiring intervention, such as physical therapy and psychology, in addition to other medical specialties. Through the outpatient clinic, individuals were able to access tests such as spirometry, electrocardiogram, tomography, catheterization, and laboratory exams to monitor the progress of rehabilitation.

The *Melhor em Casa* Program played an important role by allowing families to receive care as well as guidance on medications, prescription updates, provision of materials for wound care, and instructions for requesting geriatric diapers. Basic health units were mentioned by participants as a support service for rehabilitation. People sought out these units for medical and nutrition consultations, to obtain medications, request exams, and receive referrals to other services in the health network.

And we received good guidance, for example, when we left the hospital, we were referred to the Melhor em Casa program, and the doctor came here, evaluated my father, and recommended switching to a more modern bronchodilator. He managed to contact the lab, and we received three samples. (F02F27years)

And from the moment I was discharged, when I got home, the Melhor em Casa team came to assist me. You feel safe, you feel comforted. You're in that bad situation and you know those people are coming to check on you, to see how you are and to bring your medication and everything. (P09F37years)

To address mental health needs, individuals in post-COVID-19 condition required care from psychiatrists and psychologists. Some gained access through home consultations and services provided by Psychosocial Care Centers (CAPS), while others were still waiting to be seen through SUS. Another service in the SUS care network that was used was the Regional Pallia-

tive Care Center (*Unidade Cuidativa*), which one participant described as a source of support by offering access to therapeutic activities and physical exercise, such as Pilates.

We also had help from the psychologist at the outpatient clinic, and it helped a lot. (P09F37years)

[...] I went to Cuidativa, spoke with the social worker, explained my case, said everything, and she said Tuesday, the twenty-fourth, come at nine o'clock to see the doctor. Bring your test results, he'll assess everything and determine whether you can do Pilates, or something else, you'll be referred to something, but you have to see him first. I asked because I can't take it anymore [being stuck at home]. And she said, we'll find something for you, you'll do it, don't worry. (P06M-53years)

As for physical therapy, all participants in this study required it after hospital discharge for physical and respiratory rehabilitation. They acknowledged that the physical therapist's care was essential for regaining mobility and pulmonary function. This care was initially provided at home and later at the post-COVID outpatient clinic. When performed at home, participants paid for this service out-of-pocket until they were called to receive care through SUS. These findings are evidenced in the following statements:

Before she started physical therapy [at the SUS post-COVID outpatient clinic], we hired a private physical therapist and began treatment right away. Then she started going to the outpatient clinic, but she was already doing sessions at home, and all of that helps. (F01F40years)

I did physical therapy through the outpatient clinic at University X, and we hired a private physical therapist for home sessions. I did physical therapy every day. (P02M53years)

I did private physical therapy at home. It was a heavy expense each month, but luckily it was just a little over a month. I recovered quickly. Every day I pushed myself further; I did it three times a week. By the end of the physical therapy, I was already running. After I finished, I started working with a personal trainer. (P05M24years)

For physical therapy in the rehabilitation process, eight individuals initially accessed professionals through private services and later obtained access via SUS. Some continued with both private and public care, which they considered essential, as it enabled them to resume daily living activities, return to the la-



bor market, and reintegrate into society.

No participant reported having private health insurance, meaning that all private health care costs were paid out-of-pocket. Among the most frequently used private services were physical therapy sessions and consultations with medical specialists, both considered fundamental for monitoring COVID-19-related complications.

# Use of out-of-pocket resources to access health services

For treatment and rehabilitation, participants accessed private specialized care, covering the costs of medical consultations, medication purchases, and imaging exams themselves. This pathway to professional care was used due to long waiting times within the SUS, as illustrated in the excerpts below:

The electrocardiogram he needs to do, we're still waiting for it to be scheduled by the Health Department. They haven't scheduled it yet. (F02F-27years)

We paid for a private consultation because we still haven't managed to see a neurologist. With SUS, if you want to do an exam or anything, the wait is too long, way too long. It forces you to pay privately, and everything is expensive. (PO4F-59years)

And financially, we spent a lot. But we didn't skip any exam because of money. He didn't miss out on anything: everything he needs, he's getting. We pull funds from here and there, but he's getting everything he needs. And if we have to give something up to keep going, we'll do whatever it takes. (F05F56years)

Some participants reported the need for follow-up exams, such as tomography, laboratory tests, elec-

trocardiograms, and pulmonary function tests, which were considered essential for monitoring recovery. However, due to the high cost of these procedures in the private sector, many continue to wait for them to be performed through SUS.

What I really wanted was to see an endocrinologist, they haven't called me yet, and a nutritionist because I need to watch my diet. (P01F59years)

So, those tests [tomography], I wish I could do them privately today because it's faster. The faster you get a diagnosis, the more peace of mind you have. And psychological support too, I can't afford it. (P02M53years)

Post-COVID-19 treatment involves the use of medications to manage a variety of persistent symptoms resulting from the illness and is considered a health need. These medications resulted in significant expenses, as evidenced in the following accounts:

The box of medications I took, I think for six months, one of them cost three hundred reais. We bought them when I left the hospital. There were two medications I was taking during the first month, one of them cost over two hundred reais, and I don't remember the price of the other. Later we managed to find a better deal, we did some price searching and bought it cheaper, and some family members also helped us out by giving us medication. (P03M56years)

I take an anticoagulant, which I'll have to take for the rest of my life, Xarelto, which Dr. A. [doctor from *Melhor em Casa*] got for me for quite some time. I take medication for high blood pressure, which also helps with the heart, Losartan, Furosemide, and Amlodipine, and I take diabetes medication. I used to be on insulin, but it was switched to 500mg Metformin. (P09F37years)

## DISCUSSION

In the literature, post-COVID-19 condition is considered a diffuse and multisystemic inflammatory syndrome, characterized by recurrent or continuous health alterations and needs in individuals affected by COVID-19<sup>1</sup>. This clinical condition requires a multidisciplinary approach from health professionals.

All participants in this study living with post-COVID-19 condition described a set of signs and symptoms such as fatigue, dyspnea, partial memory loss, anxiety, and depression, which interfere with activities of daily living. These findings are consistent with other studies on COVID-19 complications<sup>4,14,21</sup>. Such complications are debilitating and limit daily ac-

tivities, reducing quality of life and physical function, and leading to fear and hopelessness due to the persistence of these conditions<sup>22</sup>.

Individuals in post-COVID-19 condition report profound changes in their identity and self-confidence, as the multiple symptoms they experienced impacted their ability to engage in everyday activities, resulting in a diminished sense of accomplishment, meaning, and purpose<sup>11</sup>. This leads to loss of productivity, difficulty in resuming daily and work activities, as well as expenses related to health care resources for diagnosis, treatment, and rehabilitation<sup>21,23</sup>.

Although most participants in this study experi-



enced a severe form of COVID-19, it is acknowledged that post-COVID-19 condition can also affect individuals who had mild cases of the infection. In this regard, a study conducted in Brazil reports that individuals with mild forms of the disease and treated at home also experienced significant health impacts after the acute phase<sup>24</sup>. Complementarily, a cohort study conducted in Norway reinforces that people with mild infections may develop post-COVID-19 condition, especially when they have pre-existing risk factors<sup>25</sup>, indicating that initial severity is not the sole determinant for the development of long-term sequelae.

In 2022, Ordinance No. 377/2022 allocated specific funding for actions and services targeting individuals with COVID-19 complications within primary health care. Despite this allocation, the structuring of the health system to serve this population has yet to be fully implemented<sup>14</sup>. This structural barrier may lead to increased reliance on urgent and emergency services, resulting in overcrowding and heightened health risks and complications.

Specialized care within SUS represents a critical bottleneck in the Brazilian health care network, as studies highlight difficulties in accessing public services and the resulting need for users to incur out-of-pocket expenses for consultations, tests, and medications<sup>11,15</sup>. A study conducted with older adults in post-COVID-19 condition also identified limitations and lack of availability in public health services, which led participants to seek private care, bearing the costs of medications, private appointments, and health plans<sup>12</sup>.

In the same vein, a study conducted with COVID-19 survivors in João Pessoa (PB) aligns with the findings of the present research by highlighting the fragmentation of care and the obligation to rely on private resources due to the public network's inability to adequately meet post-COVID-19 needs, resulting in therapeutic journeys marked by discontinuity of care and financial burden<sup>26</sup>. The recurrence of these findings across different regions of the country underscores the urgency of reorganizing care pathways and improving SUS's response to the specific needs of individuals living with COVID-19 complications.

Participants in this study emphasized the importance of public health services in the rehabilitation process, such as the post-COVID outpatient clinic and the *Melhor em Casa* Program, for providing medical care, physical therapy, referrals for exams, guidance, and access to medication. These services served as key points of support, aligning with SUS's principle of comprehensiveness. However, gaps remained in the coordination between levels of care and in the health system's response capacity, resulting in longer waiting times for care, which contributed to the pursuit of

private services.

The pursuit of private services (care, consultations, medications, exams) was justified by study participants based on the perception of greater agility and quality of care, even though it resulted in financial hardship for their families. This choice was considered necessary to ensure continuity of care in the rehabilitation process. This collective family effort to maintain access to treatment reveals a fragility in the health system when faced with the complexity of post-COVID-19 condition. In this context, the implementation of specialized services within SUS is seen as a strategy to reduce access barriers, improve the quality of care, and ensure the continuity and comprehensiveness of care over time<sup>11</sup>.

The health needs reported by participants created a demand for ongoing follow-up within the health system, corroborating findings from a cohort study which indicated that one-third of participants required more than two consultations related to prolonged symptoms or COVID-19 complications<sup>27</sup>. Long-term care is necessary to promote rehabilitation and reduce the risk of disabilities and comorbidities. However, post-discharge recommendations remain unclear, demanding greater knowledge and preparedness from health professionals to support these patients in community settings<sup>28</sup>.

As new data continue to emerge, clinical guidelines are being developed, and pathways for specialized health care are being established<sup>29</sup>. Nonetheless, health services remain fragmented, and patients often move through multiple care routes, frequently consulting one provider only to be referred to another specialized service<sup>30</sup>.

Given the complexity of care required for people in post-COVID-19 condition, it is essential to emphasize the importance of comprehensive care, addressing physical, psychological, emotional, and social needs. In this study, basic health units and CAPS were used to meet these needs, highlighting the central role of Primary Health Care (PHC) in initial assessment, welcoming, and follow-up of these individuals<sup>14</sup>.

Continuity of care, one of the core attributes of PHC, is particularly important for the rehabilitation of individuals with COVID-19 complications. The proximity between health professionals and the community fosters the development of trust, which in turn contributes to greater adherence to the rehabilitation process<sup>31</sup>. Among the actions planned for PHC teams are home visits in more complex cases, with participation of a multidisciplinary team, and attention to the rehabilitation needs of individuals with complications<sup>32</sup>. In PHC, monitoring and follow-up of people with post-COVID-19 complications have required significant adaptations, including team expansion and



psychological support<sup>31</sup>.

A scoping review study aimed at identifying and mapping the care process for monitoring and multidisciplinary follow-up of post-COVID-19 sequelae within PHC worldwide indicates that Brazil faces challenges despite having a public health system, especially related to service accessibility, which results in a more difficult care process<sup>33</sup>. This is consistent with findings from a study involving health professionals from a Multidisciplinary Team working in the Family Health Strategy (ESF), which highlights the limitations they encounter in the rehabilitation of these individuals, such as the lack of a structured care flow, since no established care pathway exists across the different levels of health care. Structural barriers, insufficient human resources, and limited support for rehabilitation within PHC are also noted<sup>31</sup>.

One of the areas highlighted as essential in the post-COVID-19 condition is physical therapy, which provides resources that help prevent and rehabilitate complications caused by COVID-19, in addition to supporting the optimization of functional independence and facilitating reintegration into society and the labor market<sup>34</sup>. This importance was recognized by participants in this study.

The need for multidisciplinary care for treatment and rehabilitation is also evidenced in other stud-

ies<sup>14,15</sup>. Based on the premise that rehabilitation is a team effort, and that for people in post-COVID-19 condition, time is crucial to preserve functionality and quality of life, multidisciplinary action is essential for the proper management of these complications and for reducing the social and physiological impairments caused by the disease, promoting effective recovery<sup>31</sup>. Thus, it is necessary for individuals in post-COVID-19 condition to be heard, and for their experiences to be validated by health professionals, family members, and friends<sup>11</sup>.

As a limitation of this study, it should be noted that it was conducted in a single service located in a medium-sized municipality in southern Brazil, which has a post-COVID outpatient clinic in its health network. All participants received care at this clinic, which prevented the inclusion of individuals who experience COVID-19 complications but do not have access to rehabilitation services.

Moreover, the study reflects the specific context of the investigated group, which may differ from other regions of the country. Although it does not allow for generalizations, the findings contribute to reflections on the challenges and strengths of the health care network in responding to post-pandemic demands, especially for people living with COVID-19 complications.

## **CONCLUSION**

Post-COVID-19 condition requires continuous and comprehensive care to address the complications affecting the physical, mental, and social health of affected individuals. Participants accessed SUS services such as Basic Health Units, specialized outpatient clinics, and the hospital network. However, due to access barriers and delays in care, many turned to the private sector, bearing out-of-pocket expenses for specialist consultations, exams, and

medications.

The absence of a structured care pathway for the follow-up of individuals in post-COVID-19 condition and the fragmentation between levels of care exacerbated these challenges. This study reinforces the need to strengthen primary health care and improve coordination with specialized services through multidisciplinary teams, in order to ensure equitable access, comprehensiveness, and continuity of care.

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#### **Declaration of competing interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.



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