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Care trajectories of COVID-19 patients: from preventive measures to rehabilitation

Trajetórias assistenciais de usuários com COVID-19: das medidas preventivas à reabilitação

Trayectorias asistenciales de usuarios con el COVID-19: de las medidas preventivas a la rehabilitación

Patty Fidelis de Almeida [1]
Elisete Casotti [1]
Rafaela Fidelis Lima Silvério [1]

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Abstract

This study aims to analyze the care trajectories of patients diagnosed with COVID-19 who were hospitalized and are currently undergoing rehabilitation regarding their use of and access to the healthcare network (HN). An evaluative, qualitative study was carried out based on interviews with patients in the city of Niterói, Rio de Janeiro State, Brazil. The care trajectories were reconstructed at three different occasions that express their experiences with the healthcare and support network during the pandemic: prevention, support and diagnosis measures; hospitalization; post-COVID-19 care, rehabilitation and support. The results indicate that the main source of information about COVID-19 was TV newscasts. Preventive hygiene measures were the most widely adopted. The family was the main support network. There was no waiting time for admission to the municipal referral hospital. Hospitalization was very well evaluated in terms of user embracement, multidisciplinary care, virtual visits and daily contact between doctor and family members. A post-discharge "care vacuum" was identified, with no follow-up by primary health care (PHC) and other public services. Low-cost health insurance plans and private specialized post-COVID-19 services were frequently and spontaneously sought until the implementation of the rehabilitation service. In summary, solitary and discontinuous care trajectories of individuals and families shed light on several challenges to the health system, including guaranteed access to coordinated PHC and expanded offer of specialized public services and rehabilitation, aligned with the principles of humanized care, in addition to the maintenance of social support measures.

COVID-19 Pandemics; Care Pathways; Health Services Accessibility

Correspondence
P. F. Almeida
Instituto de Saúde Coletiva, Universidade Federal Fluminense. Rua Marquês do Paraná 303, 3º andar, anexo ao Hospital Universitário Antônio Pedro, Niterói, RJ 224030-100, Brasil.
pattyfidelis@id.uff.br

[1] *Instituto de Saúde Coletiva, Universidade Federal Fluminense, Niterói, Brasil.*

Introduction

The SARS-CoV-2 pandemic poses an unprecedented challenge in Latin America and the Caribbean. Although these regions contain 8% of the world's population, they reported 17% of COVID-19 cases and 29% of confirmed deaths, besides an economic recession resulting in a 6.7% drop in gross domestic product (GDP) in 2020, an estimated loss of 39 million jobs and 20 million people pushed into extreme poverty, configuring a triple crisis situation: health, economic and social [1]. By July 2022, Brazil had recorded over 678,000 deaths and 33.7 million people infected [2]. The absence of coordinated action between different government levels and the deliberate position of the Federal Government, combined with normative acts that created obstacles to local responses and encouraged misinformation, partly explain the severity of the health context in Brazil [3,4], to which are added an economic recession and a significant increase in poverty [5].

The severe forms of the disease affected population groups who were older, suffered from chronic comorbidities and had high body mass index (BMI) [6,7]. However, distribution in Brazil was quite uneven, with twice the number of cases in the poorest quintile of the population compared to the richest [8]. This can be characterized as a syndemic [9], a situation in which social inequalities contribute to the worsening of COVID-19 consequences, as observed, for example, in states of the North and Northeast regions, whose health systems are more fragile [10]. This socio-economically vulnerable population group with a burden of pre-existing diseases relies primarily on the public system for health care [11].

A comprehensive response to a health problem such as COVID-19 requires simultaneous and coordinated action at different levels of care, with an obvious need for healthcare systems to provide recovery from the effects of long COVID [12]. Only in December 2021 did the Brazilian Ministry of Health approve a change in the list of services covered by the Brazilian Unified National Health System (SUS), including payment for rehabilitation of post-COVID-19 patients and functional rehabilitation of post-COVID-19 patients, through the Strategic Action and Compensation Fund [13]. Given the omission of the federal administration, municipalities and states strove to organize services and initiatives to face the effects of COVID-19, including treatment and rehabilitation [14].

The consequences for the continued care of chronic conditions such as diabetes, high blood pressure and cancer, among others, are felt differently during emergencies, with greater impact in low- and middle-income countries, whose health systems struggle to reconcile measures targeted at severe conditions with those aimed at the prevention and control of noncommunicable diseases [15]. In the case of COVID-19, the need for testing, screening, monitoring of cases and contacts and, subsequently, vaccination, increased the strain on health systems, causing, for example, the suspension of previously scheduled appointments and face-to-face visits in primary health care (PHC) and communication problems between health authorities, providers and the population in various situations [16,17].

Such evidence indicates that health emergencies require contingency plans which address the health system as a whole and not just the infectious agent [17], incorporating measures to (re)organize actions and services aimed at maintaining primary care and also respond to the needs arising from the emergency situation. In this sense, this article aims to analyze the care trajectories of patients diagnosed with COVID-19 who had been hospitalized and were undergoing rehabilitation regarding the use of and access to the various services offered by the healthcare network (HN). The goal is to identify obstacles that stand between patients and the health system, adopted strategies and possible innovations and lessons learned that support policies, organization and practices capable of responding to the emerging needs of the pandemic, the successive waves of contamination and the persistent obstacles to care trajectories in SUS.

Methodology

Study design

This is an evaluative study with a qualitative approach aimed at the production of care trajectories of COVID-19 patients with experiences of diagnosis, hospitalization and rehabilitation in the city of Niterói, Rio de Janeiro State, Brazil. The care trajectories are used to evaluate the organization and provision of health services based on the strategies and means used by patients in their search for care [18]. They represent evaluative practices that, based on the experiences of illness, enable the identification of constraints, conditions of use and access to HN and quality of care [19], which is justified in the case of a health condition – COVID-19 – whose patterns of intervention and evaluation lack studies and evidence.

Data collection and study sample

The study was carried out in Niterói, a city of 515,000 inhabitants, seat of the II Metropolitan Health Region of the state of Rio de Janeiro. It is part of a broader investigation funded through a public notice in line with the Municipal Strategic Plan, related to *Care Management and Healthcare Networks*. Data were collected at the rehabilitation service for post-COVID-19 patients, opened in August 2021 in the Gilson Cantarino Oceanic Municipal Hospital (HMON), which, in the most acute period of the pandemic, was exclusively used to treat severe cases of the disease [20]. The facility was selected for being a municipal referral center in rehabilitation, providing regular healthcare services and, at the time of data collection, treating patients who had been hospitalized.

In order to reconstruct the care trajectories, 27 face-to-face interviews were carried out between September and December 2021. The inclusion of participants met the following criteria: patients diagnosed with COVID-19 who had been hospitalized and were undergoing rehabilitation, that is, who had comprehensive care in HN and, therefore, could report on successes and challenges along the care continuum for the production of care trajectories. Since all of them met the study's inclusion criteria, the selection was based on convenience, i.e., all patients attending the rehabilitation service could be invited to participate. Those with a physical or mental condition that made it impossible to be interviewed were excluded. The participants were approached in the waiting room of the rehabilitation service and the interviews were conducted on site, in an ample and adequate location. As consultations were carried out by appointment and the number of waiting patients was small, it was possible to guarantee both distancing and privacy. The interviews were carried out by the authors and guided by a semi-structured questionnaire designed to gather personal and sociodemographic data, followed by the pandemic experiences related to the social support and healthcare networks, whose dimensions and components are described in Box 1. The questionnaire was first administered in a pilot interview to adjust content and language, which was not included in the analysis.

The interviews were carried out in an atmosphere of empathy and interested conversation between the researcher and the participant, which is a relevant aspect in addressing an event that generates suffering and loss. There was an attempt to control to some extent the anticipated interaction between researcher and participants of such studies by defining beforehand the dimensions and components of interest according to the research objectives, even though unforeseen contextual variables were considered. As most patients were accompanied (spouses and/or children), in many interviews there was spontaneous interaction of family members, whose contributions were transcribed and incorporated into the general corpus of the content analysis, since they added complementary memories to the description of the patients' care trajectories. The recordings lasted 40 minutes on average and all audios were fully transcribed. Data collection was interrupted based on theoretical saturation criteria [21], that is, the inclusion of new participants was suspended when the data obtained began to present, in the researchers' assessment, a certain level of repetition and convergence in the production of care trajectories. This analysis was performed continuously, from the beginning of the collection, considering each of the dimensions/components addressed in the interview questionnaire.

Box 1

Dimensions and components for the production of COVID-19 care trajectories.

DIMENSIONS	COMPONENTS
COVID-19 prevention, support and diagnosis measures	Preventive measures adopted
	Information sources about the pandemic
	Social, community and family support during the pandemic
	Compliance with social distancing
	Access to COVID-19 diagnosis
	Feelings after COVID-19 diagnosis
Hospitalization experience	Access to hospital admission
	Feelings regarding the need for hospitalization
	Evaluation of hospitalization
	Contact with family members/responsible persons during hospitalization
	Issuance of discharge report
Post-COVID-19 care, rehabilitation and support	Identification of post-COVID-19 after effects – patients and relatives
	Health services used in post-discharge follow-up
	Evaluation of health services for post-discharge follow-up
	Access to rehabilitation services
	Evaluation of rehabilitation service

Source: prepared by the authors.

Analysis of results

A thematic analysis of the content of the interviews was carried out to identify and describe patterns or themes, following quality ensuring criteria, such as: complete and inclusive coding of each interview, selection of relevant excerpts grouped into themes and interpretive analysis of data [22].

Then, the study aimed to reconstruct the care trajectories at three different occasions that express the experiences and journeys of COVID-19 patients in HN: prevention, support and diagnosis measures; hospitalization; post-COVID-19 care, rehabilitation and support. Within those three different instances, we identified components related to social support, access, comprehensiveness, care continuity and care satisfaction. Box 1 presents the three dimensions and components, based on studies on the subject [19,23,24] that initially guided the interview questionnaire and emerging empirical data, from which stemmed the interpretation and presentation of results.

Ethics aspects

The study was approved by the Human Sciences Research Ethics Committee of the Fluminense Federal University (opinion n. 4,456,756). The participants signed the informed consent form and were identified by numbers, according to the order in which the interviews were carried out, to guarantee anonymity.

Results

Twenty-seven participants were interviewed, most of whom were over 60 years old (18); with family income of up to two minimum wages (17); who received some type of social benefit (17); whose first contact with health services was through the Family Health Strategy (FHS) (14); who self-declared black or brown (15); and who lived with their spouse (17).

Eight participants reported having some kind of private health insurance, including low-cost plans paid by month and coinsurance systems for outpatient appointments and lab tests. Regarding habits, almost all were non-smokers and did not consume alcoholic beverages (Table 1).

COVID-19 prevention, support and diagnosis measures: from TV newscasts to family support

The main preventive measures adopted were related to sanitizing food and clothes and body hygiene. There were frequent reports of taking showers and washing all clothing items after going out, as well as of intense hand sanitizer use, measures that were still maintained. Few patients mentioned the distribution of face masks and hand sanitizers by health centers or other public bodies.

The main source of information about COVID-19 was television, especially newscasts, mentioned by all patients. Many reported having watched a lot of TV due to social distancing measures (Box 2). One of the interviewees pointed out divergent information given by different broadcasters: "*This station... Globo says one thing, Record says another. It's never quite the same, you know? Then you start wondering...*" (E9).

Information about symptoms was considered important as it encouraged the adoption of preventive actions such as social distancing and staying home. The participants considered themselves to be well-informed about COVID-19.

The closest family members (spouse, children, grandchildren) were the only support network to help with daily and outside activities, aiming to avoid crowded places such as supermarkets and drugstores (Box 2). Only one patient received food baskets from a municipal program and almost none of them (26) mentioned any type of community mobilization in the neighborhood to help during the pandemic. Family support was also important in seeking care when COVID-19 symptoms appeared.

Most participants reported having complied with social distancing measures, including the interruption of physical, leisure and collective activities. Most of them were not doing any kind of exercise at the time of the interview, although ten participants claimed they had stopped due to the disease (Table 1).

Among the 27 participants, 17 were diagnosed with COVID-19 in hospitals; 4 in emergency care units (UPA); 4 in specialized policlinics with emergency care; 1 in a basic health unit (UBS); and 1 was unable to identify the kind of health facility.

After diagnosis, 24 participants were transferred to HMON, usually on the same day. The fact that most were in the age group of highest risk and had comorbidities increased their concern and psychological distress. Particularly harrowing were the reports of elderly couples who lived alone and one of them fell ill (Box 2).

Hospitalization experience: from fear to the perception of being cared for

There were no reports of difficulties in being admitted to the municipal referral facility, nor of waiting or relocation. However, following the referral for hospitalization, the main fear was the possibility of intubation, plus the fear of dying and having no contact with the family (Box 3).

Despite the initial uneasiness, satisfaction with the care provided during hospitalization was unanimous, especially in terms of user embracement, care provided by the multidisciplinary team and attention of all staff – from reception to cleaning and clinical staff. Despite the severity of the situation, from a clinical point of view, most interviewees appreciated such attributes, which produced a feeling of reassurance regarding the treatment (Box 3).

The positive feedback about the care provided at HMON was based on comparison with private services and the perception that such standards were not offered in other public health facilities (Box 3).

Table 1

Sociodemographic characterization, first contact health service and lifestyle of research participants. Niterói, Rio de Janeiro State, Brazil, 2021.

Characteristics	n	%
Social profile		
Age group (years)		
30-39	1	3.7
40-49	1	3.7
50-59	7	25.9
60-69	7	25.9
70-79	10	37.0
+80	1	3.7
Gender		
Man	15	55.6
Woman	12	44.4
Self-declared skin color		
White	11	40.7
Brown	10	37.0
Black	5	18.5
Not informed	1	3.7
Educational level		
Illiterate	1	3.7
Incomplete elementary	5	18.5
Elementary	7	25.9
Incomplete secondary	3	11.1
Secondary	8	29.6
Incomplete tertiary	3	11.1
Marital status		
Partner	17	63.0
No partner	10	37.0
Children		
Yes	26	96.3
No	1	3.7
Health service		
1st contact at local HN		
FDP	14	51.9
Polyclinic	6	22.2
UBS	2	7.4
Service in another city	3	11.1
Unregistered	1	3.7
Not informed	1	3.7
Private and low-cost insurance		
Yes	8	29.6
Public service insurance	2	7.4
Low-cost plan	6	22.2

(continues)

Table 1 (continued)

Characteristics	n	%
Economic profile		
Household income (minimum wages)		
Up to 1	7	25.9
Up to 2	10	37.0
Up to 3	3	11.1
Up to 4	3	11.1
Over 4	2	7.4
No income	2	7.4
Main household provider		
Yes	18	66.7
No	8	29.6
Shared	1	3.7
Social benefits		
Yes	17	63.0
CBP	3	11.1
Pension	10	37.0
Emergency aid	3	11.1
Other	1	3.7
No	10	38.5
Post-COVID-19 occupation change		
Yes	10	37.0
No	17	63.0
Habits		
Drinking		
Yes	1	3.7
No	25	92.6
Not informed	1	3.7
Smoking		
Yes	3	7.7
No	24	92.3
Physical exercise		
Yes	5	18.5
No	22	81.5
Interrupted after COVID-19	10	37.0

CBP: Continuous Benefit Program; FDP: Family Doctor Program; HN: healthcare network; UBS: basic health unit.
Source: prepared by the authors, based on the interviews.

Another highly appreciated element referred to the systematic process of communication with family members. All interviewees reported receiving virtual visits via bedside videoconferencing, coordinated by the social worker and psychologist. This contact was of great value not only for the patients, some of whom were moved when describing them, but also for the family members who stayed at home, many of whom were also older adults in social isolation (Box 3).

In addition to the virtual visits, doctors would call relatives to inform them about the health status or treatment. "Sincere" communication by physicians was valued by participants and family members. Relatives had the staff's contact information and could request additional information (Box 3).

Another appreciated aspect was the issuance of a post-discharge report with the hospitalization record and care plan to be initiated or continued in other HN facilities (Box 3).

Due to the quality of care, some interviewees suggested the hospital should be used for all types of care, so that the population might have access to humanized care: "*This should not be just for COVID, but also for others things people need*" (E19).

Box 2

Relevant reports according to the analysis components of the *COVID-19 Prevention, Support and Diagnosis Measures* dimension. Niterói, Rio de Janeiro State, Brazil, 2021.

COMPONENTS	RELEVANT REPORTS
Preventive measures adopted	"*I avoided going out, wore a face mask, used hand sanitizer, showered after returning from shopping*" (E17) "*I wash all vegetables, fruit, soda bottles, juice bottles. I wash everything. It's quite a hassle!*" (E25)
Information sources about the pandemic	"*I relied a lot on TV newscasts, because social media, the famous internet, there's a lot of fake news, they make a lot of things up. Then they start saying that chayote can cure* [laughs]*! They start saying these things that are not... I started to base myself on TV newscasts, reliable sources and the city hall website*" (E1) "*I followed a lot on television the situation in hospitals, hospitalization, how things were. I'd watch it all the time. That's why I didn't leave the house, I ordered things at the market to deliver at home. I really like watching television, I turn it on first thing in the morning, I watch it for an hour, at night I watch it too. Although I don't have much schooling, I like to know what's going on, because we have to pay attention to how things are*" (E5)
Social, community and family support during the pandemic	"*No. The family doctor came to my house once with a bag of hand sanitizer. Just once. But at the very beginning of the pandemic, at the very beginning. He brought hand sanitizer, soap. That was the only time*" (E7)
Compliance with social distancing	"*We didn't do anything at Christmas last year. We'd usually have a barbecue on weekends with a four-and-a-half-meter table where we would all get together for the barbecue. Just family. We didn't do that. They liked to play bingo, the family, see? My mother, my aunts. We stopped because we couldn't be together*" (E17) "*But the main fact for me was the social distancing, that you are prevented from being with other people. That hurt a lot. Then you see your family also keeping away, your son who was studying...*" (E1)
Access to COVID-19 diagnosis	"*I did the diagnosis directly at the* [municipal hospital] *because the family health center has hardly anything, very few resources...*" (E11)
Feelings after COVID-19 diagnosis	"*Gee, I'm diabetic, I've had a heart attack, that's going to make things worse... Then I'd remember people who had already died. It was awful. So much so that, to this day, I still feel scared. Then they started talking about the so-called delta*" (E18) "*My husband took to his bed, depressed, he thought I was going to die, that I wasn't going to come back. Especially because of the news we hear every day on television*" (E21)

Source: prepared by the authors, based on the interviews.

Post-COVID-19 care, rehabilitation and support: life goes on

Many after effects were reported following hospital discharge, the most frequent being: overall weakness, especially in the legs; tiredness; lack of balance and appetite; leg swelling; persistent cough; heart and breathing problems; diarrhea; and sleeping difficulties (Box 4).

One aspect associated with the post-discharge period relates to the burden on family members. Post-COVID-19 effects required more care from those responsible for the patients, who felt exhausted and, at the same time, neglected self-care. The after effects increased the psychological suffering of patients due to physical limitations and the overload caused to family members (Box 4).

While access to hospitalization was unhindered and provided quality care, post-discharge follow-up was considered insufficient/non-existent by all interviewees, due to difficulty of access in the public network, whether for new problems and rehabilitation or for monitoring of pre-existing comorbidities (Box 4).

Reports by patients of self-medication and search for appointments and complementary tests after discharge were significant, due to medical recommendation but also on their own account, for fear of after effects of the disease. Many reported having used private services for appointments with pulmonologists and imaging tests, citing the long waiting times at SUS (Box 4).

Of the 27 interviewees, only 14 reported being assigned to FHS teams, but hardly recognizing them as a regular health service. Low-cost health insurance plans were mentioned by patients and relatives. Difficulty in accessing the public network, for both PHC appointments and specialized

Box 3

Relevant reports according to the analysis components of the COVID-19 *Hospitalization Experience* dimension. Niterói, Rio de Janeiro State, Brazil, 2021.

COMPONENTS	RELEVANT REPORTS
Access to hospital admission	"*I went to the* [municipal hospital] *to see about my kidney problem, there I took the test and it detected COVID. Then the transfer here* [municipal referral hospital] *was on the same day*" (E17)
Feelings regarding the need for hospitalization	"*She* [the doctor]*: 'I'm going to hospitalize her now'. Then I started crying and saying: 'I don't want to be intubated, because my niece died', then I said: 'I don't want to be intubated', the doctor said: 'It has to be'. Then she admitted me*" (E2) "*We said like this, I don't know if it's because we're evangelical, we are well prepared to die, you see? So I said: 'If I don't survive* [COVID-19] *it doesn't matter, I just don't want to be intubated'*" (E25)
Evaluation of hospitalization	"*Sometimes I just kept marveling at how the people here are nice, the treatment is respectful, affectionate, attentive, everyone: from the cleaning boy who came to take out the garbage to the nurses*" (E18) "*I arrived here in a stable serious condition, which then became very serious because there's a period of the disease when it gets worse, right? The eye of the hurricane they call it. But I was very well care for, the staff is wonderful, the physical therapists, the doctors... They really strive to save people here, you see? I felt quite safe. Afraid? Yes. But I felt safe*" (E21) "*Look, if I had to give a score from 0 to 10, I'd give 10, I'd give 1,000. Every day, the doctors came, the nurses, all of them very good. I was quite scared. It's COVID, right? And I have diabetes, I also have high blood pressure. That made my treatment a little more difficult. But even so, they were very patient and affectionate the whole time. I was very well cared for, I have nothing to complain about...*" (E23) "*For me, the hospital was great, the staff... I said to her: 'If there's a score of 1,000, you can tick it', because from the person who cleaned the room to the doctors. I said, this looks like a private hospital because I'm used to them, I have health insurance, so I know how the treatment is!*" (E15) "*The impression we have here is that they took a course in love. And we know that there is no course in love. You don't see anyone looking angry, it seems that they don't bring their problems in here. In the ICU there are also good doctors, nurses, technicians. I wondered if I was in a private hospital. My husband was also impressed: 'Wow, what service!'* (...) *This place is an exception, a score of 20* [laughs] *or 100. I've never seen a municipal service like this, honestly*" (E25)
Contact with family members/responsible persons during hospitalization	"*Virtual visits. The psychologist set up the video calls. First, she would talk to us to find out if we were emotionally well enough to make that contact, if we wanted to make that contact. There are people who isolate themselves, they don't like to been seen like that, attached to a ventilator, those things... And every day there was a video call. Then I would hear news... I could also give reassure them that I was being well cared for and all. That created a balance*" (E21) "*Every day, the doctor – there's nothing to complain in that respect – would call to give us information, to ask if we had any questions, to report on the patient's condition. We were always well informed*" (E17) "*I was happy for the hospital's attention. The moment was sad, but I was grateful to the hospital for showing me what was going on. They were very honest about what was going on*" (daughter E23) "*Because they left us their contact information here too, so any time we needed it, we would get in touch, we had access to the social worker. So we were able to keep in touch with the professionals here*" (granddaughter E12)
Issuance of discharge report	"*There's a list they give you at discharge and the doctor also recommends what you have to do. In my case, cardiologist and nephrologist*" (E22)

ICU: intensive care unit.

Source: prepared by the authors, based on the interviews

procedures, was the main reason for using such services to ensure regular follow-up and check-ups. The need for coinsurance payments, in addition to the monthly fees, made some patients consider it more advantageous to look up and pay for private health providers (Box 4).

There was a feeling of post-discharge "care vacuum" until the opening of the rehabilitation service at HMON in August 2021. According to some patients, health staff in PHC and polyclinics claimed they were not prepared to treat post-discharge effects of COVID-19 (Box 4).

Most of the respondents were contacted by the hospital itself to assess the need for rehabilitation, as they had been admitted to that facility. Other means of access were reported: participants who found out about the service and made direct contact, cases of referral by PHC or polyclinic, personal

Box 4

Relevant reports according to the analysis components of the *Post-COVID-19 Care, Rehabilitation and Support* dimension. Niterói, Rio de Janeiro State, Brazil, 2021.

COMPONENTS	RELEVANT REPORTS
Identification of post-COVID-19 after effects – patients and relatives	"*At the moment I can't even walk properly because of these swollen legs. I walk slowly. I can't even walk straight*" (E22) "*You are someone who's always worked independently, now I depend on her* [wife] *for practically everything. My life turned upside down. I can no longer do anything alone. I always liked doing everything. Now I don't do anything anymore*" (E11) "*So, I tell you, I wasn't going to die from COVID, I was going to die of sadness... First, because I started to feel like a nuisance at home, getting in people's way in everything. Then the social abandonment that we begin to feel. So, I was going to die of sadness, of depression, you know? Because it's a disease that affects everything. If it were only physical, fine, but the emotional part... the whole physical structure is impacted...*" (E1)
Health services used in post-discharge follow-up	"*You knock on a door and it's: 'no'. You knock on another: 'no'. Then despair begins to set in... I left* [the hospital] *one day, the next day I spent more than BRL 700 on medicine. Then I had to do some tests and get more medicine, in all it cost almost BRL 3,000. I mean, for me, who am retired, it was money that I had to borrow here and there*" (E1) "*And then it gets all confused, part is private, part is SUS. We can't wait, see? We cannot just depend on SUS*" (E11) "*When they called me* [from the rehab]*, I didn't think twice! I'm taking a medicine there on my own account, Venaflon, which the doctor prescribed because of my inflammation* [in another situation]. *So, as it's for circulation... There was a lady who had thrombosis, and she is taking this medicine. And since it's for circulation, I continue taking it every eight hours. And they say aspirin thins the blood, I also take one every other day*" (E27) "*At the end* [hospital discharge]*, the doctor said: 'He can go, his lungs are almost normal, he can finish the treatment at home'. Then I already took him to the Cartão para Todos program. I went right away, I didn't leave him at home. I made an appointment for him to see the pulmonologist and continue the treatment. When they called* [rehabilitation service]*, he had already undergone a lot of treatment...*" (wife E12) "*The x-ray is BRL 50. The electrocardiogram I think is BRL 65. Full blood tests, they do a package: HIV, COVID... if you need the package, it costs BRL 112. They do all the tests at once. Like the check-up for women during the October campaign. There's a gynecologist there, breast screening. But that's more like once a year*" (E9)
Evaluation of health services for post-discharge follow-up	"*Then I even thought that he* [FHS doctor] *was going to refer me to an orthopedist, a physical therapist, but there was no opening. Too many people. Then I didn't even do it. I did some exercises, more or less, at home...*" (E27) "*And it was here, with physical therapy, speech therapy, medical care, general practitioner, that I started to walk again, that I started to improve. But I tell you that if this place hadn't opened, to this day I would be without these treatments because the primary health centers say they are not prepared for post-COVID care*" (E1)
Access to rehabilitation services	"*It's hard to get to be referred here* [rehabilitation]*. It's hard. When I found out it was going to open, I said: 'Let's go there!', 'We're going to knock here and who's going to... you weren't hospitalized there, how are they going to accept you there? No way it's going to happen'*" (E11)
Evaluation of rehabilitation service	"*Right. I'm not leaving, now it's going to become a clinic too. I'm going to stay right here. They even asked if I was going to put a bed here to stay the night. I'm here every day* [laughs]" (E13) "*Here there's the general practitioner, there's everything. He's here, patients are seen by the practitioner, the physical therapist, the nutritionist, the speech therapist, they even dressed a wound on his foot that he already had*" (wife E12)

FHS: Family Health Strategy; SUS: Brazilian Unified National Health System.
Source: prepared by the authors, based on the interviews.

contact with hospital staff. One of the patients considered that access to rehabilitation would be more difficult for patients who had not been admitted to HMON, as the referral procedure was unknown and the other HN services were not yet making referrals at that point.

As in the case of hospitalization, the feedback on rehabilitation was quite positive. Introduction of the service resolved the difficulties in seeking care in HN and, according to reports, maintained the same standards of quality and humanization of hospitalization. The respondents praised the consultation with a general practitioner for an overall evaluation and, subsequently, the care provided by a multidisciplinary team that included speech therapist, nutritionist, psychologist and physical therapist. Due to difficulties in accessing post-COVID-19 care in the public network, there was an expectation that the rehabilitation service would meet all health demands (Box 4).

Discussion

In this study, the use of a new and challenging condition – COVID-19 – afforded an expanded view on the points of interdiction of care trajectories, imparting a sense of urgency in guaranteeing access to and integration of health care [1].

Most participants were older adults with comorbidities, the population group most susceptible to the more severe forms of the disease and to the economic, racial and gender inequalities that affect aging [25,26]. Even so, there were few reports of longitudinal follow-up by any SUS service during the pandemic or of support networks other than the family.

In the care trajectories, hand washing was identified as one of the main measures to prevent COVID-19, a practice with the highest adherence in Brazil, according to other studies, especially among older adults [27]. Although wearing face masks was considered important, washing and sanitizing food, clothes and body were highlighted in the reports. These measures were especially emphasized at the beginning of the pandemic.

While greater attention is given to social media, the findings of this study revealed the relevance of television as the main means of accessing information about COVID-19, especially TV newscasts, which seem to have a widespread penetration among older adults, according to this study. The necessary occupation of traditional media by health authorities constitutes a learned lesson, one to be better understood in terms of form, exposure and content [28].

The results indicate that, with regard to COVID-19 diagnoses, most were performed in SUS hospitals, without no relevant reports of difficult access. However, it should be noted that the participants underwent hospitalization, which suggests that these were more serious cases compared to the general population that sought testing in different types of services, both public and private [29].

Despite the lack of beds, especially for COVID-19 intensive care, in several situations [30,31], no admission difficulties were identified in care trajectories thanks to the creation of a specific municipal referral facility. Nonetheless, this finding must be analyzed with caution, since the participants were recruited in the rehabilitation service that operates in the actual hospital.

The initial fears of hospitalization and intubation were assuaged by the care provided at the hospital, with strong positive feedback regarding all staff. Besides the actual physical structure, cordiality and respect contribute to the perception of hospitality and are appreciated by patients who underwent treatment for COVID-19 [32], as also found in this study. Nevertheless, the benchmark of excellence for comparison purposes was private hospitals with great media presence for being regularly frequented by public authorities, corroborating the identification of SUS services as being of low quality.

Becoming ill with COVID-19 evokes the experience of toxic and dangerous bodies due to the need for isolation during hospitalization, with no visits allowed [33]. Among hospitalized patients in the state of Rio de Janeiro, 64.7% reported having received news or some contact from relatives [32]. In this study, virtual bedside visits were confirmed by all participants, which is another aspect considered relevant for high satisfaction with the hospital service. Having access to clear information is related to a greater perception of safety and satisfaction with the treatment [34]. In this sense, both telephone contacts and virtual visits are "soft-hard" technologies that should be widely adopted, since distance, transportation costs and lack of time are factors that can make it difficult to routinely visit hospitalized patients.

The institutionalization of the post-discharge report with the treatment plan is another aspect that contributes to continued care and low readmission [35], although in this study there was no follow-up by the other network services.

According to the reports, the greatest difficulties in using and accessing health services occurred in the third care trajectories period, represented by post-discharge needs. Transitions between care environments can be disruptive for patients and relatives, with negative effects in different areas of life, especially for older adults affected by post-COVID-19 effects [36]. Long COVID is a complex condition whose nature, frequency and etiology are still undefined [37]. In this sense, in addition to defining management, rehabilitation and clinical studies to improve long-term results [37], more in-depth research is needed on the experience of using health services due to COVID-19 after effects, especially from the perspective of patients.

Caring for the physical and mental health of people infected with COVID-19 and their families will remain a challenge for health services [38] due to the postponement of regular care, intensified by

social distancing. In Brazil, studies show that individuals with comorbidities stayed more at home, with possible effects on the worsening of chronic problems [25]. The need to intensify local health surveillance, with a special focus on post-COVID patients and their immediate family, will more than ever require the family and community approaches of FHS, which were undermined by the new federal policy guidelines and funding [39], which favor, for example, other models of PHC teams more focused on clinical and individual interventions.

A perception of post-discharge "care vacuum" prevailed in this study. The sense of abandonment between hospital discharge and the beginning of rehabilitation represented a break in care trajectories. The support of PHC and specialized SUS services proved to be absent or inaccessible, unable to meet the demands for rehabilitation and pre-existing conditions. The shortfalls in the public network provide yet another opportunity for the offer private health services in the form of low-cost insurance plans or "discount vouchers", unregulated by the Brazilian National Supplementary Health Agency (ANS) [40]. Part of the patients and relatives sought of their own accord, and without any guarantee of quality, specialized consultations to treat new and old health problems, increasing the development of solitary, fragmented and privatized care trajectories.

The results pointed to an overestimation of hospital and specialized care as an ideal model for regular monitoring of health problems, which may have been exacerbated by the emphasis on hospital care as the main strategy for coping with COVID-19 [41,42]. Likewise, the need to identify and treat after effects seems to have increased confidence in specialists. On the other hand, the public network proved to be poorly suited to deal with post-hospitalization demands, which, in the case studied, was revealed in the difficulty to access PHC and the long waiting times for specialized care.

Such results express the pressing need to strengthen PHC. Studies show a perception of continuity of care among patients who were able to access general practitioners during the pandemic, even if remotely [17]. Experiences of trust and familiarity seem to be decisive in the decision to opt for regular care with the family doctor rather than seeking treatment with unknown specialists [17]. In this sense, the COVID-19 pandemic reinforces the need for quality primary care and not the other way around. According to The Lancet Global Health Commission [43], public funding, a key element of health systems, is insufficient and feeds the vicious cycle that undermines the credibility and quality of PHC and encourages the search for alternative care.

As limitations of the study, most participants were recruited in the referral hospital where they were treated and were undergoing rehabilitation. Therefore, these are experiences that may not reflect the situation found among patients admitted to other hospitals or who suffered after effects without having had to be hospitalized. In addition, the viewpoint of health management and staff was not considered. Nevertheless, this is an unprecedented study that reconstructs the care trajectories of patients and family members who underwent intense and extensive experiences resulting from COVID-19 and make it possible to analyze the operating characteristics of local health systems. Future studies should aim at producing a logical model for planning and evaluating measures of prevention, social support, treatment and rehabilitation of COVID-19, based on different sources of information and validated.

Conclusions

Solitary and discontinuous care trajectories reveal several barriers to the care of individuals and families that, at the same time, represent areas for intervention and improvement for the management of this and other local health systems, in terms of both organization and practice. This emphasizes the need for expanded social support structures to minimize the burden on families; communication by health authorities in different media; and measures to resume care for pre-COVID-19 conditions and strengthen PHC so that it can fulfill its role of accessible first contact and care coordination, supported by specialized public services and rehabilitation networks, aligned with the principles of humanized care. One of the effects of the perception of a "care vacuum" in the post-discharge period was the search for services in the private sector, which compromises family budgets and increases fragmentation and the direct search for specialists.

Prominent among the positive aspects was the perception of quality hospital care and related rehabilitation, especially with regards to commitment and support. This finding is very significant, as it is part of a situation in which healthcare staff were subjected to work overload and high daily stress, which did not prevent patients and relatives from being the focus of care, with the help of communication mediating technologies, resulting in satisfaction, respect, trust and reassurance regarding treatment.

Identifying and caring for post-COVID-19 after effects are global challenges and have a multidimensional impact on the lives of survivors and their support network. In addition to health services that offer comprehensive, family and community follow-up, intersectoral actions should be implemented, including strategies in the area of mental, physical and leisure health, besides maintaining income transfer policies to guarantee subsistence conditions.

Contributors

P. F. Almeida contributed to the study design, data collection, analysis and interpretation of results and critical review; and approved the final version. E. Casotti contributed to data collection, analysis and interpretation of results and critical review; and approved the final version. R. F. L. Silvério contributed to data collection and analysis and interpretation of results; and approved the final version.

Additional information

ORCID: Patty Fidelis de Almeida (0000-0003-1676-3574); Elisete Casotti (0000-0003-3015-6842); Rafaela Fidelis Lima Silvério (0000-0002-3239-9891).

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Resumo

O objetivo deste trabalho é analisar as trajetórias assistenciais, relativas ao uso e acesso às redes de atenção à saúde (RAS), de usuários diagnosticados, internados e em reabilitação decorrente da COVID-19. Foi realizado estudo avaliativo, qualitativo, com base em entrevistas com usuários, no Município de Niterói, Rio de Janeiro, Brasil. As trajetórias assistenciais, a partir da análise temática, foram reconstituídas em três momentos que expressam as experiências com a rede de saúde e apoio durante a pandemia: medidas de prevenção, apoio e diagnóstico; a experiência da internação; cuidados, reabilitação e apoio pós-COVID-19. Os resultados apontam que a principal fonte de informação sobre a doença foram os telejornais; as medidas preventivas de higienização, as mais adotadas; e a família foi a principal rede de apoio. Não houve tempos de espera para internação no hospital municipal de referência. A internação foi muito bem avaliada em função do acolhimento, cuidado multiprofissional, visitas virtuais e contato diário do médico com os familiares. Identificou-se, porém, "vácuo assistencial" pós-alta, com ausência de seguimento pela atenção primária à saúde (APS) e demais serviços públicos. Foi frequente a busca espontânea por planos populares e pagamento direto para acesso aos serviços especializados no pós-COVID-19, até a implantação do serviço de reabilitação. Em síntese, trajetórias assistenciais solitárias e descontínuas de indivíduos e famílias revelam diversos desafios ao sistema de saúde, entre os quais a garantia de acesso e coordenação dos cuidados pela APS, ampliação da oferta de serviços públicos especializados e de reabilitação em redes, alinhados aos princípios do cuidado humanizado, além da manutenção das medidas de apoio social.

Pandemia COVID-19; Trajetórias Assistenciais; Acesso aos Serviços de Saúde

Resumen

Este artículo tiene por objetivo analizar las trayectorias asistenciales de usuarios diagnosticados, hospitalizados y en rehabilitación por el COVID-19 en cuanto al uso y acceso a las redes de atención a la salud (RAS). Se realizó un estudio cualitativo, evaluativo, a partir de entrevistas con usuarios en el municipio de Niterói, Rio de Janeiro, Brasil. A partir del análisis temático, las trayectorias asistenciales se reconstituyeron en tres momentos que expresan las experiencias con la red de salud y de apoyo durante la pandemia: las medidas de prevención, apoyo y diagnóstico; la experiencia de hospitalización; y los cuidados, rehabilitación y apoyo post-COVID-19. Los resultados muestran que los telediarios fueron la principal fuente de información sobre el COVID-19. Las medidas preventivas más adoptadas fueron las de higiene. La familia fue la principal red de apoyo. No hubo tiempo de espera para el ingreso en el hospital municipal de referencia. La hospitalización fue muy bien evaluada debido a la recepción, atención multidisciplinaria, visitas virtuales y contacto diario del médico con los familiares. Se identificó un "vacío asistencial" posterior al alta, sin seguimiento por parte de la atención primaria de salud (APS) y otros servicios públicos. Hubo una frecuente búsqueda espontánea de planes populares y pago directo para acceder a servicios especializados post-COVID-19 hasta la implementación del servicio de rehabilitación. Por lo tanto, las trayectorias asistenciales solitarias y discontinuas de individuos y familias revelan varios desafíos para el sistema de salud, entre ellos la garantía de acceso y coordinación de la atención por parte de la APS, la ampliación de la oferta de servicios públicos especializados y la rehabilitación en redes, combinada con los principios de cuidado humanizado, además del mantenimiento de las medidas de apoyo social.

Pandemia de COVID-19; Trayectorias Clínicas; Accesibilidad a los Servicios de Salud

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