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Family care for individuals with post-COVID-19 condition at home

Cuidado Familial à pessoa em condição pós-COVID-19 no domicílio

Cuidado familiar a la persona con condición post-COVID-19 en el domicilio

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Abstract:
Objective: to understand the dynamics of family care provided to individuals with post-COVID-19 condition at home. **Methods:** this qualitative study was based on Ingrid Elsen's attributes of family care and was conducted at a post-COVID outpatient clinic in a teaching hospital in the southern region of the state of Rio Grande do Sul, Brazil. The sample was purposive, and data collection took place between March and August 2022 through semi-structured interviews, as well as the construction of genograms and ecomaps. Data were organized using the IRAMUTEQ software and analyzed using content analysis. **Results:** a total of 20 participants were included, comprising 10 individuals with post-COVID-19 condition and 10 family members, representing 10 families. Two categories emerged: "*When we needed it, everyone came together": care for individuals with post-COVID-19 condition*; and *"When you are sick, that is when you have friends": community participation in car*e. Individuals with post-COVID-19 condition reported persistent symptoms such as fatigue, motor limitations, cognitive changes, and emotional vulnerability, which compromised their autonomy and return to daily activities. Families reorganized routines, shared responsibilities, and mobilized affective, community, and spiritual support networks. This care was complex and continuous, sustained by strong bonds and practices of protection, presence, and the promotion of well-being. **Conclusion:** family involvement revealed not only the capacity to cope with the complications and uncertainties of post-COVID-19 condition, but also the importance of institutional recognition of the family as a key agent in care.
Keywords: COVID-19; Family; Nursing; Home Environment.

Resumo:
Objetivo: compreender a dinâmica do cuidado familial oferecido à pessoa em condição pós-COVID-19 no domicílio. **Método:** pesquisa qualitativa que utilizou os atributos do cuidado familial de Ingrid Elsen, realizada em um ambulatório pós-COVID de um hospital de ensino da região sul do Rio Grande do Sul. A amostra foi intencional, e a produção de dados ocorreu entre março e agosto de 2022, por meio de entrevistas semiestruturadas, construção de genograma e ecomapa. Os dados foram organizados no programa IRAMUTEQ e interpretados mediante análise de conteúdo. **Resultados:** participaram 20 indivíduos, sendo 10 pessoas em condição pós-COVID-19 e 10 familiares, constituindo 10 famílias. Construiu-se duas categorias: "*No momento que a gente precisou, todos se abraçaram": o cuidado à pessoa em condição pós-COVID-19*; e "*Na hora que tu está mal, aí que tu tem amigo": a participação da comunidade no cuidado*. As pessoas em condição pós-COVID-19 relataram sintomas persistentes, como fadiga, limitações motoras, alterações cognitivas e fragilidade emocional, que comprometeram a autonomia e o retorno às atividades cotidianas. A família reorganizou rotinas, dividiu tarefas e mobilizou redes de apoio afetivo, comunitário e espiritual. Trata-se de um cuidado complexo e contínuo, sustentado por vínculos fortes e práticas de proteção, presença e promoção do bem-estar. **Conclusão:** a atuação da família revelou não apenas a capacidade de enfrentamento diante das complicações e incertezas da condição pós-COVID-19, mas também a importância do reconhecimento institucional desse núcleo como protagonista do cuidado.
Palavras-chave: COVID-19; Família; Enfermagem; Ambiente Domiciliar.

Resumen:
Objetivo: comprender la dinámica del cuidado familiar ofrecido a la persona con condición post-COVID-19 en el domicilio. **Método**: investigación cualitativa que utilizó los atributos del cuidado familiar de Ingrid Elsen, realizada en una consulta externa post-COVID de un hospital universitario de la región sur de Rio Grande do Sul, Brasil. La muestra fue intencional y la recogida de datos tuvo lugar entre marzo y agosto de 2022, mediante entrevistas semiestructuradas, construcción de genograma y ecomapa. Los datos se organizaron en el programa IRAMUTEQ y se interpretaron mediante análisis de contenido. **Resultados**: participaron 20 individuos, siendo 10 personas con condición post-COVID-19 y 10 familiares, constituyendo 10 familias. Se construyeron dos categorías: "*En el momento en que lo necesitamos, todos se unieron*": *el cuidado a la persona con condición post-COVID-19*; y "*Cuando estás mal, es cuando tienes amigos*": *la participación de la comunidad en el cuidado*. Las personas con condición post-COVID-19 informaron de síntomas persistentes, como fatiga, limitaciones motoras, alteraciones cognitivas y fragilidad emocional, que comprometieron la autonomía y el retorno a las actividades cotidianas. La familia reorganizó rutinas, dividió tareas y movilizó redes de apoyo afectivo, comunitario y espiritual. Se trata de un cuidado complejo y continuo, sostenido por vínculos fuertes y prácticas de protección, presencia y promoción del bienestar. **Conclusión**: la actuación de la familia reveló no solo la capacidad de afrontamiento ante las complicaciones e incertidumbres de la condición post-COVID-19, sino también la importancia del reconocimiento institucional de este núcleo como protagonista del cuidado.
Descriptors: COVID-19; Familia; Enfermería; Ambiente en el Hogar.

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INTRODUCTION

Post-COVID-19 is characterized by a set of symptoms that generally appear three months after infection with SARS-CoV-2, persist for at least two months, and cannot be explained by another diagnosis[1]. Also known as long COVID, this condition can affect multiple body systems, compromising the functionality and quality of life of those affected[2].

Among the most prevalent symptoms are dyspnea, anosmia, sleep disorders, arthralgia, headache, cough, cognitive difficulties, and emotional disorders, which hinder the return to daily activities and work, in addition to increasing the demand for health services[3].

Within this spectrum, fatigue associated with so-called "brain fog" has been described as one of the most disabling symptoms, as it compromises the performance of daily tasks and reduces autonomy[2,4]. The emotional impact is also significant, with reports of distress, fear of reinfection, relapses, and, in extreme cases, suicidal thoughts[5]. Added to this is the financial impact resulting from the inability to return to work and/or the increase in expenses for health, care, and rehabilitation[3-4].

Evidence indicates that the pandemic impacted not only COVID-19 survivors but also their families, who experienced levels of suffering higher than those of caregivers of other serious chronic diseases[6]. In this context, family dynamics undergo changes, with a redistribution of responsibilities and adaptation of routines to support the family member in rehabilitation, consolidating the family as the main locus of care[7].

The concept of family care proposed by the Brazilian nurse Ingrid Elsen is important for understanding this phenomenon, once it occurs:

> "*the actions and interactions present in the life of each family group are directed to each of its members, individually or to the group as a whole or in part, aiming at their growth, development, health and well-being, personal fulfillment, inclusion and social contribution.*"[8:23].

Family care occurs through coexistence, reflection, and interpretations that arise in the interaction process, and can be recognized through some attributes, such as presence, inclusion, promotion of life and well-being, protection, and guidance for life[8].

Family caregivers are those who live with the person in a post-COVID-19 condition, maintain an affective bond, and take responsibility for care at home. This care provided by the family demands continuous effort to preserve bonds, reorganize daily life, and cope with the disease's complications, frequently leading to caregiver burnout and abandonment of self-care[9-10].

Brazilian studies on family care describe its importance and complexity in the context of health and illness of families of newborns[11], children with special needs[12], and people with substance use disorder[13]. However, there is no research on the care of a family member in a post-COVID-19 condition from the perspective of family care.

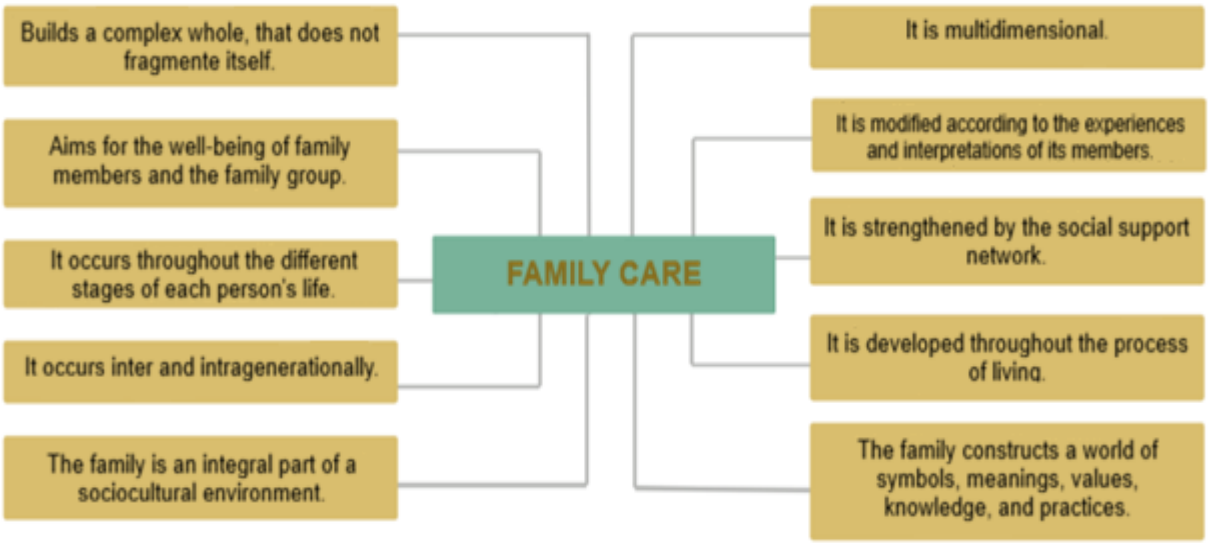
Most national studies in the field of post-COVID-19 conditions have been conducted with patients[4,10]. Furthermore, little has been explored about the experiences of families in caring for a family member in a post-COVID-19 condition[14-15]. Therefore, there is a need for qualitative research aimed at understanding the dynamics of families resulting from a critical event such as the COVID-19 pandemic.

Given the care demands presented by people recovering from COVID-19 complications, it is necessary to consider them as an emerging group, due to the sequelae and complications of the disease, the complexity of the care required, and inequalities in access to health services. From a family care perspective, this highlights the need to bring health professionals closer to families. In this sense, this study aimed to understand the dynamics of family care developed for a person in a post-COVID-19 condition at home.

METHODS

This is a qualitative research guided by the attributes of family care according to Ingrid Elsen[8], as presented in Figure 1. From this perspective, the family is described as a complex unit, embedded in a sociocultural context, responsible for constructing meanings and practices aimed at promoting the well-being of its members throughout the life cycle[8].

Figure 1. Attributes of family care by Ingrid Elsen. Pelotas/RS, Brazil, 2023.



Data collection took place from March to August 2022 at the post-COVID outpatient clinic of a teaching hospital in the southern region of the state of Rio Grande do Sul, Brazil, which opened in May 2021, using purposive sampling. This service has a multidisciplinary team composed of pulmonologists, physiatrists, physical therapists, occupational therapists, psychologists, and physical education professionals.

The inclusion criteria were: men and women aged between 18 and 59 years, diagnosed with post-COVID-19 condition at least three months prior, presence of at least two persistent symptoms, complete COVID-19 vaccination, and verbal communication skills. For family members, the criteria were: being the primary caregiver of the affected person, minimum age of 18 years, and complete vaccination, with the identification of potential participants carried out at the health service itself.

Identification was performed through the analysis of patient records and medical charts at the outpatient clinic. When participants met the inclusion criteria, they were approached on-site, informed about the research, and invited to participate. After acceptance, the invitation was extended to the family member, and interviews were scheduled according to availability, either at home or online, with the provision of a telephone contact.

Data collection involved a semi-structured interview with the person in a post-COVID-19 condition and a family caregiver, in addition to the construction of a genogram and ecomap. The interviews were conducted in person in eight cases, and, in two cases, online in a virtual room on the Webconf platform, conducted by a nurse who, at the time, was a master's student with experience in qualitative research. The transcription of the interviews was supported by a previously trained Nursing student.

Data collection was concluded due to thematic saturation, understood as the moment when the interviews began to show recurrence of content, without the addition of new elements relevant to the categories under construction[16].

The data processing was carried out with the aid of the IRAMUTEQ program, using the Descending Hierarchical Classification (DHC) method[17]. From the set of interviews and *corpus* preparation, the DHC carried out the dimensioning of elementary context units or text segments, classified according to the most frequent vocabulary, understood as significant for the qualitative analysis of the data, through the content analysis proposed by Bardin[18].

The analyses, conducted through lexical statistics and the construction of classes using the IRAMUTEQ program, provided indications for the emergence of categories discussed in the research. After data processing, the interpretation phase began in six stages: Stage 1: organization and preparation of data, including transcription and its review, carried out using

the guidelines for *corpus* preparation; Stage 2: reading the whole data, with rereadings to evaluate the transcribed content; Stage 3: coding, in the IRAMUTEQ program, which built the list of words presented in the form of a dendrogram; Step 4: coding and categorization, with evaluation of the classes presented in the dendrogram and new rereadings of the interviews; Step 5: description of categories, supported by the conceptual framework; and Step 6: extraction of meaning from the data and presentation of the results. The categories were defined by consensus, after independent reading and analytical discussion.

The research was approved by the Ethics and Research Committee of a public university, under opinion number: 5.199.407. The Free and Informed Consent Form was applied, and, to maintain anonymity, participants were identified by the abbreviation "P" (person) and "F" (family member), followed by a cardinal number, and the letter "F" (female) or "M" (male) and age; as in the examples: "P01F59years" and "F01F40years". The research met the items on the checklist of the Consolidated Criteria for Reporting Qualitative Research.

RESULTS

The study included 20 participants: 10 individuals in post-COVID-19 condition and 10 family members. Among those in post-COVID-19 condition, there were five men and five women. Ages ranged from 24 to 59 years. Regarding marital status, six individuals reported not having a partner. Regarding the need for hospitalization, eight people were hospitalized; of these, six were in the Intensive Care Unit (ICU) and five required mechanical ventilation. Hospitalization lasted between 18 and 96 days. All individuals had been diagnosed with post-COVID-19 condition for more than nine months and were in the rehabilitation process, as shown in Chart 1.

Chart 1. People with post-COVID-19 condition. Pelotas/RS, Brazil, 2023.

People with post-COVID-19 condition	Date of COVID-19 diagnosis	Need for hospitalization	Time hospitalized	Time in ICU	Need for mechanical ventilation	Time of diagnosis
P01F59years	22/05/2021	Yes	58 days	43 days	Yes	10 months
P02M53years	17/06/2021	Yes	79 days	19 days	No	10 months
P03M56years	09/07/2021	Yes	32 days	20 days	Yes	09 months
P04F59years	24/05/2021	Yes	18 days	-	No	12 months
P05M24years	06/07/2021	Yes	96 days	83 days	Yes	10 months
P06M53years	18/05/2021	No	-	-	-	12 months
P07M43years	03/06/2021	Yes	49 days	26 days	Yes	11 months
P08F45years	06/06/2021	No	-	-	-	13 months
P09F37years	31/03/2021	Yes	50 days	30 days	Yes	17 months
P10F49years	13/01/2021	Yes	51 days	37 days	No	19 months

Different levels of education were observed, ranging from primary education to completed higher education. Occupations included public transport driver, app driver, newly graduated agronomist, merchant, cleaning assistant, and school monitor; activities that require physical presence, which directly impacted the return to work after illness. All participants were absent from their professional activities at the time of data collection due to physical or cognitive limitations.

Family structures were not represented only by the nuclear family (father, mother, and children), but also by extended family, consisting of uncles, cousins, spouses, siblings, in-laws, nieces and nephews, and stepparents. Of the 10 families included, five were classified as nuclear. The family caregivers were mostly female and over 40 years of age. The characterization of the families is shown in Chart 2.

Chart 2. Families with people who have recovered from COVID-19. Pelotas/RS, Brazil, 2023.

Family (F)	Participants	Family characteristics	Person with post-COVID	Family member
F01	Mother and daughter	Nuclear	59 years, female	40 years, female
F02	Father and daughter	Extended	53 years, male	27 years, female
F03	Husband and wife	Extended	56 years, male	49 years, female
F04	Wife and husband	Extended	59 years, female	67 years, male
F05	Son and mother	Nuclear	24 years, male	56 years, female
F06	Husband and wife	Nuclear	53 years, male	49 years, female
F07	Husband and wife	Nuclear	43 years, male	46 years, female
F08	Daughter and mother	Nuclear	45 years, female	69 years, female
F09	Cousin and cousin	Extended	37 years, female	35 years, female
F10	Stepdaughter and stepmother	Extended	49 years, female	76 years, female

The textual *corpus* consisted of 2,563 text segments, with a utilization rate of 91.49%. Data analysis allowed for the construction of two categories: (1) *"When we needed it, everyone came together": care for individuals with post-COVID-19 condition*, and (2) *"When you are sick, that is when you have friends": community participation in care*.

"When we needed it, everyone came together": care for individuals with post-COVID-19 condition

The person with a post-COVID-19 condition required care from their family after hospital discharge and return home. This care included personal hygiene, feeding, wound care, medication administration and bladder catheterization for relief, temperature and oximetry checks, assistance with mobility, accompaniment to medical appointments and physical therapy sessions, and leisure time. In addition, family caregivers provided support for the needs of their sick relatives, such as helping them rest and recover at their own pace.

This care was provided by family members, such as parents, children, spouses, siblings, in-laws, and nephews/nieces. Expressions such as “always helping” and “always caring” were used by families to describe the continuous care, which involved vigilance, protection, and presence, provided to family members in rehabilitation. These findings are found in the following reports:

When I came home, I was more dependent, I needed more help. I didn't do anything, I just sat on the bed. I was always in bed, they [my children] *had to take me to the bathroom. They had to take care of my hygiene, bathe me too. They moved my bed from over there* [from the upstairs bedroom to the living room]*. They had to sleep here on the floor or on the sofa and I felt bad seeing them so uncomfortable* [...]. (P01F59years)

We practically moved house. I was only here [at a family member's house] *all the time, sleeping with them all the time. And when we came here, since I left the office I was in, I worked here* [at home]*. I worked here in my aunt's office, there's a room. And when I couldn't, I had to go out, do something, I'd let them know, and someone would come over.* (F02F27years)

My wife and daughter, we're getting ready, let's say, to start going out for walks. Because now I'm able to walk, not very far, but at least I'll be able to walk a little. (P03H56anos)

He [the person in post-COVID-19 condition] *became very frail. Very frail indeed. He could walk, and we got him a walker to use at first because we were afraid he would trip. The house has an area here with uneven surfaces, and we were very worried. So we always had to assist him* [with walking]. (F03F49years)

We [the parents of the person in post-COVID-19 condition] *helped with everything she needed. We were very careful to give her the right food, healthy food, what she needs during COVID: vitamins, we always made orange juice for her, so she ate very well. And I always take care of that, we already had this habit of eating healthier, so it was the same with her. Since she works, we worry about her not getting cold or damp. Now in winter* [we] *take her on the bus so she doesn't get cold. When it rains we are very careful not to catch colds. You have to take care not to get sick, we take care of ourselves. Prevention.* (F08F69years)

Other care provided by family members included feeding, protecting from cold and dampness, and encouraging short walks. In intra-family relationships, the development of care was permeated by bonds of trust, expressed in attitudes such as listening and willingness to help, from hospitalization to daily care at home.

Care was shared among family members, who took turns so as not to leave the sick family member alone, in addition to also sharing household chores. Family members mentioned that they participated in preparing food and in providing financial support for the purchase of medications, examinations, and consultations. Some family members paused their work activities to dedicate themselves to the person in post-COVID-19 condition and other family members. Each family member was responsible for an activity, negotiated within the family, as we observe in the following statements:

When I came home, we had to take turns because at first I couldn't be alone, and when my daughter couldn't be here, my sister, who lives two blocks away, she's a seamstress, and she would stop her work and come here to help me, she would stay with me, both her and my niece [...]. *So my sister helps me a lot, a lot indeed. Today my sister cooks because I still can't cook; any hot steam that comes out is very harmful to me. I have another sister who lives outside, she left her house to take care of the farm there, and when I'm there, she's the one who cooks. She's another person who's also being a hero because she gave up everything, she became a grandmother during this time, she couldn't watch her grandson grow up... she's there* [...]. *When we needed help, everyone rallied together to help.* (P02M53years)

In the beginning, we didn't leave him alone for a minute. We were always vigilant; if he was sleeping, we were there checking if he was breathing, just like a baby when he comes home. (F02F27years)

In reality, I depended on her [my wife] *for the first thirty days after I left the hospital; I was practically totally dependent on her. To walk, I needed support; I couldn't walk alone. I started walking some time later. As for eating, I couldn't hold a spoon firmly. I would pick up a utensil and miss my mouth, so it was quite complicated. I needed that help to eat.* (P03M56years)

All of them, all my children, helped me a lot; when one wasn't there, another was. But we always take turns; sometimes I'm not feeling well, and my daughter comes here, but thank God I've had a lot of support from my family. My sister also comes here to help me. (P04F59years)

Families organized themselves to transport family members in post-COVID-19 condition to the outpatient clinic and other health services, in order to receive care from physical therapy professionals and others. This care aimed at motor and respiratory recovery and rehabilitation. They described that, to meet this need, they used a rotation system, replacing and alternating between family members:

Sometimes, since I worked nearby, I would take her in the morning and then my brother would pick her up. Because sometimes he worked at night, slept a little, and at ten o'clock he would go there to pick her up. And that's how we did it. And now that I'm working far away, it's D. [nephew's name], *my nephew, who takes her.* (F04M67years)

The bedrooms were upstairs. So, she stayed up there. She mostly lay down. Every now and then, she would get up a little, take a short walk, but going up and down wasn't possible. Her father and brother would help us bring her down, so she wouldn't be so alone upstairs, and she would sit down here. (F10F76years)

"When you are sick, that is when you have friends": community participation in care

For people recovering from COVID-19 and their families, having the support of friends and neighbors was important during this period of illness and rehabilitation, as it strengthened family care. In some families, friends were present in various ways, such as phone calls to inquire about their health status and visits to listen and support them. They also helped with transportation to healthcare services and to participate in leisure activities. The visits were remembered and described by the people, as they conveyed a sense of security and of not being forgotten, as shown in the following findings:

Today I have a very strong friendship with my neighbor, who is the one who gives me strength, who comes here, carries me, takes me there [to the clinic], *brings me back here* [to my house] *if I need to. So for me, he was someone who called me every day during my recovery period.* (P02M53years)

But she [my friend] *came, she always came to see me and stuff. I thought I had a lot of friends, but you see that when you're sick. When you're doing well, you have friends. When you're not doing well, that's when you really have friends. You know who the real ones are. He never abandoned me and was always there for me when I came back* [visits], *if I needed anything. Sometimes you only get better in the person's presence.* (P09F37years)

The support networks built by families while caring for individuals in post-COVID-19 condition demonstrated spirituality. This care is expressed not only in traditional religious practices, but also in the construction of shared meanings and hopes.

Spirituality emerges as a collective resource, activated in times of crisis to emotionally strengthen caregivers and promote family cohesion, assuming an important role in interactions between family members, friends, and the community. By mobilizing prayers, worship chains, and diverse religious practices, families moved between different beliefs and traditions without rejecting spiritual plurality. Thus, spirituality ceases to be an exclusively individual element and becomes a collective practice and an integral part of the care network.

There were many different groups. There were Evangelicals, there were Adventists, his friend is an Evangelical pastor, he called me every day, he sent his name to many places. We have people from Umbanda, there's everything. Everyone in their own religion, in their own faith, everyone helped. It was a prayer network, my God. (F07F46years)

I have a brother who practices Umbanda. So, he asked for rituals and lots of prayers and requests, and I have friends who are evangelical Christians. My friend even fasted at church, praying for my health. They prayed all night, all these people came together, mingled, all in the same faith, and here I am. And it worked. (P09F37years)

The presence of pets in some families has proven to be a sensitive and powerful aspect of family care. These animals were understood as members of the family unit, offering emotional support, companionship, and daily comfort to people undergoing rehabilitation.

The affection expressed in these non-human bonds was mobilized during moments of loneliness, fear, and uncertainty. In addition, pets also fostered a sense of routine, security, and constant presence, expanding the scope of support networks.

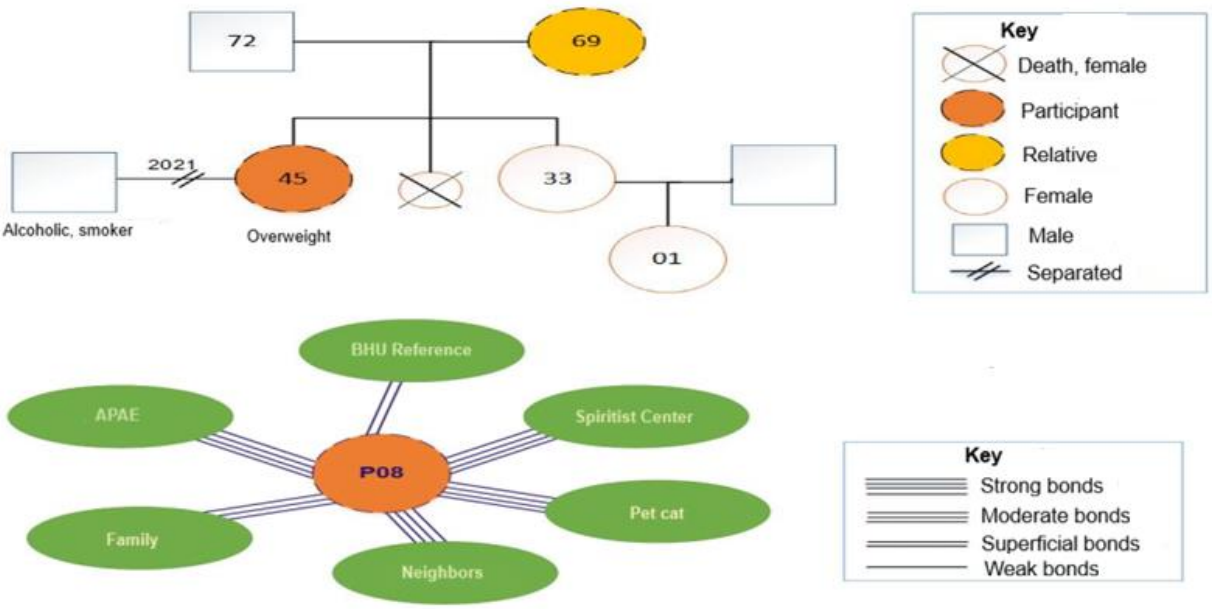
He [pet cat] *watches over me wherever I am. I'm having coffee and he's lying under the chair; if I go to the bathroom, he follows behind and meows halfway down the hallway until I come out. If I go upstairs to lie down, he follows behind. He's my companion in the house. The psychologist says it's good to have a pet. When I'm alone, he entertains me.* (P04F59years)

I don't have children, but this cat is like a child to me; she's my constant companion. And I don't regret having such a pet for a moment. My fear, when I had COVID, was that the cat would catch COVID too. Because she was always with

me, always right by my side, while I was coughing and coughing. But she appeared when I needed her most; I picked her up from the street. The best gift the pandemic gave me was her. She's a great companion, a true friend, always around. Always by my side. (P08M45years)

The genogram and ecomap of family F8, shown in Figure 2, exemplify community relationships in strengthening care for individuals in post-COVID-19 conditions:

Figure 2. Genogram and Ecomap of the F8 family. Pelotas/RS, Brazil, 2023.



DISCUSSION

The results of this research indicate that the families of people in post-COVID-19 condition develop family care, in the sense that the physical, emotional, and social rehabilitation of the family member occurs. This care is linked to protection, vigilance, and motivation for basic daily activities. Due to the needs for diverse care, family members have begun to develop actions aimed at promoting life and well-being, protection, and rehabilitation of the family member, as advocated in Elsen's attributes of family care[8].

The promotion of life and well-being is observed not only in meeting the needs of the person with post-COVID-19 condition, but also in the impact that these actions have on the family. Protection is reflected in the care adopted by the family to ensure the physical, emotional, and social safety of the person, including care for the environment, clothing, food, safety, and personal hygiene. Presence, through knowing how to listen, communicate, spend time together, care for the other, and offer emotional support, was also perceived in the families of the research.

Family care proved central to the rehabilitation process for these individuals, especially

given the needs, uncertainties, and unknowns associated with a recently discovered condition. The family began to collectively assume caregiving responsibilities, promoting the redistribution of tasks and the reconfiguration of family roles, with adaptations to routines and a redefinition of priorities in the home, in order to alleviate the burden on the primary caregiver and ensure continuity of care. In some cases, these rearrangements extended beyond the family nucleus, incorporating the support of friends and neighbors as part of a broader care network.

This reorganization is consistent with findings that point to transformations in family dynamics throughout the post-COVID-19 rehabilitation process[7] and relates to findings from a Brazilian study conducted with families that had at least one member diagnosed with and/or who died from COVID-19, which demonstrated transformations in daily family life, with repercussions on domestic activities, care for others, and self-care[19].

In the context of the post-COVID-19 condition, marked by persistent symptoms, clinical uncertainties, and emotional vulnerabilities[6], the active role of the family proved essential for the continuity of care, reinforcing the importance of health policies and practices that recognize and support this core as a partner in the rehabilitation process.

In this scenario, the occurrence of inter and intragenerational exchanges that constitute family care was observed. These exchanges, which encompass affective, instrumental, and educational dimensions, reflect what Elsen identifies as the essence of family care, a process built throughout the life cycle and mediated by the experiences and meanings attributed by family members to illness and care[8]. This perspective is corroborated by research that reinforces the importance of studying the structure and inter and intragenerational relationships, pointing to their relevance in strengthening bonds and sustaining care in people with chronic health conditions[20].

Friends, neighbors, religious institutions, and spirituality make up the support network of the families in this research. These elements promote the strengthening and continuity of family care, expanding beyond the limits of the nuclear family.

The participation of friends and neighbors in the care of the person in post-COVID-19 condition was evidenced as a significant extension of family care. The network of relationships close to the home contributed practical support such as transportation, visits and constant presence, and affective support, through listening and companionship. These bonds reinforced the feeling of belonging and security, especially in moments of emotional fragility. Recent studies indicate that, in contexts of chronic illness, solidarity among close social networks plays a relevant role in maintaining the health and well-being of families[6,15,21].

Spirituality, intertwined with religious practices, emerges as a relevant component of

the support networks activated by families during rehabilitation. This spiritual experience is not restricted to the individual, but manifests itself as a collective practice that involves family members, friends and faith communities.

Such spiritual mobilization, through prayers, fasting, worship chains and rituals, operates as a symbolic resource for coping with and strengthening emotional well-being in the face of uncertainty and suffering[22-23]. In line with this, according to Elsen[8], family care also encompasses subjective dimensions, such as the construction of meaning, values and practices that promote well-being, with spirituality being an expression of this symbolic dimension of care.

This expansion of the support network reinforces the perspective that health care is a collective phenomenon, traversed by broader social interactions than the nuclear family[15], which highlights the need for public policies that strengthen integration with health services[14].

The presence of pets alongside people with post-COVID-19 conditions within families is an element that makes up family care. This presence reveals the importance of affective bonds with non-human beings, providing emotional support in the rehabilitation process and coping with the sequelae of illness. Similar findings highlight the importance of the human-animal bond in promoting mental health, especially in contexts of chronic disease and social isolation[24-25].

The relationship between humans and their pets accompanies social changes, in which these animals have received the status of family members, coming to live inside homes and resulting in an affective bond[25]. These animals are active members of emotional support networks, constituting extended family arrangements that approach the concept of multispecies family[26]. Considering pets as a significant part of the support system reinforces the need for broader views of families, recognizing their diversity and the different ways in which care manifests itself in relationships between humans and non-humans.

Family care has also been linked to health services, albeit in a limited manner. The main reference was the post-COVID outpatient clinic, with few reports of broader interactions with the health care network. The recognition of families as partners in care is still incipient[14]. This gap reinforces the need for greater integration between professionals and families, especially in home care.

COVID-19 brought a new configuration of care, characterized by uncertainty, the need for rapid adaptation, and the persistence of symptoms without the prospect of a definitive recovery. A study highlights that the prolonged effects of COVID-19 have had a significant impact not only on patients but also on their caregivers, requiring extraordinary resilience from

them[6].

Although family care has proven effective in sustaining rehabilitation, it has faced challenges, such as caregiver overload, scarce home support services, and a lack of institutional strategies to include family members in the therapeutic process. The absence of already consolidated care strategies, as occurs in more well-known chronic diseases, reinforces the need for continuous institutional support and public policies that consider the specificities of COVID-19 in care planning[14].

Another study also highlighted that without additional external support, whether formally from health professionals or informally from social networks, family members can become overwhelmed, which can lead to negative health outcomes for both patients and caregivers[20]. When social support is adequate, caregiver/patient dyads can spend more time relating as a family, rather than just as caregivers and patients.

Reflecting on the experience of family care in light of the post-COVID-19 condition contributes to broadening the understanding of the role of the family in different contexts of chronic illness. In the post-COVID-19 context, family care has revealed itself to be a complex, multifaceted, and essential phenomenon that demands to be recognized, valued, and supported by public policies and by nursing and family health practices.

CONCLUSION

Family care for individuals in post-COVID-19 condition has proven to be a dynamic, complex, and essential process for rehabilitation. Families have reorganized their routines, assumed new roles, and mobilized support networks, demonstrating the centrality of home care in this context.

The attributes of family care, such as presence, protection, and promotion of life, highlight the importance of recognizing families as strategic partners in care, especially in situations of chronic and uncertain illness, such as the post-COVID-19 condition. The expanded support networks, including friends, neighbors, spirituality, and even pets, reveal that care goes beyond the limits of the nuclear family and is rooted in affective and community relationships.

The integrated analysis of the interviews, genograms, and ecomaps revealed that family care for individuals in post-COVID-19 condition was sustained by strong intra-family bonds and, in some cases, strengthened by religious and community networks. The ecomaps highlighted the diversity and quality of external support networks, pointing to the relevance of health institutions and affective bonds outside the family, as well as some weaknesses in interaction with the community. This broader view provided by the graphic instruments

reinforced and complemented the findings, allowing us to understand the complexity of family and community relationships mobilized in coping with the sequelae of COVID-19.

The findings highlight the importance of public policies and health practices that recognize the family as an active subject of care, considering its different arrangements and support networks. Further research is recommended to broaden the understanding of family care in diverse contexts, especially in situations of chronic and complex illness, such as the post-COVID-19 condition.

This study has limitations that should be considered. The research was conducted in a single service, located in a medium-sized city in southern Brazil, which offers a post-COVID outpatient clinic. The sample consisted only of people treated at this outpatient clinic, which restricts the inclusion of individuals with COVID-19 complications who did not have access to rehabilitation services. It should also be noted that the results reflect experiences at the time of data collection and may change over time, given the dynamic nature of the post-COVID-19 condition. Therefore, the results obtained cannot be generalized to all populations affected by COVID-19, but they offer an important basis for future research on the subject.

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