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Original Article

Understanding the process of becoming a family caregiver for stroke survivors

Conociendo el proceso de convertirse en cuidador familiar de sobrevivientes de un accidente cerebrovascular

Entendendo o processo de se tornar um cuidador familiar de sobreviventes de um acidente vascular cerebral

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Abstract

Introduction: The transition to becoming a family caregiver (FC) for a stroke survivor (SS) is a complex and challenging process that requires personal and social adaptation, influenced by role expectations and enabling factors. This role is often assumed without planning and is affected by the emotional impact of the stroke and the individual characteristics of both the caregiver and the patient. **Objective:** To explore the transition and performance process as an FC of an SS during the first year following the cerebrovascular event. **Methodology:** Qualitative research with a phenomenological approach, conducted at a medium to high complexity hospital. Five female family caregivers of stroke survivors were selected using convenience sampling. Data were collected through surveys, semi-structured and in-depth interviews, field notes, and clinical records. Data analysis was conducted using the constant comparison method. **Results:** Participants were unprepared to assume the FC role, and their performance in this role changed throughout the first year following the stroke. This change was influenced by factors related to the SS, the caregiver, and the context in which the care was provided. **Conclusion:** The implementation and development of care change throughout the first year following the stroke due to various factors. Understanding these factors can contribute to the design and implementation of more effective therapeutic approaches for family caregivers during the care process.

Keywords: Stroke, Caregivers, Role, Occupational Therapy.

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Resumen

Introducción: La transición a cuidador familiar (CF) de un sobreviviente de accidente cerebrovascular (SACV) es un proceso complejo y desafiante que requiere adaptación personal y social, influenciado por expectativas del rol y factores habilitantes. Este rol suele asumirse sin planificación, siendo afectado por el impacto emocional del accidente cerebrovascular (ACV) y las características individuales del cuidador y el paciente. **Objetivo:** Explorar el proceso de transición y desempeño como CF de un SACV durante el primer año posterior al evento cerebrovascular**. Metodología:** Investigación cualitativa con enfoque fenomenológico, realizada en un hospital de mediana a alta complejidad. Seleccionó a cinco mujeres cuidadoras familiares de SACV mediante muestreo por conveniencia. Los datos se recolectaron mediante formularios, entrevistas semiestructuradas y en profundidad, diario de campo y registros clínicos. El análisis de los datos se realizó basado en el método de comparación constante. **Resultados:** Las participantes no estaban preparadas para asumir el rol CF, y su desempeño en este rol cambió a lo largo del primer año posterior al ACV. Este cambio estuvo influido por factores propios del SACV, del cuidador y del contexto en el cual se realiza el cuidado. **Conclusión:** La implementación y desarrollo del cuidado cambian a lo largo del primer año posterior al ACV debido a diversos factores. Conocer estos factores puede contribuir al diseño e implementación de abordajes terapéuticos más efectivos para los cuidadores familiares durante el proceso de cuidado.

Palabras clave: Accidente Cerebrovascular, Cuidadores, Rol, Terapia Ocupacional.

Resumo

Introdução: A transição para se tornar um cuidador familiar (CF) de um sobrevivente de acidente vascular cerebral (SAVC) é um processo complexo e desafiador que requer adaptação pessoal e social, influenciado por expectativas de papel e fatores facilitadores. Este papel geralmente é assumido sem planejamento, sendo afetado pelo impacto emocional do AVC e pelas características individuais do cuidador e do paciente. **Objetivo:** Explorar o processo de transição e desempenho como CF de um SAVC durante o primeiro ano após o evento cerebrovascular. **Metodologia***:* Pesquisa qualitativa com abordagem fenomenológica, realizada em um hospital de média a alta complexidade. Cinco mulheres cuidadoras familiares de sobreviventes de AVC foram selecionadas através de amostragem por conveniência. Os dados foram coletados por meio de formulários, entrevistas semiestruturadas e profundas, diário de campo e registros clínicos. A análise dos dados foi realizada com base no método de comparação constante. **Resultados:** As participantes não estavam preparadas para assumir o papel de CF, e seu desempenho neste papel mudou ao longo do primeiro ano após o SAVC. Esta mudança foi influenciada por fatores relacionados ao SAVC, ao cuidador e ao contexto em que o cuidado foi prestado. **Conclusão:** A implementação e o desenvolvimento do cuidado mudam ao longo do primeiro ano após o SAVC devido a diversos fatores. Compreender esses fatores pode contribuir para o projeto e implementação de abordagens terapêuticas mais eficazes para os cuidadores familiares durante o processo de cuidado.

Palavras-chave: Acidente Vascular Cerebral, Cuidador Familiar, Papel, Terapia Ocupacional.

Introduction

Strokes (CVAs) are among the leading causes of death and disability worldwide, with a significant impact on public health both in Chile and globally (Morrissey & Lillicrap, 2022; Soto et al., 2020). Although a decrease in stroke-related mortality has been observed in recent years, the number of people affected by this condition has not declined proportionally, underscoring the persistence of this health problem (Tyagi et al., 2020; Yuliana et al., 2022).

The potential sequelae of a stroke depend on its etiology, severity, location, and the size of the vascular lesion, and may cause motor, cognitive, perceptual, sensory, and psychological deficits. Stroke survivors may experience hemiparesis or hemiplegia, fatigue, impairments in attention, memory, and executive functions, disturbances in visual fields and object recognition, depression, and communication difficulties. These consequences result in varying degrees—ranging from mild to severe—of difficulty participating in basic and instrumental activities of daily living, returning to work and leisure activities, engaging in social participation, and maintaining relationships with family and friends (Camicia et al., 2021). Given the acute, non-progressive nature of stroke-related injuries, it is expected that over time, the initial deficits will progress toward recovery. This recovery depends, among other factors, on the severity of the damage sustained, the type and timing of treatment received, and stroke-related variables.

As a result of stroke-induced deficits, it is estimated that around two-thirds of stroke survivors require assistance with their daily activities, typically provided by a family member, known as a *family caregiver* (**hereinafter FC**) (Pucciarelli et al., 2022; Bakas et al., 2022). The evolving nature of stroke-related damage means that the care needs of these patients will change over time as their condition improves (Camicia et al., 2021).

Health care work has traditionally been assigned to women, as it is considered an extension of the care provided within the family, which is part of the feminine role (Fonseca, 2019). Providing health care often generates FC overload, associated with the physical, mental, emotional, and financial burdens of caregiving. This situation is compounded by the loss of benefits derived from participation in other meaningful areas of occupational performance and by the limited social recognition of the FC role (Fonseca, 2019).

In the particular case of *stroke survivors* (**hereinafter SS**), their caregivers are typically described as family members who provide the most significant long-term support during recovery and rehabilitation (Kumar et al., 2022). This definition expands the traditional boundaries of caregiving—previously limited to assistance with daily living and health maintenance—to include the active participation of the family caregiver (FC) in tasks directly related to the rehabilitation and functional recovery of the SS. In this sense, the survivor's functional recovery becomes closely linked to the caregiver's work.

From an occupational perspective, the transition to becoming a FC for a SS entails assuming a new role, often involving a complex and demanding adaptive process. Hillman (2006) argues that individuals experience changes in their roles throughout life, which, from an occupational standpoint, constitute a critical adaptive process requiring significant personal and social reorganization. These changes encompass both the acquisition and loss of roles, as well as adjustments in how a specific role is performed (Toal-Sullivan & Henderson, 2004; Kielhofner, 2011; Camacho et al., 2016).

According to the Role Acquisition Model proposed by Heard (1977) and later adapted by Hillman & Chapparo (1995), this process functions as an open system in which internal and external role expectations, together with perceived enabling factors (personal skills and environmental supports), influence decision-making and the organization of behaviors associated with the new role.

Specific characteristics of the FC role for SS can influence how this role is assumed—often suddenly, rapidly, and under challenging circumstances due to a lack of preparation and the emotional impact of the patient's condition (Toal-Sullivan & Henderson, 2004). Moreover, the individual characteristics of both the FC and the SS as well as the environment in which they interact, play a crucial role in the acquisition and effective performance of the FC role, which is frequently assumed without prior planning (Gitlin & Rose, 2016).

Heard's model, conceived as an open system, not only explains the acquisition of a role but can also be applied to understand the evolution and maintenance of that role over time, particularly in the context of the changes experienced by the SS, the FC, and their environment (Heard, 1977; Cezar et al., 2014). This perspective suggests that the way in which the FC role is exercised must adapt as the circumstances and needs of those involved evolve.

In this sense, there is a need to investigate and understand in detail how the process of becoming and performing as a FC for a SS unfolds during the first year after the event. Such an approach would make it possible to identify the challenges, needs, and coping strategies that may arise during this critical stage of transition and adaptation for both FC and SS.

Various aspects related to the care of stroke patients and its impact on Family Caregivers (FCs) have been addressed in the literature. Saucedo-Pahua et al. (2023) developed specific theories to understand the transition of family members into caregiving roles in these circumstances; Tyagi et al. (2020) emphasized the importance of adopting a dyadic approach to post-stroke rehabilitation, involving both the patient and the caregiver in care management strategies. In this context, Silva et al. (2022) point out that informal caregivers, mostly women, experience burden and a decline in quality of life due to the demands associated with caring for people with moderate functional disability after a stroke.

Research has also explored the relationship between disability, depression, anxiety, and quality of life in both SS and their FCs. In this regard, Yuliana et al. (2022) examined how FC preparation influences the relationship between depression and quality of life in these circumstances, highlighting its crucial role in the well-being of both the patient and the caregiver. Collectively, these studies and approaches provide a comprehensive view of the challenges and opportunities involved in caring for stroke survivors and supporting their family caregivers.

The process of becoming and functioning as a FC for a SS involves a complex transition that requires adaptation, support, and understanding from both caregivers and healthcare professionals. Recent research has highlighted the importance of comprehensively addressing the needs of FCs and developing effective strategies to improve the quality of life of both patients and caregivers in the context of stroke (Dharma et al., 2018; Fadilah & Rahariyani, 2020).

Therefore, the objective of this research is to explore the process of transition and functioning as a FC for a SS during the first year after the event, analyzing it from the perspective of Occupational Science. This discipline focuses on the systematic study of people as occupational beings, including their need and capacity to adapt, engage, and structure their occupations to shape their lives. It thus provides occupational therapy with valuable insights into how and why people organize their daily lives (Navarrete, 2010).

Method

The research presented is qualitative, employing a phenomenological approach. As described by Hernández Sampieri & Mendoza Torres (2023), this approach seeks to understand phenomena from the individual perspective of each participant as well as from a collectively constructed standpoint. It is particularly appropriate for investigating realities whose essence depends on how they are experienced and perceived by the individual (Martínez, 2015).

The study was conducted in a medium- to high-complexity hospital located in Santiago, Chile, within the Metropolitan Health Service network, during 2018 and 2019. This hospital is recognized for offering specialized services in various medical areas, including intensive care, coronary care, medical-surgical, and rehabilitation units.

For participant selection, a non-probability convenience sampling strategy was employed. This method allows for the careful and deliberate selection of cases that best align with the study's objectives and established informational needs (Otzen & Manterola, 2017).

The sample size was determined using the data saturation criterion, defined as the point at which data collection and analysis no longer provide new relevant elements to answer the research question or when the data begin to repeat themselves (Rahimi & Khatooni, 2024). The sample consisted of five female family caregivers, specifically wives or long-term partners of stroke survivors, who had no prior experience as caregivers for a person with a disability.

The inclusion criteria for this study were: (1) being a family caregiver of a stroke survivor residing in Santiago, Chile; (2) caring for men between 45 and 75 years of age; (3) caring for individuals who were previously independent; (4) having suffered a stroke at least 12 months earlier; (5) having been hospitalized as a result of the stroke; and (6) having a score between 2 and 4 on the Modified Rankin Scale (mRS) (Nimbvikar et al., 2024) upon returning home. Family caregivers with cognitive impairments (score <26 on the Montreal Cognitive Assessment (MoCA)) (Gaete et al., 2020), language impairments that interfered with communication, or those receiving mental health treatment at the time of the study were excluded.

The characteristics of the recruited participants are detailed in Table 1.

Table 1. Characterization of participants.

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
Gender	Female	Female	Female	Female	Female
Age	50 years old	70 years old	75 years old	57 years old	60 years old
Relationship with the SS	Wife	Cohabitant	Wife	Wife	Wife
Home residents	Patient/Caregiver + 2 adults	Patient/Caregiver	Patient/Caregiver	Patient/Caregiver + 2 adults	Patient/Caregiver + 2 adults and 2 children
Age of the SS	51 years old	75 years old	75 years old	58 years old	64 years old
Date of the Stroke	2017	2016	2016	2018	2017
mRS at hospital discharge	3	2	4	4	4

The data collection instruments were the FC-SS Data Collection Form, a semi-structured interview, an in-depth interview, the researcher's field diary, and the review of written documents related to the clinical care of SS.

The data collection process began with a review of the hospital's database to identify potential participants, and participants were contacted by telephone and invited to participate. Once participants agreed, an initial meeting was held, during which the MoCA test was administered, the FC–SS Data Collection Form was completed, and a semi-structured interview was conducted. The results of the initial meeting were used to develop a script for the in-depth interview, which was conducted at the second meeting. All interviews were conducted individually to prevent the presence of the SS from interfering with the free expression of thoughts and emotions. The interviews were transcribed and analyzed using ATLAS.ti software.

For illustrative quotes, the following coding methods were used: P (participant number), I (interview number), and P (page number). Data analysis was based on grounded theory, employing the constant comparison method (Boeije, 2002). The research adhered to bioethical standards, considering social value, scientific ethics, equitable selection, risk-benefit ratio, informed consent, the right to withdraw, confidentiality, well-being monitoring, and access to study results (Seneviratne, 2023). The study was approved by the Human Research Ethics Committee of the Faculty of Medicine of the University of Chile (Project No. 83-2018; Minutes No. 43).

Results

Three categories were identified from the analysis of the interviews: the first, **Becoming a FC,** refers to the process of acquiring the FC role; the second, **Performing as a FC**, describes the initial performance of the role and its impact on the daily life of the FC; and finally, **Changes in FC Role Performance,** explores changes in performance during the first year.

1) Becoming a FC

The occurrence of the stroke was experienced by the FCs as a sudden, unexpected, and frightening event. They perceived it as a turning point in their lives, marking a clear before and after. The before was perceived as familiar, stable, and predictable, whereas the after was characterized by a present and future full of suffering, uncertainty, and fear

> *(Before the stroke) we would go to the square, come back, then do chores around the house, and then spend the whole afternoon at the gym. That was the life we had. We went out shopping; it was like we were always together* (P1, I1, p. 1).
>
> *It was a tremendous change; it was like having a baby again, a new birth, because from being fine one day to dawning like this the next, it was a radical change. From being self-sufficient, he went on to depend on us* (P4, E1, p. 34).
>
> *With great anguish, not knowing tomorrow, or when he might get sick again, because, I don't know, uncertainty remains—the fears, the anxieties. I have cases, as I was telling you, a friend who had it two years and eight months ago, where her son had a stroke and now, in July, he had one again* (P4, I1, p. 35).

All participants reported voluntarily assuming the role of FC for their husbands/partners, citing reasons linked to love, commitment, reciprocity for the role played by the SS as father and/or husband, and economic factors.

> *I was the one who had to take care of him, because my children were studying* (P1, I1, p. 5).
>
> *So I was the one who had to take care of him, because I had to take advantage of the fact that he was alive. I was the one who had to take care of him* (P1, I1, p. 5).
>
> *(While caring for him) I don't know, I sort of loved him more, yes, because I felt he depended so much on me, that if I wasn't there, I don't know what he would do on his own... I felt I was very connected to him* (P5, I1, p. 13).

The process of role acquisition began during the SS's hospitalization and continued at home, where the FC assumed all functions associated with the role. The hospitalization period marked the beginning of significant demands on the FCs, both self-imposed and from the social environment, pressuring them to quickly take on caregiving responsibilities.

Healthcare workers also required the FCs to engage in caregiving duties during the hospitalization while planning for the SS's future life at home.

During the hospitalization, the FCs visited the SS daily, devoting a large part of the day to tasks related to their care. During these visits, they assisted the SS with basic activities of daily living (BADL) and instrumental activities of daily living (IADL), arranged the necessary resources for care, exchanged information with healthcare staff, collaborated with them, and regulated the SS's contact with family and friends.

> [...] *He was hospitalized for ten days; we went to see him every day. He did very little; he tried to eat with his left hand. If we were there, we tried to give him food because it would drip all over his mouth* (P4, I1, p. 7).

According to the FCs' accounts, the information provided by healthcare staff regarding the possible sequelae of the stroke, its functional implications, and its eventual outcome was ambiguous and, in some cases, nonexistent. This made it difficult for them to identify the care needs their family member would present and the specific demands of their role as caregivers.

> *I was terribly anxious. I didn't know what was going to happen, because when this happens, you're not told, "He'll recover," "This happens," "That happens," "No." You never know; it depends on how his body evolves* (P4, I1, p. 7).

> [...] *At that time, we were lost; we didn't know what was happening. No one told us that S (SS) would have difficulty walking or doing his things later* (P1, I1, p. 5).

The hospital visits allowed the FCs to assess the SS's progress, not only based on the information provided by healthcare staff but also through direct observation of his functional level. In this way, the FCs developed a series of expectations about what their life and the SS's life would be like, as well as the SS's functional abilities at home. These functional expectations enabled them to make a first outline of the needs they would need to meet in their role as caregivers.

> *I thought, when he comes back, we'll have a wheelchair for him, and when I go out to sweep, he can be with me watering the garden* (P1, I1, p. 5).

> [...] *As the days went by and he was finally getting up a little, always lucid, always up to date with everything, the scare sort of subsided. It's not so bad* (P2, I1, p. 10).

> [...] *That time the OT explained it to us. She told us, "You have to let him do things on his own," so that completely changed my mind, because I had said, "I'm going to start feeding him, I'm going to give him food." And I remember that one time (the OT) caught me while I was giving him food and said, "No, he has to try to eat on his own." Of course, it gave us a different perspective on what needed to be done: for him to start validating himself as a person. I was going to start treating him like a baby... A serious mistake I had made* (P1, I1, p. 25).

The SS's return home required the FCs to quickly take on all tasks associated with their new role. The poor definition of the FC role (due to the limited social understanding of the role, combined with the scarcity and ambiguity of information provided by healthcare personnel), coupled with the FCs' lack of knowledge and skills in caregiving and the emotional impact of the situation, meant that acquiring and performing the FC role was complex. This initiated a process in which the FCs decided on, implemented, and modified caregiving tasks intuitively, refining their approach through trial and error and consulting healthcare personnel only occasionally for guidance.

> […] *I wasn't sure how I was going to manage at home with him (SS), but I didn't question it either. I mean, we were in this situation, so we had to move forward* (P2, I1, p. 10).

> […] *Maybe I made the mistake of demanding too much from him. I mean, I wanted him (SS) to be well, to be better than before. So, if we were against time, we had to make it. If the deadline was a year, we had to take advantage of that year. I mean, I couldn't let him stay. I saw that he could make progress and that he had to do it. He had to move forward* (P1, I1, p. 11).

Thus, the FCs identified their role as not only providing care to support the SS in carrying out daily activities and maintaining his health, but also as actively committing to supporting his rehabilitation process.

2) Serving as a FC

Regarding caregiving duties, these included healthcare (administering medication, accompanying the SS to healthcare services, and promoting healthy habits), collaboration with the rehabilitation process (accompanying him to sessions, providing technical aids, modifying architectural barriers in the home), assisting the SS in completing ADL and IADL, providing emotional support and containment, managing the SS's disruptive behaviors, and mediating between the SS and the environment (including individuals, organizations, and health and social security systems).

> […] *I had to help him with everything, even going to the bathroom. I had to clean him up because he couldn't clean himself. Since he couldn't stabilize himself, he kept falling* (P5, I1, p. 14).

> *Plus the new medications, making sure he didn't miss the dose, all of that. The nurse even told me I had to learn how to give myself an injection. Finally, I loaded the insulin (into the syringe), but he had to inject it with his left hand, but it still didn't work. He did it. But it was very stressful, very stressful* (P3, I1, p. 14).

> *I'm not telling you that he told the diabetologist that he (the SS) exercised, I don't know. I let him talk, and when he finished, I said (to the diabetologist), "Forgive me, but everything he told you isn't effective. He doesn't walk, he*

> *doesn't exercise, he doesn't do this, he doesn't do that, everything he told you isn't true*" (P2, I1, p. 25).

Regarding collaboration with the SS's recovery process, each FC understood their role differently. Some considered it to consist solely of managing and accompanying the SS to rehabilitation sessions. Others, however, considered that it included actively encouraging the SS's occupational participation, for which they created therapeutic activities at home and provided support aimed at promoting autonomy.

> *I had him writing, moving his arm, doing things all day long* (P1, I1, p. 11).

> *That's where we started. Every day, I took on the work, I bought him these lace-up games, my grandson brought him some little things with those doughs. My oldest son bought him some dumbbells, I made him a hook, we sat back in the dining room, and all the time* (P4, I1, p. 11).

As part of their caregiving duties, the FCs had to monitor variations in various manifestations of the SS (neurological, affective, functional, behavioral, etc.) and the environment, make decisions, and take actions aimed at what they understood as promoting the SS's well-being. This decision-making journey was marked by a lack of understanding of the clinical manifestations of stroke and the grieving process of those caring for the SS, generating uncertainty, anxiety, and constant questioning among the FCs regarding the appropriateness of their actions.

> [...] *I don't know if I made mistakes or not along the way, but I tried to help him and find things to do with therapy, who knows, but it's what I learned along the way* (P4, I1, p. 20).

The routines of the FCs were determined by their caregiving duties. The schedules for feeding, medication, exercise, and ADLs marked the time during the day, while they organized their weeks and months around rehabilitation sessions and medical checkups.

> [...] *At first, we went to the hospital three times a week. We left the house around 12, because we had the (occupational) therapist at 2, then the physical therapist, and then the speech therapist. We returned home around 7, went to the supermarket, did some shopping, and came back to make tea* (P1, I1, p. 8).

The type and degree of assistance provided by the FCs was based on factors associated with the SS (such as functional level, dependency behaviors, etc.), factors specific to the FCs (abilities, subjective perception of the SS's functional level, affective factors such as fear of something bad happening to the SS, and beliefs about the disability and the FC role), and environmental factors (presence of barriers and facilitators in the physical and social environment).

> *I wouldn't let him go up or down the stairs alone. Then he would let me know he was going up, I would go downstairs, and I would say, "Come down." I was always*

> *attentive. When he started going down alone, I would sometimes scold him, "I have to see you," I would say, or else I would secretly watch him go downstairs* (P1, I1, p. 10).
>
> […] *I helped him bathe, and it was heavy, his arm, his leg, it was really hard for him, but little by little we've been overcoming that. Now he sometimes bathes alone, and I watch over him, telling him to be careful. Sometimes I go to the fair and come back and he's bathed, so I say, 'That's good*' (P3, I1, p. 11).

The presence in the SS of clinical manifestations other than motor impairment (such as language, praxic, sensory alterations) as well as disruptive behaviors (excessive dependency, behaviors that threatened his well-being/health) generated confusion and stress in the FCs, contributing to their perception that the SS was incapable of taking responsibility for himself.

> […] *At first, he told me he had a rock on his back, he said, look at me, I have it there, and he felt something moving inside him, then I thought, is he crazy? What is happening to him*? […] (P4, I1, p. 33).

Whether the FCs performed caregiving duties directly or delegated them to a third party, they were always attentive to the well-being of the SS. Delegating caregiving duties depended on having an appropriate support network, which consisted of close family members and friends. The presence of a secondary caregiver, who regularly replaced and/or supported the FCs in performing caregiving duties, was especially important. In this research, this caregiver was only present in couples who shared their home with other family members.

> *I don't feel that I needed the help of a family member who had been in the house, not because I could still do things with my son* (P1, I1, p. 13).
>
> […] *On Thursday, they (the eldest son and SS) went to therapy last week, because on Thursdays, they go alone, I don't go with them* (P4, I1, p. 31).
>
> *We went to rehabilitation with my brother-in-law; he was the one who drove us* (P3, I1, p. 14).

Taking on the role of FC caused various changes in the caregivers' occupations. The demands associated with the FC role conflicted with the demands of the other roles they played, generating role conflicts and an occupational imbalance that also impacted them emotionally.

> *I'm an only child; my mother is already elderly. She also needs my help because she has arthritis. So, I'd say, of course, I have to take care of the gentleman (SS) here, and I'll leave my mother aside... that made me feel sorry, and I cried. I cried because I felt like I couldn't multiply myself. I had mixed feelings; I felt angry, I felt sorry, I cried... I felt anguish because I knew my mom had to go to the hospital, go to the doctor, to get her medicine* (P4, I1, p. 13).

Faced with the inability to adequately meet the demands of their different roles, the FCs prioritized the performance of the roles they considered most important or a priority, including: the FC role, family roles, and other roles they considered particularly significant.

> *I participate in church and believe in God. I have relied heavily on Him. For me, that has been fundamental. That's why I never stopped going to Mass. Masses are sacred to me* (P3, I1, p. 4).

On the contrary, they abandoned roles they considered less important or meaningful, a situation that primarily affected their free time roles, friendships, social participation, and family roles (extended family).

> […] *around the house (housework), whatever I could do in the morning, that's it. I never cut my wrists* (P2, I1, p. 9).
>
> *I visited the sick (to bring them Communion), but I spoke to the priest and told him I wouldn't be able to visit anymore because S (SS) was in the condition he was in. I still went to Mass, left him in bed, but I no longer gave Communion, or I gave it to just one person. I used to have three, four, before I didn't have any problems* (P3, I1, p. 15).

Regarding occupations associated with the roles that the FCs continued to perform, they modified their daily routines by extending their hours and organized non-caregiving occupations by moving them to morning (early morning) or evening (night) hours.

> *I would get up very early in the morning and get everything ready, and at night we would get something to eat. I also did laundry at night, but in the morning, I would clean, cook, and prepare my son's lunch* (P1, I1, p. 4).
>
> *When I have to go with him (SS) to the doctor, I leave some lunch prepared the night before, or if I have leftovers from what I cooked for the next day, I'm relaxed because if I leave early, I have to leave something prepared so he doesn't have lunch so late* (P3, I1, p. 15).

The FCs' ability to analyze situations, solve problems, plan, and make decisions was important for implementing caregiving actions, organizing their own behavior, and managing the use of the resources (material, social, and temporal) at their disposal.

3) Changes in the Performance of the FC Role Over the First Year

Over the months, the way in which the FCs provided care varied, experiencing changes in the quantity, frequency, and nature of caregiving tasks, which were influenced by factors associated with the FC, the SS, and the environment. During the initial stage, direct caregiving tasks for the SS (assistance with ADLs, health care), accompaniment to health checkups, and support for the rehabilitation process predominated, with the FCs devoting most of their day to this type of care.

> […] *At first, he went from taking almost no medication to taking a lot of medication. I had to bathe him, feed him, everything. That was a change. It was like having a baby again* (P4, I2, p. 3).

During this stage, the FCs made an effort to remain with the SS as much as possible. This behavior was based on the SS's level of dependency and the FCs' fear that something bad would happen to the SS in their absence. This fear was based not only on their perception of the SS's functional level, but also on their lack of confidence in the survivor's ability to assess risk situations and respond judiciously to them. Thus, remaining with the SS allowed the FCs not only to care for him but also to calm their own fear, providing them with peace of mind. Furthermore, the FCs' need to remain with the SS was reinforced by the SS's dependency behaviors.

> *If I had to do something, for example, get out, it was very difficult for me because I thought, don't let him fall, because since he (SS) was very weak, I would tell him, please don't move from the bed, don't get up, just stay there* (P3, I1, p. 10).

> *I felt like it was a need for me to be there; it was a joy for me to see him* […] *I noticed that he needed me to be by his side. I was calm if I was by his side, watching him, because, what was going to happen to him*? (P1, I1, p. 14).

Over time, the SS began to recover their abilities and achieved greater independence, decreasing their need for direct assistance. At the same time, as the FCs witnessed not only their progress but also their prudent behaviors regarding safety and well-being, they progressively lost their fear of something bad happening. This situation favored allowing the SSs to participate in more complex occupations, thus promoting the development of new skills, while simultaneously reducing the level of assistance provided.

> […] *one realizes that the person is feeling more useful, that they can walk around the house, they can go out for walks, and one begins to feel confident that it's more difficult for something to happen to them, but the risk is still there, although there is more confidence that they can take care of themselves* (P3, I2, p. 31).

However, even with precautions, in some cases the FCs' fears materialized, a situation that sometimes allowed them to relativize the level of risk initially perceived in the face of specific events.

> […] *I was worried that he might fall, even though he fell several times* […] *that time (I had gone out) I left his food ready and when I arrived at ten, he was eating* […] *he had just stood up on his own* (P3, I1, p. 15).

In the process of the SS's functional recovery, the loss of fear among the FCs was recursive, since the greater occupational participation achieved by the SS challenged them to face new potentially risky situations and prompted the FCs to overcome the fear caused by these confrontations.

> *Now he sits there, trying to accompany me, but since his problem is on his right side, when he tries to peel a tomato, I'm afraid he'll cut himself* (P4, I1, p. 3).

> *I helped him bathe, and it was heavy, his arm, his leg, it was really hard for him, but little by little we've been overcoming that. Now he sometimes bathes alone, and I watch over him, telling him to be careful. Sometimes I go to the fair and come back and he's bathed, so I say, 'That's good'* (P3, I1, p. 11).

Furthermore, achieving a better balance between the demands of their different roles, as well as developing skills related to managing neurological deficits, compensatory strategies, managing the disruptive behaviors of the SS, and using environmental resources, allowed the FCs to be more efficient in performing their roles. This, in turn, facilitated their access to opportunities for greater participation in the community, either for themselves or together with the SS.

> *I would get up very early in the morning and get everything ready, and at night we would get something to eat. I would also wash at night, but in the morning, I would clean and cook, and make my son's dinner* (P1, I1, p. 4).

> [...] *I used to hold back, but now I've turned things around. I'm going to my sister's, (he tells me) Oh no, it's just that I don't like going, (I reply) Don't go, stay. I'm about to leave, (and he tells me) I'm going with you. I used to beg him, 'Let's go,' and reluctantly I would go* [...] *I found it was the solution* (P2, I1, p. 14).

> *I tell him you can go for a walk, like I used to walk with the donkey23 at the beginning, to the corner... that's why, sometimes, I take him to the market and let him go with the cart. The cart helps him support himself, and that way he can take advantage of the walk* (P4, I1, p. 26).

The FCs reported that at the end of the first year, they no longer needed to be permanently present with the SS; direct caregiving duties decreased (in quantity and complexity), and care was provided primarily through supervision (in person or remotely) of the SS's performance and health status, work that also extended throughout the day.

> *I'd say I'm back, not 100 percent, but I've tried to get back to several things, because for example, since J (SS) is better now, if I have to accompany my mom to the hospital or something, I go with her* (P4, I1, p. 24).

> *Yes, because (now) I make time for everything. I also go for walks out of the blue. On Monday of this week, I went for a walk. My son told me, "Mom, go*

> *ahead, I'll stay with the kid (SS) here. If the kid is better now, he's fine." So, I went for the walk. We went to Monte26 to some therapeutic pools there. I was there all day. I refreshed myself, because I didn't even remember anything about the house, or the sick person or anything, or the hospital, not a single thing, nothing. I had a great time there* (P4, I1, p. 31).

Discussion

Taking on the FC role represented an unexpected challenge. The participants' occupational trajectory was an abrupt break from their pre-stroke life, threatening the continuity of their daily routines as they knew them and generating an uncertain and frightening future.

The FC role was acquired abruptly and unexpectedly, in the context of a situation considered undesirable (the stroke and resulting disability). Faced with this, the FCs began a process marked by lack of knowledge and emotional impact. The way in which the role was implemented and performed was defined through an intuitive process, based primarily on the FCs' subjective perceptions regarding the SS's condition, the caregiver role, and the internal and external resources available for care. As changes occurred in the SS (both in functional level and in affective and behavioral aspects), in the FCs (subjective experiences, development of caregiving skills, and balancing of their multiple roles), and in the environment, the FC role underwent a transformation. It shifted from performing tasks that prioritized direct care for the SS, requiring the constant presence of the FCs, to tasks primarily focused on supervising the survivor. These changes enabled greater occupational participation for the SS, which in turn supported their functional recovery process.

The use of Heard's (1977) Model allows us to identify the relevance of internal and external expectations surrounding the role of the family caregiver (FC), as well as enabling factors, both internal (knowledge, skills, among others) and external (material resources, support from the social environment). These elements directly influence the acquisition and performance of the role. This understanding aligns with findings reported in studies on family caregivers (FCs), which indicate that a greater level of preparation when assuming care positively impacts caregiver burden (Gitlin & Rose, 2016). Likewise, FCs who possess caregiving skills (Bernabel, 2016) and apply problem-focused coping strategies achieve better management of caregiving stress. Similarly, having cognitive processing skills (Cheng et al., 2018) and emotional regulation capabilities that match the demands of the new role facilitates more efficient decision-making (Cerquera & Galvis, 2014). Furthermore, various studies agree that social support for the FCs acts as a stress-modulating factor (García et al., 2016). In this context, Heard's model allows us to understand that the initial stage of caregiving represents the most demanding period for the FC, as proposed by Moral-Fernández et al. (2018).

Regarding the contrast between the results of the present research and those reported by other studies, although the reviewed literature does not focus specifically on the process of acquiring the FC role and the changes it experiences over time, overall, the findings indicate that assuming the FC role is an unexpected event that transforms the lives of caregivers (Lutz & Camicia, 2016; Simeone et al., 2016; Torregosa et al., 2018). In their research, Torregosa et al. (2018) argue that the way in which the FC role is performed is constantly renegotiated and changes over time based on factors specific to the FC and the environment. This is consistent with the findings of the present research, which highlight that not only the knowledge and diverse skills of the FC are critical, but also affective factors, which can become facilitators or barriers to the occupational participation of the SS.

In their study, Simeone et al. (2016) stated that FCs receive little preparation and information from healthcare institutions, which primarily hinders the initial performance of the FC role, consistent with the findings of this research. However, the participants' accounts also reveal the importance of subjective factors (such as the perception of the SS's level of disability and affective factors) for FCs in the implementation and performance of the caregiver role.

In their research, Jellema et al. (2019) report that FCs initially experience intense fear that something bad will happen to the SS, which diminishes over time, allowing them to distance themselves from the SS and resume participation in previously meaningful activities, consistent with the findings of this research. Notwithstanding the above, our results also support the conclusion that the reduction of fear among FCs enables greater occupational participation of the SS and, through this, favors their functional recovery. This also supports the conclusion that the loss of fear among FCs is a recursive process, in which increased occupational participation by the SS generates new potentially frightening situations for the FCs, challenging them to regulate their fear in order to allow for greater occupational participation, both for themselves and for the SS.

In summary, the findings of this research support the conclusion that the degree and type of assistance provided by FCs is not only related to the SS's functional level, but also to subjective aspects of the FCs (fears, beliefs, etc.), their knowledge and skills in performing tasks associated with the role, and environmental factors.

Conclusion

The way in which the FC performs their role is influenced by the functional condition of the SS, by the FC's own aspects (such as their level of preparation for the role, skills, and subjective factors), and by environmental factors. The duties performed by the FC during the first year evolved from direct assistance to the SS to responsibilities in which supervision predominated.

The FC role is constantly changing and adjusting over time, highlighting the need for programs that support FCs throughout the caregiving period, not just at the beginning. These programs should address not only the care needs of the SS, but also the specific needs of the FC and the environment in which care is provided. Further research is needed to explore in greater depth the changes experienced in the FC role, as well as the various factors that influence these changes.

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Author's Contributions

Irma Fonseca-Mardones directed the research, conceived the text, organized the sources, conducted the analysis, wrote the text, and proposed an initial version. Oscar Hernández-Lanas contributed theoretical inputs, organized sources, and wrote the final version of the text. Both authors participated in the analysis and discussion and approved the final version of the text.

Data Availability

The data supporting the results of this study are available from the corresponding author upon reasonable request.

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