



# An exploration into caring for a stroke-survivor in Lima, Peru: Emotional impact, stress factors, coping mechanisms and unmet needs of informal caregivers



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## ABSTRACT

**Introduction:** Understanding local complexities and challenges of stroke-related caregiving are essential to develop appropriate interventions. Our study aimed to characterize the impact of post-stroke care among informal caregivers in a setting of transitioning economy.

**Materials and methods:** Qualitative study based on in-depth interviews with primary caregivers of stroke survivors in Lima, Peru. Transcribed data was organized around the following themes: emotional impact of caregiving, main stress factors and coping mechanisms to deal with the caregiving role, as well as the unmet needs of caregivers.

**Results:** We interviewed twelve caregivers, mean age 52.5 years. Eight were females, who were either the spouse or child of the stroke survivor. Stroke patients had a median age of 70 years, range 53–85 years. All participants reported having experienced emotional stress and depressive symptoms as a result of caregiving. Although most had family support, reduced social activities and added unanticipated financial burdens increased caregiver's stress. None of the caregivers had received training in post-stroke care tasks after the patient's discharge and only a few had received some psychological support. Almost all expressed the need to see a professional to improve their mental health. Keeping a positive attitude towards their relative's physical post-stroke condition was a key coping mechanism.

**Conclusions:** In the absence of structured institutional responses, family members are responsible of providing care for stroke survivors, a task escorted by major emotional, financial, and social strains. This burden could be prevented or curtailed if caregivers were to be targeted by interventions providing psychological and financial support, together with basic training on post-stroke care.

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## 1. Introduction

It is well known that stroke is a major public health concern not only because of the large number of deaths, globally estimated at 6.7 million in 2012 [1], but also because of the long-term disability that it generates [2,3]. More than 80% of deaths by stroke occurred in low- and middle-income countries (LMIC) [4], where stroke occurrence has been increasing [4,5]. In South America, stroke mortality is between two and three times higher than in high-income regions of the world [4,5]. In 2007, Peru registered stroke as the 5th cause of death, scaling up drastically from the 21st position occupied in 1987 [6]. Post-stroke mortality rates in Peru after discharge are 20% [7], almost twice the worldwide average [8]. Despite the increase of deaths by stroke, much of stroke burden arises from disability [4,5,9]. Stroke impacts the quality of life of

stroke survivors and burdens their families [9–11]. Between 30 and 50% of stroke survivors live with severe disability resulting in dependency of care [4]. In Peru, the need for care among stroke survivors varies from 20% in rural settings to 39% in urban areas [4].

The literature distinguishes informal caregivers from formal ones, i.e. those who have some degree of training and get paid for their services. Informal caregivers are usually family members with no previous training [12–14]. In Peru, it is usually a family member who takes care of a relative with disability given that only 10% of people with special needs have access to adequate rehabilitation services [15]. The commitment, capacity and preparedness of an informal caregiver to provide good quality of care, while protecting their own health, have implications for stroke survivor's long-term outcomes [16]. Studies conducted on informal caregivers in Taiwan [17], the United States [18–20], and Vietnam [21], have found that family caregivers of stroke survivors need more information related to their caretaking chores, and “feel inadequately prepared to deal with the physical, cognitive and emotional needs of the stroke survivors” [17].

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Studies from other countries have shown that informal caregivers are vulnerable to physical and psychological distress [9,22–31]. These caregivers often develop depressive symptoms, combined with stress, anxiety, and grief [9,22–24,27,29,32]. Sources of psychological distress are multiple, but are usually connected to an impact on the caregivers' quality of life since they often have to stop working or change their regular social and family activities [30,33]. We wanted to know if informal caregivers' in Peru had similar experiences and their strategies to cope with them.

Informal caregiving is highly prevalent in Peru, approximately 95% of individuals with a disability in a dependency situation receive care provided by family members, usually a female relative [15]. However, very little research has been done on understanding informal caregiving conditions of stroke survivors within the Peruvian context. Doing so may encourage the implementation of effective interventions to help informal caregivers with their daily chores, and to improve their own overall quality of life [10,34]. Reducing the caregiving burden could also contribute, to improve the stroke-survivor's health and recovery. The aim of this paper is to describe the emotional impact, main stress factors, coping mechanisms, and unmet needs of individuals functioning as informal caregivers of stroke survivors, and identify elements that could inform future interventions for caregivers.

## 2. Materials and methods

### 2.1. Study design

We conducted a qualitative study to explore, through individual in-depth interviews, the experiences of a group of informal caregivers of stroke survivors. Interviews were selected as the most robust technique since it allows a thoughtful understanding of the complexity of caregivers' everyday lives as well as ensuring a close rapport between interviewer and interviewee that facilitated discussing the more sensible topics of providing care to a relative with disabilities [35].

### 2.2. Setting

The study was conducted between June and September 2013 in three different healthcare facilities in Lima, Peru: 1) a rehabilitation service of a large public hospital in northern Lima; 2) a private rehabilitation service also in the north of Lima; and 3) a primary healthcare center in southern Lima. All these facilities serve low-income people from some of the most populated districts of the country's capital city.

### 2.3. Participants and recruitment

The projected sample size of the study was 16 primary caregivers, defined as the family member that provided most of the daily care received by the stroke survivor. To be invited to participate, a person had to fulfill the following inclusion criteria: i) 18 years of age or older; ii) self-identification as a primary caregiver of a stroke survivor who had suffered a stroke at least 6 months previous to the study, had received medical attention for the acute episode within the public health system, and required assistance to perform daily domestic activities, such as eating or relieving themselves, as a result of the stroke; and iii) able to voluntarily and independently consent participation in the study.

Sixty-seven potential caregivers were contacted but only 23 were eligible. Only 15 were finally interviewed, two did not accept to be interviewed, one accepted but her relatives did not agree with her participation, one person did not understand the study and four only participated in the first interview session after which they declined to continue. Out of the 15 caregivers interviewed, we deemed that the quality of the data was poor in the case of 3 interviews; thus, this paper is based on the information provided by 12 caregivers.

Eight participants were recruited in the waiting room of the rehabilitation service of a public hospital. After some weeks in the field, not many of the users of the rehabilitation services fulfilled the inclusion criteria and it was decided to visit smaller primary healthcare centers in other underserved areas of Lima. Four other caregivers were recruited in primary healthcare facilities using the snowball sampling method, a technique that allows the identification of cases of interest from people who know other individuals who are eligible for the study [35]. After four months, the recruitment phase was halted with 15 stroke caregivers participating in the study.

### 2.4. Data collection

The research team designed a semi-structured interview guide for conducting in-depth interviews with caregivers. Participants also answered a short questionnaire designed to collect basic socio-demographic information of the caregiver and the stroke survivor. Each participant was interviewed between two and five times, depending on their availability and convenience. Each interview session lasted approximately one hour. Interviews were conducted by two trained anthropologists and performed at the health facilities or caregivers' homes.

### 2.5. Topics covered in the interviews

The interview guide covered a wide range of topics that aimed at understanding caregivers' experiences since the occurrence of the stroke event. Caregivers were first asked about the stroke including the circumstances in which the stroke occurred, the initial medical treatment provided to the patient, the initial information that the caregiver received from the medical staff, the caregiver's emotional reaction to the stroke and how they imagined that their life would be like after the stroke event. The interviews proceeded with questions about the initial changes to the caregivers' lives right after the stroke, such as the initial organization within the family of caregiving activities, help received from others, changes to their home environment, family life, employment and income, and social activities. Afterwards, current impacts on the mentioned areas were ascertained. Furthermore, the interviews included questions about the caregivers' role, why they were the ones taking care of their relative, their everyday household and leisure activities, as well as caregiving activities and their knowledge about how best to do them and their perceived needs. Additionally the caregivers' were asked about their experience with the health care system, for example, their evaluation of the consultation, service and treatment received, the need for mental health care and the care sought. Detailed information is provided in the interview guide, [Appendix 1](#).

### 2.6. Data analysis

All interviews were recorded and transcribed verbatim, producing a total of 458 pages of transcribed material. The information collected in the interviews ([Appendix 1](#), interview guide) was organized around eight topics ([Appendix 2](#), codebook). After interviews were fully coded using the ATLAS.ti 7.1 (Scientific Software Development GmbH, Berlin, Germany), the data was arranged into five domains: i) emotional impact of post-stroke care among caregivers; ii) social impacts and family relations of post-stroke care among caregivers; iii) financial impact of post-stroke care among caregivers; iv) impact on physical health among caregivers; and v) needs of caregivers, as well as the needs for support as described by caregivers.

Following a detailed scrutiny of the various types of impacts, the thematic analysis [36] yielded four major categories to assemble and report the data: emotional impact, stress factors, coping mechanisms, and needs for each of the caregivers ([Appendix 3](#), summary of themes). Stress factors were defined as all aspects mentioned by the participants related to the context of taking care of a family member that negatively

affected their life and wellbeing. Coping mechanisms were the aspects that seemed to help caregivers deal with the emotional hardship of this situation. Two authors (LB, MAP) identified commonalities and differences in participants' responses and the reasons behind such differences, and discrepancies were contrasted and resolved.

### 2.7. Ethics

The study was approved by the Institutional Review Board at Universidad Peruana Cayetano Heredia. All participants provided oral informed consent before beginning the interview.

## 3. Results

### 3.1. Caregivers characteristics

All of the 12 participants of this study were the main care providers for a family member. The mean ages was 52.5 years ( $SD \pm 13.8$ ), and most were female (8/12). Half of them cared for a parent, the other half for their spouse, and stroke patients had a median age of 70 years (range 53–85 years). Most of the caregivers (8/12) had this role for more than a year at the time of the interview. The majority of caregivers (8/12) cared for people with both motor and verbal disabilities, while the rest cared for patients who suffered exclusively from motor deficits.

The caregivers were living in seven different districts of Lima and the majority (7/12) was classified as low or low-middle socioeconomic status, based on their monthly income (Table 1). Most of the caregivers (10/12) lived with four or more other family members. Quechua was the native language in 4/12 caregivers and the majority (8/12) were immigrants from outside Lima. The major caregiving responsibilities involved feeding, bathing, toileting, and accompanying their relatives to physical therapy and/or medical appointments. Results are summarized in Table 2.

### 3.2. Emotional impact of caregiving

All participants stated that they suffered emotionally as a consequence of their family member's stroke. This suffering was declared to be at its highest immediately after the stroke occurred and during the

**Table 1**  
Sociodemographic profile of participants.

Demographic variable	Definition	No. of participants	%
Length of post-stroke period	>1 year	8	67%
	6 month–1 year	3	25%
	<6 month	1	8%
Number of people living in the same house as caretaker	1–3	2	17%
	4–6	7	58%
	7–9	2	17%
	>9	1	8%
Reported monthly income before the stroke*	S/. 375–749 [US \$142–283]	2	17%
	S/. 750–1499 [US \$283–566]	5	42%
	≥S/. 1500 [US ≥ US \$566]	3	25%
	No answer	2	17%
First language	Spanish	8	67%
	Quechua	4	33%
Origin	Lima	4	33%
	Ancash	3	25%
	Jaén	1	8%
	Ayacucho	2	17%
	Ica	1	8%
Employment status	Cuzco	1	8%
	Exclusively caretaker	5	42%
	Combine caretaking and work	7	58%
Health	Diagnosed disease	6	50%
	No diagnosis/healthy	6	50%

\* Values are in Peruvian Nuevos Soles, and calculated into US dollars using exchange rates for 2013 (<http://www.xe.com/currencytables/?from=PEN&date=2013-04-29>).

**Table 2**  
Summary of results.

Emotional impact of caregiving
• Emotional suffering was the most common consequence of becoming having to take care of their family member's post stroke condition.
• Some participants were experiencing depressive symptoms such as tiredness, sadness, extreme sensitivity, difficulty sleeping, lack of motivation and physical symptoms, e.g. headaches. One participant even expressed suicidal ideation.
Stress factors affecting caregivers
• The most frequently mentioned stress factors were the lack of independence and time to engage in social activities, e.g. going out with friends or visiting relatives. The time, effort and amount of caregiving activities are perceived as overwhelming.
• The financial impact that caregiving has on the caretakers' lives was another common stress factor.
Caregivers' coping mechanisms and support received
• Family support, especially financial support from relatives was an important support received by participants.
• They also received family help for tasks such as feeding the patient, taking the patient to the hospital, household activities, such as cooking, cleaning or taking care of the children.
• Some also received in-kind help like diapers or food.
• However, caregivers described most of these actions as occasional and unreliable.
Caregivers' perceived needs
• Almost all participants expressed the need to see a psychologist or another specialist to improve their mental health, but most of them did not receive any professional help at the time of the interview.

first few months of adjusting to their loved one's new condition of dependence. The majority (10/12) also stated they were still greatly affected emotionally by their current situation. One third of the participants clearly stated they were experiencing depressive symptoms such as tiredness, sadness, extreme sensitivity (“*ganas de llorar*”), difficulty sleeping, lack of motivation and physical symptoms, e.g. headaches. One participant even expressed suicidal ideation. Other emotions described were stress, desperation and sorrow (“*dolor*”). Overall, caregivers expressed emotional suffering, especially those taking care of a parent that used to be independent.

*“Sometimes, as I told you, when I see her like this, I get very sad. Sometimes she starts to cry and I get sad because I don't want her to be like this. I would like her to be happy. There are times where she is not happy and then I cry as a daughter. [Then] both of us are crying, she over here and I over there, as long as she doesn't see me this way.”* (J05, Daughter, Appendix 4, quote #1).

Furthermore, some caregivers spoke about how hard it was for them to see a loved one deprived of their independence, as the following quote describes:

*“[...] when we took her home, it was traumatic, unrecognizable, because after seeing her walk and doing her things, taking her home and seeing how she was drooling..., good grief! No, she couldn't even... she couldn't even get up. [Changing] her diaper [was] very hard..., for everything we had to carry her, for everything, [it was] frustrating...”* (A04, Daughter, Appendix 4, quote #2).

Two other participants stated they did not perceive any negative emotional impact at the time of the interview and both of them mentioned they felt in control of the situation.

Four caregivers —those who cared for a parent— expressed that they saw the caretaking role as an opportunity to “give back”, a way of retribution for the love and care they had received from their relative when they were in good health. Some said they felt good about being a caretaker, because this way they will not have any regrets later on. For one husband, taking care of his wife was an expression of loyalty, which made him feel good about himself. Thus, the emotional impact of being a caregiver may also include positive feelings such as a sense of fulfillment and satisfaction in being able to help their loved one.



*“Because it's your mother, you give everything. Sometimes you say..., seeing your mother this way, debilitated, you want to throw yourself on the ground... why? Why is my mother like this?... But you do it and you feel happy to take care of your mother. If you don't do it, who will?”* (A06, Son, [Appendix 4](#), quote #3).

### 3.3. Stress factors affecting caregivers

The most frequently mentioned stress factors were the lack of independence and time to engage in social activities, e.g. going out with friends or visiting relatives. The time, effort and amount of caregiving activities are perceived as overwhelming. Caregiving activities negatively affect the caregivers' autonomy who stated they do not have time for themselves or other family members.

*“Now, I am more dedicated to my mother. I cannot be anymore the kind of mother who goes out with their children, goes for a walk with them or takes them somewhere, like before. I'm more dedicated and focused on her. Before we used to go out with her, [but now] to go out... with her and my children... it is difficult... I have to go out with my sister or another person as company.”* (A02, Daughter, [Appendix 4](#), quote #4).

The financial impact that caregiving has on the caretakers' lives was another common stress factor. Some caregivers suffered an impact on their employment status and consequently on their income. Most participants (7/12) reported to have stopped working altogether in order to care for their loved one, which made them fully dependent on the financial support of other family members who may fail to do so consistently. Some of those who stopped working after the stroke happened eventually resumed work while others still depended completely on others to cover expenses at the time of the interview.

*“This [the financial situation] has most affected me, because now I have to wait for my son to give me money, while before I always solved all of the problems related to the household on my own.”* (A03, Husband, [Appendix 4](#), quote #5).

*“I said: “My god, what will my life be like now? I won't work.” And then I started thinking: “What will I do if I don't work?”* (J03, Wife, [Appendix 4](#), quote #6).

Taking care of a family member did not only affect the amount of income, but also the volume of expenses. Almost all participants mentioned the financial strain of caregiving, such as spending on diapers, medical bills for doctor appointments, medication, rehabilitation therapies and private transportation to take the patient to the health centers and hospitals. One participant reported taking a loan from family members to cover the initial post-stroke expenses.

Three caregivers mentioned lack of financial support from other family members, mostly siblings, and lack of help with the caretaking chores as important stress factors. A similar proportion, 8/12 caregivers (all of them females), described difficult tasks related to the caregiver role as stressful, especially those that require physical strength, such as carrying or moving the patient. Two caregivers expressed feeling anxious about their lack of knowledge in the care of a stroke survivor.

The emotional stress was more pronounced among those caregivers who described their relationship with the patient as “difficult”. In some cases the patient was portrayed as demanding and bad-tempered. Furthermore, some patients refused certain care activities such as taking their medication or taking a bath, which caretakers described as frustrating.

Caregivers themselves dealt with their own health issues, which often complicated caregiving. Some of these health problems appeared to be a consequence of caregiving tasks, such as hip pain. Half of the participants suffered chronic conditions such as hypertension, diabetes,

osteoporosis and early stage Alzheimer's disease. Unfortunately, caregiving hindered the chances of caregivers seeking any medical care mainly due to the inability to leave the patient at home alone.

Other stress factors mentioned by a few participants were related to the bad quality of health services received by their relative, their own age (feeling old and tired), organization of the household tasks, need to take care of the responsibilities the patient used to do before the stroke (pay the bills, run errands, take care of the family business, etc.), or regrets related to the caregiver's relationship with the patient prior to the stroke.

### 3.4. Caregivers' coping mechanisms and support received

Besides stress factors, participants also mentioned things that helped them cope with the situation. Most participants received some kind of family support, especially financial support (8/12). While some caregivers had a constant and reliable source of financial aid to cover the patient's expenses and their own, some only received enough for the patient's expenses or only occasionally. The latter happened on demand or when other relatives could provide additional money.

Besides financial support, caregivers received help, mainly by other family members, for tasks such as feeding the patient or taking the patient to the hospital. Others had help in household activities, such as cooking, cleaning or taking care of the children. Some also received in-kind help like diapers or food. However, caregivers described most of these actions as occasional and unreliable. Only one participant, who seemed to be the one least affected emotionally at the moment of the interview, shared all caregiving activities and some household activities with her sister. None of them mentioned receiving financial or practical support from public or private institutions.

Although most of the participants seem greatly affected by their caregiving situation and by their loved ones' dependent condition, many mentioned strategies that help them cope with it. Having a positive attitude towards the circumstance and towards the patient was the most frequently mentioned. As reported, they did so by coming to terms with the situation and maintaining their good humor by avoiding seeing caretaking as an obligation and by trying to keep the patient happy. One caregiver explained that sharing caregiving responsibilities helps her have a more autonomous life, which in turn lowers her emotional burden.

Social support seems to be an important factor in emotional wellbeing, which five of the participants expressed to receive. To feel better, some participants talked to other caregivers or even patients that have suffered a stroke, but most turned to family or friends for emotional support.

*“I mean, we (siblings) have always been very united, [...] we are one; this situation connected us even more, [...] in life money is not everything, not everything in life is about having something. Life is living in harmony and this has united us more...”* (A06, Son, [Appendix 4](#), quote #7).

Another coping mechanism, mentioned by five caregivers, was doing relaxing activities such as cooking, going to church, or taking on leisure activities they used to do previous to becoming the primary caregiver. In doing so, participants felt they still had a life of their own, independent from their caregiving role.

*“And I do [activities of my own], because my activities also help me get distracted, because it happens that I stress myself with my mother's illness. It is worse, when I get sick, though. So, what I do is do my normal activities as I did before.”* (A04, Daughter, [Appendix 4](#), quote #8).

Half of the participants also found strength and hope in their religion:

*“[...] I sit down and start to pray and say “please, the life of my husband is in your hands. I don't have faith in anything else, other than in You. You will give me enough courage” and I pray for half an hour, ten*

minutes, five minutes, the time that I have, then [...] afterwards I feel better to go on facing the problems I have. This is my way, it is not, as I told you, it is not that I pray and then the things get resolved, to resolve them, I have to resolve them myself." (J01, Wife, Appendix 4, quote #9).

Other coping mechanisms described were: working, having a routine, hope in the patient's recovery, reading self-help books, finding satisfaction in caregiving as a form of retribution to the patient, doing physical activity or watching television.

### 3.5. Caregivers' perceived needs

Almost all participants (11/12) expressed the need to see a psychologist or another specialist to improve their mental health, but most of them (10/12) did not received any professional help. Some of them stated they would like to look for help, but could not leave the patient by him- or herself.

Beside professional help for addressing mental health issues, caregivers mentioned the need to receive more information, especially about how to adequately care for a stroke survivor and how to do specific caretaking tasks (7/12). Some participants specifically mentioned that information about rehabilitation exercises, prevention of a new stroke, how to access professional help in mental health, and how to measure blood pressure would be helpful.

Other demands mentioned by caregivers were related to the health care system: longer rehabilitation sessions, more sensitive health care staff, more conveniently located health centers offering physical therapy and availability of health care staff that may speak to the patient in Quechua, their native tongue.

## 4. Discussion

Our study describes the experiences of informal caregivers of stroke survivors in a context where the health system does not provide them with any training, financial support or mental health services. Caregivers experienced emotional distress as a consequence of their relative's disabled condition after the stroke. This distress was more intense immediately after the stroke occurred and the emotional pain waned when the patient showed improvement or caregivers became more confident in their abilities to offer care. Although several participants were experiencing depressive symptoms, some stated that taking care of their relative was an opportunity to reciprocate the love and care they received over the years. The absence of time for social activities and the financial dependence on others were the most important stress factors among caregivers, although most of them received family support either as money, in-kind, caretaking activities or household chores. Keeping a positive attitude towards the post-stroke condition was a key coping mechanism and some also resorted to religion for hope and strength. Almost all participants expressed the need to see a professional to improve their mental health, but most were not able to access it. Furthermore, the need to receive more information about how to take care of someone was pronounced frequently. Taken together, this information confirms the already known significant burden associated with the provision of informal caregiving and signals towards areas for the development of intervention addressing the needs of caregivers.

### 4.1. Comparison with literature

Several studies have demonstrated the negative impact of caregiving on caregivers' lives and wellbeing. Due to the burden of their role as caregivers they are exposed to physical and mental risks [9,22–31] and may develop depressive symptoms and/or experience stress, anxiety, grief and psychological distress in general [9,

22–24,27,29,32]. In some cases, caregivers have reported distortions in the quality of sleep [26–28], or an increase in cardiovascular risk, among other health problems [22,25]. Being an informal caregiver has shown to impact the professional and family life of the individual [28,30,31].

Providing care to a person who has survived a stroke also has an economic impact on the family, and some interventions could be oriented towards subsidizing the cost of a performing a task of a caregiver, or by reducing the working hours of those who assume the role of caregiving [31,37]. When somebody takes on this role, it usually involves putting aside their work or their typical activities, impacting their quality of life [30,33]. Evidence shows that spouses who assume the role of caregiver are more affected than other family members who assume that role [14,30,33]. In this regard, our study complements the existing evidence by showing a marked emotional, social and financial impact on those providing care to a relative.

Among the factors that can help decrease the negative effects on caregivers, there is mutuality, understood as a feeling of intimacy and positive relationship between caregiver and care receiver [38]. Our study found such mutuality being described by caregivers. Study participants have developed multiple coping mechanisms that are similar to those found but Quinn et al. in a study where spouses acted as caregivers [14].

Furthermore, there is also evidence that caregiving can have a positive impact on those providing care since many of them can take pleasure from caregiving-related activities, as we found in our study [39]. Another study has shown that taking care of a family member allows caregivers to realize they have strengths they were not aware of before, and to reinforce ties with the person being cared for [40,41]. Caregivers that felt mistreated by the patient seemed to suffer a greater emotional distress than those who had a good relationship with the patient.

Improved knowledge about caring activities, asking for help, personal commitment and social support are other important protective factors against negative effects of a caregiving role [14,16]. In this study, the withdrawal from social activities [9], and not knowing how to take care of the patient, appeared as important stress factors that could influence the caregivers' emotional wellbeing.

### 4.2. Relevance to public health

It is well established that early rehabilitation is crucial to guarantee improved health outcomes for stroke survivors [5]. Most recommendations around the importance of therapy immediately after the stroke, point towards the need of changes at the health systems level through training and education of health professionals around prevention, treatment and rehabilitation [5]. However, our study shows that in countries like Peru, such actions are not performed by health professionals but are rather taken on by family members who often lack the necessary information and skills to perform them well and to cope with the stress associated with such activities. This has been shown to be a major problem among informal caregivers [13,42].

Currently, according to a nationwide survey around the use of time in Peruvian population shows that, in general, 1.1% of men and 2.3% of women take care of a family member with physical disability, mental disability or who is totally dependent on others [43]. The exact burden of caregiving for people with disease or disability is not known in LMIC's [9]. Moreover, caregivers' wellbeing is often overlooked when it ought to be a key component of any effort addressing the needs of a stroke survivor. Our findings can be used to refine interventions targeting caregivers that have already been developed and tested [44–47], and improve their impact.

Given the epidemiological trends pointing towards an increase of people suffering from cardiovascular problems, and therefore of stroke-related disability, there is going to be an increasing number of

people who will face the responsibility of taking on a caregiving role in the future [8,9]. Governmental programs that offer support services for family caregivers should be part of the packages offered by the national health insurance programs. There are very few studies about stroke and less so about informal caregivers in countries like Peru [48]. Also, in Peru there is a pressing need for training and support for family members who care for a relative with a disability [15].

While proving sufficient and appropriate information on caregivers' needs remains a crucial pending agenda, it is also clear that, at the macro governmental level, current structures and institutions have failed to implement policies to protect or aid informal caregivers so far. There are examples in the region and elsewhere that can provide important lessons for wide interventions such as the SAAD - *Sistema para la Autonomía y Atención a la Dependencia* (System for Autonomy and Dependency) in Spain [49], or the Uruguayan programs “*Y yo te cuido a vos*” (“And I take care of you”) for elderly people taking care of a family member [50], and the “*Programa de Asistentes Personales para Personas con Discapacidad Severa*” (Personal assistants program for people with severe disability) [51]. All of these are governmental initiatives aimed at offering professional support to those who take care of a disabled relative at home.

Experiences from studies that implemented programs for caregivers have identified that in order to prevent depression and improve the overall well being of family caregivers, programs should focus on improving depressive symptoms [52] and foster family networking around the patient [53]. Experiences in rural India with social support groups for family caregivers [54] and in the U.S. providing both educational materials and telephone assessments by nurses with a combination of information, support, and referral services [54] have proven effective in the short-term to prevent or reduce depressive symptoms among family caregivers. Some of these lessons could be taken into consideration to explore their appropriateness in Peru and develop interventions. Interventions should also provide training on providing chronic care [55].

#### 4.3. Strengths and limitations

One of the study's limitations is that we only collected data from twelve caregivers. Finding caregivers willing to participate was not an easy task, probably because of major pressing demands around time among them. Another explanation is that there are many people who cannot even access rehabilitation services, where our recruitment strategy was initially concentrated. This means that, for this study, we may have not reached those caregivers with additional needs or even more complex circumstances than the ones portrayed, including but not limited to financial exclusion and lack of access to healthcare and rehabilitation services. However, we believe that our data provides a first glimpse into an important area of research: the impacts and needs of informal caregivers in low- and middle-income countries, such as Peru.

One of the strengths is the detailed description of the multiple angles in which becoming a caregiver impacts the lives of family members. Our study shows that emotional stress is usually coupled with financial burdens, a decrease in leisure time and opportunities to engage in social interactions, regardless of the district caregivers came from. Our study also shows that caregivers have developed coping mechanisms, which would be important to understand in further detail in order to design future interventions aimed at improving the quality of life of and the care provided by caregivers. Such interventions should include recreational activities for caregivers while offering professional support to take care of the patient.

Our study also shows that caregiving could also have a positive emotional impact. A systematic review on the positive experiences of caregiving for stroke survivors found that feeling appreciated, increased self-esteem and watching the care receiver's progress had a positive impact on caregivers [34]. However, longitudinal research is needed to better understand the positive impacts of caregiving and the diversity of caring experiences [56].

Future research should focus on those caregivers that are not yet tapped into an existing health service. The perspectives of “unconnected caregivers” were not part of this research and we do not know about the emotional and physical health status of those at the margins of health care.

## 5. Conclusions

It is known that caregiving is not a burden-free zone, yet the sudden installation of post-stroke care demands on family members are accompanied by major emotional, financial, and social strains. This burden could be prevented from appearing, minimized or even curtailed in duration if caregivers were to be targeted by interventions that provide psychological support and basic training on post-stroke care.

This paper allows a first glance into the impact of caregiving among low-income citizens in Lima, Peru, providing insight into the specific strains and needs of caregivers, which could be a basis for building interventions tailored to their specific necessities, as well as programs directed towards providing emotional and practical support for caregivers. Improving the caregivers' wellbeing could, in turn, also improve the stroke-survivors' health and recovery.

## Competing interests

The authors declare that they have no competing interests.

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## Author contribution

FDC and JJM developed the idea of this study and FDC designed the study and its implementation. AI implemented the study in the field, collecting the data. AI, MAP and LB created the codebook, codified the interviews and summarized the results for each participant. MAP and LB analyzed the data. AI outlined the research paper; MAP and LB were mainly responsible for writing this paper. After the first draft, the paper was sent to AI, JJM and FDC, who all contributed to the final version submitted.

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## Appendix 1. Interview guide, in Spanish

Section A: The occurrence of the stroke and its initial care.

Section B: Initial changes introduced by the stroke.

Sections C–F: Adaptation and current situation.

### A. El ACV y la atención inicial

1. Cuénteme brevemente, ¿qué fue lo que tuvo el paciente y cómo se enfermó?
2. Cuénteme del día en que enfermó. **Esperar y luego explorar lo que sea pertinente.**
  - ¿Cuándo y dónde sucedió?
  - ¿Cómo hicieron para que reciba atención médica? ¿Cuánto tiempo demoró? **Explorar razones de posibles demoras**
  - ¿Dónde lo atendieron? ¿Por qué lo atendieron ahí?
3. ¿Cuánto tiempo se quedó hospitalizado/a?
  - ¿Alguien acompañaba al paciente durante su hospitalización?
    - ¿Por qué? **Si dice sí, explorar:** ¿Quién? ¿Qué cosas hacía para el paciente?
  - ¿Qué atención o tratamiento le dieron en ese momento?
    - ¿Qué opina de esa atención o tratamiento?
  - ¿Quién conversaba con los médicos y otros profesionales de salud? ¿Los médicos hablaban con el paciente, con la familia o con ambos? **Explorar**
4. ¿Qué les informaron o explicaron sobre la situación del paciente en esos primeros días? **Esperar, luego explorar lo que sea pertinente**
  - ¿Les explicaron qué le había sucedido y por qué sucedió? ¿Qué le dijeron?
  - ¿Les hablaron del tratamiento y rehabilitación? ¿Qué le dijeron?
  - ¿Les dijeron cómo sería o podía ser la vida del paciente después? ¿Qué le dijeron?
  - ¿Qué opina de la información que les dieron? **Por ejemplo:** ¿Era suficiente? ¿Era clara o comprensible para usted? ¿Fue útil para usted?
5. En esos días, ¿les explicaron los cuidados que necesitaría el paciente? ¿Qué le dijeron? **Explorar roles que se asignan a cuidadores** ¿Esa información fue útil? ¿Por qué sí/no?
6. ¿Cómo se sentía usted en esos primeros días? **Explorar** ¿En qué cosas pensaba? **Explorar**
  - ¿Cómo imaginaba que sería la vida del paciente? ¿Es como lo imaginó?
  - ¿Cómo imaginaba que sería su vida luego del derrame/infarto? ¿Es como lo imaginó?
7. En su opinión, ¿por qué que ocurrió el derrame/infarto? **Explorar con detalle las explicaciones** (Ej. hábitos de vida, conducta, explicaciones místicas, etc.)
  - ¿Cómo tiene usted esa información?
  - ¿Ha cambiado sus propios hábitos (alimentación, fumar, beber, etc) a partir de este suceso? ¿Por qué?

### B. Cambios iniciales generados por el ACV

8. Cuando regresaron a casa, ¿cómo estaba la salud del paciente? **Explorar secuelas**
  - ¿Qué cosas podía hacer solo?
  - ¿En qué cosas necesitaba ayuda?
9. ¿Cómo se organizaron para cuidar al paciente en ese momento? **Esperar, luego explorar lo que sea pertinente de la siguiente lista de preguntas**
  - ¿Quiénes se encargaban de atenderlo? **Si son varios:** ¿Qué hacía cada uno?
  - ¿Tenían ayuda de otras personas que no fueran de la familia? **Explorar:** ¿Por qué? ¿Quiénes eran y qué hacían esas personas?
  - ¿Tuvieron que cambiar o adaptar los espacios de la casa? ¿Cómo así?
10. ¿En esas primeras semanas, alguna persona o institución le dio información que le sirvió o le ayudó a cuidar al paciente? **Explorar. Si es pertinente** ¿Cómo sabía cómo cuidar al paciente?
11. ¿Cómo se resolvieron los asuntos personales pendientes del paciente? **Si no se menciona el trabajo del paciente, preguntar** ¿El paciente trabajaba? **Si dice sí,** ¿Cómo se resolvieron los compromisos laborales del paciente? ¿Quién se hizo cargo de ello?
12. ¿Cómo se vio afectado el hogar y los miembros de la familia en ese primer momento? **Esperar, luego explorar lo que sea pertinente de la siguiente lista de preguntas:**
  - ¿Cómo afectó la vida de los miembros de la familia?
  - ¿Cambió algo relacionado al trabajo u oficio de los miembros del hogar o de la familia?
  - ¿Cambió algo relacionado a su vida social o actividades de ocio?
  - ¿Se generó algún cambio en las relaciones familiares? **Explorar**
13. En cuánto a la economía del hogar:
  - ¿Esto generó algún cambio en los ingresos del hogar? ¿Tuvieron que hacer ajustes? **Si es pertinente** ¿Quién se empezó a hacer cargo de la misma?
  - ¿El cuidado del paciente generó gastos adicionales? ¿En qué gastos tuvieron que incurrir? **Si es pertinente** ¿Quién asumió estos gastos?

### C. El rol de cuidador principal



14. ¿Por qué es usted la persona que más se ocupa de cuidar al paciente? **Si es pertinente, explorar:** ¿Cómo así sucedió o se decidió?
  - ¿Fue así desde el principio o ha ido cambiando con el tiempo? **Explorar**
15. ¿Actualmente, alguien le apoya en el cuidado del paciente? ¿Qué funciones cumplen los demás miembros del hogar? **Explorar**
16. ¿Alguna vez han buscado ayuda de otras personas fuera del hogar para poder cuidar del paciente? Si es pertinente ¿Actualmente, recibe ayuda de alguien fuera del hogar?
17. ¿Cuando recién sucedió el derrame/infarto, sabía qué tipo de ayuda debía brindarle al paciente? ¿Tenía entonces, el mismo conocimiento que tiene ahora? ¿Qué le ayudó a aprender? **Si es pertinente solicitar ver el material que utilizó o utiliza actualmente.**
18. ¿Cómo cree que se siente el paciente con el cuidado que usted le brinda?

#### D. Tareas y actividades asociadas al rol de cuidador principal

19. ¿Qué cuidados requiere ahora el paciente? **Explorar en detalle y aclarar**
  - ¿Cuáles son los más importantes?
  - ¿Qué tipo de cuidados se necesitan para prevenir otro ACV? **Si es pertinente** ¿Cómo sabe?
  - ¿Siente que tiene la información necesaria para poder cuidar dle paciente como lo necesita?
20. ¿Sus necesidades de cuidado han cambiado con el tiempo? **Si es pertinente** ¿Cómo? ¿Qué cuidados requería antes?
21. ¿Cómo describiría su día a día? **Explorar con preguntas como:**
  - ¿A qué hora se levanta usted? ¿Y el paciente?
  - ¿Qué es lo primero que hace cuándo recién se levanta? ¿Luego?
  - ¿Qué es lo primero que hace con el paciente? ¿Luego?
  - ¿A qué hora se acuesta?
  - ¿Qué es lo último que hace antes de acostarse?
  - ¿Qué es lo último que hace antes de acostarse para el paciente?
22. ¿Cómo sabe qué necesita el paciente en diferentes momentos del día? **Si es pertinente, preguntar:**
  - ¿Siempre ha sabido? ¿Cómo ha aprendido?
  - ¿El paciente le solicita determinadas cosas? ¿Siempre ha sido así?
23. ¿Requiere de ayuda para realizar algunas tareas de cuidado? ¿Qué tipo de ayuda?
  - ¿Qué tareas de cuidado considera más difíciles y cuáles más fáciles?
  - ¿Considera que podría realizarlos mejor? ¿De qué manera?
  - ¿Qué puede ayudarlo a realizar las tareas de cuidado?
24. ¿Qué hace cuando no está haciendo alguna tarea dedicada al cuidado del paciente? ¿Qué cosa hace para sí mismo/a? **Esperar, y si no responde, preguntar** ¿Qué cosas le gusta hacer? ¿Las hace? ¿Antes las hacía?
25. ¿Cómo cuidan de la casa? **Si es pertinente**
  - ¿Quién se hace cargo?
  - ¿Qué actividades domésticas realiza usted? ¿Alguien le ayuda?

#### E. Impacto sobre el cuidador principal

26. ¿Cómo ha cambiado su vida desde que el paciente tuvo un ACV? ¿Qué cambios han sido los más importantes para usted? **Esperar. Explorar.**
  - ¿En su vida laboral? **Si es pertinente** ¿Cree que podrá volver a trabajar en algún momento? ¿Quisiera?
  - ¿En la relación con sus amigos? **Explorar** ¿Los sigue viendo? ¿En qué ocasiones? ¿Su rol como cuidador ha generado nuevos contactos, nuevas amistades?
  - ¿Ha cambiado su vida familiar o la relación con sus familiares? ¿Cómo? **Si no se menciona** ¿Cómo es su relación actual con el paciente? ¿En qué se diferencia con su relación previa al derrame/infarto?
27. **Si no es claro:** ¿Cuáles de los cambios han sido negativos o malos para usted o su familia? ¿Cuáles de los cambios han sido positivos o buenos para usted o su familia?
28. ¿Cómo se siente ahora al ser cuidador/a? ¿Se siente diferente a cuándo recién empezó a cuidar del paciente?
29. ¿Diría que se siente satisfecho con su vida actual? **Si es pertinente** ¿Cómo cree que podría mejorar?
30. ¿Cómo cree que ha cambiado la vida de las demás personas que apoyan en el cuidado del paciente? **Esperar. Explorar con las siguientes preguntas:**
  - ¿Qué dimensiones de sus vidas fueron más afectadas?
  - ¿Cuándo cree que ocurrieron los cambios más significativos? **Esperar. Si no responde, preguntar** ¿Fueron después de que sucedió el derrame/infarto o son más recientes? **Si es pertinente** ¿A qué cree que se debe?
31. En cuánto a su salud, ¿desde que ocurrió el ACV ha empezado a sufrir algún tipo de malestar o enfermedad? ¿O ha cambiado de alguna forma su situación de salud? **Si es pertinente** ¿Cómo se trata esas molestias? **Explorar sobre malestares fisiológicos y psicológicos ASOCIADOS al cuidado.**

#### F. Relación del cuidador con el sistema de salud

32. Actualmente, ¿El paciente recibe rehabilitación o tratamiento en algún hospital, en un centro de salud o en su vivienda?
 

**Si NO se atiende, explorar en detalle barreras:**

  - ¿Por qué no lo hace? **Si no responde, explorar si se relaciona a** la calidad del servicio (trato en el servicio, distancia, tiempo, costo)
  - ¿Alguna vez ha recibido tratamiento o rehabilitación? **Si es pertinente** ¿Por qué ya no?

**Si recibe atención, explorar:**

  - ¿Qué rehabilitación o tratamientos recibe? ¿Recibe tratamiento psicológico o de salud mental? **Explorar para los más importantes, lo siguiente:**
  - ¿Por qué recibe este tipo de rehabilitación o tratamientos?
  - ¿Cómo se decidió por uno u otro método? ¿ Quiénes se involucraron en la decisión? **Si no hace referencia a algún personal del sistema de salud,**



**preguntar específicamente por ello.**

- ¿Dónde lo/s recibe?
  - ¿Cada cuánto tiempo?
32. ¿Tienen alguna dificultad para cumplirlos? **Explorar barreras. Si va a tratamiento o rehabilitación:** ¿El paciente va al tratamiento solo o acompañado? **Si alguien acompaña:** ¿Participa de alguna forma de la atención o tratamiento? ¿Cómo?
33. **Si va a tratamiento o rehabilitación:** ¿Quién conversa con el personal de salud que atiende al paciente?
- ¿De qué se conversa? ¿Qué información les dan? ¿Quién se las da?
  - ¿Usted pregunta algunas cosas? ¿Qué pregunta?
  - ¿El paciente participa de las conversaciones? ¿Cómo?
34. **Sobre los servicios al paciente:** En general ¿Qué le parece el tratamiento o rehabilitación que le dan al paciente? **Esperar y explorar lo que sea pertinente:**
- ¿Le parece que el personal sabe cuidar del paciente? ¿Le parece que tienen los implementos necesarios para hacerlo?
  - ¿Cómo es el trato que le da el personal de salud?
  - ¿Qué dificultades o problemas han tenido?
  - ¿Cómo podría mejorarse este tratamiento o rehabilitación?
35. **Sobre los servicios para el cuidador o cuidadores:** En el hospital o centro de salud donde se atiende o donde se atendía el paciente:
- ¿Le han dado alguna vez información (en una conversación, una charla o folleto), sobre cómo podría cuidar mejor al paciente?
  - ¿Le han dado alguna vez información (en una conversación, una charla o folleto), sobre cómo cuidarse a usted mismo? **Si no entiende la pregunta, preguntar por su salud física y su salud mental.**
  - ¿Le preguntan a usted o a sus familiares cómo se sienten? **Explorar**
  - ¿Les han dado alguna vez apoyo o tratamiento emocional o psicológico? (**Puede referirse a un profesional o a una persona cercana**)
  - ¿Qué opina de que se ofrezca información o apoyo psicológico a las personas que deben cuidar a pacientes con ACV? **Explorar opiniones** ¿Cuál sería la mejor forma de hacerlo? (Ej. ¿Dónde? ¿Con quién? ¿En qué etapa del proceso?)
36. **Sobre la búsqueda de otros servicios para el cuidador o cuidadores (Explorar siempre luego de cada pregunta):**
- ¿Ha buscado alguna vez tratamiento emocional o psicológico por este tema?
  - ¿Ha buscado alguna vez apoyo emocional en otros lugares como la iglesia, un curandero u otras personas que podían ayudarla/o?
  - ¿Otras personas de su familia, que cuidan del paciente, lo han buscado?
  - **Si no ha buscado nada:** ¿Siente que ha necesitado alguna vez de ese apoyo o tratamiento? ¿Por qué no lo buscó?
37. **Sobre la búsqueda de información de los cuidadores:**
- ¿Ha buscado usted información sobre cómo cuidar a una persona con ACV? ¿Qué ha buscado? ¿Dónde ha buscado esa información?
  - ¿Tiene usted la información que necesita? ¿Qué le hace falta?
  - ¿Cuál sería la mejor forma de entregarle esa información? (Ej. ¿Dónde? ¿Con quién? ¿Usando qué tipo de materiales o estrategias?)

**Cierre**

- Aclare todas las dudas y preguntas del entrevistado.
- Agradézcale por su tiempo e información.

**Appendix 2. Codebook****0 Patient's condition:**

- 0.1 Pre-stroke
- 0.2 Post-stroke [right after stroke]
- 0.3 Current

**A. Caregivers' explanations of the stroke (Stroke Narrative):**

- A.1 Moment of stroke
- A.2 Individual explanation of stroke

**B. Medical care**

- B.1 Medical care right after stroke
- B.2 Family participation of moment of stroke
- B.3 Evaluation of medical care and interpersonal treatment
- B.4 Expectation of health staff towards family

**C. Role of the caregiver**

- C.1 Reasons to be the caregiver
- C.2 Caretaking tasks

- C.2.1 Current tasks
  - C.2.2 Initial tasks
  - C.3 Evaluation of tasks
    - C.3.1 Difficult tasks
    - C.3.2 Easy tasks
    - C.3.3 Factors that help doing caretaking tasks
    - C.3.4 Factors that make caretaking tasks more difficult
  - C.4 Caretaking support
    - C.4.1 Family support directed towards the patient
    - C.4.2 Professional support
    - C.4.3 Support for the caretaker himself/herself
  - C.5 Confidence with caretaking role
  - C.6 Satisfaction with being a caretaker
  - C.7 Daily routine of caretaker
  - C.8 Leisure activities of caretaker
- D. Impact of caretaking**
- D.1 Changes in the place of living (house/apartment)
  - D.2 Impact
    - D.2.1 Impact on family
    - D.2.2 Impact on work situation
    - D.2.3 Impact on income
    - D.2.4 Social impact
  - D.3 Impact on physical health
  - D.4 Emotional impact and search for help
    - D.4.1 Emotional impact
    - D.4.2 Search for professional help for mental health
  - D.5 Changes in and/or for others
  - D.6 Satisfaction with life
  - D.7 Projection of the future
  - D.8 Relationship between caretaker and patient
    - D.8.1 Pre-stroke
    - D.8.2 Current
- E. Experience of caretaker with health care system**
- E.1 Barriers of access
  - E.2 Evaluation of system
    - E.2.1 Evaluation of interpersonal treatment
    - E.2.2 Evaluation of service
  - E.3 Suggestions for improvement
  - E.4 Need for psychological help
  - E.5 Emotional support of the health care system
- F. Caregivers' needs**
- F.1 Explicit needs for caregiving
  - F.2 Explicit needs of health care system
  - F.3 Implicit needs
- G. Information received or sought**
- G.1 Medical information
    - G.1.1 Right after stroke
      - G.1.1.1 Information about causes
      - G.1.1.2 Information about stroke
      - G.1.1.3 Information about medical treatment and caretaking
      - G.1.1.4 Information about progression and prognosis
    - G.1.2 Current
  - G.2 Information from others (non-medical)
  - G.3 Evaluation of information received or sought

### Appendix 3. Summary of caregivers' emotional impacts, stress factors, coping mechanisms and needs

Code	Caregiver-patient relation	Time since stroke event	Caregiver age	Family support	Type of disability	Level of dependency	Emotional impact	Stress factors	Coping mechanisms	Professional needs	Additional needs	Social impact
A01	Daughter	2 events: 6 months and 1 year	38	Her mother and 2 daughters support the caregiver in specific tasks. Caregiver's brother helps her to carry the patient to therapy. At first, the patient's brother moved in with her and helps her with the caregiving.	Mobility and speech	He moves with help. He just sits on a wheelchair. He cannot talk but manages to communicate with some clear vocalizations	Caregiver expresses a strong emotional impact, particularly at first when patient had no memory. Actually, it's hard for her to see her father in such condition but feels she need to control her emotions and take care of him, her mother and her children. She says she feels stressed but at the same time she feels good for accomplishing her caregiver role so she "cannot regret later"	<ul style="list-style-type: none"> <li>*Unable to work due to care</li> <li>*Financial resources: cannot devote himself exclusively to the care of her father because she has to support herself and her daughters</li> <li>*Relight the patient: The caregiver finds it difficult to deal with the patient when he has to bathe or give injections.</li> <li>*Difficult tasks: it is very difficult to lower the patient down the stairs.</li> <li>*Patient's mood: when the patient is discouraged care is difficult because they he does not want to eat.</li> <li>*Overload: The caregiver feels that too many people depend on her.</li> <li>*Lack of time: the caregiver finds it difficult to do other unforeseen tasks.</li> <li>*Impact Health: caregiver says she suffer from back pain since she has to lower the patient down the stairs.</li> </ul>	<ul style="list-style-type: none"> <li>*Seek emotional support from her friends (although more at the beginning)</li> <li>*Account going to church or the cemetery to pray alone</li> <li>*Accounts taking Diazepam or Alprazolam for her headaches (but before taking care of her dad)</li> <li>*Listening to advices from other caregivers in the hospital helped her.</li> </ul>	<ul style="list-style-type: none"> <li>*In the hospital nobody offered or advised her to seek professional emotional support, although she claims to need it. Nor will they talked about their self-care.</li> <li>* Does not have professional support for patient care.</li> </ul>	<ul style="list-style-type: none"> <li>*Support care: for her is to have time to work, go out to do things and have time for herself.</li> <li>*Psychological support: because the difficulty of handling the situation, particularly at the beginning.</li> <li>*Information: nobody has explained her how to care for the patient, except for one friend who gave him some advice.</li> </ul>	She has stopped working and going out to parties or dancing. Although still sees her friends, she doesn't as often as before
A02	Daughter	9 months	43	Has her brother and sister support for taking care of the mother. Other sister helps her when she comes to visit her from Huaraz. All of them gave economical support.	Mobility and speech	Has a high level of dependency. She cannot move by herself and requires to be carried on a wheelchair. Though she cannot talk, produce some sounds and her caregiver manages to understand her needs.	She feels overwhelmed by the constant care she has to provide to her mother, and by the reduced time she has for herself and her children. She tells she suffered a strong stress that did not allow her to sleep; she is not in the mood for anything and was hard for her to get up. She is not satisfied because she does not work and	<ul style="list-style-type: none"> <li>*Pending issues: pending legal affairs of the mother that are difficult to solve.</li> <li>*Patient difficult attitude: notes when uncomfortable or boring and daughter disowns if left alone.</li> <li>*Patient's condition: do not understand what the patient needs and seeing her suffer</li> <li>*Difficult tasks: how to bathe the patient in</li> </ul>	<ul style="list-style-type: none"> <li>*Doing things willingly, not feel that is required</li> <li>*Feels he is fulfilling her role as daughter giving back the care she had with her.</li> <li>*Everything has its reward. Doing things right also teaches children how.</li> <li>*She recognizes</li> </ul>	<ul style="list-style-type: none"> <li>None. She prefers to devote herself to the care of her mother</li> </ul>	<ul style="list-style-type: none"> <li>*Information about:                             <ul style="list-style-type: none"> <li>- How to conduct therapeutic exercises through lectures of the specialist, or that those match the indications found on the Internet.</li> <li>- How to handle certain care tasks better, for example loading best to not get hurt.</li> </ul> </li> <li>*Psychological support offered for caregivers who are</li> </ul>	To assume the care has seriously impacted her relationship whit her husband (who lives in Venezuela) and takes time she wanted to her children and go out. She says doesn't have time for friends. When she has some free time she rests, sleep. She reports an improvement of relationship among the brothers. Now they are closer.

(continued on next page)

(continued)

Code	Caregiver-patient relation	Time since stroke event	Caregiver age	Family support	Type of disability	Level of dependency	Emotional impact	Stress factors	Coping mechanisms	Professional needs	Additional needs	Social impact
A03	Husband	3 years	78	Economical support from his son. Lives with his nephew (at next door) wht whom she spends time eventually.	Mobility and Speech	Speech and cognitive capacities intact. Needs help to move and bathing.	Onset was hard for not knowing how to take care of the patient. Know the caregiver is stunned by the fact he can leave the house. He comments that he would like his son visit his mother.	bed when she could not move. *Lack of time/space: not having a space to relax/time to be alone and unwind. *Impact of care in the relationship with her husband and children.	that she prefers to devote to the care of her mother and that she knows how to do it, rather than accept help from her in-laws for example. *Having her care routine facilitates care management and other tasks.	*Receive professional help for rehabilitation during 1 month, after that she has not received any professional help.	waiting in therapies. *Nursery to babysit while the patient is accompanied in therapy.	The only social life is with his nephew and sometimes with his brother. He is always at home caring the wife.
A04	Daughter	5 months	48	Has a lot of family support. She and her sister take turns to caregiver the mother, and help each other for doing domestic labors (they are neighbors). Caregiver's brother and son help her to mobilize the patient.	Mobility and speech	She cannot get up by herself. She required to be move and fed, though she can move her hands a little. Initially compromised, her ability to talk is improving. She vocalizes better now and says some words slowly.	Caregiver expresses that at first it was emotionally difficult to manage the situation, for instance, seeing the patient being fed through a probe. Though she says she feels tired and sometimes wants to cry, she feels well in general because she noted improvements in the patient. Otherwise she will be broken	*Health: the caregiver claims to have a delicate health (suffers from neuralgia) and she relates it to the emotional stress of having not a nice childhood. He also suffers from headaches and back pain from carrying so much weight due caregiving tasks. *Family situation: Her brother also depends on her to live. She cannot live independently due to a health problem. *Financial resources: need money at first. She had to leave a business she had. *Lack of security on how to care for her mother. *Patient's mood: the patient was depressed	*See the positive side: tries to take care with fun, and avoids feel it is an obligation. *Brighten the patient: makes laugh to the patient and dresses him nice so both feel better. *Self-care: back to her prior activities (like going to work) to avoid getting stressed. *Family support: claims to have a united family that has always helped her, particularly her sister and her husband.	*Has not received professional emotional support *Though she is in the ability to hire a caregiver, she would if she trusts the quality of service.	*Psychological attention: requires it but do not know where to look for. *Information about how to access professional emotional support *Information about how to do the care tasks. *Socialize/share with people in the same situation in workshops or seminars.	The caregiver doesn't report any significant social impact. Only during the first 3 months of care she had to stop working.



A05	Wife	Several events: 13 years (first event) - 1 year	77	Daughter supports economically. Patient's nephew lives half block away and help the caregiver when she must go out. Her daughter's ex husband help her lifting the patient to move and dress him. They receive occasional support from their son and daughter in law, whom contribute with food at home.	Mobility	Walks by himself with a lot of difficulty. Has an immobilized arm. He can communicate but is highly dependent. He's at risk of suffering another event.	Caregiver is very depressed for her facing situation. The patient is very demanding and jealous, which difficult her having space to go shopping. She feels alone and disowns her children for being ungrateful and not helps her. One of her daughters has cancer. Besides, she fears constantly that her husband could have a sudden heart attack, so she stays up just to watch him. He suffers from insomnia 7 year ago. Besides, has mentioned such degree of emotional discomfort that has had suicidal ideations - Thinking that everything will be over if she jumps from a bridge.	by living in a status of dependence. *Financial resources: depends solely on the income of his daughter. She has no money to bring her husband to therapy and to care for her own health. *Age and health of the caregiver: by his advanced age has a hard time mobilizing the husband in a wheelchair and lack of money cannot take care of their own health (severe headaches, early osteoporosis and possible discomfort). *Family problems: like being a burden to his daughter keeps. Her other daughter has cancer and his sons do not support it, "they are <i>malagradecidos</i> ". *Housing: housing conditions are difficult. Sharing with the patient, her daughter and two granddaughters. *Relationship to patient: the patient has a very difficult character, will demand a lot and not let her leave the house by jealousy. *Lack of social life and own space: by dependence and jealousy of the patient and the few economic resources, the caregiver has no room to do things for herself (as sewing, knitting).	The caregiver does not reported to have resources to handle the situation	The caregiver would like to hire support for patient care. She never received professional emotional support but expressed the need to go to a psychologist. She does not look for him because it is difficult to leave home and because would have to wait three months for an appointment.	*Financial support: depends exclusively on her daughter's salary. Doesn't reach for her health needs neither those of her husband *Support care: requires support en care to do more things for herself and housework (like shopping) without problems. *Psychological attention: shows and relates to have a strong emotional discomfort but doesn't seek professional care. *Information: doesn't know how to manage the health system so that they can serve the patient better (doesn't know if enroll him at PADOMI or not for fear of losing certain benefits). Also she states need to know how to measure the pressure to do so without having to go to hospital.	The caregiver almost no longer go out of the house because the dependency and jealousy of the patient.
A06	Son	7 months	33	The caregiver has a wide support net for his mothers care. He has several siblings with whom he can ask for help in caregiving, and also contribute economically.	Mobility and speech	Patient cannot move by herself. She goes on a wheelchair. She needs help to move around the house, but can feed herself. She cannot communicate well but the caregivers manage to understand her.	Caregiver says he suffer for his mother's condition. He associates losing her mother, as he knows her as the major emotional impact and regret for how he treated before. Despite this, he keeps optimist and say he is happy for being able to care of	*Lack of social/autonomy life stresses not being able to do your thing, take time for yourself *Sadness/grief to see his mother in that state and see that it is not like before. *Regret for the things he did/did when his mom was fine	*Faith in God and philosophy from self-help books/hope that his mother recovers *Has the support of his brothers and sisters *Resume his social and working life: the	Has not had professional support for patient care and sees no need to have professional emotional support for himself	*Information about: - How to care for the patient (therapy techniques) - How to feed the patient to prevent strokes *Emotional support for the patient	Care impacted his social life more meaningful way at the start. He couldn't go out or felt bad if he does. He ended his relationship because he has to devote exclusively to care his mother. Currently he is reprising his social and professional life

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Code	Caregiver-patient relation	Time since stroke event	Caregiver age	Family support	Type of disability	Level of dependency	Emotional impact	Stress factors	Coping mechanisms	Professional needs	Additional needs	Social impact
							her mother.		caregiver feels calmer for resuming her business now that his mother has improved and is more independent. *Stay positive, and feel happy to take care of her mother			because the mother is more independent.
A07	Daughter	2 years	46	She has the economically support of 3 brothers. One of them does not visit her mother. Her other brother lives with her and help her with the caregiving tasks. Her sister in law helps her occasionally	Mobility	Communicative capacity intact. She can feed herself, but need help to move and bathe. She does not use the bathroom, she uses diapers.	Says she felt sad at first, mainly because a severe infection in the patients buttock (for being long in the same position). Claims to be worried and cannot leave the patient in charge of others	*Lack of support: reports not receiving support from his siblings in the care or expense. *Impact on their relationship: having to provide care has sacrificed spending time with your partner.	Does not report any	Account receiving emotional support from the doctor at a given time (not systematically).	*Information on how to perform specific care tasks.	Relate no longer go out of the house nor walk even with her husband, to devote exclusively to her mother - the patient.
J01	Husband	1 year and a half	60	He declares not having any support for the caregiving activities. He just counts with the economically support of his son.	Mobility, speech and cognitive	Has a high level of dependency. At first she used diapers. She uses a walker now and requires help from 2 persons to move. She cannot vocalize well but her caregiver manages to understand her. Her cognitive capacity is not completely well. He imagines things and confounds past with present.	Claims that the most difficult has been dealing with seeing a loved and admired one to lose his physical and speech faculties. Claims to be desperate sometimes	*Mood patient: the patient's lack of desire to improve. *Condition husband initially told the caretaker that her husband would not improve. Currently, it costs to see her husband having to rely on her for everything, when before he was the one who made the decisions.	*Self-motivation: Claims she encouraged herself and looked for strength to do things. *Religion: Claims her faith has helped her cope *Personal emotional support: account seeking emotional support from friends or family.	Has not had support in patient care and neither for her.	*Emotional Support *Support in patient care	None explicit
J02	Husband	1 year	53	The man is the primary caregiver of the patient (His wife), but his son initially quit his job to himself care for his mother. He then went back to his job when his mother recovered a little, and the husband takes care. His kids support him occasionally, particularly the one who lives with them.	Mobility and speech	Patient cannot move by herself, requires help to walk and use the bathroom. He communicates through some vocalizations that the caregiver tries to understand.	Does not report having an emotional affection right now. Tells that at first, after stroke it was hard to make rearrange things in home, but he knows his wife is better and he and his family feels better too. He now deals with his job and patient's care with calm and satisfaction. He even has time to chat with his friends.	*Economic resource: they had to spend a bank loan 10,000 - that would be invested in a business - in recovering his wife. *Impact on household organization: that no one will cook or know how to handle home *Do not understand what the wife wants because he cannot communicate well	*Emotional support from close people *Self-motivation and get strong for his child. *Resignation to the situation and give encouragement, be in good spirits to promote patient's recovery *Religion and routine: though not pointing as a resource or	None, although she considered useful to receive psychological support to receive some guidance.	*Information on how to load and bathe the patient swiftly through lectures or training with an expert - who is concerned about stroke *Having someone who knows and takes care of the patient	It affected household organization. The caregiver has to assume many roles. *Abandonment of work activities or her children's studies: patient's children and caregiver left their work and studies to care for the patient or to avoid incurring expenses *They stopped to go out as recreation to avoid expenses and to play sport for lack of time.

J03	Wife	1 year and 10 months	52	Caregiver's brother supports her occasionally taking care of the patient and feeding her daily so she can go out. She lives with her brother and nephew who visited them almost every evening and are pending for her care.	Mobility and speech	He cannot move without help. It is possible to understand him but with difficulty. Though after his first stroke he could move with some difficulty, after his second stroke he cannot get up at all and the caregiver takes care of him. He can be alone, but just for a few hours.	Currently, the caregiver does not report any discomfort. She managed to organize her day maintaining a half time job. Claims to be tense but keeps a good mood despite everything	*Fear of not knowing how to care for the patient *Unit patient: feels "locked" unable to leave the patient alone for long. *Attitude patient: has a difficult character, is demanding and does not make an effort with the therapy that was initially offered, or let her help him.	*Keeping her: she decided to continue working despite the difficulties. She adjusted his schedule to spend time with the patient, to avoid "going crazy" as she says, and to generate an income. *Having her own space: she entertains in the evenings watching soap operas and exercising, and occasionally goes out while her brother takes care of her husband. *Pleasing the patient: Gives him anything he request, keeps him busy and entertained (internet). *Assumes care as a responsibility to her husband - the patient - and before God. *Religion: goes to church and pray God to help her stay in good spirits.	*Came to a psychologist who gave her advice on how to deal with the patient, but has not continued. *Initially they hired a therapist who went to the house, but cannot afford any longer *Hospital offered her: - Psychological care for the patient but not for her - Talks for caregivers, which she did not attend.	*Psychological support for caregivers. *Having an EsSalud center that offers therapy closest to San Juan de Miraflores. *Longer length of therapy (1 h instead of 30 min) *Taking care of herself devotes more time.	*Doesn't report any negative impact on family relationships: - The family joined after stroke to support the patient - With the wife he relates to be fine - Although it has affected their privacy. *The dependence of the patient prevents to go out as before. She goes out occasionally with friends on special dates or when someone can care for her husband. *The patient bad mood has alienated family.
J04	Wife	3 years and 2 months	57	Her 2 daughters help them occasionally	Mobility and	Has a high level of dependency. Requires	Though the caregiver says she feels suffering	*Lack of support for moving the patient	*Satisfaction of caring for her	Claims never having any professional	*Psychological attention: manifests to	The caregiver has no longer going out with

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Code	Caregiver-patient relation	Time since stroke event	Caregiver age	Family support	Type of disability	Level of dependency	Emotional impact	Stress factors	Coping mechanisms	Professional needs	Additional needs	Social impact
				either taking care of the patient or doing some domestic tasks (like iron). Other relatives visit him or send victuals as a kind of support.	speech	help to move, but speech is her greatest problem. It is difficult to understand what she needs.	"for her husband situation and for losing a daughter at the hospital, she also understand the situation as an opportunity for retribution the care he had with her and feels well for helping him"	*Unable to take the patient to his homeland, where he would have the opportunity to access traditional therapies and have the support of his family (the caregiver).	husband and that he is happy about that *Feeling that does things with love and without regret *Pray as a way to seek gather strength *Resignation for the situation she is living.	support	want to receive psychological support to become stronger. *Support with care: states be short of time to take her husband to therapy by having to care for their grandchildren.	her friends and family as she did before.
J05	Daughter	1 year and 2 months	54	The mother lived in Ayacucho, but after stroke she was moved out to Lima to stay with her daughter and seek therapy in "Hospital Cayetano". She tells that her brothers do not help her, but occasionally send her some money. Her sister, who uses to help her with certain caregiving tasks, is now hospitalized.	Mobility	Patient requires help to move, but has no difficulties to talk.	The caregiver claims to feel pain and sadness for seeing her mother - a very active person before - in a situation of dependency and bad mood. She also feels overwhelmed for the constant care she must give to and that does not allow her to pass time with her husband and generates a lot of tension between them. Finally she feels sorrow for the difficult relationship with her mother. They do not trust each other because she does not raise her.	*Lack of care and emotional support from his brothers. *Difficult relationship with the patient *Attitude of neglect and discouragement of the patient. *Difficult tasks: lift mom to take her to her therapy or out of home. She cannot do y herself and requires the help of the taxi drivers. *The caregiver has diabetes and suffers from high cholesterol. It is hard to care for herself and meet medical appointments having to be with her mother.	*Seek emotional support in a female friend *Religion: prays to gather mood/strength *Considers the possibility of taking care of a person as a job opportunity in the future.	Has not had professional support of any kind.	*Information about: - How to care better a patient. - Information on what to do if another stroke happens. *Support to do therapy with the patient, for caregiver's lack of time and doesn't to know how to do certain exercises.	Take care of her mom has created a lot of tension in their relationship with the husband who complaint about the abandonment by the caregiver's brothers. Upon his dedication to the care of the mother she is no longer going out with her friends. She relates that when she was trying to do couldn't enjoy it for thinking about whether the mother would be good or not.



## Appendix 4. Original quotes in Spanish

### Quote #1

“A veces, como le digo, cuando la veo así me pongo muy triste. A veces ella se pone a llorar y me pongo triste porque no quisiera que esté así. Me gustaría que se sienta contenta, a veces hay ratos que no está contenta y me pongo a llorar como hija, las dos nos ponemos a llorar, ella por allá y yo por allá, ella, con tal que no me vea, así.” (J05).

### Quote #2

“Cuando la llevamos a casa era un trauma, irreconocible porque después de verla caminando y que hacía sus cosas, llevarla a casa y ver de qué babeaba, ¡hay Dios bendito!, no, no podía ni siquiera... ella no sabía ni que levantar nada ese rato para cambiarla de pañal, bien bravo, cargarla, para todo la hemos cargado, para todo, desesperante.” (A04).

### Quote #3

“Porque es tu madre, das todo. En un momento a veces uno dice, ver a tu madre así postrada a veces llora, estás así, te quieres dar contra el piso, ¿Por qué?, ¿por qué mi mamá está así? Pero tú lo vas a hacer, uno se siente feliz cuidar a tu mamá. Si no lo haces tú, entonces, ¿quién?” (A06).

### Quote #4

“Ahora me dedico más a mi mamá. Ya no soy la mamá que más antes salía con los niños, los sacaba a pasear, los llevaba, más estoy dedicada y abocada a ella. Con ella sí salimos, para salir yo con ella y con mis hijos se me hace difícil. Tengo que salir con mi hermana o con otra compañía más para así poder salir también con mis hijos.” (A02).

### Quote #5

“En eso [lo financiero] es lo que más me ha afectado a mí, porque ya tengo que estar esperándolo a mi hijo que me dé; mientras que antes yo mismo solucionaba todos los problemas para la casa.” (A03).

### Quote #6

“Yo dije “Dios mío, ¿ahora que va a ser de mi vida? No trabajaré”. Y después me puse a pensar “¿Qué voy a hacer si no trabajo?” (...) Así que, me las arreglé pues. Dije “Ya, hasta tal hora trabajo.” Empecé a buscar trabajo así por medio día nomás”. (J03).

### Quote #7

“O sea, siempre nosotros hemos sido unidos, [...] somos uno solo; esta situación como que nos unió más, [...] en la vida no es todo, no es todo dinero, que en la vida no es todo tener algo. La vida es llevarse en armonía y eso nos unió más, o sea, conversamos así, mi mamá mira cómo está...” (A06).

### Quote #8

“Y uno hago porque mis actividades también me ayudan a que yo pueda estar distraída en otras cosas, porque pasa si me estreso con la enfermedad de mi mamá, es peor, me enfermo yo. Entonces, lo que yo hago es realizar mis actividades normales como las he venido haciendo.” (A04).

### Quote #9

“[...] me siento y me pongo a orar, hojoso por favor le digo, “la vida de mi esposo está en tus manos. Yo más que en ti no confío más en nada. Tú me vas a dar el valor suficiente” y me pongo a orar media hora, diez minutos, cinco minutos lo que el tiempo me va a dar, entonces, [...] yo salgo como si tuviera más cerca de seguir enfrentando mis problemas que tengo, esa es mi manera, no es, como digo, no es que me ponga a orar y las cosas se me van a resolver, para resolver, tengo que resolverlas yo”. (J01).

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