



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

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