Feasibility and acceptability of an innovative hospital-based educational training for caregivers of patients with severe stroke at the Instituto Nacional de Ciencias Neurológicas in Perú in 2023

Rosa Lizbeth Ecos Quispe

A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Public Health

University of Washington

2024

Committee:

Joseph Zunt

Nauzley Abedini

Sarah Gimbel

Program Authorized to Offer Degree:

Global Health

University of Washington

Abstract

Feasibility and acceptability of an innovative hospital-based educational training for caregivers of patients with severe stroke at the Instituto Nacional de Ciencias Neurológicas in Perú in 2023

Rosa Lizbeth Ecos Quispe

Chair of the Supervisory Committee:
Joseph Zunt
Department of Global Health

Background: Patients with severe stroke have high mortality and morbidity, and often lower quality of life. Stroke affects not only patients, but also family members and caregivers who assume new responsibilities and burdens such as emotional and psychological distress when caring for patients with new neurologic disabilities. Gaps in health care access in Lima, Perú include financial barriers for those of low socioeconomic status, the lack of a national palliative care training program, and insufficient caregiver assistance, which affects the continuity of care at a health facility as well as for home-based caregivers. All these factors negatively affect quality of life, mortality, and morbidity of patients with stroke. Caregiving training status is one of the main root causes for poor outcomes in patients with stroke. Therefore, we designed an innovative hospital-based training intervention to caregivers of patients with severe stroke.

Methods: This implementation pilot study hybrid 3 type occurred from June to November 2023 and consisted of randomizing caregivers to two intervention arms of the hospital-based training intervention (online vs in-person). We evaluated implementation outcomes in accordance with Proctor et al. to evaluate feasibility, acceptability, and fidelity, and also employed the RE-AIM framework to evaluate reach, adoption and implementation of a hospital-based caregiving training for patients with severe stroke at the Instituto Nacional de Ciencias Neurológicas in Peru. Using a convergent mixed-methods design, we simultaneously collected quantitative and qualitative data to understand and explain findings on quantitative phase. Data were analyzed separately and then merged and triangulated for results, discussion, and conclusions. The educational training included nasogastric (NG) and foley tube management, bathing and cleaning, and mobilization. The quantitative phase consisted of a randomized 1:1 allocation of participants assigned to the training intervention: in-person versus website arms. For the qualitative phase, we administered 19 questionnaires through semi-structured interviews to caregivers and nursing stroke staff who participated in training and who cared for stroke patients to gain in-depth understanding of the intervention at one-month follow-up.

Results: We recruited 38 participants and randomly assigned 19 to each intervention arm: in-person and virtual. The percentage of eligible participants enrolled in the study was 86%. All enrolled participants were retained in their assigned intervention arm. Seventy-nine percent of participants completed training, including 100% in the in-person arm compared to 57.9% of the virtual arm. Two validated questionnaires to measure caregiver's burden were applied in more than 80% of the cases. The total acceptability reported by participants was 82.9%, (in-person training 94.4% versus virtual 70.6%). Fidelity of the intervention was 95% for in-person training and for virtual training the Median website log-in counts was 2, and median time spent by each

participant at one-month follow-up was 284 minutes. We identified the following main themes from our qualitative interviews: (1) willingness to participate actively in the educational training from caregivers and nursing stroke staff (SNS); (2) barriers to training, including caregiver burden and family issues; (3) continuing care at home; (4) applying intervention components and performing follow-up; and (5) suggestions made by caregivers and SNS to add additional intervention components such as psychological support, rehabilitation, nutrition, and administrative counseling after patients' discharge.

Conclusions: The hospital-based educational training for caregivers was feasible and acceptable. Main facilitators identified were a positive influence and support for caregivers and nursing staff caring for patients with stroke. Family issues and caregiver burden were the main barriers. Further caregiver training should include additional components such as psychological support, rehabilitation and nutrition training, and administrative counseling after patient's discharge.

List of Figures

List of Tables

TABLE OF CONTENTS

INTRODUCTION

Patients with severe stroke have high mortality and morbidity, and often poor quality of life. Stroke affects not only patients, but also family members and caregivers who assume new responsibilities and burdens such as emotional and psychological distress when caring for patients with new neurologic disabilities. (1–3) To optimize quality of life for stroke patients, their caregivers often require anticipatory guidance around management of new neurologic disabilities, as well as emotional and psychological support. The field of palliative care aims to improve quality of life for patients with serious illness – including stroke – and their families. Guidelines for holistic palliative care delivery of patients with stroke include provisions to involve and support their family caregivers. (4) However, there are no such guidelines in Peru.

The incidence of stroke in Andean Latin America is between 121 to 150 per 100 000 people (5) Compared to other parts of the world, significant disability (moderate to severe disability defined as modified Rankin scale 3 to 6) following stroke is higher in South America (37% vs 51.5%, respectively). (6) A large Latin American Stroke registry, from nineteen centers from Central and South America including Perú, notes that more than a third (34.5%) of patients with stroke have a poor functional outcome (defined as modified Rankin scale 3-6) at discharge and a hospital mortality of 6.7%. (7) In low- and middle-income countries (LMICs), such as Peru, disability adjusted life years lost related to stroke have increased by 48% over the last thirty years, compared to a decrease of 25% in high income countries (HIC). (8,9) In Peru, a recent study reported an age-standardized incidence of stroke of 98.8 (95% CI: 63.8 - 154.0) per 100,000 person-years with a median time of follow-up of 7 years from a single cohort hospital in Lima. (10) Mortality rates

due to stroke remain a major concern, although mortality varies by health facility. Alvarado-Dulanto reported stroke-related mortality was 20.8% at one year follow-up in a single cohort from a public hospital, highest in severely affected patients. (11) However, at the Instituto Nacional de Ciencias Neurológicas, in Lima, the overall stroke mortality was 5.2% at discharge, and 60% of patients had moderate to severe disability. (12)

Gaps in health care access in Lima, Perú include (14–16) financial barriers for those of low socioeconomic status, (17) lack of a national palliative care training program (18,19) and insufficient caregiver assistance; (17,20,21) which affects the continuity of care at health facilities as well as for home-based caregivers. Low socioeconomic status is associated with poor outcomes in patients with stroke. The burden of caregiving falls especially hard on low-income families in highly-populated districts in Lima, the capital of Perú. (15,21) Training for caregivers of stroke patients is inconsistent; for instance, a family member without prior stroke care knowledge may be pressed into service (1–3); even for hospital-based caregivers, insufficient training is available. (19) Hospital-based staff also experience turnover, lack of financial support and limitations for accessing psychological support. (17,19,21) Peru's disability national survey found most caregivers were women, a family member, or others who were informal or not properly trained. Commonly, caregivers lost their jobs or resigned their own activities to care for loved ones. Despite having a public health insurance system in Peru, access to rehabilitation and other health services were scarce and distributed inequitably. (17) A qualitative study of three high-volume primary healthcare facilities in Lima found Peruvian caregivers of stroke patients most often assisted with bathing and hygiene, feeding, and transporting patients to medical and rehabilitation appointments. (21) Barriers described also included a misunderstanding of palliative care, with most believing it

focused on assistance at the "end-of-life", and not as the appropriate management of the unattended needs, regardless of the patient's prognosis. (22)

Rehabilitation delivered concurrently with palliative care is an innovative approach to address patients' needs. Palliative care guidelines recommend educational, emotional, and psychological support to improve high burden of caregiving. (4) Reports from INCN patients regarding the status of palliative care and caregiving after stroke have found no structured rehabilitation programs available for patients disabled by stroke; moreover, due to the COVID pandemic, continuity of care and caregiving assistance has been scarce. (20) Access to health resources was scarce, (14,17,20) and researchers found 9 of 10 patients with stroke and resultant disability in Peru did not have access to rehabilitation at a health facility although they may have received some form of rehabilitation from an untrained family member. (18) Caregiver training is not part of a structured program, but is performed on an ad hoc basis by nursing staff with scarce resources. (18,19) Additionally, many patients with severe stroke and their caregivers face physical, emotional, and social stressors that can erode quality of life, and many have limited understanding of prognosis, which can be best served by introducing palliative care concurrently with rehabilitation services. Nationally, there are no structured palliative care training programs and no formalized guidelines. (18)

Unpublished data from recent follow up phone calls with caregivers of patients with stroke who were discharged from INCN with nasogastric (NG) tubes revealed deficits in tacit knowledge and skills around management of NG tubes as well as low prognostic awareness, resulting in psychological and emotional distress for caregivers. Additionally, few patients were able to access

rehabilitative services or support around NG tube management after discharge. (18) More recently, at INCN we conducted semi-structured interviews with caregivers of patients with severe stroke and hospital stroke ward staff to determine attitudes, skills, and perspectives of caregivers of severe stroke survivors. We found concerning data from both caregivers and staff (Figure 1). (19) First, economic burdens were high for families. Family members often served as caregivers because of economic limitations, and their situations were negatively affected by reduced income and loss of jobs. All expenses that arose after discharge were paid out of pocket by a family member because access to public health insurance had administrative barriers. Second, caregiver training was often inadequate. Most family members noted they received only one training session on the day prior to or on the day of discharge. Unfortunately, the family member who received training was often not the person who would provide care to the patient. Third, caregivers did not recall receiving information about prognosis or expectations for recovery. Fourth, patient care needs remained quite high after discharge. At the time of the interview (about one-month after discharge), patients remained functionally similar, and with only slight cognitive improvement; half required at least one change of a nasogastric (NG) feeding tube or had an infectious complication requiring a physician visit to the home. Fifth, no patients received rehabilitation sessions after hospital discharge because these services were not available due to COVID pandemic restrictions. Finally, caregivers were willing to participate and receive useful information related to management of NG or Foley catheter, nutrition, in-home exercises, and patient cleaning and hygiene. (19) Nursing staff reported providing training to caregivers at least once prior to patient discharge. They kept a formal register of training performed, but training was not incorporated into a structured program. After discharge, nursing staff did not provide additional assistance. Main identified barriers to

improve training were the limited human resources and infrastructure, supplies and materials for training. (19)

All these factors negatively affect quality of life, mortality and morbidity of patients with stroke. (12,14,16) Research points to inadequate caregiving training as one of the main root causes for poor outcomes in patients with stroke. (18–21) Therefore, the main goal of this project was to evaluate feasibility and acceptability of an innovative hospital-based training for caregivers and nursing stroke staff at INCN.

Specific aims:

1. To determine feasibility, acceptability and fidelity following the Implementation Sciences Framework by Proctor et al, regarding the four educational components of NG tube and foley tube management, bathing and cleaning, and mobilization for patients after severe stroke at INCN.
2. To determine reach, adoption, and implementation following the RE-AIM framework regarding the educational training intervention for caregivers of patients with severe stroke
3. To describe the functional status at discharge and at one-month follow-up of patients with severe stroke, applying the modified Rankin scale (mRS)
4. To describe complications among patients with severe stroke at one-month follow-up.

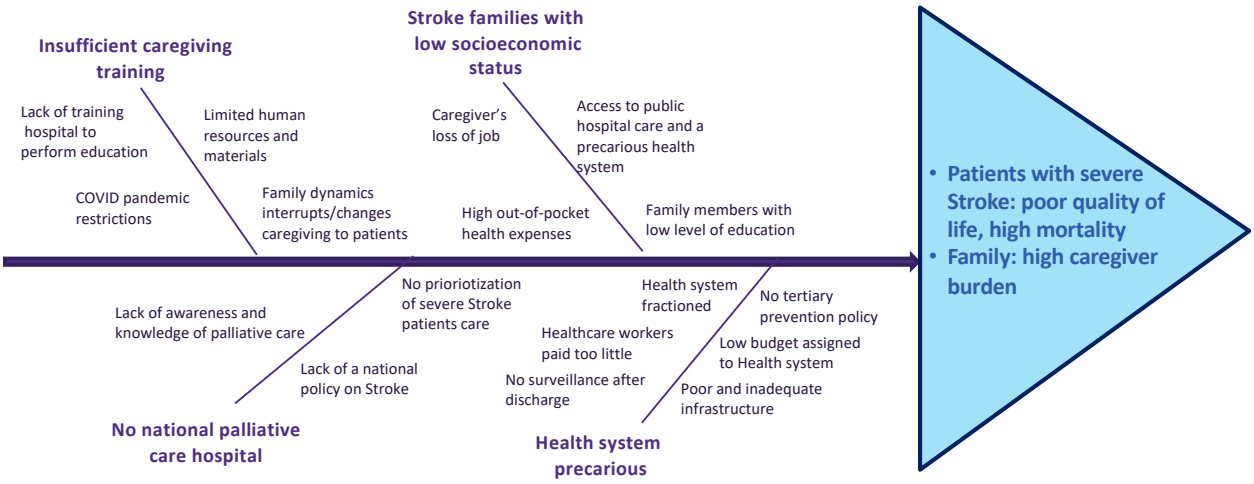


Figure 1. Fishbone diagram. Based on previous reports and preliminary data in Perú, four main root causes have been identified at the interpersonal, community and societal levels leading to poor quality of life, as well as higher mortality and morbidity for patients with stroke; (12,14,16) many affecting the continuity of care at health facilities and caregivers for patients with stroke

METHODS

We followed the PRECEDE-PROCEED model (13) for planning activities. During the PRECEDE stage, Phase 1 to 3 included the assessment of Stroke care in Perú, epidemiological and behavioral assessment of Stroke care in Lima, and gaps assessment of caregiving status of patients with severe stroke at INCN. In these phases, we performed a literature review about topics of interest, applying semi-structured interviews to SNS and caregivers, and selected the evidence-based intervention (EBI) to be applied on our target population. For phase 4, we developed and adapted the EBI to be applied in our context and based on previous qualitative information collected. During the PROCEED stage, we implemented and performed the process evaluation if this intervention through a pilot type 3 hybrid design. An impact evaluation has not been developed at this point of the study intervention.

Study Design

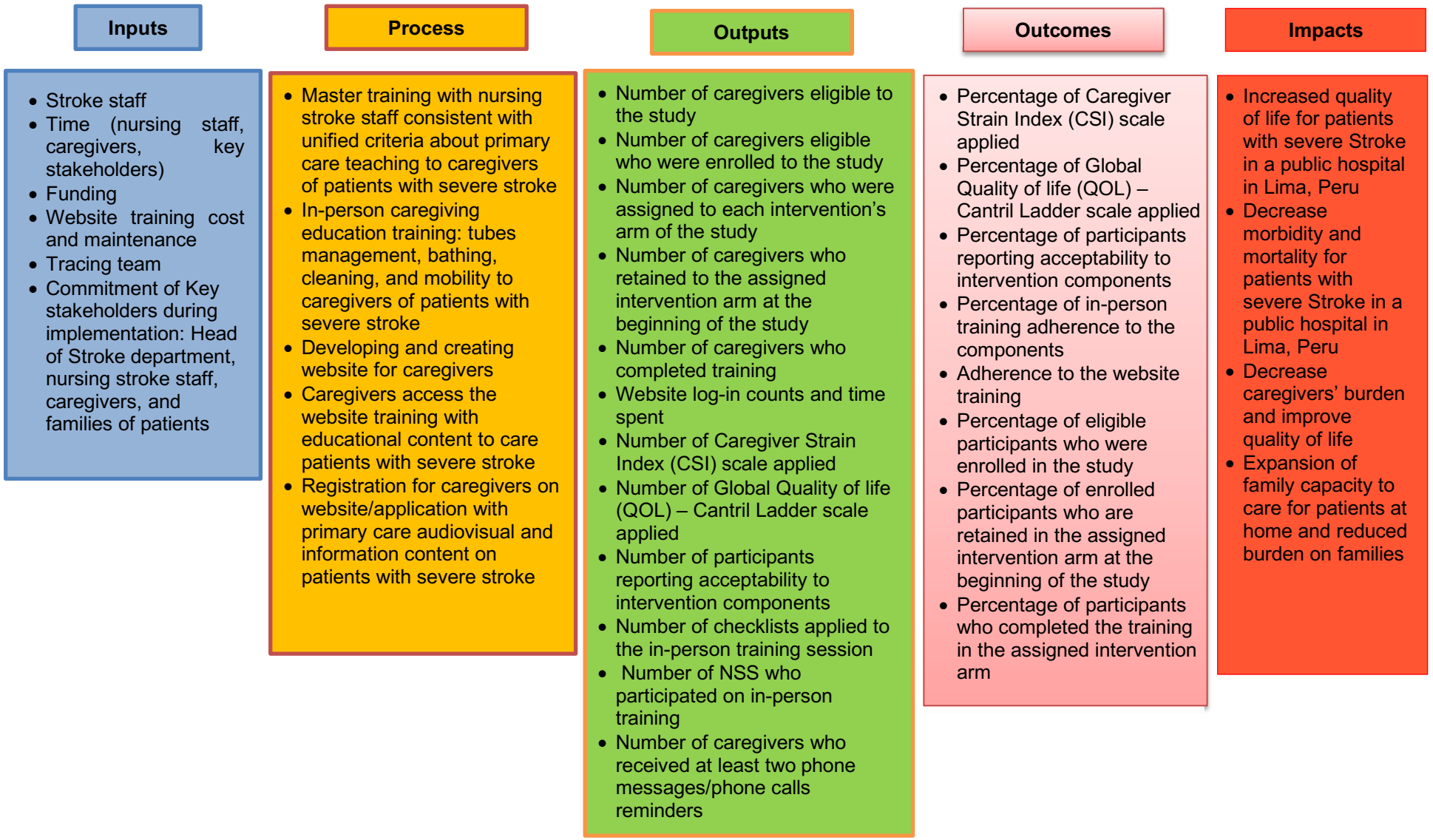
This implementation pilot study hybrid 3 type occurred from June to November 2023, caregivers were randomized to two intervention arms of the hospital-based training intervention (online vs in-person). We applied a mixed methods design (23,24) to evaluate implementation outcomes following Proctor et al., to evaluate feasibility, acceptability, and fidelity, as well as the RE-AIM framework to evaluate reach, adoption and implementation of a hospital-based caregiving training for patients with severe stroke at the Instituto Nacional de Ciencias Neurológicas in Peru. Using a convergent mixed-method design, we simultaneously collected quantitative and qualitative data to understand and explain findings. Data were analyzed separately and then merged and triangulated for results, discussion, and conclusions. In this study, we explored the feasibility and acceptability of a hospital-based caregiving training based on educational training for caregivers and nursing

stroke staff caring for patients with severe stroke; educational training was defined as the basic knowledge and skills that caregivers require to manage NG tube, foley, bathing and cleaning, and mobilization. The quantitative phase consisted of a randomized 1:1 allocation of participants to in-person or website training arms. For the qualitative phase, we administered a questionnaire through semi-structured interviews to caregivers and nursing stroke staff who participated in training and who cared for patients with stroke to gain a more in-depth understanding of the intervention at one-month follow-up. A logic model of the innovate hospital based educational training is shown in Figure 2.

Study Location and Consent

Data collection was performed at the Instituto Nacional de Ciencias Neurológicas. Patients with severe stroke were identified, as users of a NG tube, or Foley catheter, or a modified Rankin scale of 5 points before discharge. Participants were selected consecutively in the stroke unit. The investigator contacted caregivers/family to explain the objectives and procedures of the hospital-based educational training intervention and informed consent was obtained from the caregiver. Surveys were applied by telephone or website training platform; interviews for qualitative section were performed by telephone, results were recorded electronically. In-person training registers were saved electronically to the study records. Local and UW IRB approved the study protocol for both Spanish and English versions.

Figure 2. Innovative Hospital-based Educational Training at the Instituto Nacional de Ciencias Neurológicas in Peru Logic Model



Study population

Population characteristics: Caregivers or family members of in-hospital patients with severe stroke, who were at point of discharge.

Participants

Caregivers or family members (participants) of in-hospital patients with severe stroke on the Stroke Unit at INCN, who were to discharge within the next seven days). Participants were selected on the basis of having a severe stroke, defined as users of an NG tube or Foley catheter, or a modified Rankin scale of 5 points before discharge.

Inclusion criteria for participants (caregivers) included family member/s of patients with severe stroke who:

- was/were equal to or older than 18 years old
- was/were willing to participate in intervention assigned at the INCN
- had a cellphone/other electronic device with internet
- was/were willing to receive phone calls; and
- was/were willing to participate in the intervention and sign the informed consent.

Exclusion criteria for participants (caregivers) included family member/s who:

- was/were a health care worker; or
- had previously received formal training in primary care (in-person or online).

Inclusion criteria for nursing stroke staff included those:

- having worked in the Stroke Unit at INCN at least six months before the intervention
- having performed in-person caregivers training at least twice; and

- who were willing to participate in the phone interviews after providing signed informed consent.

Exclusion criteria for nursing stroke staff included those who:

- had not previously performed caregivers training for this study population.

Intervention description

An intervention description and replication (TIDieR) (25) checklist and guide was used to describe the details of the intervention.

1. ***Why***:

The intervention was an educational training on NG and foley tube management, bathing, cleaning, and mobility for caregivers of patients with severe stroke. Training was performed prior to the patients' discharge home. Interventions applying in-person sessions for educational training to manage disability symptoms and needs have been shown to be effective in improving functional capacity and quality of life for patients with stroke; (26,27) applying technological tools also may be a useful way to integrate healthcare facilities' support with community members. (15,28)

2. ***What:***

The educational package included either two in-person up-to 60-minute training sessions or access to an online training website, both with the same educational information content, where caregivers learned to manage nasogastric and foley tubes, as well as how to bathe, clean, and mobilize a patient with disability. Also, in both delivery modalities, the training was individualized based on patient needs. In-person sessions was complemented by a pamphlet including important

information and key messages. In-person educational sessions were performed in the stroke unit at INCN by stroke nursing staff. (Appendix 1)

Project phases are described as follows:

1. Preparatory phase: Development and implementation of the virtual platform (website training), which included the four components of educational training: management of NG and Foley tube, bathing and cleaning, and mobilization. Also, a workshop session with nursing stroke staff to unify criteria about training components to caregivers.

2. Implementation phase: Recruitment of participants for online website or in-person arms training

3. Measurement phase: After one-month of patient's discharge and receiving the training, the results (dependent variables) of the quantitative and qualitative component were measured on caregivers and nursing stroke staff.

4. Analysis and dissemination of the results phase: Analysis was performed based on the analysis section description, final report was made based on findings and dissemination results were done.

Activities and components for the educational training to caregivers are detailed:

1. Training for caregivers of patients with severe stroke (in-person and online website training). Trained nursing stroke staff provided caregiver's training.

Sessions	Topic	Style	Time	Target
1	Recognize the important role of caregiving. Explanations about patient's needs.	Face to face conversation or Online session	10 minutes	Caregiver

1	Teaching nasogastric tube management and recommendations.	In person-workshop/Online website	30 minutes	Caregiver
1	Bathing and cleaning	In person-workshop/Online website	20 minutes	Caregiver
2	Teaching foley catheter management and recommendations.	In person-workshop/Online website	30 minutes	Caregiver
2	Mobilization	In person-workshop/Online website	30 minutes	Caregiver
3	Application of a Caregiver Strain Index	Telephone/website at one-month	5 minutes	Caregiver
3	Measure of the quality of life of caregiver through the Global Quality of life (QOL) – Cantril Ladder	Telephone/website at one-month	5 minutes	Caregiver

3. <u>Who</u>

A workshop training with stroke nursing staff was held before training of caregivers commenced. Website was developed by the investigator team and access was available at http://entrenamientocuidadores.incn.pe/login/index.php (URL, login and password were provided) when intervention allocation began.

Sessions with stroke nursing staff to unify criteria about caregivers training was led by the head of stroke nursing staff trained and experienced on caregiving teaching.

Sessions	**Topic**	**Style**	**Time**	**Target**
1	Unifying criteria about educational approach on intervention components to caregivers: NG and Foley	Workshops	2 hours	Nursing stroke staff

	management, cleaning and bathing, and mobilization. How to communicate to families about caregiving role after discharge			

4. How

In-person and online website training were provided individually to caregivers. In-person sessions were scheduled at least one week prior to the possible patient's discharge by a member of the stroke nursing staff team. Evaluation of caregiver burden and quality of life for both in-person and online arm were applied at one-month after patient discharge by a phone call using a printed form (see appendix 2 and 3). Website access was available online; registration, username and password were assigned by the study investigator. The caregiver was also taught how to navigate the website training.

In-person training sessions for caregivers were held at the unit stroke facility at INCN at the caregiver's patient bed unit. The caregiver was trained under the supervision of a trained nursing stroke staff, so caregivers could practice the concepts and teaching in real-time. Caregivers in the online arm used their personal electronic device to access training via pre-recorded and animated videos and infographics containing the same content as the in-person training. Recorded videos were created with prior consent from professional actors serving as patients and caregivers (to maintain patient confidentiality) and two nursing staff (in order to maintain similar trained staff as those who taught in-person sessions). Photos and images of the stroke unit where the caregiver training was carried out were used in videos to recreate a similar environment as if the caregiver received face-to-face (in-person) training in the Stroke Unit.

5. ***When and how much***

In-person training consisted of two up-to 60-minutes sessions at least one week prior to the possible patient's discharge. Website training access was available at least one week prior to the patient discharge using their own technological devices, caregivers had four weeks to complete the modules content. In both cases, evaluation of caregiver burden and quality of life was performed at one-month after the patient's discharge. Intervention content was personalized based on needs of the patient with severe stroke, which was determined by stroke unit staff.

6. ***Tailoring***

Caregiving training content was assigned based on patient's needs which was determined by stroke staff evaluation.

7. ***Modification***

Any change of the intervention content was described.

8. ***How well***

Before caregiving educational training commenced, stroke nursing staff had a workshop to unify criteria on teaching components of the intervention. For in-person caregiver training sessions, the principal investigator used a checklist to ensure that content training sessions were performed according to the intervention plan. Monitoring of website content, such as availability of videos, infographics, and progress of the participants, was also performed. Caregivers received a phone call to remind them to finish website modules and evaluations. Adherence and fidelity to the intervention were measured, including median sessions attended by caregivers for in-person

training as well as median website log-in counts and median time spent by each participate at 1-month follow-up for online trainings.

Sample Size

We calculated sample size assuming 90% of participants would accept participation in the intervention and 40% of participants would reject participation in the intervention (50% of difference) at an independent two groups. For 80% power, we calculated 17 participants per group; considering a 10% withdrawal after follow-up, we calculated a total of 38 participants (19 per group)

Randomization and blinding

All participants received the training intervention through two different approaches. The intervention training was randomly allocated 1:1 to in-person or website training. Given the nature of the intervention, participants and nursing stroke staff knew participants assigned to the in-person intervention arm. Evaluation of primary outcomes were performed by an investigator who did not know the assigned group of participant's intervention.

Data Collection and Outcome Measures

Data collection was done through the data collection instrument (appendix 2), which seeks main information about caregivers and patients, primary and secondary outcomes for quantitative section; and through scales to measure caregiver's burden and quality of life (appendix 3). Interviews were performed using the semi-structured interview forms (appendix 2) to evaluate

facilitators and barriers from the educational training intervention to participants and nursing stroke staff, which was administered by telephone. Participants' identification information including data about names, telephone numbers and addresses were kept confidential and encrypted in a file, being available only to the principal investigator.

Outcomes

Primary outcomes were assessed at one-month follow-up of the patient's discharge. All participants received the training intervention via in-person or website training. The automated randomization process was performed by computer once participants signed the inform consent. For both arms, outcomes were measured by a phone call to the caregiver, lasting up to 30 minutes.

We applied an **Implementation Sciences framework by Proctor et al.** (29), to evaluate feasibility, acceptability, and fidelity of the intervention.

Primary Quantitative Outcomes: A percentage of >75% for each of these domains indicated that the intervention was feasible.

Feasibility:

To lay the groundwork for a future pilot trial, we also evaluated the feasibility of administering two validated questionnaires at one-month post-discharge follow up to assess 2 outcomes measures of interest – caregiver burden and caregiver quality of life:

Caregiver burden was assessed using a Spanish version of the Caregiver Strain Index (CSI), which has been validated in Spanish (30) and used in stroke and other areas (30,31). It consists of thirteen questions, with yes/no answers, scored on a scale of 1 to 13. A cut-off point of 7 or more is defined as a high caregiver strain. (32–35)

Caregiver quality of life was assessed using the Global Quality of life (QOL) – Cantril Ladder. It consists of a simple visual scale, numbered from 0 to 10, with 10 being the best possible life, and 0 being the worst possible life. This test has been used in stroke interventions and is effective in measuring general well-being, mental health and happiness. (32,36) The application of the test is simple and does not require much time from the participant. The levels of the score are defined as low (0 to 6), average (7 to 8) and high (9-10). (37) Feasibility was determined based on >75% of the CSI and Global QOL questionnaires being fully completed at 1 month after discharge.

Acceptability: We measured the percentage of participants reporting acceptability to intervention components at one-month follow-up. A percentage of > 50% of recruited participants who reported they agree or strongly agree about the acceptability indicated that the intervention and components were acceptable.

Fidelity to: We measured the adherence to the in-person training components by applying a checklist. A percentage of > 75% of accomplishment of the intervention's components indicated that the intervention's components were applied as it was intended to be delivered. The adherence for the website training was measured by the median of website log-in counts and the median time spent by each participant at 1-month follow-up.

We applied the **RE-AIM framework** to evaluate the hospital-based educational training for reach, adoption, and implementation.

Reach: We measured the percentage of potentially eligible participants who were excluded from the intervention and how representative they were compared to eligible participants who were enrolled in the intervention.

Adoption: We measured the percentage of eligible participants who were enrolled in the study, the percentage of enrolled participants who are retained in the assigned intervention arm at the beginning of the study, and the percentage of participants who complete the training in the assigned intervention arm. A percentage of >75% for each of these domains indicated that the intervention was adopted. Also, we measured the percentage of stroke nursing Stroke staff who participated on in-person educational training.

Implementation: We measured the percentage of caregivers who received at least two phone messages /phone call reminders to complete the website training within one-month follow up.

Secondary Quantitative Outcomes:

We hypothesized the training intervention to caregivers of patients with severe stroke could help reduce caregiver burden by increasing skills to care of patients' primary needs. It also may help with secondary outcomes such as reducing the incidence of infections, such as pneumonia or bladder infection; as well as improving the functional status of the patient. We measured the following secondary outcomes at one-month follow-up:

- Functional status of the patient with severe stroke was measured through the modified Rankin scale, before and after the intervention, to have a basal measure for future interventions or comparison. This scale is widely used as a measure of functionality and disability in stroke. This consists of six points, 0 points means no disability, 1 to 5 means some degree of disability and 6 points means dead. (32,38) Patients' modified Rankin scale was recorded from the medical record before the participant (caregiver) began the intervention.

- Percentage of patients with severe stroke who had infection such as pneumonia or bladder infection.

Qualitative Outcomes:

At one-month post-hospital follow-up, we also conducted semi-structured interviews using an open-ended questionnaire to further explore implementation science outcomes such as feasibility, acceptability, adoption, and implementation. A total of 18 semi-structured interviews were performed: 12 interviews to caregivers from both arms (6 for in-person and 6 for online website) and 6 interviews to nursing staff who participated in the in-person training. (19–21,39) Semi-structured interviews were used to allow flexibility in exploring themes. Interviews explored to what extent participants found the content important and to solicit feedback on how to improve the intervention. We specifically explored the understanding and acceptability of the recruitment and randomization process; facilitators and barriers for nursing staff to administer the intervention with fidelity; and facilitators and barriers for caregivers to enroll, be randomized, and complete the intervention.

Data analysis

Quantitative Data Analysis:

Quantitative data was measured through an experimental pilot study of feasibility, acceptability, fidelity, and adoption by comparing proportions among the assigned intervention groups. Caregivers were randomly allocated 1:1 to in-person or website training. For each arm (group), a measure of the primary outcome was performed at one-month after patient's discharge. Data

collection was from June to November 2023, Data was analyzed using STATA 15.0 software. Descriptive analysis of sociodemographic characteristics was presented by frequency and percentages for categorical variables, media, median, standard deviation, and interquartile range for numerical variables. Descriptive analysis from participants who declined to participate in the intervention were registered to perform a comparison report with participants who agreed to participate in the intervention. For bivariate analysis we compared proportions of feasibility, acceptability and adoption among two groups, using an independent two-sample t-test proportion. Significant differences were assumed by a p-value < 0.05.

Qualitative Data Analysis:

A total of 19 semi-structured interviews were performed: 12 interviews with caregivers from both arms (6 for in-person and 6 for online website) and 7 interviews with nursing staff who participated in the in-person training or served as key informants, such as the nursing stroke staff coordinator. Using systematic sampling, we selected participants to be interviewed from each group. These interviews lasted approximately 60 to 80 minutes. Semi-structured interviews were recorded electronically and performed by a trained interviewer who was not part of the stroke staff, and then recordings were transcribed. Once the transcripts were completed, they were analyzed on Atlas.ti software. A deductive approach was used to develop a predetermined codebook. However, we later applied an inductive and iterative approach to modify, add, or merge new codes based on our analysis of transcripts. See appendix 3. For creating themes, we identified the more relevant coding reports looking for patterns that could help understand the facilitators and barriers of training for caregivers and nursing stroke staff. In case of divergence between the two coders, investigators met and developed a unified criterion; an inter-coder reliability process was performed. Two

assistants collected data. Finally, findings were merged during the analysis, interpretation, discussion, and conclusions. Results were integrated and presented through contiguous narrative approach and using joint display.

RESULTS

We recruited a total of 38 participants, with 19 randomly assigned to the in-person training and 19 randomly assigned to the website training between June to November 2023 at the Stroke Unit at the Instituto Nacional de Ciencias Neurológicas in Lima, Peru

Quantitative section

Sociodemographic characteristics are shown in Table 1. Median age of participants was 40 years (IQR 18), the majority were female (71.1%, n=27), and had an informal job (44.7%, n=17). In 81.6% of participants, only one caregiver was trained per patient (n=19). Regarding patients' stroke characteristics, median age was 64.5 years (IQR 18), and stroke was ischemic in 76.4% (n=29), all patients had a median of 5 points on the modified Rankin Scale. There were three participants lost to follow-up at one-month (9.7%).

Table 1. Descriptive statistics among caregivers and patients with severe stroke enrolled in hospital-based educational training for caregivers of patients with severe stroke at one-month follow-up. (N=38)

Variables	Total (n=38)					
	categories	n (%)	mean	SD[£]	Median	IQR[&]
Caregiver's age			39.3	10.6	40	18
Caregiver's sex	Female	27 (71.1)				
	Male	11 (28.9)				
Caregiver's occupation	Informal	17 (44.7)				
	No	13 (34.2)				
	Formal	8 (21.1)				
Number of caregivers per patient	1	31 (81.6)				

	2	6 (15.8)				
	3	1 (2.6)				
Patient's age (years_			64.3	15.6	64.5	18
Patient's sex	Female	19 (50)				
	Male	19 (50)				
Stroke type	Ischaemic	29 (76.3)				
	Haemorrhagic	9 (23.7)				
Modified Rankin Scale at discharge			4.9	0.2	5	0

[&] IQR (interquartile range)
[£] SD (standard deviation)
[%] Percentage

Primary Quantitative Outcomes: Results are presented by Implementation framework (Proctor's Implementation Outcomes framework or RE-AIM). *Proctor's Implementation Outcomes framework* (29), was employed to evaluate feasibility, acceptability, and fidelity of the intervention. Results are presented in Table 2

A total of fifty potential participants were screened based on inclusion and exclusion criteria, 44 were eligible to participate in the intervention (88%).

Feasibility. We were able to apply the Caregiver Strain Index in 22 participants (n=81.5%) and the Global Quality of life (QOL) – Cantril Ladder in 24 cases (88.9%).

Acceptability. Among participants who completed the intervention at one-month follow-up, 82.9% (n=29) reported convenience and comfort with the intervention and their components.

Fidelity. Adherence to in-person training by the components of the intervention at one-month follow-up was 95%, applying a check list. Adherence to the website platform, measured by the median of website log-in counts was 2, and the median time spent by each participant at one-month follow-up was 284 minutes.

Table 2. Feasibility, acceptability, and fidelity outcomes by Proctor et al., framework of the hospital-based educational training for caregivers of patients with severe stroke at one-month follow-up

Outcomes		Total (n=35)			
		% (n)	In-person	Virtual	P value[&]
Feasibility					
Administering the Caregiver Strain Index		81.5 (22)	84.6 (11)	78.6 (11)	0.686
Administering the Global Quality of life (QOL) – Cantril Ladder		88.9 (24)	92.3 (12)	85.7 (12)	0.586
Acceptability					
% participants reporting acceptability of intervention components		82.9 (29)	94.4 (17)	70.6 (12)	0.061
Fidelity					
Adherence to the in-person training		Check list	95% (18)		
Adherence to the website platform	Median of website log-in counts			2	
	Median time spent by each participant			284 minutes	

[&] CHI square test

[%] Percentage

The *RE-AIM framework* (40) was applied to evaluate hospital-based educational training. Results are presented in Table 3

Reach. Twelve-percent (n=6/50) of potentially eligible participants (caregivers) were excluded after applying the exclusion criteria; 4 were healthcare workers and 2 had previous experience

caring for another family member with a similar condition. this excluded group had similar sociodemographic characteristics but a lower score of the mRS (4 points).

Adoption. Among 44 eligible participants, 38 provided informed consent and were enrolled in the study (86%). Reasons for declining to participate in the training were mainly family issues, which will be discussed in qualitative and discussion sections. All 19 participants in each assigned arm remained in the allocated arm at one-month follow-up. A total of 79% (n=30) participants completed training in the assigned intervention arm, 19 participants (100%) completed training in the in-person arm and 11 (57.9%) in the website arm, a statistically significant difference (p=0.001). The percentage of Stroke nursing staff who participated of in-person educational training was 41.7% (n=10/24).

Implementation. The percentage of caregivers who received at least two phone messages /phone call reminders to complete the website training within one-month follow up was 95% (n=18).

Table 3. RE-AIM framework to evaluate a hospital-based educational training for caregivers of patients with severe stroke at one-month follow-up.

Outcomes guided by RE-AIM	Total (n=35)			
	% (n)	In-person	Virtual	P value[&]
Reach				
% potentially eligible participants excluded	12 (6/50)			
¿How representative were they?	Similar demographics but lower mRS (4 points)			
Adoption				

% eligible participants enrolled in study	86 (38/44)			
% enrolled participants retained in assigned intervention arm	100 (38)	100 (19)	100 (19)	
% participants who completed training in assigned intervention arm	79 (30)	100 (19)	57.9 (11)	0.001
% stroke nursing staff (SNS) who participated on in-person educational training	41.7 (10/24)			
Implementation				
% of caregivers who received at least two phone messages /phone calls reminders to complete website training within one month after patient discharge	95 (18)			

Secondary Quantitative Outcomes:

At one-month follow-up, the median of modified Rankin scale was 4 points (IQR 1), a mean 4.5 (SD 0.7). We found two patients had died at one-month follow-up (7%).

Percentage of patients with severe stroke who had pneumonia or bladder infection was 30.8% (n=8/26), among them bladder infection was the most frequent, 23.8% (n=6/26). Other complications included bed sores (11.5%, n=3), diarrhea (11.5%, n=3), and stroke recurrence (3.9%, n=1), total (26.9%, n=7).

Qualitative section

At one-month follow-up, a total of 19 semi-structured interviews were performed: 12 interviews to caregivers from both arms (6 for in-person and 6 for online website) and 7 interviews to nursing

staff who participated in the in-person training. An additional interview of a nursing stroke staff coordinator (key informant) was performed. Following main themes found:

Caregivers were willing to participate actively in the educational training. Caregivers' response to the educational training was positive. Reasons for this positive response included a lack of previous knowledge; the desire to help their loved one and taking part in their recovery; trust in the INCN as an institution; and a trustful relationship with stroke staff. Components missing and frequently requested were nutrition, rehabilitation, and follow-up recommendations. Main barriers identified were family challenges in adapting to their "new life".

> *"Yes…They (NSS) have a lot of patience…Yes, it was noticeable they wanted you to learn because they made me practice."* CP1 (female)

Caregiver burden and family issues were the main barriers to train caregivers, to continue providing care at home, to apply intervention components, and to perform follow-up. The main reasons for not accepting the educational training were because some family members were not willing to assume the care and support of the patient due economic challenges, interpersonal conflicts, and health issues. These issues remained the same among caregivers who were enrolled and became the main limitation to having longitudinal and consistent quality of care of the patient. Some family members reported they did not follow steps and recommendations of the training because they were overloaded with family and work responsibilities (Overburdened familiar relations). Participants frequently reported that they served as the sole caregiver, or that the patient was not under their care anymore. Caregivers who were helped by other family members reported feeling more supported and relieved, but sometimes they did not apply skills

> *"Economically, eh, they (family) helped me …but no with my mother's care, no"* CP1 (female)

gained in the training to their patients given the responsibility was transferred to another caregiver. In some cases, appointing a family member as a caregiver led to conflict inside the family core due to time constraints, economic challenges, and added responsibility that a new caregiver faced in taking care of the patient. Moreover, in situations where follow-up was not completed, this was due to the trained caregiver no longer caring for the patient, or the caregiver was in charge only a few days or hours per week and received external help to do specific activities as nasogastric or tube management or cleaning.

Intervention promoted caregivers' confidence in health providers, relief, and emotional support since they felt stroke staff were willing to help them during this process; however, execution of the intervention components at the time to take care of the patient was limited due to caregivers' lack of confidence and their new family challenges arising from adjusting to the stroke.

> *"…mmm they gave me all the information about tube, how to bath, to feed. Yes, yes, I understood all the procedure they taught me and right there, nurses told me to do it so they can see if it was good or not"* CP5 (male)

Caregivers felt there were more chances to learn and gain new skills when the training was done in-person instead of virtual, fostered by the opportunity to ask questions in real-time, address doubts and have support from the SNS. Virtual training had a low performance compared to the in-person training given limited technological skills (older caregivers), caregiver's change of roles after randomization, it means they did not remain as caregivers after patient's discharge so they did not have the need or motivation to continue the virtual training, and change of patient's status, due patient's death or recovery, for instance when

> *"…it seemed good to me that it was in-person because you learn things better there. They teach you right there and make you practice. They teach you how to do it and that is already engraved in your brain...because on virtual you just look it and you don't know how to do it"* CP1 (female)

the NG or Foley tubes were withdrawn early. On the other hand, we observed a clear preference for virtual training for participants with informal and overloaded jobs. Qualitative findings suggest that these caregivers assumed a change of lifestyle in which they not only took on caregiving duties, but also became a new head of the family to support the finances and responsibilities. As such, in some cases, other caregivers or family members who were not aware of the training became involved; Caregivers who completed the virtual training were motivated mainly by the remote access to the educational training content, given the excessive and extended working hours they had to maintain to support their patient's health expenses and family needs. Although older caregivers had the same motivation at the beginning of the allocation, given technological limitations they did not complete the training, despite technological assistance provided to help them access the website platform. **Technological skills and virtual platform also played a key barrier to older caregivers**. Most caregivers who did not complete the virtual training referred to having poor skills or little knowledge on navigating websites. Despite receiving orientation and instructions for accessing the website platform and reminders to complete it, these were not sufficient to have a full understanding. However, no internet connection restrictions were reported. In addition, they showed a preference for in-person training given the complex and important aspects they had to learn, the sense of not wanting to harm their loved one. Additionally, they felt more confident if they were observed directly in in-person trainings and were provided an opportunity to ask questions and address doubts during the training.

> *"It didn't open, I wrote to the doctor…she guided me and explained me and that's it…with the help she sent me"* CV1 (female)

Stroke nursing staff (SNS) integrated and adopted the educational training for caregivers because they knew the training components and participated in the educational training development, giving feedback and pilot testing. Most important they felt rewarded because the training provided in a positive service to patients and families, a formal, and based-evidence way. Health care workers burden was an issue that must be addressed in further interventions to improve their productivity and to support the quality of the training provided. SNS found that the intervention was practical to apply and felt rewarded by giving the training. Proposals to improve it were to incentivize stroke staff with opportunities for continuous education and, hiring additional staff, adding training supplies, and including home visits to improve and maintain this intervention in the long-term and decrease healthcare workers' burden. They also suggested including other components such as psychological support to caregivers.

> *"Ah...family and caregivers are not only left with the burden of caring…it also goes with the emotional, psychological aspect…because it is a great burden…at that moment I think they arrive, they are relieved to have us. Even sometimes emotional support is what they lack. They always have their doubts, but with this education …they feel very relieved…"* NSS2 (male)

Stroke nursing staff were able to adapt some intervention components. Some educational components such as bathing and cleaning and mobilization were adapted based on caregivers' questions and needs. For instance, SNS noted the importance of teaching how to bathe a patient while seated, and mobilization in a wheelchair at home, and thus added these new elements to the training. Also, other components which were not included initially as recommendations related to the type of food, at home exercises and massages, and administrative documentations related to the public health insurances to further follow-ups, but this content was

> *"…but beyond medications…they should know and, we as family, what is the next step.? ...What else do we have to do with our family member?"* CP1 (female)

subsequently added by the staff. However, their responses may not have been fully understood by caregivers, and thus they recommended to include these important topics (nutrition and rehabilitation recommendations) in later trainings.

Caregivers consistently required additional information regarding rehabilitation, nutrition, and follow-up recommendations, and felt that a greater number of training sessions would help to increase their skills and confidence to perform the care, mostly for tubes management. SNS had the opportunity to detect, and share some missing content in the intervention. However, most perceived that these topics might be structured and included in a formal way. One of the main recommendations was psychological support, given the sudden change of life for caregivers and patients which produced anxiety.

> *"Well…about therapy…I would have liked to receive that because I don't know…I don't know what therapies she has to do… what she eats…I don't know."* CP3 (female)

Mixed methods section

The joint display shows the process of how the themes and quotes generated from qualitative analysis were used to understand findings from the quantitative phase. The integration of qualitative themes and quantitative results were applied to understand facilitators and barriers of this hospital-based educational training. This convergent approach allowed us to identify the main barriers and facilitators in the qualitative phase, and then triangulate it with quantitative results focused on feasibility, acceptability, fidelity, reach, adoption, and implementation outcomes. Based on findings, main facilitators were closely related to willingness and positive perceptions from SNS and caregivers of patients with severe stroke, and the need to acquire skills to care for a family member with severe disability due to stroke. Regarding the barriers, issues such as family

conflicts, limited technological skills of older caregivers, the lack of training content on rehabilitation and nutrition, and SNS work burden were identified as modifiers on the intervention outcomes. Results are presented in Table 4.

Table 4. Joint display of facilitators and barriers of a hospital-based educational training for caregivers of patients with severe stroke at one-month follow-up.

Themes from qualitative analysis	**Sample phrase codes**	**Quantitative analysis**	**Results from quantitative**
Caregivers were willing to participate actively in the educational training due to the quality of the training, trust in the stroke staff, and the urgency to learn basic educational care given their loved one's disability.	*"Yes…They (SNS) have a lot of patience…Yes, it was noticeable they wanted you to learn because they made me practice."* CP1 (female) *"Sure…I have already all the information, at least I have been thought something good."* CP2 (female) *"All nursing Stroke staff, are trained about all brain staff…nurses have been very good, they have explained all about nutrition, bathing and all staff."* CP3 (female)	% eligible participants enrolled in study	86%
Caregiver burden and family issues were main barriers to completing caregiver training, to continue the care at home, to apply intervention components, and to perform follow-up.	*"Well…we set a specific day, but I couldn't attend it ... I am also a mom y something happened to my daughter at school…but I had the chance to take a rain check…"* CP4 (female) *"Economically, eh, they (family) helped me …but no with my mother's care, no"* CP1 (female) *"It has shocked a lot on me, the truth I can't*	% participants who completed training in assigned intervention arm	79%

	explain…there are no words…so I know although I cry on streets when I get to my brother's …" CP2 (female) *"…at first, they said that the sister was going to take care of him and then, they said no…At the end, the one who was going to take care of him was the mother…"* SNS7 (female)		
Intervention promoted caregivers' trust, provided relief and emotional support since they felt stroke staff were willing to help them during this process. However, execution of the intervention components was limited by caregivers' lack of confidence and new family challenges.	*"…mmm they gave me all the information about tube, how to bath, to feed. Yes, yes, I understood all the procedure they thought me and right there, nurses told me to do it so they can see if it was good or not"* CP5 (male) *"yes…there is not any problem…I do the cleaning…I change her, I bath her…"* EP1 (female)	% participants reporting acceptability of intervention components	Total: 82.9%
Caregivers were perceived to have more opportunities to learn and gain new skills when the training was done in-person instead of virtual, fostered by the opportunity to ask questions in real-time, address doubts, and have support from the SNS. Virtual training had a lower performance compared to the in-person training perhaps due to caregivers' change of roles, limited	*"…it seemed good to me that it was in-person because you learn things better there. They teach you right there and make you practice. They teach you how to do it and that is already engraved in your brain...because on virtual you just look it and you don't know how to do it"* CP1 (female) *"It didn't open, I wrote to the doctor…she guided me and explained me and that's it…with the help she sent me"* CV1 (female)	% participants who completed training in the in-person arm % participants who completed training in the virtual arm % of caregivers who received at least two phone messages /phone calls reminders to complete the website	100% 57.9% 95%

technological skills (older caregivers), and the change of patient's status.			
Stroke nursing staff (SNS) integrated and adopted the educational training for caregivers. They felt comfortable and rewarded to provide training in a structured and practical way. They recommended acquiring additional staff to continue and sustain the training over time.	*"I have done this training with the patient…the patient with sequelae that was previously evaluated by the doctor… then it was coordinated with the nursing stroke coordinator …"* SNS1 (female) *"…now, with this project, we give it more time, the time is longer. Because family members expect you to teach them step by step, even now they ask for a way to film it. Because some even want it virtual…So, it is a very different thing, it is very different…"* SNS1 (female) "*Well, before the project …100%, we tried... that they receive their guidance... surely some have left, perhaps without receiving many, many classes or having received any form of care…"* SNS2 (male) *"I think they feel good, fully trained, with this I already have help. Satisfied to have*	% of nursing Stroke staff (NSS) who participated on in-person educational training Adherence to the in-person training (check list)	41.7% 95%

	helped with something" SNS3 (female) *"Right now…we are following this, and we are not stopping our work… More (staff) could be added."* SNS6 (female) *"Well, simply grateful that in this study…It gives us the opportunity to share our knowledge with the family, for the patient's recovery…for them."* SNS1 (female)		
Caregivers consistently required additional information regarding rehabilitation, nutrition, and follow-up recommendations, and they felt that a greater number of training sessions would help to increase their skills and confidence to perform the care, mostly for tube management. NSS had the opportunity to detect and share missing content in the intervention.	*"Well…about therapy…I would have liked to receive that because I don't know…I don't know what therapies she has to do… what she eats…I don't know."* CP3 (female) *"…but beyond medications…they should know and also, we as family, what is the next step.? …What else do we have to do with our family member?"* CP1 (female) *"…while the patient is there…the time he was at the hospital I would like them to train us"* CV2 (female) *"…would have been useful if they had talked more about how to deal…How to treat patients…"* CV1 (female) *"Ah...family and caregivers are not only left with the burden of caring…it also goes with the emotional, psychological*	% participants reporting acceptability of intervention components in-person training % participants reporting acceptability of intervention components virtual training	In-person: 94.4% Virtual: 70.6%

	aspect…because it is a great burden…at that moment I think they arrive, they are relieved to have us. Even sometimes emotional support is what they lack. They always have their doubts, but with this education …they feel very relieved…" SNS2 (male)		

DISCUSSION

We implemented an educational training for caregivers of patients with severe stroke to evaluate implementation science outcomes such as feasibility, acceptability, fidelity, reach, adoption, and implementation. During this process we learnt despite caregivers' characteristics and challenges (15) they gone through due their family member disability and their "new change of life" they felt supported by this intervention, also how SNS adapted and assumed this new activity in their role.

Key information was found through the implementation process that need to be addressed in an adapted caregivers' trainings, as including new components as psychological, rehabilitation and nutrition support. Phycological support (21) become a component that may allow to address the main barrier found, as caregiver burden and family challenges. By giving psychological support to family members may allow to decrease burden inside the family and caregiver, supporting and helping to the adaption process, giving useful information that promote a good decision making related to patient's care, caregivers selection and shared roles inside the family. Additionally, rehabilitation (41,42) and nutrition components would help caregivers to provide a more integrated care, satisfying patient's needs and caregiver's duties, by providing information and trainings that are not currently available as it should be at public settings at follow-up. (43,44)

These findings will be applied to upcoming studies to evaluate effectiveness, impact, and sustainability of this intervention under implementation sciences framework as RE-AIM (40) or Proctor et al,. (29) Regarding effectiveness as a main outcome, we plan to apply a quasi-experimental design including an intervention and a comparison group. An intervention group would be a tertiary setting as INCN and a primary health center from rural areas outside of Lima.

A comparison group would be another tertiary setting at Lima city that have similar characteristics as INCN. Moreover, including a primary health center from rural areas would be useful to evaluate feasibility and acceptability of the intervention in a different context where health services are not accessible and huge gaps are reported. (44) Different strategies as telemedicine, community health workers and home visits would be applied and tested if this intervention might be scalable to other similar settings, allowing the caregivers' support may be spread in all health settings as a national program in Perú.

The main limitations were the lack of comparison group or control group; however, given that we were not assessing preliminary efficacy, our design suited the clinical setting and objectives of the intervention to evaluate feasibility and acceptability of the educational training. Also, it is not clear to what extent the intervention components and knowledge were applied after the intervention, which might be related to caregivers' confidence to manage a patient with severe disabilities given the short training, so increasing the training dose may be a way to solve this issue. These limitations will be addressed in upcoming studies where effectiveness will be evaluated. Responses and findings might have been skewed due to the principal investigator and nursing stroke staff coordinator influence on caregivers and SNS, or social desirability bias; (45,46) however, to avoid this issue, semi-structured interviews and follow-up at one-month were performed by an externally trained interviewer and investigator. Given the short follow-up, this study did not measure impact and sustainability of the intervention at this point, but these outcomes will be addressed in upcoming studies with a longer follow-up.

CONCLUSIONS

Our hospital-based educational training for caregivers was feasible and acceptable, with in-person training having the best results; otherwise, website training was not acceptable for older caregivers. Main facilitators were the positive acceptance and influence on caregivers and nursing stroke staff. Main barriers identified were family challenges, caregiver heterogenicity and burden that limited the appropriate care of the patient with severe stroke. Furthermore, caregiver's training should include additional components such as psychological support, rehabilitation and nutrition training, and administrative counseling after patient's discharge.

REFERENCES

1. Zhang J, Lee DTF. Meaning in stroke family caregiving: A literature review. Geriatric Nursing. 1 de enero de 2017;38(1):48-56.
2. Gbiri CA, Olawale OA, Isaac SO. Stroke management: Informal caregivers' burdens and strians of caring for stroke survivors. Ann Phys Rehabil Med. abril de 2015;58(2):98-103.
3. Jaracz K, Grabowska-Fudala B, Kozubski W. Caregiver burden after stroke: towards a structural model. Neurol Neurochir Pol. junio de 2012;46(3):224-32.
4. Ferrell BR, Twaddle ML, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. J Palliat Med. diciembre de 2018;21(12):1684-9.
5. Soto Á, Guillén-Grima F, Morales G, Muñoz S, Aguinaga-Ontoso I, Vanegas J. Trends in Mortality from Stroke in Latin America and the Caribbean, 1979–2015. Global Heart [Internet]. abril de 2022 [citado 30 de octubre de 2022];1(26). Disponible en: https://globalheartjournal.com/articles/10.5334/gh.1114/#
6. Málaga G, De La Cruz-Saldaña T, Busta-Flores P, Carbajal A, Santiago-Mariaca K. La enfermedad cerebrovascular en el Perú: estado actual y perspectivas de investigación clínica. Acta Médica Peruana. 2018;35:51-4.
7. Arauz A, Serrano F, Ameriso SF, Pujol-Lereis V, Flores A, Bayona H, et al. Sex Differences Among Participants in the Latin American Stroke Registry. J Am Heart Assoc. 18 de febrero de 2020;9(4):e013903.
8. Owolabi MO, Thrift AG, Mahal A, Ishida M, Martins S, Johnson WD, et al. Primary stroke prevention worldwide: translating evidence into action. Lancet Public Health. enero de 2022;7(1):e74-85.
9. Alva-Díaz C, Huerta-Rosario A, Pacheco-Barrios K, Molina RA, Navarro-Flores A, Aguirre-Quispe W, et al. Neurological diseases in Peru: a systematic analysis of the global burden disease study. Arquivos de Neuro-Psiquiatria. 2020;78:282-9.
10. Lazo-Porras M, Bernabe-Ortiz A, Gilman RH, Checkley W, Smeeth L, Miranda JJ. Population-based stroke incidence estimates in Peru: Exploratory results from the CRONICAS cohort study. Lancet Reg Health Am. enero de 2022;5:100083.
11. Alvarado-Dulanto CMA, Lazo M de los Á, Loza-Herrera JD, Málaga G. Pronóstico al año tras sufrir el debut de enfermedad cerebrovascular en pacientes de un hospital nacional de Lima, Perú. Revista peruana de medicina experimental y salud pública. 2015;32:98-103.
12. Abanto C, Ton TGN, Tirschwell DL, Montano S, Quispe Y, Gonzales I, et al. Predictors of functional outcome among stroke patients in Lima, Peru. J Stroke Cerebrovasc Dis. octubre de 2013;22(7):1156-62.
13. Crosby R, Noar SM. What is a planning model? An introduction to PRECEDE-PROCEED. J Public Health Dent. Winter de 2011;71 Suppl 1:S7-15.
14. Alvarado-Dulanto CMA, Lazo M de los A, Loza-Herrera JD, Malaga G. [One year prognosis after suffering the onset of cerebrovascular disease in patients from a public hospital in Lima, Peru]. Rev Peru Med Exp Salud Publica. marzo de 2015;32(1):98-103.
15. Miranda JJ, Moscoso MG, Yan LL, Diez-Canseco F, Málaga G, Garcia HH, et al. Addressing post-stroke care in rural areas with Peru as a case study. Placing emphasis on evidence-based pragmatism. Journal of the Neurological Sciences. 2017;375:309-15.

16. O'Donnell MJ, Chin SL, Rangarajan S, Xavier D, Liu L, Zhang H, et al. Global and regional effects of potentially modifiable risk factors associated with acute stroke in 32 countries (INTERSTROKE): a case-control study. Lancet. 20 de agosto de 2016;388(10046):761-75.
17. Bernabe-Ortiz A, Diez-Canseco F, Vásquez A, Miranda JJ. Disability, caregiver's dependency and patterns of access to rehabilitation care: results from a national representative study in Peru. Disability and rehabilitation. 2016;38(6):582-8.
18. Nauzley Abedini, MD, MSc. Clinical outcomes and palliative care needs among patients with stroke requiring nasogastric tube feeding: Preliminary results from a novel neuropalliative care research collaboration in Lima, Peru [Internet]. 2022 mar 22 [citado 13 de julio de 2022]; Seattle, Washington. Disponible en: https://geriatrics.uw.edu/node/301
19. Ecos R, Abedini N, Abanto C, Zunt J. Access to education and training assistance for caregivers of severely disabled stroke patients [Internet]. Lima, Perú: University of Washigton, Seattle. USA; 2022 oct [citado 30 de octubre de 2022] p. 3. Disponible en: https://practicum.sphcm.washington.edu/MyPracticum/default.aspx
20. Zafra-Tanaka JH, Portocarrero J, Abanto C, Zunt JR, Miranda JJ. Managing Post-Stroke Care During the COVID-19 Pandemic at a Tertiary Care Level Hospital in Peru. Journal of stroke and cerebrovascular diseases. 2022;31(4):106275-106275.
21. Pesantes MA, Brandt LR, Ipince A, Miranda JJ, Diez-Canseco F. An exploration into caring for a stroke-survivor in Lima, Peru: Emotional impact, stress factors, coping mechanisms and unmet needs of informal caregivers. eNeurologicalSci. 1 de marzo de 2017;6:33-50.
22. Takaoka Y, Hamatani Y, Shibata T, Oishi S, Utsunomiya A, Kawai F, et al. Quality indicators of palliative care for cardiovascular intensive care. J Intensive Care. 14 de marzo de 2022;10(1):15.
23. Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. Health Serv Res. diciembre de 2013;48(6 Pt 2):2134-56.
24. Watkins DC, Goodwill JR, Johnson NC, Casanova A, Wei T, Allen JO, et al. An Online Behavioral Health Intervention Promoting Mental Health, Manhood, and Social Support for Young Black Men: The YBMen Project. Am J Mens Health. agosto de 2020;14(4):1557988320937215.
25. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ [Internet]. 2014;348. Disponible en: https://www.bmj.com/content/348/bmj.g1687
26. Dharma KK, Damhudi D, Yardes N, Haeriyanto S. Increase in the functional capacity and quality of life among stroke patients by family caregiver empowerment program based on adaptation model. International Journal of Nursing Sciences. 2018;5(4):357-64.
27. Gelfman LP, Kavalieratos D, Teuteberg WG, Lala A, Goldstein NE. Primary palliative care for heart failure: what is it? How do we implement it? Heart Fail Rev. septiembre de 2017;22(5):611-20.
28. Rubinstein A, Miranda JJ, Beratarrechea A, Diez-Canseco F, Kanter R, Gutierrez L, et al. Effectiveness of an mHealth intervention to improve the cardiometabolic profile of people with prehypertension in low-resource urban settings in Latin America: a randomised controlled trial. The Lancet Diabetes & Endocrinology. 2016;4(1):52-63.
29. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health. marzo de 2011;38(2):65-76.

30. López Alonso S, Serrano M. Validación del Indice de Esfuerzo del Cuidador en la población española [Validation of the Caregiver Strain Index in Spanish population]. Enfermeria Comunitaria. enero de 2005;1:12-7.
31. Feligreras-Alcalá D, Cazalilla-López MDP, Del-Pino-Casado R, Frías-Osuna A. Validity and Reliability of the Caregiver Strain Index Scale in Women during the Puerperium in Spain. Int J Environ Res Public Health. 30 de marzo de 2021;18(7).
32. Langhorne P, Baylan S. Early supported discharge services for people with acute stroke. Cochrane Database Syst Rev. 13 de julio de 2017;7(7):CD000443.
33. Shaw L, Bhattarai N, Cant R, Drummond A, Ford GA, Forster A, et al. An extended stroke rehabilitation service for people who have had a stroke: the EXTRAS RCT. Health Technol Assess. mayo de 2020;24(24):1-202.
34. Donnelly M, Power M, Russell M, Fullerton K. Randomized controlled trial of an early discharge rehabilitation service: the Belfast Community Stroke Trial. Stroke. enero de 2004;35(1):127-33.
35. Crespo M, Rivas MT. La evaluación de la carga del cuidador: una revisión más allá de la escala de Zarit. Clínica y Salud. 2015;26(1):9-15.
36. Secrest JS, Zeller R. Measuring Continuity and Discontinuity Following Stroke. Journal of Nursing Scholarship. 2003;35(3):243-7.
37. Mazur J, Szkultecka-Dębek M, Dzielska A, Drozd M, Małkowska-Szkutnik A. What does the Cantril Ladder measure in adolescence? Arch Med Sci. enero de 2018;14(1):182-9.
38. Banks JL, Marotta CA. Outcomes Validity and Reliability of the Modified Rankin Scale: Implications for Stroke Clinical Trials. Stroke. 1 de marzo de 2007;38(3):1091-6.
39. Ulin P, Robinson E, Tolley E. Qualitative Methods in Public Health: A Field Guide for Applied Research. Medicine & Science in Sports & Exercise. julio de 2005;37:1249.
40. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health. septiembre de 1999;89(9):1322-7.
41. Murrell JE, Pisegna JL, Juckett LA. Implementation strategies and outcomes for occupational therapy in adult stroke rehabilitation: a scoping review. Implementation Science. 18 de diciembre de 2021;16(1):105.
42. Jolliffe L, Lannin NA, Cadilhac DA, Hoffmann T. Systematic review of clinical practice guidelines to identify recommendations for rehabilitation after stroke and other acquired brain injuries. BMJ open. 2018;8(2):e018791.
43. Williams LS, Vickrey BG. Implementation Science. Stroke. 2021;52(12):4054-6.
44. Almubaslat F, Sanchez-Boluarte SS, Diaz MM. A review of neurological health disparities in Peru. Frontiers in Public Health [Internet]. 2023;11. Disponible en: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1210238
45. Bispo Júnior JP. Social desirability bias in qualitative health research. Rev Saude Publica. 2022;56:101.
46. Mathieu C. Chapter 4 - Performance appraisal: how to stop the dark from rising. En: Mathieu C, editor. Dark Personalities in the Workplace [Internet]. Academic Press; 2021. p. 71-96. Disponible en: https://www.sciencedirect.com/science/article/pii/B9780128158272000041

APPENDICES

Appendix 1. Data collection instrument

Quantitative section

1. Caregivers' characteristics

Age:
Sex:
Occupation:
Number of caregivers assigned per patient:
Caregiver's type:
Telephone number:

2. Clinical characteristics of patients with severe stroke

Age:
Sex:
Stroke type Ischaemic ☐
Hemorrhage ☐
Functional status at discharge: _____points on mRankin scale

3. Outcomes evaluation at one-month follow-up

1. Primary outcomes

- Caregiver Strain Index ..... points
- Global Quality of Life (QOL– Cantril Ladder ..... points
- Did you accept the recruitment process? YES ( ) NO ( )
- Did you accept the randomization process? YES ( ) NO ( )

2. Secondary outcomes

- Evaluation of the modified Rankin scale in the patient with severe stroke
-

Discharge	1-month

- Did the patient have pneumonia? YES ( ) NO ( )
- Did the patient have bladder infection? YES ( ) NO ( )

- Did the patient have bedsores? YES ( ) NO ( )
- Did the patient have any other complication? YES ( ) NO ( )
  If yes, which?.....

Report of website use during the first month (only if the assignment arm was virtual)

- Website log-in counts
- Time spent on web page at 1-month follow-up.

Qualitative section: Semi-structured interviews

Questionnaire (patient's caregiver)

Identification code:

Quantitative questions

Does the patient use nasogastric tube? Yes No

Does the patient use foley tube? Yes No

Does the patient receive in-home rehabilitation? Yes No
If yes, does the patient receive in-home rehabilitation under the supervision of a trained clinician or provider?

Qualitative questions

1. What is your relationship with the patient? When was the patient diagnosed with their stroke?
2. Is the patient permanently under your care? How much help do you receive? Who else is involved in the caregiving, i.e other family members, friends, paid caregivers?
3. What prior knowledge or training had you received about stroke, rehabilitation, or caregiving prior to this intervention?
4. Have you taken care of patients with some disability before? How long? What did you learn?
5. Which intervention did you received? In-person or online-website training? In general, how was this experienced? Was it helpful or not? Why and why not? Did you complete all sessions or website content? Why and why not?
6. How was the training did you receive from the institute's staff for the care of the patient after their stroke? Was this done before patient's discharge? How many times did you attend in-person sessions or website training? How did this training look like (what was the content)?

7. What was the most helpful information you received regarding how to care for someone in your family member's condition? How it helped you? Could you give some examples?
8. What information would have been helpful on how to care your family member's condition and you didn't receive? Why do you think this information was not provided to you?
9. If the patient has NG tube, is still, having it? If no, when NG tube was removed? Who and when did it? If yes, has NG tube been changed? How many times? Who and when did it? Has the patient had pneumonia? Is the patient taking in anything (food, medications, water) by mouth?
10. For NG tube caregiver's training. Do you feel confident to manage (cleaning, feeding) it? Can you tell me about how you manage it? For example, how do you clean it? How do you feed using this? How many times is the NG tube changed? What do you recall from the training?
11. If the patient has foley tube, is still, having it? If no, when Foley tube was removed? Who and when did it? If yes, has Foley tube been changed? How many times? Who and when did it? Has the patient had a bladder infection?
12. For Foley tube caregiver's training. Do you feel confident to manage (cleaning, positioning) it? Can you tell me how you manage it? How many times is it changed? What do you recall from the training?
13. Is the patient in the same functional state (movement, feeding, ability to care themselves) as discharge time? In what ways has it changed? Do you think or perceived the training you received helped your patient "loved one" in some way? How and why? What content or information from the training has helped you to help your patient "loved one"? Why? What other information related to this aspect would be helpful to receive?
14. Is the patient in the same mental/cognitive state as discharge time? In what ways has it changed? Some information of the training has been useful to you.
15. Is the patient aware of his/her functional and mental status, about their environment? How has it changed? How is the patient feeling emotionally with regards to their current functional or cognitive status? How has it impacted their life?
16. How are you feeling as a caregiver of someone who has had a stroke? How has this impacted your life? "When you think about the future for [loved one], what worries you?"
17. What was your perspective about the patient recovery at the discharge? And now? If it is different, why have you changed your mind? For better or for worse?
18. What would be the best way to train you or any member from your family about the care for the patient? What is the ideal time to get this training? Who should provide the training? Are you agree with the training assigned (in-person or online training?)
19. What tools do you think could help you to provide good care to the patient?
20. For in-person training: Did you feel confident and trustful on healthcare worker who thought you on your sessions training? Was the same person both days? Was nurse patient while teaching you? Was nurse really worried about your learning? What can be improved? What was your perception about it?
21. For website training: was videos useful to your learning? What video or part do you think was more important or useful? Was something wrong about videos? Explain and detail please. What was your experienced using the online website training? Did you have some problems loging it? Was something missing on this website learning? What information or method do you think would have been helpful for your learning?

22. Could you describe if the intervention was easy to take or learn? What most helped you to finish the training?
23. Finally, could you describe if you have some barriers to receiving this training. Provide examples.

We appreciate all your responses; we will not share any identification information about you or the patient. Thank you for your time!

Questionnaire (strokes staff)

Identification code:

1. Since when do you train caregivers of patients with stroke?
2. What did you teach caregivers? When do you provide this training, how many times, provide some examples. What was different compared to the current hospital-based training program? Was this change positive or negative? Why? Provide some examples.
3. When patients have a nasogastric tube, which aspects do you teach or train to caregivers? Could you provide some examples? Was it different from before training program?
4. When patient has a foley tube, which aspects do you teach or train to caregivers? Could you provide some examples? Was it different from before training program?
5. Based on current hospital-based training, in what ways do you think caregivers could be trained about how to care for a patient with severe stroke? Would you change something?
6. What were barriers to providing this training? Provide some examples. How could these be improved or solve?
7. Did you identify some facilitators to perform this intervention? What would make it more feasible?
8. What tools do you think could help to teach and train caregivers to take care of the patients? Could you provide some examples or ideas?
9. Is the current time spent to teach caregivers enough to provide all information needed? What could be different?
10. What do you think was the caregiver's perception about the in-person training? Could you provide some experience be positive or negative?
11. Is the current staff sufficient to provide caregiver's training? Would be possible to maintain the hospital-based training the current staff? If new staff is required, how many would be and what do you think could be their role?
12. How do you perceive caregivers' response to training received? What aspects could be improved to maintain this hospital-based training? Give some examples.

We appreciate all your responses; we will not share any identification information about you. Thank you for your time!

Appendix 2. Evaluation forms

Caregiver Strain Index (30)

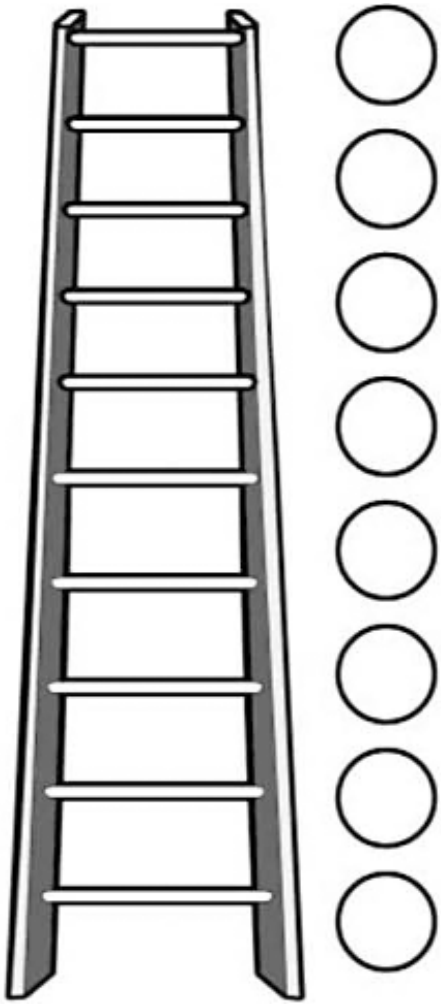
¿Cuáles de la siguientes situaciones son aplicables a usted como cuidador de ese paciente?	**SÍ**	**NO**
El sueño se turba (p. ej. porque el paciente se sube y se baja de la cama o porque vagabundea por la noche)		
Esto es muy incómodo (p. ej. porque ayudar al paciente me toma demasiado tiempo, o porque he de acudir desde muy lejos)		
Esto me somete a tensión física (p. ej. a causa de tener que levantarme de la silla una y otra vez; se requiere esfuerzo o concentración)		
Esto es aprisionante (p. ej. el ayudarle me reduce el tiempo libre o no me permite ir de visita)		
Hemos tenido que realizar reajustes en la familia (p. ej. porque ayudar al enfermo ha roto la rutina; no hay intimidad)		
He tenido que realizar cambios en mis planes personales (p. ej. he tenido que renunciar a un empleo o no he podido irme de vacaciones)		
Tengo que atender otras necesidades al mismo tiempo (p. ej. de otros miembros de la familia)		
Ha habido trastornos emocionales (p. ej. a causa de asuntos graves)		
Algún comportamiento del paciente es especialmente molesto (p. ej. incontinencia de esfínteres, no recuerda las cosas, acusa a la gente de llevarse cosas)		
Es muy desagradable ver que el paciente ha cambiado tanto con respecto a cómo era antes (p. ej. su personalidad ha cambiado)		
He tenido que realizar reajustes en el trabajo (p. ej. a causa de tener que dedicar más tiempo al paciente)		
Es una carga económica		
Me siento completamente abrumado (p. ej. a causa de preocupación por el enfermo, o preocupación por cómo voy a manejar la situación)		
Puntuación total:		

Global Quality of life (QOL) – Cantril Ladder.

Taken from The Cantril Ladder. Source: Cantril, H. (1965). The pattern of human concern. Rutgers University Press. HBSC survey(s): 2001/02, 2005/06, 2009/10, 2013/14.

Asuma que esta escalera es una forma de imaginar su vida. La parte superior de la escalera representa la mejor vida posible para usted. El último peldaño de la escalera representa la peor vida posible para usted.

Indique en qué parte de la escalera siente que se encuentra su calidad de vida en este momento marcando el círculo



La mejor vida posible

La peor vida posible

Modified Rankin Scale (mRS)

Taken from Wilson, L. J. T., Harendran, A. Grant, M., Baird, T., Schultz, U. G. R., Muir, K. W., Bone,I. (2002). Improving the assessment of outcomes in stroke: Use of a structured interview to assign grades on the Modified Rankin Scale. Stroke, 33, 22432246.

Level		Degree of disability
0	Asymptomatic	No symptoms or limitations
1	Very mild	No significant disability, presents some symptoms but no limitations to perform their usual activities and work
2	Mild	Limitations in their usual activities and previous work, but independent on activities of daily living (ADLs)
3	Moderate	Need assistance for some of the instrumental activities but not for the ADLs
4	Moderate to severe	Need assistance for ADLs, but don't need ongoing care.
5	Severe	Bedridden, incontinent, requires care (professional or not) throughout the day
6	Death	

Appendix 3. Codebook

	Code	Definition
1	before intervention_training	How was the training performed to caregivers before the implementation of the educational training to caregivers
	Caregiver	
2	Caregiver: caregiver_acceptability	Are you agree with the training assigned (in-person or online training?)
3	Caregiver: caregiver_barriers	could you describe if you have some barriers/dificulties to receiving this training. Provide examples.
4	Caregiver: caregiver_burden	How are you feeling as a caregiver of someone who has had a stroke? How has this impacted your life?
5	Caregiver: caregiver_care time	Is the patient permanently under your care? How much help do you receive? Who else is involved in the caregiving, i.e other family members, friends, paid caregivers?
6	Caregiver: caregiver_confident	Do you feel prepared to take care of your family, did the intervention help you to do this?
7	Caregiver: caregiver_previous training/experience	what prior knowledge or training had you received about stroke, rehabilitation, or caregiving prior to this intervention? Have you taken care of patients with some disability before? How long? What did you learn?
8	Caregiver: caregiver_relationship	Is the caregiver a patient relative's? friend? payed to take care the patient?
9	Caregiver: caregiver_suggestions	What would be the best way to train you or any member from your family about the care for the patient? What is the ideal time to get this training? Who should provide the training? What tools do you think could help you to provide good care to the patient? Was something missing on this website learning? What information or method do you think would have been helpful for your learning? What information would have been helpful on how to care your family member's condition and you didn't receive? Why do you think this information was not provided to you
10	Caregiver: expectations_patient	When you think about the future for [loved one], what worries you? What was your perspective about the patient recovery at the discharge? And now? If it is different, why have you changed your mind? For better or for worse?
11	Caregiver: presencial_experience	For in-person training: Did you feel confident and trustful on healthcare worker who thought you on your sessions training? Was the same person both days? Was nurse patient while teaching you?

		Was nurse really worried about your learning? What can be improved? What was your perception about it?
12	Caregiver: training_adaptations	
13	Caregiver: training_aplication	What training components caregivers apply to patient care
14	Caregiver: training_perception	During training: What was your perception about it? Could you describe if the intervention was easy to take or learn? What most helped you to finish the training?
15	Caregiver: virtual_experience	For website training: was videos useful to your learning? What video or part do you think was more important or useful? Was something wrong about videos? Explain and detail please. What was your experienced using the online website training? Did you have some problems loging it? Was something missing on this website learning? What information or method do you think would have been helpful for your learning?
	Cons	Any negative aspect, failure or disadvantages from the intervention received
16	Cons: atention_cons	Factors, barriers or issues related to the attention from stroke staff during the hospitalization or training time
17	Cons: caregiver_cons	
18	Cons: family_issues	
19	Cons: nursing_cons	What were barriers to providing this training? Provide some examples. How could these be improved or solve?
	Intervention	
21	Intervention: caregiver_foley tube training	For Foley tube caregiver's training. Do you feel confident to manage (cleaning, positioning) it? Can you tell me how you manage it? How many times is it changed? What do you recall from the training?
22	Intervention: caregiver_NG training	For NG tube caregiver's training. Do you feel confident to manage (cleaning, feeding) it? Can you tell me about how you manage it? For example, how do you clean it? How do you feed using this? How many times is the NG tube changed? What do you recall from the training?
23	Intervention: intervention_components	How was the training did you receive from the institute's staff for the care of the patient after their stroke? Was this done before patient's discharge? How many times did you attend in-person sessions or website training? How did this training look like (what was the content)?
24	Intervention: intervention_crossover	
	nursing staff	

25	nursing staff: nursing_components	What did you teach caregivers? When do you provide this training, how many times, provide some examples. What was different compared to the current hospital-based training program? Was this change positive or negative? Why? Provide some examples.
26	nursing staff: nursing_foley training	When patient has a foley tube, which aspects do you teach or train to caregivers? Could you provide some examples? Was it different from before training program?
27	nursing staff: nursing_NG training	When patients have a nasogastric tube, which aspects do you teach or train to caregivers? Could you provide some examples? Was it different from before training program?
28	nursing staff: nursing_perceptions	What do you think was the caregiver's perception about the in-person training? Could you provide some experience be positive or negative? Is the current staff sufficient to provide caregiver's training? Would be possible to maintain the hospital-based training the current staff? How do you perceive caregivers' response to training received? What aspects could be improved to maintain this hospital-based training? Give some examples.
29	nursing staff: nursing_suggestions	Based on current hospital-based training, in what ways do you think caregivers could be trained about how to care for a patient with severe stroke? Would you change something? What tools do you think could help to teach and train caregivers to take care of the patients? Could you provide some examples or ideas? Is the current time spent to teach caregivers enough to provide all information needed? What could be different? If new staff is required, how many would be and what do you think could be their role?
30	patient	Does the patient use NG or Foley tube? Does the patient require a permanent assistant?
31	patient: disease_onset	When was the patient diagnosed with their stroke?
32	patient: patient_complications	Has the patient had pneumonia? bladder infection?
33	patient: patient_foley tube	If the patient has foley tube, is still, having it? If no, when Foley tube was removed? Who and when did it? If yes, has Foley tube been changed? How many times? Who and when did it?
34	patient: patient_NG	If the patient has NG tube, is still, having it? If no, when NG tube was removed? Who and when did it? If yes, has NG tube been changed? How many times? Who and when did it? Is the patient taking in anything (food, medications, water) by mouth?

35	patient: patient_rehab	Does the patient receive rehabilitation? Which type, how many times per week, months? Are this payed by pocket? By health insurance? How many times per week/month?
36	patient: patient_status	Is the patient aware of his/her functional and mental status, about their environment? How has it changed? How is the patient feeling emotionally with regards to their current functional or cognitive status? How has it impacted their life? Is the patient in the same functional state (movement, feeding, ability to care themselves) as discharge time? In what ways has it changed? Is the patient in the same mental/cognitive state as discharge time? In what ways has it changed?
	Pros	Any benefits, pros or advantages from the intervention received What was the most helpful information you received regarding how to care for someone in your family member's condition? How it helped you? Could you give some examples?
37	Pros: caregiver_pros	
38	Pros: nursing_pros	Did you identify some facilitators to perform this intervention? What would make it more feasible?
39	tecnological support	
40	training process	How the intervention, procedures or patient identification was done?