

ORIGINAL ARTICLE

Sociocultural study on the self-perception of stroke and an analysis of doctor-patient communication

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KEYWORDS

Stroke;
Perception;
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communication

Abstract

Background: Stroke was historically attributed to magical and religious conceptions. We analyse the self-perception of stroke in stroke patients, the knowledge of vascular risk factors (VRF), and doctor-patient communication efficacy from an anthropological perspective.

Material and methods: Prospective study of stroke patients by semi-structured, in-depth interviews. Those with modified Rankin Scale >3, aphasia or severe dysarthria were excluded. The quality of the information from health staff to the patients, as well as the evaluation of this information by the health staff themselves, were analysed.

Results: The study included 100 patients (56 men), with a mean age of 61 (SD 16) years. Low educational level was present in 51%. Up to 83% did not know what was happening with the first stroke symptoms, and only 56% went to an emergency department initially. Only 19% could identify all their vascular risk factors (VRF), and up to 57% thought that the cause was due to a fortuitous factor. Poor knowledge of stroke was associated with low educational level (OR: 2.81; 95%CI, 1.14-6.90, $P=0.024$). Up to 75% of the patients did not understand the information provided by their doctor, but 65% felt well informed. Furthermore, up to 69% of physicians thought that patients were well informed; the same percentage felt that low educational level made communication difficult.

Conclusions: The knowledge of stroke and its VRF in stroke patients is low. They perceive it as something fortuitous associated to a strong emotional impact. Communication between doctors and stroke patients is relatively poor, although neither physicians nor patients detect this fact. This poor knowledge of stroke and VRF could have a negative influence on secondary prevention compliance.

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PALABRAS CLAVE

Ictus;
Percepción;
Factores de riesgo;
Comunicación médico-paciente

Estudio sociocultural sobre la autopercepción del ictus y análisis de la comunicación médico-paciente**Resumen**

Introducción: Históricamente el ictus se vinculó a concepciones mágico-religiosas. Analizamos la autopercepción del ictus en los pacientes, el conocimiento sobre factores de riesgo vascular (FRV) o desencadenantes, y la eficacia de la comunicación médico-paciente, desde un punto de vista antropológico.

Material y métodos: Estudio prospectivo de pacientes con ictus, mediante entrevistas en profundidad y observación participante. Excluimos pacientes con una escala de Rankin modificada > 3, afasia o disartria grave. Analizamos la calidad de la información ofrecida por el personal sanitario y su propia valoración, mediante encuestas abiertas.

Resultados: Se entrevistaron 100 pacientes (56 hombres), edad media 61 (DE 16). El 51% tenía un nivel educativo inferior o igual al básico. El 83% no reconocía que ocurría al sufrirlo y sólo el 56% acudió directamente a Urgencias. Un 19% identifica sus FRV y hasta el 57% piensa que lo desencadenó un factor fortuito. El desconocimiento de la enfermedad se asoció con un nivel educativo bajo (OR 2,81; IC 95% 1,14-6,90; $p = 0,024$). Un 75% no entiende el discurso biomédico, pero un 65% afirma sentirse bien informado. Por otro lado, el 69% del personal sanitario facultativo piensa que los pacientes están bien informados; similar porcentaje considera que el “bajo nivel cultural” dificulta la comunicación.

Conclusiones: El conocimiento de la enfermedad y sus FRV en los pacientes con ictus es escaso. Suelen percibirlo como algo fortuito asociado a un fuerte impacto emocional. La comunicación médico-paciente es ineficaz, ni profesionales ni pacientes detectan esta realidad. Esta falta de conocimiento de su enfermedad y sus FRV podría influir negativamente en una buena prevención secundaria.

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Introduction

Historically speaking, stroke has been understood as a paralysis beginning unexpectedly by the action of some kind of sudden or supernatural power. Etymologically speaking, the term “ictus” derives from the Latin ictus-us, referring to a “stroke of luck”, as does its equivalent in English, “stroke”, which comes from the phrase “Stroke of God’s hand”.¹ In general, cerebrovascular disease, together with the rest of the mental illnesses, have been associated with “divine punishment”, “religious curse”, “possession by demons” or “the evil eye”.

Anthropologically, a diseased state is defined by society’s conception of the disorder and the health-care system’s determination of the condition, both of which co-exist within the same culture. This is why the concept of “health” encompasses, apart from objective scientific aspects, several others that are subjective, such as mental well-being and social aspects of each culture and each historical period.²

Cerebrovascular disease is the third most important cause of death in the Western world, after heart disease and cancer, and is the number one cause of disability in adults. Its mortality, sequelae, and its cost all impact patients’ lives in a major way. We currently know that it is of vital importance for care to be provided early (at a Stroke Unit) with specific treatments, such as fibrinolysis³ in the

first few hours. However, stroke is still largely unknown in our society, which fails to perceive the risk it entails and, on occasion, is unaware of its existence.⁴⁻¹⁰ This hinders its treatment and oftentimes prevents quick action from being implemented.

We are starting from the hypothesis that most of the population is relatively unfamiliar with cerebrovascular disease and we believe that it is possible that there is still an influence of magical-religious concepts that have been carried forward throughout history. Perhaps there is inadequate perception of the disease and the knowledge regarding its causes does not correspond to reality, which gets in the way of the patient seeking proper medical care. On the other hand, it is possible that doctor-patient communication is inadequate and that this is what interferes with patients’ understanding of the illness.

In order to analyze these aspects, we have put forth three objectives:

1. To find out how patients perceive their own illness; that is, how they understand what is happening to them, what they believe has caused it, what they consider to be the main causes of stroke, and what concerns them most about the future, starting with what has happened to them.
2. To discover whether patients understand the importance of prevention with regard to their vascular risk factors

(VRF), to find out if they know what these are and what to do to prevent them.

3. To explore the levels of doctor-patient communication: what information the transmitter formulates and what percentage of that information is received by the receiver, as well as the perception that both parties have of it.

Our ultimate goal is to identify what the reality of today's society is as it refers to stroke; what conception people have of it, how they assimilate it with the means they have available. It is the first step toward trying to overcome the lack of information or assimilation of concepts. We must know where we are starting from if we are to find out how to reach a different level of understanding.

Material and methods

A prospective, observational study has been conducted with patients who had suffered a stroke in the preceding 3 to 12 months. Consecutive patients seeking care at the monographic Neurology-Cerebrovascular Clinic were included; all of them had a Modified Rankin Scale (mRS) score of 0 to 3. Patients presenting some type of impediment that kept them from being properly interviewed were excluded; examples include severe dysarthria, aphasia, and cognitive impairment. In addition, patients who had an mRS score greater than 3 were excluded, given that their physical mobility limitations might keep them from coming to the clinical several times for the interview with the specialist in Anthropology.

This is an anthropological study; hence, techniques typical of this discipline will be used: field work based on semi-structured and in-depth interviews (open-ended questions) and participant observation.

The methodology generally used in anthropological research is based on interviews and on intense observation of each case. One important issue is the balance between the depth of the information about individual cases versus the extension of the coverage, bearing in mind, too, the number of different variables that must always be included in any field research design. As an approximate empirical rule, suggested by some specialists in methodology, the community sample under study must comprise at least 100 cases in order to enable the performance to carry out complex, multivariate analysis.¹¹

When we refer to in-depth interviews, we are referring to repeated face-to-face meetings between the researcher and the respondents, aimed at understanding the prospects the respondents have with respect to their lives, experiences or situations, as expressed in their own words. On the other hand, the participating observers go into the field with the hope of establishing open relationships with the respondents. They behave in such a way as to become a non-intrusive part of the scene.^{12,13}

There is an indefinite period of time dedicated to each patient, stipulated by the different levels of communication and the fluency of the conversation, and thus, each patient sets the agenda they need. In this way, we know that the results are more accurate, given that we achieve a higher level of veracity regarding the patient's reality since, when

it comes to talking about such personal issues, it is very easy for the patient not to tell the whole truth when answering closed questions. The field work is carried out by an expert anthropologist, who oversees the in-depth interviews; it is always the same person, who functions during the interview as a mute observer. The data with respect to objective information (age, level of general education, etc.) were contrasted after the interview.

In order to design the interview scripts, previous publications¹⁴⁻¹⁷ were used as references, as well as consultation with professional anthropologists from the Autonomous University in Madrid and the University of Castilla La Mancha. Similarly, it has been reviewed by the medical team belonging to the Stroke Unit at the Department of Neurology (table 1).

As a result, qualitative and non-quantitative data have been collected, which bring us closer to the interviewee's circumstances. Subsequently, after extracting the data from the surveys, transcribing them literally, and analyzing them in-depth, variables have been created with the repeated responses to the open questions. That is, these variables were weighted once the interviewees' repeated responses have been observed; this has enabled us to work with descriptive, quantified analyses and multivariate analyses.

In order to analyze the effectiveness of the doctor-patient communication from several different angles, an open survey was distributed to the health-care personnel (physicians and nursing staff) of the Department of Neurology, where their point of view has been captured regarding communication with stroke patients. The open responses have once again been transformed into quantifiable variables.

For the statistical analysis, version 15.0 of the SPSS software package for Windows was used. The univariate analysis was performed using the χ^2 test or Fisher's exact test for dichotomous variables. Continuous variables were analyzed by means of Student's *t* test or the Mann-Whitney *U* test if normality could not be assumed. *P* values of < 0.05 were deemed to be significant. Logistic regression models were constructed to analyze the factors associated with knowledge of stroke and of its VRF. The values are presented with a 95% confidence interval (CI). The multivariate analyses were performed with those values whose *p* was < 0.2 together with gender and age by default. Multivariate analyses were carried out where the response variables consisted of: "lack of knowledge about what a stroke is", "biological interpretation of what causes stroke", "lack of knowledge about VRF", and "recognizing that he/she is suffering a stroke at the onset of symptoms".

Informed consent was obtained from all patients and health-care personnel. The work was also approved by the Clinical Research Ethics Board of our hospital.

Results

Between November, 2008, and April, 2009, in-depth interviews were conducted with a total of 100 patients (56% males), with a mean age of 61 years (SD 16, range 27-89). Eighty patients (80%) had presented a single cerebral infarct

and the remaining 20% were in follow-up due to recurring strokes.

The patients interviewed live in the North of Madrid, although many of them are from other regions in Spain and who had emigrated to Madrid and settled in this area. Only

17% had college-level studies versus just over half (51%), who had no studies whatsoever or who had only attended primary education.

Many of the patients did not know what stroke is prior to suffering one themselves; 42% had never heard about it

Table 1 Script of the in-depth interview

Patients

Demographic and clinical data

Age, gender, and level of education
 Profession: employment situation prior to the stroke
 Employment situation after the stroke
 Who does the patient live with in the home?
 Type of stroke
 Time elapsed since the stroke
 Rankin Scale

Open-ended questions

A) Perception of stroke and its triggers

Tell me about your illness. How did you live the experience? What happened to you and how did you react?
 What do you think caused the stroke? How and why did it occur?
 Do you know of any specific cause?

B) Knowledge about the stroke, the symptoms and risk factors of stroke

Explain to me what a stroke is. How would you define it?
 What symptoms did you have? Are you aware of other symptoms? Would you recognize it if it were to happen again?
 Before your stroke, had you ever heard of it? What did you think it was? Is your experience similar to what you thought before?
 How have you learned about stroke? What sources of information have you used? Which do you think is the most reliable? Who helped you to learn about stroke?
 Do you know what the vascular risk factors are?

C) Religious beliefs and neurological recovery

Are you a believer?
 What type of religion?
 Tell me, how do you feel about religion? Do you think it has affected what's happening to you?

D) Alternative medicines

Have you visited any other specialist or healer other than here in the hospital?
 Do you think any other (alternative) medicine or therapy can help you get better? What kind and how?

E) Life after stroke

How do you feel about your life now? Explain the changes in your life to me.
 Tell me some adjectives that define how you feel right now
 On a scale of 1-10, how would you assess the change in your life?
 Tell me about the projects you have for the future
 What do you fear?

F) Doctor-Patient Communication

What do you think about doctors? (Do they treat you well, inform you well, ...?)
 Do you understand the medical reports?
 Do you understand your doctors when they talk to you?

Professionals

Profession

Open-ended questions

Perception of communication with patients

Do you explain their disease to your stroke patients? How?
 Do you speak with them directly or only with their relatives?
 Do you think they are well informed about their illness and their risk factors? Explain your answer
 For you, what is the most difficult part of communicating with them?
 What do you think were their main doubts?

and, in fact, the name didn't even ring a bell with them. Of the remaining 58% who did identify the name, only 16% really knew what it referred to, *a priori*. The overwhelming majority (83%) do not recognize what's happening to them at the time they suffered the attack: they realize that it is something serious, but only 27% know that they are suffering a stroke. The rest seek medical care without knowing what is going on. The symptoms that are of greatest warning to them are difficulty walking, being unable to speak, or facial asymmetry. However, for the most part, they are unaware of the need to get to the hospital immediately. One fifth of respondents (21%) had suffered recurring episodes and even at that, 76.2% did not recognize the symptoms. A considerable number of the interviewees went directly to the Emergency Room (56%). However, there is one group of patients who first sought care from the Primary Care Physician, running the risk of being given an appointment that was not for the same day (18%), as they were unaware of the compelling need to gain time, and even more of the interviewees (25%) stayed home and rested. Insofar as the future is concerned, the patients mostly feared having another stroke (35%), followed by fear of dying after the stroke (22%), and the fear of not fully recovering or being left an invalid (19%). Ninety per cent (90%) of the respondents believe in God (Catholic religion) and 60% believe that religion has had a positive effect on their recovery from their illness.

Forty-nine per cent (49%) were able to give an approximate explanation of the biological mechanisms of their illness, but only 43% gave a rationale for the causes of their illness associated with biological mechanisms or with some risk factor. Most thought that the causes were due to an emotional upset, caused by a strong impact, or by going through a stressful situation that they felt was extreme (51%). The rest did not know what the causes were and did not show any interest in them or else associated them with fate or destiny.

Sixteen per cent (16%) of the patients were seen to have sought information about their illness on the Internet; 13% in books and libraries; 33% had asked for information from the members of their family, and 64% had asked the doctor.

Most of the interviewees claimed to have been treated very well (81%) and very well informed (65%) by the medical staff. This is in contrast with the 57% who did not know the causes of their illness, the 81% who could not identify their VRF, and the 75% who claimed to have read the reports and not understood them (table 2). Of the 45% who reported not having been well informed, most thought that the doctor had not given them enough information (68.8%) and the rest thought that they hadn't understood what the doctor had said.

The multivariate analysis of the factors that had to do with a lack of knowledge about what a stroke is, that is, not knowing how to define a stroke or defining it using a description that does not reflect the reality of stroke. This analysis revealed that a low level of formal education is independently associated with this lack of knowledge (OR 2.81; 95%CI: 1.14-6.90; $p=0.024$), adjusted for demographic data, living alone, working outside the home, and having suffered a previous stroke. Being older also tended to be related to this lack of knowledge (OR 4.22; 95%CI: 0.99-18.03; $p=0.052$) (table 3).

Table 2 Descriptive, quantified analysis

Patients	
Variable	Univariate analysis (n=100)
<i>Range (mean age $\pm$ SD)</i>	27-89 (61 $\pm$ 16)
<i>Gender n (%)</i>	
Men	56 (56%)
Women	44 (44%)
<i>Education (%)</i>	
Illiterate / Primary Education	51 (51%)
Secondary Education	32 (32%)
University Education	17 (17%)
<i>Profession prior to the stroke n (%)</i>	
Skilled profession	17 (17%)
Unskilled profession	43 (43%)
Retired	30 (30%)
Unemployed/ housewife	10 (10%)
<i>Profession after the stroke n (%)</i>	
The same	59 (59%)
Another, less-qualified job	4 (4%)
Leave due to illness or early retirement	37 (37%)
<i>Daily company n (%)</i>	
Lives with the family	80 (80%)
Some relative takes care of her / him	5 (5%)
Lives alone	13 (13%)
Lives alone with children	2 (2%)
<i>Has suffered more than one episode n (%)</i>	1 (1%)
<i>Rankin Scale n (%)</i>	
R-0	49 (49%)
R-1	32 (32%)
R-2	10 (10%)
R-3	9 (9%)
<i>Time elapsed since the stroke ($\leq$ 6 months) n (%)</i>	59 (59%)
<i>First reaction, n (%)</i>	
Emergency Room	56 (56%)
Primary Care Physician	15 (15%)
Stayed home resting	29 (29%)
<i>Believes that the first specialist who saw him / her did not recognize the stroke</i>	4 (4%)
<i>Recognizes the symptoms of stroke and what is happening to him / her, n (%)</i>	17 (17%)
<i>Describes illness in biomedical terms, n (%)</i>	49 (49%)
<i>Causes of stroke</i>	
Biological mechanisms	43 (43%)
Strong impact / emotion / stress	51 (51%)
Does not know causes / outcome	6 (6%)
Believes that the doctor knows the causes, n (%)	84 (84%)

(Continued)

Table 2 (Continued)

Patients	
Variable	Univariate analysis (n=100)
<i>Recognizes vascular risk factors n (%)</i>	
Recognizes all risk factors	19 (19%)
Recognizes some factors	50 (50%)
Doesn't recognize any risk factor	31 (31%)
<i>If they were to experience another episode, they think they would recognize it, n (%)</i>	
The symptoms experienced	65 (63%)
The symptoms experienced and others they have learned about	9 (9%)
None	27 (27%)
<i>Have learned about the illness, n (%)</i>	72 (72%)
<i>Source of information: doctors, n (%)</i>	64 (64%)
<i>Source of Information: Internet, n (%)</i>	16 (16%)
<i>Source of Information: books/ encyclopaedias, n (%)</i>	13 (13%)
<i>Sources of Information: relatives/ friends, n (%)</i>	33 (33%)
<i>Had heard about it prior to their stroke, n (%)</i>	58 (58%)
<i>They knew what it was, n (%)</i>	16 (16%)
<i>They believe their doctor treated them well, n (%)</i>	81 (81%)
<i>They feel their physicians informed them well, n (%)</i>	65 (65%)
<i>Believers, n (%)</i>	90 (90%)
<i>Belief that religion influences their recovery, n (%)</i>	
Positively	60 (60%)
Negatively	12 (12%)
No	28 (28%)
<i>Other complementary medicine (alternative medicines), n (%)</i>	12 (12%)
<i>Scale 1-10. Assessment of diminished quality of life</i>	
<i>Fears, n (%)</i>	
Harming my family / leaving my children on their own	7 (7%)
Recurrence / death	60 (60%)
Disability / not recovering	19 (19%)
<i>Doesn't understand medical reports</i>	75 (75%)
<i>Can reproduce the explanation given by their doctor and his/ her report</i>	19 (19%)
Professionals	
Variable	Univariate analysis (n=46)
Mean Age ($\pm$ SD)	65-22 (36 $\pm$ 16)
Gender, n (%)	
Men	11 (24%)
Women	35 (76%)

Table 2 (Continued)

Professionals	
Variable	Univariate analysis (n=46)
Profession (%)	
Medical personnel	17 (37%)
Nursing personnel	29 (63%)
Perception of communication with patients (%)	
Explains illness to stroke patients	39 (85%)
Speaks directly with patients	43 (43%)
Considers that they are well informed n (%)	
Medical Staff: Yes	12 (69%)
Nursing staff: Yes	14 (40%)
Difficulty when it comes to communicating, n (%)	
Medical Staff	
Cultural differences	12 (69%)
Space, status, and situation in which communicating information	5 (26%)
Nursing staff	
Cultural differences	28 (80%)
Space, status, and situation in which information is given	7 (20%)
Consideration of patients' greatest concerns, n (%)	
Recurrence / recovery	35 (74%)
Causes	7 (15%)
Diagnosis/ care	4 (11%)

A multivariate analysis was carried out on the factors that have to do with a biological interpretation of the causes of stroke; i.e. explaining stroke as a biological entity and not as some fortuitous, emotional, or supernatural event. The only factor that was independently associated was thinking that religion has no affect whatsoever on recovery (OR: 2.81; 95%CI: 1.06-7.41; p=0.036) (table 4).

None of the factors analyzed (gender, age, level of education, and having suffered a previous stroke) was independently associated with the lack of knowledge about VRF; that is to say, with the fact that the patient did not know how to list any of their VRF (Table 5). Likewise, no factor was found to be associated with recognizing that they were suffering a stroke at the onset of symptoms (table 6).

In contrast, 69% of the medical health-care personnel interviewed thought that the patients are well informed and the same percentage stated that they had provided sufficient explanation to patients and relatives. Moreover, they thought that the most important obstacle to communication with the patients is their "being uneducated". Sixty per cent (60%) of the nursing health-care personnel interviewed felt that the patients were not well informed and believed that the biggest hindrance to

Table 3 Uni- and multi-variate analysis of the factors associated with a lack of knowledge of what a stroke is^a

Variable	Univariate analysis OR (95%CI)	p	Multivariate analysis OR (95%CI)	p
Being female	1.09 (0.49-2.41)	0.843	1.70 (0.69-4.19)	0.249
Age ≥ 65 years	3.19 (1.14-7.25)	0.006	4.22 (0.99-18.03)	0.052
Low level of education ^b	3.45 (1.51-7.85)	0.005	2.81 (1.14-6.90)	0.024
Lives alone	1.63 (0.49-5.40)	0.415		
Works outside the home	0.50 (0.22-1.13)	0.096	0.53 (0.12-2.24)	0.390
Previous stroke	1.36 (0.51-3.60)	0.526		

CI: confidence interval; OR: odds ratio.

^aDoes not know how to define stroke or does so by means of a description that is not realistic.^bNo studies or only primary studies.**Table 4** Uni- and multi-variate analysis of the factors associated with a biological interpretation of the causes of stroke by the patient ^a

Variable	Univariate analysis OR (95%CI)	p	Multivariate analysis OR (95%CI)	p
<i>Being female</i>	0.51 (0.22-1.16)	0.111	0.59 (0.24-1.45)	0.253
<i>Age ≥ 65 years</i>	1.13 (0.51-2.51)	0.74	1.19 (0.48-2.94)	0.700
<i>Low level of education^b</i>	0.66 (0.29-1.47)	0.313		
<i>Lives alone</i>	0.20 (0.04-0.97)	0.031	4.64 (0.89-24.17)	0.068
<i>Works outside the home</i>	0.79 (0.35-1.77)	0.57		
<i>Previous stroke</i>	0.45 (0.16-1.29)	0.133	0.59 (0.18-1.85)	0.366
<i>Influence of religion on recovery^c</i>				
Yes, positively	1 (reference)		1 (reference)	
Yes, negatively	1.32 (0.37-4.69)	0.661	1.42 (0.38-5.34)	0.599
No	2.87 (1.13-7.24)	0.026	2.81 (1.06-7.41)	0.036

CI: confidence interval; OR: odds ratio.

^aExplaining causes of stroke as biological and not chance, emotional, or supernatural.^bNo studies or only primary studies.^cPatient perception of influence religion has on recovery.

communication with them was the situation in which the information was being given or the patient's status (80%). In both health-care groups, 74% agreed that what concerned stroke patients most was their recovery and the possible recurrence of the stroke (table 2).

Discussion

This work reveals that the perception of the causes of the illness among stroke patients is distorted, and that both the knowledge regarding the biological mechanisms of stroke,

Table 5 Uni- and multi-variate analysis of the factors associated with the lack of knowledge about vascular risk factors^a

Variable	Univariate analysis OR (95%CI)	P	Multivariate analysis OR (95%CI)	p
Being female	1.48 (0.65-3.33)	0.344	0.56 (0.23-1.37)	0.206
Age ≥ 65 years	2.03 (0.89-4.62)	0.087	0.55 (0.21-1.40)	0.211
Low level of education ^b	1.98 (0.87-4.52)	0.099	0.62 (0.24-1.56)	0.314
Lives alone	1.02 (0.30-3.39)	0.971		
Works outside the home	0.65 (0.28-1.48)	0.311		
Previous stroke	2.71 (1.01-7.26)	0.042	0.46 (0.16-1.29)	0.140

CI: confidence interval; OR: odds ratio.

^aDoes not recognize any VRF.^bNo studies or only primary studies.

Table 6 Uni- and multi-variate analysis of the factors associated with recognizing that the person is suffering a stroke at the time of symptom onset

Variable	Univariate analysis OR (95%CI)	p	Multivariate analysis OR (95%CI)	p
Being female	1.58 (0.51-4.91)	0.427	1.41 (0.45-4.35)	0.550
Age $\geq$ 65 years	0.56 (0.19-1.62)	0.284	0.70 (0.11-4.19)	0.697
Low level of education ^a	1.15 (0.40-3.27)	0.790		
Lives alone	0.63 (0.15-2.62)	0.532		
Works outside the home	2.39 (0.82-6.94)	0.101	3.00 (0.51-17.44)	0.221
Previous stroke	0.57 (0.11-1.86)	0.350		

CI: confidence interval; OR: odds ratio.

^aNo studies or only primary studies.

as well as its risk factors, is scant. Ours is an original study, since to date, we have not found any anthropological study similar to this one that deals with the perception of stroke; hence, this is a pilot study. From an anthropological point of view, a sample of 100 patients is sufficient to be able to derive preliminary data; consequently, this is a starting point for obtaining an adequate sample size for future studies.

In general, the profile of the interviewees is that of an elderly population, with a low level of education. Most of the respondents believe that the origin of their illness lies in having suffered a strong impact, being upset, an emotional blow or stress, unrelated to VRF or biological mechanisms, although during the interview these have been identified as being harmful. The concept or the belief that an emotionally stressful situation or distress can be the cause of severe illness has been deeply rooted in the popular mindset for a long time.¹⁷

Up to 60% of the interviewees feel that religion safeguards or benefits them and they have faith in its influence to achieve a fuller recovery. The perception of the illness as a fortuitous factor, unrelated to risk factors, is associated with this patient profile. In this regard, studies have been published that demonstrate that religious beliefs contribute to a favourable recovery.¹⁸ Specifically, the University of Texas conducted a study that compared recovery among stroke patients who went to church and those who did not and found that the recovery process in the group of people who went to church was slightly faster than in those who did not.¹⁹ In this study, we have limited our work to merely documenting the perception of the illness by profiles, but we do not analyze the intensity of their beliefs, or its relation with their levels of neurological recovery.

Some studies have focused on researching the degree of knowledge about stroke in the general population and most of them coincide in underscoring the insufficient knowledge about cerebrovascular disease and its VRF, even in people at high risk.³⁻⁵ Moreover, many of those studies conclude that a good understanding of stroke is not necessarily associated with a good attitude or response to the first symptoms of stroke.^{6-10,20} Similar data have been published by Williams et al.²¹ who found that, although 38% of their interviewees stated that they knew the warning signs of stroke, only 25% knew how to interpret their symptoms

correctly. Knowing about stroke was not associated with getting to the Emergency Room quickly, mostly because the patients perceived their symptoms as not being severe. Other earlier quantitative and qualitative studies report similar responses to the appearance of the initial symptoms of stroke.²²⁻²⁵ They conclude by saying that the symptoms are not easy for patients to recognize due to the fact that they vary greatly. In our study, the act of going to the Emergency Room (56%) is not seen to be related with greater knowledge about the illness at that time (17%), but rather it has to do more with other factors such as the disability it causes in the patient or the patient's attitude or that of their family members when faced with the warning signs. This hinders the use of specific therapies targeting acute stroke, which have a small window for application if they are to be effective. It has been pointed out that the delay in seeking medical care after the onset of stroke symptoms is the most common reason for the low rates of use of intravenous thrombolysis.²⁶ Hospitals can be outfitted with modern diagnostic and treatment techniques, but these will not be efficacious if the patient is too late in getting to the Emergency Room, due to a lack of adequate knowledge about the situation.

Despite stroke awareness-raising campaigns aimed at the general population, knowledge about the warning signs and VRF has not improved in recent years, as was recently demonstrated in a study carried out in 1995, 2000 and 2005.²⁷ Perhaps the campaigns' message was not properly understood by the general public and we should use simpler language, putting greater emphasis on the importance of getting to the hospital quickly.²⁸

Surprisingly, patients who have suffered the illness and have been admitted to hospital and informed (both patients and their relatives) by health-care personnel, even after having received reports and their medical discharge, then attend follow-up appointments and still do not have a good understanding of stroke. Furthermore, these patients are not aware of all their VRF and, more often than not, they interpret that an external, uncontrollable agent has caused the cerebrovascular event. These data contrast with the great concern and fear of these patients in the sense that they will suffer another stroke.

The main sources of information about stroke for our patients were their doctors, followed by family members.

However, the transmission of information from the physician to the patient was only totally effective in 25% of cases, despite the fact that more than 65% of the patients stated that they were satisfied with the information received from their doctor and the levels of communication established.

Of the 45% who said that they had not been informed, most felt that their physician had not given them the information, either because he/ she did not want to give all the information to the patient or, in a minority of cases, because they believe that the physician didn't know either. One way or another, we know that the physician has given the patient the information and that the patient has not even been aware of having received it. It may be that on occasions, because of the patient's status during their stay or at the time of discharge, only the relatives are informed and that they have not passed that information on to their family members in order to protect them or for some other reason.

On the other hand, some patients have received information but not all of them are assimilating it properly. This is a key point. If the patient does not understand the information the doctor is giving them, they will not be able to identify the causes of stroke or the risk factors that may be directly involved in the secondary prevention of stroke.

When asking health-care personnel about communication with patients, we find that most physicians believe that the patient is well informed. However, most of the personnel admit that the patient does not fully understand many of the biomedical processes involved in stroke or its triggers, as well as how they relate to symptoms. In contrast, the nursing staff is seen to be closer to the real world of their patients, citing higher percentages of those who are not well informed. In addition, when asked about the greatest difficulty they have in communicating with patients, the medical personnel state that it is the low level of education of the patients, whereas the non-medical staff find greater difficulty in the patient's physical condition, the situation he/ she is going through, and the place and conditions in which information is being given. Differences in training have been seen to affect doctor-patient communication, since they do not know how to get the message across in a more colloquial way. Numerous publications in the area of health anthropology have looked into these relevant issues. A pilot study examined the relationship between effectiveness in the methods used by the physician to inform patients of their VRF and patient decision-making with respect to treatment.²⁹

Our study is based on an anthropological approach with the support of other disciplines, such as Neurology and Neuropsychology, giving rise to an original system that combines the qualitative analysis of Anthropology, with the application of quantitative data analysis. Other qualitative studies that have analyzed the experience lived by stroke survivors can be classified into three groups: those that study an appraisal of needs among stroke patients and the relatives of stroke patients; research that examines doctor-patient communication; and, finally, analyses looking at the quality of life of stroke patients and their relatives.³⁰⁻⁶ By using this anthropological perspective, we have sought to learn more about stroke patients' perception of how they have experienced their illness, how they live it, how they

make sense of it, and how they overcome it. This methodology of in-depth interviews, based on open-ended questions, without a pre-established order and without time restrictions for the interview, enabled the patient to speak more confidentially, in a more relaxed atmosphere created by the anthropologist, making it easier to gather information that would not be possible by means of exclusively quantitative studies. On the other hand, verifiable variables are created, extracted from the privacy of their own confidences, from responses that were repeated by the patients spontaneously when interviewed, without any kind of title or link having suggested it to them. In this case, we applied the statistical methods most widely used in other disciplines to compute and analyze the information. Thus, we elaborated a broader analysis of this reality.

Many stroke survivors do not understand cerebrovascular disease except as an unforeseen, sudden event that is usually triggered by strong emotional impact or stress, unrelated to risk factors. This perception of the disease is associated with considering that religious belief affects recovery. Most patients are unable to recognize the symptoms of stroke and little more than half of them seek emergency medical care. A lack of knowledge about the association of stroke with its risk factors occurs in patients who have been previously informed by physicians. There are many gaps in doctor-patient communication and patients are not receiving the whole message being transmitted by their doctors, which may have a bearing on them not complying properly with secondary prevention measures. On the other hand, 31% of the interviewees claimed that they had not received any medical information. We know that the doctor has informed them, but we do not know whether the patient has been unable to assimilate the fact that they were being informed or if one of their relatives filtered the information and failed to pass on the necessary information. Either way, this is a communication problem that should be solved, given that the doctor must make the information reach the patient clearly, concisely, and easily understandable.

In light of this work, the Neurology Department has started up weekly informative workshops for stroke patients and their family members in an attempt to guarantee that the mechanisms of stroke and its risk factors are understood. In addition, an information sheet about their illness and care recommendations is being given to them together with their discharge report. This information sheet is written in simple, colloquial terms that are also adopted by the medical staff to provide them with explanations that are easier to understand about the causes of their illness (appendix 1).

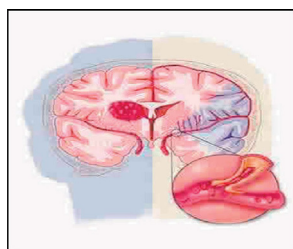
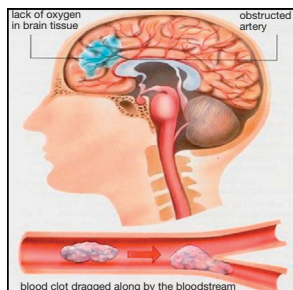
In conclusion, there is very little knowledge about stroke and related VRF in patients who have suffered one. Doctor-patient communication is ineffective and neither professionals nor patients detect this reality. This lack of knowledge about the disease and the related VRF can have a negative impact on good secondary prevention.

In light of all the above, we suggest that the systems of doctor-patient communication be improved and we recommend starting up training courses for health-care professionals in techniques of doctor-patient communication.

Conflict of interest

The authors state that there is no conflict of interest.

Appendix 1. Information about types of stroke and their causes



A Stroke is a brain injury, due to a disturbance of blood flow; it may be due to haemorrhage or brain infarction.

One way or another, the blood no longer reaches a part of the brain. When this happens, the brain no longer receives the oxygen and nutrients it needs. As a result, brain cells are damaged and the brain may stop sending signals to other parts of the body that control things such as speech, thinking, and movement.

Here is a short description of the type of stroke you have suffered.

- **Brain haemorrhage.** This happens when the arteries that go to the brain rupture, causing internal bleeding. The most common cause for this is high blood pressure, although there may be other causes.
- **Cerebral Infarction:** This happens when an artery of the brain is obstructed by a thrombus.
- **Lacunar;** this is a small brain infarct caused by a thrombus* in a small artery, which is generally associated with having high blood pressure or diabetes.
- **Artero-thrombotic** or thrombosis, caused by a thrombus*, which in this case has formed due to plaques of cholesterol in the arteries.
- **Cardioembolic;** or embolia is due to a **thrombus*** that comes from the heart. In this case, the thrombus has formed as a result of altered heart function.

***Athrombus** is a blood clot that plugs up the inside of the artery, preventing the blood from flowing normally and causing **insufficient blood supply**. The thrombus blocks the arteries of the brain, keeping blood from reaching that area of the brain for a few moments and damaging it. The damage may be permanent, but it may also be reversible.

The **factors** that can cause **these clots** may be: **cholesterol, smoking, alcohol, blood sugar, high blood pressure, heart disease** or less easily controlled factors, such as **age** or **genetic inheritance**. **Starting today, in order to keep it from happening again, you should take care of your cerebrovascular risk factors.**

Ask your doctor to clearly explain these risk factors to you and how to control them; it is important that you understand it.

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