

Perceptions of stroke in the general public and patients with stroke: a qualitative study

Sung Sug Yoon, Julie Byles

Abstract

Objectives To gain insight into people's thoughts on stroke and to inform the development of educational strategies in the community.

Design Focus group discussions: two groups of people who had a stroke and their carers, and two groups of members of the general public.

Setting New South Wales, Australia.

Participants 35 people participated: 11 from the general public, 14 people who had had a stroke, and 10 carers or partners.

Main outcome measures Views on risk factors, symptoms, treatment, information resources, and prevention.

Results All groups reported similar knowledge of risk factors. People generally mentioned stress, diet, high blood pressure, age, and smoking as causes of stroke. Participants in the community group gave little attention to symptoms. Some participants who had had a stroke did not initially identify their experience as stroke because the symptoms were not the same as those they had read about. There were mixed feelings about the extent of involvement in management decisions during hospital admission. Some felt sufficiently involved, some wanted to be more involved, and others felt incapable of being actively involved.

Conclusions Symptoms of stroke are not easy to recognise because they vary so much. Presentation of information about stroke by hospital and community health services should be improved. Simple and understandable educational materials should be developed and their effectiveness monitored.

Introduction

Studies of acute intervention for stroke have shown that outcome is more favourable if the symptoms are recognised early. However, most people do not seek timely medical attention.¹⁻⁴ Many factors contribute to delays in seeking medical treatment for acute stroke, but one that should be remediable is public lack of knowledge about symptoms, which often results in delay in seeking medical care.⁵

Our previous study on public perception of warning signs, symptoms, and treatment of stroke in an urban area of Australia showed that only 73% of respondents identified the brain as the organ affected

by stroke.⁶ When asked how they would respond to the occurrence of a stroke, 90% of respondents said they would call an ambulance or visit a hospital emergency department. However, when asked about how they would respond to various symptoms, without reference to stroke, only 23-42% indicated that they would respond in either of these recommended ways. Over half of respondents did not know of any of the existing organisations that provided information about stroke or support to patients and their families.

We have previously shown there is a lack of information available to people in the community.⁷ This deficiency continues despite evidence showing that better knowledge is associated with early presentation in hospital emergency departments.^{5,8} The benefits of hospital based education and counselling that deals with the emotional and social concerns of people with a stroke and of their carers have been described.^{9,10} Effective community education programmes are vital to increase public awareness of stroke.

We carried out a qualitative study to obtain insight into people's thoughts on stroke, including risk factors, symptoms, treatment, information resources, and prevention; to inform the development of an educational strategy for the early recognition of symptoms and for appropriate responses to these in the community; and to inform the development of an educational programme for people who have had a stroke.

Method

Design of study—We conducted focused discussions with groups of people who had had a stroke and their carers (in two groups) and with members of the general public (in two groups). The group discussions took place in a non-clinical setting in hospital. The study was approved by the Newcastle University and Hunter Area research ethics committees.

Sample—We selected people who had had a stroke from the heart and stroke register in Hunter Area Health Authority.¹¹ All of them were living in the community and had agreed to be contacted for participation in further studies. The register sent 87 information letters and consent forms to people who had had a stroke between July 1999 and July 2000. Of those, 56 letters were returned, and 27 people agreed to participate. We contacted each person to organise a date for group discussions. Fourteen out of 27 people

Centre For Clinical Epidemiology and Biostatistics, Faculty of Medicine and Health Sciences, University of Newcastle, New South Wales 2308, Australia
Sung Sug Yoon
nurse
Julie Byles
associate professor

Correspondence to:
S Yoon
sungsyoonyoon@
yahoo.com

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who had had a stroke and 10 carers attended. We recruited 11 people who had not had a stroke from the local area using a snowballing technique. This method entails identifying initial participants in the study group who go on to recommend other people for recruitment. Each of the subsequently interviewed participants is asked for further recommendation.^{12 13} The method is also useful in the generation of hypotheses and to obtain an idea of the range of responses on ideas that people have.^{14 15}

Discussion guide and procedure—We developed a discussion guide on the basis of findings of previous studies.^{6 7 16–21} Six items dealt with knowledge and perceptions of risk factors, symptoms, treatment, information resources, and reaction to symptoms. Participants also completed questionnaires that were collected anonymously. The questionnaires included items on age, sex, marital status, country of origin, education, income, and self reported risk factors (high blood pressure, angina, heart attack, previous stroke, diabetes, high cholesterol concentration, smoking, and family history of stroke). Each discussion group was moderated by the same two researchers, who ensured that each group fully discussed each item on the agenda and that all respondents had sufficient opportunity to air their views. A moderator introduced the topic and assisted the participants to discuss it, encouraging interaction and guiding the conversation. Discussions lasted 60–90 minutes, with an additional 30 minutes for refreshments and informal conversation. Every session was audiotaped, with the written consent of each participant, and transcribed verbatim. At the end, information was provided regarding support services available for people with stroke and their carers. Participants were offered the opportunity to review the transcripts and the final analysis.

Analysis

We developed higher codes from the data, including definition, risk factors, symptoms, treatment, reaction, differences, and information. We read and re-read the transcripts and notes and organised data into initial codes, then into higher codes that provided insight into identified themes. For example, one participant mentioned “It is very repeated and everything you pick up is telling you the same things” to one question in the discussion guide (“has anyone ever seen a pamphlet or poster or TV commercial on stroke? How did you feel about the information?”). This goes to initial code “presentprg”, which represented data for evaluation of present programmes then into higher codes on “information” which included initial codes of “presentprg” and “preferprg” (prefer programmes for stroke information).

We identified and discussed a hierarchical scheme of specific themes, issues, and problems that emerged from the data. We used the computer package Ethnograph 5.0 to analyse data more conveniently and effectively.²²

Results

Thirty five people attended meetings: 11 from the general public (85% of those invited), 14 of the 27 people who had had a stroke and agreed to participate (16% of those invited), and 10 carers or partners. The table

shows demographic characteristics for patients and the general public.

Perceptions of stroke

Participants in both groups described stroke as a clot or a bleed. These participants believed that a blood clot went into the brain and blocked the blood circulation, which caused the affected part of the brain to become inactive. This resulted in the body being affected in one or more ways. Participants who had experienced a stroke were more likely to speak about stroke in their own idiom rather than using terminology from text books or available educational information—for example, “Headness, just headness—you know it was not headache at all—it’s like something is going on in my brain—also dizziness.”

Participants were asked questions about the possibility of having a stroke. Most regarded the thought of any illness as an unnecessary additional worry. Indeed, they avoided thinking about any illness or other adverse events. There was a greater focus on the risk of heart attack or cancer than on the risk of having a stroke. Before they had a stroke most participants in the patient group had never thought about their lifetime chance of having a stroke and some knew nothing about stroke.

Risk factors and symptoms of stroke

All groups reported similar knowledge of risk factors for stroke. People generally mentioned stress, diet, high blood pressure, age, smoking, and genetics as causes of stroke. Few people believed that stroke can occur without any cause or without the presence of risk factors. Some people particularly emphasised stress and diet: “I always imagined that stress and frustration affected blood pressure, which sent it sky high, and then the blood pressure brought on the stroke”; “We are getting much fatter, because we’re eating so much more. Because everywhere you go there is so much you can eat and it is so easy.” With regard to prevention, people pointed to community education, change of life style, and school or institution programmes. Descriptions of symptoms by people who had had a stroke (box 1) differed from descriptions by members of the general public group, which tended towards terminology found in textbooks or in National Stroke Association publications.²³

Response to stroke symptoms

Box 2 shows how people in the general public group said they would respond to symptoms of stroke and

Characteristics of participants in group discussions of awareness of stroke

	Community groups (n=11)	Stroke groups* (n=14)
Mean (SD) age (years)	64.0 (9.3)	70.1 (5.6)
Men	4	7
Women	7	7
Country of origin:		
Australia	11	13
Overseas	0	1
High blood pressure	2	10
High cholesterol	8	3
Heart disease	0	2
History of stroke	0	2
Family history of stroke	2	6
Current smoking	2	2

Box 1: Key comments—recognition of symptoms**General public**

Had a stroke, people just think of paralysis
Swallowing and different things happen
Personality changed completely
Loss of vision for no reason
Lost control of her bladder
Tremors in your hand
Pain or something like that, maybe dizziness
Tingling sensations
Memory loss
Headaches
Blurred vision

Stroke groups

Emotional incontinence; easily laughing and crying
Speech sounds like a bird or as if drunk
Headache
Feel funny, feel heavy, strange feeling on my face
Right side falling
Face looking dreadful
Had taste like pine taste
Light headedness
No headache just bang and crying
Tongue was a bit funny for a while
The left side of my face, especially my mouth area, felt strange and tingly
Getting a little strange while I was walking around like a drunk
I lost the use of my left arm and collapsed
I had no feeling in my right arm, my face went a bit funny
Balance and double vision

how patients who had had a stroke did respond to their symptoms. Participants in the general public groups placed little importance on the symptoms. In reaction to the symptoms of numbness, tingling sensation, and weakness or paralysis of one side of the body some of them said they would lie down and take couple of paracetamol. But if they experienced difficulties in speaking (which they perceived as definitely abnormal), they would seek urgent medical attention.

Many in the stroke groups initially did not take their symptoms seriously and had waited for symptoms to abate. Most did not realise that the symptoms were related to stroke: "... not thinking it was a stroke, I had no idea," "when I had the stroke, I didn't know what it was, I never had a clue," "I didn't actually know what it was because I have never been sick." Some did not identify their experience as stroke because the symptoms did not present as expected. Both groups thought that they would not receive any medical attention for minor symptoms such as headache and dizziness.

Treatment and expectation of treatment

Participants in both groups referred to rehabilitation as including physiotherapy, speech therapy, and occupational therapy. Some people described a drug for dissolving clots in the blood vessels and procedures for removing a clot from the artery, such as endarterectomy. Most of those who had had a stroke were aware of their own drug treatment and were concerned about the side effect of drugs. Box 3 shows their expectations of treatment after admission to hospital. A serious difficulty encountered during admission was

Box 3: Expectations of treatment in stroke groups

Important to know information like what is going on
Don't know what are the expected symptoms—what will happen
Hospital did not give any treatments, just asked, "where were you, what day is it?" Sick of MMSE [mini-mental state examination]
I felt as though my treatment was passive treatment, I think I was resting more in hospital than I may have been resting at home
Hospital, not seen as a place to get better or rehabilitate
Did not explain what is going on at the hospital
One day they [doctor] will have a stroke and know what it's like
They are the experts and you go along with what the experts think is best for you
I don't think I have been involved. I think I need more explanation to be honest
The doctor said to me now you have had a stroke and you are going home and this is what you ought to do
Something physically, something mentally

that healthcare providers did not give satisfactory information about aspects of the treatment. There were mixed feelings about the extent of involvement in management decisions. Some felt sufficiently involved, some wanted to be more involved, and others felt incapable of being actively involved.

Box 2: Response to symptoms**General public**

There is nothing you can do, you just ring the ambulance
If you have enough stress you might get a headache but you certainly don't get palpitations or shortness of breath
We were not really brought up to go to the doctors very much in the country and doctors weren't as readily available
Severity is the most important thing. If it is not within your experience, it is something that you worry about
Your experience tells you that most times, almost every time, it has gone away in time

Stroke groups

Did not worry much about it and took medication for migraine and wait
Thought symptoms will be better tomorrow
Time was late so just went to bed thinking it will be better after sleep
Thought it was something else like food poisoning
I wondered what have I eaten or am I having a stroke?
I will see doctor tomorrow, I think
It was the weekend and I don't think to see a doctor about nothing because they have the weekend off, and I'd rather see them stay home, so I go on Monday
I only think vomiting at home would have been the flu and you don't worry about it
Just because you have a severe headache you don't assume you are having a stroke, just because your face is tingling (because when you have a history of an allergy that is similar) you don't assume you are having a stroke
I mean I'd know instantly if somebody's face was drooping or drooling but in this case there is no meaning

Differences between stroke and heart attack

There was some confusion in the groups between heart attack and stroke. Some participants in stroke groups identified “pain” in the chest as the distinguishing sign of heart attack. Other participants said that the only difference was whether the blood clot goes to the heart or to the brain. Some people in the general public group thought stroke was more serious than heart attack: “You’d much rather have a heart attack than a stroke because, a heart attack you get over it, and you get to do things right. A stroke needs such a long rehab and time,” “The stroke, there is more than that, the heart seems to—clear out the arteries, and will start to work again, because it’s only affecting the circulation, but the brain—seems that doesn’t come back.” Recognising symptoms of stroke in the community is seen as more difficult than recognising heart attack because stroke symptoms are much more heterogeneous. For example, “Your heart attack is sort of easier because of the chest pain, difficulty breathing, pain in your arm that sort of thing . . . Stroke, because it depends, what the function of that part of the brain is.”

Information resources

Participants in the general public groups knew little about stroke organisations or available educational materials such as pamphlets, booklets, and leaflets. Box 4 shows participants’ preferences regarding educational programmes and their evaluation of current education programmes in the area. Most people expected to receive information from their general practitioner or from community education. They preferred simple and understandable messages rather than repetitive (confusing) messages.

Discussion

This qualitative study shows that people in the community have similar understandings about the description of stroke and the possibility of having a stroke regardless of whether or not they have had a stroke. Participants expressed the view that recognising symptoms is not easy. Many patients who had had a stroke did not initially take their symptoms seriously because the symptoms did not fit the typical pattern presented in information they had received. The stroke groups emphasised that more information needs to come from hospitals as well as from community health services. Both groups in this study wanted education programmes to contain simple and understandable information.

Perception of stroke

Participants were disinclined to accept that they were ill or at risk of any kind of illness. They did not want to accept illness as part of their life. We have previously shown that people are more likely to say they have a low lifetime risk of stroke.⁷ These attitudes towards illness may counteract attempts to increase awareness of stroke in the community. Educational strategies may need to focus on the positive benefits of healthy lifestyles rather than on the negative results of risky lifestyles.

Most participants envisaged stroke as more serious than heart attack. However, because stroke symptoms present in various ways they are not easy to recognise. People who had had a stroke said that they had

confused their symptoms with those of migraine, food poisoning, and Ménière’s disease. This kind of confusion may be one cause for delay in presentation to hospital. Studies in people with myocardial infarction showed that presentation with atypical symptoms may be responsible for increased delays in many patients.^{24 25} Dracup et al found that people who thought they only had heartburn or indigestion significantly delayed seeing a doctor.²⁶

Response to symptoms

The lack of knowledge about stroke was one of the reasons for delay in early presentation at hospital. Previously our telephone survey revealed that most of the respondents (90%) would consider calling an ambulance or visiting a hospital casualty or emergency department if they thought that they were having a stroke. However, when asked how they would respond to particular symptoms, without reference to stroke, less than half and as few as 3% indicated that they would respond in this way.⁹ Other studies showed similar reasons for delay in hospital presentation.^{8 27} Most patients in our study waited until the next morning or after the weekend because they believed that the

Box 4: Information resources

General public

Preferred programmes

Tell the people, educate the people with straight out information and make it really simple to understand
Just educate the community as to what a stroke is because a lot of them wouldn’t know the possible symptoms of a stroke

A TV commercial, because it shows that recovery is very achievable

At high school

Evaluation of present programmes

If you’re going to worry people that much, if you say “if you’ve slight headache, ring for an ambulance, if you’ve got numbness in your arm,” you’re going to have so many calls, so many false alarms that it’s going to probably prove to be a bigger headache than non-education

Stroke groups

Preferred programmes

TV is the best

Family members or friends

Self help groups

Being constructive rather than reading the same thing over and over, which doesn’t sink in, like always, I have a bit of bother, I read a lot but sometimes I get through part of the chapter and think what did I read, it is just not getting through, so printed it might not get through

If GPs were to hand down little leaflets, maybe one day you will have a stroke, this is what you need to look out for, maybe if these little leaflets were handed out to us, like us people who have high blood pressure or whatever, diabetes, high cholesterol, whatever our problems are

Evaluation of present programmes

Don’t want to go [to stroke support group] because it makes me depressed and helpless, some people can’t go because of severe disability, need to have a group to share information and encourage

It is very repeated and everything you pick up is telling you the same things

What is already known on this topic

Increasing the speed of presentation to hospital after the onset of stroke depends on the level of knowledge of stroke in the general population

Among stroke patients and the general public the knowledge of stroke is poor

What this study adds

Focus group discussion showed that recognition of stroke was not easy for the general public because symptoms present in various ways

None of the available written information about stroke successfully conveyed the importance of early presentation to hospital for anyone experiencing warning signs or symptoms

symptoms would go away soon. To target populations at risk it is important to emphasise knowledge of symptoms and the appropriate response, but it is also to understand the role of defence and coping mechanisms.

Participants in both groups believed that they would not get any medical attention for symptoms that they thought were not typical or symptoms of minor stroke. Although the general public have enough knowledge to recognise symptoms of stroke, preoccupation about medical attention may contribute to delayed presentation. One prospective observational study showed that only a third of patients with myocardial infarction but without chest pain were correctly diagnosed and mortality in hospital was 23% compared with 9% among patients with chest pain. Patients without chest pain also presented later at hospital compared with those with chest pain.²⁸ Change in the attitudes of healthcare providers may encourage people who are not sure about their symptoms to present earlier.

Information resources

Patients in our study reported that they had not received enough information from healthcare providers during their stay in hospital. An intensive educational programme in hospital may not be effective in the early stage of the relationship between patients, carers, and doctors because stroke, especially in the acute stage, excessively burdens people with other concerns (for example, losing a job and financial and other fears). Previous studies have shown that the quality of relationship between the doctor and patient influences the patient's satisfaction and compliance with treatment.^{29 30} In the current study information about stroke from healthcare providers may not have been effectively transmitted to patients and carers or not retained. Discharge plans could incorporate provision of information about stroke prevention by a community stroke service.

Participants in our study recommended community education about recognising stroke and about appropriate responses by people who experience stroke. Some such educational programmes have been evaluated in other countries.^{13 17} However, planners

may need to evaluate the cost effectiveness of each educational project and consider its long term effects. As our participants emphasised, educational programmes (including printed information, visual and audio programmes, and community stroke service programmes) need to use simple and understandable information and focus on the population as a whole as well as on people at high risk.

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