

randomised controlled trial of intensive non-directive counselling sessions delivered by health visitors to 55 women with postnatal depression, which reduced median depression scores by 6 points three months after the intervention.¹⁸

Conclusions

This brief community based sleep intervention decreased infant sleep problems and symptoms of maternal depression, particularly for “depressed” mothers. The intervention reduced the need for other professional sleep services, was acceptable to mothers, was of low cost, and was minimally disruptive to families in contrast with many current strategies for postnatal depression. These findings should now be replicated in a larger study in which the intervention is offered and implemented by primary healthcare professionals.

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

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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



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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
 Had taste like pine taste
 Light headedness
 No headache just bang and crying
 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

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.

We carried out a qualitative study to obtain insight into people's thoughts on stroke, including risk factors, symptoms, treatment, information resources, and prevention. With this information we hope to inform the development of an educational strategy for the early recognition of symptoms and for appropriate responses to these in the community and 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 and with members of the general public.

Sample—We selected people who had had a stroke from the heart and stroke register in Hunter Area Health Authority.⁷ 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 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.

Discussion guide and procedure—We developed a discussion guide on the basis of findings of previous

studies.^{6,8-14} 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.

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.

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.

Participants were asked questions about the possibility of having a stroke. 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.

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

There is nothing you can do, you just ring the ambulance
 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

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
 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
 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

Box 3: Expectations of treatment in stroke groups

Important to know information like what is going on 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
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

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. 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.¹⁵

Response to stroke symptoms

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

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. 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.

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

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
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

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. 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.

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.⁶ Other studies showed similar reasons for delay in hospital presentation.^{16 17} Most patients in our study waited until the next morning or after the weekend because they believed that the symptoms would go away soon. To target populations at risk it is important not only to emphasise knowledge of symptoms and the appropriate response, but also to understand the role of defence and coping mechanisms.

Information resources

Patients in our study reported that they had not received enough information from healthcare providers during their stay in hospital. Participants 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.^{10 18} 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

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

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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