Acute Stroke and the Public's Response to Symptoms

by

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Declaration

This thesis is an original piece of work and has not been submitted for a comparable award.

ABSTRACT

Stroke is a medical emergency requiring a rapid response by the public. This thesis aims to explore our current understanding of stroke knowledge and the decision-making processes involved at the onset of stroke symptoms. Using this information, and the results from a focus group, the thesis will go on to describe the development and pilot testing of an information leaflet for those at higher risk of stroke. The thesis consists of four phases: an integrative review; semi-structured interviews; a focus group; pilot testing of an intervention.

Phase One is an integrative review of stroke knowledge in stroke patients; relatives; the public and non-stroke patients at risk of stroke. Members of the public frequently state that they would contact the emergency medical services (EMS) if they suspected stroke but few stroke patients reported that they had actually done so.

Through qualitative interviews, Phase Two explored the decision-making process in seeking medical help at the onset of stroke symptoms. The decision about what to do at the onset of symptoms was influenced by multiple factors: knowledge of stroke symptoms; perceived seriousness; emotional reaction to the event; help seeking behaviour and previous experience of seeking medical help. The factors informed a theoretical framework describing the decision-making process for seeking help after stroke.

In Phase Three, a focus group explored the information that would best encourage people with suspected stroke to seek immediate help from the EMS. It was agreed that information should: be informed by stroke survivors; be suitable for everyone; use pictures and images; describe a range of stroke symptoms; indicate that stroke is a medical emergency for which effective treatments are available.

Phase Four was informed by Phases One through Three, and pilot tested an information leaflet, in people at higher risk of stroke. The information leaflet increased the proportions of patients accessing the EMS and reduced time to seeking medical help.

This thesis has made a contribution to knowledge through the development of a theoretical framework that reflects the decision-making process for seeking help after stroke. Using this framework, the thesis has further added to knowledge by

demonstrating the potential effectiveness of an information leaflet in a higher risk population.

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LIST OF ABBREVIATIONS

A&E	Accident and Emergency
CONSORT	Consolidated Standards of Reporting Trials
CI	Confidence Interval
CS-SRM	Common-Sense Self Regulation Model
CT	Computerised Tomography
DoH	Department of Health
EMS	Emergency Medical Services
ESO	European Stroke Organization
FAST	Face Arm Speech Time Test
GP	General Practitioner
HBM	Health Belief Model
IQR	Interquartile Range
MDPH	Massachusetts Department of Public Health
MI	Myocardial Infarction
NA	Not Applicable
NAO	National Audit Office
NHS	National Health Service
NSS	National Stroke Strategy
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
RF	Risk Factors
SaS	Signs and Symptoms
TIA	Transient Ischaemic Attack
TM	Transtheoretical Model
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
UK	United Kingdom
USA	United States of America

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CHAPTER ONE
INTRODUCTION

Stroke accounts for 11% of deaths in England and Wales, and is the leading cause of severe adult disability (National Audit Office [NAO], 2005). In England alone, 110,000 people have a stroke every year and a further 20,000 people suffer a Transient Ischaemic Attack (TIA) (NAO, 2005). Stroke is defined as “a focal (or at times global) neurological impairment of sudden onset, lasting more than 24 hours (or leading to death), and of presumed vascular origin” (World Health Organisation, 2005 p.50).

Despite improvements in primary prevention (Rothwell et al. 2004), it is estimated that between 1983 and 2023 there will be an absolute increase in the number of people experiencing a first ever stroke by approximately 30% (NAO, 2005), due to the ageing population (Maasland et al. 2011). The population in England aged 65 years and over increased by nearly four million between 1952 and 2002, and the percentage of older people in England is expected to rise from 16% in 2003 to 23% in 2031 (NAO, 2005). The incidence of stroke increases with age, rising from 104 per 100,000 per year for those aged between 45 to 54 years to 113 per 100,000 per year for those between the ages of 75 and 84 years (Saver and Lutsep, 2007). The potential fall in incidence that is attributable to improved prevention is offset by the ageing population.

In England, there are at least 300,000 people living with mild to moderate post-stroke disability and approximately 900,000 stroke survivors (NAO, 2005). Whilst there have been few surveys to determine the numbers of people living with stroke in the North West of England, regional prevalence is estimated to be 5 per 1,000 population (Geddes et al. 1996). Within a population in the North West of 7.2 million this would mean that there are approximately 24,000 people surviving with stroke each year (Office for National Statistics, 2001).

A number of population-based surveys in England have explored the impact of stroke. One such survey identified that one-third of stroke survivors were moderately to severely disabled at five years following their stroke (Wilkinson et al. 1997). In a further survey involving 1,259 patients, common impairments at three months post-stroke included upper limb weakness (77%), urinary incontinence (48%), impaired consciousness (45%), dysphagia (45%), and impaired cognition (44%) (Lawrence et al. 2001). Not only can stroke result in death and disability, but the psychosocial impact on patients and their families can also be devastating. Depression, anxiety, family tensions and financial problems are all common after stroke (Wolfe, 2000).

For those who do experience a stroke or TIA, rapid access to effective stroke care and treatment can reduce death and dependency (NAO, 2005). In these early stages an accurate diagnosis can be made and interventions such as physiological monitoring, the treatment of complications and thrombolysis can take place (The European Stroke Organization (ESO) Executive Committee and the ESO Writing Committee, 2009). Access to organised stroke care is also important, as it has been shown to save lives and reduce disability (Stroke Unit Trialists' Collaboration, 2001).

Rapid admission to hospital is required so that computerised tomography (CT) imaging can be undertaken to distinguish the type of stroke, enabling the initiation of appropriate interventions. Scanning stroke patients immediately following arrival at hospital has been found to be cost effective and also increases rates of independent survival (Wardlaw, 2004). An increase in survival can also be due to patients (with ischaemic stroke) arriving at hospital within three hours of symptom onset and being potentially suitable for, and so treated with thrombolysis (Intercollegiate Stroke Working Party, 2008). Thrombolysis works by breaking up the clot that is causing the stroke. However, the delay to presentation continues to be one of the main causes of patient exclusion in receiving thrombolysis, with less than 1% of stroke patients in England currently receiving thrombolysis each year (Rudd et al. 2011).

Recognition and Pre-hospital Delays

Pre-hospital care is a key component in delivering a rapid response to suspected stroke (Morris et al. 2000). The activation of the Emergency Medical Services (EMS) is suggested as being the single most important factor in the rapid triage and treatment of acute stroke patients. Activating the EMS means that patients arrive at Accident and Emergency (A&E) departments earlier and are more rapidly evaluated, than if the General Practitioner (GP) is contacted or if patients present directly to A&E (Kothari et al. 1997; Williams et al. 1997; Menon et al. 1998; Rosamond et al. 1998; Morris et al. 2000). However, a recent review has shown that poor recognition of the warning signs of stroke is the main cause of delay in accessing the EMS (Evenson et al. 2001). Many patients do not recognise the symptoms, nor do they realise that seeking treatment is urgent, and they may even be reluctant to seek medical help (Becker et al. 2001; Evenson et al. 2001; Yoon et al. 2001).

This reluctance appears to be at odds with people's stated intentions. For example, when two studies asked members of the public about their intention to seek help for suspected stroke, between 80% (Carroll et al. 2004) and 89% (Hsia et al. 2011) reported that they would contact the EMS. In the same two studies, when stroke patients were asked what help they had actually sought only between 12% (Carroll et al. 2004) and 18% (Hsia et al. 2011) had contacted the EMS. To date, this discrepancy had only been explored in one study, where stroke patients were asked what medical help they had sought and why (Hsia et al. 2011), however this study was based in the USA, within a predominantly urban, African American population.

Although stroke and TIA present with the same symptoms, the early resolution of TIA symptoms means that TIAs are often perceived by the public as less important (Rodriguez et al. 2001). The evaluation and diagnosis of TIA should mirror that of stroke and therefore should be treated as a medical emergency (Williams et al. 1997). TIA has recently been defined as ‘a brief episode of neurologic dysfunction caused by focal brain or retinal ischaemia, with clinical symptoms lasting less than one hour, and with no evidence of acute infarction’ (Albers et al. 2002 p.1714).

A diagnosis of TIA is associated with a high risk of subsequent stroke (Coull et al. 2004). The population-based Oxford Vascular Study found that rates of stroke following a TIA were 8% at one week, 11.5% at one month and 18.2% at three months (Coull et al. 2004). About half of all strokes that occur following a TIA, will happen within the first 48 hours (Rothwell et al. 2007) and of those strokes that do occur following a TIA, up to 85% will be fatal or disabling (Stroke Foundation of New Zealand, 2008).

Despite the high risk of stroke following a TIA, many people still delay seeking help. It is believed that one of the main reasons that people may delay seeking medical help after a TIA, is a lack of recognition of the symptoms and a lack of knowledge of the increased probability of a completed stroke (Shelton and Gaines, 1995).

Public Awareness Campaigns and Interventions

In 2005, the National Stroke Strategy (NSS) reported that too few people understood what a stroke is or knew that they should contact the EMS at the onset of symptoms (Department of Health (DoH), 2007). The NSS also identified that public awareness of stroke was an essential factor in the rapid response to stroke symptoms (DoH, 2007). Consequently, the DoH have been running the *Face Arm Speech Time (FAST) to dial 999* campaign since 2009, aimed at raising the public’s awareness of stroke, however the impact of this campaign is yet to be fully evaluated, although it has been reported that stroke related calls to the EMS increased by 24% in the months following the 2010 FAST campaign (The Stroke Association, 2012). The National Sentinel Audit (2012) found that fewer patients were being admitted to hospital within 3 hours of the onset of stroke symptoms in 2010 than in 2008 (56% in 2010 compared to 60% in 2008) and suggested that the FAST campaign had not had a dramatic impact on the behaviour of patients with suspected stroke. However, the FAST campaign was not designed to evaluate rapid hospital admission and therefore a lack of effect is not surprising.

A number of studies have been successful in measuring the effects of interventions aimed at improving stroke knowledge (Becker et al. 2001; Silver et al. 2003; Handschu et al. 2006; Hodgson et al. 2007; Wall et al. 2008). But whilst stroke knowledge is important, knowledge must translate into appropriate action by immediate activation of the EMS (ESO Executive Committee and the ESO Writing Committee, 2009). It has recently been suggested that identifying the key components needed for an effective public awareness campaign aimed at reducing the delay in diagnosing and managing stroke, should be one of the top ten priorities for stroke services research (Wolfe et al. 2009).

1.1 Outline of Thesis

This overall aim of this thesis is to explore the factors that influence the decision-making process when seeking medical help at the onset of acute stroke symptoms and how these factors can be used to develop a stroke awareness intervention, the potential effectiveness of which will be tested in a high risk population. The thesis includes four phases, which are outlined below.

The first phase is an integrative review that is described in Chapter Two. The review aims to summarise the existing scientific literature exploring lay people's stroke knowledge. Questions to be answered in the integrative review are:

What levels of stroke knowledge do people have in relation to:

- Risk factors,
- Signs and symptoms,
- Action that should be taken when stroke is suspected,
- Sources of information and treatments available.

The review will conclude with suggestions for who should be targeted in future stroke awareness campaigns. Findings from the review will be used to inform the semi-structured interviews in Phase Two.

Phase Two aims to explore the decision-making process when seeking medical help at the onset of stroke symptoms and this will be presented in Chapter Three. This chapter begins by setting out the aims, methods used, subjects and sampling. The chapter will then move on to discuss the ethical issues and procedure for the identification, approach and consenting of participants. This will be followed by a discussion of methodological issues including interview approaches and the setting in which interviews took place. The data collection procedures are described within the context of a grounded theory approach, followed by the stages of data analysis and the process of credibility checking. Questions to be answered in Phase Two are:

- What are people’s recollections at the onset of stroke symptoms?
- What action is taken by patients, and those who act on their behalf at the onset of acute stroke symptoms and why?
- Which factors influence the decision to seek immediate medical help or to delay among patients and those who act on their behalf?
- What advice would people give to someone else in similar circumstances?

A discussion of the findings will be made, comparing the results of this phase with what is already known about the public’s response to stroke. Limitations of the study will be explored and recommendations made about future research.

In Chapter Four, the findings from Phases One and Two will be used to inform a focus group discussion in Phase Three. The chapter will begin by setting out the aims, methods used, ethical issues and procedure for the identification, approach and consenting of the focus group participants. The difficulties with analysing focus group data will be discussed. The focus group will explore the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. Questions to be answered in Phase Three are:

- What are the key messages that would be needed to encourage people to seek immediate help from the EMS?
- Which formats should be used to deliver stroke information?

Using the results of the focus group findings and information from the previous phases, an intervention will be developed and pre-tested. An implementation strategy in relation to the intervention will then be described.

The development, implementation and evaluation of the intervention will take place in Phase Four and this is presented in Chapter Five. This chapter will provide a detailed exploration of the potential effectiveness of a targeted intervention, in people at higher risk of stroke. This chapter will begin by describing the methods used and the setting in which this phase took place. A summary of the practical and ethical issues pertaining to Phase Four will then be discussed. Details of both the delivery of the intervention and follow-up of participants will also be outlined.

Phase Four will aim to explore the potential effectiveness of an intervention on the reaction of patients to the symptoms of stroke and TIA. Questions to be answered in Phase Four are:

- Does a targeted intervention have any impact on utilisation of the EMS in participants who experience a subsequent stroke or TIA?
- Does a targeted intervention have any impact on time from onset of symptoms to seeking first medical help in participants who experience a subsequent stroke or TIA?
- What action was taken and the factors that influenced this?
- How satisfied were participants with information provision?

The main findings from Phase Four will be reported. The findings of this phase will be compared with previous research and the main strengths and limitations will be identified. The findings will be summarised and comparisons made to previous research.

Finally in Chapter Six, the main findings will be summarised and the overall limitations of this thesis will be detailed. The potential impact of this thesis on clinical practice and future research will be outlined and the original contribution to knowledge of this thesis will be stated.

CHAPTER TWO

PHASE ONE – STROKE KNOWLEDGE AND AWARENESS: AN INTEGRATIVE REVIEW OF THE EVIDENCE

2.1 Background

To combat the effects of stroke, the time from the onset of stroke symptoms to hospital arrival must be reduced in order to provide timely and effective treatment. Many factors contribute to delays in seeking treatment for stroke, but the principal factor is believed to be a lack of public knowledge not just regarding stroke symptoms, but also in understanding the need for a rapid response (Evenson et al. 2001; Yoon et al. 2001). Achieving rapid patient presentation relies mainly on the public's ability to identify stroke symptoms, and know that the correct course of action is to contact the EMS without delay (Ferro et al. 1994; Wester et al. 1999; Derex et al. 2002; Harraf et al. 2002).

Numerous approaches have aimed to improve stroke awareness in both the USA and Europe (Becker et al. 2001; Silver et al. 2003; Handschu et al. 2006; Hodgson et al. 2007; Marx et al. 2008; Wall et al. 2008; Kleindorfer et al. 2009; van Leijden et al. 2009). One channel has been through mass media campaigns, which have had mixed success within stroke (Becker et al. 2001; Silver et al. 2003; Hodgson et al. 2007; Marx et al. 2008; Wall et al. 2008; Kleindorfer et al. 2009). Further studies have used a range of approaches in order to improve stroke knowledge. These have included: leaflet distribution (van Leijden et al. 2009); *Face Arm Speech Time to dial 911* animations (Wall et al. 2008); stroke risk factor screening (DeLemos et al. 2003); educational slides and audio programmes (Handschu et al. 2006). Studies have also reported that the public have an interest in receiving information about stroke (Morgan et al. 2005; Weltermann et al. 2003).

This review undertaken in this phase aims to summarise the existing scientific literature exploring the knowledge of: stroke patients, relatives, the public, and non-stroke patients at risk of stroke; in relation to: risk factors, signs and symptoms, action that should be taken when stroke is suspected, sources of information and treatments available. The results of this review will provide an understanding of stroke knowledge broadly and within specific populations including stroke patients, relatives of stroke and non-stroke patients, the public and non-stroke patients at higher risk of stroke. Stroke knowledge will be explored in relation to help seeking behaviour; this will provide an insight into any relationship that may exist between stroke knowledge and action; this information will be of particular value in informing the semi-structured interviews, described in Phase Two.

2.2 Methods

This review utilised an integrative review approach. The aim of an integrative review is to summarise the literature in order to provide a comprehensive understanding of a particular phenomenon or healthcare problem (Whittemore and Knafl, 2005). The integrative review method is the only approach that allows for the combination of diverse methodologies (Whittemore and Knafl, 2005). A variety of approaches were used within the identified studies, including qualitative and observational methods; because of the mixed methodologies used in the included studies the approach taken was that of an integrative review, which synthesises information from methodologically diverse studies using a descriptive summary.

Questions to be answered in the integrative review were:

What levels of stroke knowledge do people have in relation to:

- Risk factors;
- Signs and symptoms;
- Action that should be taken when stroke is suspected;
- Sources of information and treatments available.

Inclusion Criteria

Studies were included in the review if they assessed the stroke knowledge of:

- Stroke patients; relatives of stroke or non-stroke patients; the public; or non-stroke patients at higher risk of stroke.

Articles were included in the review if they reported empirical research focusing on stroke knowledge and awareness among participants in any setting. This included:

- Public places such as shopping centres and community groups; hospital settings such as out-patient clinics, hospital wards and A&E departments.

Studies were included in the review regardless of the methodology used. Studies could be:

- Observational; qualitative; or interventional.

Studies were included in the review if they assessed stroke knowledge by using:

- Open-ended or closed questions.

The method of administration of the questions could be:

- Telephone; face-to-face; postal; or on-line.

The studies included in the review were categorised under one or more of the following four topics:

- Knowledge of risk factors for stroke;
- Knowledge of stroke signs and symptoms;
- Action taken if stroke is suspected;
- Sources of stroke information;
- Treatments available for stroke.

Studies were included in the review if they were published in English, in full in a peer reviewed journal.

Exclusion Criteria

Studies that were only published as abstracts were excluded because of the limited data that could be extracted. Articles published in languages other than English were excluded, as there were not the resources for translation of these articles.

Search Strategy

A search strategy (Appendix 1) was developed to search Medline from 1966 to June 2011, and adapted to search EMBASE (1966 to June 2011), CINAHL (1966 to June 2011), AMED (1966 to June 2011) and Cochrane (1966 to June 2011). Citations were initially screened on title and those retained were screened on abstract. This was carried out independently by the author and another reviewer, Mandy Jenkinson (MJ). MJ was stroke lead within North West ambulance service, who at the time of the review was seconded to work within the Clinical Practice Research Unit at the University of Central Lancashire. If insufficient information was available to decide whether the article should be included in the review, the full paper was obtained. Disagreements over the inclusion of articles were discussed between the author and MJ and a final decision made. Any article that appeared to meet the inclusion criteria was read in full. The reference lists of included articles were also searched for any further articles of relevance.

Data Extraction

The author and MJ extracted data into an excel spreadsheet. At the time that the integrative review was undertaken (2007 to 2009) the author had been involved in reviewing evidence for the National Pre-hospital Stroke Guidelines Group. The National

Pre-hospital Guidelines Stroke Group worked with the Royal College of Physicians in developing an addendum to the 3rd Edition of the National Clinical Guidelines for Stroke. The pro forma used by the National Pre-hospital Stroke Guidelines Group was amended and used to extract data from articles included in the review. A copy of the data extraction pro forma can be found in Appendix 2. Within the proforma the quality of included studies was based on the National Institute for Health and Clinical Excellence guidelines for grading evidence (National Institute for Health and Clinical Excellence, 2007). No exclusion criteria were applied based on the pro forma.

For each article included in the review summary data were recorded, including: author, participants, demographic information, sampling, number of participants, response rate, how questions were asked (e.g. open, closed), topic area (e.g. risk factors for stroke; signs and symptoms; action taken if stroke is suspected; sources of stroke information; and treatments available for stroke), methods of questioning (e.g. postal, telephone, face-to-face, on-line) and participants' reported knowledge. Details of the information recorded for each study can be found in Tables 2.1 to 2.4.

Data Analysis

Results are presented narratively because the studies identified were heterogeneous in terms of their methodologies, study populations, interventions and outcome measures. In order to make meaningful comparisons, the data have been grouped in relation to participants (stroke patients; relatives of stroke and non-stroke patients; the public; non-stroke patients at higher risk of stroke) and the methods in which question were asked (open, closed). The number of responses, proportions and their corresponding 95% confidence intervals (CI) have been reported.

Where possible the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher et al. 2009), which is an evidence-based, minimum set of recommendations for the reporting of systematic reviews, has been used to inform the reporting and interpretation of the findings in this phase. However, as PRISMA is designed for systematic reviews, not each element of the PRISMA checklist was applicable to this integrative review, which has synthesised information from methodologically diverse studies as there were no randomised controlled trials (RCTs).

2.3 Results

From the electronic search 173 articles were identified. Following screening of the title, abstract or complete article, 51 studies met the inclusion criteria, see Figure 2.1 below.

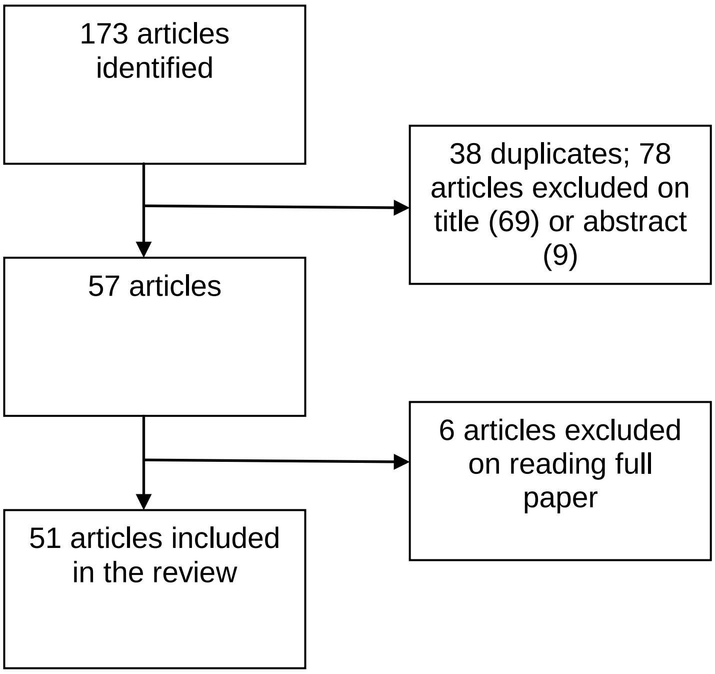

Figure 2.1. The identification and inclusion/exclusion of the review articles.

Quality of Included Studies

Of the 51 studies, 42 were cohort studies, and nine were pre and post-test studies. Overall, the quality of included studies ranged from 2- (cohort studies with a high risk of confounding bias or chance and a significant risk that the relationship is not causal) to 2++ (cohort studies of high quality with a very low risk of confounding, bias or chance and a high probability that the relationship is causal). There were no RCTs. Response rates were not reported in 23 (45%) studies and it was not possible to examine response bias because of insufficient detail provided within the individual studies. In all but five studies, the sample size was more than 100 participants. Participants were randomly selected in 22 (43%) studies. Five studies included samples from highly selected populations such as Women's Health Network, people attending first aid training, members of community organisations, and volunteers in independent settings. Only two studies used validated stroke knowledge questionnaires (Billings-Gagliardi and Mazor, 2005; Mikulik et al. 2008), both using the Stroke Action Test (Billings-Gagliardi and Mazor, 2005). A further five studies used questions from extensively used general health questionnaires such as the Behavioural Risk Factor Surveillance System Survey and the Third National Health and Nutrition Examination Survey.

Twenty-two studies used open-ended questions, twenty used a combination of open-ended and closed questions and nine asked closed questions only.

Of the studies, 42 tested participants' knowledge once. Nine studies tested knowledge pre and post interventions that aimed to provide information about stroke. Of these, five tested knowledge immediately before and after an intervention, one of these studies also tested knowledge at three months post intervention. One study tested knowledge at a range of time points between 1 and 28 days post intervention, one study tested knowledge at two time points over five years, one tested knowledge at six separate time points over three years and one study tested knowledge at three time points over 15 years.

Location of Studies and Types of Participants

The 51 studies of stroke knowledge relating to stroke/TIA are summarised in Tables 2.1 to 2.4. The published studies come from the following locations: UK (n=4); Europe (n=11); North America (n=25); South America (n=1); Asia (n=8); and Australia (n=2). In 35 studies the participants were members of the general public, in six studies the participants were stroke patients, in a further six studies knowledge was assessed in non-stroke patients at higher risk of stroke. The remaining four studies involved a mixture of patients, relatives and the public.

Table 2.1. Summary of included studies involving patients with stroke or suspected stroke

Author	Participants	Sampling	N (Response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§
Carroll	Stroke patients	Purposive sample admitted to hospital with stroke	40 (ns)	71	58%	ns	O	RF; SaS; A; I	👥
Das	Stroke patients	Consecutive stroke patients admitted to hospital	660 (ns)	88% <60	30%	ns	O; C	RF; SaS; I	👥
Hsia	Stroke patients	Consecutive stroke patients admitted to hospital	100 (ns)	ns	ns	80%	O; C	SaS; A	👥
Kim [2011]	Suspected stroke patients	Patients admitted to A&E with suspected stroke	163 (94%)	65	38%	ns	O	I; T	👥
Kothari	Suspected stroke patients	Patients admitted to A&E with suspected stroke	163 (94%)	65	50%	ns	O	RF; SaS	👥
Pandian [2006]	Stroke patients	Consecutive stroke patients admitted to A&E	102 (85%)	60	33%	ns	O	RF; SaS	ns
Williams	Stroke patients	Consecutive stroke patients admitted to 3 hospitals	67 (ns)	64	42%	37%	O	SaS	👥

ns = not stated; †O = open-ended questions; C = closed questions; ‡RF = risk factors; SaS = signs and symptoms; A = action; I = information; T = treatment;

§👥 = face-to-face.

Table 2.2. Summary of included studies involving relatives

Author	Participants	Sampling	N (response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§
Pandian[2005]	Relatives of out-patients (not stroke)	Random	942 (75%)	40	44%	ns	O	RF; SaS; A; I	👥
Pandian[2006]	Relatives of stroke patients	The relatives of consecutive stroke patients admitted to ED	45 (ns)	60	33%	ns	O	RF; SaS	ns

ns = not stated; †O = open-ended questions; ‡RF = risk factors; SaS = signs and symptoms; A = action; I = information; §👥 = face-to-face.

Table 2.3. Summary of included studies involving the public

Author	Participants	Sampling*	N (response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§	Data Collection ¶
Alkadry	Public	Random	1172 (56%)	57	72%	5%	C	RF; SaS; A	✉	
Becker	Public	Random	547 (87%)	82% <65	57%	44%	O	RF; SaS; A	☎	Pre
Becker	Public	Random	511 (85%	78% <65	54%	46%	O	RF; SaS; A	☎	Post
Bray	Public	Consecutive patients admitted to hospital	170 (71%)	72	47%	27%	O; C	SaS	👥	
Billings-Gagliardi	Public	Members of community organisations	249 (ns)	44	49%	55%	C	A	👥	
Carroll	Public	Convenience sample people visiting the hospital	40 (ns)	54	48%	ns	O	RF; SaS; A; I	👥	
Cheung	Public	Random	1222 (62%)	38	50%	ns	O; C	RF; SaS; A; I	☎	
Das	Public	Consecutive members of the public who visited hospital	4660 (ns)	88% <60	30%	ns	O	RF; SaS; I	👥	
DeLemos	Public	Convenience sample of public attending community stroke screening	186 (47%)	Ns	ns	31%	C	SaS; A	👥	Pre

Table 2.3 continued

Author	Participants	Sampling*	N (response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§	Data Collection ¶
DeLemos	People at risk	Convenience sample of public attending community stroke screening	78 (ns)	ns	ns	16%	C	RF	👥	Post
Ferris	Public	Random	1024 (95%)	92% <65	100%	32%	O; C	RF; SaS; T	☎	
Fussman	Public	Random	4841 (48%)	ns	ns	49%	O	A	☎	
Greenlund	Public	Random	61019 (53%)	81% <65	59%	23%	O; C	SaS; A	☎	
Handschu	Public	Consecutive participants attending first aid training courses	532 (87%)	29	46%	ns	O	SaS	ns	1 to 28 days post
Hodgson	Public	Random	6693 (ns)	ns	ns	ns	O	SaS	☎	At 6 time points
Hsia	Public	Community volunteers	253 (ns)	ns	41%	91%	O; C	SaS; A	👥	
Hux	Public	Convenience sample of shoppers	190 (ns)	79% <60	60%	ns	O; C	RF; SaS; A; I	👥	
Johnston	Public	Random	10112 (89%)	45	50%	9%	O	SaS	☎	
Jurkowski	Public	Random	1789 (ns)	ns	65%	12%	C	A	☎	
Kim[1997]	Public	Random	1000 (ns)	65	38%	ns	O	RF; SaS; A; I	☎	

Table 2.3 continued

Author	Participants	Sampling*	N (response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§	Data Collection ¶
Kleindorfer	Public	Random	2642 (71%)	63	60%	27%	O	RF; SaS; T	☎	1995
Kleindorfer	Public	Random	3151 (69%)	61	61%	26%	O	RF; SaS; T	☎	2000
Kleindorfer	Public	Random	3228 (67%)	62	62%	62%	O	RF; SaS; T	☎	2005
Marx	Public	Random	507 (ns)	53	56%	ns	O; C	RF; SaS; A; I	☎	Pre
Marx	Public	Random	501 (ns)	52	56%	ns	O; C	RF; SaS; A	☎	Post
Mikulik	Public	Random	592 (ns)	58	55%	ns	O; C	RF; SaS; A; I	☎	
Morgan	Public	Random	139 (57%)	100% <65	59%	ns	O; C	RF; SaS; A; I	✉	
Mosca	Public	Random	133 (15%)	65	100%	34%	O; C	RF; SaS	☎	
Müller-Nordhorn	Public	Random	28090 (37%)	64	37%	4%	O; C	RF; I	✉	
Nedeltchev	Public	Random	422 (ns)	57% <45	58%	ns	O; C	RF; SaS; A; I	👥	
Pancioli	Public	Random	1880 (71%)	63	60%	2%	O	RF; SaS; A; I	☎	
Parahoo	Public	Random	869 (46%)	77% <66	59%	ns	O; C	RF; SaS; A; I	✉	

Table 2.3 continued

Author	Participants	Sampling*	N (response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§	Data Collection ¶
Pontes-Neto	Public	Convenience	801 (ns)	18-39 (56%) 40-59 (30%) 60-79 (15%)	51%	ns	O; C	RF; SaS; A; I	👥	
Reeves	Public	Random	2512 (45%)	82% <65	59%	12%	O	RF; SaS; A	☎	
Rowe	Public	Random	602 (48%)	41	51%	33%	O; C	RF; SaS; A; I	☎	
Schneider	Public	Random	1880 (ns)	63	60%	26%	O	RF; SaS	☎	1995
Schneider	Public	Random	2173 (69%)	61	61%	27%	O	RF; SaS; A; I	☎	2000
Segura	Public	Random	3000 (18%)	45	52%	ns	O; C	RF; SaS; A	☎	
Silver	Public	Random	1619 (ns)	ns	ns	ns	O	SaS		Post
Stern	Public	Volunteers in independent settings	657 (100%)	65	82%	26%	C	RF; SaS	👥	Pre
Stern	Public	Volunteers in independent settings	657 (100%)	65	82%	22%	C	RF; SaS		Post

Table 2.3 continued

Author	Participants	Sampling*	N (response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§	Data Collection¶
Truelson	Public	Stratified by region, age and gender	811 (23%)	58	50%	ns	C	RF; SaS; A	💻	
Wall	Public	Convenience sample from the MDPH Women's Health Network	34 (100%)	58	100%	32%	C	SaS; A	👥	Pre
Wall	Public	Convenience sample from the MDPH Women's Health Network	72 (100%)	54	100%	24%	C	SaS; A	👥	Post
Wall	Public	Convenience sample from the MDPH Women's Health Network	65 (86%)	ns	100%	ns	C	SaS; A	ns	3-months
Yoon	Public	Random	1278 (62%)	49	52%	ns	O; C	RF; SaS; A; I	☎	

ns = not stated; *MDPH = Massachusetts Department of Public Health; †O = open-ended questions; C = closed questions; ‡RF = risk factors; SaS = signs and symptoms; A = action; I = information; T = treatment; §✉ = postal; 👥 = face-to-face; ☎ = telephone; 💻 = on-line; ¶Pre = pre intervention, Post = post intervention.

Table 2.4. Summary of included studies involving patients at higher risk of stroke

Author	Participants	Sampling	N (response rate)	Age	Female	Ethnicity non-Caucasian	Questions†	Topic‡	Method§
Al Shafaee	Outpatients at increased risk	Random sample of patients attending outpatient clinics at a hospital	400 (72%)	57	48%	ns	O	RF; SaS; A; I	👥
Carroll	Outpatients at increased risk	Consecutive patients attending a hospital clinic	40 (ns)	68	48%	ns	O	RF; SaS; A; I	👥
Greenlund	Patients at increased risk	Consecutive patients attending a hospital clinic	410 (ns)	81% <65	59%	23%	O; C	SaS; A	☎
Gupta	Patients at increased risk	Consecutive patients attending a hospital clinic	410 (ns)	78	50%	ns	O; C	RF; SaS	👥
Rowe	Patients at increased risk	Identified as being at risk from in-patient records	1261 (43%)	41	51%	33%	O	RF; SaS; A; I	☎
Samsa	Patients at increased risk	Identified as being at risk from in-patient records	1261 (43%)	45% <65	48%	10%	O	RF; I	☎

ns = not stated; †O = open-ended questions; C = closed questions; ‡RF = risk factors; SaS = signs and symptoms; A = action; I = information;

👥 = face-to-face; ☎ = telephone.

Knowledge of Risk Factors

The studies exploring knowledge of the risk factors for stroke can be found in Tables 2.5 through 2.8. The ability to identify risk factors appeared to be strongly related to how the questions were asked. When asked open-ended questions about the main risk factors for stroke, between 24% (CI 23% to 25%) (Das et al. 2007) and 51% (CI 49% to 53%) (Schneider et al. 2003) identified hypertension; between 0% (Pandian et al. 2006) and 50% (CI 35% to 65%) (Carroll et al. 2004) identified smoking; and between 0% (Pandian et al. 2006) and 30% (CI 26% to 35%) (Gupta et al. 2002) identified high cholesterol. Other risk factors commonly identified without the prompt of a question included diabetes and ischaemic heart disease as causes of stroke. When closed questions were asked, a much higher proportion of participants were able to identify the main risk factors for stroke. Between 29% (CI 26% to 33%) (Mikulik et al. 2008) and 98% (CI 97% to 98%) (Das et al. 2007) identified hypertension; between 24% (CI 21% to 27%) (Parahoo et al. 2003) and 95% (CI 93% to 96%) (Marx et al. 2008) identified smoking; and between 13% (CI 12.6% to 13.1%) (Müller-Nordhorn et al. 2006) and 93% (CI 92% to 94%) (Das et al. 2007; Gupta et al. 2002) identified high cholesterol. Other risk factors that were commonly identified when closed questions were asked included diabetes, ischaemic heart disease, age, alcohol excess and stress.

Knowledge of Risk Factors Amongst Different Groups

Four studies assessed knowledge of the risk factors for stroke, amongst stroke patients and all used open-ended questions. Hypertension was the most commonly identified risk factor ranging from 24% (CI 23% to 25%) to 45% (CI 42% to 48%) (Das et al. 2007; Pandian et al. 2005). Other commonly identified risk factors included smoking, cholesterol, diabetes, alcohol excess and stress (Table 2.5).

Hypertension was also the most commonly identified risk factor among the studies involving relatives, the public, and patients at higher risk of stroke (Tables 2.6 to 2.8). There were two studies that had involved relatives and both used open-ended questions. In both these studies hypertension was identified as the main risk factor for stroke, ranging from 36% (CI 33% to 39%) (Pandian et al. 2005) and 51% (CI 37% to 65%) (Pandian et al. 2006). In the 17 studies involving the public, five asked open-ended questions. Within these five studies hypertension was reported as a risk factor for stroke by between 24% (CI 23% to 25%) (Das et al. 2007) and 51% (CI 49% to 53%) (Schneider et al. 2003) of participants. As with the studies involving patients, when closed questions were used, a higher proportion of the public recognised hypertension, 36% (CI 31% to 37%) (Parahoo et al. 2003) to 98% (CI 97.5% to 98.3%) (Das et al. 2004). Six studies assessed risk factor knowledge amongst patients at higher risk of stroke. Five studies used open-ended questions and reported hypertension as the most commonly identified risk factor, ranging from 28% (CI 16% to 43%) (Carroll et al. 2004) to 58% (CI 55% to 61%) (Pandian et al. 2005). In the study that had used closed questions 98% (CI 96% to 99%) of participants had identified hypertension (Gupta et al. 2002).

Knowledge of Risk Factors and Age

A number of studies explored the association between age and knowledge of risk factors. Regardless of how questions were asked (open or closed), there was an association between the number of risk factors identified and the age of the participant (Pancioli et al. 1998; Parahoo et al. 2003; Segura et al. 2003; Carroll et al. 2004; Al Shafaee et al. 2006). Of the study that explored the association between age and knowledge of risk factors among stroke patients it was found that 57% (CI 42% to 71%) of patients younger than 75 years could name at least one stroke risk factor compared with 19% (CI 11% to 35%) of patients aged 75 years or older (Carroll et al. 2004). Three studies involved members of the public: one study reported that 72% (CI 70% to 74%) of people younger than 75 years could name at least one stroke risk factor compared with 56% (CI 54% to 58%) of people aged 75 years and over (Pancioli et al. 1998). The two other studies involving members of the public found that the number of risk factors that could be correctly identified decreased with age (Parahoo et al. 2003; Segura et al. 2003). Two studies explored risk factor knowledge and age in patients at higher risk of stroke. In one study, 50% (CI 47% to 53%) of patients under the age of 65 years were aware of their own personal risk factors for stroke, compared with 30% (CI 28% to 33%) of those aged 65 years and above (Samsa et al. 1997). In the second study, higher knowledge about stroke risk factors was significantly associated with those aged under 50 years of age (Al Shafaee et al. 2006).

Knowledge of Risk Factors and Ethnicity

Two studies explored the association between ethnicity and knowledge of risk factors amongst members of the public. When open questions were used, inadequate risk factor knowledge was 61% more likely among African Americans (Reeves et al. 2002). African American participants were also consistently less likely to identify the risks of stroke compared to Caucasian participants (Stern et al. 1999).

Table 2.5. Knowledge of risk factors for stroke among studies involving stroke patients (n % (95% CI))

Author	HT*	Smoking	Age	Cholesterol	IHD†	DM‡	AF§	Alcohol excess	Previous stroke/TIA	Stress	Diet	Inactivity	Family history	Obesity
Carroll	13	16	1	5	4	1	0	8	0	8	12	2	4	9
	33%	40%	3%	13%	10%	3%	0%	20%	0%	20%	30%	5%	10%	23%
	(20%,48%)	(26%,55%)	(0%,14%)	(6%, 27%)	(4%,23%)	(0%,14%)		(11%,35%)		(11%,35%)	(18%,45%)	(1%,17%)	(4%,23%)	(13%,38%)
Das	158	158	0	99	40	125	0	138	53	0	0	0	0	0
	24%	24%	0%	15%	6%	19%	0%	21%	8%	0%	0%	0%	0%	0%
	(21%,27%)	(21%,27%)		(12%,18%)	(4%,8%)	(16%,22%)		(18%,24%)	(6%,10%)					
Kothari	72	29	0	44	5	7	0	21	0	59	6	0	0	8
	44%	18%	0%	27%	3%	4%	0%	13%	0%	36%	4%	0%	0%	5%
	(37%,52%)	(13%,25%)		(21%,34%)	(1%, 7%)	(2%, 8%)		(9%,19%)		(29%,44%)	(2%,8%)			(3%,10%)
Pandian[2006]	46	1	0	7	2	11	0	0	0	42	0	2	4	2
	45%	1%	0%	7%	2%	11%	0%	0%	0%	41%	0%	2%	4%	3%
	(36%,55%)	(0%,5%)		(3%,14%)	(0%,7%)	(6%,19%)				(32%,51%)		(0%,7%)	(2%,10%)	(0%,8%)

*HT = hypertension; †IHD = ischaemic heart disease; ‡DM = diabetes mellitus; §AF = atrial fibrillation; ▨= open-ended questions

Table 2.6. Knowledge of risk factors for stroke among studies involving relatives (n % (95% CI))

Author	HT*	Smoking	Age	Cholesterol	IHD†	DM‡	AF§	Alcohol excess	Previous stroke/TIA	Stress	Diet	Inactivity	Family history	Obesity
Pandian[2005]	339 36% (33%,39%)	226 (24%) (21%,27%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%
Pandian[2006]	23 51% (37%,65%)	0 0%	0 0%	10 21% (12%,35%)	0 0%	1 2% (0%,12%)	0 0%	10 21% (12%,35%)	0 0%	5 12% (1%,25%)	0 0%	13 29% (18%,44%)	2 5% (2%,16%)	0 0%

*HT = hypertension; †IHD = ischaemic heart disease; ‡DM = diabetes mellitus; §AF = atrial fibrillation; ▨ = open-ended questions.

Table 2.7. Knowledge of risk factors for stroke among studies involving the public (n % (95% CI))

Author	HT*	Smoking	Age	Cholesterol	IHD†	DM‡	AF§	Alcohol excess	Previous stroke/TIA	Stress	Diet	Inactivity	Family history	Obesity	Notes
Das	1118 24% (23%,25%)	1118 24% (23%,25%)	0 0%	513 11% (10%,12%)	280 6% (5%,7%)	1165 25% (24%,26%)	0 0%	1118 24% (23%,25%)	513 11% (10%,12%)	0 0%	0 0%	0 0%	0 0%	0 0%	O*
Hux	91 48% (41%,55%)	61 32% (26%,39%)	0 0%	57 30% (24%,37%)	15 8% (5%,13%)	0 0%	0 0%	15 8% (5%,13%)	0 0%	19 10% (7%,5%)	40 21% (16%,27%)	19 10% (7%,15%)	25 13% (9%,19%)	38 20% (15%,26%)	
Kim[1997]	290 29% (26%,32%)	0 0%	30 4% (3%,5%)	70 7% (6%,9%)	0 0%	0 0%	0 0%	10 1% (0%,2%)	0 0%	70 7% (6%,9%)	0 0%	0 0%	10 1% (0%, 2%)	70 7% (6%,9%)	
Pancioli	921 49% (47%,51%)	357 19% (17%,21%)	0 0%	301 16% (14%,18%)	94 5% (4%,6%)	56 3% (2%,4%)	0 0%	75 4% (3%,5%)	0 0%	432 23% (12%,25%)	376 20% (19%,22%)	0 0%	0 0%	301 16% (14%,18%)	
Schneider	1108 51% (49%,53%)	478 22% (20%,24%)	0 0%	456 21% (19%,23%)	109 5% (4%,6%)	109 5% (4%,6%)	0 0%	109 5% (4%,6%)	0 0%	456 21% (19%,23)	239 11% (10%,12%)	239 11% (10%,12%)	174 8% (7%,9%)	391 18% (16%,20%)	Post
Cheung	1100 90% (88%,92%)	831 68% (65%,71%)	648 53% (50%,56%)	917 75% (73%,77%)	709 58% (55%,61%)	733 60% (57%,63%)	513 42% (39%,45%)	1027 84% (82%,86%)	1014 83% (81%,85%)	na	na	na	611 50% (47%,53%)	917 75% (73%,77%)	
Das	4567 98% (97%,99%)	4427 95% (94%,96%)	na	4334 93% (92%,94%)	na	3495 75% (74%,76%)	na	3728 80% (79%,81%)	na	na	na	na	na	na	C*
Ferris	na	na	na	na	911 89% (87%,91%)	na	na	na	na	na	na	na	na	na	

Table 2.7 continued

Author	HT*	Smoking	Age	Cholesterol	IHD†	DM‡	AF§	Alcohol excess	Previous stroke/TIA	Stress	Diet	Inactivity	Family history	Obesity	Notes
Marx	4818 95% (94%,96%)	4818 95% (94%,96%)	2992 59% (58%,60%)	na	3753 74% (73%,75%)	3398 67% (66%,68%)	na	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	4716 93% (92%,94%)	Pre
Mikulik	172 29% (25%,33%)	255 43% (39%,47%)	na	na	12 2% (1%,3%)	30 5% (4%,7%)	na	0 0%	24 4% (3%,6%)	184 31% (27%,35%)	0 0%	0 0%	0 0%	195 33% (29%,37%)	
Morgan	131 94% (89%,97%)	104 75% (67%,82%)	na	na	na	na	na	93 67% (59%,74%)	na	na	120 86% (79%,91%)	106 76% (68%,82%)	na	93 67% (59%,74%)	
Müller-Nordhorn	12,078 43% (42%,44%)	10,955 39% (38%,40%)	281 1% (1%,1%)	3652 13% (12%,13%)	562 2% (1%,2%)	2247 8% (7%,8%)	na	4494 16% (15%,16%)	0 0%	5056 18% (17%,18%)	3933 14% (13%,14%)	5618 20% (19%,20%)	843 3% (2%,3%)	9551 34% (33%,35%)	
Parahoo	382 44% (41%,47%)	209 24% (21%,27%)	na	na	na	0 0%	na	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	
Pontes-Neto	409 51% (48%,54%)	na	na	168 21% (18%,24%)	na	16 2% (1%,3%)	na	168 21% (18%,24%)	na	96 12% (10%,14%)	na	232 29% (26%,32%)	5% 40 (4%,7%)	na	
Segura	2760 92% (91%,93%)	2640 88% (87%,89%)	2040 68% (66%,70%)	2520 84% (83%,85%)	2520 84% (83%,85%)	1770 59% (57%,61%)	na	2700 90% (89%,91%)	na	2040 68% (66%,70%)	na	2310 77% (75%,78%)	na	87% 2610 (86%,88%)	

Table 2.7 continued

Author	HT*	Smoking	Age	Cholesterol	IHD†	DM‡	AF§	Alcohol excess	Previous stroke/TIA	Stress	Diet	Inactivity	Family history	Obesity	Notes
Truelsen	584 72% (68%,75%)	na	na	268 33% (30%,36%)	406 50% (47%,53%)	na	na	na	na	na	na	na	na	na	
Kleindorfer					845, 32% (30%,34%) knew one risk factor										1995
Kleindorfer					914, 29% (27%,31%) knew one risk factor										2000
Kleindorfer					926, 29% (27%,31%) knew one risk factor										2005
Becker					328, 60% (56%,64%) knew >1 risk factor										Pre
Becker					332, 65% (61%,69%) knew >1 risk factor										Post

na = not applicable: where closed questions meant this was not an option; *HT = hypertension; †IHD = ischaemic heart disease; ‡DM = diabetes mellitus; §AF = atrial fibrillation; ▨ = open-ended questions; O* = open questions; C* = closed questions when one study has used two types of questioning for the same topic; Pre = pre intervention; Post = post intervention.

Table 2.8. Knowledge of risk factors for stroke among studies involving patients at higher risk of stroke (n % (95% CI))

Author	HT*	Smoking	Age	Cholesterol	IHD†	DM‡	AF§	Alcohol excess	Previous stroke/TIA	Stress	Diet	Inactivity	Family history	Obesity	Notes
Al Shafaee	140 35% (30%,40%)	20 5% (3%,8%)	8 2% (1%,4%)	36 9% (7%,12%)	44 11% (8%,14%)	92 23% (19%,27%)	0 0%	16 4% (2%,6%)	4 1% (0%,3%)	0 0%	0 0%	12 3% (2%,5%)	0 0%	24 6% (4%,9%)	
Carroll	11 28% (16%,43%)	20 50% (35%,65%)	0 0%	3 8% (3%,20%)	6 15% (7%,29%)	0 0%	0 0%	4 10% (4%,23%)	0 0%	14 35% (22%,50%)	11 28% (16%,43%)	5 13% (5%,26%)	3 8% (3%,20%)	13 33% (20%,48%)	
Gupta	197 48% (43%,53%)	131 32% (28%,37%)	0 0%	123 30% (26%,35%)	33 8% (6%,11%)	0 0%	0 0%	33 8% (6%,11%)	0 0%	41 10% (7%,13%)	86 21% (17%,25%)	41 10% (7%,13%)	53 13% (10%,17%)	82 20% (16%,24%)	O*
Pandian^{2005}	339 36% (33%,39%)	226 24% (21%,27%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	
Pandian^{2006}	23 51% (37%,65%)	0 0%	0 0%	10 21% (13%,36%)	0 0%	1 2% (0%,12%)	0 0%	10 21% (13%,36%)	0 0%	5 12% (5%,24%)	0 0%	13 29% (18%,43%)	2 5% (1%,15%)	0 0%	
Gupta	402 98% (96%,99%)	390 95% (93%,97%)	na	381 93% (90%,95%	na	308 75% (71%,79%)	na	328 80% (76%,84%)	na	na	na	na	na	na	C*
Samsa					631, 50% (47%,53%) of patients < 65 years of age, aware of their own risk factors for stroke 378, 30% (28%,33%) of patients > 64 years of age, aware of their own risk factors for stroke										

na = not applicable: where closed questions meant this was not an option; *HT = hypertension; †IHD = ischaemic heart disease; ‡DM = diabetes mellitus; §AF = atrial fibrillation; ¶ ▭ = open-ended questions; *O = open questions; C* = closed questions when one study has used two types of questioning for the same topic.

Knowledge of the Signs and Symptoms of Stroke

The studies exploring knowledge about the signs and symptoms of stroke can be found in Tables 2.9 through 2.12. Regardless of who participants were or how questions were asked, the most frequently reported signs and symptoms of stroke were: speech disturbance; sided numbness and weakness or paralysis. Similar to risk factor identification, recognition of stroke symptoms was poor when open-ended questions were used (Tables 2.9 to 2.12). In one study 33% (CI 27% to 40%) of participants identified sided weakness and 11% (CI 7% to 16%) identified speech disturbance when open questions were asked compared to 90% (CI 85% to 94%) and 95% (91% to 97%) when closed questions were used (Hux et al. 2000).

Knowledge of the Signs and Symptoms of Stroke Amongst Different Groups

Four studies assessed stroke knowledge in relation to the signs or symptoms of stroke amongst stroke patients (Table 2.9). Speech disturbance was identified as a symptom of stroke by participants in all four studies, as was sided numbness and weakness or paralysis. In the two studies involving relatives (Table 2.10) paralysis was the most commonly identified symptom followed by speech disturbance (Pandian et al. 2005; 2006).

Thirty-three studies assessed stroke symptom knowledge amongst the public (Table 2.11). Speech disturbance was identified in all of the studies involving members of the public, ranging from 2% (CI 1% to 3%) (Kim et al. 1997) to 95% (CI 91% to 97%) (Hux et al. 2000). Sided numbness and weakness or paralysis were also commonly identified by participants ranging from 0% (Das et al. 2007) to 60% (CI 57% to 63%) (Kim et al. 1997). The use of closed questions when testing the public’s knowledge generally resulted in higher proportions of people identifying symptoms. For example, in one study when using open questions 11% (CI 7% to 16%) of participants reported speech disturbance, whereas with closed questions 95% (CI 91% to 97%) of participants recognised speech disturbance as a symptom of stroke (Hux et al. 2000).

In seven studies of patients at risk of stroke, four used open-ended questions (Table 2.12). In the studies that had used open questions sided, numbness and weakness or paralysis were reported by 0% (Pandian et al. 2005) to 65% (CI 60% to 70%) (Al Shafaee et al. 2006), compared to between 94% (CI 93.8% to 94.2%) (Greenlund et al. 2003) and 95% (CI 93% to 96%) (Rowe et al. 2001) of participants who had been asked using closed questions. In one study that had used both types of questions (Rowe et al. 2001), the proportion of participants identifying sided numbness and weakness or paralysis ranged from 24% (CI 21% to 27%) with open questions to 95%

(CI 93% to 96%) with closed questions. Regardless of how questions were asked, speech disturbance was mentioned in all seven studies, ranging from 5% (CI 4% to 7%) (Pandian et al 2005) to 30% (Al Shafaee et al. 2006) when open questions were asked and from 82% (CI 78% to 85%) (Gupta et al. 2002) to 93% (CI 91% to 95%) (Rowe et al. 2001) when closed questions were asked.

Only two studies asked specifically about the recognition of facial weakness (Bray et al. 2010; Truelsen et al. 2010). Within one of these studies facial weakness was only explored within the context of the Face Arm Speech Time to act fast campaign (Bray et al. 2010). All other studies asked about numbness or weakness on one side of the body or face.

Knowledge of the Signs and Symptoms of Stroke and Age

As with risk factors, several studies explored the association between age and knowledge of the signs and symptoms of stroke (Mosca et al. 2000; Yoon et al. 2001; Silver et al. 2003; Al Shafaee et al. 2006; Pandian et al. 2006). Regardless of how questions were asked or in whom, older age was associated with poorer knowledge of the signs and symptoms of stroke. Two studies explored knowledge of the signs and symptoms of stroke and age amongst stroke patients. The first study reported that more patients under 65 years (47%) (CI 40% to 55%) knew a sign or symptom of stroke compared to those patients aged 65 years and over (28%) (CI 22% to 36%) (Kothari et al. 1997). The second study found that participants aged 60 years and younger were 2.4 times more likely to identify at least one symptom of stroke (Pandian et al. 2006). Three studies involved members of the public also found that older people had poorer stroke knowledge (Pancioli et al. 1998; Mosca et al. 2000; Yoon et al. 2001; Silver et al. 2003). For example, 60% (CI 57% to 62%) of participants aged under 75 years could identify at least one sign or symptom of stroke compared with 47% (CI 42% to 52%) of participants aged 75 years or older (Pancioli et al. 1998).

Knowledge of the Signs and Symptoms of Stroke and Ethnicity

Three studies explored the association between knowledge of the signs and symptoms of stroke and ethnicity. Regardless of how questions were asked symptom knowledge was poorest amongst African American members of the public (Stern et al. 1999; Reeves et al. 2002; Ferris et al. 2005).

Knowledge Related to TIA

Only two studies assessed knowledge in relation to TIA (Johnston et al. 2003; Nedeltchev et al. 2007). In one of the studies only 8% (CI 6% to 11%) of participants recognised TIA as symptoms of stroke resolving within 24 hours and only 3% (CI 1% to 5%) of participants identified TIA as a disease that requires immediate medical help (Nedeltchev et al. 2007). In the second study only 8% (CI 7% to 9%) of participants correctly identified the definition of TIA and only 9% (CI 8% to 10%) of participants could identify a typical symptom (Johnston et al. 2003). There were insufficient data to compare knowledge between people who have had a stroke and those with TIA.

Table 2.9. Knowledge of signs and symptoms of stroke among studies involving stroke patients (n % (95% CI))

Author	Sided numbness	Weakness	Paralysis	Speech Disturbance	Confusion	Loss of co-ordination	Dizziness	Loss of vision	Consciousness	Headache	Vomiting	Motor
Das	165 25% (22%,28%)	165 25% (22%,28%)	0 0%	145 22% (19%,25%)	145 22% (19%,25%)	132 20% (17%,23%)	132 20% (17%,23%)	66 10% (8%,13%)	0 0%	53 8% (6%,10%)	0 0%	0 0%
Kothari	46 28% (22%,36%)	55 34% (27%,41%)	0 0%	46 28% (22%,36%)	8 5% (2%,10%)	57 35% [28%,43%)	25 15% (10%,22%)	0 0%	0 0%	18 11% (7%,17%)	0 0%	0 0%
Pandian^{2005}	0 0%	0 0%	63 62% (52%,71%)	5 5% (2%,11%)	0 0%	6 6% (3%,12%)	0 0%	2 2% (0%,7%)	6 6% (3%,12%)	8 8% (4%,15%)	0 0%	0 0%
Marx	na	215 43% (39%,47%)	215 43% (39%,47%)	125 25% (21%,29%)	na	30 6% (4%,9%)	na	35 7% (5%,10%)	na	na	na	na

na = not applicable: where closed questions meant this was not an option; ▨ = open-ended questions.

Table 2.10. Knowledge of signs and symptoms of stroke among studies involving relatives (n % (95% CI))

Author	Sided numbness	Weakness	Paralysis	Speech Disturbance	Confusion	Loss of co-ordination	Dizziness	Loss of vision	Consciousness	Headache	Vomiting	Motor
Pandian^{2005}	0 0%	0 0%	584 62% (59%,65%)	47 5% (4%,7%)	0 0%	57 6% (5%,8%)	0 0%	19 2% (1%,3%)	57 6% (5%,8%)	75 8% (6%,10%)	0 0%	0 0%
Pandian^{2006}	2 5% (0%,15%)	0 0%	28 62% (48%,75%)	10 22% (13%,36%)	0 0%	0 0%	2 5% (0%,15%)	1 1% (0%,12%)	0 0%	2 5% (0%,15%)	0 0%	3 6% (2%,18%)

▨= open-ended questions

Table 2.11. Knowledge of signs and symptoms of stroke among studies involving the public (n % (95% CI))

Author	Sided numbness	Weakness	Paralysis	Speech Disturbance	Confusion	Loss of co-ordination	Dizziness	Loss of vision	Consciousness	Headache	Vomiting	Motor	Notes*
Das	1025 22% (21%,23%)	1025 22% (21%,23%)	0 0%	979 21% (20%,22%)	979 21% (20%,22%)	699 15% (14%,16%)	699 15% (14%,16%)	513 11% (10%,12%)	0 0%	466 10% (9%,11%)	0 0%	0 0%	
Hodgson	0 0%	0 0%	565 49% (46%,52%)	265 23% (21%,26%)	0 0%	0 0%	496 43% (21%,26%)	277 24% (22%,27%)	0 0%	334 29% (26%,32%)	0 0%	0 0%	Pre
Hodgson	0 0%	0 0%	562 47% (44%,50%)	371 31% (28%,34%)	0 0%	0 0%	657 55% (52%,58%)	406 34% (31%,37%)	0 0%	382 32% (29%,35%)	0 0%	0 0%	During
Hodgson	0 0%	0 0%	489 46% (43%,49%)	393 37% (34%,40%)	0 0%	0 0%	627 59% (56%,62%)	361 34% (31%,37%)	0 0%	361 34% (31%,37%)	0 0%	0 0%	Post
Hodgson	0 0%	0 0%	505 44% (41%,47%)	447 39% (36%,42%)	0 0%	0 0%	723 63% (60%,66%)	505 44% (41%,47%)	0 0%	413 36% (33%,39%)	0 0%	0 0%	During2
Hodgson	0 0%	0 0%	519 48% (45%,51%)	444 41% (38%,44%)	0 0%	0 0%	682 63% (60%,66%)	487 45% (42%,48%)	0 0%	346 32% (29%,35%)	0 0%	0 0%	Post2
Hodgson	0 0%	0 0%	463 44% (41%,47%)	358 34% (31%,37%)	0 0%	0 0%	590 56% (53%,59%)	390 37% (34%,40%)	0 0%	326 31% (28%,34%)	0 0%	0 0%	Post3

Table 2.11 continued

Author	Sided numbness	Weakness	Paralysis	Speech Disturbance	Confusion	Loss of co-ordination	Dizziness	Loss of vision	Consciousness	Headache	Vomiting	Motor	Notes*
Johnston	1213 12% (115,13%)	1213 12% (115,13%)	0 0%	506 5% (4%,6%)	0 0%	1315 13% (12%,14%)	1315 13% (12%,14%)	910 9% (8%,10%)	0 0%	0 0%	0 0%	0 0%	
Kim[1997]	1 2% (0%,8%)	0 0%	39 60% (48%71%)	1 2% (0%,8%)	0.6 1% (0%,7%)	3 5% (1%,13%)	0 0%	0.6 1% (0%,7%)	3 4% (1%,12%)	0 0%	0 0%	0 0%	
Pancioli	207 11% (10%,13%)	282 15% (13%,17%)	0 0%	150 8% (7%,9%)	0 0%	0 0%	451 24% (22%,26%)	132 7% (6%,8%)	0 0%	301 16% (14%,18%)	0 0%	0 0%	
Reeves	1156 46% (4%,48%)	1156 46% (4%,48%)	0 0%	754 30% (28%,32%)	754 30% (28%,32%)	603 24% (22%,26%)	603 24% (22%,26%)	352 14% (13%,15%)	0 0%	377 15% (14%,16%)	0 0%	0 0%	
Schneider	677 36% (34%,38%)	376 20% (18%,22%)	0 0%	301 16% (14%,18%)	0 0%	0 0%	489 26% (24%,28%)	244 13% (12%,15%)	0 0%	257 19% (17%,21%)	0 0%	0 0%	
Alkadry	1078 92% (90%,93%)	na	na	1031 88% (86%,90%)	na	na	na	715 61% (58%,64%)	na	715 61% (58%,64%)	na	na	
Cheung	na	758 62% (59%,65%)	na	794 65% (62%,68%)	na	697 57% (54%,60%)	na	na	709 58% (55%,61%)	na	na	na	

Table 2.11 continued

Author	Sided numbness	Weakness	Paralysis	Speech Disturbance	Confusion	Loss of co-ordination	Dizziness	Loss of vision	Consciousness	Headache	Vomiting	Motor	Notes*
Ferris	379	0	0	266	0	0	205	195	0	287	na	na	
	37%	0%	0%	26%	0%	0%	20%	19%	0%	28%			
	(34%,40%)			(23%,29%)			(18%,23%)	(17%,22%)		(25%,31%)			
Greenlund	57358	57358	na	53697	53697	52476	52476	41493	na	37227	na	na	
	94%	94%		88%	88%	86%	86%	68%		61%			
	(93%,94%)	(93%,94%)		(87%,88%)	(87%,88%)	(85%,96%)	(85%,96%)	(67%,68%)		(60%,61%)			
Hux	63	0	0	21	0	0	42	23	13	30	0	21	O*
	33%	0%	0%	11%	0%	0%	22%	12%	7%	16%	0%	11%	
	(27%,40%)			(7%,16%)			(17%,29%)	(8%,18%)	(4%,11%)	(11%,22%)		(7%,16%)	
Hux	171	171	na	181	na	na	182	169	na	154	na	na	C†
	90%	90%		95%			96%	89%		81%			
	(85%,94%)	(85%,94%)		(91%,97%)			(92%,98%)	(84%,93%)		(75%,86%)			
Marx	0	215	215	125	0	30	0	35	0	0	0	0	O
	0%	43%	43%	25%	0%	6%	0%	7%	0%	0%	0%	0%	
		(39%,47%)	(39%,47%)	(21%,29%)		(4%,8%)		(5%,10%)					
Mikulik	0	201	0	219	0	0	0	130	20	0	0	0	
	0%	34%	0%	37%	0%	0%	0%	22%	0%	0%	0%	0%	
		(30%,38%)		(33%,41%)				(18%,25%)					
Morgan	113	113	na	102	na	49	31	na	33	38	6	na	
	81%	81%		73%		35%	22%		24%	27%	4%		
	(74%,87%)	(74%,87%)		(65%,87%)		(28%,43%)	(16%,30%)		(17%,31%)	(21%,35%)	(0%,9%)		

Table 2.11 continued

Author	Sided numbness	Weakness	Paralysis	Speech Disturbance	Confusion	Loss of co-ordination	Dizziness	Loss of vision	Consciousness	Headache	Vomiting	Motor	Notes*
Mosca	48	48	0	13	0	0	13	13	0	13	0	0	
	36%	36%	0%	10%	0%	0%	10%	10%	0%	10%	0%	0%	
	(28%,45%)	(28%,45%)		(6%,16%)			(6%,16%)	(6%,16%)		(6%,16%)			
Parahoo	na	800	na	782	na	417	na	365	269	217	na	na	
		92%		90%		48%		42%	31%	25%			
		(90%,94%)		(88%,92%)		(45%,51%)		(39%,45%)	(28%,34%)	(22%,28%)			
Rowe	145	145	0	84	0	60	60	30	0	48	0	0	O*
	24%	24%	0%	14%	0%	10%	10%	5%	0%	8%	0%	0%	
	(21%,28%)	(21%,28%)		(11%,17%)		(8%,13%)	(8%,13%)	(4%,7%)		(6%,10%)			
Rowe	572	572	na	560	na	542	542	464	na	464	na	na	C*
	95%	95%		93%		90%	90%	77%		77%			
	(93%,96%)	(93%,96%)		(91%,95%)		(87%,92)	(87%,92)	(74%,78%)		(74%,78%)			
Segura	2070	2640	na	2400	na	na	2250	2100	2400	2370	na	na	
	69%	88%		80%			75%	70%	80%	79%			
	(67%,71%)	(87%,89%)		(79%,81%)			(73%,77%)	(68%,72%)	(79%,81%)	(78%,80%)			
Truelsen	na	na	438	633	na	na	na	430	na	na	na	na	
			54%	78%				53%					
			(51%,57%)	(75%,81%)				(50%,56%)					
Yoon	205	51	115	179	0	na	268	307	na	281	na	na	
	16%	4%	9%	14%	0%		21%	24%		22%			
	(14%,18%)	(3%,5%)	(8%,11%)	(12%,16%)			(19%,23%)	(22%,26%)		(20%,24%)			

Table 2.11 continued

Author	Symptoms	Notes
Becker	213, 39% (35%,43%) knew >1 symptom	Pre
Becker	252, 46% (42%,50%) knew >1 symptom	Post
Bray	20, 12% (7%,17%) were aware of the FAST campaign: 9, 5% (3%,10%) recalling face, 7, 4% (2%,8%) arm weakness and 15, 9% (5%,14%) speech problems	
Carroll	2 (1 IQR) knew >1 symptom	Public
DeLemos	110, 59% (52%,66%) recognised 3 warning symptoms: numbness on 1 side, difficulty talking or understanding, difficulty with vision	Pre
DeLemos	74, 94% (86%,97%) recognised 3 warning symptoms: numbness on 1 side, difficulty talking or understanding, difficulty with vision	Post
DeLemos	60, 77% (66%,85%) recognised 3 warning symptoms: numbness on 1 side, difficulty talking or understanding, difficulty with vision	3-months
Handschu	1.5 (1.1 SD) mean number of stroke symptoms named	Pre
Handschu	3.4 (1.4 SD) mean number of stroke symptoms named	Post
Hsia	121, 48% (425,54%) could recall face weakness and speech problems	
Kleindorfer	1189, 45% (43%,47%) knew 1 sign or symptom	1995
Kleindorfer	1008, 32% (30%,34%) knew 1 sign or symptom	2000
Nedeltchev	Data extraction on individual symptoms not possible	2005
Pontes-Neto	176, 22% (19%,25%) could not recognise one symptom	
Silver	1.25 (1.16 SD) mean symptoms; 130, 42% (37%,48%) knew 2 or more symptoms	Pre: print
Silver	1.27 (1.24 SD) mean symptoms; 155, 39% (34%,44%) knew 2 or more symptoms	Pre: LLTV
Silver	1.32 (1.25 SD) mean symptoms; 161, 40% (35%,45%) knew 2 or more symptoms	Pre: HLTV
Silver	1.38 (1.21 SD) mean symptoms; 178, 44% (39%,49%) knew 2 or more symptoms	Pre: cont
Silver	1.17 (1.25 SD) mean symptoms; 161, 41% (36%,46%) knew 2 or more symptoms	Post: print
Silver	1.47 (1.26 SD) mean symptoms; 206, 50% (45%,55%) knew 2 or more symptoms	Post: LLTV
Silver	1.66 (1.37 SD) mean symptoms; 219, 54% (49%,59%) knew 2 or more symptoms	Post: HLTV
Silver	1.10 (1.21 SD) mean symptoms; 148, 36% (32%,41%) knew 2 or more symptoms	Post: cont
Stern	68.6 (18.8 SD) mean % correct	Pre
Stern	79.4 (17.3 SD) mean % correct	Post
Truelsen	454, 56% (53%,59%) facial weakness	

na = not applicable: where closed questions meant this was not an option; ▨ = open-ended questions; O* = open questions; C* = closed questions when one study has used two types of questioning for the same topic; LLTV = low level television; HLTV = high level television; (SD) standard deviation; (IQR) Interquartile range

Table 2.12. Knowledge of signs and symptoms of stroke among studies involving patients at higher risk of stroke (n % (95% CI))

Author	Sided numbness	Weakness	Paralysis	Speech Disturbance	Confusion	Loss of co-ordination	Dizziness	Loss of vision	Consciousness	Headache	Vomiting	Motor	Notes*
Al Shafaee	28 7% (5%,10%)	260 65% (60%,70%)	260 65% (60%,70%)	120 30% (26%,35%)	0 0%	0 0%	24 6% (4%,9%)	12 3% (2%,5%)	0 0%	12 3% (2%,5%)	0 0%	104 26% (22%,31%)	
Pandian^{2005}	0 0%	0 0%	584 62% (59%,65%)	47 5% (4%,7%)	0 0%	57 6% (5%,8%)	0 0%	19 2% (1%,3%)	57 6% (5%,8%)	75 8% (6%,10%)	0 0%	0 0%	
Pandian^{2006}	2 5% (1%,15%)	0 0%	28 62% (48%,75%)	10 22% (13%,36%)	0 0%	0 0%	2 5% (1%,15%)	1 1% (0%,12%)	0 0%	2 5% (1%,15%)	0 0%	0 0%	
Rowe	303 24% (22%,26%)	303 24% (22%,26%)	0 0%	177 14% (12%,16%)	0 0%	126 10% (8%,12%)	126 10% (8%,12%)	63 5% (4%,6%)	0 0%	101 8% (7%,10%)	0 0%	0 0%	O*
Greenlund	385 94% (91%,96%)	385 94% (91%,96%)	na	361 88% (85%,91%)	361 88% (85%,91%)	353 86% (82%,89%)	353 86% (82%,89%)	279 68% (63%,72%)	na	250 61% (56%,66%)	na	na	
Rowe	1198 95% (94%,96%)	1198 95% (94%,96%)	na	1173 93% (91%,94%)	na	1135 90% (88%,91%)	1135 90% (88%,91%)	971 77% (75%,79%)	na	971 77% (75%,79%)	na	na	C*
Gupta				336, 82% (78%,85%) of patients gave correct responses, the commonest symptom reported was weakness									

na = not applicable; where closed questions meant this was not an option; ▨ = open-ended questions; O* = open questions, C* = closed questions when one study has used two types of questioning for the same topic.

Action to be Taken When Stroke is Suspected

The studies that asked about what action should be taken when a stroke is suspected can be found in Tables 2.13 through 2.16. When participants were asked what action they would take if they suspected the symptoms of stroke between 0% (Pandian et al. 2005) and 99% (Wall et al. 2008) of participants stated that they would contact the EMS (Tables 2.13 to 2.16). Again responses are likely to reflect the way in which questions were asked. Overall, most participants would either call the EMS or their GP or doctor.

Knowledge of Action Taken Amongst Different Groups

Only two studies asked stroke patients what action they had actually taken. In both of these studies knowledge in relation to stroke action was also assessed in members of the public. In the first study, 80% (CI 65% to 90%) of the public stated that they would contact the EMS for suspected stroke (Carroll et al. 2004). In the same study stroke patients were asked what action they had actually taken and only 18% (CI 9% to 32%) had contacted the EMS, the majority (80%) had contacted their GP. In a second study 89% (CI 85% to 92%) of the public said that they would contact the EMS compared to only 12% (CI 8% to 16%) of stroke patients who had actually dialled 911 (Hsia et al. 2011). There was only one study involving relatives and in this study no relatives suggested contacting the EMS for suspected stroke, with the majority suggesting that you should go directly to hospital (Pandian et al. 2005). Among those patients at higher risk of stroke between 0% (Al Shafaee et al. 2006) and 18% (CI 9% to 32%) (Carroll et al. 2004) reported that they would contact the EMS.

Action to be Taken When Stroke is Suspected and Age

Regardless of how questions were asked older age was shown to be associated with a decreased likelihood to call the EMS amongst members of the public (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008).

Table 2.13. Action that should be taken if a stroke is suspected, among studies involving stroke patients (n % (95% CI))

Author	EMS	call GP/Dr	Go to Dr	Call Hospital	Direct to Hospital	Call for Help	Seek Medical attention	Family & Friends & Neighbours	Buy Medicine from a shop	Do nothing	Don't know
Carroll	7	32	0	0	0	0	0	0	0	0	0
	18%	80%	0%	0%	0%	0%	0%	0%	0%	0%	0%
	(9%,32%)	(65%,90%)									
Pandian[2005]	0	15	0	0	82	0	0	0	0	0	5
	0%	15%	0%	0%	80%	0%	0%	0%	0%	0%	5%
		(9%,23%)			(72%,87%)						(2%,11%)
Hsia				12, 12% (7%,20%) of patients had called 911							

▨ = open-ended questions.

Table 2.14. Action that should be taken if a stroke is suspected, among studies involving relatives (n % (95% CI))

Author	EMS	call GP/Dr	Go to Dr	Call Hospital	Direct to Hospital	Call for Help	Seek Medical attention	Family & Friends & Neighbours	Buy Medicine from a shop	Do nothing	Don't know	Other
Pandian[2005]	0	141	94	0	669	0	0	0	0	0	47	85
	0%	15%	10%	0%	71%	0%	0%	0%	0%	0%	5%	9%
		(13%,17%)	(8%,12%)		(68%,74%)						(4%,7%)	(7%,11%)

▨ = open-ended questions.

Table 2.15. Action that should be taken if a stroke is suspected, among studies involving the public (n % (95% CI))

Author	EMS	call GP/Dr	Go to Dr	Call Hospital	Direct to Hospital	Call for Help	Seek Medical attention	Family & Friends & Neighbours	Buy Medicine from a shop	Do nothing	Don't know	Notes
Carroll	32 80% (65%,90%)	8 20% (11%,35%)	0 0%	0 0%	2 5% (1%,17%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	Public
Reeves	1984 79% (77%,81%)	75 3% (2%,4%)	0 0%	0 0%	100 4% (3%,5%)	0 0%	0 0%	0 0%	0 0%	0 0%	100 4% (3%,5%)	
Rowe	421 70% (66%,73%)	24 4% (3%,6%)	18 3% (2%,5%)	12 2% (1%,3%)	54 9% (7%,12%)	48 8% (6%,10%)	6 1% (0%,2%)	0 0%	0 0%	0 0%	24 4% (3%,6%)	
Schneider	1608 74% (72%,76%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	22 1% (0%,2%)	0 0%	Post
Alkadry	1102 94% (93%,95%)	na	na	na	1102 94% (93%,95%)	na	na	na	na	na	na	
Cheung	599 49% (46%,52%)	171 14% (12%,16%)	0 0%	0 0%	354 29% (27%,32%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	

Table 2.15 continued

Author	EMS	call GP/Dr	Go to Dr	Call Hospital	Direct to Hospital	Call for Help	Seek Medical attention	Family & Friends & Neighbours	Buy Medicine from a shop	Do nothing	Don't know	Notes
DeLemos	87 47% (40%,54%)	na	na	na	na	na	na	na	na	na	na	Pre
DeLemos	76 98% (91%,99%)	na	na	na	na	na	na	na	na	na	na	Post
Mikulik	160 27% (24%,31%)	195 33% (29%,37%)	na	na	na	na	na	na	na	59 10% (8%,13%)	na	
Nedeltchev	270 64% (59%,68%)	152 36% (32%,41%)	na	na	na	na	na	na	na	0 0%	0 0%	
Parahoo	461 53% (50%,56%)	365 42% (39%,45%)	na	na	na	na	na	17 2% (1%,3%)	na	na	na	
Pontes-Neto	409 51% (48%,55%)	na	na	na	na	na	na	na	na	na	na	

Table 2.15 continued

Author	EMS	call GP/Dr	Go to Dr	Call Hospital	Direct to Hospital	Call for Help	Seek Medical attention	Family & Friends & Neighbours	Buy Medicine from a shop	Do nothing	Don't know	Notes
Segura	1350 45% (43%,47%)	1230 41% (39%,43%)	390 13% (12%,14%)	na	na	na	na	na	na	30 1% (0.7%,1.4%)	na	
Truelsen	665 82% (79%,84%)	57 7% (5%,9%)	na	na	81 10% (8%,12%)	na	na	na	na	na	na	
Yoon	856 67% (64%,70%)	128 10% (8%,12%)	115 9% (8%,11%)	0 0%	294 23% (21%,25%)	0 0%	0 0%	0 0%	0 0%	26 2% (1%,3%)	26 2% (1%,3%)	
Fussman				2469, 51% (50%,52%) would call 999 if they had speech problems 2033, 42% (41%,43%) for sudden weakness 968, 20% (19%,21%) for trouble seeing								
Hsia				225, 89% (84%,92%) of the public said they would call 911								
Marx				411, 81% (77%,84%) would call EMS Pre-intervention 411, 82% (78%,85%) would call EMS Post-intervention								
Morgan				133, 96% (91%,98%) thought it was extremely important 4, 3% (1%,7%) thought it might be important 1, 1% (1%,4%) thought it was not important to get immediate treatment								
Wall				71, 99% (93%,100%) would dial 999 following an educational intervention 63, 97% (89%,99%) would dial 999 at three months post intervention								

na = not applicable: where closed questions meant this was not an option; ▨ = open-ended questions; Pre = pre intervention; Post = post intervention.

Table 2.16. Action that should be taken if a stroke is suspected among studies involving patients at higher risk of stroke (n % (95% CI))

Author	EMS	call GP/Dr	Go to Dr	Call Hospital	Direct to Hospital	Call for Help	Seek Medical attention	Family & Friends & Neighbours	Buy Medicine from a shop	Do nothing	Don't know	Notes
Al Shafaee	0 0%	0 0%	0 0%	0 0%	292 73% (68%,77%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	80 20% (16%,24%) indigenous treatment
Carroll	29 73% (57%,84%)	11 28% (16%,43%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	
Pandian[2005]	0 0%	6 14% (6%,26%)	5 10% (5%,24%)	0 0%	32 71% (57%,82%)	0 0%	0 0%	0 0%	0 0%	0 0%	2 5% (1%15%)	

na = not applicable: where closed questions meant this was not an option; ▨ = open-ended questions.

Sources of Information

In the 15 studies that asked participants to identify the main ways in which they had gained information about stroke, a variety of sources were cited (Tables 2.17 to 2.20). The most common sources of information were through other people, such as friends/relatives, neighbours or health professionals and media such as TV, radio and newspapers/magazines.

Sources of Information Amongst Different Groups

Among the four studies that asked stroke patients about sources of stroke information between 18% (CI 9% to 32%) (Carroll et al. 2004) and 60% (CI 57% to 63%) of participants (Pandian et al. 2005) sought information from a relative or friend. A relative or friend was also the commonly cited source of stroke information among studies involving relatives, the public and patients at higher risk (Tables 2.18 to 2.20). The proportion of people who gained stroke information from health professionals was particularly low amongst patients at higher risk, ranging from 5% (CI 3% to 8%) (Al Shafaee et al. 2006) to 8% (CI 3% to 20%) (Caroll et al. 2004). This group commonly cited their own personal experience as the main source of health information, ranging from 32% (CI 29% to 35%) (Pandian et al. 2005) to 33% (CI 20% to 48%) (Carroll et al. 2004).

Table 2.17. Where people obtain information about stroke among studies involving stroke patients (n % (95% CI))

Author	Relative & / or Friend	Neighbour	TV	Radio	Newspapers & Magazines	Books & Pamphlets	Healthcare Professional	Personal Experience	Advertising & Campaigns	Internet	Workplace	Library	School
Carroll	7 18% (9%,32%)	0 0%	2 5% (1%,17%)	0 0%	0 0%	11 28% (16%,43%)	3 8% (3%,30%)	15 38% (24%,53%)	0 0%	0 0%	0 0%	0 0%	0 0%
Das	139 21% (18%,24%)	0 0%	33 5% (4%,7%)	33 5% (4%,7%)	33 5% (4%,7%)	185 28% (25%,32%)	139 21% (18%,24%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%
Pandian[2005]	61 60% (50%,69%)	0 0%	34 33% (25%,43%)	4 4% (2%,10%)	30 29% (21%,39%)	28 27% (20%,37%)	21 21% (14%,29%)	0 0%	28 27% (20%,37%)	1 1% (0%,5%)	0 0%	0 0%	0 0%
Kim [2011]	52 32% (25%,39%)	na	54 33% (26%,41%)	54 33% (26%,41%)	11 7% (4%,12%)	na	83 51% (43%,58%)	na	na	5 3% (1%,7%)	8 5% (1%,7%)	5 3% (1%,7%)	na

na = not applicable: where closed questions meant this was not an option; ▨ = open-ended questions.

Table 2.18. Where people obtain information about stroke among studies involving relatives (n % (95% CI))

Author	Relative & / or Friend	Neighbour	TV	Radio	Newspapers & Magazines	Books & Pamphlets	Healthcare Professional	Personal Experience	Advertising & Campaigns	Internet	Workplace	Library	School
Pandian[2005]	16 36% (23%,50%)	0 0%	4 9% (4%, 21%)	1 1% (0%,10%)	3 6% (2%,18%)	0 0%	4 9% (4%,21%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%

▨ = open-ended questions.

Table 2.19. Where people obtain information about stroke among studies involving the public (n % (95% CI))

Author	Relative & / or Friend	Neighbour	TV	Radio	Newspapers & Magazines	Books & Pamphlets	Healthcare Professional	Personal Experience	Advertising & Campaigns	Internet	Workplace	Library	School
Carroll	1 3% (0%,13%)	0 0%	3 8% (3%,20%)	0 0%	0 0%	6 15% (7%,29%)	5 13% (5%,26%)	8 20% (11%,35%)	0 0%	0 0%	0 0%	0 0%	0 0%
Das	1491 32% (31%,33%)	0 0%	599 12% (12%,14%)	599 12% (12%,14%)	599 12% (12%,14%)	2144 46% (45%,47%)	1118 24% (23%,25%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%
Kim^{1997}	280 28% (25%,31%)	280 28% (25%,31%)	420 42% (39%,45%)	0 0%	90 9% (7%,11%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%	20 2% (1%,3%)
Nedeltchev	0 0%	0 0%	169 40% (35%,45%)	59 14% (11%,18%)	139 33% (29%,38%)	0 0%	38 9% (7%,12%)	0 0%	0 0%	13 3% (2%,5%)	0 0%	0 0%	0 0%
Pancioli	226 12% (11%,14%)	0 0%	451 24% (22%,26%)	0 0%	376 20%0 (18%,22%)	90 9% (7%,11%)	338 18% (16%,20%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%
Schneider	282 13% (12%,14%)	0 0%	695 32% (30%,34%)	0 0%	500 23% (21%,25%)	196 9% (8%,10%)	435 20% (18%,22%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%
Yoon	332 26% (24%,26%)	0 0%	268 21% (19%,23)	0 0%	204 16% (14%,18%)	0 0%	77 6% (5%,7%)	0 0%	0 0%	0 0%	0 0%	0 0%	153 12% (10%,14%)

Table 2.19 continued

Author	Relative & / or Friend	Neighbour	TV	Radio	Newspapers & Magazines	Books & Pamphlets	Healthcare Professional	Personal Experience	Advertising & Campaigns	Internet	Workplace	Library	School
Cheung	574 47% (44%,50%)	na	428 35% (32%,38%)	110 9% (8%,11%)	489 40% (37%,43%)	208 17% (15%,19%)	98 8% (7%,10%)	na	na	na	na	na	49 4% (3%,5%)
Hux	63 33% (27%,40%)	na	59 31% (25%,38%)	na	59 31% (25%,38%)	na	27 14% (10%,20%)	63 33% (27%,40%)	na	na	13 7% (4%,11%)	na	30 16% (11%,22%)
Morgan	44 32% (25%,40%)	na	46 33% (26%,41%)	46 33% (26%,41%)	10 7% (4%,13%)	na	71 51% (43%,59%)	na	na	4 3% (1%,7%)	7 5% (2%,10%)	4 3% (1%,7%)	na
Müller-Nordhorn	12641 45% (44%,46%)	na	23034 82% (81%,82%)	23034 82% (81%,82%)	23034 82% (81%,82%)	na	5628 20% (19%,20%)	na	na	na	na	na	na
Parahoo	521 60% (57%,63%)	na	287 33% (30%,36%)	35 4% (3%,6%)	252 29% (26%,32%)	235 27% (24%,30%)	182 21% (18%,24%)	na	235 27% (24%,30%)	9 1% (0%,2%)	na	na	na
Pontes-Neto	na	112 14% (12%,17%)	na	na	na	na	na	256 32% (29%,35%)	na	na	na	na	328 41% (38%,44%)
Rowe	66 11% (9%,14%)	0%	265 44% (40%,48%)	na	169 28% (25%,32%)	78 13% (11%,16%)	114 19% (16%,22%)	na	na	na	na	na	na

na = not applicable: where closed questions meant this was not an option; ▨ = open-ended questions.

Table 2.20. Where people obtain information about stroke involving patients at higher risk of stroke (n % (95% CI))

Author	Relative & / or Friend	Neighbour	TV	Radio	Newspapers & Magazines	Books & Pamphlets	Healthcare Professional	Personal Experience	Advertising & Campaigns	Internet	Workplace	Library	School
Al Shafaee	216 54% (49%,59%)	180 45% (40%,50%)	4 1% (0%,3%)	0 0%	16 4% (2%,6%)	0 0%	20 5% (3%,8%)	0 0%	0 0%	0 0%	0 0%	0 0%	0 0%
Carroll	8 20% (11%,35%)	0 0%	5 13% (5%,26%)	0 0%	0 0%	1 3% (0%,13%)	3 8% (3%,20%)	13 33% (20%,48%)	1 3% (0%,13%)	0 0%	0 0%	0 0%	0 0%
Pandian[2005]	0 0%	6 14% (6%,26%)	0 0%	0 0%	0 0%	0 0%	0 0%	14 32% (20%,46%)	0 0%	0 0%	0 0%	0 0%	18 41% (27%,55%)
Rowe	328 26% (24%,29%)	na	265 21% (19%,23%)	na	202 16% (14%,18%)	na	76 6% (5%,7%)	na	na	na	na	na	151 12% (10%,14%)

na = not applicable: where closed questions meant this was not an option; ▨ = open-ended questions.

Intervention Studies

Nine studies used an intervention to raise awareness of stroke. Six studies were conducted in the USA, two in Germany and one in Canada. The impact of the interventions was assessed in terms of the participants' knowledge rather than looking at actual health behaviour or patient outcomes. Three studies tested knowledge pre and post a stroke awareness campaign that involved television and newspaper advertising (Becker et al. 2001; Silver et al. 2003; Hodgson et al. 2007). In communities exposed to television and newspaper advertising, the proportion able to identify the symptoms of stroke increased significantly from 52% (CI 49% to 55%) to 72% (CI 69% to 75%) (Hodgson et al. 2007) and from 39% (CI 35% to 43%) to 46% (CI 42% to 50%) (Becker et al. 2001). In a separate study, communities were exposed to either a television campaign or print advertising. There was no significant change in the community receiving newspaper advertising with the proportion of participants able to identify two symptoms of stroke falling from 42% (CI 37% to 48%) to 40% (CI 36% to 47%), but in the community receiving television advertising, 54% (CI 48% to 59%) of people were able to identify two or more symptoms compared with 40% (CI 35% to 45%) at baseline (Silver et al. 2003). Intermittent, low-level advertising was as effective as continuous, high-level advertising (Silver et al. 2003). One campaign that involved the mass media, poster adverts, flyers and public events showed no significant change in knowledge about symptoms, risk factors or actions (Marx et al. 2008). Likewise, a study that used mass media campaigns over a fifteen year period, actually showed a decrease in the public's knowledge of both the risk factors and signs and symptoms of stroke (Kleindorfer et al. 2009).

A further study used an animation to teach members of the public about the *Face Arm Speech Time to dial 911* (FAST) (Wall et al. 2008). This study reported that the proportions of participants that were able to recognise facial droop as a symptom of stroke increased from 92% to 99% (Wall et al. 2008). Similarly, 97% (CI 90% to 99%) were able to identify arm weakness or numbness after the intervention compared with 86% (CI 70% to 94%) before the intervention. At three months after the intervention 100% (CI 95% to 100%) recalled slurred speech and 99% (CI 92% to 100%) recalled arm weakness or numbness as a symptom of stroke; however, the number of participants who could remember all three components of the FAST had declined from 100% at post-test (CI 905 to 100%) to 79% (CI 67% to 87%) (Wall et al. 2008).

One study carried out stroke risk factor screening amongst members of the public combined with an educational programme. Before the campaign 59% (CI 52% to 66%) of participants were able to recognise weakness or numbness on one side, difficulty talking or understanding speech, and difficulty with vision as symptoms of stroke. Immediately after the intervention this increased to 94% (CI 86% to 97%), falling to 77% (CI 66% to 85%) when knowledge was tested three months later (DeLemos et al. 2003). Another study used an educational slide/audio programme. This study reported a mean increase of 11% ($p<0.001$) knowledge regarding stroke risk factors and the warning signs of stroke in the pre and post test groups (Stern et al. 1999). Finally, following a first aid training course about stroke that was delivered over a whole day or in six, 90 minutes sessions, the ability of participants to identify the symptoms of stroke increased from a mean of 1.5 (CI 0.4 to 2.6) to 3.4 (CI 2.0 to 4.8) symptoms (Handschu et al. 2006).

Knowledge of Treatments That Are Available for Stroke

Only three papers reported knowledge about treatment that could be given to stroke patients to break up blood clots (Ferris et al. 2005; Kleindorder et al. 2009; Kim et al. 2011). Two of the studies were carried out in the USA and involved members of the public. In one of the American-based studies, awareness of thrombolytic therapy was higher among Caucasians compared to African or Latin American respondents when asked closed questions (92%, [CI 90% to 94%] versus 84% [CI 77% to 90%] and 79% [CI 71% to 85%], respectively) (Ferris et al. 2005). In the second American study, which used open ended questions, only 4% (CI 4% to 5%) of respondents could identify thrombolysis as a potential treatment for stroke (Kleindorder et al. 2009). The third study was undertaken in South Korea and included stroke patients, of which only 18% (CI 16% to 21%) were aware of thrombolysis as a treatment for stroke when asked open questions (Kim et al. 2011). Again the difference in the proportions across studies is most likely to be a reflection of how the questions were asked.

2.4 Discussion

This is the first integrative review to explore stroke knowledge across a range of populations including stroke patients, relatives of stroke and non-stroke patients, the public and non-stroke patients at higher risk of stroke. The review has explored stroke knowledge in terms of risk factors, sign and symptoms of stroke, action that should be taken when stroke is suspected, sources of information and treatments available. The review found that across all studies and populations, hypertension was the most commonly reported risk factor for stroke and speech disturbance was the most commonly identified symptom. There was no difference in the proportions of people that could identify the main risk factors or symptoms of stroke across the populations (stroke patients, relatives of stroke or non-stroke patients, the public, non-stroke patients at higher risk of stroke).

Although hypertension was the most commonly identified risk factor for stroke, the proportions of people that were able to identify it varied considerably in different studies. Whilst some of the studies would suggest that risk factor knowledge amongst participants was very good (Cheung et al. 1999; Becker et al. 2001; Gupta et al. 2002; Segura et al. 2003; Truelsen et al. 2003; Ferris et al. 2005; Morgan et al. 2005; Das et al. 2007; Marx et al. 2008; Mikulik et al. 2008; Pontes-Neto et al. 2008) this was usually a reflection of the way in which questions had been asked. The studies that used closed questions reported high numbers of participants being able to identify risk factors compared to much lower numbers in studies that used open questions. This difference was most evident in a study that used both open and closed questions and reported that between 25% (open questions) and 98% (closed questions) of the public identified hypertension as a risk factor for stroke (Das et al. 2007). The review has identified similar issues in studies that explored stroke symptom knowledge. In one study that used both open and closed questions, only 11% identified speech problems when asked open questions, compared to 95% when closed questions were used (Hux et al. 2000).

Regardless of how questions were asked, stroke knowledge was poorest amongst older people (generally those aged 65 years and over) (Pancioli et al. 1998; Mosca et al. 2000; Becker et al. 2001; Yoon et al. 2001; Greenlund et al. 2003; Parahoo et al. 2003; Segura et al. 2003; Silver et al. 2003; Carroll et al. 2004; Al Shafaee et al. 2006; Hodgson et al. 2007; Marx et al. 2008; Kleindorder et al. 2009) and in some ethnic minority groups including people of African American and Hispanic heritage (Stern et al. 1999; Reeves et al. 2002; Ferris et al. 2005). Compared to younger people, older people were less likely to say that they would contact the EMS for stroke symptoms (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008). In a study which looked at help seeking behaviour for myocardial infarction, older age was also shown to be associated with a decreased likelihood of contacting the EMS (Schoenberg et al. 2003). However, a previous Australian study of help seeking behaviour for suspected stroke, did not find any association between older age and decreased EMS use (Mosley et al. 2007).

In this review, although a number of studies reported poor knowledge amongst older people and some ethnic minority groups, none explored possible reasons for this. Differences due to ethnicity might be explained by cultural differences in the perception of symptoms and symptom response. It has been suggested that it might be more culturally appropriate for Asian participants to seek help from sources other than the

EMS, such as seeking help from providers of indigenous treatments including massage, faith healing and homeopathy (Pandian et al 2005).

Studies examining the effects of interventions such as mass media campaigns (Becker et al. 2001; Silver et al. 2003; Hodgson et al. 2007); first aid training (Handschu et al. 2006) and educational programmes (Stern et al. 1999) have demonstrated an increase in stroke knowledge. All of these studies involved members of the public. Whilst stroke knowledge amongst the public is important, it does not necessarily translate into effective help seeking behaviour and the impact of stroke knowledge on help seeking behaviour was not measured in these studies. Individuals must also have the ability to translate the recognition of symptoms and knowledge about stroke into appropriate help seeking action by contacting the EMS. Previous research has reported that increasing awareness and knowledge is an essential step before a change in help seeking behaviour can take place (Marx et al. 2008).

In this review, two studies involved both the public and stroke patients, 80% (Caroll et al. 2004) and 89% (Hsia et al. 2011) of the public said that they would contact the EMS, whilst only 12% (Hsia et al. 2011) and 18% (Carroll et al. 2004) of stroke patients had actually done so. However, to date, these are the only studies that have directly compared the intended actions of members of the public with the actual help seeking actions of patients; within the same study it more clearly demonstrates the paradox between behavioural intention and actual help seeking behaviour.

Across all studies in this review, an intention to seek help from the EMS was reported in approximately half of all participants, across different populations (relatives of stroke and non-stroke patients, the public, and non-stroke patients at higher risk of stroke). However, less than 20% of stroke patients actually contacted the EMS following the onset of stroke symptoms (Carroll et al. 2004; Hsia et al. 2011). This suggests that although questions that assess knowledge may reveal that many people know what action they should take, this may not be translated into appropriate help seeking behaviour when stroke symptoms are experienced.

In this review the most common sources of stroke information identified were other people (friends/relatives, neighbours or health professionals) and media sources (TV, radio and newspapers/magazines). Mass media campaigns across the USA, Canada and Europe have had mixed success. Two mass media campaigns in the USA (Stern et al. 1999; Becker et al. 2001) and one in Canada (Silver et al. 2003) demonstrated an improvement in stroke knowledge. However, a further mass media campaign undertaken in the USA did not improve the public's knowledge of stroke (Kleindorfer et al. 2009). A multimedia campaign in Germany also failed to improve knowledge of stroke symptoms (Marx et al. 2008) and more importantly, the campaign did not show any effect on the intention to seek help by calling for an ambulance (81 % before vs. 82% after) (Marx et al. 2008). One of the main criticisms of these campaigns was that messages were not targeted to any specific groups within the population and it was therefore suggested that future campaigns should target only high-risk audiences (van Leijden et al. 2009). The findings from this integrative review could be used to inform future interventions in terms of who should be targeted. Compared to younger people, older people were the least likely group to say that they would contact the EMS (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008) and stroke disproportionally impacts upon this group.

The limited research into treatments for stroke means that the relationship between knowledge of treatments and subsequent help seeking behaviour is unknown in the area of stroke care. Only three papers reported knowledge about treatment that could be given to stroke patients to break up blood clots (Ferris et al. 2005; Kleindorder et al. 2009; Kim et al. 2011). Again differences in the way questions were asked led to a wide range in the proportion of people being able to identify thrombolysis as a potential treatment for stroke, 4% (Kleindorfer et al. 2009) and 92% (Ferris et al. 2005). The lack of studies reporting knowledge in relation to treatments available for stroke, suggest that further research is needed in this area to explore the degree to which perceptions of available treatments impact upon help seeking behaviour.

Limitations of the Quality of Included Studies

There are a number of limitations of the studies included in this review. The studies varied in quality, including five studies which recruited small numbers and five which sampled participants from highly selected populations. The majority of studies reported response rates, but none explored non-response. Across the studies a major limitation was the variety of methods that were used to assess stroke knowledge. If the review had included only studies which used open questions, levels of stroke knowledge would have been much lower than was reported across all studies.

Only two studies assessed stroke knowledge using a validated questionnaire (Billings-Gagliardi et al. 2005; Mikulik et al. 2008), which was based solely on stroke action and did not include stroke knowledge (Billings-Gagliardi and Mazor, 2005). The main disadvantage of this questionnaire is that it uses closed multiple choice questions and addresses only action that would be taken. As previously stated the use of closed questions may not accurately reflect ‘true’ stroke knowledge, or intended or actual help seeking behaviour.

Limitations of the Review

By combining several search strategies it can be suggested with confidence that most studies to date have been identified and included in this review. The review was limited to published studies and, as with any review, publication bias may have influenced the results (Easterbrook et al. 1991). The use of closed questions in some studies and open questions in others, and the range of populations included (stroke patients, relatives of stroke and non-stroke patients, the public, and non-stroke patients at higher risk of stroke) also limited the degree to which the study findings could be synthesised. Quantitative methods e.g. realist synthesis (Pawson et al. 2005) or meta-analysis have not been used to provide a truly synthesised review, as the heterogeneity of the studies precluded this.

2.5 Conclusion

The aim of this phase was to summarise the existing scientific literature exploring the knowledge of stroke patients, relatives, the public, and patients at risk of stroke. Following an extensive search of the literature, 51 studies were identified and included in the review.

This review has highlighted that levels of stroke knowledge in relation to risk factors, symptoms, action, sources of information and treatment vary widely: this was mainly due to the how questions were asked. However, regardless of the types of questions used, knowledge was poorest amongst participants aged 65 years and over and amongst some ethnic minority groups. The review identified that stroke knowledge and the intention to seek help from the EMS does not directly influence help seeking behaviour when a stroke occurs. The review also found limited research into the actual help seeking behaviour of stroke patients (Carroll et al. 2004; Hsia et al. 2011). There is a need for future research that identifies the type of interventions that can not only increase knowledge but also influence behaviour, and in what populations these interventions have the most impact. The lack of studies reporting knowledge in relation to treatments available for stroke, suggest that further research is needed in this area to explore the degree to which perceptions of available treatments impact upon help seeking behaviour.

Whilst it is acknowledged that this review had a number of limitations particularly in terms of the variety of methods that were used to assess stroke knowledge and the heterogeneity of the studies included which precluded a truly synthesised review; this was the first integrative review that has attempted to synthesise the research evidence in relation to stroke knowledge.

Findings from the review suggest that stroke knowledge and the intention to seek help for suspected stroke are not necessarily reflected in actual help seeking behaviour by contacting the EMS. In the following chapter, semi-structured interviews will explore the decision-making process in seeking medical help at the onset of stroke symptoms, exploring recollections of what happened at the onset of stroke symptoms; what action was taken by patients, and those who act on their behalf at the onset of symptoms and why; as well as identifying which factors influence help seeking behaviour.

CHAPTER THREE

PHASE TWO – THE DECISION MAKING PROCESS IN SEEKING HELP AFTER STROKE: A QUALITATIVE STUDY

3.1 Introduction

In the previous chapter an integrative review was undertaken to summarise the existing scientific literature exploring stroke knowledge in relation to risk factors, symptoms, action that should be taken when stroke is suspected, sources of information and treatments available. Whilst risk factor identification and the recognition of stroke symptoms were often poor when open-ended questions were used, this appeared to improve when closed questions were asked. The review highlighted the importance of increasing public awareness about stroke and seeking immediate help from the EMS. Findings from the review showed that there was no link between the intention to seek help and actual help seeking behaviour. The results from the review also showed that there is a need for future research that identifies which interventions not only increase knowledge but also influence behaviour, and in what populations these interventions have the most impact. It was also suggested that future stroke awareness and education campaigns may need to be targeted towards older people and ethnic minority groups, as these groups generally have lower levels of stroke knowledge, and yet stroke disproportionately impacts upon these groups.

This chapter describes the Phase Two study which will explore the decision-making process in seeking medical help at the onset of stroke symptoms, using semi-structured interviews. A grounded theory approach will be used to guide the sampling strategy and data analysis. The aims and objectives will be described, the methods and methodology used will also be discussed before moving on to the procedures used for the data collection and analysis. Following this, the main results will be reported. Finally, the findings will be discussed, comparing the results of this phase with what is already known about the public’s response to stroke. Limitations of this phase will be explored and recommendations will be made about future research.

3.2 Methods

In the initial planning of this phase a number of different methodological approaches were considered. Initially focus groups were considered because as unlike interviews, focus group participants share their views and opinions among peers with whom they are likely to share a common experience. This allows participants the opportunity to comment, challenge and reflect on the views of others (Kidd and Parshall, 2000). However, upon reflection it was decided that discussing a traumatic event such as the very early recognition that someone was having a stroke may be too sensitive a topic to be discussed as a group and therefore one-to-one interviews would be more suitable.

Qualitative interviews are often described as a shared journey between the participant and researcher. The literature suggests that participants do not simply recall past experiences but co-create knowledge as a result of the interaction that takes place with the researcher (Kvale, 1996). By using semi-structured questions and prompts, the role of the interviewer was one of encouraging participants to explore and describe their experiences (Sorrell and Redmond, 1995).

Aim

To explore the decision-making process when seeking medical help at the onset of stroke symptoms.

Research Objectives

To identify through semi-structured interviews:

- What are people's recollections of the onset of stroke symptoms?
- What action is taken by patients, and those who act on their behalf at the onset of acute stroke symptoms and why?
- Which factors influence the decision to seek immediate medical help or to delay among patients and those who act on their behalf?
- What advice would people give to someone else in similar circumstances?

3.3 Design

Semi-structured interviews.

Ethical Issues

Ethical approval for this phase was sought from the Local Research Ethics Committee (see Appendix 3) and the Faculty of Health Ethics Committee at the University of Central Lancashire (see Appendix 4). The author's supervisory team, ensured that the focus of this phase was maintained, and that ethical and research governance guidelines were not breached. Research and Development approval at each hospital Trust was also gained (see Appendices 5 and 6).

Setting

One Acute Trust and one GP Practice in the North West of England.

Subjects and Sampling

A purposive sample was identified to include people that had sought help immediately (within three hours of symptom onset) and who had delayed (sought medical help after three hours of symptom onset). Subjects were selected if the patient had a diagnosis of stroke or TIA made by a stroke physician or GP. For those patients who were identified by a member of the stroke team as having cognitive or communication problems that would have prevented an interview, the carer was approached to take part. Carer was defined as a spouse, close relative or friend who was with the patient at the time of stroke symptom onset. The person who had made the initial call to the EMS, NHS Direct or primary care after the onset of stroke symptoms, was identified as the potential participant in this phase, whether the patient, a relative, or other person.

Inclusion criteria: if the patient had a diagnosis of stroke or TIA made by a stroke physician or GP. For those patients who had cognitive or communication problems that would have prevented an interview, the carer was approached to take part.

Exclusion criteria: if the patient had a stroke whilst in hospital.

All types of sampling in qualitative research may be included under the umbrella term of purposeful sampling (Sandelowski et al. 1992.) It could also be argued that within qualitative research studies both selective and theoretical sampling strategies are utilised. For example, in developing a research proposal there are a set of predefined criteria from which an initial sample is identified. Following the collection and analysis of preliminary data, theoretical sampling then takes place. Selective sampling is therefore a prerequisite of many ethics committees, in order to outline which participants may be included in the study (Sandelowski et al. 1992). By selecting a sample prior to data collection taking place, this sample can only be described as selective or purposeful. It could therefore be suggested that theoretical sampling must initially include a purposive sample (Coyne, 1997). Morse (1991) views both purposive and theoretical sampling equally and states that ‘when obtaining a purposeful (or theoretical) sample, the researcher selects a participant according to the needs of the study’ (p.129).

Procedure

Potential participants were identified through the stroke and TIA registers at the acute trust and GP practice between October 2008 and April 2009. For potential participants who were identified from a stroke register at the GP practice, the GP sent out a letter of invitation (see Appendix 7) and participant information sheet (see Appendix 8). If participants were interested in taking part in this phase they were asked to complete and return a reply slip. A member of the stroke team at the Acute Trust identified potential participants from the hospital stroke or TIA register. Potential participants were given information sheets by a member of the stroke team and were then given a minimum of 24 hours before being asked by a member of the stroke team if they would like to participate. Informed consent was obtained for each participant by the author prior to any interviews taking place. All participants were interviewed within two weeks of the stroke or TIA. This timeframe was chosen in order to minimise the possibility of recall bias.

Interview Questions

Qualitative interviews were used to explore the decision-making process when seeking medical help at the onset of stroke symptoms. Semi-structured questions were originally based around the Health Belief Model (HBM) (Becker, 1974). However, during the practice interviews these questions were found to be too restrictive and did not provide sufficient flexibility to explore particular issues that arose. For example, in one of the first interviews the patient had contacted the EMS because he thought that he was having a heart attack and during the interview the author found it difficult to work out where this fitted into the HBM, resulting in a disjointed and disappointing interview.

Informed by the practice interviews the interview guide was adapted and included further prompts and cues (see Appendix 9). Interview guides are often expanded by the use of prompts and probes and by rephrasing questions that do not initially result in responses from the participant. Techniques were also used from motivational interviewing (Miller and Rollnick, 1991) where questions are rephrased and reflected to encourage the participant to talk in more depth.

The Interviews

As a health services researcher, the author had some experience of interviewing stroke patients and their families. Building rapport and the interaction between the interviewer and the participant often determines the depth and quality of interview data. In meeting the participants, usually the patient or a relative of the patient, the interview began with an introduction and explanation of the purpose of this phase. This was often the first opportunity that participants had had to ‘tell their story.’

There can be a number of reasons why people take part in research projects, and individuals recruited to qualitative studies have identified a number of benefits to participating in research interviews (Donalek, 2005). These include having the opportunity to recall and share their experiences, often for the first time and to benefit others through their participation (Donalek, 2005). However, the chance of participating in a one-to-one interview also provides participants with a voice, an opportunity to share experiences, possibly with therapeutic benefits (Shamai, 2003).

Active listening and concentration were key to engaging with participants, combined with the ability to interpret appropriate meaning and responses (Sorrell and Redmond, 1995). Non verbal cues are often essential in encouraging the participant to feel comfortable and able to share experiences (Sorrell and Redmond, 1995). Through active listening, nodding and maintaining eye contact, participants were encouraged to reflect on their experiences and the decisions that they had made when seeking medical help for suspected stroke.

Participants often use a number of strategies through which to construct and describe their views. The researcher is required to work with the participant to facilitate this construction (Nunkoosing, 2005). Participants will choose which aspects of their experience they would like to discuss. This is often decided by how significant, interesting and relevant participants perceive their experiences to be (Nunkoosing, 2005). The researcher may also influence the interview by focussing on particular aspects of the discussion (Nunkoosing, 2005). As the aim of the interview was to focus on the first part of the participant’s stroke journey, the interview centred around the earliest stages of the participant’s stroke experience. Participants often went on to describe what happened in hospital and it was imperative to re-focus the discussion around early recognition and action taken.

Although the interview involved personal and sensitive information, participants did not refuse to divulge any aspects of their experience, a problem often experienced during interviews (Nunkoosing, 2005). Participants were never defensive or unwilling to answer questions and it was not felt that the author had to enter into a process of negotiation, as can often be required in interviews that involve the discussion of personal or upsetting situations (Nunkoosing, 2005).

The setting in which the interviews took place may have directly influenced the direction and content of the interview (Sin, 2003). Interviews either took place in hospital, or at home if the patient had been discharged at the time when the interview was to be held. A number of participants were a third party, often a relative or neighbour, as they had sought help on behalf of the patient. Interviews took place with these participants in their own homes.

Interviews with individuals or patients who have experience of a particular illness or condition often take place within a hospital setting (Borbasi et al. 2002). It has been argued that the hospital environment may be unsuitable for undertaking research interviews due to a lack of privacy, including interruptions for tests and treatment (Borbasi et al. 2002). Interviews were arranged during hospital visiting times when interruptions for tests and treatment would be minimised. Interview times were also agreed with staff on the Acute Stroke Unit or Rehabilitation Ward to ensure that the interview was at a time to suit both the patient and staff.

Mutual respect is an essential element in creating a positive environment within which a research interview is conducted (Boyd, 1993; Lowenberg, 1993). Therefore, the hospital setting may not be viewed as an ideal environment in which to support the collaboration and partnership that is required between the researcher and the participant (Glesne and Peshkin, 1992). It has also been argued that an equal relationship may be difficult to achieve if the participant is receiving medical care. Subsequently, participants may agree to take part in a research interview for reasons of benevolence (National Health and Medical Research Council, 2001). However, because the author is not a health professional and participants were aware that the interviews were part of a research degree, they seemed willing to participate and genuinely felt that if they could contribute then they would be ‘making a difference’ to other people who had experience of stroke in the future.

The alternative setting was to interview the participant in their own home. However, a disadvantage of interviewing participants following discharge from hospital or following treatment are that their perceptions are likely to have changed over time (Petrie et al. 1996; Nunkoosing, 2005). The home environment can also be unpredictable: affected by factors such as the physical layout of the home (positioning of furniture, background noise) and the social environment (interruptions from other family members and pets) (Borbasi et al. 2002).

The main obstacle to interviewing participants at home was interruptions by relatives often trying to tell their side of the story. Where possible these interruptions were limited by conducting the interview in a separate room, but inevitably some interruptions did occur. The interviews were also carried out as soon as possible following the patient's stroke, to limit the effects of recall over time.

The home setting did enable the author to observe the cultural and social characteristics of the participant and often their relationship with the person who had instigated the action of seeking help when symptoms occurred. All participants whether in hospital or at home were asked about general demographic details, their current or previous occupations, general health beliefs, previous experiences of contacting health professionals and their day-to-day commitments. This was found to be a valuable experience and these accounts have been recorded in Appendix 11 to give the reader an insight into the people who took part in this study.

Interviews often end with the researcher asking the participant if there was anything else that they would like to add and by the end of an interview the discussion may become more relaxed as it winds down (Donalek, 2005). Towards the end of the interview was a crucial time when participants imparted further information and so interviews were recorded until the interview was complete. According to Corbin and Morse (2003) if interviews end abruptly this can leave the participant feeling unappreciated. Participants were always asked if they had anything further to add, they were thanked for their participation and asked if they would like a summary of the interview findings.

3.4 Data Collection

Grounded theory is a qualitative research method that was developed by Glaser and Strauss in the 1960s (Glaser and Strauss, 1967). It is a methodological approach as well as a form of analysis (Coyne, 1997; Murphy et al. 1998). The purpose of grounded theory is to generate theories that are grounded in the data (Morse and Field, 1995).

This phase has utilised the grounded theory techniques and procedures in both the research design and analysis of Strauss and Corbin (1998). The rationale for choosing this approach has been a pragmatic rather than epistemological decision. Strauss and Corbin (1998 p.4) describe their grounded theory approach as 'a cluster of useful procedures - essentially guidelines, suggested techniques but not commandments.' There is a difference between Glaser, and Strauss and Corbin in the way they undertake coding procedures and approaches to background reading and sampling. Glaser (1978) argues that researchers may undertake general reading around the area of interest but any in-depth reading should not take place until the emerging theory has been sufficiently developed (Glaser, 1978). In contrast, Strauss and Corbin (1998) highlight the importance of both past experiences and the literature in informing the research process and in generating hypotheses. It was therefore felt that Strauss and Corbin's grounded theory approach would be most suited to this phase.

Within grounded theory theoretical sampling is often used (Glaser and Strauss, 1967). This can be described as a process of data collection that is guided by the emerging theory rather than by a predetermined population (Strauss, 1987). Data are collected, coded and analysed simultaneously through constant comparison, in order to suggest where to sample next (Glaser, 1992). According to Glaser (1992) 'further codes are then developed with properties and theoretically coded connections with other categories until, each category is saturated, elaborated and integrated into the emerging theory' (Glaser, 1992 p.102). Grounded theorists have highlighted theoretical sampling as a crucial component in the development of theory (Charmaz, 2000). However, the process of making 'real' theoretical sampling decisions has not been recorded in any detail and so there is little guidance available for researchers (Draucker et al. 2007). Initially the author presumed that the patient would have initiated help seeking behaviour. However, it quickly became apparent that in a large proportion of situations a relative or carer would be the person to seek help. Recently, research has reported that callers to the EMS were predominantly family members, the patient being the caller in around only 2% of calls (Mosley et al. 2007). Therefore, patients, relatives and other bystanders were interviewed depending on who sought first medical help.

Following the coding of the first five transcripts and to inform the continuing analysis, theoretical sampling was undertaken to include people with and without prior experience of contacting the Health Service (GP, A&E or EMS) for emergency help. This was because previous experience of contacting health services appeared to play an important role in influencing the decision to seek help and from whom help should be sought. Participants who had had a previous stroke or TIA were also identified for further interviews, as the data were suggesting that previous experience of stroke or TIA did not seem to influence future help seeking behaviour and it was felt that this issue needed to be explored further.

Using a grounded theory approach as suggested by Strauss and Corbin (1998), data were initially explored using open coding of each transcription. Through constant comparison of the data within and between transcriptions, relationships between open codes were examined. Axial coding was then undertaken to explore the relationships, which resulted in the grouping of open codes. In axial coding, open codes can be grouped into sub-categories or properties: sub-categories are collections of related open codes that have been clustered together; properties provide a more in-depth meaning to the sub-category, enriching the meaning of the data (Strauss and Corbin, 1998). The data were then coded using open coding, constant comparison and axial coding until an overall core category emerged. Open coding was then replaced by selective coding, whereby any new codes were related to the core category and to the main categories rather than developing new open codes.

3.5 Data Analysis

Grounded theory uses a systematic set of data collection and analysis procedures to develop an inductively derived theory from the data (Strauss and Corbin, 1998). Within grounded theory the generation of theory is based on a comparative analysis of the data within a particular field of interest (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Morse and Field, 1995). Therefore, grounded theory with the technique of constant comparison, allows for the identification of patterns and relationships (Glaser, 1978, 1992).

Each interview was transcribed as soon as possible while the conversation was still fresh in the author’s memory. This aided not only the preliminary analysis but the early categories that were used to inform subsequent interviews. The first stage involved writing up notes about the participants and the main issues that had been raised in the interview. As suggested in grounded theory the author’s thoughts, ideas, interpretations and possible directions for further data collection were recorded after each interview (Strauss and Corbin, 1998).

Constant comparison was used to analyse the transcriptions, this process began with open coding. Open coding is a line-by-line or word-by-word analysis which was undertaken within Atlas ti (qualitative data analysis software). Open coding is the process of naming and initially grouping phenomena within each transcription.

When reading through each interview transcription, words and sentences were assigned with one open code or more. In order to assign an open code the researcher must read a piece of the transcription and ask ’What are the main issues here? What is this about?’ The text in the first column of Table 3.1 has been taken from a patient interview transcription. The open codes assigned to each part of the transcription are detailed in the second column of Table 3.1.

Table 3.1. An example of open coding

Text from transcription	**Open coding**
I just said to my wife, that's funny, my hand feels like its going numb	Carer Symptoms
And she said 'well you must have knocked it, you've hurt it.'	Carer Diagnosis
Anyway when it got to Friday	Delay
It had got worse	Wait for symptoms to improve/worsen
And it had gone to my leg, left leg as well as my left hand.	Symptoms
In the late afternoon, I decided I would come to A&E by myself	Patient action A&E
I came on the bus	Public transport

Through constant comparison of the data, relationships developed between the open codes. Axial coding was then undertaken to explore the relationships between codes. During axial coding, open codes were grouped together. In the example below (Table 3.2) axial coding involved grouping together open codes that related to whether patients sought immediate help from the EMS or delayed seeking help in order to form the properties 'immediate EMS' and 'delayed.' Informed by the open codes and properties, a sub-category emerged and was assigned the title 'help seeking behaviour.' Using this process, five sub-categories emerged which were felt to have reflected the main content of the interview data. The five sub-categories are reported in further detail in the results section of this chapter.

Table 3.2 An example of axial coding

Sub-category	**Help seeking behaviour**	
Properties	**Immediate EMS**	**Delayed**
Open codes	999 call	A&E
	Arrival at hospital	Acknowledge need for help
	Assessment/tests/treatment	Buzzer helpline
	Benefits of going to hospital	Carer action
	Carer action	Contact friend
	EMS assessment	Contact neighbour
	EMS diagnosis	Contact relatives
	EMS transport	Delay
	EMS treatment	Medical Assessment Unit
	Immediate action	NHS Direct
	No other help sought	Other help sought
	Patient action	Own/private transport
	Third party action	Patient action
	Time of onset	Public transport
	Time help sought	Third party action
	Time until ambulance arrival	Time of onset
	Time until arrival at hospital	Time help sought
		Time until arrival at hospital

As the sub-categories were developed, an overall core category was emerging. The core category ‘the decision-making process for seeking help after stroke’ was felt to provide an overarching umbrella that encompassed the sub-categories and that provided an overall description of the sub-categories and the relationships between the sub-categories.

When the core category had been identified, open coding was replaced by selective coding. This is a process in which new codes are related to the core category and to the main categories rather than developing new open codes. The coding framework that supported the data analysis can be found in Appendix 10.

The core category of ‘the decision-making process for seeking help after stroke and TIA’ encompassed the data relating to five sub-categories. The categories were then used to develop a five-stage theoretical framework that reflected the decision-making process for seeking help after stroke (see Figure 3.6). The development of the framework is discussed further in the results section of this chapter.

3.6 Data Credibility

The findings from each interview were summarised into bullet points and sent to each participant for confirmation that these represented their main views and experiences. This process is known as member checking and involves the researcher asking participants to check the accuracy of the account of their interview, thus increasing the validity of the research (Creswell, 2005). All participants felt that the summaries were an accurate reflection of their accounts. It would have been useful to have two independent people to carry out open coding of the data. Due to resources this was not possible with all of the transcriptions but was undertaken with half of the transcriptions. A good level of agreement was reached between coders and any differences in coding were discussed until a consensus was reached.

So far in this phase the choice of research design and methodology have been discussed. Both the practical and ethical issues relating to this phase have been highlighted and the process of data collection and analysis described. The main findings of this phase will now be reported.

3.7 Results

Recruitment and Summary of the Participants

Recruitment of the participants included in this phase can be seen below in Table 3.3. Carers (spouse, neighbour, friend) were interviewed rather than the patient when they had sought first medical help on the patient's behalf. The term carers will be used to describe the patient's spouse, neighbour or friend.

Table 3.3. Recruitment of participants

Setting	Method of invitation to participate	Participants eligible	Participants agreed to take part	Dates recruited
Acute Stroke Unit	Approached by member of stroke team	44 patients (or their carer)	10 patients 5 carers	October 2008 to January 2009
GP stroke register	Letter by post from General Practitioner	8 patients	3 patients	October 2008 to April 2009

The demographic profiles of all the Phase Two participants have been provided in Appendix 11, to give the reader a 'feel' for who the participants are. The profiles provide an insight into the personalities of the participants, their home and work lives, as well as their medical histories and the circumstances in which their stroke symptoms occurred. The help seeking behaviour that was undertaken by each participant has also been described.

Of the 18 participants that agreed to take part in this phase, eight sought immediate help by contacting the EMS (within three hours) and 10 delayed seeking help (beyond three hours). Demographic information about the participants in this phase can be seen in Table 3.4 below.

Table 3.4. Summary of participant characteristics

Category	**Participant Information** Sought Immediate help (n=8)	Delayed seeking help (n=10)
Patients	3	10
Carers	5	0
Participants mean age (years)	64.8	69.8
Female (n)	4	2
Home location (n)		
Urban	7	8
Rural	1	2
Location at time of stroke (n)		
Home	6	8
Out shopping	1	1
Leisure	1	0
Work	0	1
Action taken		
Contacted the EMS	8	0
Called GP	0	4
Own transport	0	1
GP, then EMS	0	2
NHS Direct	0	1
Public transport, then EMS	0	1
Son, then daughter, then EMS	0	1
Carer present at onset of symptoms		
Yes	3	0
No	5	10

Following coding of the participant transcriptions five sub-categories emerged. These are: knowledge of stroke symptoms, perceived seriousness, emotional reaction to the event, help seeking behaviour and previous experience of seeking medical help. These sub-categories will be discussed in detail below. This will be followed by a description of how the sub-categories informed the core category entitled ‘the decision-making process for seeking help after stroke’ and how these categories and the core category were then used to develop a five-stage theoretical framework that reflects the decision-making process for seeking help after stroke, this will be shown in Figure 3.6.

Knowledge of Stroke Symptoms

The first category to emerge was knowledge of stroke symptoms and this was informed by two properties: recognition of symptoms but not as stroke and the recognition of stroke symptoms (Figure 3.1). Recognition of stroke symptoms was not always related to seeking immediate help from the EMS, participants who recognised symptoms often delayed seeking help.

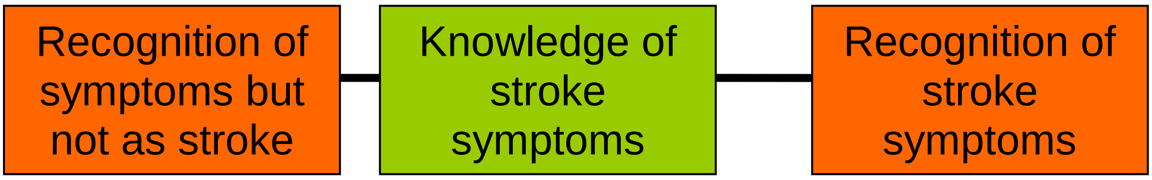

Figure 3.1. Properties informing the sub-category knowledge of stroke symptoms

Recognition of stroke symptoms – delayed seeking help

Although twelve (67%) participants recognised their symptoms as a stroke this did not appear to influence many participants in their decision to seek help with six (50%) still delaying. The following quotes refer to participants who recognised their symptoms as a stroke but who did not seek immediate help.

> "*His face just looked a bit as if his eye had drooped a little bit. I knew immediately that he'd had a stroke. I got on my phone, and rang the family which was ridiculous, I rang my daughter and I rang my son."* (Female Carer, aged 65).

> "*I knew it was a stroke*. *My wife said 'do you want to phone for the doctor or an ambulance'. I said, 'no let's leave it until later on'. I went to bed then and I woke up the next morning and I had a tingling all down one side, as well as my mouth drooping. So I tried to take the dog out, couldn't take her very far. I came back home and my wife said, 'shall we phone the doctor?' So I phoned our doctor and got through to the receptionist.*" (Male patient, aged 58 who had had a previous stroke).

> "*I knew that this was what happened in stroke but I didn't want to go to hospital. So I waited at home to see what would happen."* (Male TIA patient, aged 86).

Recognition of stroke symptoms – contacted the EMS immediately

Of the participants who recognised the symptoms of stroke, only half sought immediate help.

> "*Well you read about it don't you. I rang 999 and said 'she's fallen, her mouth's funny. I didn't use the word stroke. I said 'her mouth's funny and her arm's weird.' It was an emergency.*" (Female carer, aged 54).

> "*I did figure it was a stroke. I didn't just feel hey it's something weird going on here. I did figure it was a stroke. It was literally to phone 999.*" (Male carer, aged 59).

Recognition of symptoms but not as stroke – delayed seeking help

A third of all participants did not recognise their symptoms as a stroke. This lack of recognition of stroke symptoms in some instances, resulted in a delay in seeking help.

> "*I was putting the curtains up and I fell down, my leg just gave way and I bounced onto the bed, onto the floor, I thought oh well… And next morning I got up, I put my feet on the floor and down I went and I, I really could hardly get up. So I thought well I hadn't had a stroke because I did that silly advert (FAST) that you can put both hands up and I could do it, so I thought right, get on with it.*" (Female patient, aged 71).

> "*I had these symptoms and I didn't know what it was. I was really tired so I managed to stagger across the room, holding on to the wall and I went to bed. I slept until the next day. I rang my GP but he was on holiday so I couldn't get an appointment for a while.*" (Male patient, aged 86).

Recognition of symptoms but not as stroke – contacted the EMS immediately

In some instances the symptoms of stroke were confused with prior medical conditions. For example, one participant assumed that the symptoms were related to a previous medical problem, which in this case was a heart attack. As a consequence of this he sought immediate help from the EMS, although he had misattributed the symptoms.

"*I was losing the sense of touch in my fingers and I started to pick up my pen, the bingo pen I would be using in a moment, and it dropped out of my hand. I thought there's something peculiar here and that's when I thought, I wonder if this is anything to do with that heart attack I had three years previously… So one of the checking girls came towards me and I said can you get on to the manager, ask him to ring for an ambulance immediately, I think I'm having a heart attack.*" (Male patient, aged 68).

Perceived seriousness

The second category is perceived seriousness and is informed by four properties: symptoms perceived as serious; symptoms perceived as not serious; some symptoms perceived as more serious than others; unsure of the seriousness of symptoms (Figure 3.2). Even when patients and their families recognised the symptoms as those of a stroke or TIA, they often did not feel that the symptoms were serious enough to warrant seeking immediate help and would wait to see if symptoms improved or worsened. Some symptoms were also perceived to be more serious than others. Some participants were unsure about the perceived seriousness of the symptoms that they experienced.

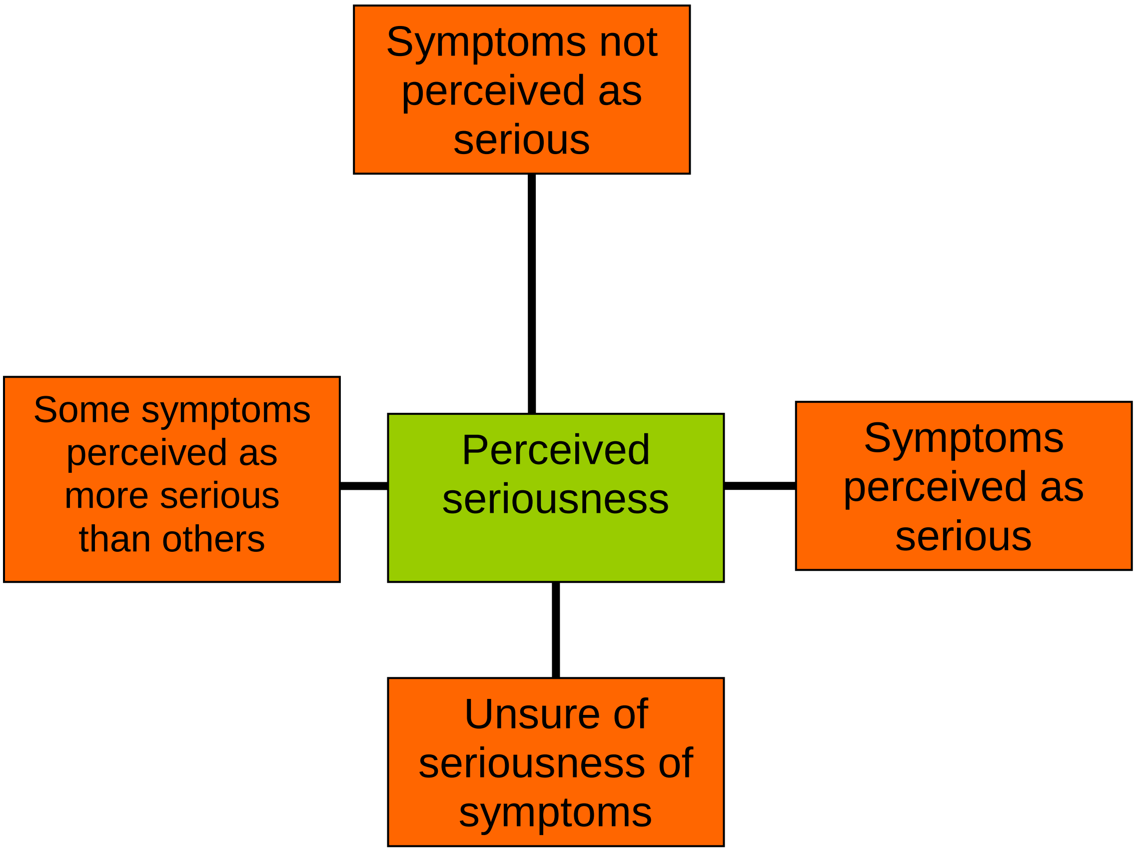

Figure 3.2. Properties informing the sub-category perceived seriousness.

Symptoms perceived as serious

Some participants recognised or were advised by others that their symptoms were serious. They often justified their decision to call the EMS by saying that 'to them' the symptoms were very severe or by saying that they felt that they had 'done the right thing.'

> “*My daughter said, ‘it’s serious, it’s important that you ring for an ambulance straight away.’ Which I did immediately.”* (Female carer, aged 65).

> “*I mean I wouldn’t dial 999 unless I thought it was an emergency but it was to me, it was a severe emergency.*” (Female TIA patient, aged 66).

> “*It was literally to get the phone, dial 999. If my father had been dead when the ambulance had arrived I would have had no pangs of guilt whatsoever that I acted immediately and that’s how I felt.*” (Male carer, aged 59).

Symptoms not perceived as serious

Nine (50%) participants did not view their symptoms as serious, of whom six (67%) nonetheless recognised their symptoms as stroke.

> “*I just got pins and needles in my hand and I thought you know, well I didn’t think anything about it. … I thought I got a tingling in my face here, now I knew then that something was wrong… And then it gradually went down into the corner of my mouth. So I thought well I’ll see what it’s like tonight*.” (Male TIA patient, aged 49).

> “*There was a questionnaire on cars and I’d filled in two or three questions and then I couldn’t make sense of the questions. I thought well that’s a stupid question, it doesn’t make sense. So I went away and walked round and came back again and they still did not make sense and I couldn’t understand it. I couldn’t get my words out and it was very, it was very funny you know it was hilarious.*” *(Male patient, aged 86).*

Some symptoms perceived more serious than others

The presence of slurred speech appeared to be associated with the decision to seek immediate help from the EMS. All eight participants who sought immediate help reported slurred speech, but slurred speech was present in only three (30%) of those participants who decided to delay seeking help. Slurred speech was also viewed as being more serious than other symptoms.

> "*We'd probably not dash straight off but if my face started drooping and my speech started slurring, it's a bit drastic, then I'd dial 999.*" (Male patient, aged 65).

> "*I could talk, I rang my daughter… my legs kept giving way and I was bouncing off things, if my speech had gone it would have been serious.*" (Female patient, aged 71).

Unsure about seriousness of symptoms

If participants were unsure about the cause of the symptoms they were more likely to contact a family member or GP for advice, or wait for symptoms to improve or worsen before seeking medical help.

> "*I just said to my wife, that's funny, my hand feels like its going numb and she said 'well you must have knocked it, you've hurt it.' I said 'I don't think so'. Anyway when it got to Friday, it had got worse and it had gone to my leg, left leg as well as my left hand. In the late afternoon, I decided I would come to A&E by myself, I came on the bus.*" (Male patient, aged 90).

> "*The next day I was worse but I thought I'll ring the doctor see what they suggested and they said straight away dial 999.*" (Male patient, aged 58).

Five participants were unsure about contacting the EMS for fear that they would be 'wasting the ambulance services' time' or that their symptoms would not be considered 'serious enough.' These participants were also aware of advertisements aimed at not calling out an ambulance unless it was an emergency.

> "*I've never called an ambulance before in my life and neither had my wife and we was sort of considering you know, is it serious enough to get an ambulance out and would they be somewhat annoyed if I was wrong. You know that's the thought you get.*" (Male patient, aged 90).

> "*Well I thought they (the ambulance) wouldn't come for me…I was really frightened because I didn't know what I would do, I felt like I was drunk, but I know I wasn't…it scared me enough to phone the doctors and well I was nearly demanding an appointment.*" *(*Female patient, aged 71).

> "*Obviously when I phoned for the ambulance, I said that you know I hope I'm not wasting your time.*" (Male carer, aged 59).

Of all the participants in this phase only one (5%) was aware that treatment for stroke was available in hospital. This participant identified thrombolysis as a potential treatment. However, despite being aware of potential treatments, this participant still delayed seeking help.

> "*Get attention within three hours and something can be done. If it's more than three hours, the effects are likely to be permanent*." (Male patient, aged 45).

Emotional reaction to the event

The third category to emerge was the emotional reaction to the event and was informed by two properties around negative emotions (Figure 3.3). Emotions can be defined as 'a strong feeling deriving from one's circumstances, mood, or relationships with others' (Oxford Dictionary, 2011). Schröder and Cowie (2006) classified 48 emotions into ten categories. The categories include negative emotions where a person is not in contro,l such as anxiety, embarrassment, fear, helplessness, powerlessness and worry. The full categorisation of emotions can be seen in Appendix 12. The emotional reaction that occurred varied widely between participants. However, all of the emotions described fell into the category of negative emotions - not in control (Schröder and Cowie, 2006). Some participants wanted to avoid the embarrassment and fuss of having an ambulance pick them up. Others felt that they were unable to cope, were afraid and needed medical assistance quickly.

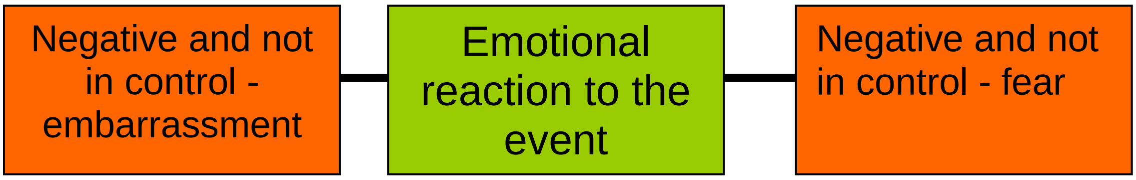

Figure 3.3. Properties informing the sub-category emotional reaction to the event.

Negative and not in control – Embarrassment

For some participants the emotional reaction that they experienced resulted in alternative ways of seeking help rather than contacting the EMS. The emotional reaction that they experienced meant that they were keen to avoid any fuss or embarrassment that they associated with the arrival of an ambulance either to their home or to a public place. Four (40%) described their chosen method of seeking help whether it be driving to hospital or contacting NHS Direct, as the option that involved the least amount of embarrassment or fuss.

> "*I resist, well I resisted it because I hate fuss and I was, I felt I was getting better. Well it seemed the least fussy option... I think men, most men sometimes, in fact a lot of them I suppose, they're too proud to admit something could be wrong.*" (Male TIA patient, aged 86).

The location of the patient at the time of the event could also influence the intensity of the emotional reaction. For example two of the four participants who were in public places at the time of onset described how they felt they had to deal with the situation.

> "*Well I suppose that the symptoms were frightening, yeah. And I would also feel embarrassed I suppose with being carted out through hundreds of people. You know I thought well I don't want that, I just want to get out of here under my own steam if possible. And I did actually manage to walk all the way through the people, down three flights of stairs into the ambulance.*" *(*Male stroke patient, aged 68).
>
> "*I'd have driven home and rung 999 but one thing I hate is getting an ambulance out, it's an embarrassment you feel stupid, so I'd much rather go and present myself at A&E.*" (Female patient, aged 65).

Negative and not in control – Fear

Of the eight participants who sought help immediately, six (75%) participants described an emotional reaction as one of the main influences in seeking help quickly.

> I: "*What made you call 999?*"
> R: "*I was scared. I was terrified.*" (Female carer, aged 65).

> "*It's scary and upsetting, I needed someone to help me.*" (Female carer, aged 59).

Help Seeking Behaviour

There were a number of routes via which participants sought help (Figure 3.4). Seven (39%) called the EMS immediately, five (28%) contacted their GP, three (17%) went directly to hospital by private or public transport, two (11%) delayed seeking help by contacting a neighbour or relative and one (5%) contacted NHS Direct.

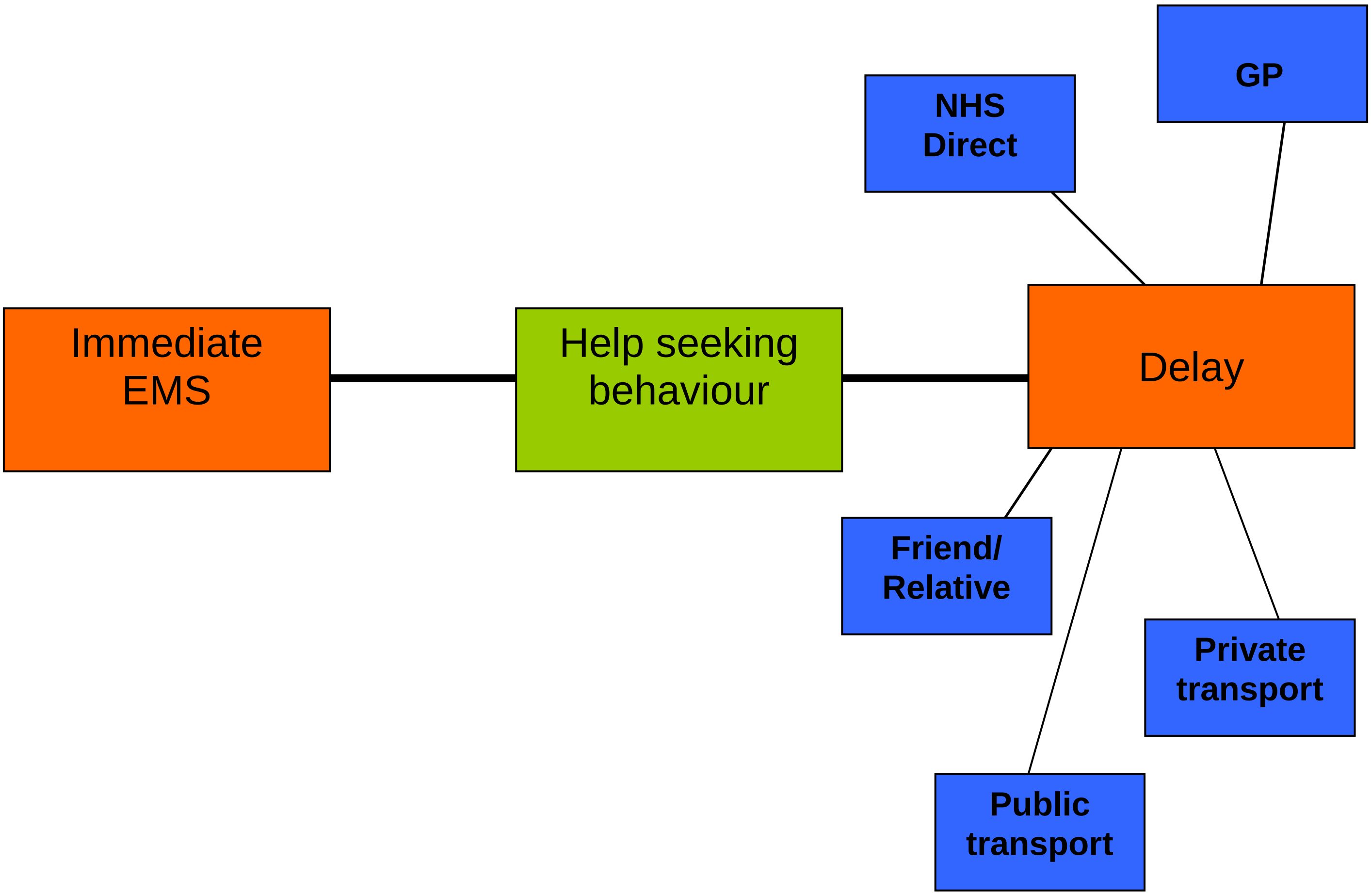

Figure 3.4. Properties informing the sub-category help seeking behaviour.

Called EMS immediately

> "*She was fully conscious and as soon as I saw her face I knew she had had a stroke. Her mouth was down and her arm was funny and I rang 999.*" (Female carer, aged 54).

> "*I said there's something wrong, I said, I'm going to call an ambulance.*" (Male carer, aged 59).

Contacted a GP

> "*I thought well I'll go, I'll phone the doctors and make an appointment. I told the girl on the thing it was urgent, I really need to come today. So I started off at a stroll and I remember bouncing into the railings and bouncing off the railings, but I got there and the doctor said you need to go hospital, so that's it.*" (Female patient, aged 71).
>
> "*I just phoned the doctor and he said come up at 9.10, this was 8.40 so up we went… this was the following morning.*" (Male patient, aged 49).
>
> "*So I phoned our doctor and got through to the receptionist.*" (Male patient, aged 58).

Contacted NHS Direct

> "*Somebody said ring, ring twen, twen, twenty four hour direct (NHS Direct) the 24 hour one... I didn't know the number and I was too dizzy to find out so I rang 118 (directory enquiries), you know and I said 'can I have the number for (NHS Direct)' and she gave it to me… She said (NHS Direct advisor)' you should ring the ambulance, would you like me to do it for you' and I said 'yes please' and she did."* (Male patient, aged 86).

Contacted a relative, friend or neighbour

> *"I got on my phone and rang the family which was ridiculous, I rang my daughter and I rang my son*." *(*Female carer, aged 65).
>
> *"He called the neighbour immediately." (*Female patient, aged 66).

Own transport or public transport to hospital

> "*Anyway I stuffed my shopping back in the trolley in a carrier bag that she had put it in and went to the car and drove to the hospital.*" (Female patient, aged 65).
>
> "*I decided I would come to A&E by myself, I came on the bus*." (Male patient, aged 90).

Previous experience of seeking medical help

Previous experience of seeking medical help, whether for stroke or another condition was often explored by participants. Previous experience of seeking medical help was informed by both positive and negative experiences (Figure 3.5).

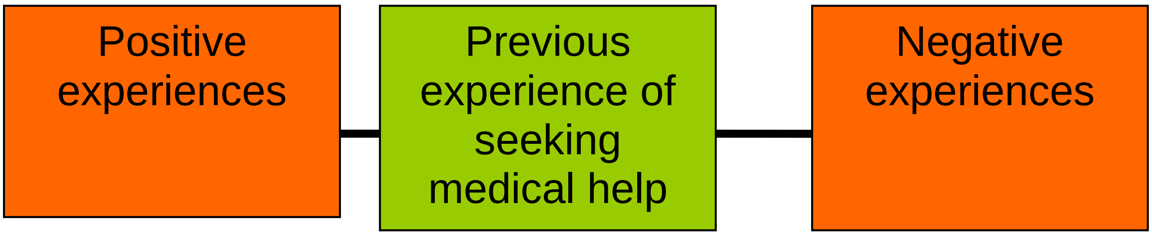

Figure 3.5. Properties informing the sub-category previous experience of seeking medical help.

Some participants had positive experiences of contacting the EMS and felt that this made them more confident in contacting the emergency services for help.

> “*I had rung 999 before and they stayed on the phone with me and it was very reassuring… so I was more aware and knew it would be ok, so I just didn’t hesitate this time.*” (Female carer, aged 54).

Others reported previous negative experiences of contacting the EMS which resulted in their decision to seek alternative sources of help.

> “*Well, I know I hate to say this, my husband died a year last February and we had a job to get an ambulance. Big long explanations and god knows what and I just couldn’t be bothered to do it. Trying to explain why you want an ambulance and what and I thought if I ring and they say why do you want an ambulance and I just say well, I feel dizzy and sick, they’re not going to come are they?*” (Female patient, aged 71).

Advice to others

All participants were asked what advice they would give to others if they experienced the symptoms of a stroke. As such the data related to ‘advice to others’ resulted as a response to a specific question rather than a category that emerged from the data. Despite participants’ experiences of stroke and TIA, a number of participants were unsure about who they should seek help from. One advised that they would contact a friend for advice, another would go to their GP but the majority, sixteen participants (89%) advised contacting the EMS, despite only 8 (44%) having done so themselves.

For some participants their interview took place following a previous TIA or stroke. Although four of these five (80%) participants advised that you should contact the EMS if stroke was suspected only two (50%) had actually done so themselves. Only two (40%) participants recalled being told specifically by a health professional that if they experienced stroke symptoms in the future that they should contact the EMS.

Development of the theoretical framework

The five sub-categories: knowledge of stroke symptoms, perceived seriousness, emotional reaction to the event, help seeking behaviour and previous experience of seeking medical help informed the development of the core category, this was entitled ‘the decision-making process for seeking help after stroke’. The categories were then used to develop a five-stage theoretical framework that reflects the decision-making process for seeking help after stroke (see Figure 3.6). This framework will be used later in the thesis to underpin the development of a new intervention.

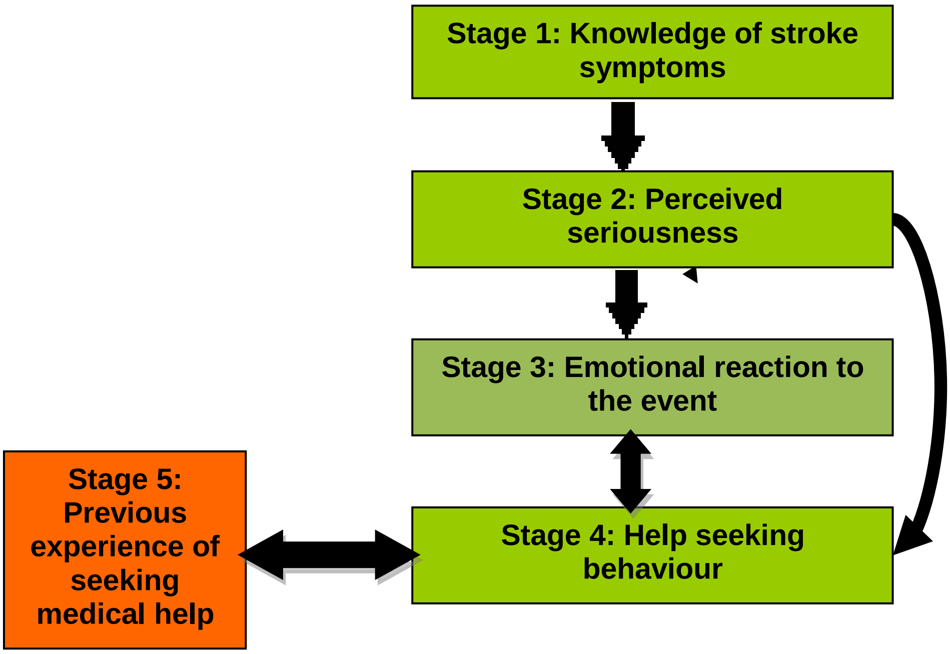

Figure 3.6. Theoretical framework to describe the decision-making process for seeking help after stroke.

Stage One of the model focusses on knowledge of stroke symptoms. In order to initiate help seeking behaviour symptoms must be recognised, although not necessarily as stroke and even when symptoms were recognised as stroke these alone are often not sufficient to motivate individuals to contact the EMS. Following the onset and recognition of symptoms the individual moves on to Stage Two, perceived seriousness. Perceiving symptoms to be serious appeared to be a major factor in initiating help seeking behaviour, although some symptoms such as speech problems were perceived to be more severe than others. For some the recognition of symptoms and realisation that symptoms were serious and required an emergency response may be the only factors that influence some people to seek medical help. For some, the onset of stroke symptoms triggered an emotional response (Stage Three) which also influenced help seeking behaviour, negative emotions such as panic and fear were more likely to prompt initiation of the EMS, whereas negative emotions such as embarrassment often resulted in avoidance of the EMS. In Stage Four medical help could be sought from a variety sources, including; EMS, GP, NHS Direct or A&E). Whilst not everyone has previous experience of seeking medical help, both negative and positive experiences could influence the type of medical help that was sought (Stage Five).

3.8 Discussion

The aim of this phase was to explore the decision-making process when seeking medical help at the onset of stroke symptoms. Through semi-structured interviews, the experiences of patients and carers informed the development of a theoretical framework, which provides an understanding of the decision-making process in which many people with stroke engage. The five categories that informed the develop of the framework (knowledge of stroke symptoms, perceived seriousness, emotional reaction to the event, help seeking behaviour and previous experience of seeking medical help) provide an insight into the different stages of help seeking behaviour that may be experienced by people when deciding whether to seek medical help. The findings from this phase highlight that knowledge of stroke symptoms alone were not sufficient to motivate individuals to seek help, a finding that is reflected in other studies not only in stroke but for other conditions such as myocardial infarction (Ho et al. 1988; Raczynski et al.1994; Reilly et al. 1994; Dracup et al. 1997). Perceived seriousness appeared to be the most influential factor in initiating help seeking behaviour, although the emotional reaction to the event and previous experience of seeking medical help also influenced the speed of response and type of medical help sought.

To date, no other studies have asked patients or carers in detail to recall the stroke symptoms that they experienced, how those symptoms were interpreted and what influence if any, they had on help seeking action that was subsequently taken. Other studies have only sought to interview participants who contacted the EMS for help (Carroll et al. 2004; Hsia et al. 2011). Whereas, this phase has involved interviewing participants who contacted the EMS, contacted their GP, rang NHS Direct and who used either public or private transport to get to hospital. By interviewing participants who accessed a variety of routes into hospital, a more in-depth exploration of the issues involved in accessing help after stroke has been gained. A previous studies have suggested that further research should seek to clarify the barriers to immediate action in response to stroke symptoms (Rosamond et al. 2005). In this phase, participants who sought help via a range of routes were identified and this has enabled the factors which influence the decision-making process in seeking help after stroke to be explored.

The discrepancy between knowledge and the intention to seek help became apparent from the results of the integrative review in Chapter Two. Despite many people stating that they would seek help from the EMS, in reality patients tend to contact a GP, friend or family member at the onset of stroke symptoms (Carroll et al. 2004; Hsia et al. 2011). The findings from Phase Two also showed that although the majority of participants advised that contacting the EMS was the correct course of action at the onset of stroke symptoms, only 44% had done so themselves.

If the public are aware that they should seek help at the onset of stroke symptoms and are not prevented physically by their symptoms from doing this, then we need to explore what it is that prevents people from seeking help from the EMS. Previous research with participants who had suspected myocardial infarction found that the decision-making process is a complex one involving symptom knowledge, beliefs, emotions and contextual factors (Pattenden et al. 2002). Similar issues have been found in this phase and will now be explored further.

Knowledge of Stroke Symptoms

The first category to emerge was knowledge of stroke symptoms. Participants reported experiencing a variety of symptoms and the variation in symptoms and their severity may partially explain the difficulty that some people have in recognising the symptoms as a stroke. Symptom recognition can be a major problem when studying illness behaviour, because symptoms often vary greatly from person to person. This has an obvious impact upon the clarity of cues to taking the appropriate help seeking action (Becker, 1974), and makes the provision of stroke knowledge challenging.

The data suggested that even when some participants recognised their symptoms as stroke this did not always appear to have a direct influence on the decision to seek immediate help from the EMS. These findings are supported by other studies, which have reported that even when symptoms were suspected to be stroke, delays in calling the EMS still occurred (Lacy et al. 2001; Rosamond et al. 2005; Fussman et al. 2010).

The proportions of participants reporting slurred speech (72%) was much higher than has been previously reported (Rosamond et al. 2005; Mosley et al. 2007). Previous research in acute stroke has suggested that the incidence of speech problems range from between 27% and 41% (Rosamond et al. 2005; Mosley et al. 2007). Although participants experienced a range of symptoms, the only symptom that appeared to be associated with contacting the EMS were those related to speech problems. All eight participants who sought immediate help reported slurred speech, whereas slurred speech was present in only three (30%) of those participants who delayed seeking help. Mosley et al (2007) also found that speech problems were the only symptoms independently associated with calls made to the EMS within one hour of stroke onset. In a further study, speech problems were associated with a decreased time delay among stroke patients seeking help (Wester et al. 1999).

Studies have shown that less than 50% of callers to the EMS recognise the problem as a stroke (Mosley 2007). The findings from Phase Two of this thesis found that 67% of participants recognised their symptoms as stroke, although only half of these participants sought immediate help by contacting the EMS. This gap between stroke knowledge and help seeking behaviour again reinforces the growing opinion that information alone is not sufficient to influence people in seeking immediate help for stroke (Fussman et al. 2010).

Perceived seriousness

The second category to emerge was perceived seriousness. A number of other studies have identified perceived seriousness as a major influence in the decision to seek help across a variety of conditions (Mechanic, 1972; Becker, 1974). Of the participants in this phase 67% did not view their symptoms as being serious, despite recognising the symptoms as stroke. Only a few studies have explored the perceived seriousness of specific symptoms (Kasl and Cobb, 1966; Safer et al. 1979). In those studies that have explored this area the main predictors of an immediate response were found to be pain or discomfort (Kasl and Cobb, 1966) and in a further study, pain and bleeding were associated with a prompt decision to seek help (Safer et al. 1979). The symptoms of stroke are often ambiguous and are not frequently accompanied by the onset of pain, and so they are often categorised as vague and therefore less severe. However, why some people associated speech problems with a more urgent response remains unclear.

Also related to myocardial infarction but of interest here are findings which suggest that delays in seeking help are often related to the belief that symptoms are not serious (Ho et al. 1988; Raczynski et al.1994; Reilly et al. 1994; Dracup et al. 1997). Even when participants perceived stroke symptoms as serious enough to require medical help, many were worried about wasting NHS time, particularly that of the EMS. Participants often felt that there would be adverse consequences if their symptoms were not serious enough to warrant use of the EMS. It may be suggested that participants who sought advice from others wanted to confirm that they had a legitimate reason to contact the EMS and that there would be no negative consequences for doing so.

Help Seeking Behaviour

The third category to emerge from the data was help seeking behaviour. Many studies have explored what advice people would give to others if the symptoms of stroke were suspected (Cheung et al. 1999; Rowe et al. 2001; Yoon et al. 2001; Reeves et al. 2002; DeLemos et al. 2003; Parahoo et al. 2003; Mikulik et al. 2008; Wall et al. 2008). However, only two previous studies have looked at what action people had actually taken for stroke and found that only 12% to 18% of stroke patients had contacted the EMS, with the majority contacting their GP for advice (Carroll et al. 2004; Hsia et al. 2011). In this phase 44% sought first medical contact from the EMS. Although these figures are higher compared with previous studies, the increased number of patients making contact with the EMS will most likely reflect the active purposive sampling of this specific group may not necessarily reflect the wider population of people who contact the EMS for suspected stroke.

In nearly all cases, people who contact the EMS are either relatives or unrelated bystanders, with patients making the call in up to only 3% of cases (Porteous et al. 1999; Mosley et al. 2007; Jones et al. 2012). In many cases it is a family member who is the first person to be contacted by the patient; in up to 68% of cases it is the family member who then seeks help from a health professional (Carroll et al. 2004).

Previous research has shown that the presence of another person at the onset of stroke symptoms is independently associated with a call to EMS being made within one hour (Mandelzweig et al. 2006; Mosley et al. 2007). However, in this phase the presence of a third party actually may have had a negative impact on the decision to seek immediate help. In the group of participants that delayed seeking help, a carer was present in 80% of cases. Patients and carers, or a third party often entered into a process of negotiation and compromise with carers (or a third party) often suggesting that they contact the EMS. Whilst patients agreed to contacting the EMS is symptoms worsened or would suggest contacting the GP for advice.

Emotional reaction to the event

The fourth category that emerged from the data related to the emotional reaction that participants experienced at the onset of symptoms. The emotional reaction to stroke or TIA is often a major influence in the decision to delay or seek help immediately. Emotional reactions may also influence the routes of help that people seek. Studies have suggested that emotionally intense people have stronger emotional reactions regardless of the nature or intensity of the situation (Hamilton et al. 2007). However, little research has explored how people control or regulate their emotional reaction to a specific stimulus or event (Hamilton et al. 2007) and this was not explored within the semi-structured interviews that were undertaken in this phase.

As the result of illness, negative emotions such as embarrassment and doubt can often result in avoidance behaviour (Janis and Mann, 1977). It is therefore important to try and understand the influence that negative emotions can have on avoidance behaviours (Lee and Hwang, 2006). As identified in this phase, emotional reactions including embarrassment were much more likely to be associated with avoidance and coping strategies. Whereas, emotions like fear and helplessness were more likely to prompt help seeking behaviour.

The importance of the emotional reaction that occurs following the onset of symptoms has also been recognised in studies of myocardial infarction and coronary heart disease (Dracup et al. 1997). Denial has also been studied widely in patients with a variety of diseases and conditions including neurological disorders and heart disease (Dracup et al. 1997). Within this phase it is likely that participants acknowledged the presence of symptoms but denied or downplayed their seriousness and/or the need for help. Denial and the use of other coping mechanisms have been shown to increase the delays in seeking help for myocardial infarction (Dracup et al. 1995).

The findings of this phase are similar to previous research which has found that there are similar general motives for delaying seeking help, which include denial of the problem and a desire to maintain independence (Amato and Bradshaw, 1985). Amato and Bradshaw (1985) also suggest that motives for delaying seeking help may involve different stages. For example avoidance and denial are likely to initially inhibit help seeking behaviour, followed by concerns about independence, fear and stigma.
It has been suggested that patients and their families need assistance in anticipating this emotional reaction. Dracup et al (1997) also suggest that the public need to be made aware about denial as a possible reaction, emphasising the serious consequences of denial when it leads to delays in seeking help for serious conditions (Dracup et al. 1997). Studies have suggested that patients should be encourages to practice their response to life-threatening symptoms so that their reaction becomes automatic, overriding the emotional response (Fetro, 1992; Raczynski et al. 1994).

Previous experience of seeking medical help

The final category relates to previous experience of seeking medical help. Previous experiences of seeking medical help were identified by many participants as influential in their decision to seek help and from whom. Positive experiences of contacting the EMS for other conditions had a positive influence on contacting the EMS for stroke. Positive experiences generally made people more confident with that particular service. As with contacting the EMS, positive experiences of primary care made people more inclined to contact their GP, as they felt that they could rely upon this service. Negative experiences of primary care and the EMS also influenced people to avoid accessing these services when stroke was suspected. This finding is similar to a previous study where those participants who reported a negative experience with physicians or hospitals were less likely to use the EMS (Schroeder et al. 2000).

Patient characteristics

Research findings have shown that older age is associated with a delay in seeking medical help (Becker et al. 2001; Hodgson et al. 2007; Marx et al. 2008). In this phase the mean age of the group that delayed seeking help was 5.2 years older than those who sought immediate help. Within Britain ill-health is often viewed as a ‘normal’ part of getting older and historically stroke has been viewed as a condition that is an inevitable part of older age (Howse et al. 2005). It has therefore been suggested that older people are more likely to accept that ill-health is part of older age and are less likely to seek medical help (Leventhal and Prohaska, 1986; Koval and Dobie, 1996).

Older people have poorer stroke knowledge and are the least likely group to say that they would take immediate action for stroke by contacting the EMS (Jones et al. 2009). This is particularly worrying given that older age is a major risk factor for stroke (Bonita, 1992). It could be suggested that older people must be informed about the treatments that are available and that recovery from stroke is influenced by seeking help at the earliest opportunity. Older people may therefore, need to be targeted as a specific group within future stroke awareness interventions.

One previous study reported that gender did not appear to influence EMS use (Schroeder et al. 2000). However, earlier studies have shown that older men are more likely to seek medical advice from their wives and children (Stoller, 1993) and recent research has shown that the patient’s daughter is the most likely person to contact the EMS for stroke on behalf of the patient (Mosley et al. 2007; Jones et al. 2012). In this phase 80% of the patients who delayed seeking help were male.

The theoretical framework

The five categories (knowledge of stroke symptoms, perceived seriousness, emotional reaction to the event, help seeking behaviour and previous experience of seeking medical help) that emerged from the semi-structured interviews, informed the development of the core category ‘the decision-making process for seeking help after stroke.’ These categories informed the development of a five-stage theoretical framework that attempts to explain the help seeking behaviour of people with suspected stroke or those who act on their behalf (Figure 3.6). The theoretical framework developed in this phase could be used to underpin future stroke awareness campaigns and interventions. This would also form the theoretical phase of the MRC framework for complex interventions (Campbell et al. 2000).

Within the health behaviour literature, models have been used to explain and predict illness and sick role behaviour (Rosenstock, 1974; Leventhal, 1998). The Health Belief Model (HBM) has made an attempt to explain action taken following the early detection of symptoms (Kirscht et al. 1976; Becket et al. 1977; Leavitt, 1979). In three studies of actual help seeking behaviour, perceived susceptibility, severity and self-efficacy were most associated with the decision to access medical help. This may be because the onset of symptoms can be an important threat to an individual through increasing health motivation or acting as a cue to taking action (Kirscht, 1974).

The Common Sense-Self Regulation Model (CS-SRM) has also been used to describe the interpretation of symptom information, which in turn can form the first step in seeking help (Hagger and Orbell, 2003; Leventhal et al. 1980). However, as with the HBM, the CS-SRM has only been used to explain help seeking behaviour within three studies (Cameron et al. 1993; Walsh et al. 2004; Farquharson et al. 2011). These studies reported that symptoms alone were not sufficient to initiate help seeking behaviour. However, the belief that symptoms were serious (Walsh et al. 2004; Cameron et al. 1993), an inability to cope and seeking advice were all significant aspects of determining if help was sought (Cameron et al. 1993).

The stages of the theoretical framework developed in this phase (Figure 3.6) are consistent with the main components of both the HBM and the CS-SRM as these models also incorporate aspects of: knowledge; perceived seriousness (or consequences); emotions (not in HBM); action or behaviour change; and personal experience (not HBM). Across the HBM, CS-SRM and the framework developed in this phase, perceived severity is the only variable to be consistently associated with help seeking behaviour.

Limitations

Although saturation was reached in the main themes reported, the number of participants that were interviewed was small and represented patients and carers from only one catchment area of an acute hospital trust. Although both purposive and theoretical sampling strategies were used to identify participants, some groups were not adequately represented. These included participants from ethnic minority groups and those who lived alone. All participants sought help at some point from their GP, the EMS or local hospital. It was not possible to identify participants who did not seek any medical help and this group were not actively sought. For these reasons, the findings of this phase may not be generalisable to other settings.

Although participants were interviewed soon after the event, the effects of recall bias may have influenced the results. Participants were asked specifically about the earliest part of their stroke experience prior to hospital admission. Recalling these early experiences may have been influenced by later experiences in hospital.

It is also a possibility in participants who delayed seeking treatment that the effects of the stroke may have impaired their ability to recognise or respond to their symptoms in a timelier manner. It is not possible to assess the impact that this type of impairment may have had on participants’ decisions to delay seeking help.

3.9 Conclusion

The aim of this phase was to explore the decision-making process of patients and carers when seeking medical help at the onset of stroke symptoms. The findings from semi-structured interviews with patients and carers suggested that help seeking behaviour after stroke is complex and is influenced by many factors. The results of this phase have informed the development of a theoretical framework, which provides an understanding of the decision-making process in which many people with stroke engage. The five categories that informed the development of the framework were: knowledge of stroke symptoms, perceived seriousness, emotional reaction to the event, help seeking behaviour, and previous experience of seeking medical help.

The findings from this phase suggest that just improving the recognition of stroke symptoms may not be enough to encourage people to contact the EMS for suspected stroke. Although many participants recognised their symptoms as a stroke, the majority felt that these symptoms were not serious enough to require emergency assessment.

This phase had a number of limitations relating to generalisability of the findings due the small sample size and lack of representation of participants from ethnic minority groups. This phase did not seek to interview those patients who do not seek medical help and this group may have additional barriers to accessing health services for suspected stroke that have not been identified here. As with any interview that takes place following a specific event, recall bias may have influenced the results and it is possible that for some patients who delayed seeking help that this may have been due to impairment as a result of their stroke rather than a conscious decision to delay seeking help.

This is the first study to explore the stroke symptoms experienced by patients, how those symptoms were interpreted and what influence if any, they had on help seeking behaviour at the onset of stroke symptoms. Unlike other studies which have focussed only on utilisation of the EMS (Carroll et al. 2004; Hsia et al. 2011), this study has involved interviewing participants who sought medical help via a variety of routes; whether they contacted the EMS, contacted their GP, rang NHS Direct, or who used either public or private transport to get to hospital. This gives a more complete picture of the issues involved in seeking medical help after stroke and TIA.

The findings from this phase suggest that any future interventions to raise awareness of stroke should make explicit the symptoms of stroke, the seriousness of stroke, the emotional reaction that may be experienced and the need for a rapid response by contacting the EMS. To date, no public awareness campaigns or interventions have been targeted at specific groups within the stroke population and the impact of stroke awareness interventions on reducing delays is unknown. The findings from this phase suggest that older males are the least likely group to contact the EMS. Older men may, therefore need to be targeted as a specific group within future stroke awareness interventions.

The next chapter takes forward the findings from this thesis so far, to inform the development of an intervention aimed at improving utilisation of the EMS. Chapter Four begins with the first stage of this process in which a focus group discussion explores the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. This will be followed in Chapter Five by the development, pre-testing, and refinement of the intervention, guided by social marketing theory.

CHAPTER FOUR

PHASE THREE – AN EXPLORATION OF THE KEY MESSAGES AND FORMATS OF STROKE INFORMATION: A FOCUS GROUP STUDY

4.1 Introduction

The integrative review in Phase One highlighted the importance of increasing public awareness about the recognition of stroke symptoms and the emergency response that is required (Jones et al. 2009). Findings from the review suggested that public awareness and educational campaigns should be targeted towards specific groups including older people (Jones et al. 2009). The review also suggested that there should be a focus on action taken for suspected stroke and not just improving stroke knowledge (Jones et al. 2009). It was therefore recommended that there is a need for future research that involves the development of stroke awareness campaigns or interventions that influence both knowledge and help seeking behaviour. The development of the theoretical framework in Phase Two provided an understanding of the decision-making process in which many people with stroke engage. It was clear that recognising the symptoms of stroke alone was not sufficient to motivate individuals to contact the EMS. Perceiving symptoms to be serious appeared to be a major factor in initiating help seeking behaviour, although how individuals reacted emotionally to the onset of symptoms and previous experience of seeking medical help all had a role to play.

This phase describes the processes that were undertaken in order to inform the development of an intervention that will be implemented in Phase Four. The intervention will aim to improve the response to suspected stroke, in terms of utilisation of the EMS and time from onset of symptoms to when first medical help is sought. In order to inform the development of the intervention, the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS will be discussed and agreed in a focus group.

This phase will begin by providing an overview of the methods used, the results from the focus group will then be reported and discussed. The development and pre-testing, implementation, effectiveness and refinement of the intervention will also be described.

4.2 Focus Groups: An Overview

In this section focus groups will be examined as a methodology, followed by the methods used in the sampling and recruitment of the focus group participants. The process of data collection and analysis will then be described, paying particular attention to the problems of analysing and presenting focus group data.

Focus groups originate back to the 1920s when they were used in the development of survey instruments (Fontana and Frey, 1994). Focus groups have been used extensively in the field of health promotion and education; for example, there is a substantial body of research where focus groups have been used to explore individual's understanding of and responses to health related messages (Freimuth and Greenberg, 1986; Kitzinger, 1994).

Focus groups are viewed as an important qualitative data collection technique (Madriz, 2000). Unlike interviews, focus group participants communicate their views and opinions among peers, with whom they are likely to share a common experience. This allows participants the opportunity to comment, challenge and reflect on the views of others (Kidd and Parshall, 2000). Focus groups are so named as they refer to the idea that group discussion takes place around a specific topic (Kitzinger, 1994).

Evidence suggests that participants in focus groups may find the experience more stimulating than other methods such as interviews (Bristol and Fern, 1996). Generating data from a number of participants during a focus group may also avoid the time consuming processes of individual interviews (Reed and Payton, 1997). Thus, the perceived advantages of focus groups are that they are economical and are also easier to organise (Drayton et al. 1989).

The Group Context

Focus groups provide the context in which group dynamics and interaction between participants results in the generation of data (Ritchie and Spencer, 1994). The opportunity to express views, opinions and experiences are enhanced by listening to others, reflecting upon this shared information and deciding whether this influences a person's own viewpoint (Ritchie and Spencer, 1994). The focus group setting allows for the flow of conversation, with new ideas and language able to emerge (Ritchie and Spencer, 1994). This group interaction provides rich data, enriched by this social context (Morgan, 1997).

It was felt that a focus group would provide a more stimulating environment in which participants would have the opportunity to review a range of public awareness materials (FAST leaflet [DoH, 2011a, FAST advert [DoH, 2011b] and the FAST heroes animation [Wall et al. 2008]) that could inform a discussion around the key messages and formats of future stroke information. Many of the definitions of focus groups refer to the interaction between participants as a way of generating data that would not emerge through other methods (Krueger, 1994). The main advantage for using focus groups is to ‘capitalise on the interaction within a group to elicit rich experiential data’ (Asbury, 1995 p.414). The focus group enabled people to review, discuss and share their views about current public awareness material for stroke and how these could be improved. The group engaged and interacted with each other by sharing information leaflets and discussing issues immediately before the focus group began. This not only sparked discussion but also ‘broke the ice’ between participants.

The advantage of using focus groups is their capacity to provide interactions based upon relationships and group dynamics that might not otherwise emerge (Dreachslin, 1998). It was felt that the interaction between members was helped by providing participants with public awareness materials that they could touch, read, watch and share with other members. Group interaction may have resulted in more detailed, richer data compared to data that may have been generated from individual interviews with similar participants (Murphy et al. 1992; Asbury, 1995).

Recruitment

The focus group involved health professionals, academics working in stroke, stroke charity representatives, patients and carers. The focus group participants provided expertise from a range of backgrounds including pre-hospital stroke care, TIA clinics and emergency care, with representation from both the NHS and academic institutions. Stroke patients and carers also brought their own personal views and experiences.

Focus group participants should not only have a common interest in the topic under discussion but should also be sampled in a way that ensures that they have similarities with other group members. These similarities may include age, race and experience of the discussion topic (Morgan, 1997). All participants were selected as they had an interest in stroke care, all participants also had either professional or personal experience of stroke.

Segmentation was considered as this is a common sampling strategy used within focus groups and involves separating participants into different groups (Morgan, 1997). Segmentation can be used for a number of reasons but it is often used to reflect the relationship of participants to the topic being discussed. For example, services users may be separated from health professionals. However, it was felt that sufficient diversity should still exist in order to encourage a comprehensive discussion (Morgan, 1997). One of the main advantages of segmentation as a sampling strategy is that it allows the identification of differences between groups, representing different views, opinions and experiences (Morgan, 1997). Conducting two focus groups, one with patients and carers and the other with health professionals was considered. However, this was decided against based on the author's own experiences of interviewing patients and carers. Patients and carers often focus on their own personal experience of stroke and what happened to them. A discussion with only patients and carers may have resulted in a discussion with a narrower focus. Whereas, involving a range of participants including health professionals, academics, patients and carers would hopefully result in a discussion with a wider perspective.

Critical in determining the dynamics of the group is the size of the group and the participants invited to take part. Diversity is essential in encouraging group discussion but extreme levels of diversity may inhibit cohesion and co-operation (Ritchie and Spencer, 1994). Participants often feel more relaxed and able to express their views when they share similarities with other group members (Ritchie and Spencer, 1994). On the other hand, if group members are very different, it can be difficult to cover any one topic in-depth. Where possible, focus groups should contain some degree of diversity, for example in terms of age, healthcare experiences and socio-economic status (Ritchie and Spencer, 1994). The participants should all have a similar experience in relation to the research topic, so that they feel able to contribute to the discussion (Ritchie and Spencer, 1994).

The composition of focus groups is essential in facilitating focus group discussions that are energetic and free-flowing. It could therefore be argued that by purposively sampling from within a segmented population there is a greater probability of achieving data saturation (Carey, 1995). However, it was decided that the focus group should be mixed not only in terms of patients, carers, health professionals and academics but also in terms of age and experience. All participants had a strong interest in the topic under discussion and by including a diverse population, it was hoped that a range of ideas and views would be generated.

There are a number of strategies that can be drawn upon when recruiting participants for focus groups. These include recruitment through:

- Informal networks of colleagues and community groups (Hawe et al. 1990).
- Existing organisations (Glesne and Peshkin, 1992).

- Individualised invitations followed up by personal telephone calls (Murphy et al. 1992).
- Confirmation of the venue, location and time (Krueger, 1994).

All participants were recruited through existing professional networks and were contacted on an individual basis. This was followed up by an informal discussion about the purpose of the focus group.

The two group moderators (including the author) had previous experience of conducting both interviews and focus groups with stroke patients and their families. The author facilitated the group discussion, whilst the second moderator observed the group, noting interactions, body language, how the group came to a consensus or how they differed in their opinions.

Focus Group Questions

A pilot focus group was not undertaken but participants were asked to review focus group questions to ensure that questions were unambiguous and easy to understand (see Appendix 13 for the focus group question guide). A common criticism of focus groups is that the question guide often heavily represents what is of interest to the researcher, rather than what may be of importance to the participants (Morgan, 1997). To avoid asking too many questions, an initial presentation and review of the public awareness materials provided a structure to the discussion meant fewer questions would be needed. As Carey (1995) suggests, if too many questions are asked, in-depth, rich information cannot be explored and the session may function as an oral questionnaire.

Group Behaviour

Group processes and models of group behaviour provide a useful insight into the dynamics and interactions that occur within focus group discussions. The five stage model shown (Figure 4.1), describes the phases that small groups experience when engaged in discussion (Tuckman and Jensen, 1977).

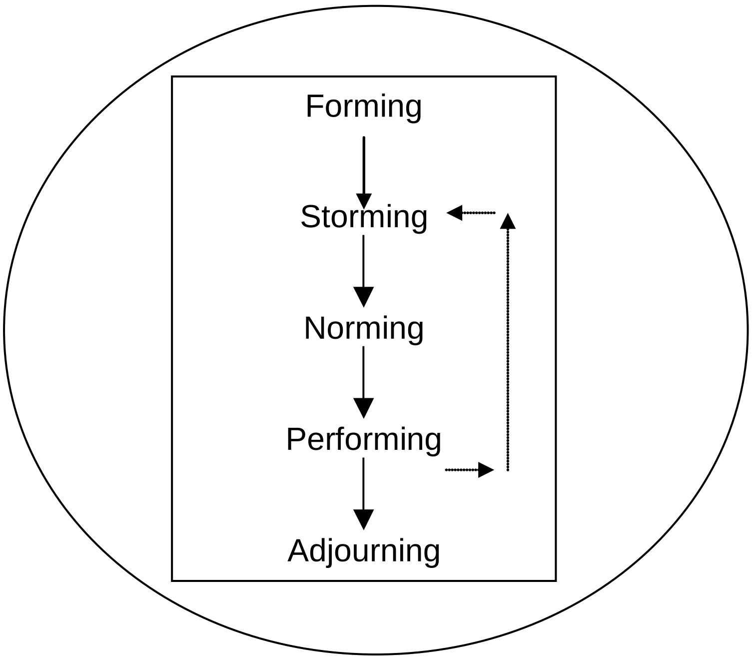

Figure 4.1. A Model of Group Phases (Tuckman and Jensen, 1977)

In the forming phase individuals are new to the group and may feel anxious and guarded. This was evident with a number of members from within the group. Individuals may also be concerned about how they will be accepted by other members. In this phase engagement between individuals may be limited, with questions and answers directed at the moderator (Tuckman and Jensen, 1977). To make the forming stage easier for participants to engage in, a short presentation was delivered outlining the purpose of the discussion and participants were encouraged to make contributions. The group were also given existing stroke public awareness materials to review. By reviewing and discussing existing public awareness material in the first instance, members of the group had the opportunity to exchange ideas and views. Two members were less confident and so were actively encouraged to take part in the discussions.

Next follows the storming phase, were there is often intragroup conflict and criticism, with particular group members attempting to exert their dominance. Two members of the group took control of the conversation in the early stages of the discussion, whilst other members were trying to interject, often without success. It was the role of the moderator to control who would contribute to the discussion next and participants were invited to make their views heard.

In the norming phase, group cohesion develops as members co-operate with each other, sharing views and finding common ground (Tuckman and Jensen, 1977). In this phase it is important that the moderator does not allow the discussions to exclude diverse attitudes and opinions (Ritchie and Spencer, 1994). All members were encouraged to express their views, and although participants sometimes had different experiences and opinions, the discussion was cohesive and explored in detail a number of themes. Group cohesiveness becomes established in the performing phase and the discussion often revisited issues brought up in the earlier phases (Tuckman and Jensen, 1977). It was felt that the norming phase was the most productive phase of the cycle, each member of the group contributed and the group appeared to be enjoying the discussion that was taking place.

The adjourning phase occurs when the group move towards the end of the discussion. When it was felt that the discussion was coming to a natural end, the main points of the discussion were re-capped and the group were asked if anyone else had anything to add. Finally the group were thanked for their participation.

4.3 Analysing Focus Group Data

To date, the literature has reported in detail how focus group participants are recruited, how focus groups are organised and conducted, but little consideration has been given to the analysis of focus group data (Krueger, 1994; Morgan, 1997; Kidd and Parshall, 2000). One area of analysis which has been debated is whether when the individual or group should be the unit of analysis (Carey and Smith, 1994; Carey 1995; Morgan, 1995).

To support the analysis of group interaction data it has been suggested that group interactions and not just individual quotations, should be reported (Wilkinson, 1998). This helps to demonstrate how the group have arrived at their comments or views as a result of interaction with each other (Wilkinson, 1998). Areas of agreement and controversy have therefore been identified and supported by quotes from individual participants.

The dynamics of the group were well balanced and each participant made a contribution at some point in the discussion. Therefore, it was not felt that areas of agreement within the data were as a result of coercion or self-censoring, as has been suggested can be the case (Carey and Smith, 1994). Some particular findings however, as reported in the results, were not viewed from the same perspective by all participants.

4.4 Methods

Aim

To explore the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. For example, Stroke Association FAST campaign material, the FAST television advertisement and stroke heroes animation.

Questions to be answered in Phase Three are:

- What are the key messages that would be needed to encourage people to seek immediate help from the EMS?
- Which formats should be used to deliver stroke information?

Setting

The University of Central Lancashire.

Subjects and Sampling

Twelve participants were identified from a convenience sample of people who were currently members of stroke research steering groups at the University of Central Lancashire.

Inclusion criteria: current member of a stroke research steering group at the University of Central Lancashire.

Data Collection

Basic demographic information was collected including; occupation, age and sex. A digital recorder was used to record the focus group discussion.

Data Analysis

The digital recording of the focus group discussion was transcribed verbatim, the transcription was then annotated with the field notes and observations that had been made by the second moderator. Each line of the transcription was coded using open codes. Constant comparison techniques were then used to identify common themes within the discussion (Glaser, 1992). The focus group was analysed as a whole, rather than analysing and comparing the contributions made by individuals. The context in which each code arose was also described, this was informed by participant contributions, areas of agreement, areas of disagreement and the body language of participants.

Data Credibility

Issues of rigour in focus group research have been addressed by suggesting that more than one researcher should analyse the data to establish reliability (McDaniel, 1996; Higginbottom, 1998). Within the context of a PhD thesis, this was not practical, however the data were fed back to participants for checking of its validity or plausibility as an explanation of what was said (Higginbottom, 1998).

Ethical Issues

Ethical approval was not required from the Local Research Ethics Committee. Therefore, ethical approval was sought from the Faculty of Health Ethics Committee at the University of Central Lancashire (Appendix 14). Due to the nature of focus groups complete anonymity cannot be guaranteed. Ground rules were set at the beginning of the focus group these included the importance of not disclosing what was said within the discussion and respecting the opinions of the other group members. Although the importance of anonymity was emphasised, it was reiterated that anonymity could not be completely ensured but confidentiality would be maintained.

Summary

Consideration of the different methodological approaches and methods used in relation to focus groups have been discussed. The ethical issues pertinent to this phase and the practical issues involved in conducting focus groups have also been outlined. Finally, a description has been provided about how the data were collected and analysed. The findings from the focus group will now be presented.

4.5 Results

Four health professionals were approached to take part, two declined and two agreed to participate, five academics were invited to take part, one declined. All patients, carers and members of a stroke charity who were invited, agreed to take part in the focus group.

The mean age of participants was 51 years, 8 (67%) were female. Four (33%) held academic roles, 3 (25%) were patients, 2 (17%) were health professionals, 2 (17%) were members of a stroke charity and 1 (8%) participant was a carer.

Following analysis of the focus group transcription, four themes emerged in relation to the format of the information provided: information should be suitable for different groups; information should be informed by stroke survivors; messages should be simple; messages should be conveyed through pictures and images.

The group also discussed messages which they felt should be included within public awareness campaigns. The following four themes relate specifically to these: including a range of stroke symptoms; stroke is a medical emergency; treatments for stroke; hope, fear and the consequences of stroke.

Information Suitable for Different Groups

Every member of the group agreed that information should be suitable to meet the needs of individuals. This included information in different languages and formats. The group discussed how information could be designed for the needs of specific groups. For example, using the Internet, e-mails and text messages may not be suitable for older people, who are less likely to have computers and mobile phones. The general opinion was that public awareness information should be available in a range of formats that suit individual needs, although the group did not discuss which formats would be most suitable for different groups or individuals.

> "*I think people need constantly educating with different formats of leaflets*." (Female carer, aged 58).
>
> "*Social marketing always uses multiple approaches, you can never rely on one approach*." (Male academic, aged 60).
>
> "*Different people will access information in different ways depending on what suits them.*" (Female health professional, aged 42).
>
> "*It's just options, a lot of people beyond a certain age don't have them [computers]*." (Female patient, aged 65).

When discussing this topic the group appeared relaxed and the observer noted that members actively encouraged each other to join in the discussion. This was the first topic that the group discussed and some quieter members did not contribute to the focus group at this stage.

Information Informed by the Experiences of Stroke Survivors

Members of the group felt that public awareness messages that included images of stroke patients would have more impact. Some members discussed the personal impact of stroke and how this may be easier to convey to the public through images of stroke patients or stories of their experiences. Not every member of the group felt that a personal perspective would be useful, although no-one suggested that the use of personal images would be detrimental.

Three participants highlighted the potential benefits of using personal experiences or images. All members listened to the views of these three participants and many nodded in agreement, although had nothing to add to this topic of discussion themselves. None of the participants appeared to object to the use of personal experiences, no-one disagreed vocally, and the observer noted that the body language of the group remained positive. It was however, still early in the discussion and some participants may have not felt able to make a contribution at this point.

> "*I prefer the Department of Health leaflet because it's got the images, the person's face on it.*" (Female member of a Stroke Charity, aged 31).
>
> "*Stroke patients and carers saying what it could be really like, I tell you that would have an impact*." (Female patient, aged 65).
>
> "*Show people what it's really like, that would do it.*" (Male patient, aged 62)

Information should be Simple

All members of the group felt strongly that any public awareness information about stroke should be straight forward and simple. This included the style and format of messages being easy and simple to understand.

Each member actively participated in the discussion around messages being suitable for all members of the public. In the field notes, all members appeared enthusiastic in their agreement that public awareness messages should be suitable for all. Body language was open, people were leaning into the table, members were nodding in agreement and the environment was one of enthusiasm, interest and involvement.

> "*Cover the majority of people.*" (Female health professional, aged 31).
>
> "*Easy to understand, simple. There's no need to make things complicated.*" (Female health professional, aged 42).
>
> "*Simple messages in simple forms.*" (Female patient, aged 65).

Pictures and Images

The group discussed the use of pictures and images in public awareness campaigns and how images can be simple, appealing, easy to understand and effective in getting the message across. The group talked about the use of pictures and images and how they could be understood without much explanation or text. The group discussed the benefit of images, as they can be simpler to understand by anyone regardless of their age, reading ability or language skills.

By this point in the discussion group cohesion had developed and the group had reached the norming phase (Tuckman and Jenson, 1977). Each member of the group contributed to the discussion of this topic. The group were energised, enthusiastic and vocal. Some members were trying to interject, everyone had something to add to the discussion. At this point the moderator had to act as ‘gate keeper,’ thanking some participants for their contributions and inviting others to speak. This enabled some of the quieter or less confident members of the group to join in.

> “*Some people can’t read...It’s a good way to cover everything.*” (Female patient, aged 65).
>
> “*I think this could be done in a series of cartoons that would be visually appealing and easy to understand by everyone.*” (Female carer, aged 58).
>
> ”*How many of us have read the text on it [FAST leaflet]? You have a quick look you see FAST, the picture, the colours.*” (Female health professional, aged 31).
>
> “*When you go to your GP surgery what do you look at in the magazines?*” (Female health professional, aged 42). All: “*The pictures.*”
>
> “*Pictures are quick and effective at getting the message across, especially if you have had a stroke and your reading is impaired.*” (Female health professional, aged 42).
>
> “*Pictures work better.*” (Female patient, aged 65).
>
> “*This visual impact is important but so is a source of further reference. If you have the bald message and nothing to follow up, I think you’re missing an opportunity.*” (Male patient, aged 72).

> ”*I think that’s alright for adults never mind children [FAST cartoon].*” (Female health professional, aged 42).

> ” *I think you get bigger impact from pictures.*” (Male patient, aged 72).

A further four themes emerged in relation to the content of the information provided: the importance of including a range of stroke symptoms; the importance of stroke as a medical emergency and making the public aware that treatments are available for stroke; hope and fear and the consequences of stroke.

A Range of Stroke Symptoms

The patients and carer in the group began to discuss the differences in the symptoms that they experienced, as compared to the symptoms within the DoH FAST campaign (Department of Health, 2009). It became clear that within the group there was a view that the public may assume that if they do not have all three symptoms of the FAST, then they may interpret their symptoms as something other than stroke. The patients and carer concurred that different symptoms present in different people. However, the health professionals and members of the stroke charity suggested that messages would be lost if a campaign listed all the possible symptoms that could occur.

> “*Mine wasn’t as dramatic as that [the FAST campaign]. My mouth wasn’t in the right place and my arm had gone a bit funny. They say it’s not as clear cut and as obvious as the advert displays. I understand why the advert has to do that, they only have a certain amount of time.*” (Male patient, aged 72).

> “*Because in my own case it doesn’t really follow that pattern. The first thing that happened to me was that I began to speak very softly and then I noticed that my leg was not working properly. A few hours later my arm wasn’t working very well. I never had my face sagging at all as far as I know.*” (Male patient, aged 62).

> “*It can present differently in different people on more than one occasion.*” (Female patient, aged 65).

> “*The problem is there is such a variety of symptoms that anyone can have when they have a stroke. It’s trying to capture the most common ones which is face, arm and speech and that’s why they’re in that campaign because they’re the most common.*” (Female health professional, aged 42).

There was much discussion around how the symptoms of stroke can present differently in different people. This part of the discussion resulted in much debate and involved each member of the group. The patients and carer within the group felt passionate that a range of symptoms should be included, not just the symptoms mentioned within the FAST campaign. Other members argued that including too many symptoms would just confuse the public and no consensus was reached.

Stroke is a Medical Emergency

The group felt that stroke is a medical emergency and the importance of dialling 999 should be emphasised. This issue was discussed mainly by the patients within the group who had strong feelings, despite the fact that none of them had actually rung for an ambulance themselves and all had delayed seeking help.

Group members nodded in agreement and the atmosphere was relaxed as the group all reached a consensus that stroke is a medical emergency.

> "*I like the phrase stroke is a heart attack in the brain. That makes you aware that it is as important as a heart attack.*" (Female patient, aged 65).
>
> "*The message must be to get an ambulance, the ambulance knows where to take you and if you arrive by ambulance you get priority treatment.*" (Male patient, aged 72).
>
> "*Stroke is an emergency. People need prompting to dial 999.*" (Female patient, aged 65).

Treatments for Stroke

Following on from the discussion around the consequences of stroke, treatments for stroke were also examined. The group felt that the public should know that treatments are available for stroke. This also linked to the discussion around hope and fear. Participants felt that if treatments for stroke were widely known, this may influence people in their decision to seek medical help more quickly. The group felt that the general attitude amongst the public was that after a stroke not much could be done. Consequently, either death or some degree of moderate to severe disability was likely.

All members agreed that the public should be made aware that treatments for stroke are available, which can prevent death and disability. The observer noted that members nodded in agreement and that the discussion was fast paced, with nearly all participants making a contribution.

> "*I think people need to be made aware that there is a lot that you can do to stop brain death.*" (Female patient, aged 65).

> "*The TV campaign does emphasise that the faster you act the more brain you save.*" (Female academic, aged 45).

> "*I think that people do think that it's serious but think that there's not a lot that you can do about it. You have a stroke, you're disabled, that's it really. Once you've actually had the stroke people need to know things can be done.*" (Female academic, aged 45).

> "*The message should be about getting into hospital as fast as you can, you may be suitable for thrombolysis.*" (Female health professional, aged 42).

Hope, Fear and the Consequences of Stroke

Spontaneously, the group discussed the consequences of stroke and how this may inform a public awareness campaign. The group felt that the public may not be aware of the consequences of a stroke and that severe disability and death were real consequences of not seeking immediate medical help. The group discussed other public awareness campaigns such as those used by the British Heart Foundation, who used fear as a theme within their chest pain advertisements (Appendix 15).

The female participants felt strongly that public awareness campaigns should not use fear as a motivator to take action after stroke. Suggesting this may be ineffective, resulting in avoidance and fear, rather than action. However, the male participants in the group felt very differently. The male participants suggested the opposite, that fear would prompt people to take action for suspected stroke.

After debating the use of fear within health awareness campaigns, the group also discussed messages of hope. The group concurred that that a message of fear must also be followed by one of hope. For stroke, it was agreed that the public should be made aware that treatment is available for stroke and that a full recovery is also possible.

> "*Temper it with humour, not scary.*" (Female patient, aged 65).

> "*My mum says she doesn't like it [DoH campaign on TV] because it's scary.*" (Female health professional, aged 42). "*Good*." (Male patient, aged 72).
>
> "*Not frightening like in a cartoon [FAST stroke heroes animation].*" (Female academic, aged 50).
>
> "*Do you know what to make it scary, looking at what it could do. Look at smoking, they look at what could be happening, they paint a very bleak picture. It should be the same for stroke.*" (Male patient, aged 62).
>
> "*If you look at social marketing campaigns, at what's been successful. The campaigns by the Department of Health when they scare people have to be reinforced then by something or hope basically. There is something that you can do. Fear followed by hope. There has to be a motivation or something else there or people will just stick their head in the sand.*" (Female member of a Stroke Charity, aged 31).
>
> "*Stroke, it's still not clear that they can die, or live with a very serious disability, so getting that across might be a good motivator, so that people actually act.*" (Male patient, aged 72).
>
> "*One third of people die, one third are seriously disabled and one third recover.*" (Male patient, aged 72).
>
> "*The outcome could be pretty shitty really and if that's hammered home and people become aware of it that might spur them to dial 999.*" (Male patient, aged 62).

Again this topic generated much discussion and a passionate debate took place around the consequences of stroke. With male members of the group suggesting that the consequences of stroke should be made clear to the public and female participants suggesting that people required more gentle persuasion. The discussion became quite intense with male and female participants differing in their opinions throughout. Again each member of the group contributed to this topic of discussion.

4.6 Discussion

The aim of this phase was to explore through a focus group, the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. The findings suggest that the key messages in terms of format and presentation were simplicity and that simplicity and suitability of stroke information may be facilitated through the use of pictures and images and messages that are clear and easily understood by everyone. The key messages in terms of content were classic stroke symptoms; stroke as a medical emergency, that treatments are available for stroke and the importance of contacting the EMS.

The focus group suggested that information should be suitable for different groups but did not state which formats would be best suited to whom. The group did highlight that some formats, for example the Internet, e-mails and text messages may not be suitable for use with older people. This is supported by the findings of a survey by the Office for National Statistics who reported that adults aged 65 plus were the least likely group to use the Internet, with 70 per cent stating they had never used it (Office for National Statistics, 2009). It was also suggested by the group that pictures and images would be the most widely understood format regardless of language or reading ability.

Older people and others may relate more to the use of personal perspectives, a technique that has long been used in public awareness campaigns. For example, the *Face Arm Speech Time to dial 999* (FAST) campaign uses images of people who have had a stroke (DoH, 2009). Further to the use of personal perspectives, images, pictures and animations have been used in recent stroke campaigns (Wall et al. 2008; DoH 2009). One such study reported significant increases in the public's ability to recognise facial droop and arm weakness or numbness, as well as increasing the proportion of participants who recognised calling the EMS as the correct course of action from 81.9% to 98.6% and Wall et al. (2008) found that during concept testing, participants felt that the message provided a comfortable, upbeat, "less scary" approach to a serious health issue, and that the messages were simple, direct, and uncluttered, describing the style as simple but appealing (Wall et al. 2008). These are similar findings to this phase in which participants described stroke information that should consist of messages that were simple, effective and that could be understood by everyone.

Whilst the patients are carer agreed that stroke symptoms can present differently from person-to-person. The health professionals and members of the stroke charity suggested that messages would be lost if a campaign listed all the possible symptoms that could occur. Whilst it is acknowledged that the symptoms of stroke may vary, is not possible to list all symptoms within an intervention, as this may dilute the message around the main symptoms that are most likely to be experienced. Stroke classically presents with the sudden onset of neurological loss e.g. one or more of: facial droop, limb weakness or numbness, difficulty speaking or understanding speech. The Face Arm Speech Test (FAST) was designed for use initially by ambulance personnel in identifying patients with suspected stroke (Harbison et al. 2003). However, the FAST like other scales may be insensitive to posterior infarcts (Nor et al. 2004). As the classic symptoms of stroke have been used as the basis of the FAST mass media campaign by both the Stroke Association and DoH; facial weakness, arm weakness and speech problems are likely to be the main stroke symptoms that are used in any future stroke awareness interventions.

The focus group members not only discussed the symptoms of stroke but also the consequences of stroke, with the male and female participants differing in their opinions. Male participants suggested making clear that death and disability were a potential consequence of stroke if people delayed seeking help. Whilst the female participants suggested that an emphasis should be put on the treatments that were available for stroke, highlighting that seeking medical help quickly could save lives and reduce disability. The consequences of stroke are well documented and a number of population-based surveys have explored the impact of stroke. One such survey identified that one-third of stroke survivors had died and another third were moderately to severely disabled at five years following their stroke (Wilkinson et al. 1997). Although stroke accounts for 11% of all adult deaths in the UK and is the leading cause of adult disability (NAO, 2005), anecdotal evidence suggests that the consequences of stroke are not widely understood amongst the general public.

A number of health campaigns, both past and present have used fear as a strategy around which to base their health messages with varying degrees of success (Job, 1988). Emotion has been long recognised as an important element that influences health behaviour (Mayne, 1999). Previous research has found that negative emotions can act as a facilitator or barrier to help seeking behaviour (Lee and Hwang, 2006). Negative emotions can be linked to avoidance behaviour (Janis and Mann, 1977; Lee and Hwang, 2006) and the female members of the group felt that ‘fear-based’ messages may actually have the opposite effect than intended. This is a view supported by Job (1988), who suggested that the ineffective use of fear in health campaigns may not only waste time and resources but may encourage a ‘denial type’ response.

The recognition of stroke symptoms by the public and activation of the EMS are the most important factors in instigating pre-hospital stroke care (Evenson et al. 2001) and this was recognised within the focus group discussion. Therefore, the importance of dialling 999 should be emphasised any stroke awareness interventions.

Limitations

A convenience sample was used to identify participants and some groups were not adequately represented, these included participants from ethnic minority groups who were not represented ‘in person’. However, there were two representatives from a patient charity that advocates for stroke patients. Focus groups have been criticised for reporting unrepresentative data from small group discussions (Tuck, 1976). This criticism is often applied to any qualitative research method that does not involve large samples (Tuck, 1976). The findings only represent the views and experiences of the focus group participants but provide important information with which to inform the development of a new stroke awareness intervention.

It can be argued that focus groups do not reflect reality but rather the process of developing a group perspective within a specific group of people (Reed and Payton, 1997). However, the participants who took part in the focus group all had either personal or professional experience of stroke and therefore, it was felt that their views would not differ significantly outside of the focus group context.

4.7 Conclusion

The aim of this phase was to explore the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. A focus group revealed four themes in relation to the format in which information should be provided: information should be suitable for different groups; information should be informed by stroke survivors; messages should be simple; messages should be conveyed through pictures and images. Four further themes, around the content of public awareness campaigns for stroke also emerged: a range of stroke symptoms should be described; stroke is a medical emergency; treatments for stroke; hope, fear and the consequences of stroke.

The findings from the focus group suggested that the content of any stroke awareness interventions should be simple and suitable for everyone and that simplicity may be facilitated through the use of pictures and images. This would also help to ensure that information could be understood by older people who may have problems with eyesight, people from ethnic minority groups who may not read English, and those who may have poor literacy skills. It was also suggested that the format of information should be accessible by a range of people, especially older people who may not be as likely to access information from the internet, via e-mail, or text message (Office for National Statistics, 2009). The findings suggest that key messages within a future intervention should include how to recognise classic stroke symptoms; stroke is a medical emergency; treatments are available for stroke and the importance of contacting the EMS.

This study has a number of limitations mainly due to the small convenience sample which limits the generalizability of the findings from the focus group. However, the results of the focus group provided important suggestions on the key messages and format of information to be included in future stroke awareness interventions.

The following chapter will describe the development, implementation and evaluation of an intervention, which has been under-pinned by the theoretical framework developed in Phase Two and focus group findings from this phase. The purpose of the intervention is to improve help seeking behaviour at the onset of stroke, in a high risk population. Assessment of the potential effectiveness of the intervention will be discussed in relation to its impact on utilisation of the EMS and time from onset to medical help sought. An exploration of (patient and carer) information needs via semi-structured interviews will also be described and discussed.

CHAPTER FIVE

PHASE FOUR – THE DEVELOPMENT AND IMPLMENTATION OF A TARGETED INTERVENTION DESIGNED TO INFLUENCE THE HELP SEEKING BEHAVIOUR AFTER STROKE AND TIA:

A PILOT STUDY

5.1 Introduction

The previous chapter outlined the data collection and analysis of a focus group, the aim of the focus group was to explore the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. The findings from the focus group suggested that the key considerations for any new stroke awareness interventions should be simplicity of format and presentation, the use of pictures and images and messages that are clear and easily understood by everyone. The key considerations in terms of content were the recognition of stroke symptoms, stroke as a medical emergency, making the public aware that treatments are available for stroke and the importance of contacting the EMS.

The findings reported so far in this thesis have been used to inform the development of a new intervention aimed improving help seeking behaviour at the onset of stroke symptoms. This phase will begin by outlining the development of the intervention. The later sections (from 5.3) will describe the methods used and the setting in which the implementation and evaluation of the intervention took place. A summary of the practical and ethical issues will then be discussed. Details of both the delivery of the intervention and follow-up of participants will then be outlined. The main findings will be reported and compared with previous research. Finally, the main strengths and limitations will be identified.

5.2 The Development of the Intervention

The theoretical framework developed in Phase Two (Figure 3.6) and focus group findings in Phase Three have been used to inform the content and format of a new intervention. The intervention has been designed to raise awareness of stroke and encourage people to seek immediate help from the EMS. The development of the intervention will now be described.

A five-stage theoretical framework that reflects the decision-making process for seeking help after stroke was developed in Phase Two (Figure 3.6). Stage One of this framework focussed on knowledge of stroke symptoms, because in order to initiate help seeking behaviour, symptoms must be recognised. Evidence in the literature also suggests that increasing awareness and knowledge is the first step in changing behaviour (Prochaska and Velicer, 1997). The patients and carers in the focus group suggested, that based on their own experiences, a range of stroke symptoms beyond those included in the FAST campaign should be included within the new intervention. However, the other focus group members suggested that messages would be lost if an intervention listed all the possible symptoms that could occur. Because the FAST campaign has recently been used by both the Stroke Association and DoH within their public awareness campaigns, the FAST symptoms will be included in the new intervention. Whilst it is acknowledged that the symptoms of stroke may vary, it is not practical to list all stroke symptoms within an intervention, because this may dilute the message around the main symptoms that are most likely to be experienced. Therefore, the FAST leaflet produced by the DoH will be included within the intervention to increase awareness of classic stroke symptoms.

Perceiving symptoms to be serious appeared to be a major factor in initiating help seeking behaviour amongst the participants who took part in semi-structured interviews. Therefore, perceived seriousness formed Stage Two of the theoretical framework (Figure 3.6). For some of the interview participants the realisation that symptoms were serious and therefore required an emergency response, may have been the only factors that influenced them to seek medical help. The focus group members in Phase Three felt that stroke symptoms should be taken seriously and the message that stroke is a medical emergency should be emphasised. Therefore, the message that stroke is a medical emergency has been included within the intervention.

Although some of the interview participants in Phase Two described knowing that they should get to hospital quickly, few knew why. The focus group members felt that the public may not be aware of the consequences of a stroke and that severe disability and death were real consequences of not seeking immediate medical help. Therefore, the message that time lost, is brain lost, has been included within the new intervention.

During the Phase Two interviews only one participant was aware of the treatments that are available for stroke patients in hospital. Therefore, knowledge of treatments for stroke was not included within the theoretical framework (Figure 3.6). However, the focus group members felt that it was important for the public to know about treatments that are available for stroke. This also linked to the focus group discussion around hope and fear. Focus Group members felt that if treatments for stroke were widely known, this may influence people in their decision to seek medical help more quickly. The group felt that the general attitude amongst the public was that after a stroke not much could be done. The intervention has therefore, included the message that treatments are available for stroke.

For some, the onset of stroke symptoms triggered an emotional response such as fear panic or embarrassment, this is reflected in Stage Three of the theoretical framework (Figure 3.6). During the semi-structured interviews it became apparent that the emotional reaction to the onset of stroke symptoms could also influence help seeking behaviour. Negative emotions such as panic and fear were more likely to prompt initiation of the EMS, whereas negative emotions such as embarrassment often resulted in avoidance of the EMS. Therefore, the intervention has included a message around how people may feel when stroke is suspected.

Stage Four of the theoretical framework is about help seeking behaviour because participants sought medical help from a variety sources, including; EMS, GP, NHS Direct, and A&E. Contacting the EMS for suspected stroke is suggested as being the single most important factor in the rapid triage and treatment of acute stroke patients (Kothari et al. 1997; Williams et al. 1997; Menon et al. 1998; Rosamond et al. 1998; Morris et al. 2000). The focus group members emphasised that stroke is a medical emergency for which people should contact the EMS. Therefore the importance of dialling 999 is a key message within the intervention.

There are a number of strategies through which health information can be disseminated (Evans, 2006). Over recent years the dissemination of health information has changed, becoming more dynamic, through the utilisation of multi-modal models of communication (Evans, 2006). Social marketing is a strategy that uses a variety of approaches such as mediation (through a health care provider), message placement (for example in clinics) and community level outreach (Evans, 2006). Social marketing often involves the delivery of key messages to a targeted or segmented audience (Evans, 2006).

The social marketing wheel (see Figure 5.1 below) has been used to guide the development, pre-testing, implementation and effectiveness of the new intervention.

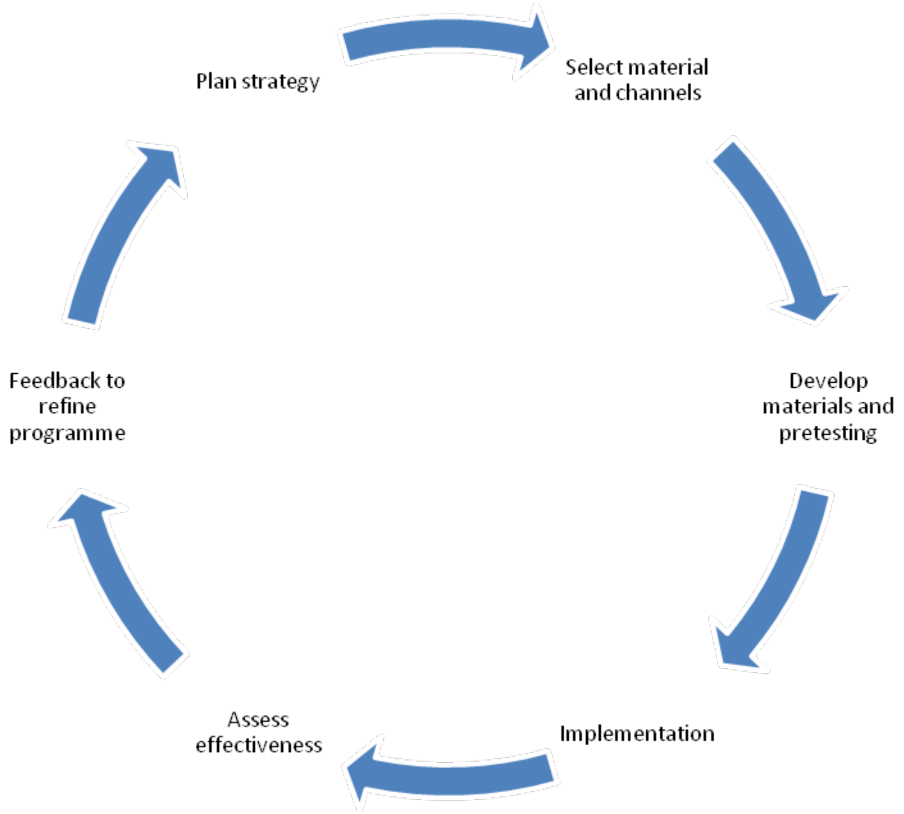

Figure 5.1. Social marketing wheel (Evans, 2006).

The next sections describe how the development of the intervention fits within the stages of the social marketing wheel.

Plan Strategy

Recent research has suggested that interventions may need to be targeted at those at highest risk of stroke, as this may improve help seeking behaviour but may also be the most beneficial use of resources (Dracup et al. 1997). Therefore, the Phase Four study has been designed around an intervention that will be implemented using a targeted, message placement approach (Evans, 2006). This will involve delivery of the intervention within a TIA clinic setting, in order to target patients at higher risk of stroke.

Select Material and Channels

There are numerous approaches and channels through which public awareness campaigns have been targeted. One channel is through mass media campaigns, which have had mixed success within stroke. A public awareness campaign undertaken in the USA did not improve the public's knowledge of stroke (Kleindorfer et al. 2009) and a multimedia campaign in Germany also failed to improve knowledge of stroke symptoms (Marx et al. 2008). One of the main criticisms of these campaigns has been that messages were not targeted to any specific groups within the population. Mass media campaigns can be costly (Lecouturier et al. 2010) and the cost-effectiveness of mass media campaigns in stroke has yet to be addressed. Furthermore, no mass media campaigns have improved the numbers of stroke patients contacting the EMS over a sustained period, nor have any reduced the time delay from onset to presentation at hospital.

A further limitation in relation to mass media campaigns is that they can often be viewed as entertainment, rather than a medium for imparting information that should be retained and acted upon (Caldwell and Miaskowski, 2002). Also at any one time there may be a number of health related mass media campaigns, competing with each other and diluting the messages conveyed (Caldwell and Miaskowski, 2002). Mass media campaigns may only convey the same message regardless of the specific needs of the audience that it reaches. The messages are often impersonal and do not equip individuals with the skills to affect behaviour change or action (Caldwell and Miaskowski, 2002).

However, a national campaign in the Netherlands which included targeting individuals by distributing leaflets to individual households resulted in an increased level of stroke knowledge (van Leijden et al. 2009) and further studies reported that the public have an interest in receiving information about stroke (Morgan et al. 2005; Weltermann et al. 2003). The preferred format for stroke information was identified as being leaflets (44%) in one study (Mikulik et al. 2008) and health professionals (32%) or leaflets (34%) in a further study (Weltermann et al. 2003).

A mass media campaign would not be viable within the context of a PhD thesis and there is limited evidence to suggest that this approach would be successful in improving the response to stroke symptoms (Caldwell and Miaskowski, 2002; Marx et al. 2008). Based on the results of this thesis so far and the findings from previous research, a more targeted approach is recommended (ESO, 2009; van Leijden et al. 2009; Fussman et al. 2010). Therefore, the Phase Four study will involve the development of a leaflet that will be given to patients and carers attending a TIA clinic who are at higher risk of stroke than the general population.

The focus group members suggested that older people may be unlikely to access information via the Internet, e-mail or text message and so a more traditional approach was taken. Leaflets are relatively easy and cheap to produce (Albert and Chadwick, 1992) and may be the most appropriate format of information given that the average age of patients attending the TIA clinic is over 70. The focus group suggested that key considerations for any new stroke awareness intervention should be simplicity of format and presentation and that simplicity and suitability may be facilitated through the use of pictures and images. The focus group emphasised the importance of messages that are clear and easily understood.

A leaflet was chosen as the most appropriate format to provide key stroke messages because there is evidence to suggest that leaflets can be a valuable information tool, especially when reinforced by verbal messages (Mumford, 1997). The disadvantage of using leaflets is that patients are overloaded with leaflets in most NHS clinics and waiting areas (Robertson et al. 2002). However, it is hoped that the patients' heightened awareness of stroke and TIA will make the messages within the leaflet more relevant to them. These messages will also be reinforced by a TIA nurse, who will read through the leaflet with each patient and then will give patients a copy of the leaflet to take home. A copy of the leaflet can be found in Appendix 16.

Develop Materials and Pre-testing

The focus group in Phase Three provided the opportunity to explore the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. From the focus group discussion it was suggested that the format of the messages within the intervention should be simple, easily understood by a range of people and that the use of pictures and images may help to achieve this. It was also suggested that the content of the intervention should include key messages about the importance of how to recognise stroke symptoms, stroke as a medical emergency, as well as making the public aware that treatments are available for stroke and that they should contact the EMS.

Prior to implementation of the intervention, feedback was gained regarding the format and content of the leaflet. The leaflet was produced with a range of different background colours and fonts. Health professionals with specific expertise in conditions such as aphasia were asked to suggest improvements or revisions. Focus group members and health professionals were again asked for their opinions in selecting the most user friendly versions and the leaflet was adapted accordingly.

Health literacy can be an important component in enabling patients to understand and modify behaviour based on exposure to health messages (McCray, 2005). Health literacy has a number of components including, interactive literacy whereby an individual has the ability to translate text into meaningful information and critical literacy, which enables information to be acted upon (Nutbeam, 2000). Health literacy is important to consider, given that 20% of the UK population have the lowest levels of adult literacy (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999).

A key aspect of health literacy is ensuring that written information is developed with a readability level that is appropriate for the target population. The most commonly used readability measurement tool is the Flesch ease of reading test (Flesch, 1948). The test provides a score that indicates the comprehension difficulty of written text. The higher the score the easier the text is to read. The test was performed on the leaflet to ensure that the word and sentence length were appropriate, given the target audience. The leaflet scored 69.3, at the top range of a suggested score of between 60 and 70.

Implementation

The intervention was implemented through a weekday, consultant-led TIA clinic at an acute hospital trust in Lancashire: around 1,000 patients attend the TIA clinic on an annual basis. Of patients attending a TIA clinic approximately 55% will have a diagnosis of stroke or TIA (Birns et al. 2006; Giles and Rothwell, 2007; Murray et al. 2007). Of patients diagnosed with a TIA, it has been estimated that a stroke or recurrent TIA will occur in between 10-20% of patients by three months (Johnston et al. 2000; Coull et al. 2004; Eliasziw et al. 2004). This is more than twice the risk of myocardial infarction or death in patients presenting with acute coronary syndromes (Johnston, 2007). Although only about 50% of patients referred to TIA clinics have a confirmed diagnosis of stroke or TIA (Rothwell et al. 2005) other patients attending the clinic may also have a number of risk factors that are associated with an increased risk of stroke or TIA such as hypertension or atrial fibrillation (Wolf et al. 1991; Wolf et al. 1992).

A consecutive sample of patients who attended the clinic were provided with the leaflet, the content of which was explained by a TIA nurse, who then gave the patient the leaflet to take home. For South Asian patients whose first language was not English a TIA nurse translated the content of the leaflet into Gujarati, Urdu or Hindi.

Assess Effectiveness (Pilot Testing)

The effectiveness of the intervention was assessed three months after receipt of the leaflet, which patients had received when they attended the TIA clinic. Patient data were collected on the type of help sought (GP, A&E, EMS) and time from onset to seeking help. Qualitative interviews explored in-depth any impact that the intervention may have had on help seeking behaviour. Interviews also took place with patients who did not receive the intervention, to explore their experiences and information needs.

Feedback to Refine Programme

If this intervention demonstrates potential effectiveness by increasing utilisation of the EMS or reducing delays, it is hoped that the intervention will be tested in a larger scale and potentially definitive study. Before any further testing the results of the semi-structured interviews will be explored to determine if the intervention needs to be adapted, if for example, specific recommendations have been made in relation to the key messages or format. Ultimately if the intervention demonstrates effectiveness in a definitive study then it could be implemented into practice.

The following sections of this chapter will describe the Phase Four study, which involves the implementation and evaluation of the intervention designed to improve help seeking behaviour in a high risk population. The potential effectiveness of the intervention will be measured by assessing utilisation of the EMS and time from onset to seeking medical help in those people who have a subsequent stroke or TIA. In those who do experience a subsequent stroke or TIA, semi-structured interviews will explore the impact of the intervention on action taken, as well as information needs.

5.3 Methods

Where possible the Consolidated Standards of Reporting Trials (CONSORT) Statement (Schulz et al. 2010), which is an evidence-based, minimum set of recommendations for reporting randomised controlled trials (RCTs), has been used to inform the reporting and interpretation of the findings in this phase. However, as CONSORT is designed as a tool to aid the reporting of RCTs not every item within the CONSORT checklist is applicable to this study.

Aim

To explore the potential effectiveness of a targeted intervention in people at risk of stroke by assessing the impact of the intervention on utilisation of the EMS and time from onset to medical help sought.

Specific objectives are:

- Identify people at risk of stroke and allocate them to intervention and control groups.
- Provide usual care to one group and the previously developed intervention to the other.

At three months:

- Identify people in the intervention and control groups who have had a subsequent stroke or TIA.
- Of the people who have had a stroke or TIA, identify action and time taken to access health services.
- Compare actions and times between groups.
- Through qualitative interviews in both groups, explore what action was taken and the factors that influenced actions.
- Through qualitative interviews in both groups, explore satisfaction with information provision.

Ethical Issues

Ethical approval for this phase was sought from the Local Research Ethics Committee but upon review by the committee, approval was not required (see Appendix 17). Faculty of Health Ethics Committee at the University of Central Lancashire was sought and granted (see Appendix 18). Research and Development approval at the Acute Trust in which this phase took place was not required but a letter of access was obtained (see Appendix 19).

Providing patients and carers with additional information about stroke and TIA is important and should reflect how the intervention could be delivered in future clinical practice. Therefore, the intervention was provided during the TIA clinic by a TIA nurse. If any intervention is to be delivered in future clinical practice then it must be delivered at the most appropriate time for both the patient and members of the clinical team

5.4 Design

A mixed methods study.

Setting

Consultant-led TIA clinic at one acute hospital trust.

Subjects and Sampling

Patients were identified from a consecutive sample of patients attending any of the TIA clinics at an acute trust in the North West of England.

Inclusion criteria: patients (and carers) attending a TIA clinic; 18 years or older.

Exclusion criteria: patients who had severe cognitive or communication problems as identified by a consultant and who did not have a carer (defined as a relative).

Intervention

The intervention consisted of a leaflet that was designed to improve help seeking behaviour after stroke and TIA. The content of the leaflet was explained by a TIA nurse, who gave the patient a copy of the leaflet to take home.

Outcomes

Primary

1. Utilisation of the EMS rather than other routes of access to health care, by participants who had a subsequent stroke or TIA.

Secondary

1. Time from onset of symptoms to contact with the EMS in participants who have a subsequent stroke or TIA.
2. Views on actions taken and the factors that influenced actions.
3. Satisfaction with information provision.

Sample Size

Of patients attending a TIA clinic approximately 55% will have a diagnosis of stroke or TIA (Birns et al. 2006; Giles and Rothwell, 2007; Murray et al. 2007). Of patients diagnosed with a TIA, it is estimated that a stroke or recurrent TIA will occur in between 10-20% of patients by three months (Johnston et al. 2000; Coull et al. 2004; Eliasziw et al. 2004). Using these estimates, it was calculated that recruiting 400 consecutive patients attending a TIA clinic we would identify approximately 200 with a stroke or TIA, of whom around 20-40 would have a subsequent stroke or TIA. If there are 200 participants in two groups there would be between 10-20 events in each group, which would be sufficient to provide an indication of the potential effectiveness of the intervention.

At the study site between 1,000 and 1,100 patients attend the TIA clinics each year, equating to twenty patients per week. A sample size of 400 means recruiting participants over approximately a 20 week period.

5.5 Procedure

Intervention – Stage 1

Control Group

Patients who attended the TIA clinic over a 24 week period were identified by a TIA nurse. At the time of data collection, information about each patient was routinely recorded in the TIA register, this information is described in further detail in the section below, entitled ‘baseline data collection’. These patients received usual care which consisted of no written information about the symptoms of stroke or TIA. Patients received written information about medication only. Patients may have been told verbally about the signs and symptoms of stroke by individual staff members and the need to contact the EMS, but this practice was not standardised.

Intervention Group

After the control group had been identified, a further group of consecutive patients were recruited over a 24 week period. In addition to usual care, these patients received the intervention which was an information leaflet that the TIA nurse talked through with the patient. The TIA nurse highlighted the important signs and symptoms of stroke or recurrent TIA and emphasised the need to contact the EMS if these symptoms were suspected in the future. The TIA nurse also described the emotional response that may be experienced but reinforced that treatments were available for stroke in hospital. The patient was then given the leaflet to take home.

Baseline Data Collection

For the participants in both the control and intervention groups casemix data were retrieved from the TIA register. This included: demographics (age, sex, ethnicity), date and time of symptom onset; symptoms experienced, date and time of first contact for medical help (i.e. GP, NHS Direct, EMS, self-presentation to an A&E Department and clinical diagnosis. Type of first medical help was recorded from the TIA register, where possible this was cross matched with patients' hospital records. If there were any discrepancies the information on the hospital computer system was used.

Outcome Assessment

At three months post-baseline, hospital records were checked for any subsequent admissions or A&E presentations in the three month period following attendance at the TIA clinic. If a patient had a confirmed clinical diagnosis of a subsequent stroke or TIA, details of the admission (or attendance at A&E if not admitted) were recorded. Data were collected from the patients' case notes and hospital computer system and included: previous medical history, date and time of symptom onset, first contact for medical help, arrival mode to hospital, date and time of admission and final diagnosis.

Interview Data

For patients who had had a subsequent stroke or TIA, status was checked with their GP to ensure that potential participants were not contacted inappropriately. Potential participants were then contacted by the author to ask if they would like to take part in a face-to-face interview. Participants were also given the opportunity to ask any questions about this phase. If participants agreed, they were sent the participant information sheet (Appendix 20). The author contacted potential participants one week later to confirm if they would still like to take part and if so, to arrange an interview at their home. At this stage potential participants were again given the opportunity to ask questions about this phase. Informed consent was obtained by the author prior to any interviews taking place. If a patient had severe communication or cognitive difficulties, which would prevent them from taking part in an interview, their carer was invited to participate. The semi-structured interviews were based on an interview guide (Appendix 21). Questions focussed on the symptoms that the patient had experienced, who they had contacted for help and why, as well as exploring the information that they had received at the TIA clinic and from other sources.

5.6 Data Analysis

Clinical Data

The baseline and outcome assessment data were analysed for both the control and intervention groups. A comparison of the data between groups was then made at the same two time points. Demographic and diagnostic information were analysed, on type of medical help sought (i.e. EMS, GP, private transport) followed by time from onset to first medical help sought. Onset times and times that medical help was sought were poorly documented in both the TIA register and patient case notes. This meant that the analysis around the time data have been presented in days, as these data were more readily available. Participants in both the control and intervention groups were categorised by age (under 65 years, 65 years or older), in line with previous research which has assessed stroke knowledge and help seeking behaviour (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008).

Data on utilisation of the EMS and time from onset to first medical help sought were compared between the control and intervention groups at three months. Although there were a number of patients who had a subsequent admission to hospital for non- stroke conditions, the focus of the analysis was based on those patients who had a subsequent stroke or TIA. The groups were compared using descriptive rather than inferential analyses. Categorical data (e.g. sex, diagnosis) were described with counts and percentages. Interval (e.g. time from onset to seeking help) and ratio data (e.g. age) were described using medians and inter-quartile ranges. At outcome assessment where direct comparisons of the control and intervention group have been made, the difference between groups and associated 95% confidence intervals have been reported.

Interview Data

All interviews were digitally recorded. The interview recordings were transcribed verbatim and were read through a number of times. Content analysis (facilitated by Atlas ti. software) was used to analyse the data line by line. Following the coding of the first few interviews the codes were clustered into categories. Constant comparison (Strauss and Corbin, 1998) was then used to analyse the remaining data. During constant comparison, codes were compared with phases of the theoretical framework developed in Phase Two, (Figure 3.6) to develop an overall analytical framework. Where possible, the categories were mapped onto the existing theoretical framework. As questions about information provision were specific to this phase, the results relating to this category will not be included within the theoretical framework but will be discussed separately.

To ensure data credibility a selection of the transcriptions were also coded by another researcher. A good level of agreement was reached between the author and the other researcher, any differences in coding were discussed until a consensus was reached.

The findings from each interview were summarised into bullet points and sent to each participant for confirmation that these represented their main views and experiences. Nearly all participants felt that the summaries were an accurate reflection of their experiences. However, one participant wanted to add to their summary, when this had been carried out, the transcription was re-coded, the additional comments did not generate any further codes. The findings from both the clinical and interview data will now be presented.

5.7 Results

In this phase the main findings from Phase Four will be presented. The baseline characteristics of the control group will be presented followed by the baseline characteristics of the intervention group. The outcome assessment data for the control and intervention groups will then be reported. A comparison of the control and intervention group data will then be made at both baseline and three months, this will only be compared for those patients who went on to have a second stroke or TIA. The interview data for both groups will then be presented, this will begin with details about the recruitment of participants and will include demographic information. Analysis of the data will be mapped to the theoretical framework that was developed in Phase Two (Figure 3.6).

Participant Recruitment

A flow diagram of recruitment and assessment can be seen in Figure 5.2. Two hundred control group participants were recruited consecutively from 12th March to 15th September 2010. A further 200 consecutive participants were recruited to the intervention group between 16th September 2010 and 3rd March 2011. Following the collection of baseline and three month outcome assessment data, any patients who were identified as having had a subsequent stroke or TIA were invited to take part in an interview.

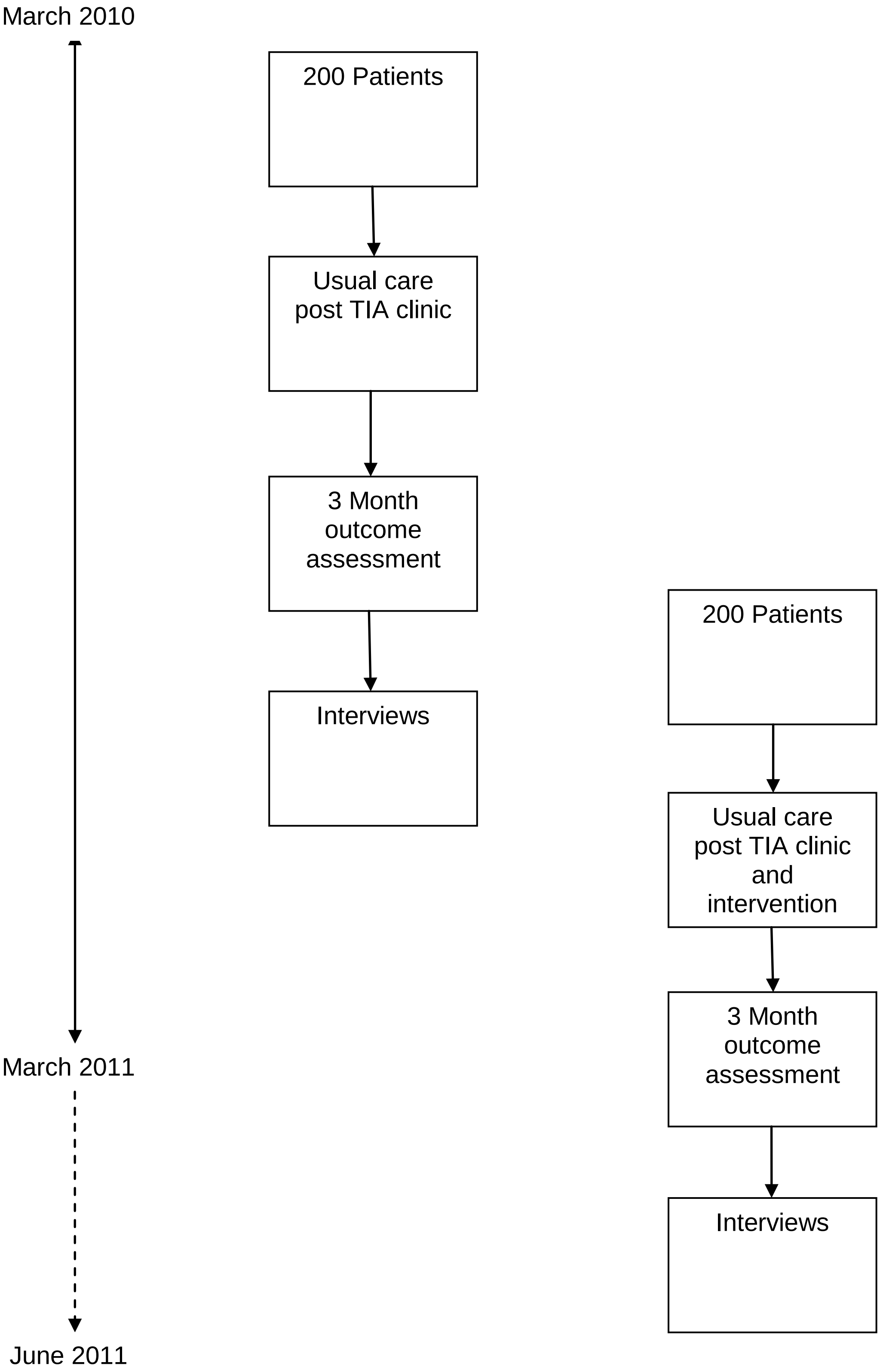

Figure 5.2. Flow diagram of participant recruitment

Baseline Characteristics

Table 5.1. Participant characteristics at baseline. Figures are n (%) unless otherwise stated.

Characteristics	Control Group N=200	Intervention Group N=200
Median Age (IQR)	71 (58 to 79)	73 (59 to 80)
Age ≥ 65	123 (62)	134 (67)
Female	96 (48)	111 (56)
Ethnicity		
White British	188 (94)	191 (96)
South Asian	8 (4)	3 (2)
Black Caribbean	3 (2)	3 (2)
White European	1 (0)	1 (0)
Chinese	0 (0)	1 (0)
Hispanic	0 (0)	1 (0)

IQR = interquartile range

The median age was similar in both groups, with a higher proportion of females in the intervention group. Similar proportions of participants were White British with small numbers of patients representing ethnic minority groups.

Diagnosis at Baseline TIA Clinic Attendance (Control Group and Intervention Groups)

The diagnosis for participants attending the TIA clinic can be found in Table 5.2. A slightly larger proportion of patients had a diagnosis of stroke or TIA in the intervention group (134 [67%]), compared to the control group (123 ([62%]). Median age in both groups for participants with a final diagnosis of stroke or TIA was 71 years (IQR, 59 to 80).

Table 5.2. Diagnosis for participants attending the TIA clinic. Figures are n (%)

Diagnosis	**Control Group N=200**	**Intervention Group N=200**
Stroke	26 (13)	47 (24)
TIA	97 (49)	87 (44)
Other	73 (36)	61 (30)
Missing	4 (2)	5 (2)

Of the control group participants 73 (36%) had a recorded diagnosis other than stroke or TIA and of the intervention group participants 61 (30%) had a recorded diagnosis other than stroke or TIA. Details of the other diagnoses for participants attending the TIA clinic are shown in Table 5.3.

Table 5.3. Other diagnoses for participants attending the TIA clinic. Figures are n (%)

Diagnosis	**Control Group N=73**	**Intervention Group N=61**
Syncope	27 (37)	24 (40)
Migraine	8 (11)	3 (5)
Transient Global Amnesia	4 (5)	5 (8)
Seizures	5 (7)	5 (8)
Dementia	3 (4)	2 (3)
Functional Presentation	2 (3)	0 (0)
Depression	2 (3)	0 (0)
Other*	22 (30)	22 (36)

* The diagnosis of other included: hypoglycaemia, falls, Parkinson’s disease, macular degeneration, cerebral tremor, vertigo, hypotension, atrial fibrillation, anxiety, confusion and chronic vascular disease.

Symptoms

Symptoms experienced at the time of onset were not well documented. Of the participants in the control group who had a diagnosis of stroke or TIA only 39 (32%) had any symptoms documented in the TIA register, as did only 31 (23%) participants in the intervention group. The majority of stroke and TIA participants in both groups had paralysis or weakness, sensory or speech problems (Table 5.4).

Table 5.4. Symptoms experienced at baseline. Figures are n (%)

Symptoms	Control Group* N=39	Intervention Group* N=31
Paralysis or limb weakness	19 (49)	16 (52)
Sensory problems	5 (13)	1 (3)
Speech problems	5 (13)	5 (16)
Speech problems and limb weakness	3 (8)	4 (13)
Facial weakness	2 (5)	1 (3)
Sensory problems and limb weakness	1 (2)	1 (3)
Speech problems and facial weakness	1 (2)	1 (3)
Speech and visual problems	1 (2)	1 (3)
Visual problems	1 (2)	1 (3)
Migraine	1 (2)	0 (0)

*Column percentages do not add up to 100 because of rounding.

First Medical Help Sought

First Medical Help Sought (Control Group)

Table 5.5 below shows a cross tabulation of participant diagnosis and first medical help sought. Following the onset of symptoms participants' first medical help was most commonly sought from a GP (118 participants, 59%). The proportion of participants seeking first medical help from a GP was highest among the 22 (85%) participants who had a final diagnosis of stroke (Table 5.5).

Table 5.5. Cross tabulation of first medical help sought and final diagnosis (control group). Figures are n (%)

Diagnosis	GP	EMS	Private Transport	A&E	Missing	Total
Stroke	22 (84)	2 (8)	1 (4)	1 (4)	0 (0)	26 (100)
TIA	53 (55)	22 (23)	17 (17)	4 (4)	1 (1)	97 100)
Other	41 (56)	18 (25)	9 (12)	1 (1)	4 (6)	73 (100)
Missing	2 (50)	1 (25)	0 (0)	0 (0)	1 (25)	4 (100)
Total	118 (59)	43 (22)	27 (13)	6 (3)	6 (3)	200 (100)

First Medical Help Sought (Intervention Group)

As in the control group, first medical help was most commonly sought from a GP (118, 47%). Again, the proportion of participants seeking first medical help from a GP was highest among the 26 (55%) participants who had a final diagnosis of stroke (Table 5.6).

Table 5.6. Cross tabulation of first medical help sought and final diagnosis (intervention group). Figures are n (%)

Diagnosis	**GP**	**EMS**	**Private Transport**	**A&E**	**Missing**	**Total**
Stroke	26 (55)	12 (26)	6 (13)	0 (0)	3 (6)	47 (100)
TIA	36 (41)	26 (30)	19 (22)	0 (0)	6 (7)	87 (100)
Other	30 (48)	23 (36)	6 (9)	1 (2)	3 (5)	63 (100)
Missing*	1 (33)	1 (33)	1 (33)	0 (0)	0 (0)	3 (100)
Total	93 (47)	62 (31)	32 (16)	1 (0)	12 (6)	200 (100)

*Row percentages do not add up to 100 because of rounding.

First Medical Help Sought and Age (Control Group)

Amongst control group participants, first medical help sought was compared with age (irrespective of diagnosis) in both participants aged under 65 years or aged 65 years and over. The proportions of participants seeking help from a GP were slightly higher in the older age group (62% versus 55%) (Table 5.7).

Table 5.7. Cross tabulation of first medical help sought and age group (control group). Figures are n (%)

Age Group	**GP**	**EMS**	**Private Transport**	**A&E**	**Missing**	**Total**
Under 65	42 (55)	13 (17)	19 (25)	1 (1)	2 (2)	77 (100)
65 or over	76 (62)	30 (24)	8 (7)	5 (4)	4 (3)	123 (100)
Total	118 (59)	43 (22)	27 (13)	6 (3)	6 (3)	200 (100)

First Medical Help Sought and Age (Intervention Group)

When comparing age with first medical contact in the intervention group, in both participants aged under 65 years or aged 65 years and over, the most common source of first medical help was from a GP. The proportions of participants seeking help from a GP were higher in the older age group (51% versus 38%) (Table 5.8).

Table 5.8. Cross tabulation of first medical help sought and age group (intervention group). Figures are n (%)

Age Group	**GP**	**EMS**	**Private Transport**	**A&E**	**Missing**	**Total**
Under 65	25 (38)	18 (27)	16 (24)	0 (0)	7 (11)	66 (100)
65 or over	68 (51)	44 (33)	16 (12)	1 (1)	5 (3)	134 (100)
Total	93 (46)	62 (31)	32 (16)	1 (1)	12 (6)	200 (100)

Time from Symptom Onset to First Medical Help Sought (Control and Intervention Groups)

In the control group time of onset was recorded for 191 (96%) participants and time of first medical help was recorded for 196 (98%). Time from onset to first help sought ranged from 0 to 34 days. Over half of all participants sought help within 24 hours (Table 5.9). In the intervention group time of onset was recorded for 184 (92%) participants and time of first help sought was recorded for 193 (97%). Time of onset and time of first help sought was documented for 184 (92%) participants. Time from onset to first help sought ranged from 0 to 41 days. A higher proportion of participants in the intervention group sought help on the same day compared to the control group (65% versus 51%) (Table 5.9).

Table 5.9. Time from onset to first medical help sought. Figures are n (%)

Time from onset to help sought	**Control Group N=200**	**Intervention Group N=200**
Within 24 hours	102 (51)	129 (65)
Within 7 days	68 (34)	32 (16)
Within 14 days	10 (5)	11 (6)
Within 1 month	6 (3)	9 (4)
Over 1 month	5 (2)	3 (1)
Not documented	9 (5)	16 (8)

Outcome Assessment (Control and Intervention Groups)

Of the 200 participants in the control group who attended the TIA clinic 29 (15%) were admitted to hospital at least once within the subsequent three months. Of the 29 participants, 10 had a final diagnosis of stroke or TIA, the characteristics of these participants can be seen in table 5.10. Of the 200 participants in the intervention group, 30 (15%) were re-admitted to hospital. Of those 30 participants, 14 (47%) had a final diagnosis of stroke or TIA, Table 5.10 shows participant characteristics. Participants in both the control and intervention groups who were re-admitted to hospital with a diagnosis of stroke or TIA, all had a diagnosis of stroke or TIA when seen previously at the TIA clinic.

Table 5.10. Participant characteristics at outcome assessment

Characteristics	**Control Group N=10**	**Intervention Group N=14**
Median Age (IQR)	76 (58 to 92)	71 (64 to 78)
Female	5 (50)	10 (71)
Ethnicity		
White British	10 (100)	11 (79)
South Asian	0 (0)	2 (14)
Hispanic	0 (0)	1 (7)
Stroke	8 (80)	2 (14)
TIA	2 (20)	12 (86)

IQR = interquartile range

Symptoms at outcome assessment

The majority of participants in both the control and intervention groups with a diagnosis of stroke or TIA had paralysis or limb weakness or speech problems combined with limb weakness (Table 5.11)

Table 5.11 Symptoms experienced when participants had a subsequent event

Symptoms	**Control Group N=10**	**Intervention Group* N=14**
Paralysis or limb weakness	4 (40)	3 (21)
Speech problems	0 (0)	2 (14)
Speech problems and limb weakness	3 (30)	6 (43)
Speech problems and memory loss	1 (10)	0 (0)
Leaning to one side and sleepy	1 (10)	0 (0)
Collapsed	1 (10)	0 (0)
Visual problems and limb weakness	0 (0)	1 (7)
Visual problems	0 (0)	1 (7)
Headache	0 (0)	1 (7)

*Column percentages do not add up to 100 because of rounding.

First Medical Help Sought at the Onset of Second Stroke or TIA (Control Group)

Table 5.12 shows the medical help that was sought initially and when participants in the control group experienced a subsequent stroke or TIA. When 10 participants experienced a second stroke or TIA, six (60%) contacted a GP. The same six participants had also contacted a GP when they had their initial stroke or TIA. Two participants who had previously contacted the EMS when they had their initial stroke did so again. Only two participants changed their behaviour, one who had contacted their GP initially went directly to A&E. A further participant, who had initially contacted the EMS, went direct to A&E when they experienced a subsequent event.

Table 5.12. Cross tabulation of number of stroke and TIA participants seeking medical help at baseline and at 3 months post-stroke (control group)

Baseline	**3 months**		
	GP	**A&E**	**EMS**
GP	6	1	0
A&E	0	0	0
EMS	0	1	2

First Medical Help Sought at Onset of Second Stroke or TIA (Intervention Group)

Table 5.13 shows the medical help that was sought initially and when intervention group participants experienced a subsequent stroke or TIA. All six (43%) participants who had sought initial medical help from their GP either went directly to A&E or contacted the EMS on their subsequent admission. The help seeking behaviour of three participants who had initially gone directly to A&E also improved as they contacted the EMS when they experienced a second event.

Table 5.13. Cross tabulation of number of stroke and TIA participants seeking help at baseline and at three months post-stroke (intervention group)

Baseline	**3 months**		
	GP	**A&E**	**EMS**
GP	0	2	4
A&E	0	0	3
EMS	0	1	4

Time from Symptom Onset to First Medical Help Sought

Of the control group participants who had a subsequent stroke or TIA, seven (70%) participants sought help within 24 hours, compared to eight (80%) at baseline. The remaining three participants (30%) sought medical help within seven days. In the intervention group nine participants (64%) sought help within 24 hours compared to 7 (50%) at baseline, the remaining five participants (36%) sought help within seven days.

Comparison of the Control and Intervention Groups at Baseline and at Outcome Assessment, Three Months Post First Stroke or TIA.

Table 5.14 compares the help seeking behaviour of the control and intervention groups at outcome assessment. There was a significant difference in the number of participants contacting a GP for a subsequent stroke or TIA between the intervention and control group participants. None of the intervention group participants sought help from a GP when they had a subsequent event, whilst the proportion of participants in the control group still seeking help from a GP remained unchanged. There was also a significant difference in the number of participants seeking help from the EMS between the control and intervention groups. There was no significant difference between groups in the numbers of participants going directly to A&E or in seeking help within 24 hours.

Table 5.14. A comparison of the control and intervention groups at outcome assessment, for those participants who went on to have a second stroke or TIA within 3 months.

Participant characteristics, medical help sought, final diagnosis	**Outcome assessment (following second stroke/TIA)**		
	Control group n=10	**Intervention group n=14**	**Difference Between Groups (Intervention – Control) [95% CI]**
Medical help sought from:			
GP n (%)	6 (60)	0 (0)	-6 (-60)[-90 to -30]*
EMS n (%)	2 (20)	11 (79)	9 (59)[26 to 91]*
A&E n (%)	2 (20)	3 (21)	1 (1)[-0.3 to 0.3]
Medical help sought within 24 hours n (%)	7 (70)	9 (64)	2 (6)[-44 to 32]

*Significant

Interview Data (Control and Intervention Group)

Participants who had a subsequent stroke or TIA were interviewed at three months, following their initial attendance at the TIA clinic. The recruitment and summary of the participants who took part in semi-structured interviews will now be described, followed by the main results of the semi-structured interviews.

Recruitment and Summary of the Participants

Of the 10 participants in the control group that had a second stroke or TIA, 2 died and 2 did not want to take part in the interviews. Six agreed to be interviewed, including five patients and one carer (patient's sister). Of the 14 participants that had a second stroke or TIA in the intervention group, 2 died, 2 did not want to take part in the interviews, 2 had dementia and no carer and 8 agreed to be interviewed. Demographic information about the participants can be seen in Table 5.15 below. As in Phase Two, the demographic profiles of all the Phase Four participants have been provided in Appendix 22. The profiles provide an insight into the personalities of the participants, their home and work lives, as well as their medical histories and the circumstances in which their stroke symptoms occurred. The help seeking behaviour that was undertaken by each participant has also been described.

Table 5.15. Demographics for the control and intervention group participants

Category	**Participant Information**	
	Control group (n=6)	**Intervention group (n=8)**
Patient	5	8
Carer	1	0
Median Age (IQR)	65 (54 to 74)	72 (64 to 81)
Female	3	5
Urban	6	6
Rural	0	2

Analysis of the data in Phase Two resulted in the development of a theoretical framework that aimed to explain the decision-making process for seeking help after stroke (see figure 3.6). Semi-structured interviews with participants in Phase Four also explored what action was taken and the factors that influenced this, as well as satisfaction with information provision. The data from the Phase Four interviews have been mapped against the theoretical framework and are presented below. As questions about information provision were specific to this phase, the results relating to this category have not been included within the theoretical framework.

Stroke Knowledge (Control Group)

All participants described the symptoms that the patient had experienced and whether they recognised the symptoms as a stroke or TIA. When participants experienced their first stroke or TIA only 1 (17%) participant recognised their symptoms as a stroke.

> "*We [family] were just talking away, chatting away, I started trying to tell them. I knew exactly what I was going to say, what I was going to tell them but it didn't come out, it came out all gobbeldy gook. I tried again... So I just sat quietly. I mean if it was me and I saw someone doing it I would have picked up on it straight away. I knew what it was. I didn't say anything on the day. I ate my lunch got in the car and drove home*." (Female patient, aged 79).

The majority of participants (5, 83%) did not relate their symptoms to a stroke or TIA.

> "*It was just down one side...and my speech went as well.... I didn't know what it was, I didn't have a clue.*" (Female patient, aged 52).

> "*I couldn't get up to turn the television off and I thought, 'oh my leg has gone to sleep'... And I gave it a good rub and no, it wasn't better and I walked over here and walked back and I was still...I was sort of dragging it along the way really, not picking it up properly. It was sort of...I just thought it had gone to sleep. So I walked through to the back kitchen and it was no different, so I came back in here and I sat down and my arm went all floppy. I thought, 'Oh crikey – my arm's gone all funny an'all now.' It goes limp like a ...you can't do anything with it and I thought, 'What am I going to do?' I thought, 'I don't know.*" (Female Patient, aged 70).

> "*I didn't know what it was at all. I didn't know what was wrong with me, I had no idea. I didn't know what happened with a stroke.*" (Female Patient, aged 70).
> "*I first noticed that I couldn't pick up my toast. I have arthritis of the neck and I thought that it was a trapped nerve or something... I'd never heard of it [TIA] before. I thought strokes were when you were incapable and everything but not mini-strokes.*" (Male patient, aged 73).

> "*The first time it happened I had no idea, 'I thought what is this?' I'd never heard of a TIA until I went to see the GP and he said that's what it was.*" (Male patient, aged 55).

One participant recognised the symptoms as stroke because she had been a nurse for many years. Despite this, she did not think that 'anything could be done for her in hospital.'

> "*Nothing happens at the weekend and it was a Sunday…. I mean what would have been the point in me going into hospital then?"* (Female patient, aged 79).

When participants experienced a subsequent stroke or TIA half still did not recognise their symptoms as a stroke or TIA.

> "*I knew they went sort of partly paralysed or they couldn't walk but I didn't really know what happened. I'd never had someone with stroke in the family before so I'd never saw anybody, you know.*" (Female Patient, aged 70).

> "*My leg wouldn't work, I couldn't put any weight on it but I didn't know why. So I rang my GP later on that day and made an appointment.*" (Male patient, aged 59).

Stroke Knowledge (Intervention Group)

As in the control group, all participants described the symptoms that they experienced. When participants experienced their first stroke or TIA, 4 (50%) participants recognised their symptoms as a stroke.

> "*I felt strange, I couldn't remember the day of the week. My brother had a bad stroke so we all knew what it was.*" (Male patient, aged 65).
>
> "*I lost my speech, I knew what I wanted to say but I couldn't get my words out. I knew it was a stroke.*" (Male patient, aged 63).
>
> *"I was talking to my wife and suddenly one or two words wouldn't come out and I just couldn't speak right.... I had a good idea it was a stroke.*" (Male patient, aged 78).
>
> "*The first time I had a stroke, I went into the bathroom and all of a sudden it felt numb on my right arm. So I thought I've had a stroke here."* (Female patient, aged 71).
>
> The other 4 (50%) participants did not recognise their symptoms as a stroke or TIA.
>
> *'My speech was all rubbish... What I did manage to get out was not rational words... But I didn't really know what was wrong*.' (Female patient, aged 88).
>
> *"I could only see half my room. I had to turn round so the half of the room I couldn't see before. I didn't know where I was. It was so strange, it was unbelievable. I went back into the living room and sat down*." (Female patient, aged 82).
>
> *"I couldn't speak properly, that was the first thing and then my husband said you're talking a lot of double Dutch. Then I lost my speech completely and I couldn't walk particularly well. I thought oh well it must be a virus.*" (Female patient, aged 74).
>
> *"I was talking like I was drunk. My mouth wasn't dropped or anything like that. I just wanted to sleep and I was like that all day.*" (Female patient, aged 52).

When participants experienced a subsequent stroke or TIA, all recognised their symptoms as a stroke or TIA.

> Interviewer: “*And you rang an ambulance this time?*”
>
> Participant: “*I did, immediately yes... I just recognised what it was the second time. I thought I’d better get onto this quickly you know with the hospital and so on let them have a look at me*.” (Female patient, aged 74)
>
> “*I rang for an ambulance, I would ring for an ambulance again, I wouldn’t hesitate, it’s an emergency.*” (Male patient, aged 63)
>
> Interviewer: “*You said that someone told you that if it happens again you should go to hospital?*”
>
> Participant: “*Well I did do. They told me to do that at the hospital. They told me to ring for an ambulance at the clinic.*” (Female patient, aged 88).

Perceived Seriousness (Control Group)

Even after experiencing a second stroke or TIA, there was still some uncertainty amongst the control group participants about the symptoms that they had experienced being serious enough to justify ringing for an ambulance, regardless of whether they recognised these symptoms as a stroke or TIA. Some talked generally about their perceived seriousness of some conditions and what would prompt them to contact the EMS.

> “*Tuesday morning I rang the GP and got in straight away. I actually got a taxi in because I knew what had happened. Sunday, you know, I mean what would have been the point in me going into hospital then? I worked there you know. I hadn’t collapsed.*” (Female patient, aged 79).
>
> Interviewer: “*So how serious does something have to be before ringing for an ambulance?*”
>
> Participant: “*That’s for really bad things isn’t it? Like when I broke my leg. If I burnt myself, something that I couldn’t drive up and get sorted. There’s no way*

> *you can take your car to the hospital these days, you'd have to get the bus. So I doctor myself mostly.*" (Female patient, aged 79).
> "*I thought, 'shall I just go to bed and ignore it?' I thought, well, I didn't know what it was, I didn't know what was wrong with me.*" (Female patient, aged 70).

> *"Well if I thought something was serious I would ring for an ambulance. I mean if it would have been a heart attack I would have known and I would have rung for an ambulance there and then.*" (Male patient, aged 59).

> "*I thought I'll wait and see what happens. If it gets worse or better, so I thought I'd sleep on it.*" (Male patient, aged 55).

Perceived Seriousness (Intervention Group)

Amongst the intervention group participants some were unsure about the cause of the symptoms when they had their first stroke or TIA, some perceived them as serious and others did not.

> "*I thought there must be something drastically wrong with me but I didn't know what so I rung NHS Direct.*" (Female patient, aged 82).

> "'*I didn't think much about what it was... I wasn't alarmed.*" (Female patient, aged 88).

> *"I didn't bother going to the doctor. My husband said the next day you best go and see the doctor... I thought it's nothing it'll go away.*" (Female patient, aged 74).

When a second stroke or TIA was experienced, participants were more likely to recognise their symptoms, were more likely to view their symptoms as serious, and acknowledge that they required urgent medical attention in hospital.

> "*I think probably because I knew things were related to the stroke and the sooner I got to hospital, I thought the better.*" (Male patient, aged 78).

> *"We had to pursue it, it was an emergency and we took it from there. I went to A&E and then the stroke unit afterwards.'*" (Male patient, aged 65).

Emotional Reaction to the Event (Control Group)

Within the control group four (40%) participants described an emotional reaction at the onset of their symptoms. Two participants described not wanting to worry their family members and one patient deliberately hid her symptoms from her family.

> "My daughter turned up with her husband. I think it must be awful for a child to look after the mother who looks absolutely hideous... As me, I don't want to be seen like that." (Female patient, aged 52).
>
> Interviewer: "*On the Sunday that you were out with your family [when the stroke happened] did you think about telling your family at all?*"
>
> Participant: "*No I wouldn't worry my son. I told him after I'd been to hospital.*" (Female patient, aged 79).

One participant described his fear of experiencing a second stroke.

> "*The second time it happened I knew what it was. I knew and I was scared of what might happen. I knew I had to get to hospital.*" (Male patient, aged 59).

One participant described feeling embarrassed at having to ring for an ambulance.

> "*When I had the stroke I knew this was something different. I did feel a bit stupid, I didn't want all the neighbours looking, people making a fuss but I had had to ring for one [an ambulance].*" (Male patient, aged 55).

Emotional Reaction to the Event (Intervention Group)

Unlike the control group participants, the participants in the intervention group did not refer to any emotional reaction to the onset of symptoms. The decision to seek help appeared to be about recognising the symptoms and/or deciding on the seriousness of those symptoms.

Help Seeking Behaviour (Control Group)

Figure 6.2 shows the help seeking behaviour of participants in the control group when they sought help for their initial stroke or TIA, and then their help seeking behaviour when they experienced a subsequent event.

> "*My daughter and her husband drove me to hospital the first time... The second time I was on the bus and I couldn't remember. I couldn't say the name [of the bus stop] and then it dawned on me that I was having another one. So I rung my husband at school but they said he was on a course. Luckily, one or two people came out of school to collect me off the bus and took me to the school. Later one of them drove me home.*" (Female patient, aged 52).

> "*I phoned my cousin, I said 'I don't feel so well' my voice was going. I only just managed to say it... So, they came round right away. I did the same thing the second time.*" (Female patient, aged 79).

> "*I thought it's not right. So I went to see the GP the same day. I did that [went to see GP] both times actually.*" (Male patient, aged 77).

> "*The GP was my first thought... The second one, I knew it was worse and I couldn't have got to my GP, it was the middle of the night, so my wife drove me.*" (Male patient, aged 59).

> "*I rang my GP the first time but the second time I knew I had to ring an ambulance and that's what I did.*" (Male patient, aged 55).

> Interviewer: "*Would you ever have considered, in that situation ringing for an ambulance?*"

> Participant: "*Funny that isn't it? I've never thought about it. No I wouldn't, I would have got my husband... I don't think that I'd ring an ambulance for myself. No I don't think I would. I'd just get on with it.*" (Female patient, aged 52).

> "*I went to my GP. Obviously your GP should be the first port of call. I don't think much of going into A&E these days.*" (Female patient, aged 79).

Help Seeking Behaviour (Intervention Group)

Figure 5.3 shows the help seeking behaviour of participants in the intervention group when they sought help for their initial stroke or TIA and when they experienced a subsequent event.

> "*The first time my sister rung the GP and they told us to go to hospital, so my sister drove us. The next one, my sister recognised the symptoms. She called*

> *for an ambulance and they came in a car [rapid responder] to see what I was like.*" (Female patient, aged 88).
>
> *"I thought there must be something drastically wrong with me, so I rung NHS Direct... The day after I started having more funny dos. I thought this time it was a stroke so I called NHS Direct. I think it's quicker, I can talk to somebody that knows what they're doing when I ring NHS Direct. I can rely on them. I do get a lot of help from them... I think they're very good, very efficient people actually.*" (Female patient, aged 82).
>
> "*The first one was different because I thought it was a virus and I went to the GP. The second time it (the stroke symptoms) was exactly the same. I didn't lose my speech but I had all the numbness and I was a bit wobbly on my legs.... I rang an ambulance immediately.*" (Female patient, aged 74).
>
> "*My husband, he phoned our son and he took us to the hospital. The second time we phoned the ambulance right away.*" (Female patient, aged 52).
> *"I was in the supermarket the first time. I drove into the local A&E and they checked me out... The next one I knew what it was and rung for an ambulance right away.*" (Male patient, aged 63).
>
> "*The first one we rung primary care and they sent an ambulance straight away. When it happened again, I knew the sooner I got there [to hospital] the better. My son only lives locally. My wife phoned my son and he took me directly there.*" (Male patient, aged 78).
>
> "*The first one I made an appointment to see my GP a few days later...the second time we went to the hospital in my daughter's car because that's what I'd been told to do if it happened again." (*Female patient, aged 71).

Previous Experience of Seeking Medical Help (Control Group)

Most of the control group participants did not have any experience of seeking medical help in an emergency situation. One participant who did not have any previous experience of contacting the EMS talked about possible charges for ringing for an ambulance. When participants were asked if they had any previous experience of contacting the EMS, most replied that they had not and would not consider doing so in the future, even though they had experienced more than one stroke or TIA.

> "*If you ring for an ambulance they ask you can you get a taxi and lots of other questions. You might have to pay if it's not an emergency.*" (Female patient, aged 70).
>
> Interviewer: "*Have you ever rung for an ambulance before?*"
>
> Participant: "*No not for myself, no. I don't think I would.*" (Male patient, aged 77).
>
> Interviewer: "*Have you ever rung for an ambulance before?*"
>
> Participant: "No, I wouldn't ring for one for me, I'd just get on with it." (Female patient, aged 52).
>
> Interviewer: "*Have you ever rung for an ambulance before?*"
>
> Participant: "*No, I wouldn't do for me. I'd leave that decision up to the wife.*" (Male patient, aged 59).

Previous Experience of Seeking Medical Help (Intervention Group)

Two participants talked about their previous experiences of contacting health services in an emergency situation and how they often relied on NHS Direct or the GP for help in emergency situations. When participants were asked about their previous experiences of contacting the EMS, the remaining six all stated, that based on their previous experiences they would contact the EMS for suspected stroke.

> *"I rely on them [NHS Direct], I get a lot of help from them. Other times when I've had angina attacks they've sent the doctor out and yes I've had a lot of help from them. I think they're very good, very efficient people actually."* (Female patient, aged 82).
>
> *"As a rule we've got a really good GP, so I don't know why he didn't get back to us that day. I'm the worst person to be with if anything goes wrong. I've always phoned Primary care or the doctor.*" (Female patient, aged 52).

> Interviewer: *“Have you ever rung for an ambulance before?”*
>
> Participant: *“I rang an ambulance immediately last time and I’d do the same again.*” (Female patient, aged 74).
>
> Interviewer: *“You said that you rang for an ambulance. If you or someone you knew experienced similar symptoms again, what would you?”*
>
> Participant: “*Ring for an ambulance, that’s what I did, ring for an ambulance, without a doubt*.” (Male patient, aged 63).

Information, Advice and Resources (Control Group)

All participants were asked what advice or information they had received whilst at the TIA clinic and whether this was sufficient to meet their needs. Participants talked about both the information that they received, the information they sought for themselves and their information needs. Compared to the intervention group, the control group reported negative experiences in relation to the lack of information they received. Participants described using the Internet to find information about stroke and TIA, as well as making appointments with GPs to find out more information.

> *“On one occasion I asked one of the doctors ‘what shall we do?’ and the advice from the doctors was ‘well it depends on what she’s like and if you’re really bothered ring for an ambulance.’ And I was like, well at what point do I get really bothered? I went away thinking you’ve told me absolutely nothing here and we just worked it out ourselves as went along.”* (Female patient, aged 52).
>
> “*I thought, ‘what am I going to do if it happens again? What am I supposed to do?’ he (doctor at hospital) hadn’t told me what to do and I hadn’t asked him what to do. I never thought about it happening again. I just thought that’ll be a one off and that’ll be it like, you know. So I thought, ‘I think I better go to the GP’s and get some advice on what to do’. So I rang the GP to see if anybody could see me...He said ‘if it happens again and it lasts an hour you must ring us right away. Don’t hang on longer than an hour’. When it did happen again I rang my cousin and waited an hour. I rung her back and I said ‘It’s still here.’ So we hung on for another quarter of an hour or so*.” (Female patient, aged 70).

> “*My GP gave me some information from the Internet. On a sheet, yeah, diagrams and everything, what happens and what it looks like*.” (Male patient, aged 77).

> “*No-one said what I should do but my GP surgery wasn’t open, so getting to hospital was the only choice I had anyway. Some information about what to do would have been useful.*” (Male patient, aged 59).

> “‘*I don’t remember being given any information but I did my own research on the Internet anyway. That was helpful.*” (Male patient, aged 55).

Information, Advice and Resources (Intervention Group)

Participants in the intervention group were asked about the information that they received during their attendance at the TIA clinic and whether this information alone was sufficient to meet their needs.

> “*I’ve got a leaflet about it [stroke]. I can look now if I wanted because it’s here in this drawer for reference to if necessary... I found it really interesting because I’d never heard of a TIA.”* (Female patient, aged 88).

> *“Yes I’ve got it (leaflet) here. If I feel anything funny I look at the leaflet. Then realise that I’m not having another stroke. It’s very informative and I can read it at my leisure. When you’re in a clinic with people you get easily distracted and so it’s hard to take information in that people tell you.*” (Female patient, aged 82).

> “*I’ve never had anything like that before. I had a second one on the Friday and the thing that really helped me was you know the leaflet on the FAST and then when the second one happened I thought I’d better get to the hospital right away and we rang the ambulance.*” (Female patient, aged 74).

> “*I can remember that your face drops and you flop to one side... I’ve got it [the leaflet] somewhere upstairs to refer to if I need to.*” (Female patient, aged 52).

> “*I can’t no, not really, I can’t remember any of the messages but I would refer back to it (the leaflet) if I was worried about something. ‘Face, er, I can see it but I can’t remember. But I would ring for an ambulance I wouldn’t hesitate.*” (Male patient, aged 63).

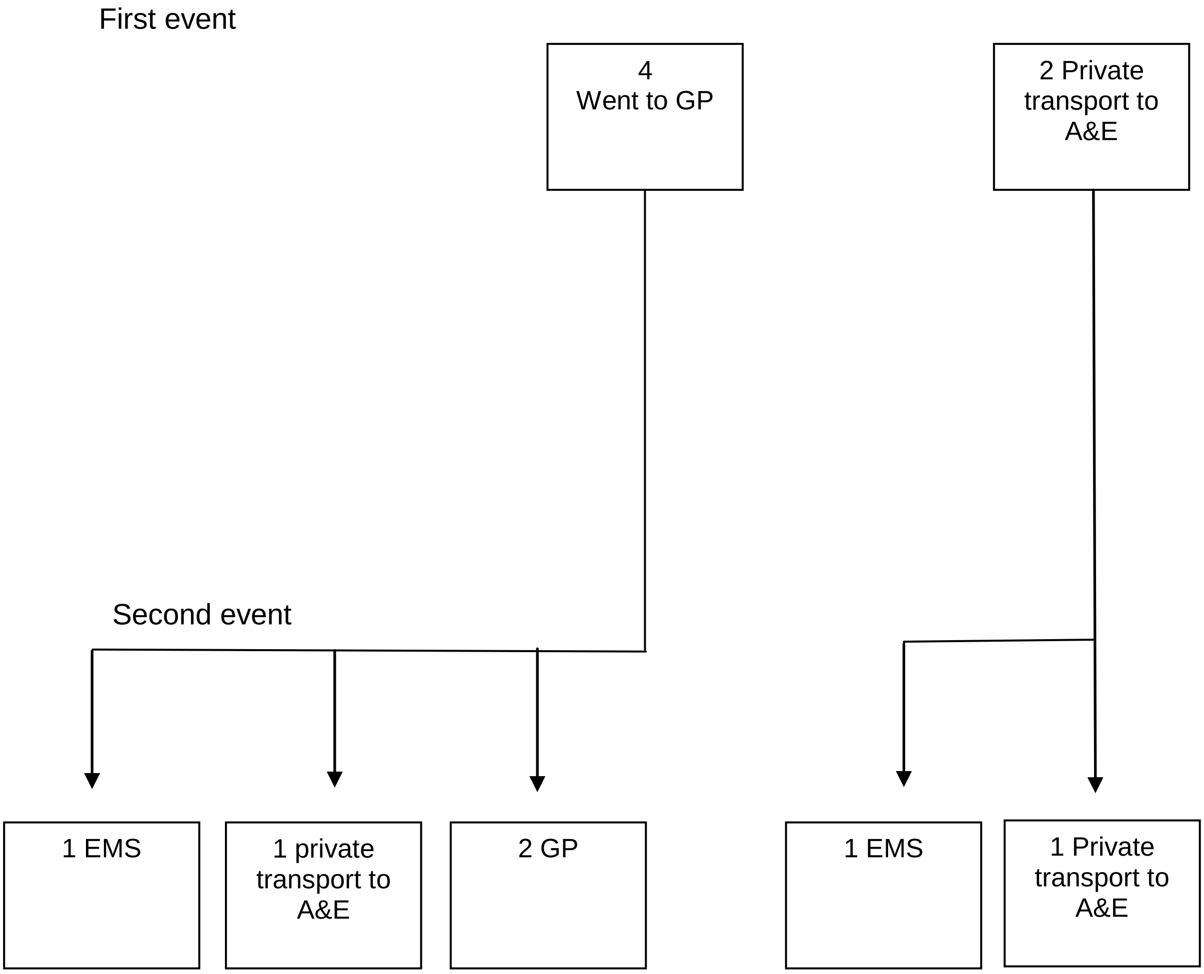

Figure 5.3. Help seeking behaviour of control group participants who were interviewed.

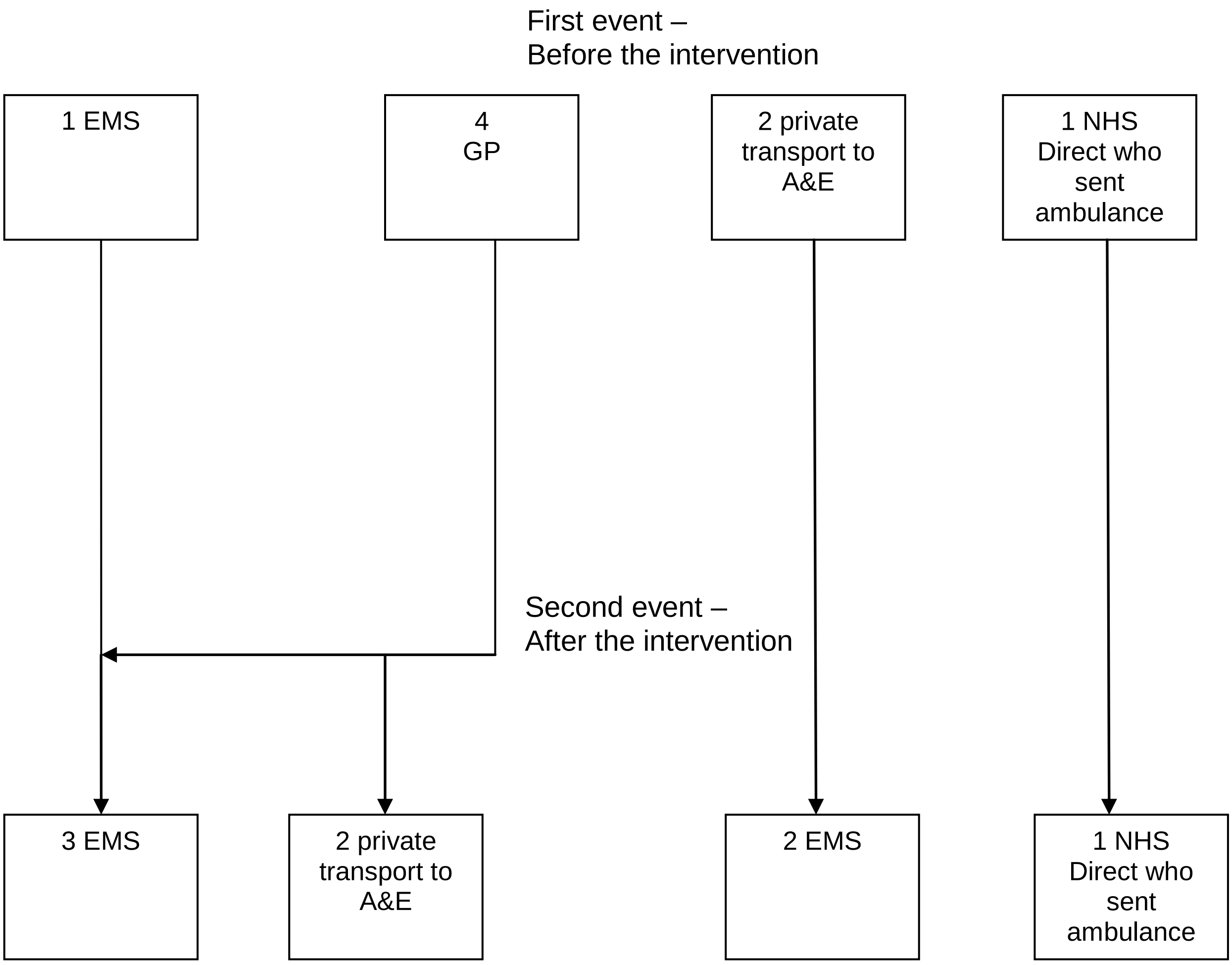

Figure 5.4. Help seeking behaviour of intervention group participants who were interviewed.

In this phase the main findings have shown that a targeted intervention has the potential to improve help seeking behaviour after stroke and TIA by increasing the proportions of participants accessing the EMS and seeking medical help within 24 hours. The interview data have explored the decision-making process in seeking help after stroke. The qualitative results also suggest that participants who received the intervention were more satisfied in terms of their information needs.

The findings from this phase will now be discussed and compared with existing research evidence. Based on the qualitative results from this phase, the theoretical framework developed in Phase Two (Figure 3.6) will be adapted. The main strengths and limitations of Phase Four will also be identified.

5.8 Discussion

The aim of this phase was to assess the potential effectiveness of a targeted intervention in people at risk of stroke by assessing the impact of the intervention on utilisation of the EMS and time from onset to medical help sought. Qualitative interviews explored what action was taken and the factors that influenced actions, as well as satisfaction with information provision. By implementing an intervention, within a targeted, at risk population, the results of this phase have suggested that an information leaflet, the content of which was explained by a TIA nurse, has the potential to improve help seeking behaviour after stroke and TIA. The results also suggest that participants who received the intervention were more satisfied in terms of their information needs. This discussion provides a summary of the Phase Four results, relating them where possible to the literature. The limitations of this phase will also be described. This discussion will:

- Examine the characteristics and help seeking behaviour of the participants at baseline;
- Compare the characteristics and help seeking behaviour of participants at outcome assessment (three month follow up);
- Examine the decision-making process for seeking help after stroke;
- Identify the limitations of this phase.

Help seeking behaviour and participant characteristics at baseline

Patient Characteristics

The median age of all participants (regardless of diagnosis) attending the TIA clinic at baseline was 71 years in the control group and 73 years in the intervention group. The median age of participants with a final diagnosis of stroke or TIA at baseline was 71 years in both the control and intervention groups, similar to figures reported in other studies (Johnston et al. 2000; Chandratheva et al. 2010). The proportions of patients with a confirmed diagnosis of stroke or TIA in both the intervention and control group who were aged 60 years or over, were also similar to the proportions of older patients reported in other studies (Johnston et al. 2000; Chandratheva et al. 2010). Previous studies have reported that older people are the least likely group to say that they would seek help from the EMS (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008). As the median age of patients attending TIA clinics is over 70 years, delivering an intervention within a TIA clinic setting targets older people who may be reluctant to seek help from the EMS for a suspected stroke or TIA. The median age in this study reflects that in others (Johnston et al. 2000; Chandratheva et al. 2010) and so it is reasonable to suggest that older people could be targeted with future stroke awareness interventions within the context of a TIA clinic.

Of the patients who attended the TIA clinic 48% and 56% were female (control and intervention groups, respectively). Of those participants who had a confirmed diagnosis of stroke or TIA 53% and 55% were female (control and intervention groups, respectively). As to whether this modest different between the sexes, in terms of having an event has implications for the intervention is less clear. There is no evidence that stroke knowledge is any different between males and females (Jones et al. 2009), however, older males are more likely to delay seeking medical help after stroke (Stoller, 1993).

The proportion of participants from ethnic minority groups attending the TIA clinic at baseline was 6% in the control group and 5% in the intervention group, the majority being of South Asian heritage. These figures are lower than expected, given that ethnic minority groups represent 15% of the local population (www.Lancashire.gov.uk, 2010). However, it has been reported that many patients from ethnic minority groups are less likely to access health services, mainly due to cultural and language barriers (Atkinson et al. 2001). South Asian groups in particular are also up to four times more likely than Caucasian patients, to seek advice from their GP, rather than going to hospital (Smaje, 1995). The incidence of stroke among ethnic minority groups in the UK is twice that of stroke among Caucasians (Stewart et al. 1999). This therefore suggests that there are a number of people of South Asian heritage that did not attend the TIA clinic for suspected stroke or TIA, whether or not patients sought help from other sources such as a GP is unknown. Minority groups tend to have lower levels of stroke knowledge (Jones et al. 2009) and so are likely to be one of the groups that would benefit from the intervention.

Type of Help Sought

Contacting the EMS is known to be one way in which pre-hospital delays can be reduced (Ritter et al. 2007). In this study overall, 53% sought help from a GP, 27% contacted the EMS and 18% self-presented at A&E. No previous studies have explored the ways in which patients seek help for suspected TIA and only one other UK-based study has reported the actual help seeking behaviour of stroke patients. Carroll et al. (2004) found that 80% of stroke patients sought help from their GP, 15% contacted the EMS and 5% self-presented at A&E (Carroll et al. 2004). However, this study was based on the medical help sought by only 40 stroke patients (Carroll et al. 2004). A further study, undertaken in the USA examined the action taken by 100 stroke patients in a predominantly African American population, reporting that only 12% of stroke patients had contacted the EMS, with the majority, 75% contacting a friend or relative for help (Hsia et al. 2011). The proportions of patients seeking help from the EMS in this phase are higher than has been previously reported (Carroll et al. 2004; Hsia et al. 2011). However, the existing research evidence is scare and limited particularly in relation to sample size (Carroll et al. 2004) and participant selection (Carroll et al. 2004; Hsia et al. 2011).

At baseline the majority of participants sought help from a GP. Within both the control and intervention groups the proportions of participants seeking help from a GP was slightly higher in those aged 65 years and over compared to those under 65 years of age. The results from the integrative review in Phase One suggested that stroke knowledge was poorest amongst those aged 65 years and over (Jones et al. 2009) and research also suggests that older people are the least likely group to state that they would seek help from the EMS at the onset of stroke (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008).

Time to First Medical Help Sought

The three month risk of stroke following a TIA ranges from 10% to 20% (Johnston et al. 2000; Coull et al. 2004; Eliasziw et al. 2004). However, following a TIA the highest risk of stroke is within the first 48 hours (Johnston et al. 2000). Patients attending the TIA clinic did not always seek immediate help and were often referred by a GP. TIA symptoms are frequently ignored by patients and their relatives, which can lead to a delay in diagnosis and treatment (Lavallée et al. 2007). Just over half of the control group (51.0%) sought medical help within the first 24 hours of symptom onset, compared to 64.5% of the intervention group. These findings reflect those found in other recent studies (Giles and Rothwell, 2007; Lavallée et al. 2007). In the EXPRESS and SOS-TIA studies over 40% of patients did not seek help within 24 hours of symptom onset and patients were even less likely to seek help if symptoms were first recognised over a weekend (41% versus 61%, respectively) (Giles and Rothwell, 2007; Lavallée et al. 2007). The delay in seeking help after stroke and TIA has negative implications for accessing specialist stroke care including interventions such as thrombolysis and secondary prevention (Smith et al. 2008; ESO, 2009).

Exact times from the onset of symptoms to when medical help was sought were difficult to calculate for the majority of participants. Often onset time could only be narrowed down to day rather than time. At baseline, exact times to help sought could only be calculated for 10% of participants in the control group and 15% of participants in the intervention group. This was due to times for both symptom onset and help sought being poorly documented in the TIA register. As a consequence, times to medical help sought had to be presented in days and months. Research has suggested that the times for stroke onset are poorly documented within patient case notes; with only between one-third and one-half of acute stroke admissions having a specific stroke onset time recorded (The Paul Coverdell Prototype Registries Writing Group, 2005).

Final Diagnosis

Of the control group participants attending the TIA clinic 62% were given a diagnosis of stroke or TIA, similarly 67% of participants in the intervention group had a final diagnosis of stroke or TIA. These proportions are similar to those that have been reported in a study of 1085 patients with suspected TIA, where 65% of people referred to an urgent TIA clinic had a final diagnosis of stroke or TIA (Lavallée et al. 2007).

In this phase a lower proportion of participants had a diagnosis other than stroke or TIA (36% and 30%, control and intervention groups respectively) compared to one research study, in which almost half of the referrals (49%), had an alternative diagnosis (Murray et al. 2007). The most common alternative diagnoses included; migraine, syncope, transient global amnesia, seizures and dementia. Although not all patients who attend TIA clinics will have had a stroke or TIA. This study suggests that overall around 67% of patients had a final diagnosis of stroke or TIA. The risk of stroke after TIA ranges from 10% to 20%, this is more than twice the risk of myocardial infarction or death in patients presenting with acute coronary syndromes (Johnston, 2007). Therefore, TIA clinic settings have an important role in educating patients and carers about the recognition of stroke symptoms and the importance of seeking medical help, even if symptoms have resolved (Johnston et al. 2003).

Symptoms

When participants arrived at the TIA clinic, the most commonly reported clinical features in both the control and intervention groups were hemiparesis, hemi-sensory loss, speech problems and speech problems combined with limb weakness, similar symptoms have also been commonly reported in another recent study (Murray et al. 2007) and suggest that patients more frequently describe ‘classic’ stroke symptoms.

Help Seeking Behaviour and Participant Characteristics at Outcome Assessment

Patient Characteristics

At outcome assessment the median age of the control group participants was 76 years and 50% were female; of the intervention group participants, the median age was 71 years and 71% were female. The proportion of female participants in the intervention group was higher than might be expected. With the proportions of females who have had a stroke and TIA being approximately 55% of an overall stroke population (Williams et al. 1999). The age range is similar to that reported in other studies (Johnston et al. 2000; Chandratheva et al. 2010). Although the numbers reported here are small, they are reasonably reflective of an overall TIA clinic population.

At baseline, around 5% of participants overall were from ethnic minority groups. At outcome assessment all of the control group participants were White British. Within the intervention group 21% of participants were from ethnic minority groups. Due to the small number of participants, any comparisons with the local population are difficult to make however, the proportion of ethnic minority group participants in the intervention group does reflect the local ethnic minority group population, which makes up 15% of residents within the City of Preston (www.Lancashire.gov.uk, 2010).

Type of Help Sought

When data were collected at three months, the ways in which participants had sought help differed between the control and intervention groups. At outcome assessment the same proportion of participants in the control group (60%) sought help from a GP when they experienced a second TIA or stroke. In comparison, the proportion of participants who sought help from a GP in the intervention group decreased from 43% at baseline to 0% at outcome assessment. Between first and second events the proportions of participants who sought help from the EMS actually decreased from 30% to 20% amongst the control group participants. In comparison, the proportion of participants seeking help from the EMS in the intervention group increased from 36% to 79%. The proportions of patients contacting the EMS in the intervention group were much higher that have been previously reported (Carroll et al. 2004; Hsia et al. 2011). However, as previously mentioned the existing research evidence is scare.

Time to First Medical Help Sought

The proportion of participants in the control group who had had a subsequent stroke or TIA and who sought medical help within 24 hours decreased slightly from 80% at baseline to 70% outcome assessment. Whereas, medical help sought by the intervention group participants within 24 hours increased from 50% at baseline to 64%.

This reduction in delay to seeking medical help in the intervention group may partly be explained by the higher proportions of patients accessing medical help via the EMS, as studies have shown that activation of the EMS is the main predictor of reduced pre-hospital delay (Ritter et al. 2007).

Of the participants in the control group who went on to have a second stroke or TIA, those aged 65 years or over were 45% less likely to seek help within 24 hours compared to those aged under 65. Whereas, in the intervention group those aged 65 years and over were 25% less likely to seek help within 24 hours compared to younger participants. Whilst these results should be interpreted with caution due to the limited sample size, it is encouraging that the intervention may have decreased pre-hospital delays amongst older people, who are recognised as being the least likely group to say that they would contact the EMS for suspected stroke (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008).

Final Diagnosis

Final diagnosis information was recorded for all participants who were re-admitted to hospital. In the control group, of the 29 participants who were re-admitted within three months, 28% had a subsequent stroke and 7% had a TIA. Given that 123 patients had a diagnosis at baseline of stroke or TIA, this represents a recurrence rate of 8% within three months. In the intervention group, of the 30 participants who were re-admitted, 40% had a subsequent stroke and 7% had a TIA. Given that 134 had a diagnosis at baseline of stroke or TIA, this represents a recurrence rate of 10%. These figures are lower than expected, with rates of stroke following TIA more likely to be between 10% and 20% at three months (Johnston et al. 2000; Coull et al. 2004; Eliasziw et al. 2004) and are likely to be as a result of the small sample size.

Symptoms

When participants arrived at hospital the most common clinical features to be reported were hemiparesis and speech problems. These also reflect the symptoms most commonly reported by participants at baseline and suggest that patients commonly identify and report classic stroke symptoms such as those included in the FAST.

The Decision-Making Process

The results from the qualitative interviews will now be examined, with a particular emphasis on the decision-making process for seeking help after stroke and TIA. The categories from the Phase Four qualitative analysis have been mapped against the theoretical framework developed in Phase Two (Figure 3.6). Consequently, the framework has been amended (Figure 5.5) so that in the future it can more effectively underpin stroke awareness interventions. Stage one of the framework now incorporates specific elements of stroke knowledge. These are: the recognition of stroke symptoms, respond to stroke as a medical emergency and knowledge of treatments or the potential benefits of seeking medical help early after stroke

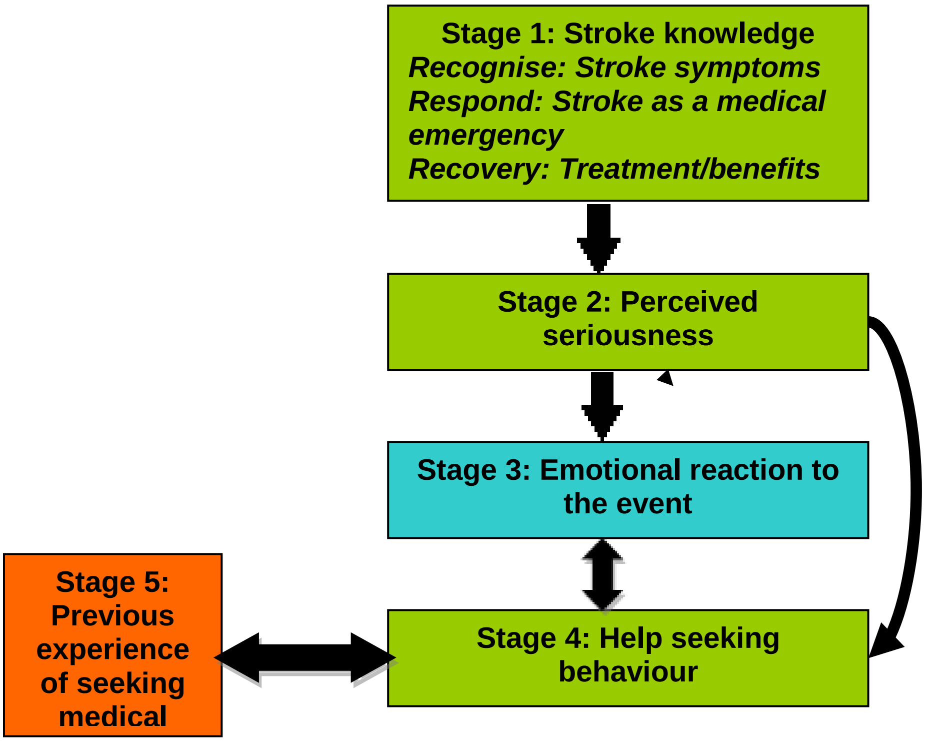

Figure 5.5. Theoretical framework to describe the decision-making process for seeking help after stroke.

Stage 1: Stroke Knowledge

During the interviews participants were asked to describe their stroke symptoms and say whether or not they thought that they were related to a stroke or TIA. In the control group, despite experiencing a previous TIA or stroke, half of all patients still did not recognise the symptoms that they experienced compared to the intervention group, who all recognised their symptoms when they had a subsequent event.

The leaflet given to patients at the TIA clinic, which the nurse talked through with them, contained a specific message stating that treatments are available for stroke at hospital. However, in this phase although some patients knew that they should act quickly by contacting the EMS, few knew why. Only one participant talked about the benefit of seeking urgent medical help and this was as a direct result of a personal experience in which a family member had had a severe stroke.

Although previous research has suggested that motivation to call the EMS can be promoted by increasing positive outcome expectations (Fussman et al. 2010), the majority of participants did not talk about treatments that were available or the benefits of getting to hospital quickly. Neither did participants relate contacting the EMS and early access to specialist stroke services with an improved outcome. Theories such as the common sense self-regulation model (CS-SRM) (Hagger and Orbell, 2003) attempt to explain how the response to symptoms is often influenced by perceptions about the cause of the symptoms, anticipated consequences, and views about the treatments that are available. The results of these interviews suggest that patients who delayed seeking help were often unsure of the symptoms of stroke, the likely consequences and/or potential treatments.

The CS-SRM also suggests that individuals develop their understanding of a particular illness based on a number of factors including: knowledge of the illness at a cultural level; communication with family, friends and health professionals; and personal experience of illness (Hagger and Orbell, 2003). The research undertaken in this phase suggests that even when participants had experience of a stroke at baseline, this alone was not sufficient to influence behaviour when they had a subsequent event. These findings reflect those of an earlier study, which looked at the help seeking behaviour of those accessing primary care, reporting that symptoms alone were not enough to initiate help seeking behaviour. (Cameron et al. 1993).

Stage 2: Perceived Seriousness

In the control group there was uncertainty around the perceived seriousness of symptoms and whether symptoms were serious enough to justify contacting the EMS, even though participants had previously experienced a stroke or TIA. Participants described situations in which they thought contacting the EMS would be justified, these included a mix of serious and non-serious conditions such as a broken leg, burns or heart attack. Unlike the conditions identified by participants here, the symptoms of stroke are not often accompanied with pain or discomfort and may therefore be perceived as less serious. Many studies have found that pain, discomfort and bleeding were most likely to be associated with an immediate decision to seek medical help (Kasl and Cobb, 1966; Safer et al.1979). Intervention group participants were more likely than control group participants to describe stroke as serious and requiring an emergency response. The findings reported here are supported by research undertaken by Cameron et al. (1993) who found that the belief that symptoms were serious was a significant aspect of determining help seeking behaviour (Cameron et al. 1993).

One study has explored the intended behaviour of the public in relation to specific stroke symptoms and concluded that the intention to contact the EMS at the onset of stroke symptoms was not driven by knowledge alone (Mikulik et al. 2008). Interestingly, this study found that intended behaviour was driven by the perceived seriousness and treatability of stroke (Mikulik et al. 2008). An earlier study of myocardial infarction also found that people who responded most rapidly to their symptoms, believed their symptoms to be more serious than those who delayed seeking help (Burnett et al. 1995).

The Health Belief Model (HBM) is commonly used to explain and predict illness and sick role behaviour (Becker, 1974; Rosenstock, 1974). The model suggests that the combined levels of susceptibility and severity provide the force that an individual requires in order to consider any change in help seeking behaviour (Rosenstock, 1974). A cost-benefit analysis of the perceived benefits and barriers is then undertaken by the individual resulting in a preferred course of action (Rosenstock, 1974). Applying the HBM to stroke highlights the current problems in raising public awareness and improving help seeking action for suspected stroke. If the public are unsure about the seriousness of stroke symptoms and the potential severity of stroke, they may be less likely to seek immediate help from the EMS. The patients in the intervention group appeared to not only be more likely to recognise their symptoms as stroke but also perceived symptoms to be serious and requiring urgent medical attention. Of the few studies that have used the HBM to explore the actual utilisation of health services, perceived severity was one of the main factors in predicting help seeking behaviour (Kirschtet al. 1976; Becket et al. 1977; Leavitt, 1979).

Stage 3: Emotional Reaction to the Event

The participants in the control group experienced a range of emotions including fear and embarrassment. However, the participants in the intervention group did not report experiencing any emotional reaction at the onset of their subsequent stroke or TIA. Following the findings from the Phase Two interviews, the intervention included a message about the potential emotional reaction that may be experienced. In Phase Four it may be that participants who received the intervention developed a ‘mental picture' of the potential threat of having a subsequent stroke or TIA and built an action plan as suggested by the CS-SRM (Hagger and Orbell, 2003). Reassurance from the TIA nurse that stroke is serious and that there may be an emotional response, may also have influenced help seeking behaviour of the intervention group participants by helping participants to pre-empt their emotional reactions, replacing fear and panic with clear instructions about contacting the EMS for help.

Stage 4: Help Seeking Behaviour

There was a slight decrease in the proportions of the control group participants seeking help from the EMS between baseline and outcome assessment (30% to 20%). However, help sought from the EMS in the intervention group markedly improved from 35.7% to 78.6%. As the number of participants who had a subsequent stroke or TIA within three months was small, no definitive conclusions can be drawn from the data, but they do point to the potential effectiveness of the intervention. Although the intervention may have influenced help seeking behaviour, the influence of other external factors, such as personal experiences, the impact of advice from family, friends and other media messages are not known but should be considered and tested for in future studies.

Stage 5: Previous Experience of Seeking Medical Help

Two participants described positive past experiences of front line services, such as Primary Care and NHS Direct. They often felt that they could rely upon this service and this is what they had 'always done' and so remained reluctant to access the EMS in the first instance. Their confidence in accessing other services, underpinned by previous positive experiences, resulted in some participants repeating the help seeking behaviour that they were most familiar with. It may therefore be suggested, that if we want to change the help seeking behaviour of these participants, advice about contacting the EMS for suspected stroke in the future, would have to be given by those front line services that they trust and rely on. Trust is known to play a central role in all medical relationships and is an important contributor to improving the utilisation of health care services (Mechanic and Schlesinger, 1996).

Information, Advice and Resources

During the interviews, participants were asked about the information that they had received or had sought out for themselves. Participants in the control group were much more likely to seek out their own sources of information and were more likely to be dissatisfied in terms of their information needs. These concerns about poor information provision have been highlighted in the National Stroke Strategy, which reported that almost half of patients and carers felt that their information needs had not been met (DoH, 2007). A potential benefit of the intervention may include greater levels of patient and carer satisfaction, with no participants in the intervention group reporting that their information needs had not be addressed, compared to higher levels of dissatisfaction within the control group.

Limitations

This study has several limitations. As the intervention was information based, randomisation of the intervention at a patient level was not considered to be appropriate due to the high risk of contamination (Eldridge and Kerry, 2012). Therefore, a two-group pre-test-post-test design including a control group was chosen rather than a RCT. This design enabled the potential effectiveness of the intervention to be measured by comparing the help seeking behaviour of the control and intervention group at baseline and at outcome assessment. This type of quasi-experimental approach reduces the risk of contamination between participants thus improving the external validity of the design. By assigning intact groups to either the control or intervention groups, it is possible that participants were not aware of which group they had been assigned to (Dimitrov and Rumrill, 2003). This type of design however, is more sensitive to problems with internal validity (Dimitrov and Rumrill, 2003) and therefore the extent to which differences in post-test measures may be attributable to characteristic differences such as the exposure to other health messages and personal experiences rather than to the intervention are not known.

This was an exploratory study and as such the numbers of participants were relatively small. This study was also based in just one TIA clinic within the North West of England. However, the age ranges and sex of all the participants attending the TIA clinic were similar to figures reported in other studies (Johnston et al. 2000; Chandratheva et al. 2010), although the number of patients with a confirmed diagnosis of stroke or TIA was lower than may have been expected at outcome assessment (Johnston et al. 2000; Chandratheva et al. 2010). At baseline, around 5% of participants overall were from ethnic minority groups. Due to the small number of participants, any comparisons of ethnic group with the local population were difficult to make. The local ethnic minority group population, makes up 15% of residents within the City of Preston (www.Lancashire.gov.uk, 2010). Therefore, the overall numbers of participants from ethnic minority groups was lower than the local population, apart from the intervention group participants, of whom 21% were from ethnic minority groups, mainly of South Asian heritage. The TIA clinic involved in the study was consultant-led (Consultant Neurologist with a special interest in stroke neurology and Consultant

Stroke Physician), at the time of the study approximately 1,000 patients were seen at the TIA clinic each year, which ran Monday to Friday. Therefore, the findings of this study may only be generalisable within local or similar populations.

The nurse had a role in the delivery of the intervention by reading through the content of the leaflet with each patient and then giving the patient a copy of the leaflet to take home. Although it has been shown that the intervention may have the potential to improve the proportions of patients seeking help from the EMS, the extent to which the nurse influenced the success of the intervention, over and above the provision of the leaflet is not known. This may simply be due to the fact that the nurse spent time reading the leaflet with the patient or it may be due to the personal characteristics of that particular nurse.

The study design compared only the intervention (leaflet read through and distributed by a TIA nurse within a TIA clinic setting) and control group. The study design may have been improved by comparing more than one group for example, one group who receive the intervention in its current format (leaflet read through and distributed by a TIA nurse within a TIA clinic setting), a second group who receive the leaflet only (without any explanation or reinforcement from the TIA nurse) and a control group. Any future research in this area should look specifically at the role of the nurse in the delivery of the intervention and the cost implications of this.

The impact of the intervention was only assessed up to three months post stroke or TIA. A number of other intervention studies have measured the impact of interventions immediately post implementation (Stern et al. 1999; Becker et al. 2001; Silver et al. 2003; Handschu et al. 2006; Marx et al. 2008), before, after and at three months (DeLemos et al. 2003; Wall et al. 2008) and two studies have measured the impact of mass media campaigns over a period of between three and fifteen years (Hodgson et al. 2007; Kleindorfer et al. 2009). Further research could explore the potential effectiveness of the intervention developed in this thesis in the longer term and certainly beyond three months, although the majority of subsequent strokes or TIAs will have occurred within this time period.

Stroke knowledge was explored in the context of semi-structured interviews rather than using a validated tool. In previous studies stroke knowledge has been captured using a variety of methods including focus groups, questionnaires and interviews. (Jones et al. 2009) However, there is only one validated stroke knowledge questionnaire and this is based solely on stroke action (Billings-Gagliardi and Mazor, 2005). The main disadvantage of this tool is that it uses multiple choice questions. As the previous literature has demonstrated the use of multiple choice questions may not accurately reflect ‘true’ stroke knowledge or help seeking action (Jones et al. 2009). For example, scenario based questioning, with the use of open questions based around mini scenarios, may be more likely to accurately reflect what a person would actually do in a real life situation (Renold, 2002). Scenarios have been used in previous research to tap into attitudes and beliefs regardless of whether participants have had any direct experience of a particular situation (Renold, 2002). In order to measure stroke knowledge, a stroke knowledge questionnaire would also have to be able to detect changes in levels of stroke knowledge and how this may relate to actual help seeking behaviour.

Participants who attended the TIA clinic and who subsequently had another stroke or TIA were invited to take part in an interview. During the interview participants were asked about their help seeking behaviour. As the interview took place at three months post attendance at the TIA clinic (the median time from attendance at the TIA clinic and the interview, was 99 days in the control group and 101 days in the intervention group), it is possible that there may have been some recall bias, although the extent to which this may have influenced the results is not known. The recall of information depends entirely on memory which can often be imperfect (Hassan, 2006) and participants’ accounts of events when they had their stroke or TIA could have been influenced by their later experiences in hospital. However, there are no reasons why recall bias would be different between the two study groups.

5.9 Conclusion

Activation of the EMS following stroke or TIA appears to be a complex process that is influenced by a number of factors. The semi-structured interviews undertaken suggest that people do need a basic knowledge about stroke in order to recognise symptoms and be aware that they should contact the EMS. However, knowledge alone is not sufficient to influence the actual help seeking behaviour of many patients and carers. The action that is taken by a patient or someone on their behalf may depend on a number of factors including knowledge of stroke symptoms and stroke as a medical emergency, knowledge of treatment for stroke and the benefits of this, the patient’s emotional reaction to the event, previous experience of health services, as well as the ability to translate the recognition of symptoms and knowledge about stroke into appropriate help seeking action by contacting the EMS.

By implementing an intervention, within a targeted, at risk population, the results of this phase have suggested that the intervention has the potential to improve help seeking behaviour after stroke and TIA by increasing the proportions of participants utilising the EMS and seeking medical help within 24 hours. The results of the phase also suggest that patients who received the intervention were more satisfied in terms of their information needs.

However, this study has several limitations which include a quasi-experimental design which is more sensitive to threats to internal validity such as exposure to other health messages and personal experiences other than the intervention. Although the numbers of participants are small, they are reasonably reflective of an overall TIA clinic population in terms of age, sex and final diagnosis at baseline. The nurse had a role in the delivery of the intervention by reading through the content of the leaflet with each patient and then giving the patient a copy of the leaflet to take home. It is not known the extent to which the role of the nurse influenced the success of the intervention. The impact of the intervention was only assessed up to three months post stroke or TIA. Although saturation was reached in the main themes reported, the number of participants who experienced a subsequent stroke or TIA were fewer than anticipated and so the number of participants interviewed was small and represented patients and carers from only one acute hospital trust.

Further research is needed to explore the feasibility of interventions for improving help seeking behaviour after stroke and TIA. A feasibility trial combined with a qualitative evaluation should be considered in assessing the impact of interventions for improving help seeking behaviour among higher risk patients after stroke or TIA.

The final concluding chapter of this thesis will now describe the main findings of each phase, recommendations will be made for future research and the original contributions to knowledge that this thesis has made will be outlined.

CHAPTER SIX

CONCLUSION

This thesis consisted of a programme of work, which explored the factors that influence the decision-making process when seeking medical help at the onset of acute stroke symptoms. This programme led to the development of a theoretical framework; the theoretical framework and results of a focus group were used to underpin the development a new stroke awareness intervention, which was then tested in a population at high risk of stroke. This final chapter aims to provide a summary of the major findings of this thesis: implications for future research will be outlined and the original contribution to knowledge that this programme of work has made will be highlighted.

The programme of work consisted of four phases. An integrative review was undertaken in Phase One. The aim of the review was to summarise the existing scientific literature exploring the knowledge of stroke patients, relatives, the public, and patients at risk of stroke; in relation to: stroke risk factors, stroke symptoms, action that should be taken when stroke is suspected, and sources of information and available treatments for stroke. Following an extensive search of the literature, 51 studies were identified and included in the review.

Across all studies and populations, hypertension was the most commonly reported risk factor for stroke. The most commonly identified symptoms of stroke were speech problems, sided numbness, weakness or paralysis. The majority of studies reported that most participants said they would contact the EMS. However, despite up to 89% of the public reporting that they would intend to contact the EMS at the onset of acute stroke symptoms, less than 20% of stroke patients had actually done so (Carroll et al. 2004; Hsia et al. 2011). Stroke information was mostly gained from friends and family. Only two studies had asked participants about their knowledge in relation to the treatments that were available for stroke, with thrombolysis being identified by as few as 4% of stroke patients (Kleindorfer et al. 2009). However, regardless of the types of questions used, knowledge was poorest amongst participants aged 65 years and over and amongst some ethnic minority groups. Nine studies in the review used an intervention to raise awareness of stroke. The majority of intervention studies showed an increase in stroke knowledge (Becker et al. 2001; Silver et al. 2003; Handschu et al. 2006; Hodgson et al. 2007; Wall et al. 2008).

The review identified that knowledge of stroke symptoms and the intention to seek help from the EMS for suspected stroke was not necessarily reflected in help seeking behaviour. Therefore, there is a need for future research that identifies the type of interventions that can both increase knowledge and influence behaviour, and explore in what populations these interventions have the most impact. Future stroke awareness interventions may need to be targeted towards older people, as these are the least likely group to say that they would contact the EMS for suspected stroke (Becker et al. 2001; Greenlund et al. 2003; Hodgson et al. 2007; Marx et al. 2008).

There were a number of limitations of the studies included in the review. The studies varied in quality, including five which sampled participants from highly selected populations. Across the studies a major limitation was the variety of methods that were used to assess stroke knowledge. Consequently, whilst risk factor identification and the recognition of stroke symptoms were often poor when open-ended questions were used, this appeared to improve when closed questions were asked. The results of the review could not be synthesised in a meta-analysis because of the mixed methodologies used in the included studies. Therefore, the approach taken was that of an integrative review, which synthesises information from methodologically diverse studies using a descriptive summary.

Whilst it is acknowledged that the review has a number of limitations, this was the first integrative review that has attempted to synthesise the research evidence in relation to stroke knowledge. Findings from the review suggested that stroke knowledge and the intention to seek help for suspected stroke was not necessarily reflected in actual help seeking behaviour by contacting the EMS. Therefore, semi-structured interviews in Phase Two sought to explore further the factors that influenced the decision to seek help for stroke.

The aim in Phase Two was to explore the decision-making process when seeking medical help at the onset of stroke symptoms. Eighteen participants took part in semi-structured interviews; eight who sought immediate help by contacting the EMS and ten who delayed seeking help. A grounded theory approach was used to guide both the sampling strategy and analysis of the data. Following analysis of the data five sub-categories emerged, which were: knowledge of stroke symptoms, perceived seriousness, emotional reaction to the event, help seeking behaviour, and previous experience of seeking medical help. These categories were then used to inform the development of a theoretical framework based around the core category entitled ‘the decision-making process for seeking help after stroke.’

The findings from this phase suggested that being able to recognise the symptoms of stroke alone did not appear to influence the decision to contact the EMS. Stroke symptoms were often viewed as not serious enough to warrant seeking immediate help. A number of previous studies have also identified perceived seriousness as a major influence in the decision to seek help for a variety of conditions but particularly within myocardial infarction (Ho et al. 1988; Raczynski et al. 1994; Reilly et al. 1994; Dracup et al. 1997). Participants who did not have any speech disturbance often considered their symptoms to be less severe than they would if speech disturbance had been present. Many participants also reacted emotionally to the onset of symptoms with some participants delaying seeking medical help as they did not want the fuss and embarrassment that they associated with the arrival of an ambulance. Both positive and negative previous experiences of seeking medical help could influence who to seek help from for suspected stroke. Some participants who had positive experiences of contacting the EMS felt that this made them more confident in contacting the emergency services for help. Others reported previous negative experiences of contacting the EMS, which resulted in their decision to seek alternative sources of help.

Although purposive and theoretical sampling strategies were used to identify participants, some groups were not adequately represented, particularly ethnic minority groups. All participants sought help at some point from their GP, the EMS or local hospital. It was not possible to identify participants who did not seek any medical help and this group was not actively sought. Saturation was reached in the main categories reported. The sample represents the views and experiences of stroke patients and their carers from a population within the catchment area of an acute hospital trust. The conclusions drawn from the data should be generalisable to similar populations.

The findings from Phase Two suggest that any future interventions to raise awareness of stroke should make explicit the symptoms of stroke, the seriousness of stroke, the likely emotional reaction to the event and the need for a rapid response by contacting the EMS.

In order to inform the development of an intervention, the aim in Phase Three was to explore the key messages and formats of stroke information that may encourage people with suspected stroke to seek immediate help from the EMS. In Phase Three, content analysis of a focus group with twelve participants was undertaken and revealed four themes in relation to the format in which information should be provided: information should be suitable for different groups; information should be informed by stroke survivors; messages should be simple; messages should be conveyed through pictures and images. Four further themes, around the content of public awareness campaigns for stroke also emerged: recognising a range of stroke symptoms should be described; stroke is a medical emergency; treatments for stroke; hope, fear and the consequences of stroke.

The findings from the focus group suggested that the content of any stroke awareness interventions should be simple and suitable for everyone and that this simplicity and suitability may be facilitated through the use of pictures and images. The use of images would also help to ensure that information could be understood by older people who may have problems with eyesight, people from ethnic minority groups who may not read English, and those with lower levels of education who may have poor literacy skills. It was suggested that the medium of the information should also be accessible to a range of people, especially older people who may not be as likely to access information from the internet, via e-mail, or text message (Office for National Statistics, 2009).

A convenience sample was used to identify the focus group participants and some groups were not adequately represented ‘in person’, these included participants from ethnic minority groups. However, there were two representatives from a charity that advocates for stroke patients. The findings, while only representing the views and experiences of the focus group participants, provide important information with which to inform the development of a new stroke awareness intervention. There is no reason to think that the comments regarding the content and format of stroke information would be significantly different if the focus group had been conducted elsewhere. The results from the focus group provided information on the key messages and format of information to be included in future interventions to improve stroke awareness.

The theoretical framework developed in Phase Two and the focus group findings in Phase Three were used to inform the content and format of a new intervention to raise awareness of stroke and encourage people to seek immediate help from the EMS. The Phase Four aim was to explore the potential effectiveness of the intervention in a population at a higher risk of stroke by assessing the impact of the intervention on utilisation of the EMS and time from the onset of stroke symptoms to first medical help sought.

In Phase Four, for those participants who had a stroke or TIA, the proportions of control group participants who sought help from the EMS decreased compared to a 43%

increase in the intervention group. Significantly more patients contacted their GP when they had a stroke or TIA in the control group compared to the intervention group. None of the intervention group participants sought help from a GP when they had a stroke or TIA, whilst the proportion of participants in the control group who sought help from a GP remained unchanged. The proportion of participants in the control group who had had a stroke or TIA and who sought medical help within 24 hours decreased slightly compared to a small increase amongst the intervention group.

Semi-structured interviews with participants in Phase Four explored the actions that were taken for suspected stroke by patients and carers and the factors that influenced this, as well as satisfaction with information provision. The categories from the Phase Four qualitative analysis were mapped against the theoretical framework developed in Phase Two, in order to amend the framework so that it more accurately reflects help seeking behaviour at the onset of symptoms; this was shown in Figure 5.4. The framework which seeks to describe the decision-making process for seeking help after stroke consists of five stages, these are: stroke knowledge (recognition of stroke symptoms, stroke as a medical emergency, and knowledge of treatments or the potential benefits of seeking medical help early after stroke); perceived seriousness; emotional reaction to the event; help seeking behaviour; and previous experience of seeking medical help. The theoretical framework developed in Phase Two and refined in Phase Four of this thesis could underpin future stroke awareness interventions; this would also form the theoretical phase of the MRC framework for complex interventions (Campbell et al. 2000).

Phase Four had several limitations. This was an exploratory study and as such the numbers of participants was relatively small. This study was also based in just one TIA clinic within the North West of England, which was consultant-led (Consultant Neurologist with a special interest in stroke neurology and Consultant Stroke Physician). At the time of the study approximately 1,000 patients were seen at the TIA clinic each year, which ran Monday to Friday. Therefore, while the findings of this study should be interpreted with some caution, they may be generalisable within TIA clinics that have a similar configuration and serve similar populations.

As the intervention was information-based, randomisation of the intervention at a patient level was not considered to be appropriate due to the high risk of contamination (Eldridge and Kerry, 2012). Therefore, a two-group pre-test-post-test design including a control group was chosen, rather than a randomised controlled trial. However, this quasi-experimental design is more sensitive to problems with internal validity (Dimitrov and Rumrill, 2003); the extent to which differences in post-test measures may be attributable to characteristic differences such as the exposure to other health messages and personal experiences rather than to the intervention are not known.

The nurse at the clinic had a role in the delivery of the intervention by reading through the content of the leaflet with each patient and then giving the patient a copy of the leaflet to take home. Although it has been shown that the intervention may have the potential to improve the proportions of patients seeking help from the EMS, it is not known the extent to which the nurse influenced the success of the intervention. This may simply be due to the fact that the nurse spent time reading the leaflet with the patient or it may be due to the personal characteristics of that particular nurse.

The study design compared only the intervention (leaflet read through and distributed by a TIA nurse within a TIA clinic setting) and control group. The study design may have been improved by comparing more than one group; for example, one group who receive the intervention in its current format (leaflet read through and distributed by a TIA nurse within a TIA clinic setting), a second group who receive the leaflet only (without any explanation or reinforcement from the TIA nurse) and a control group.

It appears that the intervention not only improved stroke symptom recognition but also improved help seeking behaviour. Participants in the intervention group were more likely to recognise their symptoms, realise the seriousness of their symptoms and initiate an emergency response by contacting the EMS. The intervention also appears to have improved the satisfaction of patients in relation to information and advice. The intervention group were more likely to be satisfied with information provision. Participants who did not receive the intervention were more likely to seek out their own sources of information and feel dissatisfied in terms of their information needs.

Phase four has shown that a targeted intervention can be delivered to patients at higher risk of stroke, within the context of a TIA clinic. The intervention may also have the potential to increase the proportions of patients accessing the EMS, may contribute towards reducing pre-hospital delays and may improve patient satisfaction with information.

6.1 Further Research

Further research is needed to explore the feasibility of interventions for improving help seeking behaviour after stroke and TIA. Within this study the extent to which the role of the nurse influenced the success of the intervention over and above the leaflet is not known. Further research in this area should also explore the role of the nurse in the delivery of the intervention. Any future research should explore a range of ways in which the intervention could be implemented and any associated cost implications (e.g. leaflet read through and distributed by a nurse; leaflet given to patients without any explanation or reinforcement; leaflet posted to patients with or without follow-up and additional explanations). Depending on the likelihood of contamination, interventions could be assessed using a feasibility trial design with either randomisation at an individual patient level or cluster randomisation. A qualitative evaluation should also be included to determine if the intervention needs to adapted, if for example, specific recommendations are made in relation to the key messages or format. Following a feasibility trial, the most appropriate interventions could be tested more definitively in a multi-centre evaluation study.

6.2 Contribution to Knowledge

The overall aim of this thesis was to explore the factors that influenced the decision-making process when seeking medical help at the onset of stroke symptoms. These factors were used to develop a stroke awareness intervention which was then tested in a high risk population. This thesis has contributed to knowledge by reviewing the literature on stroke awareness and developing a theoretical framework that aimed to reflect the decision-making process for seeking help after stroke. Subsequently, the theoretical framework and results from a focus group were used to underpin the development of a stroke awareness intervention that was piloted within a high risk population. The intervention demonstrated the potential to improve help seeking behaviour after stroke and TIA by increasing the proportions of patients accessing the EMS and reducing the delay in seeking help from the EMS. This is the first study to have explored the impact of an intervention aimed at improving help seeking behaviour within populations at higher risk of stroke.

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APPENDIX 1 – PHASE ONE SEARCH STRATEGY

1	Stroke/
2	Emergency medical services/
3	Emergency medical technicians/
4	Emergency treatment/
5	Emergency medicine/
6	Ambulances/
7	Air ambulances/
8	Patient admission/
9	Telemedicine/
10	Prehospital.ab,tw,ti.
11	Pre-hospital.ab,tw,ti.
12	Paramedic.ab,tw,ti.
13	Emergency nurses.ab,tw,ti.
14	Emergency technician.ab,tw,ti.
15	Emergency practitioner.ab,tw,ti.
16	Emergency dispatch.ab,tw,ti.
17	Emergency despatch.ab,tw,ti.
18	First responder.ab,tw,ti.
19	Emergency rescue.ab,tw,ti.
20	Emergency triage.ab,tw,ti.
21	Emergencies.ab,tw,ti.
22	Public awareness.ab.tw.ti.
23	Knowledge.ab.tw.ti.
24	Screen$.ab.tw.ti
25	Educat$.ab.tw.ti
26	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27	1 and 26
28	Limit 27 to English language
29	Limit 28 to human

/ = medical subject heading (MeSH)
exp = explode subject heading
* = focus subject heading
ab = abstract word search
tw = text word search
ti = title word search
$ = any ending

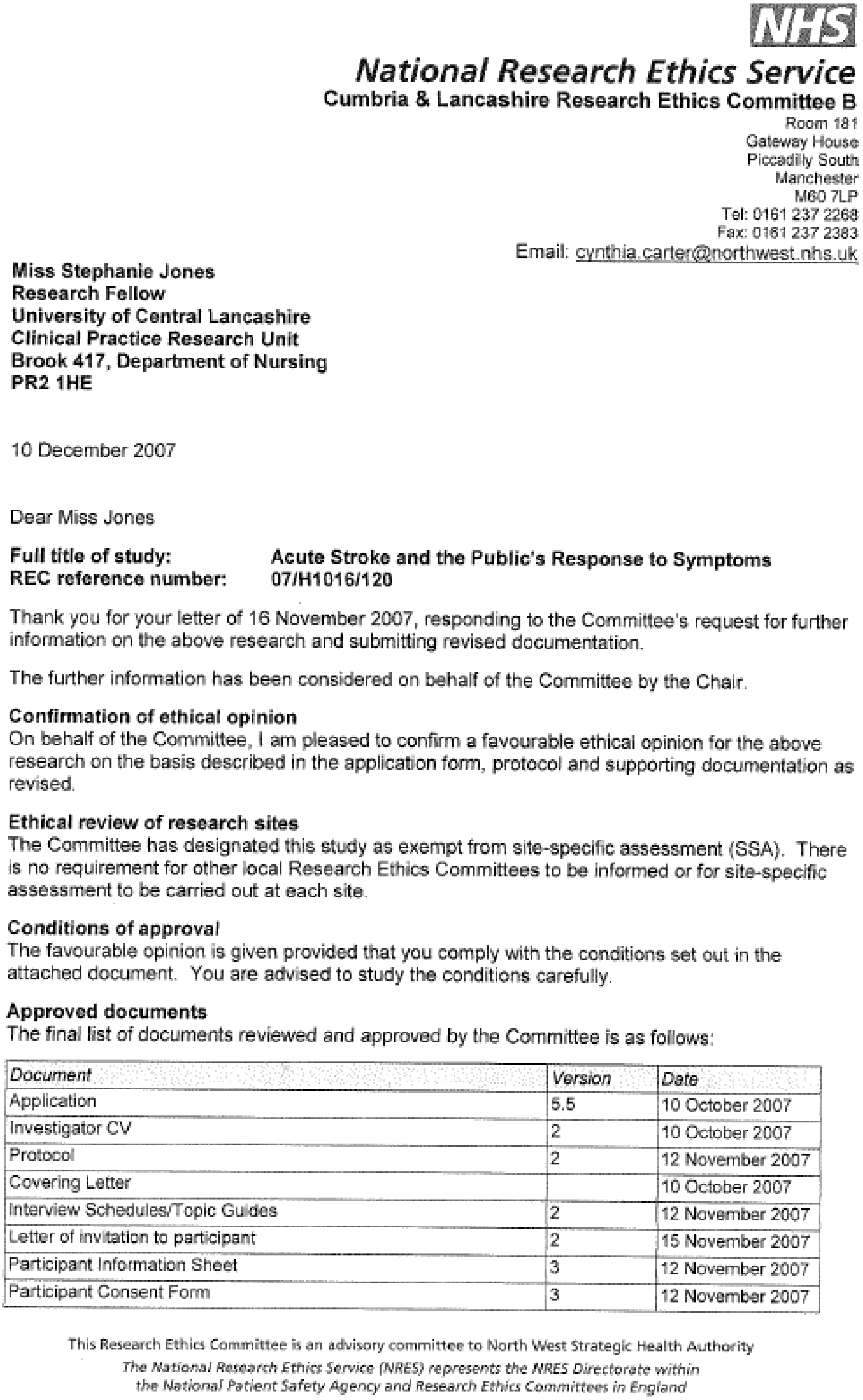
APPENDIX 2 – DATA EXTRACTION PROFORMA

Criteria	**Data**
Title	
Author (Year)	
Topic area	
In what year or time period was the study carried out	
What is the research question	
What are the main and relevant conclusions of the study	
Do the researchers acknowledge the limitations of this study	
List any limitations acknowledged by the researchers	
Are other limitations possible	
List any other possible limitations	
In which country is the study based	
What is the study design (open or closed) (face-to-face, telephone, postal, on-line)	
Are inclusion criteria listed	
List inclusion criteria	
Are exclusion criteria listed	
List exclusion criteria	

What is the sample size	
How is the sample size justified	
Is the study prospective or retrospective	
Who are the population	
Were there any potential biases	
If yes to potential biases please list	
Stroke or TIA	
Type of stroke	
Female (%)	
Age (mean)	
Ethnicity (%)	
Response rate (n and %)	
Were patients treated differently	
If yes, how were patients treated differently	
Did the study involve any interventions	
If the study involved interventions please list them	
What is the duration of intervention	

At what time point were they recorded	
Main results reported	
Who recorded the measurements/carried out interviews	
Is the study a randomised or quasi-randomised trial	

APPENDIX 3 – PHASE TWO LOCAL RESEARCH ETHICS COMMITTEE APPROVAL



NHS

National Research Ethics Service
Cumbria & Lancashire Research Ethics Committee B
Room 181
Gateway House
Piccadilly South
Manchester
M60 7LP
Tel: 0161 237 2268
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Email: cynthia.carter@northwest.nhs.uk

Miss Stephanie Jones
Research Fellow
University of Central Lancashire
Clinical Practice Research Unit
Brook 417, Department of Nursing
PR2 1HE

10 December 2007

Dear Miss Jones

Full title of study:	**Acute Stroke and the Public's Response to Symptoms**
REC reference number:	**07/H1016/120**

Thank you for your letter of 16 November 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites
The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval
The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents
The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application	5.5	10 October 2007
Investigator CV	2	10 October 2007
Protocol	2	12 November 2007
Covering Letter		10 October 2007
Interview Schedules/Topic Guides	2	12 November 2007
Letter of invitation to participant	2	15 November 2007
Participant Information Sheet	3	12 November 2007
Participant Consent Form	3	12 November 2007

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

APPENDIX 4 – PHASE TWO FACULTY OF HEALTH ETHICS APPROVAL

22nd March 2007

Stephanie Jones & Caroline Watkins
Nursing
University of Central Lancashire

Dear Stephanie & Caroline

Re: Faculty of Health Ethics Committee (FHEC) Application - (Reg. No.007): Application to Register for a Research Degree

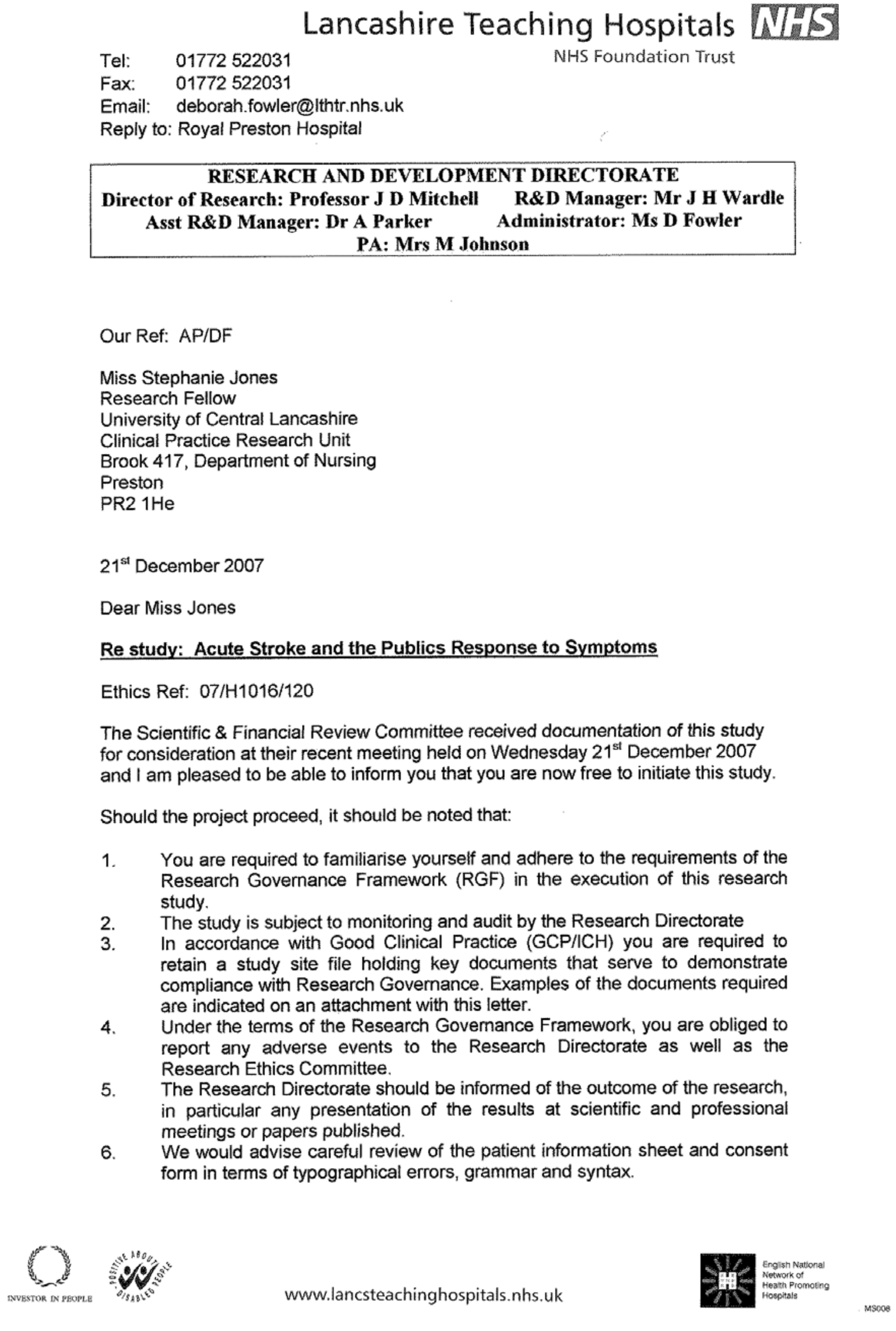
On the basis of the information contained in the Research Degrees Application form, the FHEC does not envisage any insoluble ethical issues arising and therefore has no objection to the project ‘Strategies for Knowledge and Behaviour Change in Stroke’ proceeding to registration.

However, before any data collection from research participants commences, a full proposal application will need to be submitted to and approved by FHEC. When you make this application, please ensure that you quote the Registration reference number (above) on your FHEC application form. You may find it convenient to make separate proposal applications for different stages of the project, especially if the design of the later stages is highly dependent on the findings from the earlier stages. Please refer to the FHEC ‘Notes for Applicants’ for further guidance.

Yours sincerely

Chris Sutton
Chair
Faculty of Health Ethics Committee

APPENDIX 5 – PHASE TWO RESEARCH AND DEVELOPMENT APPROVAL (PRESTON)



Lancashire Teaching Hospitals NHS
NHS Foundation Trust

Tel: 01772 522031
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Email: deborah.fowler@lthtr.nhs.uk
Reply to: Royal Preston Hospital

RESEARCH AND DEVELOPMENT DIRECTORATE
Director of Research: Professor J D Mitchell **R&D Manager: Mr J H Wardle**
Asst R&D Manager: Dr A Parker **Administrator: Ms D Fowler**
PA: Mrs M Johnson

Our Ref: AP/DF

Miss Stephanie Jones
Research Fellow
University of Central Lancashire
Clinical Practice Research Unit
Brook 417, Department of Nursing
Preston
PR2 1He

21st December 2007

Dear Miss Jones

Re study: Acute Stroke and the Publics Response to Symptoms

Ethics Ref: 07/H1016/120

The Scientific & Financial Review Committee received documentation of this study for consideration at their recent meeting held on Wednesday 21st December 2007 and I am pleased to be able to inform you that you are now free to initiate this study.

Should the project proceed, it should be noted that:

1. You are required to familiarise yourself and adhere to the requirements of the Research Governance Framework (RGF) in the execution of this research study.
2. The study is subject to monitoring and audit by the Research Directorate
3. In accordance with Good Clinical Practice (GCP/ICH) you are required to retain a study site file holding key documents that serve to demonstrate compliance with Research Governance. Examples of the documents required are indicated on an attachment with this letter.
4. Under the terms of the Research Governance Framework, you are obliged to report any adverse events to the Research Directorate as well as the Research Ethics Committee.
5. The Research Directorate should be informed of the outcome of the research, in particular any presentation of the results at scientific and professional meetings or papers published.
6. We would advise careful review of the patient information sheet and consent form in terms of typographical errors, grammar and syntax.

APPENDIX 6 – PHASE TWO RESEARCH AND DEVELOPMENT APPROVAL (BLACKPOOL)

Research & Development Department

Today's Research ~ Tomorrow's Care
researchideas@bfwhospitals.nhs.uk

Blackpool, Fylde and Wyre Hospitals
NHS Foundation Trust

Home 5
Blackpool Victoria Hospital
Whinney Heys Road
Blackpool
Lancashire
FY3 8NR

Telephone: 01253 655547

Director: Dr Peter Isaacs

Acting R&D Co-ordinator: Christine Morris
R&D Facilitator: Nicky Richardson
Nicola.Richardson@bfwhospitals.nhs.uk

Ref/PI/NJR/348

16th January 2008

Stephanie Jones
Project Co-Ordinator
University of Central Lancashire
Department of Nursing
Clinical Practice Research Unit
Preston
PR1 2HE

Dear Stephanie

Research Protocol: **Acute Stroke and the Public Response.**
REC Reference: **07/H1016/120**
R&D Reference: **RD0348**

I am pleased to inform you that the research approval administration process for your project has been completed successfully.

Details of your research project will be entered onto the database maintained by the R&D Office.

All research carried out within the Blackpool, Fylde & Wyre Hospitals NHS Trust should be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (Second Edition, DH 2005).

In accordance with ICH/GCP (Good Clinical Practice) you are required to retain a study site file holding key documents that serve to demonstrate compliance with Research Governance. *(See enclosed checklist)*

Under the terms of the Research Governance Framework, you are obliged to report any adverse events to the R&D Department in line with your protocol.

The R&D Department must be informed of any amendments to the project.

Chairman: Miss Beverly J Lester LL.B.   Chief Executive: Mr Julian Hartley

The R&D Office will send out a short questionnaire for monitoring purposes. If your project is for less than one year, monitoring will occur at the end of the project. We will also contact you at the predicted closure date of your research to follow up on your progress.

The R&D Department should be informed of the outcome of the research, in particular any presentation of the results at scientific or professional meetings, papers published or direct and indirect impacts on patient care.

May I also draw your attention to the need to comply with the Health & Safety at Work Act, the Data Protection Act and the Human Tissue Act 2004.

Please contact us if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely

Dr P E T Isaacs
Research & Development Director

Copy to:

Suzanne Tytler, Director Manager for General Medicine, BVH
Joanne Howard, Stroke Research Nurse, Home 5, BVH

APPENDIX 7 – PHASE TWO GP LETTER OF INVITATION

2nd January 2008

Dear (Insert Name),

Re: Acute Stroke and the Response to Symptoms

In conjunction with the University of Central Lancashire, I would like to invite you to take part in a research project. The project aims to explore how people respond when they suspect they have the symptoms of stroke. You have been invited to take part because you have experience of stroke and health services. We would like to give you the opportunity to tell us about this experience. We are expecting to involve between 8-12 people from your GP surgery. If more than 12 people express an interest in taking part there is a possibility that you may not be chosen to participate.

If you do decide to take part a member of the project team will visit you at home or at another suitable place if you prefer, to conduct an interview. In the interview you will be asked questions designed to allow you to express your views about what happened when you first had your stroke. The interview will take about an hour.

If you wish to take part in the project please return the attached reply slip in the envelope provided. In the meantime if you have any questions or would like any further information please contact Stephanie Jones (Project Co-ordinator) on Tel: 01772 895107.

Yours sincerely

Dr Ronnie Lowe

✂

	Yes	No
I would like to take part in the above project	☐	☐

Print Name ________________________ Tel No. ___________________

Signed ________________________

APPENDIX 8 – PHASE TWO PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Acute Stroke and the Public's Response to Symptoms

Information Sheet

Introduction

You are being invited to take part in the above project. Before you decide, it is important for you to understand why the project is being carried out and what it will involve. Please take time to read the following project information. Please ask the project co-ordinator if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

The aim of the project is to explore people's experience of, and reaction to, stroke symptoms. To do this we will be interviewing people who have had a stroke. We aim to use the findings of this study to inform future public awareness campaigns.

Why have I been invited?

You have been invited to take part because you have experience of stroke and health services. We would like to give you the opportunity to tell us about this experience. We are expecting to involve about thirty-six people altogether.

Do I have to take part?

It is your decision whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to complete a consent form; a copy of which you will keep. We are required to ensure that everyone who takes part in the project has given informed consent. The consent form is evidence that that you understand what your inclusion in this project will involve and that you have agreed to take part in the study. If you decide to take part and complete a consent form, you are still free to withdraw at any time and without giving a reason. Your decision to take part or not, will not affect your current or future care.

What will happen to me if I take part?

A member of the project team will visit you in hospital, at home or at another suitable place if you prefer to conduct an interview. In the interview you will be asked questions designed to allow you to express your views about what happened when you first had your stroke.

The interviews will be recorded. At any time during the interview the recorder can be stopped and parts or all of the interview deleted. At a later point, what was said during the interview will be typed onto paper. We will give you a copy of this typed up information so that you can approve your comments and review, add or delete any information that you feel necessary. As a further measure of confidentiality the recordings will be destroyed, approximately 12 months after the study is complete. This is to allow time for checking the accuracy of the transcripts. Once we have carried out all the interviews we will send out a final report to people who took part, should they like a copy. All information included in this report will be anonymous.

What will happen to the results of the research?

It is intended that as a result of the research, we will be able to raise public awareness of stroke more effectively. The results of the study will be published in reports, journal articles, and may be presented at conferences. Direct quotations from your interview may be used in publications, these will be anonymised so that you cannot be identified. If you would prefer not to be quoted directly, do not initial section 6 on the consent form. If you would like a copy of the reports please contact the project co-ordinator. You will not be identified in any report or publication that is produced.

Expenses

If you would prefer your interview to take place at a local venue other than hospital or your home we would be happy to arrange transport for you. If you arrange your own transport we will cover any travel expenses. These will include petrol costs (23 pence per mile), taxi and bus fares.

What are the possible disadvantages and risks of taking part?

There are no potential disadvantages or risks to taking part in this study. You will however be required to give up between one to two hours of your time. You may feel a little uncomfortable when recalling events that happened when you had your stroke. We would encourage you to discuss taking part in this study with a relative or carer. If you do become upset at any point during the interview we may ask for your permission to inform your relative or carer about what happened.

What are the possible benefits of taking part?

The project aims to understand what influences people's decisions about seeking medical help or not after stroke. You may not gain any direct benefit from taking part in the research. It is hoped that the results from this research will help to inform future education and public awareness campaigns.

Will my taking part in this project be kept confidential?

All information, which is collected about you during the course of the research for example, contact and personal details will be kept strictly confidential. All information will have any identifiers removed so that you cannot be recognised from it.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the co-ordinator who will do their best to answer your questions (Stephanie Jones 01772 895107). If you remain unhappy and wish to complain formally, you can do this through by contacting 01772 895140 or write to Professor Caroline Watkins, Clinical Practice Research Unit, Brook 417, Department of Nursing, University of Central Lancashire, Preston, PR1 2HE.

What will happen to the information I give?

We may use the information that you supply in other related research projects. If this should happen you will not be identified in any future research.

Who is organising and funding the research?

This research is funded by the University of Central Lancashire. The team working on the project are based at The University of Central Lancashire, Preston. There is no payment to the team for including individuals in the study.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by a Local Research Ethics Committee and the Faculty of Health Ethics Committee at the University of Central Lancashire.

Contact for Further Information

If you require further information please contact Stephanie Jones at the University of Central Lancashire, Preston on the following telephone number: 01772 895107.

Thank you for taking the time to read through this information and for considering this request.

Stephanie Jones (Research Co-ordinator)

Centre Number:

Study Number:

Patient Identification Number for this project:

CONSENT FORM

Title of Project: Acute Stroke and the Public's Response to Symptoms

Name of Researcher: Stephanie Jones

Please read each section below and initial the corresponding box. If you do not consent to sections 6 and 7 you can still take part in the study.

	Please initial box
1. I confirm that I have read and understand the information sheet dated 12th November 2007 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my current or future medical care or legal rights being affected.	☐
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Central Lancashire, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
4. I agree to my GP being informed of my participation in the study	☐
5. I agree to take part in the above study.	☐
6. I agree to direct quotations being used in publications and reports	☐
7. I agree to anonymised data being used in future related research projects	☐

______________________	________________	________________
Name	Signature	Date
______________________	________________	________________
Project co-ordinator	Signature	Date

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

(November 12th 2008)

APPENDIX 9 – PHASE TWO INTERVIEW GUIDE

Questions
1. Go back to the beginning … when did you first realise that something was wrong? Tell me what happened.
2. What did you think was the problem? Did you know any of the symptoms of stroke before?
3. How serious did you think your symptoms were? Did you think they'd get better or worse? If things went worse, what did you think? How did you feel?
4. How likely did you think this would be to happen to you?
5. What did you do when you first realised that something was wrong? (If sought help) What did they say/do?
6. What did you think was wrong?
7. What prompted you to take that course of action?
8. Did you think there would be any benefits of going to your GP/hospital? Are you aware of any treatments that can be given for stroke in the early stages?
9. What prevented you from calling for an ambulance/going to your GP or going to hospital straight away? Did you consider any other possible actions? If a delay: You waited before contacting EMS/your GP, why was this? Did anything prevent you from seeking help sooner? How did you feel about that? (e.g physical symptoms prevented action). How did you feel about the way you managed the symptoms? Did you feel able to cope with what was happening?
10. Generally, how do you feel about contacting the EMS/GP? Did that influence your decision to contact EMS/GP? Has that changed since or as a result of you stroke?
11. How did you feel about contacting someone for help? Did you feel confident in contacting someone for help? Did you feel confident in who to contact for help?
12. At what point did you make a decision to contact the EMS/GP? What was going through your mind?
13. What would you advise someone to do if they had a stroke? What would you advise them to do?
14. Is there anything that you think people can do to make a stroke less likely?

APPENDIX 10 – CODING FRAMEWORK

Core Category - the decision-making process for seeking help after stroke.			
Open coding	**Axial coding**	**Main sub-categories**	**Properties of the sub-categories**
Carer recognised symptoms Didn't recognise symptoms as stroke Didn't recognise symptoms as TIA Previous experience of stroke Previous stroke Public awareness Recognised symptoms as stroke Recognised symptoms as TIA Self/patient diagnosis Stroke knowledge Symptoms	Carer recognised symptoms Self/patient diagnosis Recognised symptoms as stroke Recognised symptoms as TIA Stroke knowledge Symptoms Didn't recognise symptoms as stroke Didn't recognise symptoms as TIA	Knowledge of stroke symptoms	Recognition of stroke symptoms Recognition of symptoms but not as stroke
Medical emergency Speech perceived as more serious Symptoms not perceived as serious Symptoms perceived as serious Unsure of seriousness of symptoms Wait for symptoms to improve or worsen Worried about wasting time (EMS or relative)	Symptoms not perceived as serious Symptoms perceived as serious Medical emergency Unsure of seriousness of symptoms Wait for symptoms to improve or worsen Worried about wasting time (EMS or relative) Some symptoms perceived as more serious than others Speech perceived as more serious	Perceived seriousness	Symptoms not perceived as serious Symptoms perceived as serious Unsure of seriousness of symptoms Some symptoms perceived as more serious than others

Open coding	Axial coding	Main sub-categories	Properties of the sub-categories
Dignity Embarrassment Fear Fuss Nerves Panic Patient feelings to the event Pride Upset	Fear Nerves Panic Upset Embarrassment Fuss Pride	Emotional reaction to the event	Negative and not in control – fear Negative and not in control - embarrassment

Open coding	**Axial coding**	**Main sub-categories**	**Properties of the sub-categories**
999 call A&E Arrival at hospital Assessment/tests/treatment Acknowledge need for help Benefits of going to hospital Buzzer helpline Carer action Contact friend Contact neighbour Contact relatives Delay EMS assessment EMS diagnosis EMS transport EMS treatment Immediate action Medical Assessment Unit NHS Direct No other help sought Other help sought Own/private transport Patient action Public transport Third party action	999 call Arrival at hospital Assessment/tests/treatment Benefits of going to hospital Carer action EMS assessment EMS diagnosis EMS transport EMS treatment Immediate action No other help sought Patient action A&E Acknowledge need for help Buzzer helpline Carer action Contact friend Contact neighbour Contact relatives Delay Medical Assessment Unit NHS Direct Other help sought Own/private transport Patient action Public transport Third party action	Help seeking behaviour	Immediate EMS Delay GP NHS Direct Friend/relative Public transport Private transport

Open coding	Axial coding	Main sub-categories	Properties of the sub-categories
Past experience of driving to hospital Past medical history Positive experience Previous experience of contacting GP Previous experiences of contacting the EMS Previous experience of going to hospital Negative experience	Previous experience of seeking medical advice – positive Past medical history Positive experience Previous experience of contacting GP Previous experiences of contacting the EMS Previous experience of going to hospital Previous experience of seeking medical advice – negative Past experience of driving to hospital Past medical history Previous experience of contacting GP Previous experiences of contacting the EMS Previous experience of going to hospital Negative experience	Previous experience of seeking medical advice	Positive experiences Negative experiences

APPENDIX 11 – DEMOGRAPHIC PROFILES OF THE PHASE TWO PARTICIPANTS

Decision Making Process – B1

B1 – is the 54 year old daughter of the patient. She is retired and lives with her husband in a rural location, approximately 20 minutes drive from her mother's house. She is a housewife and a prominent figure within her small, local community. She is an active member of the community and comes across as a caring and considerate daughter. The patient has hypertension and diabetes. The patient's symptoms included collapse, facial droop, slurred speech and arm weakness. The patient's daughter has previous experience of contacting the emergency services.

Patient has a buzzer helpline, she pressed the buzzer but her daughter couldn't hear anything from her. The patient's daughter and son-in-law didn't know whether she had pressed it accidentally or whether something had happened.

↓

The patient's daughter drove over to the patient's house 6 miles away.

↓

"I knew she had had a stroke because her mouth was down and her arm was funny and I rang 999."

Decision Making Process – B2

B2 – is the 59 year old son of the patient. He lives with his father and mother in an urban location and is recently retired from the armed forces. He is very opinionated and has a strong personality. The patient had a number of health problems including: hypertension, heart disease and arthritis. The patient's symptoms included facial droop (including eye and mouth), slurred speech and leg weakness. The patient's son has some previous experience of contacting the emergency services.

The patient and his son were watching a football match on TV. The patient's son asked him to change the TV channel. When his father replied he noticed that he had slurred speech. The patient's son described his symptoms, "*his eyes had drooped and his mouth was hanging, so I walked round and faced him. I said what's up with you? He said nothing, but it was very drunken talk."*

The patient's son thought that there was something wrong and called the ambulance.

Decision Making Process – B3

B3 – is the 54 year old husband of the patient. They live in an urban location. The patient and her husband are very outgoing and have an active social life. The patient works as a barmaid and her husband is DJ. Both the patient and her husband consider themselves to be ‘ok’ in terms of their health but they are both heavy drinkers and smokers and use recreational drugs. The patient’s symptoms included facial weakness, dribbling from the mouth and left hand weakness. The patient’s husband has contacted the emergency services on one previous occasion.

The patient and her husband were sat on the settee. The patient began to cough and her husband realised that her face and drooped and she was dribbling. He recognised the symptoms as a stroke.

↓

The doctor advised the patient’s husband to dial 999.

↓

The patient’s husband dialled 999.

↓

He rang the GP knowing that he would then be given the out of hours doctor. The out of hours doctor rang back within three minutes.

Decision Making Process – B4

B4 – is the 65 year old wife of the patient, they live in an urban location with family close by. The patient is retired but was a housewife. The patient’s wife is friendly but appeared to be quite a nervous person. The patient smokes between 60 and 70 cigarettes a day and drinks a moderate amount of alcohol. The patient also has hypertension. The patient’s symptoms included slurred speech and confusion. The family have experience of contacting the emergency services on a regular basis because their grandson has severe asthma.

The patient walked into the living room. His wife noticed that he had facial weakness and slurred speech.

↓

The patient’s wife asked the patient how he felt and he responded by saying “he felt funny.” She suspected a stroke and dialled 999 immediately.

Decision Making Process – B8

B8 - is the 65 year old wife of the patient, they are both retired and live in an urban location. The patient's wife describes herself as a nervous person who often relies on her husband and other members of the family for support. She is a retired administrative assistant. The patient was previously fit and well and had no prior health problems. The patient's symptoms included facial weakness and loss of balance. Neither the patient nor his wife have any experience of contacting the emergency medical services.

Whilst out shopping the patient became confused and tried to cross a road when a car was coming.

↓

The patient's wife recognised that his face looked like it had drooped and his eye had drooped a little bit.

↓

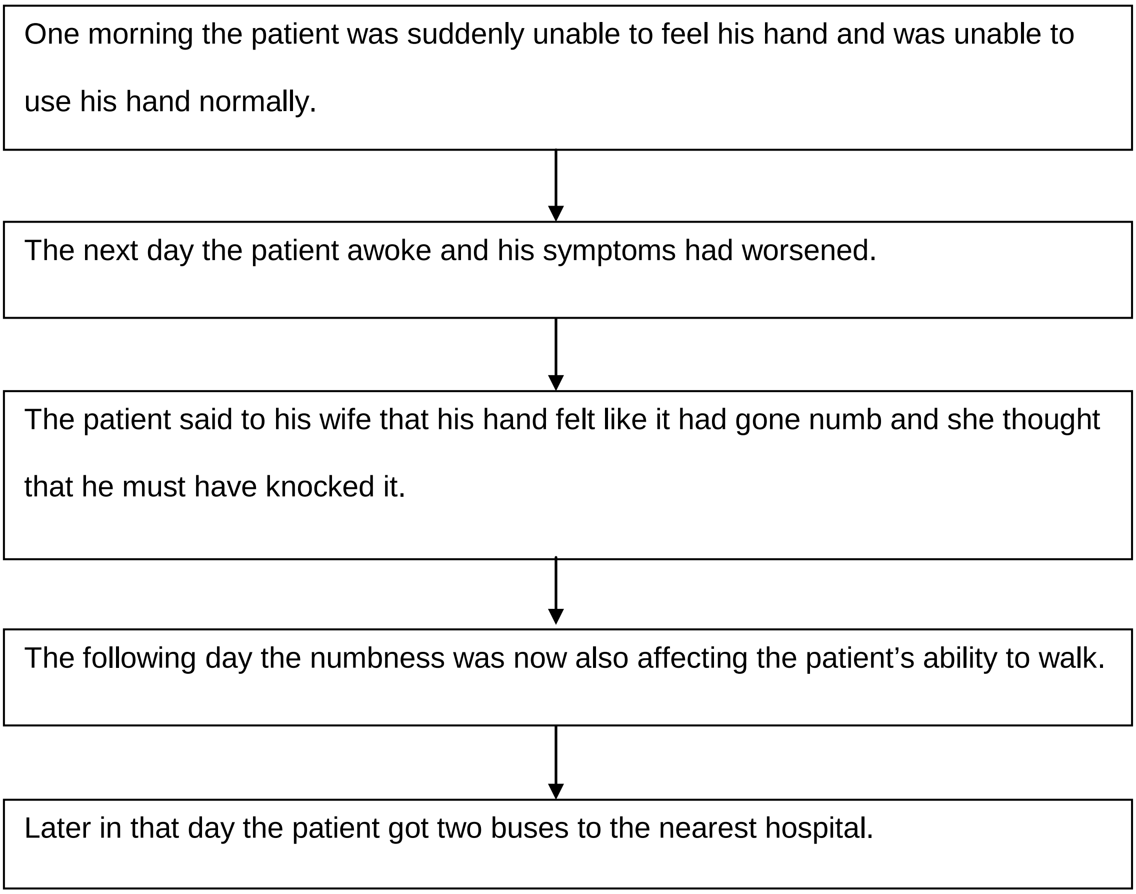
The patient's wife recognised the symptoms as stroke.

↓

The patient's wife rang her son and then her daughter. Her son-in-law advised her to ring for an the ambulance.

Decision Making Process – RPH1

RPH 1 – is a 90 year old male. He lives in a bungalow with his wife in an urban location and is a retired engineer. He seems to be a very determined and happy gentleman who thinks that people ‘should just get on with it.’ He has no previous history of stroke or TIA but has hypertension. The patient’s symptoms included hand, arm and leg weakness. The patient has no previous experience of contacting the emergency medical services.



One morning the patient was suddenly unable to feel his hand and was unable to use his hand normally.

The next day the patient awoke and his symptoms had worsened.

The patient said to his wife that his hand felt like it had gone numb and she thought that he must have knocked it.

The following day the numbness was now also affecting the patient’s ability to walk.

Later in that day the patient got two buses to the nearest hospital.

Decision Making Process – RPH2

RPH 2 – is a 65 year old male and lives with his wife. They have very busy lives and have run a dairy farm with their son. The farm is the patient's priority and he says that he doesn't really socialise outside of the family. The farm is in a rural location on the outskirts of a city. The patient has a history of heart problems, TIA and stroke. The patient's symptoms included hand, arm and leg weakness/numbness.

On a Sunday morning the patient recognised that he was having a stroke. He lay on the sofa and waited for the symptoms to resolve.

↓

At lunchtime the patient was unable to get to the toilet. His wife decided that she was would drive him to hospital as it was Sunday and the GP surgery wasn't open.

Decision Making Process – RPH3

RPH 3 – is a 58 year old male. He lives with his wife in an urban location. He is recently retired from employment with a large aeronautical manufacturer. His wife suffers from a degenerative condition for which she spends a lot of time in hospital. His wife’s health is the focus of the family, due to the seriousness of her condition and her deterioration over recent years. The patient had no previous health problems. The patient’s symptoms included slurred speech, facial droop, hand, arm and leg weakness. The patient has previous experience of contacting the emergency medical services for his wife.

On a Thursday evening the patient noticed that his mouth was starting to drop.

His wife asked the patient if he wanted to phone for the GP or an ambulance but he decided to stay at home and wait to see if his symptoms worsened.

The next morning he woke up and had tingling all down one side and his mouth had drooped.

He tried to take the dog out but could not get very far. Again his wife asked if they should phone for an ambulance or the GP.

The patient phoned his GP and got through to the receptionist. The receptionist advised him to dial 999.

The patient dialled 999.

Decision Making Process – RPH 4

RPH 4 – is a 71 year old female. Previously she had been fit and well and lives alone following the death of her husband a few years ago. She describes herself as a ‘bit of a dare devil’ and her hobbies including climbing and walking. She describes herself as very independent and has an important role within her extended family. She is still of the opinion that if you dial 999 you have to justify why they should send an ambulance out to you. The patient had no previous health problems. Her symptoms included slurred speech, dizziness and leg weakness. She feels that it would be unlikely that she would call an ambulance in the event of any illness. This is influenced by a negative experience that she had when contacting the ambulance service on behalf of her husband. She did not know what was wrong with her husband and found this difficult to communicate over the phone. An ambulance was eventually sent out but her husband sadly died.

When getting out of bed the patient could not walk and had to crawl on the floor, she was looking after her granddaughter at the time. She phoned her daughter to pick her up, but she didn’t tell her that was feeling unwell.

She went upstairs and tried to put curtains up. She said ‘I was trying to prove to myself that I was ok.’

The next morning the patient still had difficulty walking. She suspected stroke but did not have any arm weakness as suggested in the FAST public awareness campaign and so ruled out that it could be a stroke.

The patient’s GP suspected stroke and offered to ring for an ambulance but the patient went home first and her daughter drove her to hospital later that day.

Decision Making Process – RPH 5

RPH 5 – is a 76 year old male. He has suffered from multiple sclerosis (MS) for the past 20 years. He lives with his wife in sheltered accommodation. He feels that he has coped well with his MS and his wife agrees. The patient's symptoms included slurred speech and leg weakness. Prior to having his stroke neither he nor his wife had ever called for an ambulance. However, they both believe that if you require an ambulance you should always ring 999. They feel that if you are not seriously ill the hospital would still 'check you over' and send you home.

During the night the patient fell out of bed. The patient's wife contacted the sheltered housing manager, who rang for an ambulance.

↓

The ambulance crew arrived and put the patient back into bed.

↓

The patient's wife suspected that the patient may have had a stroke when he fell out of bed again. The patient also had slurred speech.

↓

The patient's wife contacted the sheltered housing manager, who rang for an ambulance. This time the ambulance took the patient to hospital.

Decision Making Process – TIA 1

TIA 1 – is a 49 year old male. He is fully independent and lives with his wife in an urban location. For most of his career the patient ran his own building company but for health reasons is now a taxi driver. He has no previous history of stroke or TIA but has had two heart attacks. The only symptom reported was facial weakness which last for approximately 17 hours. He has no previous experience of contacting the emergency medical services.

The patient was driving a taxi when he experienced numbness in his hand. The corner of his mouth also began to droop. He drove home after arranging for another driver to collect his passenger.

The patient's wife recognised his symptoms as a TIA. The patient said that he wanted to wait until later on that evening to see if the symptoms would improve.

The following morning the patient rang his GP surgery and his wife took him for his appointment the same day.

Decision Making Process – TIA 2

TIA 2- is an 84 year old male. He is fully independent and lives alone in an urban location. He is a retired musician. He had a previous stroke in July 2005. The has hypertension and heart disease. The patient's symptoms included confusion and visual disturbance. The patient has no prior experience of contacting the emergency services.

The patient woke in the middle of the night and didn't feel 'quite right.' He went back to sleep and when he woke up the next morning he realised that he had had a TIA.

↓

The patient tried to convince himself that there was nothing wrong despite the realisation that he had had a TIA.

↓

The patient managed to get himself out of bed and downstairs. He rang a neighbour as he wanted confirmation as to what the problem was.

↓

His neighbour drove over to the patient's house. She then contacted the patient's GP on his behalf. Later that day she then drove the patient to the GP surgery.

Decision Making Process – TIA 3

TIA 3 – is a 66 year old female. She is fully independent and lives with her husband. She is a retired teacher who now looks after her grandchild on a regular basis whilst her daughter is at work. She had a previous stroke in April 2008. The patient's symptoms included loss of consciousness, loss of speech, facial weakness and visual disturbance. The patient has no prior experience of contacting the emergency medical services.

Whilst in the kitchen preparing lunch the patient suddenly became confused, her speech became slurred and her mouth had drooped at one side.

↓

The patient's husband recognised immediately that she was having another stroke and dialled for an ambulance.

↓

The patient's husband explained his decision to call an ambulance as it appeared obvious that his wife required immediate attention. 'She'd gone grey, she looked glazed and I knew there was something wrong.'

Decision Making Process – TIA 4

TIA 4 – is a 71 year old male. He is fully independent and lives with his wife in a rural location. Although generally fit and well both he and his wife are heavy smokers. He has been retired for a number of years after running a local car sales business. His wife had a stroke 6 months ago and she has made a full recovery. The patient has no previous history of stroke or TIA but has hypertension, hypercholesterolaemia and is heavy smoker. The patient's symptoms included slurred speech and limb weakness (arm and leg). The patient recently contacted the emergency medical services when his wife had a stroke.

Early one evening the patient suddenly felt unwell. The patient's wife asked him 'if he felt ok.' The patient responded 'I just feel a little bit lousy, I think I'll just go and have a lie down.'

His wife gave him a drink of water and told him to take as aspirin. She suspected that he had had a TIA after having had a stroke herself but said that 'she was staying out of it.'

As the patient got out of his chair he had to hold onto the sideboard to steady himself. He fell onto the bed with his head hanging off the edge.

The patient slept through until the next morning. The patient rang his GP surgery but his GP was on holiday. He made an appointment and went to see his GP six days later.

Decision Making Process – TIA 5

TIA 5 – is an 85 year old male. He lives with his wife in a quiet street on the outskirts of a small town. He is fully independent and is the main carer for his elderly, frail wife. He has been retired for the past 20 years and has a busy life running the house and caring for his wife who suffers from severe arthritis. He is extremely house proud and of very smart appearance. Prior to his TIA he was fit and well, with no prior history of stroke or TIA. He has had a pacemaker since 2002. Despite his age Mr X described himself as a fit man and was proud that he was in ‘such good shape’ for his age.

When symptoms arose he was concerned that he did not have time to be ill. His wife needed him and he was concerned about who would look after his wife if he had to go into hospital. His wife was his primary concern and feelings about his own health were often put to one side.

When his symptoms began they included slurred speech, an inability to write or answer questions correctly and a headache. For the first three hours of his symptoms being present he did not want the ‘fuss’ of contacting anyone for help and only sough help as a result of pressure from his daughter. In total his symptoms lasted for approximately 9 hours.

Symptoms began. The patient couldn’t understand written questions and had difficulty writing, he had slurred speech and a headache.

↓

The patient’s wife laughed at his slurred speech.

↓

The patient’s daughter rang and recognised that he had slurred speech over the phone, she also recognised the symptoms as a stroke. The patient’s daughter suggested that he should ring for an ambulance.

↓

The patient’s daughter rang a friend for advice and NHS Direct in Scotland who could not assist. The patient’s daughter threatened to get in the car and drive to the patient’s house.

↓

The patient said “no, I hated the idea. I said I’ll be alright in a minute…. I resist, well I resisted it because I hate fuss and I was, I felt I was getting better…. I was convinced in a couple of minutes I’d be alright…. No, I was convinced it was a false alarm and I just didn’t want a fuss.”

The patient said “If she was going to get in her car, I would have done anything to stop her, and I would have climbed Blackpool Tower.”

The patient said “I wanted the least fuss possible and I thought if I can talk to some, to someone over the phone, it’s worth, it’s better than having a vehicle coming down the road with the flashing lights. I was aiming for the least fuss.”

The patient felt that to ring an ambulance in public was a criticism of the person “it’s a sort of a criticism of you isn’t it.”

The patient compromised with his daughter and called 118 for the number for NHS Direct and then called NHS Direct. NHS Direct suspected stroke and called the ambulance service on behalf of the patient.

NHS Direct said “you should ring the ambulance, would you like me to do it for you”? I said yes please and she did.

Ambulance arrived.

Decision Making Process – GP1

GP 1 - is a 68 year old male. He lives with his wife in an urban location. He is a pleasant gentleman who appears to be quite calm and gentle. He is a retired railway worker. He has no previous history of stroke or TIA but had suffered a previous heart attack. Besides this heart attack he considers himself to be fit and well. He had been a smoker but had given up over 10 years ago. The patient's symptoms included hand, arm, and leg weakness and slurred speech. The patient has no previous experience of contacting the emergency medical services.

Whilst at bingo on a Saturday afternoon, the patient felt 'an electric shock' between his elbow and shoulder blade. He rubbed his elbow a couple of times and ignored it.

Whilst taking his jacket off the patient began to lose sensation in his fingers.

The patient suspected that the symptoms were related to a heart attack that he had three years previously. "*Oh my God I thought, no I don't want another heart attack, not in the middle of this place, a thousand people sitting here ready to start playing bingo*."

The patient asked a member of staff to contact the manager. "*Ask him to ring for an ambulance immediately, I think I'm having a heart attack.*"

The manager dialled 999.

Decision Making Process – GP2

GP 2 – is a 65 year old female who lives with her husband. She is retired and her social life revolves around her family. She is a retired confectioner. She had no previous health problems, although both her parents had had strokes during their lifetimes. Symptoms included loss of consciousness and limb weakness. She has no previous experience of contacting the emergency medical services.

The patient was sat in the breakfast room, she suddenly felt strange and realised she was going to fall off the chair. He lost consciousness and fell.

↓

The patient’s husband ran to get a neighbour to look after his wife.

↓

He then rang the ambulance immediately.

Decision Making Process – GP 3

GP 3 – is a 66 year old female who lives alone in a city suburb. She appears to have a strong personality and is extremely independent following the loss of her husband over 10 years ago. She is a retired care assistant. The patient has a history of stroke and TIA, she also has diabetes, asthma and had had a heart attack in the past. The patient's symptoms included slurred speech, arm weakness and the inability to walk in a straight line. The patient has previous experience of contacting the emergency medical services.

The patient was in a supermarket doing her shopping. She described an almighty headache. She felt confused and was unable to walk in a straight line.

↓

The patient 5 or 6 items in her shopping trolley and wanted to pay for these items so made her way to the till. When trying to get money from her purse her hand wouldn't work properly and she felt embarrassed. The shop assistant serving the patients asked if she was ok and advised her to go to the doctor.

↓

The patient didn't want the fuss or embarrassment of an ambulance arriving at a busy supermarket.

↓

The patients decided to get into her car and drove to the hospital approximately 2 miles away.

APPENDIX 12 – CATEGORISATION OF EMOTIONS ACCORDING TO SCHRÖDER AND COWIE (2006)

Negative and Forceful	Anger, annoyance, disgust, irritation, rage
Negative and passive	Boredom, despair, disappointment, hurt
Negative and not in control	Anxiety, embarrassment, fear, helplessness, powerlessness, worry
Negative thoughts	Doubt, envy, frustration, guilt, shame
Agitation	Shock, stress, tension
Positive thoughts	Courage, hope, pride, satisfaction, trust
Positive and lively	Amusement, delight, elation, excitement, happiness, joy, pleasure
Positive and quiet	Calm, relaxed, relieved, content, serene
Caring	Affection, empathy, friendliness, love
Reactive	Interest, politeness, surprise

APPENDIX 13 – PHASE THREE FOCUS GROUP QUESTION GUIDE

The focus group members will be asked to read through the FAST campaign material, including the FAST television advertisement and leaflets. It is anticipated that the focus group discussion will involve issues around the content and format of each of the educational resources. However, below are some example questions.

Example focus group questions

Which format did you find most useful? Why?

How did you find the presentation of the written information?

Could anything have been improved in terms of size or text? Font?

Was there too little/too much/right amount of information?

What were the most important messages that you picked up from the information?

What key messages would be important to include in any new stroke awareness materials? Why

How suitable do you feel that this (leaflet, TV advert) would be for older people/ ethnic minority groups/carers?

APPENDIX 14 – PHASE THREE FOCUS GROUP FACULTY OF HEALTH ETHICS APPROVAL

11 December 2009

Stephanie Jones
School of Nursing & Caring Sciences
University of Central Lancashire

Dear Stephanie

Re: Faculty of Health & Social Care Ethics Committee (FHEC)
Application - (Proposal No. 388)

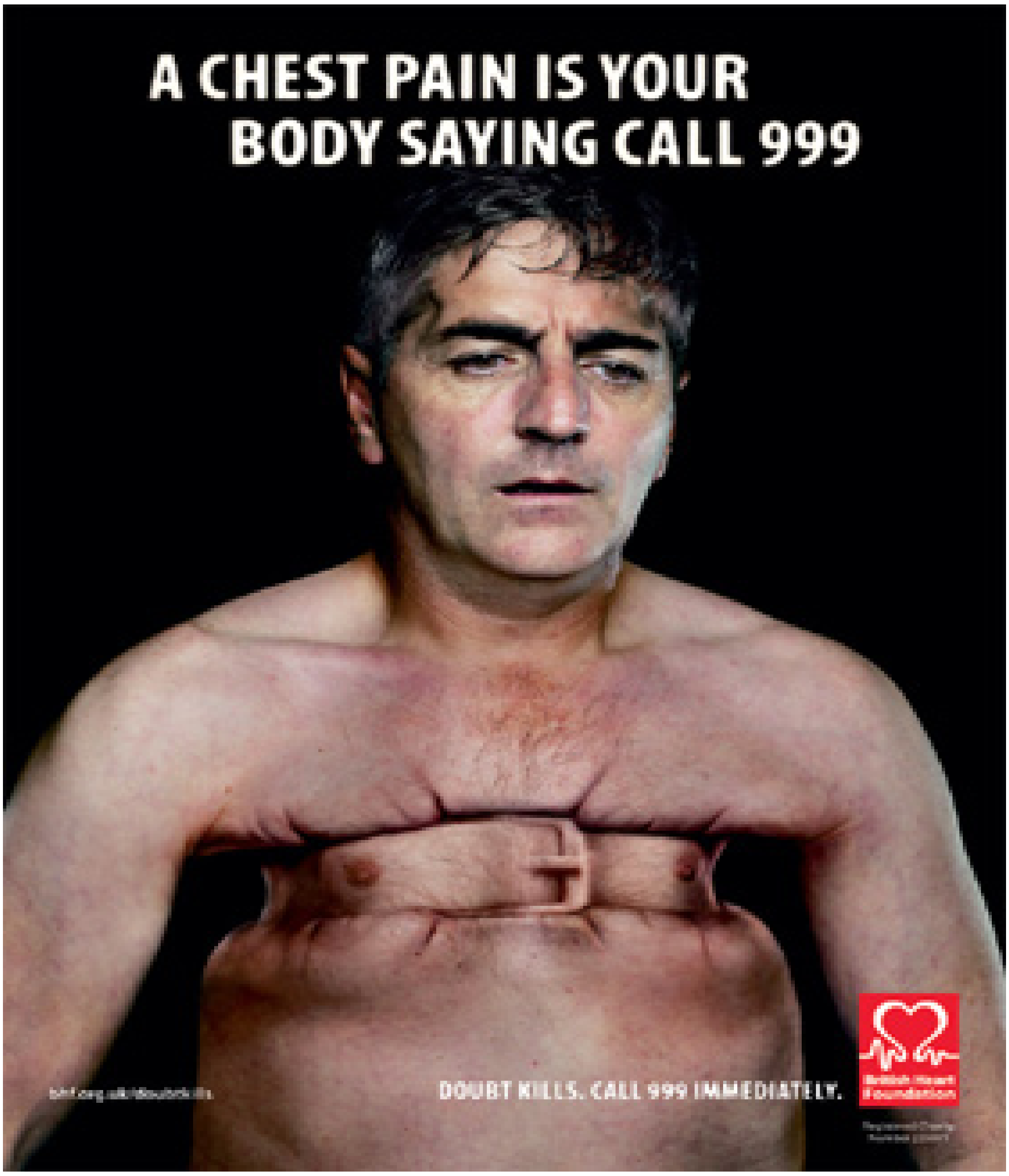
The FHEC has granted approval of your proposal application 'An evaluation of stroke educational materials' on the basis described in its 'Notes for Applicants'.

We shall e-mail you a copy of the end-of-project report form to complete within a month of the anticipated date of project completion you specified on your application form. This should be completed, within three months, to complete the ethics governance procedures or, alternatively, an amended end-of-project date forwarded to Research Office.

Yours sincerely

Damien McElvenny
Chair
Faculty of Health Ethics Committee

APPENDIX 15 – BRITISH HEART FOUNDATION CAMPAIGN



APPENDIX 16 – INTERVENTION LEAFLET

Stroke: Know the Symptoms

Has their **face fallen** on one side?

Can they **raise both arms** and keep them there?

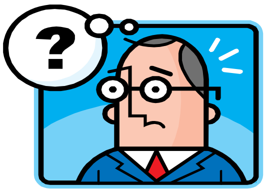
Is their **speech slurred**?

If the answer is yes to **any one** of the above dial **999 immediately**.

Stroke is a medical emergency.

Time lost is brain lost.

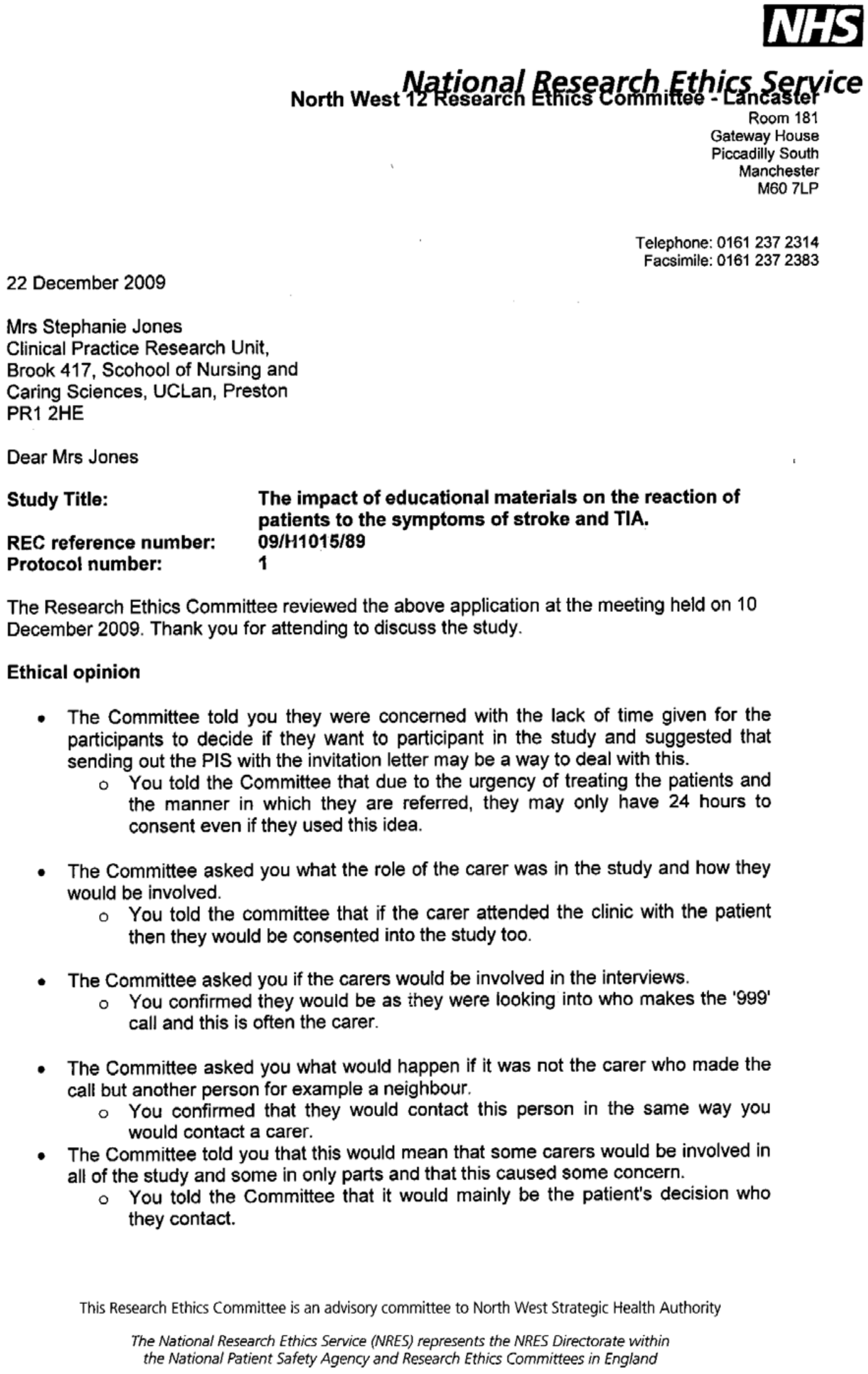
Treatment is available for stroke at hospital.



You may be scared, worried and unsure.

But you must dial **999 immediately**.

APPENDIX 17 – PHASE FOUR LOCAL RESEARCH ETHICS COMMITTEE APPROVAL NOT REQUIRED



NHS
National Research Ethics Service
North West 12 Research Ethics Committee - Lancaster
Room 181
Gateway House
Piccadilly South
Manchester
M60 7LP

Telephone: 0161 237 2314
Facsimile: 0161 237 2383

22 December 2009

Mrs Stephanie Jones
Clinical Practice Research Unit,
Brook 417, Scohool of Nursing and
Caring Sciences, UCLan, Preston
PR1 2HE

Dear Mrs Jones

Study Title:	**The impact of educational materials on the reaction of patients to the symptoms of stroke and TIA.**
REC reference number:	**09/H1015/89**
Protocol number:	**1**

The Research Ethics Committee reviewed the above application at the meeting held on 10 December 2009. Thank you for attending to discuss the study.

Ethical opinion

- The Committee told you they were concerned with the lack of time given for the participants to decide if they want to participant in the study and suggested that sending out the PIS with the invitation letter may be a way to deal with this.
    - You told the Committee that due to the urgency of treating the patients and the manner in which they are referred, they may only have 24 hours to consent even if they used this idea.

- The Committee asked you what the role of the carer was in the study and how they would be involved.
    - You told the committee that if the carer attended the clinic with the patient then they would be consented into the study too.

- The Committee asked you if the carers would be involved in the interviews.
    - You confirmed they would be as they were looking into who makes the '999' call and this is often the carer.

- The Committee asked you what would happen if it was not the carer who made the call but another person for example a neighbour.
    - You confirmed that they would contact this person in the same way you would contact a carer.
- The Committee told you that this would mean that some carers would be involved in all of the study and some in only parts and that this caused some concern.
    - You told the Committee that it would mainly be the patient's decision who they contact.

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

- The Committee suggested to you that doing a retrospective study on patients who attended the clinic 3 months ago could help with the problem of ensuring participants have had enough time to decide to take part in the study.
    - You told the Committee that TIA clinics are rapidly changing and that there may be significant changes over 3 months.

- The Committee asked you if the participants would know what a TIA is.
    - You confirmed they would.

- The Committee asked you if literature is definitely being brought into the service.
    - You told the Committee that educational information is already available but that they were aiming to target higher risk participants.

- The Committee asked you what box you should have ticked on A35 on the IRAS form.
    - You confirmed you had sent an email to Dr S Parker clarifying this but that you would have selected the second box 'The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.'

- The Committee asked you if you are only interviewing 10 of the 250 participants.
    - You confirmed that they will only be interviewing participants who are in the intervention group and that the control group is just for statistics. You informed the Committee that you have done a previous piece of work looking into different ways participants access the service, for example via their GP, and you do not need to interview the control group as they won't be receiving the information.

- The Committee told you, you will need to interview the control group to see if the educational information worked.
    - You told the Committee that you are giving targeted information to find out if it will affect future decisions.

- The Committee asked you if you have the information about how many people who have attended the meeting go on to have a second stroke.
    - You told the Committee the study was looking into the demographics e.g. speed and accessibility of the service and that this was the main objective of the study.

- The Committee asked you how you would find out if a patient had gone on to have a further stroke.
    - You told the Committee that you would follow up on the stoke register to see if a participant had had a further stroke.
- The Committee told you that you would need to take consent for this.

- The Committee asked you if you had considered doing this study without the control group as service development. I.e. all patients would receive the information and the data collected during the previous study could be audited to obtain the relevant demographics.
    - You confirmed you had not considered this.

- The Committee told you that the PIS does not warn participants that they may be approached for future interviews and it should include this.

- The Committee told you that you should include editing rights on the consent forms.

- The Committee asked if you had any experience interviewing people who have had a stroke.
    - You confirmed you had.

- The Committee asked you if you would be using the stroke register to check if participants were still alive or if you had a system in place to ensure you do not try and contact participants who have passed away.
    - You told the Committee that you would check with the participants GP.
- The Committee told you this needed to be included on the consent form.

- The Committee asked you why you are specifically including Hindi speakers and wondered if you would be including participants who speak other languages.
    - You told the Committee you specifically mentioned Hindi as the DVD is in Hindi but that there are translators available for other languages.

- The Committee asked you about the discrepancy between the answer you provided in Question A22 and A23 on the IRAS form concerning patients becoming distressed.
    - You told the Committee that if this happened they would speak with the patient's carer, stroke consultant or nurse with the patient's permission to discuss the issues.

The members of the Committee present decided that it was unable to give a favourable ethical opinion of the research, for the following reasons:

a) The Committee felt that you would not be able to answer your research question using the current methodology. The Committee thought there would be two options you could take to continue with this study.
    - Remove the control group from the study and provide **all** patients in the clinic with the educational information. You could then use the data collected form your previous study to obtain the standard demographics and conduct the study as service development. However, the Committee understood from the information given to them by you during the meeting that this is a rapidly changing service and the data collected from the previous study may be outdated and no longer valid. The Committee therefore suggested that you deliver the service as standard for a period of time (e.g. 3 months) and then distribute the educational information to **all** patients in the clinic. This would allow you to compare the data collected from the 3 months previous to the distribution of the information to the data collected after the information had been given out to all patients.
      If you chose to do this, the Committee would advise you to liaise with your R & D department to confirm they were happy that this was service development

    - Alternatively you could provide the educational information to the group of participants and not to the control group as initially stated in the application, but you must interview both groups in order to be able to compare the data. If you chose to conduct the study like this then the Committee would make the following suggestions to be included in a re-submission.

b) Additions to consent form

  - Include editing rights
  - Include that the participants GP may be contacted.
  - Include that medical records may be accessed.

b) The Committee thought there would need to be a new Participant Information Sheet and Consent form for carers

c) The Committee would need to see the letter that would be sent to the GP when finding out if participants had passed away.

d) The Committee felt there was not enough time to take consent. The Committee thought that it would be a good idea to provide all suitable participants the information and then ask if they were happy to be sent more information regarding the study therefore allowing participants more time do decide if they wish to take part.

e) Amendments to Patient Information Sheet.
  - Change 'referenced to TIA' to mini stroke
  - Include on the PIS 1 that participants may be contacted for future interviews.

I regret to inform you therefore that the application is not approved.

Options for further ethical review

You may submit a new application for ethical review, taking into account the Committee's concerns. You should enter details of this application on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application. We recommend that the application is submitted again to this Committee, but you may opt to submit to another Research Ethics Committee within this domain.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify the relevant Research Ethics Service manager (see below) in writing within 90 days of the date of this letter. If the appeal is allowed, another REC will be appointed to give a second opinion within 60 days and the second REC will be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the meeting of the second REC and will be able to attend and/or make written representations if you wish to do so.

The contact point for appeals is:

Joan Kirkbride
Head of Operations
National Research Ethics Service
C/o Janet Kelly
Darlington Primary Care Trust
Dr. Piper House
King Street
Darlington
Co. Durham
DL3 6JL

Tel: 01325 746167
Mobile: 07979 806425
Email: joan.kirkbride@nres.npsa.nhs.uk

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	*Date*
Covering Letter		24 November 2009
REC application	2.0	23 November 2009
Protocol	1	25 November 2009
Investigator CV	1	23 November 2009
Participant Information Sheet: Stage 1	1	25 November 2009
Participant Information Sheet: Stage 2	1	25 November 2009
Participant Consent Form: Stage 1	1	25 November 2009
Participant Consent Form: Stage 2	1	25 November 2009
Interview Schedules/Topic Guides	1	24 November 2009
Academic supervisor CV	1	23 November 2009
Joanna McAdam CV	1	23 November 2009
Referees or other scientific critique report		
A35 clarification via email		27 November 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

North West 12 Research Ethics Committee - Lancaster

Attendance at Committee meeting on 10 December 2009

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Brenda Ashcroft	Lecturer	Yes	
Mr David Barber	Pharmacist	Yes	
Dr Lisa Booth	Senior Lecturer	Yes	
Dr Nigel Calvert	Associate Director of Public Health	Yes	
Mrs Andrina Lawrence	Lay Member	Yes	
Prof Henry Leese	Professor of Biology	Yes	
Dr Anas Olabi	Consultant Paediatrician	Yes	
Dr John Shakespeare	Retired GP	Yes	
Mrs Valerie Skinner	Nurse (Retired)	Yes	
Mr Stephen Smart	Lay Member	Yes	
Professor Jois Stansfield	Professor of Speech Pathology	Yes	
Dr Jane Stuart	Lay Member	Yes	
Dr Gary Whittle	Consultant in Dental Public Health (retired)	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Rowen Callaghan	Assistant REC Co-ordinator
Dr Sian Parker	REC Co-ordinator

APPENDIX 18 – PHASE FOUR FACULTY OF HEALTH ETHICS APPROVAL

22nd March 2007

Stephanie Jones & Caroline Watkins
Nursing
University of Central Lancashire

Dear Stephanie & Caroline

Re: Faculty of Health Ethics Committee (FHEC) Application - (Reg. No.007): Application to Register for a Research Degree

On the basis of the information contained in the Research Degrees Application form, the FHEC does not envisage any insoluble ethical issues arising and therefore has no objection to the project ‘Strategies for Knowledge and Behaviour Change in Stroke’ proceeding to registration.

However, before any data collection from research participants commences, a full proposal application will need to be submitted to and approved by FHEC. When you make this application, please ensure that you quote the Registration reference number (above) on your FHEC application form. You may find it convenient to make separate proposal applications for different stages of the project, especially if the design of the later stages is highly dependent on the findings from the earlier stages. Please refer to the FHEC ‘Notes for Applicants’ for further guidance.

Yours sincerely

Chris Sutton
Chair
Faculty of Health Ethics Committee

APPENDIX 19 – PHASE THREE RESEARCH AND DEVELOPMENT LETTER OF ACCESS

Lancashire Teaching Hospitals NHS
NHS Foundation Trust

Tel: 01772 522031
Fax: 01772 523184
Email: Lin.Nelson@lthtr.nhs.uk
Reply to: Royal Preston Hospital

RESEARCH AND DEVELOPMENT DIRECTORATE
Director of Research: Professor J D Mitchell
R&D Manager: Lin Nelson
R&D Coordinator & Curriculum Manager: Debi Fowler
Research Assistant: Rasi Gunasekara
Clerical Officer: Natasha Kemp

Our Ref: JDM/LN

Mrs Stephanie Jones
Address Brook 417, Clinical Practice Research Unit,
University of Central Lancashire,
Preston
Post Code PR1 2HE

Dear Stephanie,

Re: R&D Ref: 1395

The Impact of Educational Materials on the Reaction of Patients to the Symptoms of Stroke and TIA – Stage 2

The above study was reviewed on behalf of Lancashire Teaching Hospitals NHS Foundation Trust by the Research Committee on Wednesday, 24th March 2010

At that time a final decision on ethical approval was not available and the committee wished to request additional information before making a decision.

In response to comments made by the Ethics Committee I now understand that you no longer wish to take this study forward as a piece of Research but wish to continue the project as Service Evaluation.

Service Evaluation is defined as being “designed and conducted solely to define or judge current care*” and does not require ethical review. The study similarly does not require formal research governance review however you are expected to ensure that conform to the principles of the Research Governance Framework with regard to the conduct of you study and should inform the Research Directorate when you intend to start you study. You will also be requested to supply regular progress reports and a final summary when the study concludes. You should also seek the cooperation and support of the clinical teams in the Emergency Department or the area where your work will take place.

On the basis that the work is considered as Service Evaluation and on the understanding that you comply with the requirements mentioned above, you have permission to conduct your study at Lancashire Teaching Hospitals NHS Foundation Trust.

Please do not hesitate to contact me if you require clarification or further information.

Yours sincerely

Mrs Lin Nelson
Research and Development Manager

Cc: Dr Michael Leathley

APPENDIX 20 – PHASE FOUR PARTICIPANT INFORMATION SHEET AND CONSENT FORM

The Impact of Educational Materials on the Reaction of Patients to the Symptoms of Stroke and TIA – Stage 2

Participant Information Sheet

Introduction

You are being invited to take part in the above project. Before you decide, it is important for you to understand why the project is being carried out and what it will involve. Please take time to read the following project information. Please ask the project co-ordinator if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

The aim of the project is to try to improve people's knowledge of stroke through providing educational materials. To do this we will be interviewing people who have had a stroke or TIA. It is hoped that the findings from the study will help us to understand how people respond to the symptoms of stroke or TIA. We aim to use the findings of this study to inform future public awareness campaigns.

Why have I been invited?

You have been invited to take part because you have attended a TIA clinic within the last three months, and recently have subsequently had a stroke or TIA. We are expecting to interview up to twenty people altogether.

Do I have to take part?

It is your decision whether or not to take part. We encourage you to talk to a relative or friend first if you are unsure whether or not to take part.

What will happen to me if I take part?

We have to ensure that everyone who takes part in the project has given informed consent. If you do decide to take part, you will be given this information sheet to keep and be asked to complete a consent form, a copy of which will be for you to keep. The consent form is evidence that you understand what your inclusion in the project will involve and that you have agreed to take part in the study. If you decide to take part and complete a consent form, you are still free to withdraw from the study at any time and without giving a reason. If you do decide to withdraw, it will not affect your current or future care.

Following consent to take part, a member of the research team will contact you to arrange to complete the interview over the phone, at your own home or at another venue such as the TIA clinic if you prefer. The interview will last between 20 minutes and one hour and will consist of questions designed to allow you to express your views about what happened when you had your most recent stroke or TIA and how you responded to the symptoms that you experienced. The interview will be recorded using a digital voice recorder. We may contact you within 48-72 hours of the interview to clarify any of the issues discussed to check our understanding. The voice recording from the interview will then be listened to and typed into a written version. Your participation in the study will not affect your current or future care.

Will my taking part in this project be kept confidential?

All information, which is collected about you during the course of the research, for example, contact details will be kept strictly confidential. The only people who will have access to this information will be the research team at the University of Central Lancashire. All interview data will be anonymised and the voice recordings from the interviews will be destroyed, approximately 12 months after the study is complete. We will keep a written copy of the interview for 5 years. All personal information will be removed from the written version so it will not be possible to identify you personally.

What will happen to the information I give?

Anonymised interview data will be kept secure in locked cupboards, in locked rooms at the University. We may use the data that you supply in this and future research projects, publications and presentations. This may include direct quotations. If we do use your interview data, it will have any personal information removed so that you cannot be identified.

What will happen to the results of the research?

It is intended that as a result of the research, we will be able to raise public awareness of stroke more effectively. The results of the study will be published in reports, journal articles, and may be presented at conferences. If you would like a copy of the reports please contact the project co-ordinator. You will not be identified in any report or publication that is produced.

Expenses

If you would prefer your interview to take place somewhere other than your home, for example at the hospital, we would be happy to arrange transport for you. If you arrange your own transport we will cover any travel expenses. These will include petrol costs (23 pence per mile), taxi and bus fares.

What are the possible disadvantages and risks of taking part?

There are no potential disadvantages or risks to taking part in this study. You will however be required to give up approximately one hour of your time. You may feel a little uncomfortable when recalling events that happened when you had your stroke. You can stop the interview at anytime you wish to do so.

What are the possible benefits of taking part?

You may not gain any direct benefit from taking part in the research, but it is hoped that the results will help to inform future stroke education for the stroke patients and the public.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (Stephanie Jones 01772 895107 or Joanna McAdam 01772 895106). If you remain unhappy and wish to complain formally, you can do this by contacting 01772 895140 and writing to Professor Caroline Watkins, Clinical Practice Research Unit, University of Central Lancashire, Preston, PR1 2HE.

Who is organising and funding the research?

This research is funded by the University of Central Lancashire. The team working on the project are based at The University of Central Lancashire, Preston. There is no payment to the team for including individuals in the study.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by a Local Research Ethics Committee and the Faculty of Health Ethics Committee at the University of Central Lancashire.

Contact for Further Information

If you require further information please contact Stephanie Jones at the University of Central Lancashire, Preston on the following telephone number: 01772 895107.

Thank you for taking the time to read through this information and for considering this request.

Stephanie Jones (Project Co-ordinator)

Patient Identification Number for this project:

Patient Consent Form – Stage 2

Title of Project: The Impact of Educational Materials on the Reaction of Patients to the Symptoms of Stroke and TIA – Stage 2

Name of Researcher: ……………………………………………………….

Please initial box

1. I confirm that I have read and understand the information sheet dated .... (version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my current or future medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes, contact details and data collected during the study, may be looked at by individuals from the University of Central Lancashire, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information. ☐

4. I agree to take part in the above study. ☐

5. I agree to anonymised data being used in future related research projects including direct quotations. ☐

____________________	_______________	____________________
Name (please print)	Date	Signature
____________________	_______________	____________________
Researcher (please print)	Date	Signature

When completed, 1 for participant; 1 for researcher site file

APPENDIX 21 – PHASE FOUR INTERVIEW GUIDE

Can you tell me what happened?

How were you feeling at this point?

What did you think was wrong at the time?

What made you think that is was a (MI, stroke etc)?

What symptoms did you have? When did they start?

What was happening? What did you think was wrong?

Who did you contact for help?

Did you consider contacting another source of help? (your GP, 999, family member etc).

How long did you wait between the start of symptoms contacting someone for help/driving to hospital/contacting your GP/dialling 999?

Can you tell me a little bit more about why you waited a while?

Can you tell me a little bit more about why you decided to ring 999 straight away?

What influenced you to (contact your GP first, contact a family member ring 999)?

Have you ever received any information from a health professional about stroke?

Do you remember receiving any information about stroke when you attended the TIA clinic?

Did any of the information that you were shown influence your decision to dial 999/delay?

What were the most important messages that you picked up from the information?

Was there too little/too much/right amount of information?

How helpful did you find this information?

Did you feel that is was useful/relevant to you?

Did you feel that the information that you received applied to the symptoms that you were having? (Did they make the connection?)

Did you find your own source of information about stroke/TIA?

Thinking back to the symptoms that you had before you attended the TIA clinic? Did you do anything differently this time round? If so why? If not, why not?

Have you rung 999 before? Would you feel confident in doing so? Confidence in that situation?

What treatments available for stroke?

APPENDIX 22 – DEMOGRAPHIC PROFILES OF THE PHASE FOUR PARTICIPANTS

Decision Making Process – Reg 7 (Control Group)

The patient is male, 72 years of age and lives with his wife. He has an active social life and still enjoys travelling with his wife. The patient is a retired engineer. The patient would advise contacting your GP for suspected stroke or TIA. The patient has severe arthritis in his back and neck and has atrial fibrillation. The patient has no previous experience of contacting the emergency medical services.

The patient experienced arm weakness whilst eating his breakfast and booked an appointment to see his GP.

↓

The patient went to see his GP 2 days later.

↓

When the patient experienced a second event he had numbness on one side of his face, which he thought was a trapped nerve.

↓

The patient contacted his GP for advice.

Decision Making Process – Reg 30 (Control Group)

Reg 30 is a female patient, 70 years of age and lives alone. She is a retired shop assistant. The patient is quite isolated and although she is able to get out of the house she rarely does so. She has hypertension and has had a number of recent falls but remains independent. The patient experienced right sided leg and arm weakness. The patient would recommend contacting your doctor or hospital for suspected stroke or TIA. The patient has no previous experience of contacting the emergency medical services.

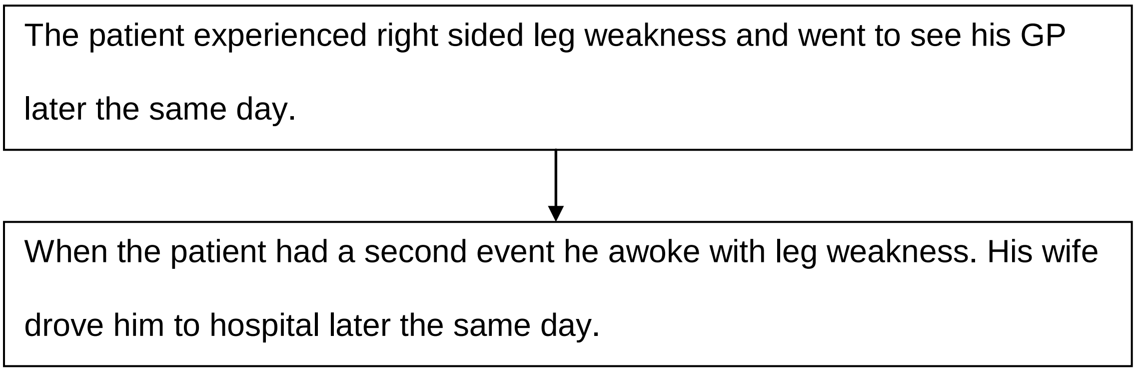
The patient experienced right sided weakness and rang her cousin for advice. Her sister came to the patient’s house and then drove her to hospital.

When the patient experiences similar symptoms she waiting an hour to see if her symptoms would resolve before again rang her cousin for advice.

The patient’s cousin came to the house and after waiting to see if the symptoms resolved decided that they should ring for an ambulance.

Decision Making Process – Reg 48 (Control Group)

Reg 48 is a male patient, aged 59 years who lives with his wife. He works as a plumber. He is a quiet man who is keen to carry on working having made a full recovery from two previous strokes. The patient awoke with leg weakness. The patient has had a previous stroke and has diabetes. The patient would advise going to hospital but not necessarily by ambulance. The patient has no previous experience of contacting the Emergency Medical Services.



The patient experienced right sided leg weakness and went to see his GP later the same day.

When the patient had a second event he awoke with leg weakness. His wife drove him to hospital later the same day.

Decision Making Process – Reg 127 (Control Group)

Reg 127 is a male patient who is 55 years of age and lives alone. He works as a security guard, although at the time he was interviewed he was unable to work. He is a strong character and is frustrated that he has not made a full recovery. When the patient had a TIA he experienced leg weakness and slurred speech. When he had a subsequent stroke he experienced leg and arm weakness and slurred speech. The patient has hypertension, hypercholesterolemia and up until recently was a heavy smoker. The patient has no previous experience of contacting the emergency medical services.

The patient experienced leg weakness and slurred speech and went to see his GP the next day.

↓

When the patient experienced a subsequent stroke, he rang for an ambulance immediately.

Decision Making Process – Reg 186 (Control Group)

Reg 186 is a female patient who is 79 years of age and lives alone. She is a retired nurse but worked as a sister in the community setting for many years. She has a strong personality and is very independent. She has an active social life, mainly involving activities organised through the church and retired nurses association. She survived breast cancer and has arthritis but is generally fit and well. The patient experienced slurred speech when she experienced both her first and subsequent TIA. The patient would recommend contacting your GP for suspected stroke or TIA. Although the patient has experience of contacting the emergency medical services, she described ringing for an ambulance as something that should only be done for serious problems such as severe burns.

Whilst out for lunch with her family she experienced slurred speech. She realised that she was having a stroke or TIA but sat in silence throughout lunch. She didn’t mention anything to her family and drove herself home.

↓

The following day was a bank holiday Monday and so she waited until the Tuesday to make an appointment with her GP.

↓

When the patient experienced slurred speech again, she made an appointment to see her GP a few days later.

Decision Making Process – Reg 198 (Control Group)

Reg 198 is a female patient aged 52 years who lives with her husband. She is a retired teacher. She has severe epilepsy and has had to retire from teaching on medical grounds. The patient experienced slurred speech when she had a TIA and limb weakness and slurred speech when she had a stroke. The patient would recommend going to hospital for suspected stroke or TIA. The patient has some previous experience of contacting the emergency medical services.

She experienced slurred speech and her husband decided to drive her to A&E later the same day.

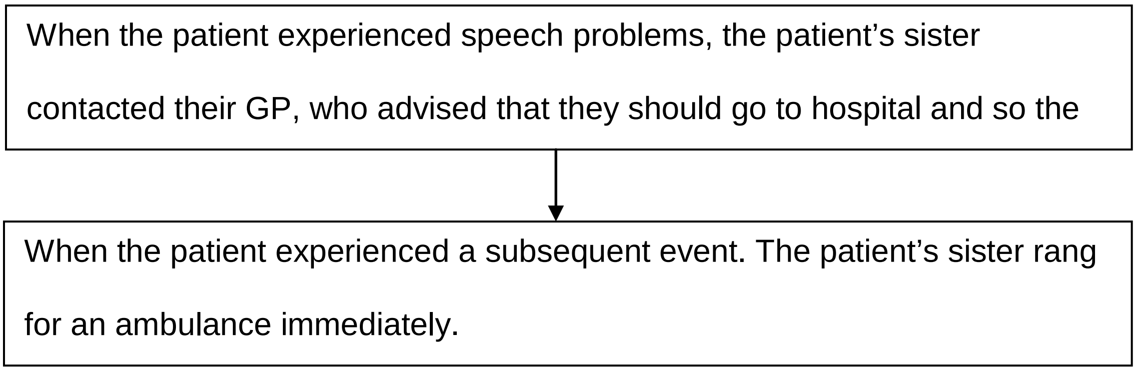
↓

Whilst on a bus the patient again experienced slurred speech and upper limb weakness. On recognising the symptoms she rang her husband who was unavailable. A friend came to collect her and took her home. The patient rang her daughter who drove her to hospital.

Decision Making Process – Reg 17 (Intervention Group)

Reg 17 is a female patient, aged 88. She is a retired housewife. She lives with her sister who is of a similar age. She has a number of health problems including short term memory loss, diabetes, hypertension, atrial fibrillation, hypercholesterol, diabetic neuropathy and retinopathy. She has also survived breast cancer. The patient's symptoms included slurred speech and limb weakness. When the patient had a subsequent event she experiences slurred speech and collapsed.

They describe being reassured that they should ring for an ambulance if the patient experienced stroke-like symptoms in the future. The patient's sister said that this reassurance gave her the confidence to ring 999 when her sister experienced another TIA. The patient and her sister would recommend dialling 999 for suspected stroke. They had no prior experience of contacting the emergency medical services.



When the patient experienced speech problems, the patient's sister contacted their GP, who advised that they should go to hospital and so the

When the patient experienced a subsequent event. The patient's sister rang for an ambulance immediately.

Decision Making Process – Reg 31 (Intervention Group)

Reg 31 is a female patient aged 82 years. She is widowed and lives alone. She is a retired secretary. She has a strong personality and is proud that she is able to maintain her independence. She spends much of her time with family, especially her daughter and granddaughter. She has a number of health problems including diabetes, hyperthyroidism, hypertension, arthritis, ischaemic heart disease, angina and emphysema. The patient's symptoms included upper and lower limb weakness. When she experienced a subsequent event she reported visual disturbance, upper and lower limb weakness. She has had a number of angina attacks and finds NHS Direct useful in advising her about what to do in these situations. Despite receiving the educational and behavioural change intervention, the patient would still recommend contacting NHS Direct for suspected stroke. The patient has no previous experience of contacting the emergency medical services but has past experience of contacting NHS Direct.

When she experienced the symptoms of stroke she contacted NHS Direct. She has had a number of angina attacks and finds NHS Direct useful in advising her about what to do in these situations.

Following her stroke and attendance at the TIA clinic, she had a further TIA. As she has done before the patient contacted NHS Direct.

Decision Making Process – Reg 47 (Intervention Group)

Reg 47 is a female patients aged 73 years of age. She is a retired teacher and lives with her husband. Before she experienced her TIA she had been in relatively good health and has only hypertension and hypercholesterolemia. The patient’s symptoms on both occasions included slurred speech and lower limb weakness. The patient would recommend dialling 999 for suspected stroke or TIA. The patient had some previous experience of contacting the emergency medical services.

She experienced slurred speech and lower limb weakness and waited until the following day before she contacted her GP.

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The patient again experienced slurred speech and lower limb weakness and waited until the following day before she contacted her GP. The patient recognised the symptoms and realised that she had to get to hospital straight away. She asked her husband to ring for an ambulance.

Decision Making Process – Reg 48 (Intervention Group)

Reg 48 is a female patient aged 51 years who lives with her husband. She has a strong personality and works as a care assistant. She has had no previous health problems but is overweight and is a very heavy smoker. On both occasions the patient's symptoms included slurred speech and unresponsiveness. The patient has kept the information given to her at the TIA clinic but couldn't remember where she had put it. The patient herself said that she would only ring for an ambulance for suspected TIA or stroke if the patient had slurred speech or had lost consciousness. The patient had some previous experience of contacting the emergency medical services.

When she experienced her first stroke, she had slurred speech and was becoming unresponsive. Her husband decided to contact primary care for advice, who advised that he should call 999.

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When the patient experienced similar symptoms a second time her husband rang for an ambulance.

Decision Making Process – Reg 49 (Intervention Group)

Reg 49 is a male patient aged 65 years of age. He is a self employed builder. He lives with his wife and has grown up children who are health professionals. He has no other health problems. The patient's symptoms included sudden memory loss and slurred speech. The patient was aware that treatment for stroke should be sought quickly and he would recommend going to A&E at the onset of stroke or TIA symptoms.

Although the patient received the intervention and knew that he should go to hospital quickly, he still sought what he described as 'professional advice' from his daughter and felt that she knew best as she was a pharmacist and worked at the local hospital. The patient had no previous experience of contacting the emergency medical services.

When the patient first experienced sudden memory loss and slurred speech it was a Saturday and he rang his daughter who is a pharmacist for advice.

His daughter contacted primary care who advised that the patient should go and see his GP the following Monday. Following advice from his daughter the patient decided to go to hospital the next day.

Because of a family history of stroke, the patient's daughter suggested that the patient should go to hospital and as she was a health professional the family did not feel that the patient needed an ambulance.

Decision Making Process – Reg 78 (Intervention Group)

Reg 78 is a male patient aged 63 years of age. He is an accountant and lives with his wife. He has hypertension, diabetes and is an ex-smoker. When he experienced a second TIA which resulted in slurred speech he dialled for an ambulance immediately. On both occasions the patient experiences slurred speech. The patient kept the information that he received at the TIA clinic. He could not remember any of the key messages but stated that he had kept the information to refer back to. The patient had close friends who had had strokes and so knew what symptoms to look out for. He also knew that strokes were serious and required immediate medical help which should be sought by dialling 999. The patient had previous experience of contacting the emergency medical services.

The patient experienced slurred speech whilst in a supermarket in London.

He recognised his symptoms as a stroke and drove to hospital immediately.

He did not want the fuss of having an ambulance arriving at the hospital.

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When he experienced a second TIA which resulted in slurred speech he dialled for an ambulance immediately.

Decision Making Process – Reg 90 (Intervention Group)

Reg 90 is a male patient aged 78 years. He is a retired railway worker and lives with his wife. He still enjoys gardening and has an active social life. He has a history of stroke, TIA and hypercholesterolemia. The patient’s symptoms included slurred speech and facial weakness. The patient would recommend going to A&E for suspected stroke. The patient had no previous experience of contacting the emergency medical services.

The patient experienced slurred speech and facial weakness. Although the patient and his wife recognised the symptoms as a stroke they were unsure as to what they should do and so after a few hours the patient’s wife contacted primary care for advice.

Primary care arranged for an ambulance to be sent out.

When the patient experienced his second stroke, both the patient and his wife again recognised the symptoms. They knew that the patient had to get to hospital quickly but rather than ringing for an ambulance they rang their son, who then took the patient to hospital.

Decision Making Process – Reg 169 (Intervention Group)

Reg 169 is a female patient aged 71 years. She is a retired care assistant and lives alone, although her daughter lives in the same street. She enjoys caring for her grandchildren and has an active social life. The patient has a history of TIA, breast cancer and ulcerative colitis. When the patient had her first stroke her symptoms included arm and leg weakness. When the patient had a second stroke she also experienced facial weakness. Despite recognising her symptoms as a stroke, the patient did still not view her symptoms as serious enough to warrant ringing for an ambulance but knew that she needed to get to A&E. The patient would recommend going to A&E for suspected stroke but not by ambulance. The patient had previous experience of contacting the emergency medical services.

The patient experienced arm and leg weakness and recognised the symptoms as stroke. She made an appointment to see her GP four days later.

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When the patient experienced her second stroke, she recognised the symptoms again as a stroke. The patient’s daughter drove her immediately to hospital.