

**REDUCING UNCERTAINTY:
AN EXPLORATORY STUDY OF PEOPLE'S
TREATMENT DECISIONS AFTER TRANSIENT
ISCHAEMIC ATTACK OR MINOR STROKE**

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ABSTRACT

Little is known about people's responses to the impact of a transient ischaemic attack or minor stroke on their health status and future risk of stroke. In this thesis my aims are: to explore how the experience of TIA or minor stroke affects people's perception of their health and their uptake of health maintenance measures; to examine people's assessment, interpretation and perceptions of evidence in relation to their stroke risk; to explore the ways in which people reach decisions about treatment options in the light of their personal experience and in the context of evidence-based healthcare; and to explore the effect of anticipated regret in these processes.

I conducted 28 audiotaped one-to one interviews with a purposive sample of 20 participants, each of whom had previously experienced a TIA or minor stroke. Ten of them had carotid endarterectomy in addition to best medical treatment (BMT). The data collection and analysis used a reflexive approach, based on my clinical nursing practice in this field, and was informed by the constant comparative method of grounded theory.

My findings show that the experience of TIA diminishes people's quality of life and leads to a process of acknowledgement versus denial of its potential threat to health. People access evidence from formal and informal sources in the process of reaching decisions about their treatment. Their decisions tend to be deterministic in nature, even when they are aware of the scientific evidence.

I present a theoretical framework, in which the central theme is the person's use of strategies to reduce uncertainty relating to their risk of stroke. I propose that people's primary aim in seeking health care, accessing information, and making treatment choices after TIA or minor stroke, is to reduce their perception of uncertainty about the threat of a future stroke, rather than to reduce stroke risk itself.

I discuss the implications of these findings in relation to directions for future research, health care policy and nursing practice.

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LIST OF ABBREVIATIONS

AAA	Abdominal aortic aneurysm
ACST	Asymptomatic Carotid Surgery Trial
BMI	Body mass index
BMT	Best medical treatment
BP	Blood pressure
CEA	Carotid endarterectomy
CT	Computed tomography
EBHC	Evidence-based health care
EBM	Evidence-based medicine
EBPC	Evidence-based patient choice
ECST	European Carotid Surgery Trial
GP	General medical Practitioner
GT	Grounded theory
ICA	Internal carotid artery
JG	Jo Gibson (as interviewer)
LDL	Low density lipoprotein
LREC	Local Research Ethics Committee
mmHg	Millimetres of mercury (blood pressure)
MR	Magnetic resonance
MRC	Medical Research Council
NASCET	North American Symptomatic Carotid Endarterectomy Trial
NHS	National Health Service
NNT	Number needed to treat
RCT	Randomized controlled trial
RR	Relative risk
SDM	Shared decision making
TIA	Transient ischaemic attack

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CHAPTER 1

INTRODUCTION

1) Background

Strokes affect 120 000 people every year in the UK, and account for 11% of all deaths (Office for National Statistics, 2005). Stroke is also a source of significant morbidity: the condition has a greater disability impact than any other chronic disease, and it is the largest cause of complex disability (Adamson, Beswick and Ebrahim, 2004). Stroke is defined as: '*a clinical syndrome, of presumed vascular origin, typified by rapidly developing signs of focal or global disturbance of cerebral functions lasting more than 24 hours or leading to death*' (World Health Organisation, 1978). The majority of strokes (69%) are due to cerebral infarction, with smaller numbers from haemorrhagic or unknown causes (Wolfe et al., 2002). The implementation of effective measures to reduce the incidence of stroke will clearly reduce this burden of death and disability. A person's stroke risk is known to be increased by factors common to other atherosclerotic conditions, such as smoking, hypertension, diabetes mellitus and hypercholesterolaemia. Primary stroke risk reduction measures have therefore been developed, with the aim of addressing such factors conferring high risk of stroke in the whole population.

It has been recognised since the time of the ancient Greeks that the risk of stroke is higher in people who have had a recent transient ischaemic attack (TIA; sometimes called a mini-stroke or warning stroke). Writings attributed to Hippocrates (460-370 B.C.) asserted that '*Unaccustomed attacks of numbness and anaesthesia are signs of impending apoplexy*' (Thompson, 1996). A widely accepted definition of a TIA is that it is a sudden, focal neurologic deficit that lasts for less than 24 hours, is presumed to be of vascular origin, and is confined to an area of the brain or eye perfused by a specific artery (National Institutes of Health, 1975). This definition has become contentious in recent years (Albers et al., 2002) and will be discussed later, but for the sake of consistency I will adhere to it throughout this thesis.

Despite the transient nature of the symptoms, those who have experienced a TIA, like minor stroke, perceive themselves to have an impaired health status (Duncan et al.,

1997). Although this is an important issue for clinicians to be aware of, a TIA tends to be treated in clinical practice as simply an important marker for increased stroke risk, rather than as a potentially distressing syndrome in its own right. However, the patient's experience and understanding of the TIA will influence their subsequent actions in seeking healthcare; if, indeed, they do so at all. It is important that people seek urgent medical advice after a TIA, since they have a considerably increased risk of completed stroke in the future, variously estimated at between 10% - 20.1% in the first three months alone (Johnston et al., 2000; Coull, Lovett and Rothwell, 2004; Eliasziw et al., 2004). This is similar to the risk of recurrent stroke after a first minor stroke (Coull, Lovett and Rothwell, 2004). A reduction in the incidence of disabling or fatal strokes can therefore be achieved by developing health services to diagnose TIAs, to investigate the causative factors and to instigate appropriate effective secondary risk reduction measures in those affected by them.

The last 50 years has seen the development and evaluation of many techniques to reduce the risk of stroke after TIA. These include addressing the person's risk factors for stroke, such as uncontrolled hypertension, diabetes, hypercholesterolaemia and smoking. Drug therapy with antiplatelet agents, statins and antihypertensives has also been found to reduce stroke risk, and is now recommended for almost all patients after TIA or minor stroke (PROGRESS Collaborative Group, 2001; Royal College of Physicians, 2004a). In addition, severe stenosis of the carotid arteries is known to be associated with the highest stroke risk in people who have had TIA (European Carotid Surgery Trialists' (ECST) Collaborative Group, 1998), and, to a lesser extent, in those with no prior symptoms (Medical Research Council (MRC) Asymptomatic Carotid Surgery Trial (ACST) Collaborative Group, 2004).

Carotid stenosis can be corrected by the surgical procedure of carotid endarterectomy (CEA). However, CEA itself carries a risk, of around 5%, of precipitating a stroke (European Carotid Surgery Trialists' Collaborative Group [ECST], 1998; Halliday et al., 2004). This is clearly a potentially disastrous outcome for a patient who has previously had only transient symptoms from which they have fully recovered. They would have been by no means certain to have had a further cerebral ischaemic event if they had not had surgery, with at most, a 20% risk without surgery of having a disabling

or fatal stroke. Perhaps partly because of the clinical dilemma posed by this situation, the risks of major stroke and death with or without CEA in this situation have been rigorously researched in the past 20 years. The relative risks of surgery versus medical treatment alone for numerous subgroups of patients with carotid stenosis are now well established. CEA is now strongly recommended (in addition to best medical treatment) for those patients who have had a recent TIA or minor stroke and who have an ipsilateral internal carotid artery stenosis of greater than 70% of the internal carotid artery diameter. In this situation, surgery reduces the patient's long term (3-year) stroke risk from 16.8% to 10.3%; including a 30-day postoperative combined stroke and death rate of 7.5% (ECST, 1998).

CEA is an unusually well-researched surgical procedure, about which there is level 1 (Grade A) evidence for patients with symptomatic and asymptomatic carotid stenosis (Naylor, 2004a). The accumulation of evidence about the effectiveness of CEA has occurred during a period when there has been increasing pressure for the effectiveness of all clinical investigations, treatments and procedures to be better understood and applied appropriately: evidence-based health care (EBHC). An often-quoted definition of EBHC (evidence-based medicine in the original) is: *'the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients'* (Sackett et al., 1996). This definition clearly implies that decision-making in healthcare is the exclusive remit of health professionals, who make decisions *about* their patients.

More recently, however, there has been a growing movement for health services to combine an evidence-based approach with the use of strategies to enable patients themselves to have a voice in making decisions about their care. This movement has been termed evidence-based patient choice (EBPC) (Edwards and Elwyn, 2001) or shared decision-making (SDM) (Makoul and Clayman, 2006). The movement has been driven by ethical considerations of patient autonomy, scientific data suggesting that patients may experience better health outcomes if they are better informed and are able to participate in decisions about their care, and political movements in the British National Health Service towards promoting patient choice (Department of Health, 2003).

Nurses, who have traditionally had a role in caring for and educating patients who are facing threats to their health, have been pioneers in enabling patients to become better informed about their condition and its treatment. Nurses are increasingly called upon to act as patients' advocates; we thus have an important role to play in promoting SDM, to ensure that patients are assisted to make choices which are congruent with their own personal values and expectations, rather than those of health professionals or others.

Many years of large-scale medical research have contributed to the strong evidence base underpinning the epidemiology of TIA and stroke, and the effectiveness of CEA in reducing the risk of stroke in people with significant carotid stenosis. For the health professional faced with a patient at risk of major stroke after a TIA, high quality information about the risks and benefits of treatments such as antiplatelet drugs, statin therapy, and CEA, is readily accessible. However, the experiences, understanding and preferences of people who have themselves had a TIA or minor stroke, and how - or indeed, if - they make choices about treatment to reduce their risk of a major, disabling or fatal stroke, are still little understood. The impact of a TIA on patients' everyday lives is also an unexplored subject. The study on which this thesis is based is an attempt to redress this. The key objectives of the study are to explore the lived experience of TIA and minor stroke, and how individuals perceive and respond to this potential threat to their health.

2) Thesis outline

The literature review for this thesis incorporates several interlinked themes. Chapter 2 reviews the literature on the epidemiology of stroke and TIA, and on methods of reducing stroke risk. Chapter 3 examines studies of patients' experiences, quality of life issues and public understanding in the context of TIA and stroke. Chapter 4 examines the issues of EBHC and SDM in more detail, particularly with reference to the growing movement towards patient autonomy and its potential conflicts with the EBHC approach, and the role of the nurse in enhancing patient-centred approaches to care. This chapter also includes a detailed analysis of the development of CEA and its evidence base, including its political context. The review concludes with a discussion of the

origin of the initial research idea within my own clinical practice, and the aims of the study.

This thesis has evolved considerably from my original starting point, early plans and ideas, and Chapter 5 opens with an outline of how the study was designed and developed. Sections then follow on the methodology used: discussion of the suitability of grounded theory, phenomenological and interview-based approaches, ethical issues, and the practical considerations of how I conducted the data collection and analysis.

Chapter 6 outlines the demographics, personal history and profile of each participant, In this chapter I have given a brief account of each participant, paying due regard to anonymity, to help the reader picture these participants in their mind. Here I also discuss issues arising during recruitment and theoretical sampling.

In Chapters 7 to 10 I present the four main themes of the final analytical framework: The lived experience of TIA; Sources of evidence; Weighing up the odds; and Living with uncertainty. It will be seen that the actual experience of TIA is central to shaping participants' choices and decisions about their health, in relation to the core concept of 'reducing uncertainty'.

Chapter 11 then revisits these themes to discuss them in the context of the scientific, clinical and political background of the study. In this chapter I will also introduce some additional theoretical material from the literature which is related to the emergent themes I have discovered during the development of the thesis. In this way I hope to reflect the chronological development of my contribution to the knowledge base. This final chapter also includes a critique of, and reflections on, the research process, directions for future research, and conclusions and recommendations for clinical nursing.

3) Notes on terminology and language

I have used the word 'patient' throughout to refer to any person who has sought or is undergoing healthcare. Where I refer to specific individuals who have taken part in the

study; I have used the word participant, in order to distinguish the distinct role they had in the context of this research – although in the clinical context they continued, of course, to be patients. I have used the term ‘clinician’ to refer to any health professional undertaking clinical practice, except where I need to refer to a specific individual or profession.

The reader will, by now, have realised that this thesis is written in the first person. My reasons for this are twofold. First, many researchers, writers and readers now accept (as do I) that the use of the active, rather than passive voice in academic writing is clearer, less ambiguous and more readable (Webb, 1992).

My second reason is that the traditional use of the passive third person voice overlooks the integral role of the researcher in the research process, by implying that the approach used is pure, objective and disinterested. However, all researchers have some subjectivity and emotional involvement in their work. This is especially true of qualitative approaches, where writing in the first person is now ‘the rule rather than the exception’ (Wolcott, 2001, p21). This work has been shaped by my clinical practice, personal experiences and by my responses to the emerging data. The use of the first person in this thesis is an attempt to acknowledge these influences and to highlight the reflexive nature of the study.

CHAPTER 2

REDUCING THE INCIDENCE OF STROKE: CLINICAL CONTEXT AND LITERATURE REVIEW

1) The burden of stroke

Most of us in developed countries will find our lives affected by stroke – whether it is we ourselves who experience one, or someone close to us. The high incidence of stroke, as discussed earlier, means that around 120 000 people in the UK experience a stroke each year (Royal College of Physicians, 2004a). The condition more often affects people in later life, with a lifetime risk of around 25% in men and 20% in women after the age of 45 (Bonita, 1992). Stroke is also the third biggest cause of death, with fatal strokes accounting for 11% of all deaths in the UK (Office for National Statistics, 2005). Death from stroke tends to be a sudden and unexpected event, with an overall 30-day mortality after stroke of about 25% (Hankey, 2003), rising to almost 60% in those aged over 80 (Marini et al., 2004), and may thus be particularly distressing for family members to cope with.

However, many people fear having a disabling stroke as much as, if not more than, a fatal one. Six months after a stroke, 53% of survivors will have some degree of physical dependence on others, with 23% of all survivors requiring long-term institutional care (Wade, 1994). The most common impairments in stroke survivors are cognitive problems (33%), problems with the lower limbs (30%), and speech or language impairment (27%) (Wade, 1994). There are also emotional consequences, with 37% of long-term (5 year) stroke survivors having depression or borderline depression scores (Wilkinson et al., 1997). Even minor strokes, whose survivors can independently perform all basic activities of daily living, are associated with significantly reduced quality of life in physical, emotional, social and mental health function (Duncan et al., 1997). In addition to the effects of stroke on its survivors themselves, many more people have to cope with the aftermath of a stroke affecting a family member. Such caregivers, who may themselves be elderly, have been found to have poorer mental well-being than the population norm, despite having better physical health (Li et al., 2004).

It is clear that a stroke can have devastating effects on the long-term health of survivors and their carers, and there are many people coping with such problems. The prevalence of stroke, measured as the proportion of stroke survivors in the population, is estimated at 1.87% in the US, even in those under 75 years of age (Muntner et al., 2002). In the UK, Geddes et al. (1996) estimate stroke prevalence as 0.468%, equivalent to about 300 000 people who are living with the after effects of a stroke.

The high prevalence of stroke also has economic implications. It is estimated that 3% of the healthcare budgets of industrialised countries is spent on the acute treatment of patients after stroke, not taking into account the treatment of comorbid conditions or the social costs of disability (Evers et al., 2004). Wolfe (2000) estimates that stroke services account for 4-6% of the UK National Health Service budget. There are, in addition, financial and social costs for stroke patients themselves. The effects of a disabling or fatal stroke cause particular problems for younger stroke patients and their families, who are likely to have financial and domestic obligations. A disabling stroke can also precipitate dramatic and distressing life changes for an older person, perhaps resulting in greater dependency on kin or necessitating a loss of independent living and a move to residential care. Despite its greater prevalence in industrialised countries and its traditional position (along with coronary heart disease) as a '*disease of affluence*', stroke is in fact more common in poorer socio-economic groups (Whitehead, 1992; p231). People of poorer economic or educational backgrounds may also find it more difficult to seek assistance to identify and reduce their stroke risk, and may also experience greater difficulties socially and financially after a stroke, than more affluent people.

Stroke is a common and therefore costly condition to treat, and it is not surprising that substantial healthcare and health research resources are expended on researching, developing and improving services for those affected by stroke, in order to reduce, or help them adjust to, their disability and to enhance their independence and quality of life. This expenditure reflects the intensive, costly and time-consuming processes of acute care and rehabilitation after stroke. But paradoxically, precisely because acute care and rehabilitation consume so many health resources, it follows that the implementation of effective measures to reduce the incidence of stroke can be highly effective at reducing the financial burden of stroke treatment. Yet until recently, acute

treatment and rehabilitation after stroke has dominated research, health policy, and clinical practice in cerebrovascular diseases. Whilst acute care and rehabilitation are undoubtedly important, a more straightforward strategy to reduce the burden of death and disability imposed by stroke is to implement measures to reduce the incidence of stroke (Wolf, 1998). Two main approaches are primary risk reduction (prevention): the use of measures to reduce the development of cerebrovascular disease in the general population by reducing exposure to causal and risk factors; and secondary risk reduction (prevention): identifying and targeting interventions at those who are known to be at higher risk, and the use of early diagnosis and treatment (Tones and Green, 2004). A third level, tertiary prevention, is not the focus of this thesis¹.

2) Stroke: Primary risk reduction

Most strokes are classified as ischaemic in aetiology, arising from atherothrombosis affecting the cerebral circulation, or from embolisation from other sources of thrombus (for example in atrial fibrillation). These account for 69% of all strokes. Most of the remaining 31% are due to primary (13%) or subarachnoid (6%) haemorrhage (Wolfe et al., 2002). This thesis focuses mainly on reduction of the risk of ischaemic stroke.

A host of modifiable risk factors has been identified for ischaemic stroke. These risk factors are similar to those for other atherothrombotic conditions such as coronary heart disease and peripheral vascular disease. The implementation of effective measures to address these risk factors in the general population will reduce the risk of development of significant cerebrovascular disease and thus reduce stroke incidence.

¹ I have chosen to avoid use of the term 'prevention' which is common in health promotion. It is misleading because it could be inferred that, provided all risk factors are identified and treated, all strokes can be completely prevented. The Concise Oxford English Dictionary defines the verb 'prevent' as 'to hinder, to make impossible'. This surely cannot be a realistic outcome of treatment for stroke risk factors, and in fact, some people who have strokes are not found to have any uncontrolled risk factors. I have adhered to the less elegant, but more accurate, terms 'primary and secondary stroke risk reduction' in order to better reflect this uncertainty. My reasons for doing so will, I hope, become clearer later in this thesis, when I discuss people's perceptions of and responses to stroke risk and its reduction.

a) Treatment of hypertension

Raised diastolic blood pressure (BP) is known to be associated with increased stroke risk, with a 46% increased risk of stroke with every 7.5mmHg increase in diastolic pressure. Conversely, the use of antihypertensives to reduce blood pressure leads to a corresponding fall in stroke incidence (42% reduction for an average blood-pressure reduction of 5.8mmHg). Interestingly, this relationship is apparent even at diastolic pressures considered as normal (under 90mmHg) (Collins et al., 1990). The relationship is even stronger in the 60-79 year age group, with a reduction in stroke risk of approximately one third for every 10mmHg reduction in systolic BP (Lawes et al., 2004). Similarly, in those with isolated systolic hypertension, most common in older people (systolic BP above 160 but diastolic below 90mmHg), antihypertensive medication has been shown to reduce stroke risk by 36% over 4.5 years (SHEP Cooperative Research Group, 1991).

It is also known that restricting the consumption of dietary salt is beneficial in the treatment of hypertension, resulting in typical reductions in systolic pressure of around 5 mmHg in patients on low sodium versus high sodium diets (Jurgens and Graudal, 2004). Some patients experience benefits of greater magnitude, to the extent that they can stop or reduce their antihypertensive medication (Hooper et al., 2004). However, for people with normal blood pressure, reduction in salt intake is of little benefit, resulting in a clinically insignificant mean reduction in systolic blood pressure of only 1.27 mmHg (Jurgens and Graudal, 2004). Nor does a low sodium diet affect these people's 5-year risk of developing hypertension *de novo* (Hooper et al., 2004). There is also no reliable long-term evidence that reduction of salt intake reduces cardiovascular morbidity and mortality (Scientific Advisory Committee on Nutrition, 2003). However, despite the absence of evidence for benefits in reducing salt consumption in order to reduce the incidence of hypertension, current public health advice in the UK (www.salt.gov.uk) advocates that the general population should reduce its salt consumption. Such measures are likely only to benefit those who have already developed hypertension (whether or not it has ever been diagnosed).

b) Tobacco use

There is a strong relationship between cigarette smoking and stroke incidence, with tobacco use increasing risk by some 50%. The increase in risk is dose-dependent, with people who are heavier users of tobacco being at highest risk (Shinton and Beevers, 1989), independent of other risk factors. However, the individual's risk of stroke and other vascular diseases falls rapidly on cessation of smoking, reaching the same level as those who have never smoked within 5 years of quitting (Wolf et al., 1988). Smoking cessation is most likely to be successful if a combination of professional support (Rice and Stead, 2004) and pharmacological therapy, either nicotine replacement therapy (Silagy et al., 2004) or bupropion (Hughes, Stead and Lancaster, 2003), is used. Such interventions increase quit rates typically 1.5 to 2-fold compared with control groups.

c) Physical activity

Exercise has a beneficial effect on stroke risk factors such as hypertension, obesity, dyslipidaemia and glucose tolerance. Both moderate and heavy exercise have been shown to significantly reduce the relative risk of stroke (RR 0.41) in men, but not women, (Kiely et al., 1994). Other researchers have demonstrated benefits in both sexes, and increasing benefits with more strenuous activity (Gillum, Mussolino and Ingram, 1996).

d) Dyslipidaemia

Elevated total cholesterol and elevated low-density lipoprotein (LDL) cholesterol are both associated with increased stroke risk. Randomised trials of statin therapy have shown typical relative risk reductions for stroke of 25% (Straus, Majumdar and McAlister, 2002) to 30% (Warshafsky et al., 1999). The benefits of statin therapy are thought to be partly due to its ability to stabilise atheromatous plaque, reducing its thrombogenicity, as well as its effect on dyslipidaemia *per se*. Other lipid-lowering therapies, such as fibrates, resins or dietary modification, have not been demonstrated to reduce stroke risk (Bucher, Griffith and Guyatt, 1998).

e) Diabetes mellitus

Although the presence of diabetes mellitus itself (type 1 or type 2) is an independent risk factor for stroke, there is no evidence that stroke risk is increased by poor glycaemic control (Diabetes Control and Complications Research Group, 1993; The University Group Diabetes Program, 1970; UK Prospective Diabetes Study Group, 1998). It is thought that the increased stroke rate in people with diabetes is caused by excess incidence of hypertension and hyperlipidaemia compared with non-diabetic people (Straus, Majumadar and McAlister, 2002).

f) Dietary measures

Obesity has been demonstrated by prospective cohort study to be an independent risk factor for stroke. Men with a body mass index (BMI) of 30 or greater have twice the stroke risk of those with a BMI of 20-30, and each unit increase in BMI is associated with a 6% increase in relative stroke risk (Kurth et al., 2002). Other dietary measures which may reduce stroke risk include reducing dietary sodium intake in hypertension, consumption of fish and fish oils (Skerrett and Hennekens, 2003), and consumption of fruit and vegetables (Johnsen et al., 2003). There is also a possible link between raised plasma homocysteine (tHcy) and increased stroke risk (Perry et al., 1995), and it is known that tHcy can be reduced by intake of dietary or supplemental folic acid (Boushey et al., 1995).

g) Medical therapy: antiplatelet and antithrombotic agents

The use of antiplatelet agents such as aspirin is only recommended for reduction of stroke risk in people who have other vascular disease (e.g. coronary artery disease or peripheral vascular disease). In these groups, as well as those who have had a stroke or TIA, antiplatelet therapy with aspirin reduces stroke risk (Antiplatelet Trialists' Collaboration, 1994). A newer agent, clopidogrel, is useful for patients who are unable to take aspirin (CAPRIE, 1996). Although clopidogrel confers slightly greater long-term reduction in risk, current clinical guidelines do not recommend its use in preference to aspirin except in high-risk groups (Royal College of Physicians, 2004a). A combination

of aspirin and clopidogrel does not confer any significant benefit in reducing vascular events; it does, however, increase the risk of haemorrhage compared with clopidogrel alone (Diener et al., 2004).

People with atrial fibrillation have a high risk of stroke from embolisation of cardiac thrombus. Anticoagulation with warfarin significantly reduces their risk (odds ratio versus placebo: 0.3). Aspirin is also moderately effective with an odds ratio versus placebo of 0.68, but is not as effective as warfarin in head-to-head studies (odds ratio 0.64). Anticoagulant therapy is associated with an increased risk of haemorrhage, but this does not outweigh the benefits of reduced stroke risk (Segal et al., 2004).

3) Secondary risk reduction: the problem of identifying people at risk of stroke

Whilst primary risk reduction addresses stroke risk in the whole population, secondary risk reduction focuses on measures to reduce the risk of a major cerebral ischaemic event in people who are already known to have significant cerebrovascular disease, but who have not yet had a disabling stroke. The target population for secondary risk reduction measures is those people who have had a TIA or minor recovered stroke, and those who are known to have significant cerebrovascular disease in the absence of symptoms. The annual incidence of TIA in the UK is estimated at 0.035% (Coull, Lovett and Rothwell, 2004) to 0.04% (Dennis et al., 1989). This is equivalent to about 21 000 people per year in the UK. Many more people have a minor stroke from which they quickly and fully recover. A large (n=10112) telephone survey of the US population revealed that TIA prevalence was 2.3%. Most had hemispheric symptoms; only 9% had amaurosis fugax alone, although 37% had both hemispheric and eye symptoms. In addition, a further 3.2% of respondents reported having experienced symptoms consistent with a TIA but had not sought medical attention. Of those who had sought advice on experiencing a TIA, 36% waited more than 24 hours before doing so (Johnston et al., 2003). These results suggest that only one in every four people who has a TIA seeks medical advice within 24 hours, and that almost 60% of TIAs are never reported to a health professional, perhaps because of the transient nature of the symptoms and a lack of understanding of their potential seriousness. Others do seek

medical advice but the TIA may be still undiagnosed (Koudstaal, Gerritsma and van Gijn, 1989).

It is imperative that people who experience symptoms of a TIA seek urgent medical advice. TIA is an important indicator of future stroke risk, even more so than a previous completed stroke. Three-month stroke risk is estimated to be 8 times higher in those who have had a TIA than after a first completed stroke (Kennedy et al., 2002), with the early (3 month) risk of stroke after TIA being variously reported as 10% - 20.1% (Johnston et al., 2000; Coull et al., 2004; Eliasziw et al., 2004). About half of such strokes are estimated to occur within 2 days of the first TIA (Johnston et al., 2000). It is difficult to see how these very early strokes could be avoided, if only 25% of people seek medical advice within 24 hours of a TIA. However, the recent development and validation of prognostic scores to predict people's risk of very early stroke after TIA may be an important tool in emergency management (Johnston et al., 2007). It is also known that there is a 25.1% risk of any further adverse event, including recurrent TIA, stroke, hospitalisation for cardiac arrhythmia, and death, in the 3 months following a TIA (Johnston et al., 2000). Although stroke risk is highest in the first few months after a TIA, there is also an increased long-term risk of stroke (3.4 % per year after the first) and of myocardial infarction (3.1%) (Hankey, 1991). The annual death rate after TIA is about 7%, of which two-thirds are due to stroke or cardiac disease (Hankey, Slattery and Warlow, 2003). The total five-year risk of further stroke after any first cerebral ischaemic event (whether TIA, minor stroke, or disabling stroke) is estimated at 30-43% (Mant, Wade and Winner, 2004). Even in 'low-risk' patients who have survived the initial high-risk period after a TIA, the ten-year risk of major vascular events (stroke, myocardial infarction or vascular death) is 42.8% (Clark, Murphy and Rothwell, 2003). Short- and long-term secondary risk reduction measures are therefore essential to reduce this burden of excess mortality and morbidity.

In addition to those who have already been identified as having had a TIA or minor stroke, many more people in the general population have severe asymptomatic cerebrovascular disease and thus may also benefit from secondary risk reduction measures. However, as these people have, by definition, had no symptoms, they may never be identified as being at risk of stroke. There is no systematic programme of screening in the UK for asymptomatic carotid disease, although it has been argued that

this is a necessary measure to reduce the incidence of stroke (Toole, 2004). As a result of lack of symptoms, or lack of recognition and self-reporting of symptoms, many people who are at high risk of stroke and who would benefit from secondary risk reduction measures are thus never identified and treated by health services.

Apart from the difficulty in ensuring that all those who experience TIAs or minor strokes seek immediate medical advice, the lack of emphasis on secondary stroke risk reduction is in stark contrast to the higher profile within stroke services of acute treatment and rehabilitation for the condition. These services correspond to 'tertiary prevention', which aims to provide treatment and rehabilitation to reduce the complications of established disease (Tones and Green, 2004). Traditionally, most stroke services in the British NHS have been managed under the auspices of rehabilitation departments rather than acute care, which reflects the intensive, skilled and time-consuming nature of the rehabilitation process. Recently, however, the availability of rapid access neurovascular services for patients with TIA or minor stroke symptoms has been mandated in the UK by the National Service Framework for Older People (Department of Health, 2001). Current guidelines specify that eligible patients should be assessed in a neurovascular clinic and have necessary stroke risk reduction measures implemented within seven days of their TIA or first stroke (Royal College of Physicians, 2004a). This is essential for specialist investigations such as carotid Duplex ultrasound scanning to be accessed, but also, more fundamentally, because the diagnosis of TIA is by no means straightforward (Kraaijeveld et al. 1984; Koudstaal, Gerritsma and van Gijn, 1989). Not all patients with TIAs or minor strokes present with classic carotid territory symptoms, and the symptoms are, by definition, transient and often unwitnessed. Indeed, 40% of patients in one series who were referred to a regional neurovascular clinic with a non-specialist physician's diagnosis of TIA had not, in fact, had a TIA (Martin et al., 1997). If the diagnosis of TIA is not correctly made, then some patients may receive inappropriate treatment after a non-cerebrovascular event, giving rise to the unnecessary use of healthcare resources and possibly exposing the patient to avoidable risk, such as adverse drug reactions. Other patients who have had a genuine TIA or minor stroke may not have their condition recognised, investigated and treated appropriately. Currently, over 80% of UK acute hospitals now have a stroke unit, but only two-thirds have a neurovascular clinic service for rapid assessment and

management of TIAs and minor strokes. Of these, only half are able to see and investigate patients presenting with TIA or minor stroke within 14 days (Royal College of Physicians, 2004b), let alone within the recommended seven-day limit. Therefore, at least two-thirds of acute hospitals in the UK are unable to provide the urgent investigation and treatment needed after TIA or minor stroke.

It follows that, if a patient is to obtain the urgent assessment, investigation and advice they need after a TIA or minor stroke, they (or a relative or friend) must firstly recognise the significance of their symptoms and seek early medical advice. The health professional they consult must then, in turn, appreciate the importance of the presenting symptoms, the necessity for urgent investigation and treatment, and must be aware of any local neurovascular service provision. Even if these criteria are fulfilled, the patient still has, at best, only a one-in-three chance of being able to gain access to the rapid assessment and treatment that they need. It is little wonder, therefore, that many people in the UK go on to have a disabling or fatal stroke after a TIA or minor stroke, without ever having had the opportunity to address their stroke risk factors. When patients do not receive prompt investigation and diagnosis, they are denied the chance to become informed of the options for treatment, and thus are prevented from making informed decisions about their own health.

4) Defining a transient ischaemic attack

The most commonly used definition of a transient ischaemic attack (TIA) is nearly 30 years old (National Institutes of Health, 1975). This definition limits TIA to *“a sudden, focal neurologic deficit that lasts for less than 24 hours, is of presumed vascular origin, and which is confined to an area of the brain or eye perfused by a specific artery”*. A deficit which has not completely resolved within 24 hours, even if it is partially resolved by this time, is defined as a stroke. However, the 24 hour limit was chosen for convenience rather than because of any relationship to the natural history and underlying pathology of the condition. Some 50% of TIAs resolve in under 30 minutes, and only 13.8% of all patients presenting with any cerebrovascular event experience complete resolution of their symptoms within the 1-24 hour time interval (Levy, 1988). Shortlived TIAs, whose symptoms last less than one hour, are rarely associated with any

demonstrable ischaemic lesion on computed tomography (CT) scanning. However, those patients who have had a "TIA" of several hours' duration, but which has since completely resolved, often do have cerebral ischaemic lesions which are indistinguishable from those found after completed stroke. It has therefore been suggested that the diagnosis of TIA should be redefined. Under the proposed new definition, any symptoms which last for more than one hour, or which are associated with ischaemic lesions on CT scanning, or both, should be reclassified as a stroke (Albers et al., 2002).

This distinction is not a trivial one. Treatments for acute stroke, notably thrombolysis, should be administered within 3 hours of the onset of symptoms for greatest benefit. Using the classic definition of TIA, some patients whose symptoms have not yet resolved at 3 hours after onset may still recover within the ensuing 21 hours, and would therefore be deemed not to have had a stroke. Waiting until 24 hours had elapsed would make it impossible for any patient to receive thrombolysis. Revising the definition means that the diagnosis is established earlier, enabling treatment decisions to be made. The proposed new definition is thus both a closer reflection of the underlying pathology, and a pragmatic step towards improving access to treatment for acute stroke. In practice, however, many patients do not seek medical advice for several hours after the onset of TIA or stroke symptoms, particularly if their symptoms are mild.

The extent to which TIA is a useful marker for cerebrovascular disease is also the subject of debate. Although early (one month) stroke risk is high after TIA, most people who have carotid stenosis and subsequently develop a stroke have never had, or become aware of, any prior symptoms. Others may have had minor symptoms which have been ignored or misinterpreted (by the patient themselves or by health professionals), have had atypical symptoms, or may perhaps have had a 'silent' TIA, occurring during sleep or causing transient focal cerebral ischaemia but without symptoms (Toole, 2004). In addition, up to 10% of people aged over 65 years can be found to have previously silent cerebral infarcts on brain imaging (Brott et al., 1994). There is good evidence that treating asymptomatic (or 'presymptomatic' [Toole, 2004]) high-grade carotid stenosis with carotid endarterectomy will reduce the incidence of stroke, (Halliday et al., 2004) but at present there is no screening programme for the condition and thus no systematic

way of identifying those at risk. Asymptomatic stenosis is, at present, most often detected incidentally, perhaps during investigation for another condition or by initial detection of a carotid bruit (itself not a reliable sign). However, diagnosis and treatment of symptomatic carotid stenosis is also somewhat arbitrary, given the less than 100% correlation between TIA and subsequent stroke, and the difficulties inherent both for patients in identifying and reporting TIAs, and for health professionals in diagnosing them.

5) Current guidelines in secondary stroke risk reduction

Secondary risk reduction is an important part of reducing the burden of stroke mortality and morbidity, and has therefore merited much attention in recent guidelines for clinical practice. It is now recommended that all patients who have had an acute stroke or TIA should have an individualised plan for stroke risk reduction implemented within seven days of the event (Royal College of Physicians, 2004). Factors which need to be considered include lifestyle changes (smoking, exercise, diet and weight control, reducing salt and alcohol intake); blood pressure management; antithrombotic treatment; antilipid agents; assessment and treatment of carotid stenosis; and consideration of stopping hormone replacement therapy. Individuals' needs will vary, but, unless contraindicated, all patients should commence an antiplatelet agent or anticoagulant, and statin therapy if total serum cholesterol is >3.5 mmol/L. Some investigators also recommend that all patients, even those who are normotensive, should commence combination therapy with the antihypertensive drugs perindopril 4mg and indapamide 2-2.5mg (PROGRESS Collaborative Group, 2001). Treating only overt hypertension or hyperlipidaemia in these individuals is not enough to reduce their stroke risk (Muir, 2004). Certainly, their blood pressure should be monitored and antihypertensives started if it is persistently higher than 140/85 mmHg (or higher than 130/80 in people with diabetes mellitus). However, stroke risk factors are often inadequately controlled after TIA or minor stroke (Joseph et al., 1999; Sappok et al., 2001), even in the hands of a specialist neurovascular clinic (Mouradian et al., 2002).

All patients who have had a non-disabling carotid territory event should also have assessment and treatment of carotid stenosis by duplex scanning and carotid

endarterectomy. If surgery is necessary, it should take place as early as possible, but at least within two weeks of the TIA or minor stroke (Royal College of Physicians, 2004a). The topic of carotid endarterectomy is complex and I will discuss it further in Chapter 4.

6) Chapter summary

There are many effective measures which people can take to reduce their risk of stroke, whether via primary or secondary risk reduction. Despite this, it is not a straightforward task to enable people to identify themselves as being at risk of cerebrovascular disease, nor to access the help they need in order to reduce their stroke risk. The significance of TIA and minor stroke in identifying those at highest risk of further cerebrovascular events is not fully understood. However, in the absence of screening programmes for latent carotid stenosis and other risk factors, it remains an important route via which patients at high risk of a disabling or fatal stroke present to health professionals.

There is strong evidence that timely investigation and implementation of the interventions described above will substantially reduce the individual's risk of stroke. However, patients who have had a TIA or minor stroke have other healthcare needs apart from risk reduction, important though this is. Little attention has been paid to the impact of the TIA or minor stroke itself on the individual's health perception and status, or of the anxiety that it generates. A TIA is a potentially distressing syndrome in its own right, not just because of its implication that the patient is at high risk of having a further major stroke. Nor does the literature I have discussed so far attempt to examine lay perceptions and knowledge of TIA, stroke, and stroke risk, or the patient's role in making decisions about risk reduction measures. These factors are a vital consideration in the implementation of measures to improve access to and uptake of TIA and stroke services.

CHAPTER 3:
PUBLIC UNDERSTANDING AND LAY PERCEPTIONS OF
TRANSIENT ISCHAEMIC ATTACK AND STROKE

1) Lay understanding and beliefs about stroke risk reduction

In the previous chapter I have discussed the main primary and secondary measures which can be used to reduce people's risk of stroke. These measures, however, can only be beneficial if they are implemented appropriately. According to the Health Belief Model, health-related behaviour depends on several variables: perceived susceptibility, severity, benefits, barriers, and self-efficacy (Rosenstock, Strecher and Becker, 1988). In the context of stroke risk reduction, these variables equate to: the person becoming aware of their stroke risk; placing sufficient importance on avoiding a potential stroke to make appropriate healthcare choices; understanding that the risk can be modified, knowing how to access appropriate healthcare advice and interventions; having confidence that adhering to these choices will reduce their risk of stroke, and being able to adhere to appropriate behaviour modification (e.g. smoking cessation) and therapeutic regimes (e.g. taking prescribed medication). In addition, secondary risk reduction of stroke relies on people who experience the symptoms of a TIA or minor stroke, and those to whom the symptoms are reported, responding appropriately and quickly so that necessary investigations and known effective treatments are initiated. The goal of reducing stroke risk is clearly complex and not easy to achieve.

Until the last 25 years or so, interest in stroke amongst health professionals was confined mainly to helping to improve function for those with residual disability, with little understanding or interest in reducing stroke risk or treating acute stroke (Caplan, 1998). It is not surprising, therefore, that knowledge about stroke risk factors and treatments is still inadequate and inaccurate amongst the lay population.

Among the general population, surveys have indicated that recognition of the major risk factors for stroke is poor. Ramsden et al.'s (1994) Canadian study found that poor diet (40%) and hypertension (36%) were the most commonly named risk factors, with stress also being wrongly named by 36% as a risk factor. Hux, Rogers and Mongar (2000)

found that among the adult public, 94% could name one or more risk factors without being prompted, including hypertension (50%), and smoking and high cholesterol (about 30% each). On prompting, however, over three-quarters of the sample recognised each of these and other common risk factors. Similarly, Rowe, Frankel and Sanders (2001) found that most of the main risk factors for stroke were recognised, on prompting, by over 80% of their sample.

Although most people can, without prompting, name one risk factor for stroke, knowledge of more than one risk factor is uncommon in the lay public. Reeves, Hogan and Rafferty (2002) asked respondents to name what they thought were the three most important risk factors for stroke. They found that only 28% could correctly name three, and, as in other researchers' work, a substantial minority (20%) gave no correct responses. The most common responses were hypertension (32%), smoking (29%), stress (27%), physical inactivity (26%) and diet (25%). Several characteristics were independently associated with poorer knowledge, including older age, male sex, black ethnic origin, lower educational level, poorer self-reported health, and current smoking. The relationship of these characteristics to poorer knowledge to these characteristics is especially significant, since they are also associated with higher risk of stroke (Sacco, 1998). Schneider et al. (2003) also found that most members (72%) of a sample of the U.S. public could name at least one modifiable stroke risk factor, of which the most commonly cited were hypertension (51%), smoking (22%), and high cholesterol (21%). In common with other studies (Ramsden et al., 1994; Reeves, Hogan and Rafferty., 2002), stress was also thought wrongly to be a risk factor by 21%. Again, people who were aged over 75 years, black, or male, had significantly poorer knowledge of risk factors. Knowledge of specific risk factors has, however, been found to be somewhat better in those who report that they themselves have that risk factor (Pancioli et al., 1998). For example, hypertension was identified by 57% of people with hypertension (vs. 9% overall sample); smoking by 35% of smokers (vs. 19%); and diabetes by 13% of people with diabetes (vs. 3%). Even so, the majority of people in these groups appeared to be unaware of their increased risk.

It is also noteworthy that most respondents in these studies named modifiable risk factors, whereas non-modifiable risk factors were mentioned only rarely. Typically,

heredity was mentioned by around 8% of respondents (Reeves et al., 2002; Schneider et al., 2003), older age by 4% and gender by only 0.5% (Reeves et al., 2002). These findings derived from survey methods have been corroborated by an Australian study using qualitative focus group methods, in which stress, diet, high blood pressure, older age and smoking were most commonly named as risk factors (Yoon and Byles, 2002).

Even people who have already sustained a stroke may be unaware of the common risk factors. A study of 163 patients admitted to a hospital emergency department with possible stroke symptoms found that 57% of the sample, and only 42% of those aged over 65 years, could correctly name even one risk factor for stroke (Kothari et al., 1997). Of those who named one or more risk factors, hypertension (27%), high cholesterol (17%), smoking (11%) and alcohol use (8%) were most commonly mentioned. Stress was also wrongly named by 22%. In this study, patients were interviewed within only 48 hours of admission to hospital, in order to minimise any possible learning effect from in-hospital stroke education materials. The stress of their acute illness and hospitalisation, however, may have adversely reflected their recall.

All the studies I have described above approached the subject of stroke risk by asking participants to name one or more risk factors for stroke. The alternative approach of providing the name of a risk factor and then asking participants to identify one or more diseases associated with it, appears to be little used. One study, however, of 55 patients with hypertension, found that this approach yielded a higher proportion of respondents stating a correct association between hypertension and stroke. A majority (71%) of respondents were aware that stroke was a potential consequence, and they in fact overestimated their personal stroke risk (Taylor and Ward, 2003).

It would seem, then, that the public's knowledge of stroke risk factors, in a number of industrialised countries, is poor, especially for non-modifiable risk factors. Those most at risk – older people, males, people of black ethnic origin, and those with lower socioeconomic status – have the poorest knowledge. Furthermore, even people who are aware that they themselves have high cholesterol, hypertension, or diabetes, or who are smokers, do not necessarily acknowledge that these are risk factors for stroke.

It is, of course, not enough for a person to merely have knowledge of risk factors for stroke in order to reduce their own risk. In addition, they must also identify whether the risk factor applies to them, understand what action (if any) can be taken, and take that action. However, little research has considered how people's knowledge of risk factors relates to knowledge of methods of risk reduction (Rowe, Frankel and Sanders, 2001), or to what extent such knowledge is translated into health behaviours to modify risk. It has been identified, however, that long-term adherence to risk reduction measures such as antihypertensive and antithrombotic therapy, treatment for diabetes and hyperlipidaemia, and smoking cessation, is not easy to achieve even in the context of secondary stroke risk reduction (Sappok et al., 2001; Mouradian et al., 2002). The reasons for poor adherence are complex, but may include lack of knowledge, negative views of drug treatment, including safety concerns, and ineffective styles of clinician-patient interaction (Gascon et al., 2004).

2) Lay understanding of stroke symptoms and treatments

In order to gain access to prompt treatment for stroke, and to enable secondary risk reduction measures to be put in place after a minor stroke or transient ischaemic attack, an important first step is for people to recognise the significance of their symptoms, and to seek prompt medical advice. The literature suggests, however, that lay knowledge of stroke symptoms, action to be taken and possible treatment, is poor.

Surveys of the general population have revealed that around 60% of all respondents are able to name at least one warning sign of stroke, with dizziness, numbness, headache and weakness being named most frequently (Pancioli et al., 1998; Rowe, Frankel and Sanders, 2001). Smaller numbers mentioned slurred speech or visual disturbance, and specific unilateral weakness or numbness. Symptoms wrongly thought to be associated with stroke were chest pain, other pain and breathlessness (Schneider et al., 2003), perhaps due to confusion between definitions or symptoms of coronary artery disease and stroke (Reeves, Hogan and Rafferty, 2002). As with stroke risk factors, those at highest risk of stroke tended to have the poorest knowledge of stroke symptoms (Pancioli et al., 1998; Schneider et al., 2003). Hux, Rogers and Mongar (2000) found a similar level of knowledge, with 71% of their sample correctly naming at least one

warning sign. Numbness or tingling (63%) and dizziness (42%) were named most often. In another study, when presented with a list of 7 genuine and false stroke symptoms, only 17% of respondents could correctly classify all 7 (Greenlund et al., 2003).

The situation of a survey is an artificial one, and may not represent people's interpretation of stroke symptoms when they, or a companion, actually experience them (Rowe, Frankel and Sanders, 2001). However, further studies have indicated that in real-life situations, patients and witnesses often lack awareness of and misinterpret the symptoms of stroke. Kothari et al. (1997) found that 39% of a sample of patients admitted to hospital in the preceding 48 hours with stroke symptoms (excluding those with speech or cognitive impairment) could not name a single warning sign. Another study of calls made by or on behalf of patients to an emergency ambulance service, which subsequently led to admission to a stroke unit, revealed that recognition of actual stroke symptoms was poor. Fewer than one in five callers mentioned stroke as a possible cause of the acute problem, 25.5% described speech problems, 21.9% motor deficits, and 4.8% loss of consciousness. 21% of patients were described as having had a fall. From the symptoms described, however, the ambulance dispatcher suspected stroke in 51.7% of cases (Handschu et al., 2003).

People's knowledge of the correct action to take if they suspect they or someone else is having a stroke is generally good (Greenlund et al., 2003). 95% of respondents indicated that they would seek urgent medical help (e.g. 'go to hospital') if they suspected they were having a stroke, with 70% specifying that they would telephone 911 for an emergency ambulance (Rowe, Frankel and Sanders, 2001). However, this knowledge is not readily translated into practice. Even those who were participating in a clinical trial (the Asymptomatic Carotid Atherosclerosis Study), and who had been provided with comprehensive information about TIA and stroke, delayed reporting their symptoms, with only 25% reporting within 24 hours, and 40% within 3 days of their first TIA or stroke (Castaldo et al., 1997). Studies of admission patterns have found that of patients who attend hospital emergency departments with stroke, 35% do so within 3 hours (Kothari et al., 1997) or within 6 hours (Jorgensen et al., 1998), and 50% later than 14 hours after the onset of stroke symptoms (Jorgensen et al., 1998). Severity of symptoms, and a previous history of TIA, are both associated with prompt attendance (Jorgensen et

al., 1998). There appears to be no correlation between knowledge of stroke risk factors and symptoms, and prompt presentation to hospital, but those who attend by telephoning for an ambulance are more likely to arrive within 3 hours of onset than those who come by private transport or who initially contact their primary care physician (Kothari et al., 1997; Barsan et al., 1993; Williams et al., 1997). A number of factors have been found to be independently associated with delayed admission. These include living alone and retired working status (Jorgensen et al., 1998), mild symptoms, gradual onset, failure to contact another person at onset of symptoms, failure to call an ambulance, and visiting a primary care facility first (Wester et al, 1999). These delays may also be due to people not identifying their initial symptoms as stroke, because they do not correspond to the type or severity of symptoms they have previously heard or read about (Yoon and Byles, 2002).

The evidence suggests that public awareness of common symptoms of stroke is poor. Like their knowledge of risk factors, knowledge of stroke symptoms is worse in those more likely to have a stroke themselves. By definition, knowledge of one's non-modifiable risk factors cannot be translated into action to reduce the risk. Better knowledge of their risk may have a role, however, in helping people in higher risk groups, such as older people, to recognise the early symptoms of stroke in themselves or a companion, and thus enabling them to access prompt medical advice. However, many people delay seeking help for many hours after the onset of stroke symptoms, suggesting that translating knowledge into action is a complex process.

3) Laypersons' perceptions of the impact of stroke

It could, perhaps, be postulated that people do not seek help when they have a stroke, even if they recognise the symptoms, because they are unconcerned about the possible consequences of stroke. This is most unlikely to be the case. Surveys of healthy adults, and of those who have already had a stroke, demonstrate that people correctly believe that stroke would substantially reduce their quality of life. Severe disabling stroke with associated dysphasia is considered by many individuals to be a devastating outcome, perhaps even worse than death (Samsa et al., 1998), but people would also expect a less severe stroke, causing partial hemiparesis of their non-dominant side, to reduce their

quality of life by more than 50% (Adar et al., 1994). These beliefs reflect the position of stroke as a major cause of adult disability, and the actual effects of stroke on quality of life.

The impact of stroke as it is perceived by stroke survivors has also been researched in a number of qualitative studies. It has been found that the experiences of recovering from and living with the effects of stroke have profound physical, practical, cognitive, emotional and social consequences (O'Connell et al., 2001). The effects of stroke on the performance of everyday personal care and household activities are well documented, but there are also consequences for social functioning and the loss of valued roles within the person's family and wider community (Pound, Gompertz and Ebrahim, 1998). The direct consequences of stroke give rise to the need for adaptation. Adapting to life after stroke is viewed as a process of transition, including elements of deterioration, loss and helplessness, regret, uncertainty, and anxiety, but also of resiliency (Hilton, 2002). The process of recovery and rehabilitation after stroke has also been described. Recovery is perceived in terms of congruence between the person's life before and after the stroke (Dowswell et al., 2000).

Adaptation and recovery after stroke is seen as an ongoing process, in which the social context of recovery and social re-engagement is more important than physical function alone (Burton, 2000). Stroke patients tend to see recovery as a return to their pre-stroke existence and activities, and find it difficult to accept a lower functional level than the goals they have set themselves. As a result, stress, depression and diminished social function are also common (Hafsteinsdottir and Grypdonck, 1997). People have a range of expectations and wishes about their own involvement in decisions about their care after stroke (Yoon and Byles, 2002). They also describe some positive aspects of recovery from stroke, notably a greater appreciation of ordinary life, and enhanced supportive personal relationships (Pilkington, 1999). The importance of maintaining hope after stroke has also been described, including the use of active participation in care, having inner strength, and aiming for realistic goals (Bays, 2001).

4) Lay understanding and perceptions of transient ischaemic attack

Although the public's knowledge base about stroke, and its impact on quality of life, is fairly well understood, there is a dearth of similar research about the impact of transient ischaemic attack and about public understanding of the condition. The reasons for this probably lie in the transient nature of the condition itself. Firstly, TIAs are difficult to diagnose accurately, due to their short-lived and often unwitnessed nature. This makes any systematic study of the condition difficult, because of a potential lack of rigour in identifying suitable research participants and in applying inclusion and exclusion criteria. Secondly, patients who have had a TIA may present to health services via a variety of routes in primary care or emergency services, and may also be referred on to specialist clinicians as diverse as neurologists, stroke physicians, specialists in elderly medicine, ophthalmologists and vascular surgeons. This diversity of patterns of care makes the co-ordination of studies difficult. Thirdly, clinicians and researchers might simply assume that a condition which gives rise only to transient symptoms is not likely to have a significant impact on quality of life, even though its use as a marker for stroke risk is well understood. These factors also apply to some extent to minor strokes, where the symptoms may have partially or completely resolved before the person seeks medical advice.

Laypersons' knowledge of TIAs has been evaluated by Johnston et al. (2003). Their survey of 10,112 respondents found that only one person in 12 could correctly define a TIA (as a 'mini-stroke' or in similar terms), and a similar proportion could name at least one typical symptom. The researchers also asked those who reported that they had ever been given a diagnosis of TIA (2.3% of the sample) about the healthcare advice they had sought. 63% had initially consulted their primary care physician; 64% saw a doctor within 24 hours, with 16% being first seen over a week later. Only 23% recalled having consulted a neurologist. The design of the study did not allow for any exploration of people's reasons for seeking advice or why delays occurred; whether because the patient did not seek advice promptly, or because they had difficulty in accessing health services. A further 3.2% of the sample, who had not had a physician-diagnosed TIA, nonetheless reported previous symptoms such as transient unilateral paraesthesia or paresis, or transient dysphasia, which are strongly suggestive of a TIA. (Reports of other non-specific symptoms such as dizziness or loss of balance were excluded.) One must

exercise caution in assuming that all these people had a genuine TIA. However, given the difficulty experienced by clinicians in making a correct diagnosis, perhaps 40% of those who had been given the diagnosis of TIA by a primary care physician might also not have had one (Martin et al., 1997). Assuming, however, that people in both groups had in fact all had a TIA, it would have been interesting to explore why over half of them did not seek medical advice, as well as the reasons for delays for those who did seek advice. The number of unreported TIAs in this study was similar to Shelton and Gaines' (1995) findings. They identified that only 38% of patients with a recent stroke who had had a previous TIA had sought medical attention at the time of the event. Only 18% realised the TIA was a possible warning sign of stroke or another serious problem, with most believing it was of little importance at the time. Those who did not see a doctor (including some who made an appointment but cancelled it or failed to attend), gave a variety of reasons for this. These included feeling that the problem was unimportant because it had resolved (33%); believing that there was nothing a doctor could do (27%); being 'afraid to find out' (13%); or being concerned about the expense, time or transport difficulties involved in seeking help (28%). Overall, of those who did not seek medical advice, over three-quarters lacked understanding of, or denied the significance of, the symptoms.

Literature about TIA is available to the general public via healthcare and voluntary organisations, but, in common with many other medical conditions and treatments (Coulter, Entwistle and Gilbert, 1999), such literature is of variable quality. For example, the leaflet available from the Stroke Association (Bryan, 1999) gives a clear and concise description of the condition, common risk factors, action to be taken by the patient, investigations, and treatments. However, information from NHS Direct (2004) contains several errors. These include including listing non-specific symptoms such as vertigo and forgetfulness; omitting to mention the role of hypercholesterolaemia and drug therapy; and citing phlebitis as a possible cause of thromboembolism. Perhaps most seriously, there is no advice on the appropriate action to take if a person suspects that they are having a TIA (although it is stated that TIAs should always be investigated). It is therefore difficult for a layperson to become well informed about TIA if the available health promotion information is inaccurate or incomplete.

It is not only laypersons who fail to recognise and respond appropriately to TIAs. Health professionals themselves also lack awareness of the correct definition and treatment of a TIA, with the result that the condition is 'underrecognized, underreported, and undertreated' (Albers et al., 2002). A UK study of nearly 300 general practitioners (GPs) (Mead et al., 1996) revealed that whilst almost all would recommend antiplatelet therapy with aspirin after TIA, only 39% would refer more than half of patients to a specialist (mainly to general or elderly care physicians). Most (76%) would arrange some further investigations directly, but 12% of GPs would neither refer nor arrange investigations. Only 11% would refer for carotid duplex, and the authors surmised that this low uptake might have been due to perceived difficulties in accessing this service. This situation still persists, with less than half of UK neurovascular clinics having the resources to be able to see new patients with TIA within 14 days. Waiting times of several weeks or even months for carotid Duplex scanning are also common (Royal College of Physicians, 2004b).

Diagnostic uncertainty is introduced by the large number of people (about 50%) who do not report their TIA. However, an additional source of error is introduced by the variable interpretation of the symptoms by clinicians, resulting in poor interobserver agreement about the diagnosis of TIA (Kraaijeveld et al., 1984; Koudstall, Gerritsma and van Gijn, 1989; Martin et al., 1997). The reasons for this may lie in the transient nature of the condition, and the resulting difficulties faced by clinicians in basing a diagnosis on the patients' self-reported symptoms, in the absence of any objective signs or current symptoms. Furthermore, the clinician must rely (in the absence of a witness to the event) on the report of a patient who, by definition, may have had transient cognitive impairment at the time of the event. This gives rise to difficulty in obtaining an accurate description of the symptoms. The clinician's diagnostic uncertainty about the occurrence of a TIA will, in turn, compound the patient's difficulties in deciding on an appropriate course of action.

The short and long-term risk of completed stroke is known to be higher after a reported TIA, and previously unreported TIAs are commonly identified when patients newly presenting with stroke are questioned. There have, however, been few studies examining the effects of TIA on quality of life in the absence of a subsequent stroke. Sorensen et al. (1989) found that their sample of 201 patients who had TIAs

experienced a diminution of their quality of life and occupational status. Their problems included decreased working capacity, fatigue and impaired memory. Duncan et al. (1997) assessed activities of daily living, depression, health status and health utility in 184 people with TIA, and compared them with 304 patients who had had mild stroke and a control group of 654 asymptomatic people who were at high risk of stroke. TIA had no effect on the performance of activities of daily living compared with the asymptomatic group, but performance was significantly impaired in the mild stroke group. However, health status (MOS-36) was similarly impaired in the TIA and stroke groups, in all domains except in relation to physical function. People with TIA reported poorer scores for general health, mental health, emotional role, social function, vitality and pain compared with the asymptomatic group. Depression ratings were also higher in the TIA and stroke groups. A smaller German study, however, (Schnider et al., 1996) of 59 people with TIAs or minor strokes found little effect on physical or mental health.

These findings indicate that the effects of TIA and mild stroke may reach far beyond their impact on physical function. It has not been explained why TIAs have this effect in the absence of persistent symptoms. It may partly be a consequence of being 'labelled' as having a health problem. People might also place restrictions on their own activity in the erroneous belief that this might reduce the risk of another TIA or a stroke, or they may have such restrictions imposed on them by family and friends. However, caution must be exercised, since the studies described did not attempt to verify the original diagnosis of TIA. As I have discussed, TIA is often misdiagnosed, and it may be that some members of the TIA groups had, in fact, had a mild stroke, which could have resulted in a different spectrum of impact on quality of life. No studies identified have attempted to use qualitative methodologies to examine patients' experiences and perceptions of their health after TIA in more depth.

This overview of research on public understanding and patients' experiences of TIA demonstrates a dearth of knowledge about the impact of TIA in the public awareness of stroke risk, and on quality of life after TIA. To expand on Albers et al. (2002), TIAs are not just "*under-recognised, under-reported and undertreated*", they are also underinvestigated and under-researched. Urgent and appropriate treatment after TIA is, however, essential if these patients are to reduce their risk of a major stroke. TIA also

appears to be associated with diminished quality of life, even in the absence of a subsequent stroke, and this aspect of the condition merits greater attention.

5) Chapter summary

The research I have reviewed suggests that people's understanding of stroke risk factors and symptoms, and the correct action to take in the event of such symptoms, is poor. There is little literature available on public understanding of TIA, but the available evidence suggests that it, too, is very poor. However, people are well aware of the potential effects of a completed stroke on their quality of life. TIA itself has also been shown to reduce quality of life, particularly in emotional and social domains. Lay persons' perspectives on the impact of TIA have not previously been studied.

It follows that, although their knowledge base is currently poor, lay persons could be expected to be highly motivated to reduce their stroke risk, whether through primary risk reduction, or after a TIA or minor stroke. In order to do this, however, they need to become more aware of appropriate methods of risk reduction. Patients are increasingly expecting and taking on an active role in making decisions about their own health, and the field of stroke should be no exception to this trend. In the next chapter I will discuss the development of patient involvement in evidence-based healthcare, and the importance of nursing in this field, before moving on to examine a particular case of evidence-based healthcare of great importance in secondary risk reduction of stroke – carotid endarterectomy.

CHAPTER 4

PROMOTING SHARED DECISION MAKING IN REDUCING PEOPLE'S STROKE RISK

1) Introduction

In the previous chapters I have discussed the topics of stroke risk reduction, and the impact of TIA and minor stroke on individuals who experience them. In this clinical field, as in others, patients are increasingly involved in making decisions about their own health. This movement has coincided with the expansion of the evidence-based approach to healthcare – EBHC. It is perhaps no coincidence that these two changes in the delivery of healthcare have coincided. The development of EBHC was a reaction to the traditional, authoritarian style of healthcare, in which ‘doctor (or nurse) knows best’, and in which patients were the passive recipients of care. People were not expected to have the knowledge base to challenge or contribute to decisions about their own health. With the growth of EBHC, decision-making became a more explicit and open process. The participation of patients in decision-making was a consequence of this, although it is true that EBHC can still be interpreted in an authoritarian style, with little or no contribution from the patient towards decision-making.

In this chapter, I will discuss the origins and development of EBHC, and then focus more closely on the role of the nurse in EBHC, especially in relation to shared decision-making. I will then turn to a specific example of EBHC in the reduction of stroke risk: carotid endarterectomy. I will examine its historical development, clinical trials, patient perspectives, and the use of EBHC in practice in this clinical area. I will then discuss the clinical starting point for the research study on which this thesis is based, and finally I will outline the aims of the study.

2) The origins of evidence-based healthcare

The first recorded description of a randomised trial design was made by a seventeenth-century physician, John Baptista van Helmont (1662). He offered a wager that if he took a group of patients with fever and treated half with blood-letting (the standard treatment

at the time) and half without, fewer patients in the non-bloodletting group would die. He specified that the patients in each group should be chosen 'by lot'; that is, randomly. Although it would appear that the trial was never carried out, it has historical interest as the first recorded suggestion that the effectiveness of medical treatments should be assessed by randomised trial, rather than by tradition and clinical experience.

The principle of randomisation to intervention and control groups became well-established in the biological sciences, but it was not until the mid 20th century that the first report of a randomised trial in medicine was published (Streptomycin in Tuberculosis Trials Committee, 1948). The trial entailed a comparison of the newly developed drug, streptomycin, versus the standard treatment for tuberculosis. It is interesting to note that this first trial was itself considered to be ethically justified according to the standards of the time, and was therefore conducted, primarily because the drug was scarce and expensive to produce. If the drug had been less expensive, it would most likely have been administered routinely on the basis of clinical judgement, without any question of a randomised trial being conducted. Furthermore, patients were not asked for their consent before they were allocated to the study, and were not even informed that they were taking part in a study at all, in contrast to today's emphasis on research governance and patient involvement in research and clinical practice.

The design of this study quickly became the model for assessing the effectiveness of any new treatment or intervention in medicine. However, by the 1980s, the proliferation of such studies – of variable quality – made it increasingly difficult for any single clinician to appraise them and to determine the most appropriate treatment for an individual patient.

Systematic methods for locating, appraising and applying research findings to clinical practice were developed as a response to the problems of implementing increasingly larger bodies of research evidence into clinical practice. The field of evidence-based medicine (EBM) was originally defined as *'the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients'* (Sackett et al., 1996). The evidence-based approach in healthcare was described as having several stages: converting a need for clinical information into an answerable

question; efficiently tracking down the best evidence with which to answer it; critically appraising that evidence for its validity and usefulness; applying the results of this appraisal to clinical practice; and evaluating one's performance (Sackett et al., 1997, p3).

This description of the processes of EBM leads to the question of how we decide on what is the 'best' evidence. The implementation of EBM is now underpinned by a hierarchy of levels of evidence. Several hierarchies have been devised, but one example places homogeneous systematic reviews (Level 1a evidence) at the top, smaller trials and case control studies in the middle, and expert consensus (Level 5) at the bottom (Phillips et al, 2001). Perhaps the most widely used and authoritative source of systematic reviews is the Cochrane collaboration (www.cochrane.org). Evidence is then implemented in clinical practice partly by the development of clinical guidelines. For example, in the Stroke Guidelines of the Royal College of Physicians (2004), the administration of aspirin post-stroke or TIA (p42) is an A* recommendation, being based on Level 1a evidence, whereas the monitoring of vital signs in acute stroke (p34) is a D-rated recommendation, based on consensus of the working party (Level IV evidence). This example illustrates the potential pitfalls of too-slavish deference to the doctrine of high quality evidence. It is most unlikely that anyone would suggest that the monitoring of conscious level, blood pressure and so forth in the acute phase of stroke were unimportant compared with the administration of aspirin, but there is no evidence, other than 'expert' opinion, to support this routine practice. Indeed, the very fact that such monitoring is regarded as an essential component of care makes it difficult, even impossible, to conduct a randomised trial in the first place (although one could make a case for research comparing, for example, manual versus automatic monitoring). With EBM, the highest quality evidence is obtained for those components of healthcare which are most testable, but these are not necessarily the most important.

3) Nursing and shared decision-making

Since its development, criticism has been levelled at the philosophy of EBM for not making enough allowance for patients' autonomy in decisions about their health.

However, well-known definitions of EBM do in fact acknowledge the necessity to pay

heed to patient autonomy, by means of the use of clinical expertise in facilitating *'the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care.'* (Sackett, 1997). The incorporation of patients' values and expectations into EBM may be argued to reflect the desire to move away from a paternalistic and clinician-led style of decision-making, towards decisions being shared by professionals and patients. For this approach to be meaningful, however, the evidence base must be accessible to patients and comprehensible to them. It must also reflect their perspective as a patient – not just as a layperson.

The Cochrane library website states that:

"Healthcare consumers and patients need high-quality evidence about the effectiveness of treatments. This empowers them, with their healthcare practitioners, to make the best possible decisions." (Cochrane Library, 2006).

This statement implies that patients should be able to make sound decisions about their healthcare options, provided they have access to current evidence. But there are inherent difficulties in helping patients, who may have little or no understanding of the process of health research and its statistical and scientific underpinnings, to negotiate their way through complex and sometimes contradictory evidence sources. Furthermore, it is not at all clear that this evidence-led approach will actually help patients to make decisions which are congruent with their values and expectations. Instead, the patient's involvement in the decision-making process may be more meaningful if, rather than merely attempting to duplicate the clinician's appraisal of the formal evidence, they are enabled to bring their unique perspective to the process. For example, it has become increasingly apparent that patients' and practitioners' treatment preferences may differ (Montgomery and Fahey, 2001), when examining treatment options with qualitatively different benefits, such as trading off longevity against quality of life. Therefore, it has been argued that the process of making decisions in healthcare must entail a combined strategy, incorporating three major components: the patient's beliefs, values and expectations, the expert judgement of the practitioner, and the best evidence available (Haynes, Devereaux and Guyatt, 2002).

From this integrative approach, interest has developed in the application of EBHC in a more patient-focused approach, termed evidence-based patient choice (EBPC) (Hope, 1996; Edwards and Elwyn, 2001), or shared decision-making (SDM) (Strull, Lo and Charles, 1984; Makoul and Clayman, 2006). (These terms are used synonymously, though they are not identical in meaning, but I will refer hereafter to SDM as this is the more commonly used term.) SDM has two main components: enabling patients to make decisions about their own treatment, to the extent that they wish to do so; and exploring methods of promoting patients' understanding about proposed treatments, again to the extent that they wish. Clearly, one cannot make an evidence-based decision without having some access to, and understanding of, the available evidence. In this context, informed consent is not merely a medico-legal requirement but can be regarded as a formal recognition and a practical application of the SDM approach.

Nurses have an important part to play in the practice of SDM. In recent years, nurses have developed a great deal of expertise in the role of providing the patient with, and helping them to interpret, information about their health and illness, as it affects them as an individual. Nurses are therefore well placed to advocate for the patient's values and expectations. Advocacy is a complex concept in nursing, and tends in practice to take reactive rather than proactive forms (Vaartio and Leino-Kilpi, 2005). Attributes of the nursing advocacy role include safeguarding patients' autonomy, acting on behalf of patients, and championing social justice in the provision of healthcare (Bu and Jezewski, 2007). Teaching, informing and supporting are also believed to be key roles in the nursing advocacy process (Chafey et al., 1998). Advocacy is a natural consequence of the way that nursing concerns itself with the impact of illness and health on the person. This is one of the defining characteristics of nursing as opposed to medicine: medicine focuses primarily on the diagnosis and treatment of illness *per se*; nursing, on the impact of that illness.¹ Nurses are not necessarily the only, or even the best, candidate for the role of patient advocate (Hewitt, 2002). Nonetheless, the well-established advocacy roles of safeguarding patients' autonomy, and of teaching,

¹ Of course, nurses do diagnose, prescribe and administer treatment; while doctors are also concerned with how the experience of illness is affecting the patient's day-to-day life. The distinction I am making is between the core activity of each profession, and is not intended to imply that nurses do not 'cure' or that doctors do not 'care'.

informing and supporting, make the nurse an important contributor to the implementation of SDM.

There is great interest within the nursing profession in developing as an evidence-based discipline. This has occurred particularly in those fields, such as wound care and health promotion, where nurses most commonly tend to instigate treatments. However, many opportunities also exist for the development and practice of evidence-based approaches to nursing in any setting where patients are nursed, regardless of the range and complexity of the treatments under consideration. These opportunities are largely due to the uptake of the expanded concept of SDM. In addition to clarifying the patient's understanding of proposed treatments, the nurse can have a valuable role in helping the patient to identify their values and expectations and thus in supporting them to reach decisions about their care. This is an important part of the nursing role, whether or not the nurse plays any part in assessing the patient's clinical suitability for one or more alternative treatments, or in the prescription and delivery of treatment. Perhaps, as patients seek to become more well informed and to play a greater part in decisions about their own treatment, so the contribution of evidence-based nursing – which has its roots in the focus of nursing on the patient, rather than on their pathology - will become increasingly important.

The focus of the remainder of this chapter is the historical development and evidence base of carotid endarterectomy (CEA) for the reduction of stroke risk. CEA is a complex surgical procedure, and the nurse's role in the clinical care of these patients is unlikely to entail taking overall responsibility for the detailed assessment of symptoms and pathology, or making a judgement about the clinical appropriateness of CEA. However, as I will show, the paradox of CEA (a risk-reducing operation itself carrying small but significant risk of causing a stroke) means that the nurse can potentially have a very valuable role in advocating the patient's perspective and in supporting the patient to reach a decision about their treatment.

4) The rise, fall, and rise of carotid endarterectomy

Hippocrates was the first person to document that transient ischaemic attacks may herald stroke, around 2400 years ago. For centuries, however, it was thought that strokes were caused only by haemorrhagic or occlusive disease of the intracerebral arteries. A better understanding of the aetiology of stroke was achieved by the early 20th century, when it was realised that carotid artery atheroma could lead to stroke via a process of distal embolisation into the intracerebral arteries (Hunt, 1914). By the 1950s, the operation of carotid endarterectomy (CEA) began to develop. The first surgical CEA was performed by DeBakey in 1953 (DeBakey, 1975). In this case the patient survived for many years, eventually dying of complications of coronary artery disease. A year later, Eastcott, Pickering and Rob (1954) published an account of the first UK operation for carotid occlusive disease - an end-to-end anastomosis of the common and distal internal carotid arteries. This patient also survived in good health for over 20 years.

Following this early work, CEA rapidly became the standard operation for carotid occlusive disease. It was widely used from the 1960s to the mid 1980s in both Europe and, more commonly, in the USA, as a means of reducing the risk of stroke in patients with either asymptomatic or symptomatic carotid stenosis. It is estimated that about one million people world-wide had the operation between 1974 and 1985 (Barnett, 1990; 1991), with about 1500 procedures being performed annually in Great Britain and Ireland by 1984 (Murie and Morris, 1986). However, by the mid-1980s, concern was mounting about the safety of CEA, due to the small but important risk of perioperative stroke. It was not known whether this risk outweighed the effectiveness of the operation in reducing future stroke risk - an especially important concern since the operation was intended solely to reduce stroke risk rather than to relieve current symptoms.² At this time, several published case series reported huge variations in mortality and morbidity (i.e. stroke) rates, with a ten-fold difference in morbidity between the lowest and highest. Rates of 1.4% mortality and 2.1% mortality/morbidity (Zeiger et al., 1987); 2.7% mortality and 8% mortality/morbidity (Slavish, Nicholas and Gee, 1984); 2.8% mortality and 9.5% mortality/morbidity (Brott and Thalinger, 1984); 3.6% mortality and

² Even with 'symptomatic' carotid stenosis, patients usually have recent rather than current symptoms when they come to have CEA.

14.5% mortality/morbidity (Muuronen, 1984); and 21.1% mortality/morbidity (Easton and Sherman, 1977) were cited. High mortality and morbidity rates were a particular concern because of the lack of knowledge about the natural history of the condition with best medical treatment. It is also likely that the published series would have underestimated the true mortality and morbidity rates, due to publication bias. There was also disagreement about the most appropriate indications for CEA, with only one-third of the patients in one series having had an operation which was fully agreed to have been appropriate, when reviewed retrospectively by an expert panel (Winslow et al., 1988).

As a result of these concerns and the emergence of more rigorous standards of audit and research required to support treatment decisions, there was a backlash against CEA during the 1980s and a decline in its use. Having increased from 15,000 procedures in 1971 to 107,000 in 1985, there was a dramatic decline to 83,000 CEAs in 1986 in the United States (Pokras and Dyken, 1988). The need for robust evidence of the effectiveness of CEA in reducing stroke incidence in both symptomatic and asymptomatic people was identified, and several randomised trials were set up in the mid to late 1980s.

It is revealing to examine in more detail the reasons why the efficacy and safety of CEA were selected for study in major clinical trials. Randomised controlled trials (RCTs) are relatively unusual in the evaluation of surgical procedures, compared with the hegemony of this method in the testing of new drug therapies (Lilford et al., 2004). Instead, surgical techniques and procedures have traditionally evolved without rigorous controlled trials, and there may be considerable variation in the selection and deployment of surgical intervention. In this way, surgical procedures have become routine practice with little formal evidence for their safety or efficacy. In addition, it is difficult to control all the potential confounding variables when conducting a trial of a surgical procedure. The existence of a learning curve means that a surgeon's or institution's skills with a new procedure may initially be poor, but will usually improve with time. There may also be variations in individual surgeons' skills and techniques and in the quality of pre-, peri- and postoperative nursing care. These problems are particularly difficult to overcome in surgery, but they also affect trials of other

procedures such as endoscopy, and, to some degree, any medical and other therapies where the clinician's skill may improve with experience (Frader and Caniano, 1998). There is also a view that the element of uncertainty which is inherent in any trial – that is, the acknowledgement that the clinician is unsure as to the treatment of choice – sits uneasily with the clear exposition of the optimum treatment which patients might be assumed to expect from a surgeon (Hankey, 1999). This view is supported by research suggesting that surgeons have a poorer tolerance of uncertainty than their physician counterparts (McCulloch et al., 2005).

These inherent difficulties relating to the conduct of RCTs of surgical procedures call into question the reasons why the efficacy of CEA was considered to be an important subject for research. The answer may lie in the aim of the operation. CEA is not performed to relieve existing symptoms, but is an attempt to avoid an adverse event which may - or may not - happen in the future. The patient who has had a TIA or minor stroke, or who is found to have asymptomatic carotid disease, might never go on to have a major stroke. As I will discuss shortly, we now have a clear understanding of the stroke risk for patients found to have mild, moderate and severe carotid stenosis. Even for those patients in whom according to the ECST (1991) findings, surgery is indicated (those with >70% stenosis), their three-year stroke risk is 17% without surgery. This can be alternatively expressed by saying that over 80% of all carotid endarterectomies are unnecessary (Hoeftnagels, 1999). But, as Shaw pointed out:

'When an operation is once performed, nobody can ever prove that it was unnecessary.'

Shaw, 1906, p12).

In the example of CEA, we can never prove postoperatively that this individual patient's operation was one of the unnecessary ones. The operation reduces the patient's long-term risk of stroke; it does not eliminate that risk altogether. Yet the case series described earlier indicated that many patients undergoing CEA in the 1970s and 1980s - more than 1 in 5 for one series (Easton and Sherman, 1977) - experienced a disabling or fatal stroke as a direct consequence of the operation. Furthermore, each stroke or fatality might never have occurred otherwise. Alternatively, even if the patient were to have a

stroke on medical treatment, this might not otherwise have occurred for many months or years, and therefore CEA may have brought forward its timing. It was recognised that for the patient, having a stroke in the near future as a result of surgery could reasonably be considered as a worse outcome than having a stroke of similar severity in several years' time (Matchar, 1990; Cina, Clase and Haynes, 2002). An obvious ethical and decision-making dilemma emerged. Surgeons were performing CEA on patients who were free of symptoms at the time of operation, with no guarantee of benefit, but with the likelihood of causing disabling or fatal consequences for some of those patients. Faced with this stark example of the '*prevention paradox*', (Rose, 1981, p1850), it is not surprising that vascular surgeons became reluctant to continue to perform CEA without further evidence of its benefits.

Prior to the ECST (1991; 1998) and NASCET (1991) trials, the risks of CEA had been identified to some extent through case series. However, there was still uncertainty about the natural history of carotid stenosis, and about the patient's relative risk of stroke with or without surgery. CEA was an irreversible surgical intervention which was known to carry at least some risk of stroke. Yet the procedure was performed with the aim of reducing the patient's risk of stroke. In the absence of robust evidence, this created a substantial area of decision-making difficulty for clinicians and patients alike. The trials were set up to reduce this uncertainty. Indeed, eligibility for inclusion in ECST was explicitly based on the principle of clinical equipoise: patients were only eligible for the trial if their neurologist or surgeon was '*substantially uncertain*' as to whether to recommend immediate surgery or best medical treatment (ECST, 1991, p1236).

5) The evidence base for carotid endarterectomy

a) Trials of carotid endarterectomy in recently symptomatic carotid stenosis

The first randomised trial of CEA was the Joint Study of Extracranial Arterial Occlusion (Fields et al., 1970). Although this demonstrated a reduction in long term risk of stroke after surgery, this reduction was outweighed by the study's high perioperative mortality and morbidity rates. Subsequently, the effectiveness of CEA in patients with recent symptoms of carotid artery disease has been evaluated in two major trials: the

European Carotid Surgery Trial (ECST, 1991; 1998), and the North American Symptomatic Carotid Endarterectomy Trial (NASCET, 1991). ECST had a sample of 3024 patients; NASCET, 2885. Both trials randomised patients with recent (<6 months) symptoms of TIA or minor recovered stroke to two treatment arms: either current best medical treatment (BMT) alone, or BMT plus CEA. Criteria for inclusion in the trials included the existence of substantial uncertainty on the part of the clinician as to whether surgery was likely to be of benefit or not. If the patient's physician felt that the patient would clearly benefit, or clearly not benefit, from the surgery, the patient was excluded. The grounds on which this judgement was made were not specified, but it is likely to have been a non-systematic evaluation, based on clinical judgement, especially in the absence of robust probabilistic evidence. Due to widely divergent opinions among the clinicians taking part in the trial, this meant that patients with a wide range of degree of carotid stenosis and other clinical characteristics were included in the trials. Both trials were fully randomised, but the nature of surgical intervention meant that full blinding of patients and clinicians to the treatment allocation was not possible. However, outcomes were assessed by independent reviewers who were blinded to the treatment allocation.

Although ECST and NASCET were very similar in their aims and design, there were two important differences. First, the method of measurement of carotid stenosis was not the same; ECST measured the degree of internal carotid artery stenosis compared with an approximation of the diameter of the carotid bulb, while NASCET used the diameter of the distal internal carotid artery as its reference. This makes direct comparison of the trials potentially confusing, as the values for carotid stenosis derived are not equivalent. Roughly, 80% stenosis in ECST is equivalent to 70% in NASCET. I shall use ECST-derived figures in this discussion unless stated otherwise. The second important difference was that ECST stratified patients according to whether they had mild (0-29%), moderate (30-69%) and severe (70-99%) internal carotid artery stenosis, while NASCET had only two categories: moderate (0-69%) and severe (70-99%).

Despite these methodological differences between the trials, they reported closely comparable results. Both trials found that for patients with recent carotid territory symptoms (amaurosis fugax or TIA) and an ipsilateral internal carotid stenosis of 70-

99%, surgery was more effective than BMT alone in reducing the long-term stroke/surgical death rate. In ECST the perioperative stroke or death rate for surgery was 7.5%, with an additional 2.8% risk of postoperative ipsilateral stroke in the following 3 years, compared to a 3 year risk of 16.8% in the control group (ECST, 1991). In NASCET, the perioperative stroke or death rate for severe stenosis was 5.8%, with an additional 3.2% risk of stroke in the next 2 years, compared with 26% in the control group. Many of the strokes which occurred in both treatment arms were minor ones from which patients recovered quickly and fully, but the incidence of fatal or disabling strokes was also reduced in the surgical group, from 13.1% to 2.5% (NASCET, 1991). For patients in ECST with stenosis of less than 30%, surgery was found to be less effective than BMT, while for the patients in both studies with 30-69% stenosis, the outcomes of either treatment were evenly balanced.

Further analysis of the final results of both trials has suggested some additional refinements. Factors which confer a higher likelihood of benefit from CEA include: male sex, age >75 years, higher degree of stenosis (90-99%), hemispheric symptoms (sensorimotor TIA) rather than ocular symptoms, contralateral occlusion, carotid plaque irregularity, and other comorbidities (Naylor, Rothwell and Bell, 2003). While some of these factors (for example older age) also confer a higher surgical risk of stroke or death, this is outweighed by the higher baseline risk of stroke with medical treatment alone in these patients. CEA for symptomatic carotid stenosis has also been evaluated in a Cochrane database review (Cina, Clase and Haynes, 1999).

Another RCT, the US Veterans' Trial (Mayberg et al., 1991), also reported a significantly reduced rate of stroke in patients undergoing surgery for > 50% carotid stenosis. Despite its methodological soundness, the small size of this trial (N=189) meant that its impact on clinical practice was overshadowed by ECST and NASCET's combined sample of nearly 6000 patients.

It is perhaps surprising to find, in view of the high quality of the ECST and NASCET studies, that the authors were in fact cautious about drawing general conclusions. The ECST authors concluded that the only reliable generalisations that could be made from their study were:

'firstly, surgery carries serious risks and, second, successful surgery avoids the large majority of the excess risk of ipsilateral ischaemic stroke associated with severe (70-99%) carotid artery stenosis.' (ECST, 1991; p1241).

It is interesting to note that the caveat about the risks of surgery was given prominence by the authors, ahead of the conclusion about its benefits. This emphatic statement served to highlight the need for caution in generalising the study's results, robust though they were, to other groups of patients, and to surgeons and institutions whose perioperative stroke and death rates were higher than those of the ECST collaborators or were unknown. It also highlighted the need for careful audit of subsequent clinical practice.

Both ECST and NASCET were well conducted, large scale, multi-centre clinical trials, with full randomisation to CEA or control, although, due to the nature of surgical intervention, blinding of the clinical team and patient was not possible. However, an attempt was made to overcome any potential bias in reporting and evaluating outcome events (stroke or death) by using a blinded clinical audit committee to classify them. Patients were followed up for 3 years or more, and complications arising from the process of preoperative investigation, particularly angiography, were included when assessing perioperative mortality and morbidity.

However, these trials, although acknowledged to be methodologically robust, were not without critics. Criticisms of both trials concerned, firstly, variations in the treatment for the medical arm of the trial. For example, the dose of aspirin given as an antiplatelet agent was left to the discretion of the clinician. The management of other risk factors for stroke, such as hypertension, was also unspecified and likely to vary substantially. Secondly, although the trials rightly focused on the crucial and robust end-points of stroke/death versus stroke-free survival, there was no assessment of quality of life, anxiety and depression in either arm of the trials. These were important factors to consider for these patients, who were faced with the paradox of undergoing potentially harmful surgery with no guarantee of long-term benefit (Rose, 1981). Also, although both studies were explicit in their methods for measuring carotid stenosis, the studies

are not directly comparable because of the different measures used. This can lead to confusion in interpreting the results.

An important concern for the application of the results in present day practice is that BMT has moved on in the 14 years since ECST and NASCET reported their early results. It has been mooted that, although it would be ethically impossible to re-run the trials now, the results might be very different in the light of advances in BMT. However this view overlooks the undeniable advantage of successful CEA in conferring immediate reduction in stroke risk (Naylor, 2004a) – although this is, of course, dependent on the patient having no postoperative complications. In other words, CEA will either immediately cause a stroke or immediately reduce the risk of one, whereas certain medical treatments, such as weight loss, smoking cessation and so on will exert a more gradual effect. In the surgical arm of the trial, too, there have been changes. Few patients today undergo the previously standard investigation of carotid angiography, which itself confers a small risk of stroke. Most institutions now use duplex scanning, supplemented with magnetic resonance angiogram, both of which are non-invasive and hence virtually risk-free investigations. There have also been treatment innovations, such as in the use of locoregional anaesthesia rather than general anaesthesia, and the development of carotid artery stent placement procedures. However, the effectiveness of these alternatives is yet to be fully evaluated.

b) Carotid endarterectomy for asymptomatic carotid stenosis

People who have not had symptoms of TIA or minor stroke, but who have a carotid stenosis, are also at risk of subsequent stroke. The Asymptomatic Carotid Surgery Trial (ACST) (N= 3120) studied the balance of risks for CEA in these patients (Halliday et al., 2004). For patients with 70% ICA stenosis or greater, CEA conferred lower long-term (5 year) risk of stroke than conservative treatment. The net 5-year risks of stroke or death were 6.4% in the CEA group (including a 3.1% perioperative stroke/death rate), versus 11.8% in the conservative group. This benefit was confined, however, only to patients under the age of 75. For older patients, the 5-year risk of death from other causes outweighed any potential impact from CEA. The authors cautioned that the results should only be applied to institutions where the perioperative risks were similar

to those in the study centres. A higher rate of perioperative stroke/death would negate any benefits from the long-term reduction of stroke risk.

The potential benefit of CEA for asymptomatic carotid disease is limited by the difficulty of identifying patients who have a severe carotid stenosis but who have not had any carotid territory symptoms. In the absence of symptoms, the condition can only be detected either incidentally, or by screening. The introduction of such a screening programme is, however, not currently widely advocated.

Despite the robustness of the ACST results, the use of CEA for asymptomatic disease warrants further careful evaluation and discussion. The 5-year risk of stroke with BMT for these patients has been shown to be about 12%, compared with a perioperative risk of 3.1%. This means that the remaining 88% would survive, stroke-free, for 5 years without surgery. But if they have CEA, 12 people in every 400 (3.1%) will have a stroke (or die) from short term complications of the procedure. Approximately 10 of them (88% of twelve) would not have had a stroke in the following 5 years with conservative treatment only (assuming that surgical and non-surgical stroke risk are not related). This leaves just two patients in 400 who have a perioperative stroke which they would have had anyway on BMT. Assuming that *“it is better to have a stroke 3 years from (now) than within the subsequent month”*³ (Cina, Clase and Haynes, 1999), this immediate stroke risk represents a worse outcome, as it confers a significant reduction in the patient’s stroke-free lifespan. Looking at 5-year mortality and morbidity, the absolute risk reduction is 5.4%. Even those patients who experience an uneventful postoperative recovery after CEA will inevitably have had a temporary reduction in their health and quality of life, simply by having undergone hospitalisation, surgery, and a period of convalescence, plus, possibly, pre-operative anxiety about the outcome of the operation. It is debatable whether the performance of 100 operations to avoid about 5 strokes from asymptomatic disease is worthwhile.

³ This is, of course, only an assumption, and is one I will challenge later in this thesis.

c) Patients' perspectives in CEA

CEA in both symptomatic and asymptomatic disease is a paradigm case of an evidence-based surgical procedure. However, no matter how compelling the scientific evidence for this, or indeed any other, treatment, it is ultimately for the patient to decide whether they wish to undergo it. In order to make an informed choice, they therefore need, firstly, to be apprised of the outcome of relevant clinical trials, and of the track record of the institution and surgeon they are consulting. Secondly, they need to evaluate the extent to which the scientific evidence applies to their individual situation. Thirdly, they need to consider their feelings about immediate versus long-term risk. It is probably reasonable to assume that a patient would rather not have a stroke at all. However, people's preferences about having a smaller, short-term risk of stroke, versus a larger but longer-term risk (i.e. the possibility of a stroke today versus a stroke sometime in the next few years) are likely to be complex. This issue has been investigated in two small studies.

The first study (Adar et al., 1994), aimed to evaluate patients' attitudes towards immediate versus long-term risk in CEA. Respondents were asked to indicate their hypothetical willingness to undergo CEA for asymptomatic carotid stenosis (with a suggested perioperative risk of stroke of 2%) at various hypothetical yearly stroke rates without surgery. The researchers found that as the non-surgical stroke risk increased, so did the participants' willingness to have surgery. However, the sample only included healthy volunteers and recovering stroke patients, not people who were actually facing the decision. The authors concluded that further research was required into the attitudes and preferences of those who were genuinely facing this decision, and that the clinicians' responsibility in clinical practice was to provide the most accurate information available to help patients to evaluate their chances and risks.

More recently, Kirkpatrick et al. (2004; additional personal communication, 2005) conducted a study of the level of risk that patients were prepared to accept in carotid surgery, in the light of the ACST study results (Halliday et al., 2004). Whilst most patients (74%) felt that surgery would be appropriate only if their 3-year stroke risk

without it was greater than 20%, only 19% felt that surgery was appropriate if their risk was 12% (a situation equivalent to the 3-year risk without surgery found in ACST). However, they almost all agreed that they would be willing to have surgery in line with the ACST recommendations if they were advised to by a doctor. It would therefore appear that 81% of the study population felt that the implementation of the ACST findings represented an unacceptably small degree of reduction in stroke risk to justify surgery – but would nonetheless be willing to have CEA according to the findings if their doctor advised it. The authors also found that patients' preferred mode of information presentation was as the 'likelihood of benefit'; that is, number needed to treat (NNT), rather than as absolute or relative risk reduction. The authors concluded that both NNT and absolute risk should be presented.

A similar discrepancy has been observed in a study of patients' expectation of benefit from medication to reduce the risk of myocardial infarction (Trewby et al., 2002). Only 27% were willing to take medication in order to reduce their 5-year risk of myocardial infarction by up to 5%, whilst 67% would take medication in the same scenario if their doctor recommended it. In both these studies it appears that the doctor's opinion, rather than evidence itself, has a potentially greater influence on patients' treatment choices.

The subject of how to present information about risk to patients about CEA has also been investigated by Lloyd et al. (2001). This study examined patients' recall of the written and verbal information given to them by their surgeon about their risk of stroke with or without CEA, by means of a postal questionnaire sent one month after the consultation (but before surgery had taken place). Most patients remembered that if they proceeded with surgery their long-term risk of stroke would be reduced, but their recall of the actual figures involved was extremely variable. Over 10% thought that their perioperative risk of stroke was at least 50%, whilst some thought there was no risk at all, and 11% did not know. Many patients also wrongly believed that CEA would improve unrelated symptoms such as angina or breathlessness. The authors concluded that patients either had little understanding of the risks of CEA, or quickly forgot them.

Although there are few studies of patients' perspectives in CEA, it appears that patients' comprehension and interpretation of the scientific evidence is inaccurate, incomplete

and, at times, contradictory. These difficulties add to the problems discussed earlier of providing timely, appropriate, and patient-focused care after TIA or minor stroke. In the light of these problems, I now turn to the question of whether, and to what extent, the evidence base relating to CEA is currently applied in clinical practice.

6) Is evidence-based healthcare practised in the treatment of carotid stenosis?

An essential, but problematic, step in EBHC is the implementation of evidence-based guidelines. For this to take place the guidelines need to be relevant to the problems of clinical practice; accessible by, and accessed by, clinicians; interpreted correctly and appropriately for the individual setting; put into practice systematically; and ultimately the results of treatment must be audited to ensure that the treatment is high quality and that its outcomes are favourable.

There are several potential stumbling blocks in the practice of EBHC for patients with TIA. Firstly, as I have discussed in Chapter 3, there is a lack of awareness of stroke amongst the public, and an even greater lack of awareness of TIA. Therefore a lay person is unlikely to recognise the signs of a TIA or to appreciate its significance when either they themselves, or a friend or family member, experiences one. If the TIA is not recognised as a serious event, the person might never seek medical advice and thus will not have the opportunity to have further investigation and treatment. This can happen, of course, with almost any medical condition, but it is known to be an especially common occurrence with TIA, perhaps because of the transient nature of the symptoms.

Secondly, there may be delays in primary care; for example if the health professional who assesses the patient does not diagnose a TIA, or refer the patient appropriately. The patient themselves may also be a source of delay, if they do not perceive TIA symptoms as an emergency. Thirdly, there may be problems at the point of referral from primary to secondary care, or within secondary care itself, if the patient is referred swiftly but investigation and treatment is delayed. Although referral for investigation of carotid stenosis should be treated as an urgent matter, it may still take weeks - if not months - for the patient to eventually have surgery after the initial presentation of symptoms (National Audit Office, 2005). The longer the delay, the more chance there is for a major stroke to occur in the interim. As a result of these factors, the practical difficulties

of identifying patients with TIA, and investigating and treating them swiftly, are not proving easy to resolve. CEA can undoubtedly be effective, but it is useless if patients cannot or do not access it. Worse, CEA is also harmful if it is performed inappropriately, whether this is due to inappropriate patient selection or lengthy delays.

Even if an accessible and efficient service is put in place to 'fast track' patients who have had TIA and who might undergo CEA, the emphasis on surgical intervention might itself unwittingly lead to a de-emphasis on best medical therapy such as control of hypertension, antiplatelet therapy and so on. Patients who are investigated and are not suitable for CEA (for example, because they have ICA stenosis of less than 70%) may then feel falsely reassured, assuming that because they do not warrant an operation that they have a low or zero risk of stroke. Similarly, patients who do have CEA may view surgery as a cure and thus neglect other health measures. It cannot be overemphasised that CEA is an adjunct to best medical therapy, not a replacement for it. Having CEA after TIA or stroke has been found to be associated with lower cholesterol levels, and with higher use of statins and antiplatelet agents, but there is no significant association with blood pressure or blood glucose control (Touze et al., 2006). This suggests that for some parameters of risk, patients who have CEA will also receive better overall management of their stroke risk factors.

Even if diagnosis, referral and treatment do occur in a timely and appropriate fashion after a TIA, it is not safe to assume that the outcomes of either BMT or CEA will be the same as those in the ECST or NASCET trials. Firstly, BMT has evolved since the trials took place. If a major randomised trial could be conducted now, it is likely that a lower stroke and death rate would be found in the control group, due to these advances in BMT. Therefore the net benefit of CEA over BMT alone will be reduced. However, CEA still has an important role in reducing stroke risk, not least because its benefits are immediate, whereas medical interventions such as control of high cholesterol may take some time to take effect (Naylor, 2004a). Secondly, an issue for all clinical trials is whether the same results can be obtained in everyday practice, outside the intense scrutiny and artificial conditions of a trial. CEA is no exception to this. The transfer of clinical trial results into clinical reality has a number of potential problems. These include the need to replicate the standard of care provided in the trial in everyday

practice. If the surgeon or the care team do not work to this standard, their results may not be as good as the trial results. Another factor is the generalisation of trial data to other populations. Clinical trials can only properly be applied to patients who meet the trial's selection criteria, and the benefits cannot necessarily be extrapolated to other groups who vary in age, gender and concomitant health problems.

For these reasons, continuing audit of individuals', centres' and collective results is necessary. In the UK, the audit data compiled for the National Vascular Database (Vascular Society, 2004) show that outcomes are comparable to the ECST results. The combined immediate stroke and mortality rate is 2.7%, although not all surgeons and centres contribute their data, and in some cases, data entry is incomplete. However, there are commonly long delays before surgery takes place. In a systematic review of 51 studies of the outcome of CEA, the risk of stroke and death has been found to range from 2.3% to 7.7%, although the mean risk was 5.6%, consistent with ECST and NASCET. Much of the variability may be accounted for by lack of independent assessment, with the highest stroke and death rates reported in studies where evaluation was performed by an independent neurologist (Rothwell, Slattery and Warlow, 1996). In the light of this variability, those performing CEA should advise patients of their own track record, based on rigorous clinical audit, rather than quoting data from the clinical trials.

Some strokes are not related to carotid plaque development, and many carotid territory strokes will occur without a prior 'warning' TIA. Therefore, even if it were possible for all those with genuine carotid territory TIA to access swift investigation and CEA where appropriate, there would still only be a small reduction in the incidence of stroke. Since CEA and the preceding investigations are relatively costly interventions, surgery may be a less cost-effective measure for reducing stroke incidence compared to other interventions. Since 1991, when the ECST and NASCET results were published, the performance of CEA has increased dramatically. However, there has been no corresponding fall in the incidence of stroke and stroke deaths. This has led some authors to debate whether CEA is justified on public health grounds (Baird, 1995; Lambert, 1995). There are limited funds available in a centrally funded health service such as the NHS. If there were to be a fixed sum to be spent on reducing the burden of stroke, it could arguably be best used in conservative treatments such as the control of

hypertension, rather than on CEA. Although such issues of rationing are increasingly being raised, no health service so far is run on purely utilitarian grounds in this way. Faced with a patient who has had a TIA, who meets the clinical criteria for CEA, and who wishes to have the operation, a clinician would not withhold treatment on the grounds that the money could more efficiently reduce the stroke risk of a greater number of patients if it were used differently. However, the odds are high that that particular patient will not, in fact, derive any benefit from CEA: the number needed to treat (NNT) for CEA after a TIA is 9. That is, nine patients must have surgery in order to enable an extra one of them to be alive and stroke-free 3 years later (ECST, 1998). (If the analysis is restricted to disabling strokes, the NNT is even larger at 18.) The other eight patients out of nine will have derived no benefit from the operation, at least in terms of its primary endpoint of stroke-free survival. There is no way of determining, either in advance or in the years to come, which one of the nine was the one who benefited.

Of course, other interventions to reduce the risk of stroke, such as statin therapy, will also benefit only a few of the many people who are prescribed them, and may harm a small number (owing to adverse drug reactions). But CEA carries a unique irony. No other treatment to reduce the risk of ischaemic stroke risk itself causes ischaemic stroke. If we assume the risk of perioperative stroke to be about 5%, it can be deduced that CEA has been the direct cause of 50,000 strokes worldwide since the operation was pioneered, assuming 1 million procedures have been performed (Naylor, 2004b).

To summarise, CEA is undoubtedly an effective way of reducing the risk of stroke for selected patients, but the operation is known to carry substantial risks. Its effectiveness is reduced, although its risks remain the same, if patients are not appropriately identified and referred, or if treatment is not swift and high quality. Although the surgical treatment of carotid artery stenosis is only a small part of public health strategy aimed at reducing stroke mortality and morbidity, CEA has been more thoroughly researched than perhaps any other surgical procedure. The substantial, though complex, evidence base makes it a fruitful topic for an exploration of nursing in the context of shared decision making.

7) Clinical starting point

In the previous sections, I have explored the development of EBM and its relevance to nursing, and have analysed the field of stroke risk reduction in this context. This discussion, together with the previous chapters, sets the scientific context for this thesis. This study, however, did not arise principally from the scientific literature, but from my clinical background in vascular nursing. I now turn, therefore, to the personal context for this thesis.

I have long been fascinated by risk-reducing surgery. Almost any surgical procedure will temporarily reduce the patient's health status, by subjecting them, for example, to general anaesthesia and the formation of a surgical wound. This temporary reduction in health is usually accepted by patients and health professionals as a necessary cost in order to gain a benefit; namely, improved health status, or longevity in the future. But some patients, who are not presently experiencing unpleasant or life-threatening symptoms, undergo surgery in order to reduce or eliminate their risk of a condition which they might – or might not - develop in the future: risk-reducing surgery. Since the natural history of most diseases is, to some extent, unpredictable, there is no certainty that the condition which it is hoped to avoid by such procedures would ever have developed if surgery had not been undertaken. This is, of course, very common in health care: vaccination programmes are undertaken to reduce people's risk of developing infectious diseases which they might never come into contact with, and the widespread use of medication to reduce the incidence of stroke and coronary artery disease will inevitably mean that some people take medication to reduce their risk of a condition which they might never have developed even without the intervention. Unfortunately, but perhaps inevitably, some people will be seriously harmed by such interventions; for example, if they develop a life-threatening haemorrhage after taking aspirin to reduce their risk of vascular disease. The performance of surgery to reduce risk is a rarer phenomenon, and is somewhat at odds with the traditional, but erroneous, image of surgery as a curative or life-saving procedure (Fox, 1992). Examples include the use of prophylactic bilateral mastectomy in women who are at high risk of developing breast cancer, elective abdominal aortic aneurysm (AAA) repair for asymptomatic patients to reduce death rates from AAA rupture, and, the clinical starting point of this thesis,

carotid endarterectomy (CEA) to reduce the patient's long-term risk of ischaemic stroke.

Whilst, broadly speaking, any major surgical procedure intended to preserve life and restore or maintain health may, in a few cases, have detrimental effects instead; CEA is unique. It is probably the only operation which may cause the precise event it aimed to avoid – namely a disabling or fatal stroke. I was first made aware of the poignant irony facing patients undergoing CEA when I was working as a staff nurse on a vascular unit over 10 years ago. Nurses are accustomed to supporting patients who are anxious about their forthcoming surgery, but the preoperative anxiety displayed by patients admitted for CEA seemed to be unusually distressing. These patients were normally physically well when they came to hospital, yet were undergoing surgery with no certainty of benefit. Indeed, a few patients had permanently disabling strokes after CEA – an outcome which is, perhaps understandably, the most feared by patients (Solomon et al, 1994). In contrast to many of the other patients on the vascular ward, who were, for example, having surgery to try to salvage an ischaemic limb, or to alleviate severe pain, patients undergoing CEA had little or nothing in the way of current symptoms, despite having had a previous TIA or minor stroke. The central paradox of surgery - that the patient agrees to be made (temporarily) ill, and runs the risk of permanent harm, in exchange for the chance of a long-term improvement in their health (Fox, 1992), was clearly apparent, both to the patient and to the staff caring for them. The well-known doctrine that hospitals should first do the patient no harm (Nightingale, 1863) was not strictly applicable to these patients: rather, we could say that hospitals should only run the risk of harming patients if they were fully informed of the risks, and if the chance and magnitude of potential benefits outweighed the risk of harm. I was aware of this difficult dilemma facing the patients in our unit; an issue which evolved, during discussion with the senior vascular surgeon on the unit (PL Harris, 1994, personal communication), into an initial idea for a study into how patients cope with the uncertainty and potential risk of CEA. These initial thoughts were expanded once I moved in to a post with additional responsibilities for patients attending outpatients' clinics before and after vascular surgery, where I gained a broader perspective of the dilemma which these patients faced.

8) Aims of the study

The aims of the study evolved as the study progressed and new themes emerged. I will discuss this process of theme generation in a later chapter. In this thesis, I hope to contribute to the following areas of knowledge.

- 1) The lived experience and impact of TIA: to explore systematically the subjective experiences of people with recent TIA, in order to achieve a greater understanding of factors relevant to symptomatic people accessing care, to explore how the experience of TIA affects individuals' perceptions of their health, and their uptake of health maintenance measures.
- 2) Sources of evidence: to examine the ways in which people access and interpret information and evidence about their risk of stroke after a TIA or minor stroke, and to explore their perceptions of evidence in the context of EBHC.
- 3) Weighing up the odds: to understand how, and to what extent, people integrate their personal experiences with the information and evidence they have accessed in order to make decisions about measures to reduce their risk of stroke after TIA or minor stroke.
- 4) Minimizing potential for regret: to gain insights into people's perceptions of potential adverse outcomes of proposed surgery or medical treatment, and the effect of anticipated regret on people's lived experience of stroke risk.
- 5) Reducing uncertainty: To explore the links between these themes in order to create a conceptual framework relating to living with stroke risk.

CHAPTER 5: DESIGN AND METHOD

1) Designing the study

My intention in this chapter is, firstly, to give an account of how I collected and analysed the data, and to discuss the methodological approach I took. However, I am also going to discuss how I went about designing the study and how the study changed as it progressed. This is because the evolution of the study design was itself an important source of knowledge. The different approaches I considered, and the problems that I faced, in their own way enriched my exploration of the subjects of interest in this thesis, as much as the more formally laid-out findings. In addition, I also want to emphasise that I found the process of research design far from straightforward, and that the selection of what and how to investigate required rigorous exposition. This complexity is particularly apparent in the qualitative research paradigms (though it is not exclusive to them), where theory generation, rather than theory testing, is the aim. I wished to be able to respond to the data which was generated, in order to take the research forward, rather than defining the study design and methods in every detail beforehand. The reflexive approach I used incorporates self-critique and appraisal, and my discussion of the development of the study is intended to enhance the rigour of the findings (Koch and Harrington, 1998). Therefore, the focus of this study legitimately includes its own genesis.

Before turning to a detailed account and critique of the methodological approach I took, and the specific methods I used, I will therefore start by examining the process by which the study came into existence. I have described the clinical background to the study in the previous chapter, and in light of this background, my initial starting point was therefore to design a study of the personal consequences to patients of undergoing CEA. My early ideas included a mixture of methodologies: possibilities included a qualitative study of the lived experience of patients having CEA; application of such tools as the Hospital Anxiety and Depression scale and Decisional Conflict scale (O'Connor, 1995), and possibly the incorporation of a randomised trial of the effects of an information package about CEA for these patients on their understanding of surgical and non-surgical risks, and also on psychological parameters such as anxiety and depression.

Although I was considering a number of different methodologies, I was already conversant with qualitative approaches, as I already had some practical experience of qualitative interview methods from previously undertaking Master's level studies (Gibson, 1995). I felt that a qualitative phase was the most appropriate starting point for the study. These were uncharted waters: despite the wealth of research data relating to stroke risk reduction and CEA in the scientific literature, the experiences of people who had TIAs and underwent surgery were represented only by a small number of studies, none of them of a qualitative design.

I then decided that it would be sensible to limit the scope of the study by focusing more closely on people's experiences of CEA and the events surrounding it, rather than also undertaking a randomised trial of information-sharing techniques. I also realised that it would be important to include participants who were not having CEA as well as those who were, in order to elucidate whether and to what extent their experiences were due to their being at risk of stroke, or due to surgery itself. The methods I proposed using included a qualitative interview-based enquiry, anxiety and depression ratings, and a decisional conflict scale (O'Connor, 1995). Had I included a randomised trial at this stage, there was a danger that the qualitative part of the study would have been relegated to the status of merely a preliminary 'scene-setting' enquiry. I would therefore have had less scope for undertaking a detailed analysis.

The limits that I placed on the scope of the study corresponded to the first two stages in the Medical Research Council (MRC) framework for the evaluation of complex interventions (MRC, 2000). In this framework, stage 1 entails a theoretical and modelling phase (often based on existing literature), while stage 2 entails the assessment of theory and evidence, for example using qualitative research approaches, in order to develop an understanding of the intervention. The later stages in this framework (exploratory and full randomised trials, and long-term implementation and evaluation) were outside the scope of my study.

At the point of applying for PhD registration, I had a definite and fairly detailed research proposal. However, although the research proposal was required to fulfil the function of being a plan of the work to be undertaken, it was also, literally, a proposal:

that is, a starting point and a suggestion for possible directions of travel, rather than a definitive route map. Once I began the study in earnest, and as I began to gather data, it was apparent that the lived experiences of participants were an exciting area for research in their own right. The themes that were emerging were more complex than I could do justice to if this stage was only a part of the study. As the data piled up, and the themes developed in complexity, I increasingly felt torn between sticking to my original plan and exploring these themes in detail. In particular, I realised that my previous assumptions about the most appropriate ‘direction of travel’ or overall design for the study were very wide of the mark. I had originally assumed that the theme of decision-making about CEA or other treatment choices would emerge as a central concept in participants’ experiences, and that the concepts of decisional conflict and styles or locus of decision-making would be appropriate areas to explore further with the use of validated tools. But during the interviews, and particularly during analysis of these early interviews, I found that other emergent themes appeared to be far more important to participants.

This is, of course, a core problem in qualitative research design and in grounded theory (GT) approaches in particular. The basis of GT – that emergent theory must be grounded in the data – implies that the ‘direction of travel’ will not be known in advance and that new themes should – indeed must – be pursued as they emerge. I will discuss the methodological issues this raises later in this chapter. There were, of course, challenges in conducting the qualitative phase of the study in such a way as to allow proper consideration of these emerging themes, while still allowing me to explore my original ideas. However, quite apart from the problem of how to integrate these new themes into my work, my primary difficulty was in deciding whether they were of sufficient significance to justify my changing the whole structure of the study from my original research proposal, in order to accommodate them and give me the scope to explore them more fully. I decided that if I were to stick rigidly to my original plans, I would merely be measuring what was measurable (e.g. decisional conflict), not what was actually important to the participants. The emerging themes (which could reasonably be said to be more important to the participants than my *a priori* assumptions of what those themes might be) could not be relegated to side issues, but had to assume a central place in the emergent framework of the entire study. In

particular, the emerging theme of participants' lived experience of TIA demanded a shift from my proposed approach for this part of the study. This exploration of participants' experiences was intended purely to discover meaning rather than to build theory, which was more akin to a phenomenological approach rather than GT. Furthermore, by changing the design of the study to a purely qualitative one, I would actually enhance the validity of the study. Rather than detract from the central themes which emerged by going on to measure what were (as was increasingly apparent) rather tangential issues, I would be able to do justice to the real concerns and themes raised by the participants, which had previously been almost entirely overlooked. This would also give me the greatest opportunity of making a novel contribution to the knowledge base.

2) Suitability and limitations of a qualitative methodology

In order to achieve the aims of this study, a qualitative approach to data collection and analysis, with the use of "*thick description*" (Geertz, 1973), was most appropriate. As I developed my ideas for the research, it was apparent that there was already a wealth of findings derived from methodologies such as randomised trials, epidemiological studies and the like. This material was clearly an important part of the background to my interest in patients' perspectives of TIA and CEA. However, my reflections on clinical practice and my early engagement with the literature had left me with many unanswered questions. These questions were all rooted within the emic perspective, and were about the views, feelings and interpretations of people who had experienced TIA or minor stroke and who had received medical or surgical treatment for carotid stenosis. When I undertook a more focused interrogation of the literature, I found that this was an area that was ripe for exploration, since there were no previous studies of a similar nature. It seemed that the prevailing climate of stroke research had been so intent on the admirable aim of trying to determine the most effective ways of reducing stroke risk, that we were in danger of losing sight of the individuals who were facing this situation. Although my observations had indicated that the perspectives of patients themselves were paramount in clinical practice, they were virtually invisible in the literature. There seemed a dichotomy between the impersonal nature of most of the literature, and the ways in which I had observed people actually responding to the risk of stroke and

interacting with the clinicians caring for them (that is, in a far from impersonal manner on both sides). I was therefore interested in exploring how, and to what extent, people at risk of stroke themselves appraised and interpreted the scientific literature.

Another essential feature of my approach to this part of the study was the contextualisation of the findings, incorporating both the context of people's everyday lives and the healthcare climate. In this sense, the context of the proposed study incorporated numerous factors: my own personal and professional background; the participants' lives; the clinical setting in which participants had received treatment, and the political and cultural background of healthcare and health services research.

Although, as I have discussed, I decided against using mixed qualitative and quantitative methods in the study itself, nonetheless the study owed a great deal to the quantitative perspective. This perspective was not just part of the context of the study; it was an important component of the study design, in that I was interested (among other things) in how participants accessed and interpreted the formal evidence base about reducing stroke risk. However, I felt that the unquestioning use of triangulated or mixed methods, via the formal incorporation of qualitative and quantitative approaches, would undermine rather than enhance the robustness of my work. A study incorporating mixed methods would be in danger of allowing one approach to dominate (Dootson, 1995). For these reasons, I confined my exploration of quantitative approaches to the subject to an analysis of the existing literature. In doing this, my aim was not to seek a formal confirmation of the findings of the qualitative study, but to "*enlarge the landscape of the enquiry, offering a deeper and more comprehensive picture*" (Tobin and Begley, 2004).

The demonstration of rigour in a qualitative enquiry needs to be appropriate to the specific paradigm, rather than trying to copy the traditional trio of validity, reliability and generalisation (or external validity) which are essential in ensuring the quality of quantitative research. The inapplicability of these concepts to qualitative enquiry has led to critics dismissing the entire field as non-rigorous and subjective (Denzin and Lincoln, 1994). I did not wish to reject the concept of rigour, but to re-interpret the term in a way that was more appropriate to the focus of the study. Rigour, also presented as

'goodness' in qualitative research, is not merely an evaluative process in assessing the quality of a study, but should be an integral and embedded part of the whole process of research (Tobin and Begley, 2004). A possible framework for the demonstration of goodness in qualitative enquiry is suggested by Arminio and Hultgren (2002); who suggest that several concepts must be embedded throughout the study in order to ensure its quality (Table 1).

Table 1: Framework for the demonstration of 'goodness' in qualitative enquiry.

i. Foundation - epistemology and theory	The philosophical stance and context of the study
ii. Approach	Methodology
iii. Collection of data	Method
iv. Representation of voice	The researcher reflects on their relationship with participants and with the phenomena being explored
v. The art of making meaning	Interpretation and presentation
vi. Implications for professional practice	Related to context of study

These concepts are a useful starting point to developing rigour in many different qualitative approaches. My use of specific approaches to ensure rigour in grounded theory is explored in the next section.

3) Methodologies : the use of grounded theory and phenomenological approaches

The philosophy and method of grounded theory (GT) was originally expounded by Glaser and Strauss (1967) and it is now a well established approach for "*discovering theories, concepts, hypotheses, and propositions directly from data rather than from a priori assumptions, other research, or existing theoretical frameworks*" (Taylor and

Bogdan, 1998). Since its original development in the 1960s as a social science methodology, GT has been used increasingly widely in nursing and allied health research. However, it is doubtful whether some of the nursing literature that claims to use a GT approach would be recognised as such by the original proponents of the method. Many published studies, for example, use the term to describe a study that is simply descriptive in nature and has little or no development of key themes and contextualisation. GT is distinguished from other qualitative methodologies by the primacy of the data, rather than existing frameworks or hypotheses, in generating theory. Although, as Glaser (1978) said, “*everything is data*” to the grounded theorist; it is also possible to reverse this statement and to assert that in GT “*data is everything*”. This corollary implies that concepts and themes can only be derived from the data, not from a previous hypothesis, and subsequently integrated with previous research findings. Other important attributes are the focus on interpretation, rather than solely on lived experience, and the attempt to move beyond descriptive accounts of lived experience towards a contextualised analysis of the concepts that have been uncovered. However, the methods typically used in many different qualitative research approaches (e.g. semistructured interviews; iterative analysis, and the use of ‘thick description’ in accounts of the research) are similar. It is therefore not surprising that students of qualitative research approaches sometimes find it hard to determine whether a published study or a proposed study design is ‘really’ GT or another type of study.

My understanding, however, is that a too-slavish adherence to one school of research methodology or another can actually detract from the quality of the work and the validity of its findings. Engaging in lengthy debate about whether a study is, for example, ‘really’ GT or phenomenology, or attempting to ensure that the design of the research and analysis fits neatly into one or other methodological box, can hinder rather than help the emergence of reliable findings. This has been discussed in detail by Avis (2003), who argues that the rigid compartmentalisation of the three main methodological theories of qualitative research (phenomenology, grounded theory, and ethnography) is a flawed response to the perceived dominant paradigm of positivism. This has taken the form of making misguided attempts to define the boundaries of the main qualitative paradigms in the same rigid way that the positivist tradition is perceived to function. The overemphasis on theory can be counterproductive; instead,

Avis argues for the development of a “*pragmatic epistemology*” and by implication, a pragmatic methodological approach. This means that the rigour of a qualitative research study should be judged primarily on the validity of the arguments put forward in support of a claim to new evidence-based knowledge. It is less important to demonstrate that the methods used to gain that evidence are in accordance with the predetermined rules relating to a specific methodology. Although the tried-and-tested techniques associated with methodologies such as GT may be useful, the test of their utility is whether the end results of the enquiry are valid and justifiable, not how closely the ‘approved’ method was followed. The corollary of this argument is that the researcher cannot demonstrate the validity of their findings solely by stating that they followed the rules of ‘how to do’ GT or any other method.

The GT approach involves two significant strategies: the constant comparative method, and theoretical sampling. The constant comparative method involves researchers analyzing and developing coding and concepts for the data alongside the process of data collection. This is an inductive process, in which the researcher tries to build concepts and theories that flow directly from the data.

Within the strategy of theoretical sampling, the sample size and composition is not predetermined (although some indicative number and scope may be needed for such purposes as gaining ethical approval, seeking access to the field and applying for funding). Instead, the researcher selects appropriate participants on the basis of their potential to enable the expansion or refinement of the emerging concepts and theory. However, finding good informants is not easy; just because a potential participant has the superficial characteristics (e.g. their medical and demographic details) that suggest they may be a useful informant, there is no guarantee that they will contribute to the emerging themes of interest, especially as the study develops and those themes become more abstract.

The methodology I developed for this study, then, was most closely allied with GT (Strauss and Corbin, 1990). However, a ‘purist’ GT insistence on starting with a *tabula rasa*, and avoiding gathering sources of data from the literature until data collection is complete (Glaser, 1992), was incompatible with the way in which my study had

developed from the literature and from my own clinical experiences. Indeed, it is hard to see how such a purist data-led approach could ever be achieved. All research has some sort of starting point, and all researchers have their own agenda (whether or not they are willing to explicitly state it or are even fully aware of it themselves), which is derived from their own personal and professional experiences. It is inevitable that the researcher's own standpoint, whether they acknowledge it or not (and perhaps particularly if they do not) will affect the way in which data is collected and interpreted. No matter how hard they try to 'let the data speak', it will still be filtered and distorted by the researcher's preconceptions. It is in the nature of making assumptions that most of the time we do not fully appreciate that we are making them, and therefore we do not acknowledge them. In the light of this argument, it seems to create an artificial distinction to insist that the researcher avoids contaminating their data collection with prior knowledge of the literature, because it is impossible for them to avoid the influence of so many other external factors. However, it must be acknowledged that it is important that the literature is revisited during and after the data collection phase, in order to take account of emergent themes. This acknowledgement of my previous knowledge and preconceptions was part of the reflexive approach I took to the study. Reflexivity implied that I was part of the world I was studying, affected it and was affected by it. This approach enhanced the rigour of the research

By contrast, a more pragmatic acceptance of the use of the literature in shaping the early stages as well as the late stages of the study (Strauss and Corbin, 1990), fitted well with my approach. My study was, of course, partly about people's responses to biomedical sources (and other sources) of evidence about stroke risk, and this meant that I could not have conducted the study at all without the incorporation of some of the background literature on this topic. In addition, however, my professional stance, as a nurse engaged in clinical work with the client group I was studying, meant that many of my assumptions were related to my nursing background and my clinically focused understanding of the healthcare available to these patients, as well as to the scientific literature which underpinned the topic. Rather than trying to ignore or 'un-learn' this background, it made sense to try to understand it better in order to start to question my assumptions. Trawling the literature and reading or re-reading the many contributions relating to TIA and the reduction of stroke risk was a task that I tried to approach with

an open-minded perspective. I was interested not only in what the findings of such research were, but in such matters as how the literature was worded and in particular, how it fitted in with my emerging ideas about the patient's perspective on TIA and stroke risk. For example, although numerous authors had indicated the importance of TIA as a marker for stroke, the literature was almost silent on such subjects as people's practical and emotional response to having a TIA. In this way I used the scientific and clinical context of the study as a basic skeleton rather than a restrictive framework, where the gaps in the literature were potentially more important than those areas which were more fully delineated.

Although, as I have described above, it was essential to the subject area and to the genesis of the study, that I was fully conversant with the scientific literature on stroke risk reduction, none the less I did not attempt to impose theory from other studies onto my emerging framework (Stern, 1985). As far as possible, the data I gathered determined the direction of the research questions, what was explored, what further literature was searched, and the number of participants.

In the first parts of the study (described in chapters 6 and 7), I took a somewhat different approach. I found that the style and structure of the first part of nearly every interview, in which the participant described their initial experience of and response to their TIA or minor stroke, was different from the later parts of the interview. Reflecting on this, I realised that this material was worthwhile in its own right, as an account of individuals' lived experience of TIA, without any attempt to contextualise and build theory. Therefore I adopted a phenomenological stance to this topic. I will discuss in more detail how this theme was developed in chapter 7.

In taking a phenomenological approach to this part of the study, I was attempting to describe participants' immediate experience of the TIA in order to '*render lived experience intelligible*' (Dobbie, 1991). I wanted to understand people's prereflective experience; that is, the meaning or sense of the experience, rather than conducting an in-depth exploration of the context of the TIA at this stage. My analysis of this part of the study was essentially a thematic analysis in order to develop an '*understanding of the world*' (van Manen, 1990, p79) rather than an attempt to build theory.

It is odd that in almost all research reports within the phenomenological tradition, the results and analysis focus on themes rather than on the avowed emphasis on the individuality of experience. As Crotty (1996, p13) points out, “*an express search for individual, subjective meanings is curiously linked to a method that systematically discards individual, subjective meanings unless they are shared with other respondents*”. In order to try to overcome this paradox, and to give a voice to the participants’ individual experiences, my study relied heavily in parts on the use of “*thick description*” (Geertz 1973; 1988) of individuals’ experiences as they were, with little or no reference to their context. This was particularly apparent in the first parts of the study to be described (Chapters 6 and 7), but ran through all sections of the research.

The processes of data collection and analysis took place alongside each other and fed into each other. My initial focus was sharpened by the data I collected from participants (Strauss and Corbin, 1990). I transcribed each interview as soon as possible after it had taken place, and undertook preliminary analysis to derive some emergent categories. These tentative categories then partially informed the content of the next interviews, in order to confirm or refute their repeated presence. With each interview, I had two constant (but unspoken) questions in mind: ‘What is happening here and now in this data?’ and ‘How does this fit with my existing categories?’ In the first part of the study which focused on the lived experience of TIA (chapter 7), the first of these questions was uppermost. The second of these questions entailed the constant comparison method of data analysis (Strauss and Corbin, 1990). This enabled me to identify the categories which were most significant to participants, to gradually build up a picture of how the categories related to each other, to cluster them into major themes, and to develop a core category to which all the other categories related. As far as possible, the initial categories were given labels that were derived directly from participants’ own words. As the study progressed, four main categories began to emerge, each with a number of sub-categories. There were connections between many of these sub-categories, even across the main category boundaries. An overarching theme also emerged.

It seems to be a perennially difficult problem for GT research to determine when data collection is complete. The concept of category saturation implies that once no new categories are emerging, saturation has occurred. However, it is always possible that just

one more interview will throw up a major new theme. It is easy to be sure that the theory has not reached saturation, but impossible to be sure that it has done so. Even if I had interviewed perhaps 200 participants, I could not have been sure that the 201st person would not have something to tell me which might add new insights to the theory I had developed. I realised that the traditional definition of saturation, that of reaching a point where no new categories were being uncovered, was difficult to apply to a research study of this design. Instead, I felt that a robust theory could be defined as one that could withstand the challenge of a contradictory piece of data.

It seemed that some researchers and writers on grounded theory had tried to equate saturation with having uncovered 'everything'; having the last word on the subject. This is analogous to the determination of statistical significance in the positivist paradigm. My feeling was that instead, category saturation and the development of a robust theory was about being able to justify the truth and authenticity of what had been uncovered. This allowed for the possibility that a different theory might also be true, were the study to have involved a different sample, method, or researcher, but that this did not detract from the rigour of my theory.

Chiovitti and Piran (2003) suggest a practical framework for enhancing and demonstrating rigour in GT studies. This incorporates eight methods, grouped into three standards: Credibility, auditability, and fittingness (Table 2). I have used the methods in this framework throughout this thesis.

Table 2. Methods of research practice for enhancing standards of rigour. Adapted from Chiovitti and Piran (2003).

STANDARDS OF RIGOUR	SUGGESTED METHODS OF RESEARCH PRACTICE
Credibility	<ol style="list-style-type: none"> 1. Let participants guide the enquiry process 2. Check the theoretical construction generated against participants' meaning of the phenomenon 3. Use participants' actual words in the theory 4. Articulate the researcher's personal views and insights about the phenomenon explored
Auditability	<ol style="list-style-type: none"> 5. Specify the criteria built into the researcher's thinking 6. Specify how and why participants in the study were selected
Fittingness	<ol style="list-style-type: none"> 7. Delineate the scope of the research in terms of the sample, setting and the level of the theory generated 8. Describe how the literature relates to each category which emerged in the theory

My use of a reflexive approach, incorporating self-critique and self-appraisal, was also a source of rigour (Koch and Harrington, 1998). Reflexivity implies that the researcher is part of the world being studied, affects and is affected by it. Reflexivity is a characteristic of ethnographic approaches (Boyle, 1994) and phenomenological approaches (Holloway and Wheeler, 2002). In phenomenological research, the use of reflexivity is related to the foundations of the approach within Heideggerian hermeneutics, in which interpretation is integral to human existence (Todres and Wheeler, 2001). Within GT, the term reflexivity is not commonly used. However, the concept of theoretical sensitivity, which is a fundamental aspect of GT, has much in common with reflexivity. Theoretical sensitivity represents *“an ability not only to use personal and professional experience imaginatively, but also literature...to make creative use of one's knowledge and experience”* (Strauss and Corbin, 1990, p44).

Others have argued that attention needs to be paid to the relationships between interviewers and interviewees as a necessary part of enhancing rigour in GT (Hall and Callery, 2001). I felt that reflexivity was therefore an essential construct in GT.

4) Selecting and developing an approach to data collection

The focus of my study was the individual's response to the experience of TIA or minor stroke. This focus lent itself to an interview-based approach, and even to some extent a narrative approach, to data collection. I was interested in people's lived experience: the events that had taken place and their personal responses to these events. These events were unique to each person, and I recognised that they might be highly personal, making an individual interview the most appropriate and least threatening way of exploring the subject.

I decided against using formal participant observation methods for a number of reasons. Firstly, I was already working in the setting in my clinical role, and was therefore a 'participant observer' in the field already. This was not a formal source of data, but it was inevitable that my continued observations and experiences would influence and inform the direction of the research. Indeed, it was through informal observation that I had been drawn towards undertaking the research in the first place. The participant observer method also held potential ethical and practical difficulties. My clinical role and research role would have been uncomfortably close, resulting in possible confusion for patients. I did not cease to act as a registered nurse during data collection, of course, but the focus of the interaction was very different. During interviews, my primary purpose was to help myself to advance my research, in terms of gathering the data I needed. The interaction was therefore mainly for my benefit. During patient consultations in the clinic and on the ward, however, my focus had, as always, to be on the needs of the patient. If I had attempted to use these clinical interactions for formal data collection, the inherent incompatibility of the two approaches might have resulted in an unsatisfactory situation where neither the patient's needs, nor my needs as a researcher, were being met. The latter would have diminished the quality of my research, but more importantly, I did not want to diminish the quality of the care and attention which patients received. I felt that any research activity, which was not central

to the clinical care which patients needed, should only be done if there was no other reasonable way of conducting the activity, and if the benefits outweighed the disadvantages to patients. In this case, I felt that the possible benefits of undertaking formal participant observation would be outweighed by its potential to detract from my clinical role.

Instead, an entirely separate interview (both in terms of time and location) meant that people were voluntarily giving me their time, reducing the risk of possible coercion which they might have felt from my collecting data during clinical consultations, and enabled them to focus on the practical business of their hospital visit at that time. It also meant that the quality of the data I collected during interviews would be enhanced by avoiding an excessive focus on the practical matters which might be uppermost in their minds at that time. I wanted to understand the issues relating to their TIA or minor stroke which were important to them in their life as a whole, not just those which were important in the context of the hospital setting and healthcare system.

Another possible method, especially when considering the interactions which participants had with health professionals when coming to treatment decisions, was pure observation, for example, audio- or videotaping and subsequent analysis of patient/professional interactions. I decided against this, because I would have been making the assumption that decision-making was an event which occurred within a defined timeframe (for example during a specific consultation), rather than a process. I would also be in danger of ignoring important processes such as reflection and information-seeking (by both patient and health professional) which might occur outside the consultation room. The process of observation might also alter the interaction itself, so that even if the patient were to reach the same decision, it would not be reached in the same way. I would also have been assuming (wrongly, as it turned out) that the process of decision-making was the most important issue to study in order to understand participants' experiences.

Even with the interview-based method that I used, which did not involve the direct observation of clinical practice, it was apparent that my conduct of the study did change practice. The consultant surgeon whose patients I was recruiting told me that he felt that

he was now giving patients a more detailed explanation about their treatment options than he used to, as he felt he was - indirectly - being watched by me. He knew that if his consultation style was perceived by the patient to be lacking, this might be discussed during the research interview.

Most researchers undertaking qualitative research interviews soon become aware of the intrusion of irrelevant matters, or insignificant “noise” (Morse, 1994, p31) in the interviews. The interviewer may experience difficulty in keeping participants focused on the subject it is wished to investigate. Instead, participants may spend a great deal of interview time discussing apparently trivial and tangential matters. This can consume considerable amounts of interview and transcription time, and there is a more serious danger of the researcher becoming side-tracked from the original focus of the study. Yet in the tradition of GT, codes and concepts must arise from the participants themselves, rather than from an agenda imposed by the researcher. This inevitably creates conflicts between the researcher’s need to maintain a focus to the study, and their need to avoid overlooking promising new themes. The researcher must maintain a delicate balance between two conflicting needs : staying ‘on track’ in terms of the original research design, and allowing, or enabling, participants to recount their stories in their own way and so as to reflect their own perspectives (Davies and Dodd, 2002). It is the participant’s perspectives which are relevant, rather than those imposed by the researcher’ implicit preconceptions or explicit interview schedule.

At the outset, my research plan was to focus on studying people’s decisions about their treatment options after experiencing a TIA. My aim, as embodied in the research proposal and the outline interview schedule, was to identify and explore what I thought was an important and interesting topic: namely, people’s use of evidence and information in making treatment decisions after TIA. However, I found that the participants themselves had a different agenda.

The first inkling that my agenda might not coincide with that of the participants was, with hindsight, apparent from the very first interviews. My interview guide started (after a brief recap from me of the purpose and form of the interview) with the request ‘Can you go back to the beginning, tell me how it all started?’ This apparently simple

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enquiry opened the way to a remarkably detailed and vivid account of the person's TIA or minor stroke and the surrounding events. They demonstrated almost total recall of even the most minute details of what had happened, and of their response to the event. It was only after this topic had been offloaded, so to speak, that I was able to move in more closely to focus on the general themes of decision making and information sharing as outlined in my original proposal. In conducting preliminary coding of these early interviews, I classified this entire 'preamble' as merely 'Experience of TIA' and paid it little attention.

However, after the third interview that had taken the same pattern, I began to look more closely at this data. It was apparent to me that this was a story that people needed, even felt compelled, to share in great detail, and I was interested to find out why. Two things were apparent from this re-reading - firstly, that the experience of TIA was a very vivid one. Minute details of the event were described to me, and the participants' recall was remarkably clear. Even the physical shape of the transcripts was different, with a long, virtually uninterrupted monologue for this section, changing to a more conversational style (with more contributions from me as the interviewer) as we moved on to the topics of information and decision-making about their health. Whilst one could argue that my opening question had invited this disclosure, none the less the breadth and detail of people's accounts of their TIA was far more than could be accounted for by my brief opening question. I also reflected that, in addition, I myself had chosen not to interrupt these lengthy accounts (other than very brief interjections to encourage them to continue). I did not try to hurry the interview forward, but allowed them to say all they had to say about the experience of TIA itself before moving on to my agenda. In allowing the participants to tell me their stories, was I, perhaps, demonstrating my own interest in what they had to say? It did not feel so at the time of the interviews; I recall feeling that this was all just 'junk data' which had to be put to one side before we could move on to the real purpose of the study. But if this was the case, I questioned why I had not tried to steer the interviews more rapidly onto the discussion of my agenda. On returning to the first three or four interview transcripts and recoding these sections in more depth, it was apparent that the participants' accounts of the TIA reflected the central role of the event in shaping their subsequent feelings and actions. I began to

identify a wealth of novel themes within these accounts, and I realised that the experience of TIA was of importance and interest in its own right.

The second important point which became apparent was that the themes which I had planned to explore would not make sense except in the context of the TIA story. The TIA was a pivotal moment for most of the participants, and was itself a source of knowledge (that is, very specific knowledge about one's own health and one's response to the threat of ill-health, rather than about TIA and stroke in general). It therefore seemed essential for me to gain a detailed understanding of the experience of TIA, in order to study people's consequent feelings and behaviours.

This issue demonstrated to me the central role of serendipity in qualitative research. A series of '*accidents and sagacity*'; that is, insight and good judgement¹, neatly encapsulates the process of theme generation in GT research. It was by chance that my opening question led to the divulging of participants' experiences of TIA, but it was only through judgement and insight that I reached an appreciation of the significance of this theme.

5) Practical issues of being a practitioner and researcher

Quite apart from my role in designing and undertaking the study, I was already part of the healthcare milieu for these patients. I was usually present in the outpatients' setting when they were discussing their test results and treatment options with the consultant surgeon. Part of my clinical role was to address any queries or concerns they had (as I would be for any patient attending vascular outpatients' clinics at my hospital). Clearly, this dual role as researcher and practitioner had ethical implications, which I will discuss shortly, but it also raised practical issues.

Advanced nursing practice roles have from their inception included 'research' as a key domain of professional activity (Davies and Hughes, 1995; Furlong and Smith, 2005), with the implication that engagement in both research and clinical practice is mutually

¹ The word 'serendipity' derives from a story by Walpole (1754), '*The Three Princes of Serendip*' where the eponymous heroes '*were always making discoveries, by accidents and sagacity, of things they were not in quest of*'. (Serendip was the former name for present-day Sri Lanka.)

beneficial for both activities. There were, of course, some advantages to the conduct of the research in my being an 'insider'. Not least of these was that there was little difficulty in gaining access to the field, as is often experienced by qualitative researchers. Although I had to gain the permission of managers and clinicians before commencing data collection, this was not as difficult as it might have been if I had been an external researcher. In addition, those patients who were potential participants knew that I had a clinical role and therefore, perhaps, were more willing to take part in an interview than they might have been if I had been a researcher from outside the setting. I was also familiar with working practices and processes, so I could use this familiarity to my advantage in running the study smoothly. As I have mentioned in my discussion of the use of an interview-based approach, I was effectively already a participant observer in the field, and was, whether I intended to or not, unobtrusively gathering data about the healthcare interactions taking place; indeed, I had been doing so for some time in the development of the research. Although this was not formally a part of the research protocol, it is hard to see how I could have avoided doing this. Just as I could not switch off my clinical role entirely in order to engage in research data collection, nor could I completely disengage from my research when engaged in clinical practice. It would have been an artificial distinction to allow my professional experiences to shape the research in the beginning, but not to allow this process to continue once the work was formally underway.

My status as an insider, however, caused two major methodological problems: broadly speaking arising from how the participants related to me, and also from how I related to them. Firstly, the participants knew that I was a nurse specialist, employed by the hospital where they were being treated. Also, I was part of the team which was treating them after their TIA or minor stroke. In some cases, this meant that lengthy explanations of my entirely separate research role were needed. I provided both written information and a verbal explanation about the purpose of the research. However, despite my assurances that the interview was not part of their routine care, and was completely anonymous and confidential, a few of the participants found it difficult to appreciate the role I had as a researcher. Either they appeared to think of me solely in my clinical role, or they thought I was acting on behalf of the hospital for some sort of 'patient satisfaction' study. I felt it was rather saddening that people might think that I

was not interested in their perspectives as such, but only in as much as those perspectives reflected the quality of their hospital care. This was not said directly, but was implied by their comments, often before or after the interview itself. This occurred only in a few interviews. This misconception was, perhaps, due to the unfamiliarity to most people of interview-based research approaches, as much as to the fact that I had a clinical role. In these cases, I steered the interview back on track by re-emphasising the purpose of the study. I was also concerned that this misconception might lead people to say only the 'right' things and to avoid being critical of the hospital or healthcare system. Although participants might be more willing in general to confide in a trusted professional rather than a researcher who was from outside the clinical setting, this advantage might be offset by their being reluctant to make comments which could be interpreted as critical of the healthcare system. However, when I reflected on the number of negative comments that were in fact made by several participants, for example about treatment delays, this somewhat alleviated my concerns on this point.

It is probable that an independent researcher, rather than someone like myself who was part of the clinical team, would have obtained different data and would have generated a different analysis. However, this was in some ways a strength of the study design, rather than a weakness. It has been argued that the cultures and focus of academic researchers and practitioners in nursing are discordant (Mulhall, 1997), but that clinical research must be practitioner-based if it is to make a difference to practice (Rolfe, 1998). My clinical role therefore enhanced the validity of the research approach, by linking theory, research and practice in order to enhance nursing expertise (Prymachuk, 1996).

The second potential problem was not so much that the participants were aware that I was a nurse specialist, but that I was aware of this role myself. It was hard to step away from the comfort zone of my established role in order to step into 'researcher' mode. This problem had two manifestations. One was that I held some clinical responsibility for the participants, as they had undergone or were undergoing medical care at the time of the study. This responsibility was compounded by the fact that they were 'my' patients. Of course, even if I had been undertaking research in a field where I was not directly employed, I would still have had a responsibility, as a registered nurse, to act in the best interests of participants. The fact that I was directly involved in their care,

however, made it even more difficult for me to temporarily step away from this nursing role. The second manifestation of my awareness of my dual role was that I was potentially too familiar with the specific healthcare setting and was therefore 'blind' to important issues arising from the organisation and culture of the setting. This is a difficult phenomenon to evaluate; it is axiomatic that 'we don't know what we don't know'; we are not aware of the things we are unaware of.

The solution to the first issue, that of having clinical responsibilities towards participants, was in the way I dealt with participants' practical concerns. During the course of the interview itself I would respond to any practical queries as briefly as possible, but would make a note of the matter (mental or written) to enable time for it to be discussed further after the formal interview had ended. In this way, I was able to maintain the flow and direction of the interview, without neglecting my professional responsibility to address participants' practical concerns. Those that were raised were mainly of a fairly straightforward procedural nature, for example queries about medication, or about the process of hospital admission for those having surgery in the near future. These queries were well within my usual clinical remit and expertise, and I did not need to refer any participants on to another professional. Had I needed to do so, I would have done so only with the express permission of the participant.

My second difficulty – that of my familiarity with the context of the study - was more difficult to resolve, but I attempted to do so by the process of 'bracketing'. This term arose in phenomenological research and is an important part of an exploratory research design, especially when the researcher, like myself, is very familiar with the setting of the research. However, all researchers will have assumptions and preconceptions about the study they are undertaking, even if the field of study is previously unknown to them. Since I could not 'unlearn' my formal and tacit knowledge about the research topic and its setting, instead I attempted to set aside my knowledge and assumptions by such techniques as reflective self-questioning (Strauss and Corbin, 1990), in order to look at the subject "*with wide-open eyes, with knowledge, facts, theories held at bay* (Oiler, 1982). This enabled me to create an impression of 'acceptable incompetence' (Reid, 1991), or intelligent naivety, in order to challenge and ask questions about things which previously I would have taken for granted as an insider.

The bracketing process is in some ways analogous to the necessity for the direction of the study and the concepts developed to be led by the data rather than by previous work or the researcher's perspective. It was essential for bracketing to occur at many stages of the research (Gearing, 2004): during the design of the study, during interviews, and during analysis. I was constantly having to set aside my previous understanding and experience (that is, to set it outside the brackets) in order to focus on the meaning of the data being uncovered. However, what was equally important was the process of 'unbracketing'; that is, re-integrating the emerging themes with the concepts already developed, and with the existing literature. This did not just occur at the conclusion of the study, or even after each interview, but was a continuous process. Even when conducting an interview I was constantly flipping from the stance of attending to what was being said, to asking myself how it fitted with what I already knew (from previous participants and from earlier in that particular interview). This was important in order to enable me to explore further emergent themes. Again, during transcription and analysis, I paid attention to the topics being described, as well as to consideration of how they related to the concepts I had already begun to develop.

6) Ethical issues

Research approval was sought and granted through the Local Research Ethics Committee (LREC). Although I had expected some problems with gaining ethical approval due to the qualitative design of the study, LRECs being more familiar with studies using experimental design, in fact I was required to make only a few minor changes to the protocol before the study was approved (Appendix 1). However, there were a number of ethical issues which I had to address when designing and conducting the study.

It was extremely important that, as a practitioner in the field in which I was also researching, I did not breach the participants' right to confidentiality. I was careful not to divulge details of the interviews to any other member of the healthcare team. I emphasised this when explaining the study to participants and gaining consent. To preserve anonymity, a number of steps were necessary. Firstly, the details of participants' identities (for example, names and addresses) which I needed for

administrative purposes were kept separately from any other study data. Data sheets containing medical and social details for each participant were identified only by the individual's reference number for the study and by sex and date of birth. Interview tapes and transcripts were labelled only with the participant's study reference number. In transcription, all identifying details, such as names of participants, family members, and healthcare staff, and specific locations, were concealed. Of course, the primary goal of this was to ensure that the participants' right to confidentiality was preserved. In addition, however, the fact that I could reassure them about the steps I would take to preserve their anonymity may have encouraged them to take part in the study. Although it would have been apparent to my surgical and other colleagues which patients were potential participants, their eventual participation or otherwise was not something my colleagues were entitled to know (although of course the participant might themselves incidentally choose to mention their involvement in the study, for example at a follow-up clinic visit). Participants were also assured that whether or not they took part in the study, it would not affect their current or future care. Many participants did identify perceived deficiencies in their treatment, with some criticising the actions of particular members of staff in various healthcare settings. This demonstrated to some extent that they trusted me and my conduct of the study.

I have described earlier how my existing clinical role had some practical benefits and drawbacks for the study, but there was also an ethical dimension to this problem. Butler (2003) has discussed the potential ethical problems of conducting research in one's own clinical workplace. She summarises the main issues as falling under the headings of recruitment; data validity, data analysis; and role conflict/confusion, which I will use below.

a. Recruitment

Because I was a practising clinical member of the healthcare team, it was possible that patients, when approached, would feel obligated to participate in the study. This might be due to simple reciprocity (a belief that they were obliged to help me and my research because my colleagues and I were helping them) or because they might believe that they would be treated less favourably if they did not take part. I went to some pains to emphasise that their participation was entirely voluntary and had no influence on the

rest of their treatment. If they did not wish to participate, they were still free - as any patient would be - to seek my advice in my clinical role. For this reason, among others, I conducted the interviews at participants' own homes. This created a distance from the hospital setting and, I hoped, it enabled them to see me purely in my researcher's role, away from the clinical environment. I also created a 'cooling-off' period by approaching potential participants (in person or occasionally by telephone) and briefly explaining the study, then giving or sending the study information sheet and contacting them again a few days later, to ascertain if they were willing to take part. Only then did I set a date for the first interview. In this way, I did not assume that they had given consent at any point, and even if they had, I allowed time for them to change their minds. They were also free to end the interview at any time without giving a reason, and to decline to discuss any specific matter if they did not wish to. Current research governance procedures now preclude the researcher / interviewer making the first approach in participant recruitment, but at the time of my study it was an acceptable procedure.

Out of those patients I initially approached, two did decline to take part. I have no way of knowing whether those who did participate felt they did so 'voluntarily', but I felt I could assume this with more confidence, since the two who did decline had presumably not felt that they were pressurised to take part.

b. Data validity

Because I was a nurse practising in the field of vascular surgery, the assumptions I made during the process of data collection would be very different from the viewpoint of a researcher with less knowledge of the clinical setting (whether or not they were a registered nurse). Some authors argue that practitioners in a setting should not conduct research in that setting because they will, due to habituation, be blind to what is obvious to others. Of course, I have no way of knowing whether the study would have been very different if conducted by someone not familiar with the setting, but it is very likely that it would. However, this does not imply that the outsider's view would necessarily be the 'true' one, with the implication that my view was 'false', being biased by my experience and familiarity in the clinical area. I prefer to think that any qualitative research cannot be carried out without some subjectivity on the part of the investigator, no matter what her background, and that an outsider may in fact be in danger of

claiming to possess a spurious degree of objectivity which is impossible to attain. Furthermore, there were advantages to being familiar with the setting: access was relatively easy; there was no need for a long period of familiarisation, and most important, my interest in the subject matter was genuine and rooted in my clinical practice, and was therefore more likely to lead to findings which had meaning within the context of the clinical setting.

c. Issues of data analysis

My interpretation of the data was, like the data collection itself, influenced by my knowledge of the clinical setting. Whilst this could be said to be a source of bias, it could conversely be argued to be essential for the analysis to be grounded in clinical reality. It is next to impossible for any researcher to allow for all their assumptions and preconceptions: indeed, the more deeply held one's assumptions are, the more likely one is to be unaware of them. The most dangerous assumption, though, would be to assume that one has none (a danger which is possibly more, rather than less, likely, if one is new to a setting and therefore feels that one cannot help but have a fresh viewpoint). I was constantly aware of the need to ask myself how the emerging data fitted with my preconceptions, and in fact, I altered the scope of the study considerably as a result of the wholly unexpected emergence of major new themes. In this way I hope that I allowed myself to be guided by the data as it was, rather than by my assumptions about what I 'ought to' find.

d. Issues of role conflict/confusion

As a registered nurse, I had both a general and a specific duty of care towards the participants: The general duty of care would apply to my conducting research in any clinical area of practice, but the specific duty of care arose because I was part of the healthcare team for these patients and thus had a contractual, as well as a general professional, obligation towards them.

During the course of data collection, my duty of care as a registered nurse was always my first concern, but I was also bound by the need to treat the matters discussed during the interview as confidential. I addressed this potential conflict by incorporating a statement in the consent process, to the effect that any information shared would not be

divulged to others, unless the participant had queries or concerns about their clinical care. In this case, I would gain their permission to refer the matter to the appropriate healthcare practitioner.

At the end of each interview, I addressed any clinical concerns which the participant had raised during the interview and which I had not been able to answer fully during the interview itself. Most of these were of a straightforward nature; for example, queries about a forthcoming hospital stay, or about a medication regime. I also asked whether they had any other concerns about their health or treatment they wished to talk to me about.

In one case, however, the matter was not so easy to resolve. This involved a participant whose understanding and interpretation of the risks of stroke with CEA versus BMT was very different from the actual quoted risks. He had therefore declined to have CEA despite having had a carotid territory TIA and having a tight ICA stenosis (in which situation, the long term risk of stroke was greater with conservative treatment than with surgery). Instead of a perioperative stroke risk of 5%, he believed that it was 70% (as opposed to about 20% for non-surgical treatment), so not surprisingly he had declined surgery. After clarifying his perceptions of the risk, I explained at the end of the interview what the risks were in terms of his current situation. About 12 months had already passed since his TIA, so at the time of the interview, his risk of stroke would indeed be lower without CEA than with it and therefore it was wise not to be contemplating surgery at that moment. I decided against explaining in detail that his comprehension of the relative risks had been wrong. Such an explanation would perhaps have clarified his knowledge, but would not have helped him in the sense of enabling him to make a better-informed decision; in fact, it might have caused him concern to know that he had based his original decision on a less-than-perfect understanding. I also ensured (as with all the participants) that he understood the necessity to seek immediate medical advice if he suspected that he was having another TIA or stroke. I wanted to ensure that all the participants felt comfortable with the interview process, and that they did not feel coerced into either taking part, or that they felt they were obliged to divulge anything they did not wish to. As mentioned previously, all but two of those who I approached were willing to participate. I interpreted the fact that two

people had declined as evidence that I had not been overly 'heavy handed' in the recruitment process, and that those who did take part were therefore doing so voluntarily. Having agreed to take part, however, it was also important that those who did participate felt comfortable with the specific matters they were disclosing. As we were discussing matters relating to people's life experiences, on one or two occasions participants mentioned events which were clearly distressing for them, for example the death of a spouse. When a participant was clearly distressed, I suggested that I stop the audiotape recording and allow time for the participant to regather their thoughts. They agreed to this and were able to resume the interview after a short break. Another participant, after a lengthy interview, started to tell me about his concerns relating to the local provision of healthcare but then changed tack, saying he did not want to discuss it. He asked for the interview to be ended shortly after this as he did not want to discuss what he felt was a matter of 'politics'.

At the end of the interviews, I allowed some time for a brief recapitulation of what had been said, and checked again that the participant was willing for me to use the interview recording and transcript as part of the study. At this point, I also addressed any clinical concerns which the participant had raised during the interview and which I had not been able to answer fully during the interview itself.

By these measures, I tried to ensure true voluntary participation in the study, and to downplay my clinical role as far as possible, without denying participants the opportunity to tap into my clinical skills if they wished to do so. The depth and content of the interviews demonstrates that I achieved this. From my perspective, I felt that I had stepped into a different role during the interviews – but in addition to, rather than in place of, my role as a nurse.

7) Methods used in data collection and analysis

I identified potential participants during the course of vascular surgical clinics where I was working. The full inclusion and exclusion criteria are listed in Appendix 3. All participants had experienced a recent episode of amaurosis fugax, carotid territory TIA or fully recovered minor stroke, had completed any necessary investigations including a

carotid duplex scan, and had come to a decision about their treatment plan. My initial participants formed a convenience sample, but later on, I switched to a more purposive style of sampling in the following ways. Firstly, in order to fully explore the newly-emerged theme of 'the experience of TIA', I recruited only those people who had had TIA or amaurosis fugax, rather than a minor recovered stroke. Secondly, my earlier participants had mostly chosen to undergo CEA, so later on in the study I tried to balance this with an equal number who were having BMT alone, in order to fully explore both perspectives. Thirdly, I was very keen to interview someone who had declined a 'clinically indicated' CEA, but it proved very difficult to find such a person. The first person I approached declined to be interviewed (perhaps not surprisingly, since they had also declined CEA), but the second such person did agree. The involvement of all these potential participants had already been included in the research proposal.

After the clinic consultation with the surgeon was complete, and a treatment plan had been decided on (in terms of surgical or medical treatment), I briefly checked the person's casenotes to ensure that they met the inclusion criteria. I then approached the person and briefly explained the study to them, and gave them an information sheet (Appendix 4). At this point I also reviewed their casenotes to gain demographic details and information about their medical history (Appendix 5). I arranged to telephone them a few days later, at which point I asked if they were willing to take part in the study. If they were, I scheduled a mutually convenient day and time for the interview. In a couple of cases, I was unable to speak to the person at the time of their original clinic visit as I was busy with another patient. In these cases, I posted the information leaflet with a brief covering note, and again telephoned them a few days later, as for the face-to-face recruitment process.

For patients who were undergoing CEA, a first interview was conducted typically 1-2 weeks preoperatively. This was followed by a second interview approximately 4 weeks after surgery with each of these participants, with one exception. This was a woman who sustained a perioperative stroke. I felt it would be potentially too distressing for her to look back, in the setting of a research interview, on her decision to have surgery. There was also one participant who I interviewed postoperatively only, because there was insufficient time between his clinic visit and admission to hospital for me to arrange

a preoperative interview with him. Participants who were having BMT alone were interviewed about two weeks after recruitment.

Each interview was conducted at the participant's home. Prior to the interview starting, I briefly explained the study, and asked the person to sign the consent form (Appendix 6). With the participant's permission, I recorded the interview using a hand-held tape recorder. When I felt that the interview had drawn to a close (after anything from 15 to 53 minutes), I said that I had asked everything I wanted to ask, and checked whether the participant wished to add anything further. After formally ending the interview, and the recording of it, I ensured that I addressed any clinical or other concerns that had been raised by the participant. I also checked again to ascertain if they had any questions they wished to ask me. Afterwards, I transcribed each interview in full.

For the early interviews, I used an outline interview schedule (Appendix 7), but even in the early stages, I tried to attend as much to the themes of interest to the participant as to my own agenda. In later interviews, I began to explore the emerging themes in more detail, using the constant comparative method of GT (Strauss and Corbin, 1990).

I also made brief notes both before each interview, and afterwards, to enable me to reflect on the content and process of the interview. The pre-interview notes were also useful to help me to sharpen my focus, and acted as an aide-memoire of emerging themes which I particularly wished to attend to.

The first three participants' interviews were a pilot study, to establish whether the method and approach was appropriate and useful. I was able to derive some tentative but potentially interesting data from these interviews. However, I found that the rather formal 'semistructured interview' guide I had painstakingly developed was too restrictive and did not closely reflect the content of the interviews.

I carried out analysis concurrently with data collection, as is accepted practice in grounded theory. I transcribed and analysed each interview before moving on to further data collection (except on one or two occasions when the scheduling of the interviews did not allow for this). However, I was also aware that the process of analysis could

occur 'in action', that is, during the course of an interview itself. Each interview was shaped by those which had preceded it, but also took its own direction as I probed and explored topics as they emerged. It was a challenge to continue to attend to what the participant was saying at that moment, whilst simultaneously trying to relate their experiences to the overall structure of the emerging theory. With those participants who gave two interviews, my preparation for the second interview was especially influenced by the analysis of the first. I used this as an opportunity to explore and clarify some topics in more detail.

I also made field notes immediately after each interview, before transcription. These notes were intended to add contextual detail and to be an additional data source, but were also an important part of the analytical process. I was able to use some of the material from my field notes to derive tentative categories which were then built on by the more formal analysis.

The process of data analysis entailed several stages. Firstly, I read the transcript through several times and made hand-written marginal notes, to give me an overview of the content and 'shape' of the interview (Appendix 9). This led to the emergence of some tentative initial codes. I then undertook a more formal and systematic coding, analysing the transcript line-by line and assigning each incident or idea to a category, either a new one or one related to those already uncovered. As far as possible, these primary categories were "*in vivo*" codes (Strauss and Corbin, 1990, p69), derived from the participants' own words.

After the early interviews, any tentative codes emerging from this initial reading and the open coding process were explored to identify how they related to those codes which I had already derived, or if they were entirely novel. I began to attempt to cluster the codes which had emerged. These were then used as the starting point for the constant comparative method of data analysis throughout the rest of the study. After later interviews, I compared new data with the previously developed codes and clusters.

I used a basic word processing package to transcribe and sort the data. At a later stage in the study I attempted to use a specialised software package to help with the linkage of

categories into themes and the development of an overall analytical framework.

However, I found that, useful though such a programme potentially was in handling large amounts of data, it was not helpful at this stage in the study. I found that I was better able to study and interpret the data in detail without it, and that it led to a feeling of remoteness from the data, compared to the close involvement I felt I had during the more laborious process of analysing and sorting the data by hand..

In order to develop the overall framework, I sorted and re-sorted the emerging categories into themes, by arranging and rearranging paper printouts of the category headings into coherent groupings by hand. I revisited this process regularly during data collection, and began to generate four main clusters of categories. Although there were many links and overlaps between the categories, I generated four major themes, with links between them, and an overarching theme.

8) Chapter summary

In this chapter I have discussed the evolution of the study, choice of approach and methodology, issues of rigour, the practical and ethical difficulties encountered during the design and conduct of the research, and the methods used. This discussion now sets the scene for exposition of the findings of the study, which I turn to in the following five chapters.

CHAPTER 6

FINDINGS: ABOUT THE PARTICIPANTS

1) Introduction

It is conventional for the findings of an account of research involving human participants, whether a short paper or a thesis, to include a summary of the sample under study. This includes the demographic and medical profile of participants, with some details of any difficulties encountered in recruitment and follow up of the sample. This summary is of course important, and is included in this chapter. However, it seems that this process of reducing the sample down to its common features (that is, to such factors as age range, gender and medical history) is inadequate in qualitative research.

A key characteristic of all qualitative research methods is that there is an intention for the researcher to immerse themselves in the world of the participant, in order to attempt to achieve an authentic insight into people's experiences, thoughts and actions (Silverman, 1993. p91). By using an interactionist perspective in data collection and analysis, the researcher aims to give a vivid portrayal of each participant's character and background. The findings of a qualitative research study are best understood in the context of this knowledge.

However, if the initial description of the sample merely involves aggregating together all the participants and fails to try to describe them as individuals, the author will struggle to convey each participant's world view to the reader. "*Thick description*" (Geertz, 1973; 1988) is often used in the account of the findings and analysis, in an attempt to convey participants' experiences and feelings relating to the themes and concepts which have emerged from the data. However, the participants' experiences tend to be depersonalised and decontextualised by being subjected to the process of data analysis, concept development and theory generation. Without having some understanding of the individuals from whose experiences the concepts have been derived, the reader will have difficulty in fully appreciating these concepts. In addition to confusing the reader, there may even be a danger that the author herself will begin to lose sight of the participants as people, when analysing the mass of data generated.

The traditional approach to writing up qualitative interview-based research findings focuses on the author's selection and interpretation of the data, usually heavily illustrated with direct quotes from the participants. I have used this as the structure for most of the findings, but I nonetheless felt that this approach would fail to give a true 'voice' to the participants. I wanted to avoid the error, universal in research of experimental or survey design, but often apparent in qualitative studies too, of apparently '*deserting (the) subjects at the last minute, leaving folks and findings to fend for themselves, seemingly untainted by human hands and most certainly untouched by human hearts*'. Instead, I wished to acknowledge my reflexive approach, and the stance that researchers (myself included) are '*humans who conduct research among (people) rather than on them*' (Wolcott, 2001, p20; original emphasis). Geertz (1973) also suggests that "*thick description*" in qualitative research should encompass process, content and people – that is, that the research participants should be described, just as much as the theoretical concepts which are then derived from the data. By doing this, the author can help readers to feel that they were present when the researcher did the research; saw, heard, and felt what he or she did, and can draw similar conclusions (Geertz, 1988). Alvesson and Skoldberg (2000; p13) have also put forward the view that grounded theory should be based on "*the idiographic study of particular cases rather than the nomothetic study of mass data*". This assertion supports a focus on the unique and individual, rather than a search for overarching generalities.

Therefore, in order to give the participants a 'voice', I have provided 'pen portraits' of the participants in this chapter. I hope to convey to the reader a mini-biography of each person, to give some flavour of the context in which they experienced their TIA or minor stroke, and their individual response to this event. To protect anonymity, minor details have been modified. I will follow this with a discussion of recruitment and a summary of the characteristics of the participants.

2) Pen portraits

Participant 1: Mrs A.

Mrs A is a 64 year old woman. She is widowed and has one grown up daughter who lives nearby, and a son who lives abroad. She lives alone on the outskirts of a small town, near to her sister and to several good friends. Prior to retirement she worked as a nurse. She takes an interest in her health, and describes herself as being an active person, enjoying gardening and walking.

She described her health as having been good until she experienced a short episode of transient loss of vision in her right eye. She assumed this was a problem with the eye itself and was in fact referred by her GP to an ophthalmologist. It was not until about 12 months later that she discovered that she had severe stenosis of both carotid arteries. She had not previously paid much attention to her health, but at this point she immediately stopped smoking (having previously smoked 15 cigarettes per day), made some dietary changes, such as cutting out chocolate, and was prescribed aspirin and a statin. She also underwent a right CEA, from which she recovered well with no complications. She felt that the operation might have been avoided if she had been made aware earlier of her risk factors for stroke, such as her raised cholesterol.

Participant 2: Mr B.

Mr B is a 64 year old man. He is married and works part-time as a joiner. He lives on the outskirts of a small town. He is a practical man who enjoys 'do it yourself' and using his computer. He also enjoys travelling and at the time of the interviews was planning a trip to Australia to see his brother.

Mr B had been in good health until, some two years before the interviews, he had several TIAs, which he described as a weakness on his left side and '*talking rubbish*'. It was found that he had atrial fibrillation and he consequently started taking warfarin. However, he later had a minor stroke, resulting in hemiparesis of his right leg, and on investigation was found to have a tight stenosis of the left internal carotid artery (ICA).

Mr B had a left CEA in October 1999. Although he recovered well from the operation, he did feel that he would not be able to be as active as he had previously been or would have liked to be. In some ways he found it frustrating not to be able to be as active as he used to be, but was very positive about his plans to travel and to be as active as possible. He was strongly aware of the irony of the potential stroke risk of CEA, particularly as he had to stop taking warfarin for the perioperative period, which itself was intended to reduce his stroke risk. Having had CEA, and, as he expressed it, '*done everything I can*', he felt that he was able to stop worrying about the possibility of a stroke and to take up plans for the future again.

Participant 3: Mr C.

Mr C is a 50 year old man. He is married with two grown up daughters, both of whom live nearby. He lives in a small town. He owns and manages a local catering business, which he built up over a number of years of very hard work. He is proud of his achievements in business and in providing his family with a comfortable lifestyle.

Mr C had previously paid little attention to his health, partly because he had had no significant health problems, but also because he was focused on his work and supporting his family. It was therefore a shock to him to have a TIA one day at work and to be admitted to hospital as a result. He described in some detail the feelings he had on having the TIA, of fear, a '*survival instinct*', and feeling uncommunicative for some days and weeks after the event itself and he had, apparently, recovered.

Following this he had a carotid duplex scan and was found to have a severe stenosis of the right ICA, and he had right CEA in November 1999.

Although, in common with most of the participants, Mr C made some health-related changes to his life after the TIA (such as stopping smoking, starting antiplatelet medication and cholesterol-lowering medication), he also changed his outlook on life quite dramatically. He was no longer focused on his work and the necessity to provide materially for his family, but said that he now appreciated that there were other facets of his life which he had neglected; for example, spending time with his family. This was evident during the interviews. Preoperatively, although he was pleasant and communicative, he was clearly worried about the future and was unusually articulate

about the relative risks of stroke with or without CEA, and the impact this could have on him. After surgery, however, he talked at even greater length about how the experience had caused him to '*revalue, re-look at the whole structure of life, how I feel about things, (and) changed me spiritually, emotionally*'. The anxiety he had expressed earlier had now gone.

Because Mr C was unusually articulate in describing his feelings and decision processes about the TIA, I have included the transcript of his first interview in Appendix 8. It seemed that the extent to which he personally analysed his situation was unusual, but he was also an exceptionally informative interviewee, in that he was able to describe his feelings and thoughts in great depth.

Participant 4: Mrs D.

Mrs D is a 67 year old woman who was widowed about a year ago. She has seven adult children, two of whom live close by. She did not go out to work but had spent her adult life looking after her family. She clearly has a caring family, but is anxious to maintain her independence and says she would not want to be a burden on her adult children if she were unable to look after herself.

Mrs D had a minor stroke with a left hemiparesis and subsequently had a right CEA. She also had other medical problems including angina and polymyalgia rheumatica. At the time of her original stroke, her serum cholesterol was found to be elevated at 9 mmol/L; she subsequently started taking pravastatin.

Her family were, as I said, supportive and indeed one or other of them accompanied her to most of her medical consultations. While she said that her children had emphasised that any medical decisions were '*up to you, mother*', it was also clear that they did influence her treatment decisions and preferences. She said that the children had discussed her situation amongst themselves, and she was concerned about the impact of a potential stroke on her family. This potential impact related to the possible distress for one of them visiting her home to see her and finding that she had had a stroke. She was also concerned about the problems her family might face if she needed long-term care. She felt that it was important to keep well, and to be cheerful, as much or even more for

the sake of other people as for herself. She mentioned a good friend who had been influential in helping her decide to have surgery. Her friend had had numerous operations and had suffered with arthritis for many years, but '*didn't let it get her down*'. Another influence appeared to be the example of her late husband, who had died in the previous year, after having had cancer and '*a long seven years*' during which time '*he never complained*'. Her desire not to burden her family or friends was not just confined to the potential effects of a disabling stroke, but to the emotional labour she perceived that she would cause if she expressed feelings of anxiety or sadness. She told me that she was in fact very frightened but tried to hide this from her children, largely because their father had died recently and they were still grieving for him.

After the tape-recorded interview, I discussed some of these feelings with her. My perception, from what she had told me, was that her family cared about her very much (accompanying her to medical consultations and so on). It seemed that she found it difficult to step out of her caring role as their mother, but this was, perhaps, a time in her life when she needed their emotional support.

Unfortunately, Mrs D had a perioperative stroke with a left hemiparesis, three days postoperatively. She remained in hospital for several weeks before returning home. I saw her in my clinical capacity several times before her discharge, but I felt that a formal postoperative interview would have been inappropriate and possibly distressing for her.

Participant 5: Mrs E.

Mrs E is a 58 year old woman and is widowed, with adult children. She left school at 15 and worked in banking until her early retirement. She had a stroke with a right sided hemiparesis four years before the study, but recovered very well. She then had several TIAs affecting her left side, followed by a right CEA in 1997. However, she then had a further right sided stroke some six months before these interviews, from which she recovered fully in three days. It was only on a routine visit to the vascular clinic that she mentioned this stroke, after which she had a left CEA within a fortnight. She also has angina and hypertension.

Mrs.E lived alone and was very concerned that if she were to have a stroke, she would lose her independence. Having had two strokes already, although she had made a full recovery on both occasions, she felt that she *'could not possibly live like that'* and that *'if to survive means to be crippled then forget it.'* When symptoms arose, she tended to take the action that she felt was most appropriate without recourse to the advice of a health professional. For example, when she had her second minor stroke, she simply rested and took aspirin tablets regularly, for three days until the symptoms resolved. Only after this did she consult her general practitioner, but declined an offer of a re-referral to see the neurologist she had previously seen. However, on her routine follow-up appointment in the vascular clinic some months later, she mentioned that she had had another stroke, had further Duplex scanning and agreed to have CEA within a few weeks.

After surgery, her need for independence was evident in the frustration she expressed at the length of time it took to recover her previous level of fitness. She appreciated the importance of reducing her risk of stroke in order to maintain her independence, but was not at all concerned about her risk of a fatal stroke or cardiac event. Having been widowed at the age of 41 when her children were still young, she felt that she had *'done all I want on this earth... If I'm going (to die) I want to go quick'*. It appeared that she felt at odds with the aims of the healthcare system in this respect, which, in her words was *'determined to keep me alive until I'm 90, but I don't want to be here when I'm 90'*.

Participant 6: Mr F.

Mr F is a 79 year old man. He lives with his wife on the outskirts of a large market town. He left school at the age of 14, and worked firstly as a policeman and then as a company sales representative until his retirement.

He has had several episodes of care with the vascular team, including elective abdominal aortic aneurysm repair, arterial bypass grafting and most recently a transfemoral amputation some two years prior to the study. He had regained a high degree of independence and was able to walk with a prosthetic limb.

He came to the vascular clinic having had two TIAs about four weeks apart. On both occasions he experienced transient hemiparesis of his right hand and arm; the first

episode lasting 20 minutes, the second, three to four hours. He was seen at home by his general practitioner and then by a stroke physician, who diagnosed atrial fibrillation and commenced digoxin and warfarin. His echocardiogram was unremarkable. After this he was referred to the vascular team. On duplex scanning he had a 50-59% stenosis of the symptomatic left ICA. It was planned to continue with medical management and to re-scan at six monthly intervals to assess if the stenosis was stable or progressing.

Having had many previous vascular procedures, he was relieved to be told by the surgeon that was not to have CEA at this time: *'Good news, you've escaped the knife!'*. However, he felt that whatever was decided by the medical team, he would agree to – *'This has got to be done because it's an advantage. They won't do these things (investigations and treatment) unless there's something behind it.'* It was clear that he felt his role in the process was firstly to agree to the decisions of health professionals, rather than to play a more active role in decision-making. Although he was happy to take this passive role, he did feel it was important to seek information and ask questions about his treatment *'for my own peace of mind'*. This trust was partly due to the previous experiences he had had, but was also a general trust of all health professionals who, he felt, had far greater knowledge than he did. He also felt that he had a part to play in reporting any new symptoms promptly, and in following other health advice: *'I'd had my cholesterol done, and it turned out 6.7, and she (practice nurse) said you'll have to go on the diet which I've been doing, very very strict'*. It was apparent that, although he had had numerous vascular procedures and clearly had extensive atherosclerotic disease, he had not made the connection between his other health problems and the TIAs: *'I couldn't understand why suddenly it should happen, because I hadn't felt anything'*.

Participant 7: Mr G.

Mr G is a 64 year old man. He recently retired from his occupation as managing director of the company he owned, although he still maintained some business interests via consultancy work. He had completed full-time education at 18. He was recently divorced with one teenage daughter, who now lived with her mother. He described his interests as gardening and golf.

Mr G had diabetes mellitus for about 12 years, for which he took oral medication. He otherwise considered himself to be healthy, until he experienced an episode of amaurosis fugax in the right eye. He attended the Emergency department at his local hospital and was referred by them for immediate assessment in the emergency eye clinic. He also sought a private consultation. As a result he was prescribed aspirin and was referred for a carotid duplex scan. The scan showed 50-55% bilateral ICA stenosis, and so he continued with BMT.

Mr G was clearly someone who tried to look after his health, and even before his diagnosis of diabetes mellitus had adhered to a healthy diet. In addition to regular review with the diabetic clinic, he had a yearly medical at a private hospital. In the light of this, he felt it was surprising he had experienced any health problems. He did not appear to connect his diagnosis of diabetes with the development of carotid artery stenosis.

He discussed the option of CEA, saying that if *'the professionals think it's necessary, then you've got to take that on board... they've got the expertise'*. He understood, however, that his carotid artery stenosis did not indicate that surgery would be an appropriate option: *'I was told that that (50-55%) was sort of normal, for the age group'*. The fact that two different professionals (an ophthalmologist and a vascular surgeon) had both said that surgery was not warranted gave him greater confidence in the reliability of the advice: *'if they're both saying the same thing, then you've got to say well, there's an accord there... so you follow that instruction.'* If, however, there had not been a consensus of medical opinion, he would have felt justified in making a more autonomous decision. He also felt that he had an important role to play in adhering to best medical treatment: *'anything I can do to prevent it getting any worse I shall do'*. He was very much more aware of his health and his mortality than before, but accepted that he might experience health problems in the future that could not be predicted or avoided.

Participant 8: Mr H.

Mr H is a 69 year old man, who is retired from his work as an accountant. He lives with his wife. He had previously had vascular surgery some 30 years ago, which he described as an 'aorta patch', and had had intermittent claudication since then. About three months

before the interview took place, he had a TIA affecting his left arm and leg. He described this as lasting about 5 minutes. Three weeks after this he had a further episode, affecting his right arm and leg, and also causing some expressive dysphasia. This episode lasted several hours.

At the time of the second event, Mr H was found to have atrial fibrillation and was prescribed warfarin and sotalol. He was also found to have previously undiagnosed diabetes mellitus, for which he was given appropriate dietary advice. Carotid duplex scanning showed that he had 50-55% left ICA stenosis and 15-49% right ICA stenosis.

Mr H and the clinicians he consulted attributed the cause of the TIAs to his atrial fibrillation rather than the moderate carotid stenosis. He himself recognised, however, that his previous aortic surgery (at the age of 42) meant that he was a likely candidate for carotid disease as well, hence the need to pursue carotid duplex scanning. He found both TIAs to be frightening experiences, and thought that he was having a stroke. He was unusual in seeking medical advice (via his GP) the same day on both occasions, perhaps because of this attribution of his symptoms.

His attitude to the TIAs was that although it was a frightening experience, it was *'maybe a good thing to get some sort of warning... to make sure it doesn't happen again, as far as you can.'* He was aware that, even though he was adhering closely to his prescribed treatment, that it was not possible to eliminate the risk of stroke altogether. He described warfarin as giving *'about 60% security, whereas the aspirin will only give you 20%'* (relative risk reduction).

He found his lifestyle limited by having had the TIAs in two main ways. Firstly having to take warfarin curtailed some of his activities, particularly taking skiing holidays which he had previously enjoyed, due to the risk of haemorrhage. Secondly, although he felt physically as fit as before, his activities were curtailed by other people: *'everybody's always telling me to be careful, and have a rest...people around me have convinced me that I'm a bit fragile'*. This protective attitude from others reduced his own confidence.

Participant 9: Mrs J.

Mrs J is an 80 year old woman who is retired from clerical work. She is widowed and lives alone. She had a coronary artery bypass graft (CABG) eight years earlier, but was now fit and active. However, she was awaiting a cataract operation in the next few months. She had had several episodes of amaurosis fugax affecting the right eye. She was referred by her GP to an ophthalmologist, then to a vascular surgeon. Duplex scanning revealed left ICA stenosis of 1-15%, and right ICA stenosis of 15-49%.

Mrs J was frightened by the episodes of amaurosis fugax: *'I was frightened because I thought I was going to go blind.'* However, she only consulted her GP after several episodes had occurred. After duplex scanning, she saw a vascular surgeon who told her that *'He wasn't going to operate, he said it wasn't bad enough.'* She was relieved, mainly because of her previous history of CABG: *'I didn't want it (an operation) to upset my heart, because I got over the bypass so well.'* However, she was unsure what the reasons were for her not being offered CEA: *'Is he not doing an operation because of my heart, or is he not doing an operation because I don't really need one?'*

Mrs J did not connect the symptoms she had had with a vascular cause: *'I never thought it was anything to do with the arteries...I wouldn't connect the eye with the arteries. The heart, yes, but not the eye.'* She was still having infrequent episodes of amaurosis fugax, and hoped that her forthcoming cataract surgery might resolve these.

Participant 10: Mr K.

Mr K is a 69 year old man, who worked until his retirement for a rail company, having left school at the age of 15. He is married and lives with his wife. He had several major health problems in the past, notably a myocardial infarction some 20 years earlier, and coronary angioplasty ten years ago. However, he remained well and active, with only infrequent symptoms of angina. Some six months before the first interview he had a minor stroke. The symptoms of left-sided hemiparesis and expressive dysphasia resolved within 48 hours. Subsequent CT scanning showed no abnormality, but carotid duplex scanning showed a 70-80% right ICA stenosis. He underwent right CEA and recovered uneventfully.

Mr K initially sought help after the stroke on the insistence of his wife and a neighbour who she called on to help. He was clear about the role of other people in the process of seeking help, saying that had he been living alone he would have telephoned another family member (rather than seeking medical advice in the first instance). Although, as he put it, he was told *'really you haven't got a choice'*, he said that he weighed the chances of stroke with and without surgery and *'I decided to go ahead and have it done'*. He felt it was reassuring to be *'told straight out ... the cards are on the table'*. He recognised that there was a weighing up of odds, and said: *'It is a gamble basically. If it comes off, great stuff, you know – you've got to take a chance.'* He also felt that he was lucky to have had a minor stroke rather than a more disabling one, as this acted as a warning. He was influenced in this by knowing a family member and several acquaintances who had had disabling strokes.

In the preoperative period he was extremely aware of any minor symptom, and experienced fear and anxiety that another stroke might be occurring: *'you might get a little bit of giddiness, or anything like that... it's a frightening thought, is there something going wrong again...you see you don't know. Every little thing, is it something to do with it'*.

After the operation, he regarded himself as free of risk and hence free of worry and uncertainty: *'if I come through it... you're cured and that's it. You shouldn't have any more problems... if there are no more problems there's nothing else to worry about.'* This freedom from uncertainty and anxiety outweighed even a hypothetical high risk of perioperative stroke: *'There is no option...it's just not worth the worry...if somebody says that it's going to be a twenty to twenty-five percent chance that it won't work (i.e. risk of perioperative stroke) then I'd have to take some time...I might say I'd toss the coin and I'll take a chance'*.

Participant 11: Mrs L.

Mrs L is a 71 year old woman, who is married and lives with her husband. She worked in a post office until her retirement at age 65. She was previously in good health other than for hypertension. She had two TIAs both affecting her right arm, and lasting no more than a few hours, about a month before the first interview. Carotid duplex scan

revealed 70-80% ICA stenosis bilaterally. She underwent CEA on the symptomatic left side about two months after her first symptoms.

Her first reaction to the TIA was fear, and she realised it might have been *'a slight stroke'*, especially as her husband had previously had a more serious stroke. However, she did not seek any professional advice until she had seen her daughter two days later. Her daughter realised that she *'looked down in the dumps'*, insisted that she see a doctor, and took her to the emergency department of the local hospital.

She recalled the stroke risks of surgery and BMT as 5% and 15%, and felt that *'you've no choice really, I mean you must go along with it'*. Nonetheless, her worry about the 5% perioperative risk of stroke was significantly diminishing her quality of life during the short waiting period before the operation. However, she felt that not to have surgery would be worse: *'the least twinge and you'd think oh, I'm going to have [a stroke] any minute...you'd never forgive yourself, would you?... I'm worrying one way or the other at the moment. But at least when it's been done I don't think I shall worry half as much as what I am doing at the moment.'* She anticipated that she would experience regret about her choice if she were to have a stroke after declining to have CEA. However, if she declined CEA, she believed that her awareness of her long-term risk of stroke would affect her quality of life. She was also concerned about the potential impact of a stroke on her family.

After the operation and a swift recovery, she said she felt *'tons better...I really don't think about it now'*. She felt physically better and was even more active in her home than previously: *'I'd been feeling tired and listless, which really wasn't like me at all... but now it's no problem.'* Although she had expressed a lot of anxiety about the possibility of a perioperative stroke beforehand, afterwards she said that *'five per cent [perioperative stroke risk] was neither here nor there.'*

Participant 12: Mr M.

Mr M is a 72 year old man who is married and lives with his wife. He is retired from his work as an administrator in the NHS. He had no significant health problems when he experienced an episode of amaurosis fugax of the right eye. He was referred to an

ophthalmologist and then on to a vascular surgeon. Duplex scanning revealed a 75-80% ICA stenosis and he had right CEA about a fortnight after the first interview. Although he sought advice from his GP the day after the event, and was told it was probably a *'mini-stroke'*, he was not referred urgently for specialist assessment. It was some three months later that he saw an ophthalmologist and the duplex scanning was arranged. All this took several months, so when he eventually saw a vascular surgeon Mr M was surprised to be treated with some urgency. He realised then that the condition was potentially very serious: *'I was absolutely stunned, because I just did not expect to have to have surgery'*. Although he was unable to recall the stroke risks of surgery and BMT in numerical terms, he felt that surgery would reduce his risk: *'I'm hoping that it will take away a lot of the risk that was there regarding having the stroke.'* Although, as this statement indicated, he was aware that his stroke risk could not be eliminated, he was very clear about his decision to have the operation. This decision was made swiftly, and was based on confidence in the surgeon as well as the numerical risks: *'I didn't have any doubts when [the surgeon] explained what the odds were. There was only one course to take...I have confidence in [the surgeon], yes, he gave me a lot of confidence... his manner was good... I didn't feel that I needed to go home and think about it.'* He also felt that not to have surgery would expose him to prolonged anxiety and uncertainty: *'I wouldn't like to live like that, wondering when it's (a stroke) going to happen next.'*

After the operation, he focused on maintaining his health and also felt that he now appreciated his good health: *'It does give you a more appreciative outlook on life, you just realise you should have been more sensible when you were younger...sensible eating, just keep making progress.'* He felt that having had the operation, the risk of stroke had been eliminated *'(the risk) is pretty well gone completely, yes, which is a great comfort really,* Also, however, the anxiety which had been engendered by his realisation that he was at risk of a stroke, was completely eradicated: *'The worry's gone now – the worry came all at once because I wasn't thinking that I was going to have any sort of severe stroke at all, it was all explained to me, and I did become aware of it for a short time, but now that worry's gone, and I don't want it to come back.'*

Participant 13: died after recruitment but before interview.

Participant 14: Mr N

Mr N is an 81 year old man who left school at 14, saw active service in the Second World War, and then worked as a heating engineer until retirement. He lives with his wife who has severe arthritis and whose mobility is limited. Apart from hypertension, his own health was good until he experienced several episodes of amaurosis fugax in the right eye, two carotid territory TIAs affecting the right arm and, on another occasion, the left arm. Duplex scanning and magnetic resonance angiogram both showed tight stenoses of the left and right ICA. As his symptoms and pathology were bilateral he had both left and right CEA, about six weeks apart. I conducted the interviews before the first operation and after the second one.

He initially attributed the symptoms to a 'mini-stroke', a diagnosis with which he was familiar because his sister had a disabling stroke in the past. He was sanguine about the possibility of a fatal stroke, but felt that a disabling stroke was a worse potential outcome: *'it doesn't bother me that there's something wrong, as long as it knocks me off altogether because I don't want to end like that...to be a burden to everybody else around you.'* Although he was still fit and active, he felt that his age contributed to this attitude and that he had outlived most of his peers: *'we all moved into this locality just after the last war, and what it was, it was Homes for Heroes...every house had a man of my age, been in the forces, and now there's two of us left...when you've seen them all go, you know it's going to come.'* He was convinced that surgery was the only option, and felt that he was certain to have a stroke without it: *'There's no choice, it has to be done...if it isn't done then I am going to have a stroke aren't I?... without a doubt I will.'* Although he was certain about his choice of the surgical option, he recognised that this gave him only *'a good chance that I might not have another.'* He was also concerned about the impact of a stroke on his wife, as she needed his assistance to use a wheelchair when out of the house.

After the second of the two operations, Mr N felt that his risk of stroke had been eliminated: *'It's gone away. I don't think I'm going to have (a stroke) now...I more or*

less knew I was going to have one before... I think 100% certain that I was going to have one.' He felt that the surgery '*has cured me altogether.*'

Participant 15: Mr P.

Mr P is a 78 year old man who is married and lives with his wife. He is retired from his career as a chartered accountant and latterly as a company director. He had carcinoma of the prostate, though this was controlled with medical treatment, diabetes mellitus for which he adhered to an appropriate diet, and hypertension. He experienced an episode of right amaurosis fugax associated with a headache; duplex scanning found bilateral ICA stenosis of 15-49%.

He initially attributed his symptoms to a '*break in transmission*' as his image of the television screen was affected. He then thought it might be an optical problem relating to a cataract operation he had had several months earlier. It was on his wife's insistence that he went to consult his GP the next day. Mr P said that it was the headache rather than the amaurosis fugax which was the most worrying symptom and the one that prompted him to visit his GP. At the time of the duplex scan he was told that '*it's no worse than I would have expected, and it's no better than I would have expected*'. He saw a vascular surgeon a few weeks later and was told that '*it's about 50%, that's what I would expect in a person of your age*'.

Mr P had had hypertension for around 20 years and described in some detail the monitoring and medication that had been necessary over the years. He was also recently commenced on a statin for hypercholesterolaemia. He felt that the medication was making him fatigued, and that he had less energy than he used to. However, despite these possible side effects, he did not question the necessity for medical treatment to control his risk factors: '*I don't think they would have given it to me if it wasn't necessary. I think they felt it was necessary*'. He felt that the side effects were worthwhile: '*It's a question of, does that drug treat the problem that you've got, and are the side effects capable of being accepted.*' However, he did not appear to be aware of the likely connection between his known risk factors of diabetes mellitus and hypertension, and TIA or stroke, despite my asking a direct question about this.

Participant 16: Mr Q.

Mr Q is a 69 year old man who has retired from his job as a heavy goods vehicle fitter. He had experienced a myocardial infarction at the age of 47, but had maintained a good level of health since then. He experienced several episodes of left amaurosis fugax and TIAs affecting his right arm. Duplex scanning revealed a left ICA stenosis of 70-80% and right ICA stenosis of 80-90%. He underwent left CEA (the symptomatic side) within a few weeks. I was unable to conduct a preoperative interview due to the short timescale, but saw him about 4 weeks later.

He told me that he had expected to be *'below the 70% (stenosis) ... it was a bit of a shock'*, because he felt very fit and well, and that he had looked after his health – despite having a previous myocardial infarction and smoking cigarettes. He felt that he had to have surgery because *'I'm enjoying life and I want it to go on, without having a stroke...If I had done nothing, I don't think I'd have stood much chance.'* He also felt that it was safer, if he were to have a stroke, to have it while in hospital for CEA than at home or elsewhere. He also felt that he would have experienced long term anxiety if he had not had CEA: *'I'd be in a state of panic, continuous. After seeing the scans.'* He had also sought corroboration of the information he had been given by clinicians by searching the internet.

Participant 17: Mrs R.

Mrs R is a 74 year old woman who is married and lives with her husband. She completed her education at the age of 15 and spent most of her adult life as a full-time homemaker. She was in previously good health apart from hypertension.

Mrs R experienced an episode of hemiparesis of her right arm, leg and face. Following this she had duplex scanning which showed 1-14% left ICA stenosis. She saw a vascular surgeon but did not have CEA. Aspirin and statin therapy were added to her antihypertensive medication.

Her initial impression of the TIA was that her foot was stuck to something on the floor. As the symptoms spread to her arm and face, it was her husband who suggested calling out the GP on-call. She did not think it was a serious problem herself as she did not feel ill as such, and said that she would probably not have sought medical advice if it had not been for her husband's insistence.

She was admitted to hospital for about 36 hours and was then referred for duplex scanning as an outpatient. She felt that the new medication she was taking was important: *'I suppose if it's going to ward off a major stroke as they say, I'm quite prepared to take whatever (medication)... I mean, these things happen, nobody knows'*. She had very little awareness of strokes before her own TIA, and now tried not to think about it as she did not feel ill: *'If you start thinking, every little thing that happens to you, you think oh is this connected to the stroke sort of thing, so as I say I try not to think about it... I've blocked it out altogether, I mean I'm not ill, I don't feel ill.'*

Participant 18: Mr S.

Mr S is a 64 year old man who is married and lives with his wife. He has held a variety of jobs, his current one being as a security guard. He regarded himself as being in good health apart from hypertension. He experienced a TIA lasting about an hour, affecting his left arm and leg, and also with expressive dysphasia, and consulted his GP a few days later. He had duplex scanning which revealed bilateral 15-49% ICA stenosis.

Mr S felt that his wife had been more aware of the TIA than he was himself; and said that she wanted to call an ambulance when it first occurred. He disagreed, and only consulted his GP at his wife's insistence. His experienced feelings of surprise and concern when his GP told him he had had a 'mini-stroke': *'I were a bit concerned really because I thought, well, it didn't run in the family or anything, and it's frightening really, it frightened me when they told me that'*. He felt that the lack of family history of stroke made his diagnosis surprising, and attributed the event to elements of his stressful lifestyle: *'I think I know why it happened. I think I were doing too many hours at work...what I ate, I mean one time I went to work I'd take things like meat and potato pies, four, and I'd ate all the lot...I used to get stressed out at work'*.

Mr S only realised that the TIA might have long-term implications when he saw a vascular surgeon. The knowledge that he might have another episode was a source of concern: *'He told me what I should do, what I shouldn't do, I had to go back and see him and then I started worrying then. Because he said it can happen again...and then I thought well, when?'* (original emphases). However, after his carotid duplex scan, this worry abated, as the stenosis was not severe: *'If they'd have been is it 70% or something, then they'd have had to do something about it and clear 'em out, but...what did he say it was, about 50% or summat like that...he said if I keep taking the aspirin, that does the same job...but I don't want it to be breaking pieces off and going back up into my head again.'* He felt it was very important to adhere to the prescribed medical treatment: *'I think that it's helping us along, it's keeping my blood pressure down... I'm 100% behind what the doctor's given me...I got a diet thing at the surgery and I've took notice, not took notice of all it said, but a lot of it I did.'*

Participant 19: declined CEA, and declined to be interviewed.

Participant 20: Mr T.

Mr T is a 79 year old man who is retired from work in insurance. He is married but lives alone. His wife has severe Alzheimer's disease and lives in a nursing home where Mr T visits her twice a day.

Mr T had previously had carcinoma of the prostate for which he underwent surgery some three years ago. He also has hypertension. He experienced a TIA affecting his right hand, with some dysarthria. He was admitted to hospital but the symptoms resolved within a few hours and he was discharged home within 48 hours. CT brain scan had been normal, but a duplex scan, performed 5 months later, showed an 80-99% left ICA stenosis. This scan was performed by a non-specialist sonographer, and he was offered a repeat scan with the specialist vascular investigations unit, which he declined. He had seen a vascular surgeon, and on seeing his own GP he had made a decision not to have any more investigations or to have CEA (the GP's letter stated that Mr T had made 'an informed decision').

Mr T was alone when he experienced his first symptom of the TIA, and his first response was to phone his son: *I rang my son (at work in neighbouring town), with great difficulty, because I couldn't use this hand at all, and said I think I've had a stroke, and he said oh, I'll get (grandson) round, my grandson came round and arranged for an ambulance to come and collect me and took me to hospital.'*

He said that he knew that the event was a stroke: *'I've read about it and I've heard of people having strokes, but I knew straight away that it was a stroke, I don't know why but I did.'* His immediate feelings were of *'Panic! Panic, that's why I rang my son. But I realised it wasn't too bad, you know, a minor one.'* At the time of the interview, nearly 12 months later, however, he was satisfied that he would not have another stroke: *'I feel I'm in the clear, I've no signs of having a stroke, no twinges or anything like that...I think it's finished with, I may be wrong.'* He felt that there was no point in worrying about the possibility of another stroke, although he realised it was possible: *'Why worry? I've had a good life. Every day is a bonus, yes?...I don't worry much about anything...It could happen to me again, but I'm prepared to take that chance.'*

Participant 21: BMT: declined to be interviewed.

Participant 22: Mrs U

Mrs U is a 75 year old woman who lives with her husband. Her husband has had treatment including surgery for cancer for the past year and his prognosis is poor. (I was not aware of this on recruiting Mrs U to the study.) Prior to retirement Mrs U worked as a shop assistant. She has angina and hypertension. She had had several episodes of amaurosis fugax of the left eye over a two year period, the most recent being about several months ago. She had one episode affecting the right eye. Duplex scanning showed bilateral 50-60% ICA stenosis two years ago. A more recent scan by a non-specialist sonographer showed an 80% right ICA stenosis. However, when this was repeated by a specialist vascular technologist, it showed 50-60% left ICA stenosis, and 60-65% on the right. These latter results were confirmed by MR scanning. She was having medical treatment including antihypertensives, statin therapy and clopidogrel.

Mrs U did not specifically seek any health advice after the episodes, but mentioned them when she had a routine check with her optician. He said it was *'probably vascular*

problems' and referred her to her GP. However, the possibility had already occurred to her, because she was aware of the risk factors she already had: *'I know blood pressure, I know that's got to do with circulation...you know you read, in magazines, so we all have more knowledge of things...I think they associate high blood pressure or cholesterol with heart problems and strokes, so I had all those problems, so obviously...'* As a result of this, she was already anxious, and was relieved to have a definitive diagnosis: *'I think when you've got symptoms and you're not well, you're glad when somebody diagnoses it...they've got to the bottom of it, haven't they?'*

After having the scan which showed 80% stenosis, she was seen at a medical clinic and the possibility of CEA was discussed. At this point she felt there was *'no choice. I was going to have to have the surgery or have a major stroke I suppose.'* Once the scan was repeated and the degree of ICA stenosis was found to be less than 70%, she felt that the risks of having CEA outweighed her stroke risk with BMT: *'I was just as likely to have a stroke during the surgery, and not as much, you know, percentage-wise, I wouldn't have one without the surgery.'* She was aware that she still might have a stroke with BMT, but this possibility was not a major concern for her, particularly in the context of her husband's health: *'My own personal problems don't come to the fore, it's my husband's problems really now, that's the biggest...this (stroke) might happen or it might not, but my husband's it's definitely happening...the oncologist said (to him) I'll give you 18 months so why should I be worrying about a stroke when they've given us 18 months.'* It was, however, important for her that she kept well in order to support him: *'I've got to keep well, and put a good foot forward as they say, put your best foot forward, for my husband.'*

Participant 23: Mr V

Mr V is a 78 year old man who is married and lives with his wife. He is retired from work as a sales executive. He is in good health. He experienced a TIA with hemiparesis of his right leg, lasting about 20 minutes before he fully recovered. Duplex scanning showed 1-14% right ICA stenosis and 15-49% left ICA stenosis. He was also found to have hypertension, and commenced antihypertensive medication, aspirin and statin therapy.

Mr V's wife noticed the symptoms before he did when he was driving her home after a shopping trip: *'she kept saying, "Your driving's a bit erratic this morning", I said what do you mean? She said "You're jerking." I said as far as I know I'm quite alright...she kept saying once or twice, "Look, you're jerking again." I said no I'm not, but I couldn't understand it.'* After returning home, he himself noticed the problem: *'I sat down in the chair, just reading the newspaper, 10 minutes, and I come to get up and I thought, I can't move my leg, my right leg has gone...it wasn't pins and needles it was just dead.'* It was on his wife's insistence that he consulted his GP: *'I said there's no need to fuss, because she's a born worrier you see, she said "No, I'm going to ring the doctor".'*

Mr V had felt that it was unnecessary to seek initial medical advice or to have further investigations: *'I thought they were making a fuss over nothing, I'm perfectly alright, anyway they would insist I do it, so I went along with it.'* He also found that his usual activity level was curtailed after the TIA: *'(GP) said I shouldn't drive for a month at least, the rules and regulations you see...and my wife said "well what about him mowing the lawn", and (the GP said) I think for the time being it'd be better if he didn't"...I felt I could do it but they insist I didn't'.* Although he found these limitations frustrating, he also felt that the concern behind such advice was positive: *'It's nice to know that people are concerned and do all these tests on you, instead of saying oh, he's alright now, get on with his life.'*

After the duplex scan he described the findings as *just a slight narrowing on the neck scan, he said it's nothing to get alarmed about or worry about.* He felt fortunate to have had a TIA rather than a completed stroke: *'I mean some people, they lose the use of an arm or a leg don't they...I never worried about it, I never thought oh heck, I've had a stroke, what am I going to do, I've just sort of accepted it...it could have affected me like that...and I say thank heaven it didn't.'*

3) Recruitment and summary of the participants

Of 23 people who I approached to take part in the study, two declined and 21 agreed. One of them died unexpectedly of ischaemic heart disease shortly after having been

recruited, leaving 20 who gave interviews. Those who were having CEA each gave two interviews, with the exception of one man whose operation date was too close at hand for a pre-operative interview to be arranged, and one woman who experienced a perioperative stroke and was not re-interviewed.

Table 3 gives a summary of the personal details of the 20 participants. Whilst it is unwise to attempt to generalise from a study of this type to other populations and settings, it will be seen that the age and sex distribution of the participants was not unexpected for a population with cerebrovascular disease, 14 of them being over 65 and with a mean age of 70.2 years. TIA and stroke are, of course, more prevalent in older age groups. The proportion of men to women was also, as expected, around 2:1. These figures are similar to the data from the National Vascular Database for carotid endarterectomy, where the mean age is 69.8 and the proportion of males to females is 1.95:1 (Vascular Society, 2004). All the participants had been married; 14 lived with their spouse, and one was married but his wife was resident in a nursing home. Five were now widowed or divorced, and lived alone. 14 of them had finished their full time education at the statutory school leaving age (14-16 years), although many of these participants had undergone vocational training later on and had worked in skilled occupations. Their occupations or previous occupations were evenly divided between manual/clerical jobs and professional/managerial jobs. All but four had retired from paid employment; two (both women) had not undertaken paid employment since marriage.

Table 3: Personal characteristics of participants

	Category	Number
Age	50-59	2
	60-69	8
	70-79	9
	80 or over	1
Mean 70.2 years		
Range 50-81 years		
Sex	Male	13
	Female	7
Marital status	Single (never married)	0
	Married/with partner	15
	Widowed/divorced	5
Age left full-time education	16 or under	14
	17-19	3
	20 or older	3
(Former)occupation	Home-maker	2
	Clerical	4
	Manual	5 (2 still working)
	Professional/management	9 (2 still working)

Ten participants had symptoms of TIA with sensory-motor symptoms; of these, four also had expressive dysphasia and two had amaurosis fugax. Six participants had symptoms only of amaurosis fugax; while four had experienced a minor completed stroke.

All those with an ICA stenosis of less than 70% on the symptomatic side did not have CEA, and, with one exception, all those with ICA stenosis greater than 70% had the operation.

Table 4: Participants' symptoms of cerebrovascular disease

SYMPTOMS	FREQUENCY
Amaurosis fugax only	6
TIA - dysphasia only	0
TIA – sensory motor and dysphasia	4
Sensory motor TIA and amaurosis fu	2
Completed stroke	4
TOTAL	20

Table 5: Participants' degree of internal carotid artery stenosis (symptomatic side, or more severe stenosis if bilateral symptoms)

ICA stenosis (%)	CEA+BMT	BMT
1- 14%	-	1
15- 49%	-	5
50 – 59%	-	2
60 – 69%	-	1
70- 79%	6	-
80-89%	-	1
90-99%	4	-
TOTAL	10	10

Eight participants had experienced other forms of atherosclerotic disease: ischaemic heart disease in seven cases, peripheral vascular disease in one. All but one of the participants was taking an antiplatelet agent (aspirin or clopidogrel) or warfarin. However, only 12 had been prescribed statin therapy.

Table 6: Other medical conditions and medication

Condition or medication	Number of participants
Ischaemic heart disease	7
Hypertension	13
Diabetes mellitus	3
Prostate cancer	2
Peripheral arterial disease	1
Antiplatelet drug	16
Statin	12
Warfarin	3

4) Chapter summary

In this chapter I have given an outline of the participants in the study, in terms of their medical and demographic characteristics. However, I have also endeavoured to provide a more in-depth portrait of each participant. These portraits also give an indication of my first impressionistic interpretations of the interviews. In the following four chapters I will expand and deepen these first impressions in order to fully delineate the findings of the study.

CHAPTER 7: FINDINGS

THE LIVED EXPERIENCE OF TRANSIENT ISCHAEMIC ATTACK

1) Introduction

An analysis of people's experiences of TIA is a central theme of this thesis for two reasons. First, in order to understand how and to what extent people make choices about ways of reducing their risk of stroke after TIA or minor stroke, an important starting point was for me to gain an understanding of the experience itself, and of people's perceptions of its immediate and long-term impact. This would provide the context for these choices. Secondly, from a broader perspective, an exploration of participants' experiences of TIA might shed light on several important practical issues: why people delay or fail to seek help after a TIA, on their needs for support and information, and on appropriate nursing or other interventions to help them.

I discussed in Chapter 3 how the literature demonstrates that people's understanding of stroke symptoms and treatments, and the correct action to take, is poor. We also know that stroke can have a devastating impact on quality of life. There is, however, very little known about the impact of TIA, particularly from a qualitative research perspective, and about laypersons' understanding of the condition. The studies I described earlier, however, (Sorensen et al., 1989; Duncan et al., 1997) do suggest that the effects of a TIA may reach far beyond its impact on the person's physical function. Of course, TIAs have no permanent physical effects, since by definition, the symptoms always resolve within 24 hours. Since the literature had shed little light this subject, I was therefore puzzled as to why the experience of TIA should have a long-term effect on quality of life. I hypothesised that, perhaps, it was partly a consequence of patients perceiving themselves to be 'labelled' as having a health problem. People might also place restrictions on their own activity in the erroneous belief that this might reduce the risk of another TIA or a stroke, or they might have such restrictions imposed on them by family and friends.

In addition to its inherent impact or potential impact on quality of life, TIA is, of course, an important marker for long-term stroke risk. From a public health perspective, the

implementation of effective risk reduction measures relies on those experiencing the symptoms of a TIA, and those to whom the symptoms are reported, responding appropriately so that effective investigations and treatments are initiated promptly. In addition, since TIA itself can affect quality of life, services for patients with TIA should also aim to address this issue. However, if patients did not access the appropriate services in the first place, we, as nurses, could do nothing to ameliorate the impact of TIA on stroke risk and quality of life. An important first step in addressing these issues was for me to explore patients' perceptions of symptoms, healthcare interventions and the impact of TIA.

My aims for this section of the thesis were therefore twofold: firstly, to explore the subjective experiences of people with recent TIA and secondly, to achieve a greater understanding of factors which were relevant to them accessing treatment

2) Emergence of the theme: 'Dross or diamonds?'

The experience of TIA itself was not, at first, intended to be a part of this thesis, and did not feature in my original research plans. However, in my early interviews, participants, without exception, related their experience of TIA to me in great detail. On reflection, this is hardly surprising, since my usual opening line (after describing the purpose of the study) was 'can you go back to the beginning, and tell me how it all started?'; a request which clearly invited a narrative approach. My intention at that time was to enable participants to find a route into the interview process by simply relating their story, before moving on to what was (I thought) the heart of the study. Most of us, I suspect, are more comfortable with autobiography than with discussing our feelings and concerns with a comparative stranger, and I hoped that this approach would enable participants to become comfortable with the interview process before gradually moving on to disclosing more difficult issues. However, far from being a "*conversation with a purpose*" in the tradition of qualitative interviewing (Chenitz, 1986), the first 10 minutes or more of each interview in fact resembled more of a monologue from the participant, after my initial question. My impression was, at first, that participants had a story to tell about their TIA, which they wanted or needed to tell in great detail. But I was not, at least at first, paying a great deal of attention to the story itself, either in the

interview or during analysis. In early coding of these interviews I simply coded most of this material as 'experience of TIA', with little further analysis.

At this point I felt that:

'It is apparent that in the patient's agenda, talking about their experience of stroke or TIA is as important as the aims of the study which had been explained to them, and it is a story which I had to listen to before I could address my provisional agenda. Indeed it seems that the decision-making process and attitudes to treatment options can only be understood and interpreted in the context of this story.' (Field notes, May 2001).

I recognised that participants had an agenda of their own, which I perceived as being different from and, perhaps, in conflict with, my 'provisional agenda'. While I recognised that the experience of TIA was important in providing a context for other matters, I did not appreciate at this time its significance as a theme in its own right.

Some time after this, and after finding the same pattern in subsequent interviews, it occurred to me that I should take a second look at the data in this section of each interview. On doing this, I discovered that it was, in fact, not just "insignificant 'noise'" (Morse, 1994, p31), but dealt with events and concerns which were of great importance to participants, and therefore deserved to be re-analysed in more detail. I noted at this time that:

'Having a TIA is, by definition, a transient event lasting less than 24 hours, but can subsequently place a great restriction on the individual's lifestyle, both from the individual's limiting of their own activity and due to the protective attitude of their spouse or family.' (Field notes, January 2002).

After this point I began to, firstly, explore the participant's experience of the TIA itself in greater detail during each interview. I also reviewed and reanalysed the previous interviews in more depth with respect to this theme. Further, I ensured that future

participants who were recruited had all had TIAs rather than minor recovered strokes, in order to maximise my chance of collecting data relating to the theme.

In total, I interviewed 16 participants who had had TIAs, carrying out 21 interviews with them in total. 11 of them were male and 5 were female. Their mean age was 71.6 years (range: 50-81 years). Table 7 summarises their individual symptoms of TIA. Those included had had amaurosis fugax, hemispheric TIAs affecting sensorimotor function, or both. Four other people were interviewed who had minor recovered strokes. These interviews were excluded from the analysis discussed in this chapter, but the material was included in the analysis of later themes.

Table 7: Participants' symptoms of TIA

Symptoms	No. of participants
Ocular symptoms alone (amaurosis fugax)	6
Hemispheric TIA – sensory /motor deficit	4
Hemispheric TIA – sensory/motor deficit and dysphasia	4
Both hemispheric TIA and ocular symptoms	2

3) Themes

a) Acknowledgement versus denial

The conflicting phenomena of acknowledgement and denial constituted the central theme of participants' experiences of TIA. In order to seek help, they needed to understand and acknowledge that the TIA was a significant episode which warranted them seeking further advice. They might not, however, acknowledge its full significance, at least initially. The TIA, by definition, was a transient and sudden event, which affected a person who had, in most cases, previously perceived their health to be good. Even if they did have other significant health problems, they did not, at any rate, perceive themselves to be at risk of stroke itself prior to the TIA. Although some participants recognised very quickly that their TIA might have serious implications, many initially ignored or played down its significance. However, recognition of the

symptoms and acknowledgement of their significance was essential in order to seek lay or medical help and thus to reduce their future risk of stroke. This acknowledgement may have necessitated them altering their perception of their health status.

Longer-term denial of the significance of the TIA might arise, perhaps, because of their swift physical recovery from the event. It was difficult for participants to take seriously the potential implications for their health, since in most cases, they felt physically well. This swift recovery belied the actual impact of the TIA on their long-term stroke risk, and it was easy for participants to assume – certainly at first but also, maybe, in the longer term – that the implications for their health were not serious. Also, perhaps, for those who were advised to make changes to their lifestyle in order to reduce their stroke risk but were unable to do so, the resulting cognitive dissonance could be resolved by engaging in denial of the significance of the TIA.

b) Perceptions: Describing the TIA

I encountered a paradox when analysing participants' descriptions of their TIA experiences. As I have discussed, they were surprisingly eager to tell me their story of their TIA experiences, and spontaneously recounted the events at and around the time of their TIA in great detail. However, despite this desire to relate the story, the actual symptoms themselves were, for some people, a difficult experience to verbalise. They expressed frustration at being unable to explain what their symptoms felt like, or to be able to give them a name, although they usually recognised that the symptoms were potentially serious. In fact, the very 'oddness' of the symptoms – the fact that they had never previously experienced anything similar – was often what prompted them to seek advice, rather than the perceived type or severity of the symptoms themselves.

'It was frustrating...something I couldn't explain...I couldn't describe... it was just a void. It was just a feeling of nothing' (Participant 3, motor/speech TIA).

'...you just- you know there's something wrong...You don't need a name for it, maybe you can't explain it, you know that this arm just ...is useless... it wasn't numbness as such, it's just useless.' (Participant 8, motor TIA).

The difficulty they had in verbalising their symptoms also affected their ability to communicate what was happening at the time of the TIA, and was compounded for some by expressive dysphasia:

'the response from the medical team I felt was quite good but I couldn't reciprocate it, because I ...had no feelings to respond with' (Participant 3, motor/speech TIA).

The unusual nature of the symptoms was not necessarily interpreted as seriousness, however:

'I sort of couldn't move my leg, and then when I sort of went to lift my arm up, that's when I really noticed, it was very heavy... to be quite truthful with you I thought it was funny. Because I didn't feel ill or anything... no pain... I felt perfectly fit' (Participant 17 – motor TIA).

As this participant revealed, there was an absence of what they would interpret as 'serious' symptoms such as pain or malaise:

'I don't know why it should have happened, because I mean, other than that I felt absolutely great' (Participant 6 - motor TIA).

'there's no pain involved, it's just the uselessness' (Participant 8 – motor TIA).

'the first thing I noticed was, um I felt normal, I'd just got up in the morning ...and I stood up, and fell down' (Participant 18- motor TIA).

'It came and went and I never thought any more about it...(but) I felt alright' (Participant 22 – amaurosis fugax).

'I was alright after that...I said I don't need to go to the doctor, it's quite alright, I felt fine by then' (Participant 23 – motor TIA).

Although for some people, their perception of the serious nature of the symptoms, or their ‘oddness’, prompted them to seek medical advice, participants did in fact initially attribute their symptoms to a variety of sources. Only four thought at the time that they were having a stroke, of whom two qualified this as a ‘minor’ or ‘slight’ stroke - a reasonably accurate self-diagnosis. Others externalised the symptoms or assumed at first that it was a trivial event. Those who had amaurosis fugax tended to assume it was a symptom of eye disease or migraine. Table 8 gives details of the participants’ initial self-attribution of their symptoms.

Table 8: Initial attribution of TIA symptoms by participants

Attribution	Examples (participant identity in brackets)
Stroke	<p><i>‘I thought I was having a stroke’ (08)</i></p> <p><i>‘I did think it could possibly be a slight stroke’ (11)</i></p> <p><i>‘I knew it was a mini stroke’ (14)</i></p> <p><i>‘I realised it was a stroke’ (20)</i></p>
Externalisation	<p><i>‘I thought it was a break in (television) transmission’ (15)</i></p> <p><i>‘I thought there was something on the floor and my foot had stuck to it’ (17)</i></p> <p><i>‘I thought I must have tripped up or something’ (18)</i></p> <p><i>‘I thought it was the light coming through the window’ (22)</i></p> <p><i>‘my wife said ‘your driving’s erratic, you’re jerking a bit’’ (23)</i></p>
Eye problem	<p><i>‘my eyes’ (01)</i></p> <p><i>‘I just thought a film had come over my eye’ (07)</i></p> <p><i>‘I thought it was to do with the cataract’ (09)</i></p> <p><i>‘just something with the eye’ (12)</i></p>
Migraine	<p><i>‘(I thought it was) migraine’ (12)</i></p> <p><i>‘I thought it was just a migraine but when it went on so long I realised it was something different’ (16)</i></p>
Trivial / self-limiting event	<p><i>‘A little wobble’ (3)</i></p> <p><i>‘Thought it was a one off thing’ (22)</i></p>

c) Perceptions: out of the blue

By definition, a TIA has a sudden onset, and many participants were surprised and shocked at experiencing symptoms 'out of the blue'.

'I was watching television and ...all of a sudden it just went (dead), just to the elbow' (Participant 11, motor TIA).

'I'd just been out to take the dog for a walk and I came in, and I was speaking to my friend on the phone and the wife ...said' what's the matter with you? 'You're slurring your speech' (Participant 10 – motor/speech TIA).

'I'd had my breakfast and done a few jobs in the flat, and then I went to make a mid-morning drink and I poured it out, carried it through here, and I couldn't hold the beaker. I just couldn't hold it at all.' (Participant 20 – motor TIA).

This surprise was heightened by their previous perceptions of having good health, or of taking care of their health.

'(it was) completely out of the blue. And we've always eaten sensibly' (Participant 12, motor TIA).

For others, although the symptoms themselves were equally sudden and surprising, with hindsight they were able to identify that they had underlying health and lifestyle risk factors for TIA or stroke.

'I think I know why it happened, I think I were doing too many hours at work....what I ate, I mean one time I went to work I'd take things like meat and potato pies, four, and I'd ate all the lot (Participant 18 – motor/speech TIA)

Even some of those who had previous related health problems felt that the TIA was an unexpected and inexplicable event:

'when it happened that first time, I couldn't think, what the hell's happening here, but I've no idea why it should have happened... what caused it I haven't the foggiest idea' (Participant 6 – motor TIA. He had previously undergone numerous interventions for lower extremity arterial disease).

The resolution of symptoms was equally sudden:

'I woke again at 4 o'clock in the morning, and all of a sudden I realised that...my left arm and my leg was stiff but I could move it, and I could actually speak again' (Participant 10 – motor/speech TIA).

'I couldn't pick anything up at all, I had great difficulty in using the knife and fork... and then suddenly it came back.' (Participant 20 – motor/speech TIA).

The sudden onset of the symptoms itself conveyed a sense of seriousness and for some people, prompted them to seek medical advice. However, if the symptoms resolved quickly, they might dismiss them:

'Wednesday, prior to the Friday I had what I called a little wobble... I took no notice of it' (Participant 3 – motor/speech TIA – he was taken to hospital on the following Friday after another TIA).

Participants' initial perceptions, then, of the TIA were that it was an unusual event; for most, quite unlike anything they had ever experienced before. They perceived that the symptoms had developed suddenly and had generally resolved in a similar fashion. Despite the lack of pain or malaise, the unusual nature of the symptoms, their sudden onset, or both, prompted them (or another person on their behalf) to take further action.

d) Immediate response to the TIA: Ignoring the symptoms

By the very fact that they were taking part in this study, all the participants had sought medical advice about the TIA. In light of their perception of the symptoms as sudden, unusual and (for most) worrisome in nature, one would perhaps expect participants to

take some immediate action. However, this was not always the case. The transient nature of the symptoms led some patients to ignore them initially:

'I had what I called a little wobble...I took no notice of it...I probably initially thought oh, this isn't happening to me' (Participant 3 – motor/speech TIA)

Or if they did take some notice of the TIA, other priorities meant that their first action was not to seek advice:

'I was fitting an electric shower for a friend, and I'd just got to the top of the stairs with my toolbox, and it happened on my left eye again ... as though it was just in the bottom half of the eye... that only lasted for a couple of seconds, so I finished fitting the shower – got to do, the job comes first – and the following day I made an appointment to see my doctor.' (Participant 16 – amaurosis fugax).

Often, they sought medical advice only if they had a further TIA or if a family member urged them to do so, or realised that in fact they had a medical problem only when this was validated by someone else, usually a family member.

'She (wife) come flying upstairs, um what did she say now, "I'll get an ambulance" and I says "Oh don't be silly", and I'm saying "what's happening like..." ' (JG: did you feel it might be something serious or) 'She thought there were, I thought no. because I'd never had, never experienced anything like that in my life' (Participant 18 – motor TIA).

'I felt fine after that. Course, she (wife) got alarmed a bit and she said, in the back of her mind I think, oh, it's a stroke or something like that...she said I'm going to get the doctor' (Participant 23 – motor TIA).

Even when they had reported their symptoms, they might not regard them as serious:

'I might not have rang the doctor, had she (wife) not been there, I might have said well it's gone now, so...I might have ignored it...I think she (GP) told me that it was

an 'A' 'I' – what do you call it...didn't know what it meant, and didn't mean much to me, (pause) I had no feelings really, it had gone and that was that' (Participant 8 – two motor TIAs).

There was a common pattern of denial of the initial symptoms, or at least of their significance, which influenced participants' readiness to seek further help. Denial was exacerbated by the transient nature of the symptoms.

e) Immediate response to the TIA: Fear and anxiety

Some participants described experiencing fear or anxiety during or after having a TIA, due to the nature of the symptoms themselves and their sudden onset:

'I was frightened, I thought I was going to go blind' (Participant 9, amaurosis fugax).

'I said to (my husband), ooh, I've gone absolutely dead, I said ooh Jack I'm frightened' (Participant 11 – motor TIA).

'I were a bit concerned, I were worried about what had happened, you know, and I thought I wonder what it is' (Participant 18 – motor TIA).

It was not just the symptoms themselves which caused concern, however. The uncertainty and unpredictability of the situation, and concern about whether the symptoms would return or worsen, was also a source of worry. Some participants experienced fear because they believed they were having a stroke at the time of the TIA. This is understandable, given that strokes and TIAs may have identical early symptoms, differing essentially only in their duration. Participants had greater awareness of strokes than of TIAs, and some of them therefore assumed they were having a stroke.

'I thought I was having a stroke, yes, and I was afraid it wouldn't go away' (Participant 8 – motor TIA).

'I knew straight away that it was a stroke, I don't know why but I did' (JG: and what were your feelings at that point?) Panic! (laughs) Panic, that's why I rang my son.' (Participant 20 – motor TIA).

For some people, fear and anxiety were compounded in the aftermath of the TIA, rather than arising from the immediate impact of the event itself. Fear was generated if the participant realised the implication of a TIA for their future stroke risk. Living with this situation was a source of fear, because of the possibility of stroke, and uncertainty about its timing. Awareness of their stroke risk, and thus their concern about it, could also be heightened by healthcare consultation:

'It didn't worry me at the time, but it wasn't until I saw (the surgeon) that the alarm bells really rang' (Participant 12 – ocular symptoms).

'Oh, I was worried, oh yeah, but it made me worry more when they said that I'd had a stroke' (Participant 18 – motor TIA. His symptoms lasted less than 24 hours and he had a normal CT scan, so according to the standard definition he had in fact had a TIA rather than a stroke).

Having a TIA was, for many people, in itself a frightening and anxiety-provoking event. Of course, its implications for the person's future risk of stroke could be expected to cause alarm (if the person was aware of these risks). However, even without knowledge of these implications, the immediate emotions experienced on having a TIA were often fear and anxiety. The literature on TIA pays scant attention to this issue, most authors treating TIA as simply a warning sign of possible stroke, rather than an unpleasant syndrome in its own right. It is rather as if we were to treat pain, for example, as only a warning of underlying disease, and investigated its cause without attempting also to relieve the symptom itself and the emotional distress it caused. There is, of course, no equivalent to an analgesic for TIAs, but nonetheless, someone who has had a TIA has experienced a potentially frightening and emotionally distressing event, and their response to this needs to be addressed as much as their stroke risk factors. Indeed, the very fact that participants wanted to tell me their 'TIA stories' in such detail was, in some way, a measure of the emotional impact of the TIA itself.

f) Immediate response to the TIA: seeking help

In most cases, participants did not independently seek professional healthcare advice after their TIA. Instead, they sought, or were given, help from a family member, friend, or work colleague who either summoned medical help, or supported the participant in seeking advice. They would, it seemed, have been very reluctant to seek medical help at all without this corroboration and support from another person, or even two:

(my wife) noticed it first, and ...she went upstairs, we've got a retired detective sergeant from the CID who lives upstairs, and he came down, and he rang for the ambulance...(JG: if you had been somebody living on your own, what do you think you might have done?) I think I'd have got in contact with somebody, I would have rung somebody, because I realised there was something wrong' (Participant 10 – motor/speech TIA).

This reluctance to seek medical help without the corroboration of another person may have been due to the transient nature of the symptoms. Participants felt they needed the support of another person, even if this person had not themselves witnessed the TIA, in order to justify seeking help, especially if the symptoms had been very short lived. The lack of symptoms such as pain or malaise also made people reluctant to seek help:

'there's no pain, nothing whatsoever (JG: if you'd been on your own... do you think you would have called the doctor?) 'well to be quite truthful I don't think so...if I had recovered as quickly as I did well then I wouldn't have bothered...the ambulance came and I just walked to the ambulance, no problem whatsoever' (Participant 17 – motor TIA).

For the following participant, her physical symptoms had resolved within minutes, but the ensuing emotional distress was clearly still apparent to her daughter a few days later:

'I thought oh dear, I'd better go to the doctor's...and then on the Tuesday I went down to my daughter's, and - "Mother, what's wrong with you?", because I looked

down in the dumps, so in the end I told her, so we rang the doctor's, she said you must go and see the doctor' (Original emphasis - Participant 11 - motor TIA).

A TIA might also be more obvious or worrying for an onlooker than for the person experiencing it. This man had a TIA which affected his right leg and consequently his control of his car accelerator pedal:

'she (wife) kept saying, "your driving's a bit erratic this morning", I said "what do you mean?" She said "you're jerking". I said "as far as I know I'm quite alright", we carried on and she kept saying once or twice "Look, you're jerking again," I said "no I'm not" ... I hadn't noticed anything at all' (Participant 23 – motor TIA).

'I went down again... and she (wife) come flying upstairs, and what did she say now, "I'll get an ambulance"' and I says oh don't be silly...I didn't know what had happened at the time...(JG: did you feel it might be something serious or) 'she thought there were, I thought no' (Participant 18 - motor TIA).

It seemed that the transience of the symptoms was a factor in participants' belief that the condition was not serious and their consequent reluctance to seek help. Although some of them did think that they were having a stroke, others did not, because to them, a stroke was defined as a severe, permanent and disabling condition. The transient nature of their TIA symptoms led to a tendency to overlook the possibility that the event was related to stroke:

'well, it didn't really worry me...some people, they lose the use of an arm or a leg don't they...I've had none of those reactions, apart from the leg being a bit numb, which I thought, well that's nothing...I never thought oh heck, I've had a stroke' (Participant 23 – motor TIA).

Perhaps it is a feature of denial that people are reluctant to seek medical help under their own volition. If there is a mismatch between the patient's and other person's perception of the seriousness of the TIA, it seems that the patient's reluctance is overcome by the other person's persuasion, whether or not they have actually asked for this support.

Even if the patient is intending to seek help, the fear and distress caused by the TIA, or the nature of the symptoms themselves, may make them need to have the support of another person in doing so. This pattern of lay consultation about symptoms is common to other conditions, with female kin being most likely to be consulted, rather than males or acquaintances (Edwardson, Dean and Brauer, 1995; Stoller and Wisniewski, 2003). There may also of course, be transient cognitive impairment at the time of the TIA which may cloud the patient's perception of the seriousness of the symptoms and the appropriate course of action. It seems that very few people seek medical advice after a TIA without first consulting a relative or friend. The corollary of this is, of course, that many people may have TIAs for which they do not seek healthcare advice, and which they do not even discuss with anyone else.

g) Long-term impact: Taking defensive action

The long-term impact of the TIA manifested itself most obviously in the variety of practical measures taken by participants to reduce their risk of further TIA or stroke. In order for them to take these measures, they had to be aware of the risk of further events, aware of pertinent risk factors, and able to address them. Some changes were advised by health professionals, while other changes were made spontaneously. Dietary changes were common, as was taking prescribed medication. Six of the participants who had had TIAs were also advised and chose to have carotid endarterectomy. Participants mainly took these steps in order to reduce their stroke risk, but they also felt a sense of obligation to take defensive action, in order to reciprocate the concern and effort expended by their health professionals:

'Once people have made the effort to do tests on you...I feel that yes, I should do something...because everybody has made the effort.' (Participant 3 – motor TIA)

People's choices about healthcare measures to reduce stroke risk are a theme I will discuss in detail in Chapter 9, and so I will not elaborate further on these choices here.

In addition to stroke risk-reduction measures, some participants made behavioural changes in order to avoid activities which they felt might precipitate another TIA or

stroke, even though there was no logical basis for such changes. It seemed that the prospect of having another TIA, to say nothing of a completed stroke, was a worrying prospect:

'I got terrified of having a shower ...I started having baths as a matter of fact because I was so scared' (Participant 8 – had motor TIAs whilst taking showers on two separate occasions).

'I did say to (the stroke physician) when he saw me, I said now what do you want me to do, do you want me to take it easy, he said no, carry on exactly, living and doing what you always have done, so I told him I usually go swimming ...on a Wednesday, he said OK, carry on.' (Participant 6 – motor TIA).

'I suppose if you start thinking, every least little thing that happens to you, you think, "oh is this connected to the stroke" sort of thing, so I try not to think about it' (Participant 17 – motor TIA)

Some had more than one TIA, and although they recovered swiftly and fully each time and tried to maintain their everyday activities, they found the symptoms themselves difficult to cope with, with additional worry and distress for those around them:

'I know if I don't have it (CEA) I've no chance. I have too many of these (TIAs) now. Like I say, yesterday, er, I have small ones. During the day I'll suddenly think, oh, and I'll shut my eye (but) I just carry on as if...I wouldn't let it stop my life, you might as well pack up. (Wife: my worry is that I can't see what's happening when he's pushing me (in a wheelchair), and sometimes he's stopping. I say "are you alright?" and he's stopped perhaps to have a look at his watch or something.)' (Participant 14 – amaurosis fugax).

Clearly, avoiding adverse events after a TIA - whether these events were a further TIA, a stroke, or a consequence, such as a fall, arising from them – was important to participants. They combined a sometimes fatalistic attitude with a variety of effective or admittedly irrational means of reducing their risk.

h) Long-term impact: Changed perception of self

A TIA could alter people's self image in relation to their health, their mortality, and their current quality of life. For some participants, the TIA dramatically changed their perception of their health. This was particularly marked in those who had few previous health problems, and was heightened by the sudden nature of the TIA.

'I've always kept my health, this has absolutely shattered me.' (Participant 11- motor TIA)

This changed perception could be caused by the TIA itself, or by the medical investigations which ensued:

'they said my cholesterol was high and blood pressure was high and fat content was high and sugar was high, so – I'm a wreck really although I thought I was fit!'
(Participant 8 – motor TIAs)

'I (was) in a state of panic, continuous. After seeing the (carotid) scans' (Participant 16 – amaurosis fugax).

In contrast, this participant felt that the TIA was a minor problem compared to his diagnosis of cancer 3 years earlier:

'To me there's less problem with that than the cancer I had, cancer of the prostate, that was more of a worry to me....cancer is more serious than a stroke, yes, to me it was anyhow.' (Participant 20 – motor/speech TIA).

Their awareness of their future stroke risk was heightened by the TIA, and living with this risk diminished their quality of life:

'I'd be worrying a lot, yes, wondering when or where or how it (stroke) was going to happen...it would be in the back of my mind...which takes some of the pleasure out of life' (Participant 12 - amaurosis fugax – interview before CEA).

On the other hand, having a TIA but avoiding a permanent stroke made some people more appreciative of their present health status and quality of life:

'It's changed me spiritually, emotionally...to respect what I've got, not just physically, but what I've got inside me' (Participant 3- motor TIA).

Some participants, particularly older people, accepted with some equanimity that they might have a fatal stroke, although they still feared having a disabling stroke:

'When you get older, I dare say if I'd've been in my twenties and it happened I'd've been frightened, but when you get to my age (81) you know, you're going to go in the next few years anyway, so ... about once a month I go to a nursing home to see (a friend) ... and one of the people in the home who's had a stroke, now I would rather not end up like that, so it doesn't bother me that there's something wrong, as long as it knocks me off altogether because I don't want to end up like that' (Participant 14 – amaurosis fugax).

'I feel I'm in the clear, I've no signs of er having a stroke, no twinges or anything like that...I may be wrong but I'm nearly 80, goddammit, I won't worry about that...I've had a good life, had a good life. Every day is a bonus.' (Participant 20 – motor TIA).

It was common for family and friends to adopt a protective attitude towards participants after TIA, which further restricted their activity and reinforced their awareness of their changed status. This attitude was in contrast to the participant's own perception of their health:

'you have to admit that you're not as fit as you thought you were, everybody's always telling me to be careful, and have a rest...people around me have sort of convinced me that I'm a bit fragile...we had people here last night...and they say "well we'd better go, it's gone 10 o'clock now, because you get tired", and I said, well no, I don't get tired (but) they're telling me that I get tired' (Participant 8 – motor TIA)

'he (husband) goes mad at me – "you've got that Hoover out again" (laughs). But um no, I feel fine now, great.' (Participant 11 – motor TIA).

Having a TIA also, for some people, precipitated lifestyle changes which they reflected their new priorities in life:

'It's a new start, the fact that my lifestyle should change...I did sacrifice a great deal, not just physically but emotionally, for the company, thinking that I was on the right road doing the right thing...and then to have the second chance ... that lesson has taught me to revalue, re-look at the whole structure of my life, how I feel about things, what I worry about, what I don't need to worry about any more, what I care for... it's changed me' (Participant 3- motor TIA – reduced his working hours in family business).

'When I first had that mild stroke I started thinking, I thought well if anything happened to me, um it'd be better for (Husband) for us to be nearer to (our daughter) ...you never think you're old but you are ...you start to realise you are getting older and you've got to start thinking about these things' (Participant 11 – motor TIA – planned to move home to be nearer her daughter).

It seemed that, particularly for previously fit people, the TIA permanently changed their perception of their health, despite having no permanent physical symptoms. This could account for the diminishment in quality of life found by other researchers (Sorensen et al., 1989; Duncan et al., 1997). For some older people and those with previous health problems, the reduction in health status they inferred from the TIA was viewed with greater equanimity. However, having a TIA rather than a completed stroke could be seen as a positive outcome and even, for some people, enabled them to respond constructively by taking measures to appreciate and enhance their quality of life.

i) Long-term impact: A fortunate warning

Some participants felt they were fortunate to have had a TIA rather than a permanent, possibly severe, stroke. The TIA gave the participant the opportunity to seek healthcare

advice and to make changes to reduce their future stroke risk. This was particularly noticeable in those who had had CEA:

'Right at the beginning I felt presenting the way it did, in my eye rather than a stroke, I felt that ...I couldn't ignore it...(it was) something I had to take notice of...I'm hoping that I can forget about it now, as long as I stick to my aspirin and diet and pills and so on' (Participant 1 – amaurosis fugax – after CEA).

'It was a tap on the shoulder...I probably wouldn't have changed, I probably would have waited for the big one, and that would have been the end of it...so I do appreciate that I've had this warning...I'm a better person for it, that's how I feel' (Participant 3 – motor/speech TIA).

'I'm quite happy that things have turned out like this, And all things being equal, I hope to carry on for quite a number of years yet.' (Participant 12 – amaurosis fugax).

'I felt perfectly fit, and I mean I suppose if my face, or I couldn't move or anything like that, I would have been frightened, because there was a lady in the ward that was really very very bad, so in other words I thought to myself well I'm lucky' (Participant 17 – motor TIA).

'it's a good thing in a way, it's nice to know that people are concerned and do all these tests for you...(a neighbour) has had a stroke and er it's affected his brain, he just doesn't know people, what time of day it is or anything, I suppose you've got that in the back of your mind, it could have affected me like that...and I say thank heaven it didn't.' (Participant 23 – motor TIA).

Some recognised that adherence to the medical advice they were given would only reduce, not eliminate, their long-term risk of stroke, but they nonetheless felt fortunate to have the opportunity to reduce this risk:

'Maybe it was a good thing, a good thing to get some sort of warning, and say 'aye aye, you know, it's all going wrong here...it's just a warning, make sure it doesn't happen again, as far as you can...they say it might happen again, the warfarin will give you about 60% security, whereas the aspirin will give you only 20%'
(Participant 8 – motor TIAs).

4) Discussion

My findings confirm those of other authors (Sorensen et al., 1989; Duncan et al., 1997) in identifying that the experience of having a TIA permanently changes people's quality of life and their perception of their health. I found that the immediate impact of a TIA was, for most people, that of a sudden event, whose symptoms themselves could be distressing and worrying. Their initial response was often to try to ignore or deny the significance of the symptoms, and only to seek help via the agency or persuasion of a lay person such as a family member. Despite its transient symptoms, having a TIA marked a divide between a healthy past and an uncertain future, particularly for those in previously good health, or with a self-perception of good health. People were also prompted to seek health advice and to adopt changed health behaviours, such as changes in diet and adherence to medication regimes. In this way, they used the TIA as a warning that they needed to take action in order to reduce their risk of a major stroke in the future. The ability of participants to make positive health changes to some extent ameliorated the negative effects of being aware of their heightened stroke risk. For some people, their appreciation of their present quality of life was also enhanced. It seems that recovered TIA is not an asymptomatic condition, yet that is how it is treated at present by the healthcare system – solely as an indicator of future stroke risk, with no appreciation of its impact on quality of life.

Participants in the study found the experience of TIA difficult to describe, and this factor, together with the transience of symptoms, could explain why TIAs are often 'underrecognised, underreported, and undertreated' (Albers et al., 2002). Participants experienced denial of their symptoms and delays in seeking help. However, all the participants eventually did seek medical attention, often via the intervention of a family member or other intermediary.

The emotional impact of having a TIA has been underestimated. There is scant literature on the subject, and the condition is mostly treated by the healthcare system in terms of its significance as a marker for stroke risk. Important though this is, nurses who are caring for patients after TIA must also recognise and respond to the emotional impact of the event. This is important partly because unrecognised fear and anxiety about the TIA will make it difficult for the patient to realistically understand and address their risk of stroke risk. Equally important, the patient's long-term quality of life may be reduced if their concerns are not addressed.

If stroke risk is to be reduced, it is vital that people who have TIAs report them promptly. The findings I have presented only included the views of those who did report their symptoms. Those who do not report their symptoms cannot be assumed to share these views. Although a study of this group would be logistically difficult to conduct, the factors relating to early and delayed reporting of symptoms in those who do seek healthcare advice could be explored. It has previously been identified that public understanding of stroke and TIA symptoms is poor. Since many of the participants who had TIAs initially attributed their symptoms to other causes, this subject merits further research. The influence of family or friends appears to be paramount, and so public education and services need to target not just those at risk, but others who may support a patient to seek help.

5) Chapter summary

People benefit from reporting a TIA because they can then access investigations and interventions to reduce their stroke risk. Rapid access to services for the investigation and treatment of patients after TIA is an important measure to reduce the incidence of stroke and stroke-related disability. However, such measures may adversely affect patients' health perception and anxiety level, because haste of consultation may be interpreted as seriousness. Nurses working with these patients in primary and secondary care settings must ensure that their service offers prompt and comprehensive care in order to address stroke risk factors, within an approach designed to avoid unnecessarily increasing anxiety. Emphasis on the importance of interventions, such as control of

hypertension or hyperlipidaemia, antiplatelet therapy, and surgery, may improve compliance, but also may increase anxiety.

The data I have discussed above show how people respond to the experience of having a TIA. But this leaves many questions unanswered: how people then comprehend and interpret their risk of stroke; how they live with the uncertainty of knowing they are at risk of having a stroke, how they choose between the treatments available to reduce that risk; what sources of information and evidence do they use in making these choices, and whether in fact they feel that they, themselves, have choices at all about the treatments available to them. It is important to help people to understand their stroke risk realistically, and to stress the positive nature of a TIA in warning of stroke risk before a major stroke occurs. However, after a TIA, the majority of people will never have a major stroke, particularly if interventions are taken up. Compliance with risk reduction measures may be achieved at a high cost if people then suffer long-term anxiety and diminished quality of life because of their awareness of their risk of stroke.

CHAPTER 8: FINDINGS

SOURCES OF EVIDENCE USED IN MAKING DECISIONS ABOUT CAROTID ENDARTERECTOMY AFTER TIA OR MINOR STROKE

1) Introduction

In the previous chapter I have explored how people experience and respond to the impact of a TIA. One aspect of their response was to take steps to reduce their risk of a further completed stroke. As I discussed in Chapters 2 and 4, there is a wealth of high quality scientific evidence of the effectiveness of interventions in this field. Certainly, the quality of the evidence base for CEA is unparalleled within surgery. I had identified that one way in which participants responded to a TIA was as a 'fortunate warning' of their previously hidden stroke risk, enabling them to take steps to reduce their risk. Consequently I was interested to find out how - if at all - participants themselves used this evidence when making decisions about medical and surgical treatments. I also wanted to identify whether the EBHC hierarchy of levels of evidence (Phillips et al., 2001) was congruent with the factors which, in practice, influenced patients' decisions in this clinical setting.

Patients considering CEA face a dilemma, despite the sound scientific evidence base relating to the procedure. Essentially, the patient has a choice of whether to undergo surgery and risk precipitating an immediate stroke, or to opt for non-surgical management and live with the possibility of a future stroke for the rest of their life. Whichever option they choose, there is no certainty of benefit or harm (Hankey, 1999). Although 'gold standard' evidence demonstrates that CEA will reduce the overall risk of stroke for patients who meet certain clinical and radiological criteria, ultimately, the decision to have surgery must take into account patient's values and preferences about the risks involved.

In this chapter, my intention is to begin to explore the factors affecting participants' treatment choices after TIA or recovered stroke. My specific aims are to examine the use of evidence by participants who were making decisions about CEA, and to identify

whether EBM's hierarchy of evidence was congruent with the factors which, in practice, influenced participants' decisions in this clinical situation.

2) Categories

Coding and analysis of the data identified that participants used three major types of evidence: scientific evidence; clinical evidence; and a wide range of soft evidence.

a) Scientific evidence.

This category incorporated participants' use of data relating to the known risks of surgical and medical treatment, derived from randomised trials; that is, their use of grade 1a evidence. Typically, they had been told that they had a 5% risk of perioperative stroke with CEA, with a 1% per year risk thereafter, versus a 20% 3-year risk of stroke with BMT. These figures applied to those with 70% or greater ICA stenosis; those with lower grades of stenosis had a lower risk of stroke with BMT but would have much the same perioperative risk of stroke. This is, of course, an oversimplification. Randomised trial design compares different treatments applied to the two (or more) arms of the trial, but the individuals who participate in the trial will be more, or less, likely to benefit than the sample as a whole. However, the way that the data were presented to them, and their appreciation of its applicability to their personal situation, meant that for many participants:

'in the end there was no decision' (Participant 3; preoperative).

This might imply that the decision was straightforward. This was indeed the case for some people, in that they found that the actual choice between options was obvious, but it did not necessarily follow that they found it an easy decision to make. Making the 'wrong' decision had potentially serious consequences, if it were to lead to, for example, a perioperative stroke. This meant that, although intellectually it was a simple choice to make, the emotional context of the decision was complex. Furthermore, participants did not always recall the risks of the different treatment options accurately, and the risk of having a stroke without surgery was often overestimated or thought of as

a certainty. The inaccuracy of participants' perceptions of the risks may or may not have affected their ultimate decisions, but their inaccurate recall of the facts certainly affected their feelings about the potential impact of a possible stroke:

'if somebody tells you there's a 50% chance of having a stroke (without surgery) that's in your mind all the time' (Participant 1 – postoperative. Actual 3-year stroke risk without surgery would in fact be about 20%).

Participants based their decisions on a comparison of the relative risks, rather than on absolute risks. The exact figures presented, then, seemed to matter very little, provided that participants perceived that one option was preferable:

'I felt that the risk of having the operation far outweighed the risk of having another attack within 12 months' (Participant 3 – preoperative).

Participants often recalled the quoted surgical stroke risk of 5%, but would have been willing to consider surgery even if the risks of surgical and non-surgical treatment were similar.

(JG: If you had a friend who was in the same situation what would you say to them?)
'I would advise to go ahead with it. Even if there's a 20 or 25% chance that you're going to suffer another stroke (with surgery), ...I would say it's just not worth the worry (of not having surgery)' ... (JG: how high would that (surgical) risk have to be before you start thinking, oh, it's not worth having it?) 'Oh well, if somebody says that it's going to be a 20 to 25% chance that it won't work then I'd have to take some time...I might turn round and say I'd toss the coin and I'll take a chance.'
(Participant 10 – postoperative).

Participants believed that the benefits of surgery were that they reduced their overall stroke risk and the long-term anxiety they experienced about this risk. But in addition, surgery compressed the bulk of the remaining risk into a shorter time span (i.e. the perioperative period). Whilst this reduced participants' long term anxiety about stroke

once they had recovered from surgery, it also increased their anxiety about their short term risk:

'if somebody said to you " right, there's a 5% chance I'm going to kill you in the next 10 minutes" ... that would (make me) ... apprehensive" (Participant 3 – preoperative).

Patients having CEA were aware that they had a risk of stroke with both surgical and medical treatment, but felt that the treatment had been *'tested, and so is safe'* (Participant 1). In other words, the mere fact that randomised trials of the treatment had been conducted was a guarantee of its safety, even though the participants did not have any detailed understanding of the methods and outcomes of the trials. The decision to have surgery might be clear cut, but participants were aware of the difficult dilemma they faced:

'you're damned if you do and damned if you don't, I'd have a stroke if I didn't have surgery, and I might have the stroke under the operation' (Participant 4 – preoperative).

Despite their inaccurate recall of the statistics, and the myriad additional factors I will describe in the forthcoming sections, all but two of the patients recruited made a decision about CEA which was in accord with the scientific evidence as it applied to their clinical situation. Of the two who did not, one declined to be interviewed (perhaps unsurprisingly, since he had also declined any further medical or surgical intervention.) I was able to conduct one interview, however, with a participant who had declined CEA despite having been advised that it was medically 'indicated'. He had had a TIA and was found to have a 70% internal carotid stenosis. On interviewing him, it emerged that his recall and interpretation of the risks of CEA were very inaccurate:

'he (surgeon) said if you don't have another stroke in 12 months, there's an 80% chance you'll not have one (but) if you have the operation done there's a 70% chance it'll give you a stroke. So I said well there's no argument then, I'm not having

it done...and he agreed, he said "fair enough". (Participant 20 – actual perioperative stroke risk normally quoted was 5%).

It seemed that his recall of the non-operative stroke risk was correct, but that he had confused the perioperative risk of CEA with the degree of carotid stenosis (70%). My reaction to this and to his 'incorrect' decision was interesting. During the interview, I asked him to describe his understanding of the risks and benefits no less than three times, even though his first exposition had been very clear (if incorrect). This was not so much to check my understanding, but to clarify his interpretation of the data. This reflected my surprise at hearing such inaccurate figures. Prior to this interview I had hypothesised that his decision might be based on 'soft' data, and that he would feel he had gone against medical advice in not having surgery. But his interpretation of the scientific data was such that he also interpreted the surgeon's comments to him as being in agreement with this decision.

It seems, then, that the presentation of scientific evidence which was, by current standards, high quality, made the choice between medical and surgical options obvious. Nonetheless, the process of coming to a decision was still far from straightforward. Their actual recall of the statistics presented to them was often translated (by them) into less precise measures (such as 'more' or 'less' chance rather than relative or absolute risks). The mere fact that the evidence existed seemed to be enough to convince them of the appropriate action, without them feeling the need to examine or even recall the actual facts in detail. Only if their recall contradicted the facts (as with Participant 20) did they go 'against' the prevailing medical opinion. The actual risk reduction conferred by surgery was important, of course, but an additional benefit was the 'compression of risk', in that provided they survived CEA unharmed, they felt that they could effectively forget about their long term stroke risk.

b) Clinical evidence.

I developed the category of clinical evidence to encapsulate the participants' understanding and interpretation of their own medical condition. This enabled them to understand their individual situation in the context of the trial data. All participants had

had a clinical examination and additional diagnostic tests, such as serum cholesterol assay and echocardiogram. All had had duplex ultrasound scanning of the carotid arteries, to determine the degree of internal carotid artery (ICA) stenosis. The degree of stenosis of an artery, like many biological variables, is continuous (from 0 to 100%). However, for the purposes of clinical trials and everyday clinical practice, it is treated as categorical data. A stenosis greater than 70% is defined as 'severe', and lesser degrees are classified as 'mild' or 'moderate'. This reflects the limitations of the process of duplex imaging and reporting, in which the degree of stenosis is usually only stated to be within a 10% range. Similarly, when coming to an understanding of their own clinical situation, participants also interpreted the continuous variable of ICA stenosis as categorical data, even though they often did recall the quoted degree of stenosis. It seemed that the concept of a gradient of risk, where higher degree of stenosis conferred higher stroke risk, was not often utilised. Carotid stenosis of less than 70% was believed to confer a negligible risk or no risk of future stroke, while a stenosis of greater than 70% was more serious:

'it's OK, it's 50% (stenosis), so that's it' (Participant 6 – BMT).

'he (doctor) said it was 50-55% blockage, and that's not too bad...he said up to 80% they're not really too keen on doing surgery' (Participant 7 – BMT).

A 50% stenosis, in these examples, was viewed as 'OK', conferring little or no risk of stroke. This is not merely of academic interest, but also has practical implications. If such patients believe that a 'not too bad' carotid duplex scan implies that they have a low or even zero risk of stroke, they may neglect to take up interventions such as lifestyle changes and medication to reduce their risk. They may also be less likely to recognise and report stroke symptoms if they do arise, if they believe that their risk of a stroke is low.

I found an exception to this pattern with one participant who had had several scans performed by different practitioners (both duplex and MR scans) which had conflicting results. It was clear that she understood that there was a gradual increase in her stroke risk, the higher the stenosis:

'I've had about 3 or 4 scans...so from being like 50 to 60 (per cent) it was going definite 60, and now it's like 65... once it gets to 70 I think it's, the options close...I'll have to have the surgery... I just hope it keeps 65 % for a few years...if it (a stroke) happens it happens ' (Participant 22 - BMT).

Further information about the plaque morphology in the ICA was also identified by some patients as important:

'the other thing that helped to make my mind up is when (the surgeon) commented (that) the restriction in the artery is loose, it's flaky, which is more dangerous than being hardened' (Participant 10 – postoperative).

It seemed that participants usually remembered quite accurately the details of their own investigation results, particularly the degree of carotid stenosis. In using this data to inform their decisions about treatment options, however, they undertook a process of reframing of the data. The continuous variable of carotid stenosis was translated into categorical data, in which the stroke risk was either high or low – even, perhaps, zero. Their interpretation of the meaning of 'high risk', for those with severe ICA stenosis, was often of a greater magnitude than their actual 3-year stroke risk without surgery (about 20%). In this situation, they saw stroke as a very likely event; even as a certainty. It may be that, in order to accept the intervention of CEA (itself a potentially risky and certainly unpleasant experience), they had to convince themselves that the surgery was worthwhile. This entailed believing that, without surgery, they would certainly be one of the unfortunate 20% to have a stroke in the future, not one of the 80% who would not have one. In this way they resolved the cognitive dissonance (Festinger, 1957) of undergoing risky and unpleasant surgery with no certainty of benefit, by reinterpreting their long term risk as very high or certain. Likewise, for those who did not have surgery but who had moderate ICA stenosis, the reframing process enabled them to convince themselves that their long-term risk of stroke was negligible. This allowed them to avoid confronting the unpleasant reality that, even with BMT, they did in fact have around a 10% 3-year risk of stroke.

c) Soft evidence

In addition to the scientific and clinical evidence described above, participants also used a wide range of other resources to inform and support their decision. I propose that these were, in effect, used as sources of evidence by participants, even though they would not be conventionally regarded as such.

Participants used two main types of 'soft evidence': those based on their personal beliefs and experiences, and others which related to their interaction with the healthcare system.

i) Personal experiences and beliefs about stroke

Previous knowledge of stroke, and encounters with people who had had strokes, were an important source of understanding. Stroke was seen as a devastating condition:

'you hear these horrendous stories about people having strokes and they can't talk, can't walk, so obviously that was a factor' (Participant 3 - preoperative).

'you look at some of them poor rascals in there (stroke club) who haven't had the choice, it's happened to them... and I don't think I could live with that, the way some of them are...wheelchair bound and er speechless and what have you' (Participant 10 – preoperative).

Aside from the potential impact of a major stroke on themselves, participants felt it was important to avoid a stroke in order to avoid physical dependence on others, or the impact of a fatal stroke on their family and friends. They recognised that a severe or fatal stroke 'would devastate...my loved ones' lives' (Participant 3 – preoperative). Perhaps for this reason, they sought to involve family members in their decision:

'my wife was with me, and ...she said...I don't want to be losing you yet, because, I hadn't annoyed enough people... she said go ahead and get it done...I think with the wife being with me, which I insisted on her being there, because...it's as much her

loss or gain as mine, so...she helped me make my mind up. (Participant 10 – preoperative).

'so that's why I had the operation, I had it because I want my independence' (Participant 5 - postoperative).

The most desirable outcome was, not surprisingly, perceived to be not having a stroke at all. But if it were to happen, the timing and place were important. For those who had CEA, the operation meant that they felt they could exercise some control over this. This was important because they believed that having a stroke while at home would be worse than having one in the hospital environment postoperatively, both from the perspective of its impact on their family, and on their chances of a good recovery:

'well I wouldn't like to be here and have one (a stroke) on my own...and the (adult) children to come in and find me' (Participant 5 - preoperative).

'the way I looked at it was, at least if I have a stroke during the operation, I'm in somewhere where it can be dealt with...I'd have got treatment immediately...and also I stood a better chance, if treatment is there immediately, I'm only assuming this...if I'm going to have a stroke let's have it in there... I'm safer there (hospital) (Participant 16 - postoperative).

Participants perceived having a stroke as a serious, even fatal, event, and therefore felt that reducing their stroke risk was worthwhile. However, the uncertainty of knowing that they might have a stroke at any time was a source of anxiety. The benefit of surgery was not solely in reducing the risk of stroke, but in reducing this uncertainty, by compressing the (reduced) risk into the perioperative time period.

ii) Personal experiences and beliefs about TIA

All participants had had a TIA or recovered stroke. I have described in detail in Chapter 7 how this influenced them to take steps to reduce their risk of further events. TIA or minor strokes were a frightening experience, and were a strong motivator for participants to undergo treatment:

'(when you have a TIA) you make all sorts of promises, you'll do anything they (health professionals) tell you to do'(Participant 8 – BMT).

'I might not have been as lucky, if it had been permanent...if it (TIA) had been the big one, if it had left me (disabled) but having that warning, it brought me to ... having the option to have it put right' (Participant 10 – preoperative).

For participants who had recurrent TIAs, this influence was particularly marked. As well as indicating that they were at risk of stroke, the TIAs themselves were unpleasant and affected their quality of life:

'I know if I don't have it (CEA) I've no chance. I have too many of these (TIAs) now. (Participant 14 – preoperative).

Participants had found the experience of having a TIA or minor stroke to be sufficiently noteworthy to have sought advice about it. They felt fortunate to have had a TIA, rather than a completed stroke, as their presenting symptom. They used the event not just as a warning sign, but also as evidence of how a more serious cerebrovascular event might affect them. It was treated as a warning that had to be heeded – a *'wake up call'* (Participant 3).

iii) Personal experiences and beliefs: health status

In addition to their knowledge, experiences and beliefs about TIA and stroke, participants also considered their current health status to be a factor which influenced their decisions about treatment choices. In particular, younger or previously fit participants felt that treatment was important to maintain their current health and quality of life:

'you've got more recuperating powers (from surgery) I should think at my age'. (Participant 2, aged 64).

'I'm sure that some people would say...let's not risk having anything (surgery) done (but) not in my case. Not at all, no. Because I've got far too much to lose (Participant 3, aged 50).

'As soon as he'd (surgeon) finished I said I've got to go for it (surgery)...I'm enjoying life and I want it to go on, without having a stroke' (Participant 16 – aged 79).

Others used their previous (successful) experiences of treatment for other conditions as an indicator that treatment was likely to be beneficial after their TIA:

'the other thing that helped me make my mind up is the fact that I'd had (coronary) angioplasty... I thought to myself that if it does that to my heart you could ... you've got this carotid artery going in, well if that's blocked, well it's gotta be cleared.'
(Participant 10 – postoperative).

In contrast, one participant who chose not to have CEA, despite having a 70% ICA stenosis, had a fatalistic attitude towards his health:

'I wouldn't be here if I had a major stroke. It'd see me off...it could happen to me again...but I'm prepared to take that chance...I've had a good life. Very good life. No worries.' (Participant 20 – BMT).

In order for people to have treatment to reduce their risk of stroke, they therefore needed to believe that their current health status was worth preserving, that their health would be worse if they were to have a stroke, and that they had the physical ability to make a successful recovery. Their own evaluation of their health status can, in this context, be regarded as an important source of evidence.

iv) Personal beliefs and experiences : Instinct/gut feeling

I have described above how participants used facets of their own experience and perception of their health, in addition to more formal sources of evidence, in making treatment decisions. However, even in the face of scientific and clinical evidence about

CEA, some aspects of participants' understanding of their clinical problems and their decisions about treatment had an instinctive quality:

'you don't need to be told about these things (symptoms) do you, you just feel them, you just know there's something wrong' (Participant 8 – BMT).

'right at the beginning I felt...that the way we've been (surgery) was the only way to go' (Participant 1- postoperative).

They did not feel the need to analyse and explore the options for treatment, instead relying on 'just knowing'. This may have been a product of the clarity of the scientific and clinical evidence. Since the formal evidence was perceived as 'clear cut' it was easy for participants to make a decision; in consequence, they felt that the choice was intuitively obvious.

v) Personal experiences and beliefs about the healthcare system

In addition to their personal beliefs and experiences relating to their own health and to the potential impact of stroke, participants also used soft evidence derived from their interactions with the healthcare system. At the time of interview, each participant had had several interactions with a range of clinicians such as their GP, vascular surgeon, vascular technologist, accident and emergency department staff, and stroke physician. The formal exposition of their treatment options was, of course, an important consideration. But other aspects of these interactions were also influential.

vi) Reputations

The reputation of the clinicians and the hospital helped participants to decide on the best course of treatment and who should undertake it. This reputation was derived from participants' own past experiences or from other sources. This was particularly apparent for those undergoing surgery. A good reputation confirmed their formal understanding of the risks and benefits of surgery, and contributed to the development of trust:

'I didn't want to blot his (surgeon's) copybook, he said he hasn't lost anyone yet' (Participant 2) (demonstrating a rather touching concern for not being responsible for spoiling the surgeon's track record!).

'as for being in hospital, each time I've been in, they've been very good' (Participant 4).

'I knew that (surgeon) had been doing this operation for some time and I was quite confident with the team, I knew the anaesthetist... you have to put yourselves in their hands...so you have to be completely confident that it's going to be OK' (Participant 1 – retired hospital employee).

'I don't think there's anything (surgeon) would do that's not necessary, because as far as I'm concerned, well to put it quite bluntly I put my life in his hands' (Participant 6 – had previous vascular surgery).

'My GP said "I know a very good man" (surgeon)' (Participant 14 - preoperative).

'I'm 100% behind what that doctor (GP)'s given me, I really am, 'cause she's very good, actually in that surgery they all are' (Participant 18 – BMT).

Some participants also sought out, or were given, lay opinions from acquaintances about the hospital service and clinicians, and the treatment itself:

'if you're going to go under the knife, you try and get some homework done on them, and he (surgeon) comes out a shining light' (Participant 3).

'I've heard of different people who have had this operation and it's been successful...other people had good results...it certainly gave me confidence... (Participant 12 - preoperative).

The good reputation of the healthcare institution and the clinicians was influential in shaping the participants' interpretation of the formal scientific evidence as it applied to

their unique situation. Positive comments from lay acquaintances and from people such as their GP contributed to the belief that they would avoid having a serious stroke with the treatment they underwent. This enabled them to be *'completely confident that it's going to be OK'* (Participant 1).

None of the participants sought out more formal data about the surgeon's or institution's morbidity and mortality rates for CEA, although these had been compiled for several years via input into the National Vascular Database (Vascular Society, 2004). This information, although it could have been provided, was not fully in the public domain.

vii) Implication of seriousness

After they had initially sought medical attention, participants had usually had urgent consultations and investigations and, where appropriate, surgery. This haste, to them, implied that their medical condition was serious and warranted urgent treatment. This was in stark contrast to the perceived constraints on the British NHS and the lengthy waiting lists for treatment of other conditions:

'(I asked) how many months will I wait for this, and he said in a fortnight...they think she's heading for a major stroke, it could happen any time, we want to avoid it, I can see the logic' (Participant 5 - preoperative).

'they won't give you these things unless it's necessary, because I mean it's costing too much for the national health service to do it, so if they say it, they're saying it because they know that I need it' (Participant 6 – BMT).

'I can't say that I've had any delays with appointments or kept waiting more than I'd expect to wait, only a matter of weeks' (Participant 22 – BMT).

The speed with which interventions were planned and carried out meant that participants had little opportunity for a lengthy perusal of their options:

'he (surgeon) said "go home and think about it" and I thought what's the point in going home to think about having it done. If I'd have come home I wouldn't have

gone back again. So I made up my mind then and there within five minutes... (if I'd gone home) I would have thought no, I'll leave it as it is for the time being, which would be a stupid thing to do. But then when he said come in within the fortnight (for operation), well I nearly fell off the chair then... but it was well worth it.'
(Participant 11 - postoperative).

In contrast, if they experienced any delays in consultation and treatment, they interpreted this to mean that the problem was not considered to be urgent:

'I got a head scan quite quickly, and then on the morning that I was due to see him they rang me up and said due to unforeseen circumstances he can't see you today... and it was quite a while after that before ... they made another appointment... and we both thought well it can't be that serious, otherwise they'd have wanted me back'
(Participant 15 - BMT).

Non-verbal clues from health professionals were also detected and used by participants to reinforce the verbal information:

'it was just seeing (the surgeon's) face and hearing what he said at the time'
(Participant 12 - preoperative).

'it's nice to know that people are concerned and do all these tests for you, instead of saying oh he's alright now, get on with his life...I'm surprised because ...you hear such bad reports about the national health service' (Participant 23 -BMT).

They also expressed reciprocity - if the health professionals were taking the situation seriously, the patient should do likewise:

'Once people have made the effort to do tests on you and give people results, I feel...I should do something and go ahead' (Participant 3- preoperative).

It was clear that the influence of health professionals on participants' perception of their choices was not confined solely to the direct provision of information and advice. The

speed and exhaustiveness of the medical investigations themselves conveyed a sense of urgency and seriousness, irrespective of the actual results of those investigations.

viii) Uniformity of evidence from diverse sources

A consistent attitude which was displayed by the health professionals involved helped to clarify participants' decisions:

'everything that was done from the information given to me and... all the personalities that I met...their positive attitude helped me confirm that we had made the right decision (Participant 3 – postoperative).

'More or less everybody's on the same plane...getting reassurance throughout is very good actually, right from the start...there's nobody throwing a spanner in the works, along the line' (Participant 10 – preoperative).

If there had been a dissenting voice amongst the professionals, this would put the decision more firmly in the hands of the patient:

'if there was a conflict, I'd be somewhere in the middle, and that would have to be a layman's decision' (Participant 7- BMT)

Only one participant had formally sought additional information, via the internet. His aim was not to seek out alternative views, but to recapitulate the information given by the health professionals:

'When (surgeon) discovered what it was and he gave me all the information, I'm on the internet and you can find out anything on there, anything and everything, and I went through all this again on the internet (JG: what did you find?) Exactly, everything (surgeon) had said to me ... not that I didn't trust him, I trusted him wholeheartedly...I just like to go over it in my mind' (Participant 16 – postoperative).

3) Discussion

Despite the existence of level Ia evidence and grade A treatment recommendations about CEA, the scientific data played a relatively small part in participants' deliberations. In fact, it appeared that the existence of gold standard evidence reduced participants' sense of having a free choice in the decision about treatment options, although, they did feel that such decisions were theirs to make, rather than being made by health professionals.

Scientific and clinical evidence were recognised as the basis for the practitioners' advice, but the participants' validation of their decisions mostly took the form of seeking 'soft evidence'. Their decisions usually concurred with the scientific and clinical evidence, but this did not mean that participants came to their choice of treatment via an appraisal of this evidence. Instead, they mostly accepted the treatment option favoured by the clinicians – but not unquestioningly. Rather than scrutinising the scientific and clinical evidence per se, instead, the trustworthiness of these data was evaluated by cross-checking with other sources. These sources included: the participants' own beliefs about stroke; their experience of the TIA; personal health beliefs; instinct; practitioners' and institutions' reputations; speed of interventions; and the consistency of the information given.

Such matters as these are not usually held to be sources of evidence, but are merely a context for the scientific and clinical evidence ('patients' values and preferences'). But consider this broader definition of 'evidence':

"knowledge derived from a variety of sources that has been subjected to testing and has been found credible" (Higgs and Jones, 2000, p311).

In the context of this definition, it is valid to say that patients might use other sources of information about their proposed treatment: perhaps the healthcare experience of a trusted friend; their beliefs about their own health, or their judgement of the trustworthiness of clinicians or healthcare institutions, as evidence which they personally have 'subjected to testing and found credible'. It has also been argued that

nurses regard a similar range of experiential knowledge, derived from their personal professional practice, as a reliable source of evidence which can inform their practice (Thompson, 2003).

There is a growing trend towards greater openness in healthcare, exemplified by such practices as the publication in the national press of mortality rates for cardiac surgery (Bosely, Carvel and Evans, 2005). As this trend continues, it may become common practice for surgeons of any specialty to discuss their individual complication rates for a proposed operation, compared to the national average, with the patient. But my data suggest that such information, important though it is, is only one piece of the patient's evidence jigsaw. It is possible, for example, that the mortality statistics for a surgeon with a high death rate could easily be outweighed, in a patient's mind, by a success story from an acquaintance who has been treated in the past by that surgeon. But we have entered an era where patient choice is increasingly at the forefront of the NHS strategy. The trend towards publication of mortality and morbidity data suggests that patients may start to demand to see the surgeons with the most unblemished record. This approach has serious flaws, notably the difficulty in adjusting for casemix. However, given the multiplicity and complexity of the evidence which is in fact considered by patients, it is likely that the elements of 'soft evidence' which I have described will still be influential.

The use of evidence-based medicine, and its better understanding by patients themselves, is a cornerstone of the movement towards enhancing patient choice, exemplified as shared decision-making (SDM). Yet there is a paradox. If the scientific evidence base for a particular treatment becomes more highly developed and is readily available to the public, patients themselves feel, rightly, that (assuming they agree with the goal of the treatment) that they have 'no decision'. Patients may feel that their treatment options close down as the evidence base strengthens. In effect, the treatment 'chooses' the patient, rather than vice versa. Yet patients still describe how they use 'soft evidence' in coming to decisions about treatment. It may be that, since they have a poor understanding of the minutiae of the scientific principles used to develop the evidence base, they do not, in fact, judge it in the same way as do health professionals or researchers. Instead, they judge the validity of the evidence not by a formal

examination of the methodology of the studies contributing to it, but by an informal, and usually tacit, evaluation of its trustworthiness. This is judged on such factors as their previous experiences, lay acquaintances' advice, and even the manner of the person conveying the information. These measures may also be used partly as a means of wresting back some control over the decision in a situation in which they feel powerless. It seems that EBM in its formal sense may have a rather small part to play in patient choice, with choice instead being exercised where the evidence base is less robust. Ironically, although both EBM and patient choice are seen as desirable aims in healthcare, in this context they are in conflict.

4) Chapter summary

The findings in this chapter go beyond simply incorporating patient's values and preferences in EBHC, towards supporting an alternative hierarchy of evidence in order to achieve SDM. The trustworthiness of the proposed treatment appears to be the most important 'evidence'. This trustworthiness may be conveyed by scientific data, or by less formal measures. The framing of recommendations, both in the context of the patient's symptoms and in the seriousness conveyed to them, is also important. Neither scientific nor experiential 'evidence' should be pre-eminent, but the interaction between the two should inform decisions (Rycroft-Malone et al., 2004).

People adopt an instinctive, heuristic approach to decision-making about treatment choices after TIA or recovered stroke. Having made a decision, they then engage in post-hoc rationalisation, drawing evidence from a wide variety of sources, in order to validate the trustworthiness of that decision. It is possible that just one dissenting piece of information, from a clinical or layperson's opinion – *'a spanner in the works'* (*Participant 10*) – might undermine their decision.

The practice of SDM implies that patients need information about the scientific evidence base in order to satisfy themselves that their treatment is as safe and effective as possible. However, soft evidence also appears to be vital to help patients reach decisions about their care. Nurses and other practitioners need to appreciate the sources of evidence which patients use, in order to help them to access relevant and high quality

evidence, to balance evidence from different sources, and to make choices which are congruent with their values and expectations. In the next chapter I will explore how participants process and 'weigh up' the range of evidence about their risk of stroke and their treatment options, in order to come to decisions about treatment.

CHAPTER 9: RESULTS

WEIGHING UP THE ODDS: DECIDING ABOUT TREATMENT AFTER TIA OR MINOR STROKE

1) Introduction

In the last two chapters I have described people's experiences of TIA and its immediate and long-term consequences, and the sources of the evidence that people gather in order to make decisions about their treatment options after TIA and minor stroke. I now turn to the question of how (and to what extent) people use and interpret the evidence which they have gathered from the sources described, in the process of decision-making.

Life is, of course, a series of gambles; we all take numerous risks every day of our lives. However, in making everyday choices, people do not usually consciously gather and then compare data about the risks and benefits of each option. In the context of healthcare, however, it is at least possible for the comparison of risks and benefits to be much more explicit. People who have had a TIA and the consequent investigations can potentially have access to data about their future stroke risks with different treatment options. This scientific evidence is accurate, scientifically sound, and detailed, when judged by prevailing standards of evidence-based healthcare. For some people, the key decision is whether to undergo CEA or BMT alone. For others, the selection of the most appropriate medication and lifestyle changes is the most important consideration. However, whatever the final treatment plan, its primary purpose is to reduce the person's risk of future strokes. There is usually no intention that the planned treatment will ameliorate unpleasant symptoms. This is firstly, because the treatments on offer are not designed to resolve symptoms, but also because the patient is assumed to have no persistent symptoms in any case. Instead, the secondary stroke risk reduction measures that are put in place are intended to treat 'silent killers' such as hypertension, dyslipidaemia and carotid stenosis. These conditions do not in themselves usually cause unpleasant symptoms, and any symptoms they do cause are paid little heed except as a useful warning of the presence of the condition (e.g. headaches due to hypertension;

TIA with carotid stenosis); they are only of therapeutic interest because of the risks of vascular disease they confer. In the treatment of many medical conditions, the risks of any particular mode of treatment (for example, the risk of perioperative complications in joint replacement surgery for osteoarthritis) are considered in comparison to the intended benefit: that is, relief from symptoms or from the progression of a condition which is affecting the patient's current quality of life.¹ But in TIA and recovered stroke, the risks of treatment (most obviously, perioperative stroke in CEA, but also such effects as the risk of haemorrhage with anticoagulant therapy) must be computed in comparison to the risk of a stroke in the future on a different (or no) treatment. In contrast to a curative procedure, it is untrue to say that patients (and clinicians) undertake a 'risk-benefit analysis'; it is, in effect, a 'risk-risk analysis'. A judgement must therefore be made about the comparative disutility of the potential risks of any proposed treatment, versus the disutility of the alternative treatment option (which may be 'no treatment'). The intended benefits of treatment are not expressed in terms of the relief of symptoms, but only in terms of reduced risk – a benefit that is conspicuous only when it is absent. The discussion that follows on the ways in which people interpret and use the 'evidence base' must be read in this context.

From the perspective of improving public health and the provision of measures to reduce the risk of stroke, there must be an explicit and systematic process of appraisal of the available evidence, and comparison of the risks and benefits of different treatments. I have discussed in Chapters 2 and 4 how this process has translated into health policy and practice, by the development, for example, of clinical guidelines and targets for service provision in the British National Health Service (Royal College of Physicians, 2004a). But in the context of public health strategy, it is patients themselves who have

¹ Of course, some other conditions do not follow this model. For example, a woman with early breast cancer may be aware of the irony of having treatment (such as surgery and chemotherapy) whose unpleasant effects may far outweigh the effects of the cancer itself on her current state of physical health. Concern has also been expressed over the increasing trend towards early diagnosis, often as a result of screening, which risks subjecting people to unpleasant and risky treatment for conditions which might have remained asymptomatic for the rest of their life – abdominal aortic aneurysm and some cancers being examples. Indeed, it has recently been estimated that the rate of overdiagnosis in breast cancer screening is 10% so that one in ten women will have 'unnecessary' treatment (Zackrisson et al., 2006).

to live with the risks of different treatment options, and clinicians who have to help them to do so. In the previous chapter I explained how people at risk of stroke gather evidence from a range of formal and unconventional sources to inform their treatment decisions. I now turn to examining how participants actually process this evidence in order to weigh up the odds of the different treatment options, and to discuss how the evidence itself is perceived and transformed during this process.

2) Understanding and reinterpretation of the odds: relative and absolute risks.

All participants had had their risk of stroke with different treatment options described to them by at least one health professional. But their understanding of what these ‘odds’ meant was highly variable, and often differed markedly from their actual risk of stroke. Most people who were considering CEA recalled having been told their risk of stroke with or without the operation. An explicit recall of the absolute risks was uncommon, but was spontaneously described by a few participants:

‘There’s a 5% chance of you having a stroke under the operation, or there’s a 15% chance within the next 12 months if you don’t have the operation.’ (Participant 11-preoperative).

Most people reinterpreted the figures in a different format in order to actually inform their treatment decisions. This reinterpretation often took the form of evaluating the options as virtually certain or extremely unlikely; that is, in a non-numeric form, and with gross exaggeration of the true risks:

‘As soon as he (surgeon) seen me, he said I had to have it, you know...I’d need to have it otherwise I’d have another stroke... he said 20% (risk) but then he said it’s only 6% with the operation.’ (Participant 4 – my emphasis).

'it was almost (the neurologist) saying "this has to be operated on...you're going to have a major stroke" ...he spelt out, told me all the percentages and everything.'
(Participant 5 - preoperative - original emphasis).

The same participant also felt that the clinical explanation of the risks was not reflected in their personal interpretation of those risks:

'it's all very well for them (doctors), they don't have to go through it... they say 'Oh yes, you need something ... percentage this, percentage that', they're not actually going through it. They don't know what, how you feel.' (Participant 5 – postoperative).

So although their recall of the actual data about the risks and benefits of treatments for carotid stenosis was often fairly accurate, participants reinterpreted it into a black-and-white, categorical opinion (*'this has to be operated on'*). This categorical reinterpretation was reinforced by the attitude conveyed by health professionals, who appeared to favour one treatment choice over another. Participants' reinterpretation of the data also incorporated their human response to the situation; they felt that examining the odds from the dispassionate perspective of a clinician was very different from appreciating that those odds applied to oneself, with the attendant implications of possible disability or death.

Mostly, those participants who were able to quote numerical values for their stroke risk with CEA or BMT, cited the absolute risks. This was normally how the statistics had been presented to them by clinicians, and although their recall was not necessarily accurate, they usually adhered to this style of presentation. However, when they discussed how they actually used these figures in coming to a decision, two things happened. First, the numerical values were translated into less precise verbal estimations of their risk, such as high versus low, more or less risk. Second, some of them also converted the data on absolute risk into a relative risk format:

'They say it might happen again, the warfarin will give you about 60% security, whereas the aspirin will give you only 20%...there's a 40% risk that I still might have another one, yes, because the warfarin can only give you a certain amount of security, bring the risk down' (Participant 8 – figures cited were relative risk reductions).

'We know that the operation was a risk but it's far greater risk of leaving it and having a stroke' (Participant 12 – preoperative).

The next participant weighed up a 'guarantee' that he would not have a stroke subsequent to successful CEA, with his implied certainty that he would have another stroke without surgery. He believed that without CEA, there would definitely be a 'next one', even though he had cited a 35-40% absolute risk. For him the only uncertainty related to the timing and magnitude of the stroke:

'There's a 35 to 40% chance of having one (stroke) if I don't have the operation, and it's not an option, no, it's one of those things you've got to go ahead with and that's it...you haven't got an option because if the operation's a success, the chances are that you won't have, you will never have another stroke, it's very clear, more or less guaranteed...but the thing is, you're living with the fear all the time, is the next one going to be the big one, waiting for something to happen' (Participant 10 – preoperative).

The most extreme stance on the relative risks of treatments was an 'all or nothing' belief described by this man: he estimated his stroke risk with CEA (both perioperative and long term) as effectively zero, and his risk without surgery as certain:

'I didn't have a lot of concerns, it never worried me that I was going to have it done (CEA), I knew it had to be done...I never thought about it, I just thought oh, it'll be alright...I don't think I'm going to have one (a stroke) now. I more or less knew I

was going to have one before (surgery) ... and now that it has cured me altogether, it's marvellous.' (Participant 14 - postoperative).

It can be seen that these expositions of participants' weighing up of the risks are a world apart from the dispassionate language of the randomised trial and clinical guideline, although the evidence base to which they relate is clearly derived from such sources. The absolute risk data were meaningless unless they were compared to the absolute risks of an alternative course of action. Although figures about absolute risks had been given to the participants and were sometimes recalled by them, in order to apply those figures to treatment decisions they had to be translated into relative risks (in either numeric or non-numeric terms). In this way, participants related the statistics given to them to their own situation. But the participants did not only interpret their risk of stroke from a cognitive standpoint. They also used evocative re-workings of their risk of stroke in order to understand the risk of stroke in terms of its potential impact on their life.

3) Perceptions of the magnitude of risk: how big is 5%?

Most participants recalled the absolute risk data given to them: in particular, for those considering CEA, the 5% risk of perioperative stroke. Participants often converted this 5% risk into non-numerical form, but their perception of this risk was not confined to consideration of its magnitude. They could clearly understand and explain to me the magnitude of the surgical risk, but their perception of that risk could change over time, sometimes dominating their thoughts, at other times being diminished:

'That 5% was, as I say it became a great big bubble, it was like Windows on Microsoft, I could open this one and this would pop up, or that would pop up, and all these questions had to be asked and, you know, qualified, what happens if I do have this operation and I came out with having a stroke ...all the permutations, all the questions that your inner mind asks yourself...so it was quite a big 5%...it blows up, magnifies up into something really horrendous...but the encouragement (after talking to the surgeon),, the information was all collated and formulated into a

package that I could understand...and then this 5% started to diminish to an acceptable fear rate of 5%.' (Participant 3 - preoperative).

Or, more simply expressed:

'I try to push it (the surgical risk) to the back of my mind, I don't think about it.'
(Participant 10 – preoperative).

Participants' perception of the significance the risk of surgery was, not surprisingly, different before and after CEA. This was discussed in terms of actual risk data after surgery, and was also evident in the participants' level of anxiety after surgery, compared with the pre-operative period:

'The surgeon said there's a 5% chance of you having a stroke under the operation, or there's a 15% chance within the next 12 months if you don't have the operation' (JG: how did you feel when the surgeon said there was that 5% chance, with the operation?) 'well that's what's worrying me, to be honest...it's there all the time, you know, I mean my husband keeps saying stop worrying about it, it'll be alright... I'm worried sick, I'm not eating, I'm not sleeping properly, I'm just dreading it.'
(Participant 11 – preoperative).

But the same participant, when re-interviewed postoperatively, appeared to have forgotten the anxiety she had expressed beforehand, as if it had never existed:

'(If the surgical risk had been 10%) I would have been worried a little bit I think, but I mean, 5% was neither here nor there' (Participant 11 – postoperative).

It appeared, then, that preoperative anxiety which was disproportionate to the numerical risks often occurred, even with a precise recall of the quoted surgical risks. The 5% risk of having a perioperative stroke dominated these participants' thoughts for a great deal

more than 5% of the time. It seemed that their fear of having a stroke, or even of death or disability in general, was distilled into this one statistic.

With hindsight, we can say that, rather than having a 5% risk of stroke with CEA, instead, 5% of patients will have a stroke (100% risk), and the remaining 95% will not (zero risk). After successful CEA, patients viewed their perioperative stroke risk as zero, since they had not had a stroke. I did not interview any participants postoperatively who had had a stroke, but one can speculate that their perception of that risk was as an inevitability (i.e. 100%). My clinical experience with such patients suggests that they did indeed view the stroke as an event that had been bound to happen sooner or later, whether with or without surgery.

The emotional impact of this 5% perioperative risk did not seem to be paralleled with participants choosing between other potentially harmful treatment options (for example, anticoagulation therapy). This emotional impact reflected, perhaps, the irony of undergoing 'stroke prevention' surgery which, for some people, would in fact be 'stroke causation' surgery. Participants recognised that CEA was itself a risk factor for stroke (Naylor, 2004a). This ironic fact was reinterpreted as anxiety.

These findings need to be considered in the context of how information about medical risk is best presented to patients and the public. Data about relative risk reduction may give a false impression (e.g. an impressive-sounding 50% relative risk reduction may only equate to a fraction of a percentage of absolute risk reduction if the baseline risk is low). But my data suggest that even the absolute risks, as quoted to and by participants, can also be reinterpreted (by patients themselves) to engender an overwhelming anxiety about the risks involved. Even if clinicians consciously and conscientiously try to present unbiased and clear data, expressed in terms of absolute risks, patients will tend to reconfigure that data to make it meaningful, due to the emotional import of the data for their personal situation. The patient may well intellectually understand the meaning of 5% absolute risk of stroke, but their lived experience of that 5% risk is, in effect, 100% and for a short time, the risk dominates their emotional landscape.

4) Shared decision-making, autonomy, or ‘doctor knows best’?

I have examined how participants re-interpreted and evaluated the data presented to them to inform their decision about CEA and other treatment choices relating to reducing stroke risk. I now turn to the decision itself.

Many decision styles are possible in healthcare, from complete patient autonomy, to complete dependence on medical or other decision makers, and all shades of shared decision making in between these two extremes. The fact that a decision needs to be made implies that there is an element of uncertainty about the outcome of the decision. This uncertainty may be shouldered by the patient, clinician, or both. The simplicity of a linear model of decision-making style, ranging from patient autonomy to total dependence (Hack, Degner and Dyck, 1994), belies the complexity of some the intermediate positions on the scale. It is clear, however, that the patient needs at least some information in order to reach a decision - if only to be aware that there is more than one option available. If a patient is to make an informed choice – either between treatments, or to elect to hand that choice back to the clinician - their need for information encompasses at least two, and usually three purposes. First, they need to know what to expect; second, they need to make a choice of how much autonomy they want in making a decision about treatment; and third, they have to make or contribute to that choice (unless they opt to simply go along with the clinician’s preference). In most cases, the clinician will have a preference for one treatment option or another (whether or not they consciously convey this preference to the patient). Sometimes, if the choice is between two options where there is no robust evidence in favour of one or other option (for example, with local versus general anaesthetic for CEA [Rerkasem, Bond and Rothwell, 2004]), it is more likely that the patient will be encouraged to make a choice based on their personal preferences. With other decisions, where one treatment option has overwhelming benefits for mortality and morbidity over another, the clinician is more likely to ‘sell’ that option to the patient. But the patient cannot make a decision, or even decide whether to cede decision making to the clinician, without at least some information about the main treatment options.

My findings suggested that most participants felt that they had a rôle in deciding between treatment options. But it seemed that the existence of patient choice was more akin to a power of veto or, perhaps in a few cases, a casting vote, than an autonomous choice.

Many participants expressed a feeling that the information they had acquired about their clinical situation left them in no doubt as to the correct course of action. In effect, the decision was 'made' by the clinical picture:

'As soon as he (surgeon) seen me, he said I had to have it, you know' (Participant 4 – preoperative).

Yet it was also made clear to this same participant that the decision to have CEA was not the surgeon's, nor her family's, but hers alone:

'The family, the children said, you know, we can't – we can only advise you mother, we can't tell you to have it, it's up to you, (but) they didn't say no and they didn't say yes sort of thing, it's just it's up to you.... (My son) said to (surgeon), he said to him 'there's seven of us (adult children) and we've talked about it', and he said 'It's nothing to do with you, it's down to your mother,' (the surgeon) said to him. He said 'We know that, and my mother's decided she'd have it.' (Participant 4 – preoperative).

An example of clinician-led decision-making was described by the following participant, whose approach was to follow the advice of the medical staff unquestioningly, because:

'I didn't know what kind of treatment I would need. They know, they're the professionals, and whatever treatment they've decided, OK, that's it...whatever they put me on, I think to myself, well they must be right...I abide by whatever instructions I'm given, I always have done.' (Participant 6 – BMT).

However, my notes on this interview indicate a different story:

'About 2 years earlier he (Participant 6) had refused amputation of a severely ischaemic leg – he went home to take his time in coming to a decision and 2 or 3 weeks later decided to undergo amputation - HIS choice. Why is the present situation different?' (Notes on transcribing).

I reflected that perhaps he did not perceive that his current situation was a threat to his life, or quality of life, to the same extent as a mutilating operation like the amputation, so was happy to have little or no influence on decisions about it. He also recognised that his trust in the surgeon in particular, and in healthcare generally, played a part:

'If I find anything, any problem, I want to know what it is. I can't put it right, but someone can...when I go to the doctor's he's the man that knows.' (Participant 6 - BMT).

It was relatively easy for participants to make decisions if they had received consistent medical advice. In effect, the decision was 'made' by the clinical situation. However, if there was a difference of medical opinion, this participant recognised that he would have to take fuller responsibility for decision-making:

'Two different specialists have said it's OK at that level (of carotid stenosis), I'm saying well fine, I'll go with whatever you say...but then if there was a conflict, I'd be somewhere in the middle, and having to take a decision, and that would have to be a sort of layman's decision' (Participant 7 – BMT).

The patient had the final say - the casting vote - in such cases of equivocal or differing medical opinion.

It was a rare individual who deliberately took ownership of the decisions about their treatment. This participant had deliberated at length about the treatment options,

although he recognised that he would have come to the same conclusion if he had simply deferred to the surgeon's decision:

'It's obviously down to me initially, but (the surgeon) came over so well that at the end of the day there was no decision, it was yes, we'll do it. ... (but) it's up to me, because I can always say no to the operation, because I'm not in a life-threatening (emergency) situation now... now I've made the decision, it's taken me probably longer than it's taken me to decide on what I would have considered in priority a lot more detailed, a lot more important (decisions) in my life... it was a big decision, because it would change my life if it didn't go right... I've put the percentages, this 5% against the 20% and reviewed it and analysed it again and again and again and kicked it around.' (Participant 3 – preoperative).

I was eager to interview people who had made decisions which were contrary to medical advice. However, patients with carotid stenosis usually made decisions about their treatment which were in line with the scientific evidence base and the preference of the clinicians. One man who had had CEA, expressed the view that his decision to undergo surgery was somewhat at odds with the surgeon's advice. It was clear that although the surgeon was ambivalent about performing CEA, and prior to this the neurologist was in two minds about referring this participant to the surgeon, this participant chose to have surgery:

'I don't think he (surgeon) wanted to do it really, he said they like you to be 100% fit for one thing... why I don't know, because if I was 100% fit and it happens, it can happen just the same can't it... but I'm not going to get any fitter... he said he's willing to take the risk, because there's a risk on his side if anything happens to me ... but he said the final (decision) is with me... I had to make the choice in the end' (Participant 2 – preoperative).

'I would always have the operation, if somebody recommended it. I mean they didn't want to do it to be honest. They thought I was – I hadn't recovered enough (from a

minor stroke)... Mr (neurologist) he said, well, if you're willing to take it I'll put you through, but he said it's up to the surgeon you know, whether he'll do it or not.'
(Participant 2 – postoperative).

It proved very difficult to find a potential participant who had declined CEA when the operation was the clinician's preferred option. The first potential candidate also (unsurprisingly perhaps) declined to be interviewed. However, I then identified a second person who was in this position. He had two reasons for declining surgery: Firstly that he was not particularly worried about the prospect of having a stroke:

'I wouldn't be here if I had a major stroke. It'd see me off...It could happen to me again...but I'm prepared to take that chance...I've had a good life.' (Participant 20 – BMT).

In addition, however, he had misheard or misinterpreted the figures relating to his risk of stroke:

'He said if you don't have another stroke within 12 months, there's an 80% chance you'll not have one...he said if you have the operation done there's a 70% chance it'll give you a stroke. So I said well there's no argument then, I'm not having it done...and he agreed with me that it didn't need doing' (Participant 20 - BMT).

My surprise at this was reflected in my response:

'My reaction to an 'incorrect' decision – during this interview I asked the participant to go over the risks/benefits and his understanding of them 3 times – to check my understanding of what he'd said, or to check his understanding? Because his recall of what had been said (at consultations) was almost certainly incorrect - reflects my surprise/confusion. It wasn't the response I was expecting!' (Notes on transcription, interview with Participant 20).

Although his impression of the risk of surgery was incorrect, it led to the same decision as his sanguine attitude to the prospect of a future stroke, so the issue of decision conflict did not arise for him. But it did for me, with my knowledge of what the surgical risk actually was; hence my detailed and repetitive questioning during the interview.

No matter how much the mantra of patient choice is invoked, even the most impartial conveyance of information about a patient's clinical situation and options must betray at least a hint of the clinician's preferred option. It was clear that although participants understood that the decision about treatment options was theirs alone, the subtext of the discussion with the clinician usually led them to choose the 'correct' option. They could, in effect, choose any treatment they wished as long as it was also the clinician's choice. But if they declined the clinician's preferred treatment, their decision would be called into question and they might be given an opportunity to reconsider:

'I said there's no argument, I'm not having it done...and he (surgeon) said fair enough, and then after that, this annoyed me then, I keep getting all these calls to have another scan and all this business, I'm not going through it again.' (Participant 20 – BMT).

5) Discussion

In order to come to a decision about their treatment after TIA or minor stroke, people need to gather evidence about the options available and their risks and benefits; they then reinterpret the evidence in the light of their own values, experiences and preferences. This reinterpretation does not itself stand still; the magnitude of the risks may appear to wax and wane over time. But ultimately the person has to make a decision, even if that decision is merely a choice to cede decision making to someone else: a decision not to make a choice is still a decision.

The philosophical importance of self-determination has its roots in the work of the founder of modern existentialism, the Danish philosopher Søren Kierkegaard (1813-

1855).² In his writings, Kierkegaard developed the concept that in order to exist one must make choices, and that what one chooses defines what and who one is. Making choices, having autonomy, is the essence of being human.³ Therefore to deny someone their autonomy in making choices about their life is to deny them the most fundamental aspect of their humanity.

This principle is especially important in the context of decisions about healthcare options, because of their potentially serious impact on the person's quality (and quantity) of life. A decision about a surgical operation which may cause a fatal stroke is clearly more significant than most of our everyday choices. It follows that only the patient can make that decision, because an adverse outcome is arguably more devastating for them than for anyone else (although it is, of course, distressing for family members and, to a lesser extent, for the clinicians concerned). But only the patient is in possession of the knowledge of how they really feel about the possible outcomes, notwithstanding the efforts which were made by the participants in this study to enable me to share in their thoughts. Even the most articulate among them struggled at times to convey their feelings to me. It was clear, though, that they felt that it was important that they were able to make the decision – even if their decision was in fact to 'not make' a choice; that is, to agree with the clinician's preferred option.

The potentially serious implications of such decisions for patients' quality of life means that making decisions about healthcare options is clearly far too important a matter for patients to abrogate responsibility for it to the healthcare professionals. Hence the principle and practice of patient choice has developed. But in stroke risk reduction, as in many other areas of healthcare, the available information which could influence people's decisions is so vast and complex that it is practically impossible for an experienced clinician or researcher, let alone a lay person, to assimilate it all. Faced with

² My attention was first drawn to the interpretation of the work of Kierkegaard in the context of patient choice by Edwards and Elwyn (2001).

³ A more recent reinterpretation can be found in the words of Professor Dumbledore to Harry Potter: '*It is our choices, Harry, that show what we truly are, far more than our abilities.*' (Rowling, 1998, p245).

such a plethora of complex scientific data, it is not surprising that patients often seek less formal sources of evidence such as lay opinion and 'intuition', to supplement or possibly take the place of making sense of the scientific evidence, especially since such decisions are so often made at a stressful time in their life. The central dilemma in SDM is that although (or, more precisely, because) these are such important decisions, which patients must take the opportunity to make for themselves, it is in fact impossible for them to gain full possession of the scientific evidence and clinical know-how to inform those decisions. Many participants made comments to indicate that the clinician is '*the person who really knows what they are talking about*' (Participant 12 – preoperative). But even the most knowledgeable clinician cannot know what their patients are feeling and experiencing for themselves. Hence the patient, being aware of their lack of medical knowledge, may want to defer decision making to the clinician, and likewise, the clinician, being themselves aware of similar limitations in their knowledge of the patient's views and feelings, wants to defer to the patient. Somehow, a compromise has to be reached between these conflicting desires, and a decision made which both parties are happy with. This explains why, although participants almost all felt that the clinicians had said there was no choice but to have the 'recommended' treatment, whether CEA or BMT, they also told me that the decision was ultimately their own.

Patients' decisions about treatment for carotid stenosis take place in, and are informed by, a climate in which there is abundant evidence about the risks of CEA and BMT after TIA. It is interesting to speculate as to what patients' views might have been if I had conducted this study prior to the publication of the main results of ECST and NASCET. Even as things stood, with the availability of (supposedly) objective evidence, patients' treatment choices were difficult. Those choices would probably have been even harder to make when the available evidence was less robust, based as it previously was on small scale randomized trials and case series. In such a situation, patients would perhaps be most likely to base their decision on trust and the reputation of the clinician, effectively choosing to cede decision-making to the clinician. Yet if, perhaps, a surgeon had had a patient experience a fatal stroke recently following CEA, their subsequent patients' trust in them and in the procedure might be reduced (as would their own

confidence). It is easy to see why the development of high quality randomised trial-based evidence in this clinical situation was given such a high priority. In this way, the occasional occurrence of a perioperative stroke or fatality could be placed in a proper context. The policy decisions to conduct the major randomised trials may themselves have had their roots in the decision-making dilemmas facing patients and clinicians. The development of the evidence base meant, firstly, that clinicians could make a more accurate appraisal of the likely risks of CEA and BMT for an individual patient. But perhaps just as importantly, they could also make the patient aware of these risks and thus could pass the ultimate responsibility for decision making back into the hands of the patient.

The choice of surgical or medical treatment after TIA or minor stroke has to be made for each patient. But it is a choice that no-one – neither patient nor clinician – appears very keen to make. It appears that the development of the principles of informed consent and SDM may be a means for clinicians to absolve themselves of responsibility for adverse effects of treatment. If a clinician administers a treatment without advising a patient of a possible complication which then occurs, the patient can have legal redress. But if the patient is warned of the risks of a procedure, chooses to have the procedure and then suffers one of the complications, they have no legal grounds for complaint (if the procedure has been carried out correctly). A clinician can only give a realistic picture of the risks if the evidence is available, so the generation of high quality evidence will not only help to inform appropriate treatment decisions so as to avoid adverse effects, but will also help to protect the clinician from litigation if complications occur.

I am not suggesting that the clinicians' primary aim in all this is to avoid litigation. But the development of SDM is not just an incidental consequence of EBHC. It was precisely because we needed SDM that EBHC was developed. If patients can choose their own treatment, then any adverse events, other than those arising from poor clinical practice, effectively become the patient's responsibility. So the unpleasant fact for a surgeon in having, effectively, 'caused' a major stroke, is somewhat tempered by the

reflection that the patient went into it with a full understanding of the risk. Distressing though this scenario is for the surgeon and team as well as for the patient, it would probably be even more upsetting if they felt that the patient had not really wanted the operation or had not understood the risks. However, from the patient's perspective, it might be harder to live with an adverse event if one felt personally responsible for it. It might be easier to believe that one was simply following sound medical advice. So, although for ethical and legal reasons, patients will always be the ones who make treatment decisions, in the face of potential treatment complications it is more comforting for them to believe that they had 'no choice'. The development of EBHC and consequently of SDM thus helps both patient and clinician to cope with the uncomfortable reality that adverse treatment effects occur.

6) Chapter summary

In this chapter I have demonstrated how participants processed the 'evidence' about their clinical situation, and subsequently reached a decision about their treatment options. It seems that even the robust evidence derived from RCTs can be modified in the process of decision making. Risks, when viewed in the context of their potential impact on the patient themselves, can take on an importance far removed from their actual numerical value. For most people, their decision about CEA versus BMT is in line with the 'recommended' treatment. But they still recognize that it is a choice they, and only they, can make. I have also discussed some of the philosophical implications of patient choice, and how it might be beneficial to clinicians and to the healthcare system for patients to make their own treatment choices.

But no matter how clear the symptoms, how thorough the clinical investigations, and comprehensive the supporting evidence base, we can still only give one truthful answer to the patient who asks: 'Am I going to have a stroke?': that is, 'I don't know'. This uncertainty is my final theme in this thesis and is discussed in the next chapter.

CHAPTER 10

LIVING WITH RISK AND UNCERTAINTY: MINIMISING THE POTENTIAL FOR REGRET

1) Introduction

In the previous chapters I have explored people's experiences of TIA, the ways in which they gather evidence from a variety of sources following the experience of TIA or minor stroke, and how they weigh up this evidence in order to reach decisions about their treatment options. However, this still leaves an important question unanswered; namely, 'What will happen next?'

The question of whether or not someone will eventually experience a serious stroke is one that only time can answer, no matter how detailed the epidemiological data and how carefully the person may adhere to treatments designed to reduce their risk. But a different question, that of how the person lives with this uncertainty, knowing themselves to be at risk of stroke, is one on which I hope to shed some light in this chapter.

The uncertainty which may be experienced by people who know themselves to be at risk of stroke is, in many ways, a commonplace phenomenon. We all, at times, experience anxiety about what lies in store for us; anxiety which is often disproportionate to the actual likelihood of a possible event, or to its significance. But, as I explained in the last chapter, we are unlikely to know the precise magnitude of most of the risks we face in our everyday lives. Indeed, many everyday decisions are taken unconsciously, or at least without conscious calculation or estimation of the risks of the possible courses of action. However, in matters relating to health, it is often possible to quantify people's risks of adverse events. The recent hegemony of evidence-based approaches has resulted in a situation where patients can potentially have access to precise, scientifically based data about their future risk of stroke, and the potential impact on that risk of various interventions. Thus the process of information sharing

does not heighten only their awareness of the potential risks of treatment, but often, will also quantify those risks with great precision. But – and this is the reason why I have avoided use of the term ‘stroke *prevention*’ throughout this thesis – people can only hope to lower their risk of stroke, not to abolish the risk altogether. For example, after successful CEA, the 3-year stroke risk is known to be 2.8% (ECST, 1991) – clearly not the equivalent of zero risk, which the term ‘stroke prevention’ would imply. This leads to a paradox. After a person has begun treatment to reduce their risk of stroke after a TIA, they may then come to have a lower overall risk of stroke than they would have done if they had had no cerebrovascular symptoms, and may even, perhaps, have a lower risk of stroke than their peers. Yet their awareness of that risk (no matter how low the actual risk) has probably been increased. A number of factors conspire to heighten this awareness. These factors include: the impact of the experience of TIA or minor stroke itself, the subsequent investigations which may expose previously hidden pathology such as carotid stenosis or hypertension (which are themselves usually asymptomatic conditions), and, of course, the exposition by clinicians of the person’s ‘high’ risk of stroke. So their question: ‘What happens next?’ must address the phenomenon of living with awareness of risk and the uncertainty about the future which this engenders; not just the phenomenon of being at risk of a stroke.

2) Probability, risk, and certainty

All the participants I interviewed had previously been given, and elicited, some complex data (both formal and informal) about their risk of stroke, and the potential reduction of that risk with various interventions. Given the complexity of the data, it was unsurprising that they simplified it in the process of decision-making. Mostly, as I have described, this entailed reformulating the data into a more comprehensible form. For example, rather than expressing absolute or relative risks, they used the terms ‘more’ or ‘less’ risk. As a result, the risk of stroke was seen as a discontinuous variable, rather than as a point on a continuum. This is also precisely what happens with research and clinical evidence: people’s degree of carotid stenosis and stroke risk are usually expressed in clinical trials and guidelines in terms such as severe, high-risk, mild,

moderate, or low risk (or in numerical categories which correspond to these terms). This entails translation of the data from continuous into categoric forms. Participants' views reflected this use of discontinuous variables, but their reformulation of their stroke risk was not confined only to simple categorisation. They also expressed their stroke risk as all-or-nothing, thereby converting the risk data into certainties rather than probabilities:

"If it isn't done then I am going to have a stroke aren't I?... without a doubt I will...it isn't an option for me, no. I know if I don't have it (CEA) I've no chance."
(Participant 14 – preoperative).

"I don't think I'm going to have one now (a stroke)...it (surgery) has cured me altogether" (participant 14 - postoperative).

"I feel I'm in the clear, I've no signs of having a stroke, no twinges or anything like that...I think it's finished with" (Participant 20 – BMT).

This 'all or nothing' attitude to risk was also reinforced by discussion with health professionals – or at least, by the participants' recall of such discussions:

"He (surgeon) said if you don't have the operation you'll have a stroke" (Participant 4 – preoperative).

"It was almost (the neurologist) saying this has to be operated on...you're going to have a major stroke" (Participant 5 – preoperative).

"He (surgeon) said if I come through it (CEA), that's, you're cured and that's it. You shouldn't have any more problems" (Participant 10 – postoperative).

It is clear that these reformulations of individual risk go beyond a simple process of classification or stratification. A low risk of an event (no matter how low) is not precisely equivalent to zero risk, yet many participants did appear to believe that their

stroke risk was zero after having had medical, and particularly surgical, intervention. Conversely, being at high risk does not equate to certainty of an event, yet several participants were convinced that a stroke would have been an inevitability if it had not been for medical or surgical intervention. It may be that this reconceptualisation was necessary in order for them to accept the necessity for unpleasant, and potentially risky, treatment. If, conversely, they had believed that the natural course of events would be that they would not have a stroke in the future (or perhaps if they were sanguine about this outcome), they could not have accepted the risk of undergoing CEA or other treatments which themselves had potential adverse effects. One will only take steps to try to avoid an event if one believes that that event will otherwise happen, that such measures will be achievable and effective, and also that the event is undesirable. Conversely, if one has already made a decision about a course of action, perhaps based on 'soft evidence' (as described in Chapter 8), one will then convince oneself and others of the correctness of the course of action by believing that it is an essential step if one is to avoid the adverse event (that is, that the event will be inevitable if one does not take the action). This reformulation of beliefs which are not fully congruent with a person's actions is supported by cognitive dissonance theory (Festinger, 1957). For some participants, the process of making a decision about treatments took this pattern: risks were not necessarily analysed before the decision was made, but were evaluated afterwards in order to justify an 'instinctive' choice of treatment. This re-analysis often involved reformulation of their risk of stroke without intervention as '100%'.

Similarly, it was notable that once treatment had been undertaken, participants often felt themselves to be entirely free of the risk of stroke. This was especially apparent with CEA rather than with medical treatments. Participants had to justify to themselves the need for them to have undergone the unpleasant (even if with hindsight, entirely successful) procedure of CEA. This was easier to do if they persuaded themselves of the inevitability of a stroke if they had opted for non-surgical treatment. Otherwise, their operation could be regarded as pointless.

3) Coping with risk: denial as a coping strategy

I have already discussed how denial and acknowledgement of the significance of the event can come into conflict with each other in the person's experience of, and initial response to, a TIA (Chapter 7). A similar pattern was also evident in the ways in which people lived with their long-term risk. If a person's risk of stroke cannot be eliminated, then they must find a way of living with that risk, and in order to do so must develop coping mechanisms. One such mechanism is denial. It seemed that participants strove to ignore their risk of stroke, as if it had in fact been eliminated; in effect, to try to deny that they were at risk. This might happen at any stage of their journey, but particularly once they had had their planned treatment:

'As I say, once I used to think about having another stroke, but now it doesn't bother me at all, I don't even think about it to be honest, there's no time that I think of it...I've done everything I can, so there's no use worrying about it now' (Participant 2 - postoperative).

'I did think it could possibly be a slight stroke, you know, with (husband) having had one...I thought, well you hope it's not...' (Participant 11 - preoperative).

'it's much better, much better...I really don't think about it now, but I know I would have done (without CEA). I'd have been worried sick' (Participant 11 - postoperative).

'I suppose if you start thinking, every least little thing that happens to you, you think, oh is this connected to the stroke, so as I say I try not to think about it...I've just blocked it out altogether, I mean I'm not ill, I don't feel ill' (Participant 17 -BMT).

The corollary of this is, however, that having developed such an effective coping mechanism (that is, denial of their residual risk of stroke), people might then take less seriously the necessity for ongoing measures to minimize their risk, such as control of

hypertension and other known risk factors. Therefore, ironically, a person's denial of risk might lead to their being at higher risk than if they acknowledged the inevitable limitations of the treatment they had already had in eliminating the possibility of a stroke. I did not uncover any evidence of this occurring, but it seems logical to assume that if a person is in denial about their risk of stroke, they are less likely to take steps to minimise their risk. It would not be surprising if they were also unable to appreciate that this is what they were doing and to articulate it in an interview.

An alternative explanation of this apparent denial can be developed. If a particular measure is recommended in order to reduce a person's stroke risk, they can respond in two possible ways. One is to adhere to the recommended measure (stopping smoking, for example), and the other is not to adhere to it, or to do so only partially. However, if the person does not adhere to the recommendation, they must alter their beliefs about its relation to stroke risk. They may persuade themselves that the recommended step will have no impact on their stroke risk, for example, by surmising that the deleterious effects of factors such as cigarette smoking are irreversible. They may also use the strategy of convincing themselves that the risk of a future stroke is not, in their case, a significant one. This 'discounting' of the risk may take the form of denial of the statistical significance of the risk, or denial of its potential personal significance; that is, either in its likelihood or in its potential impact. In this way, cognitive dissonance (Festinger, 1957) between one's beliefs and one's behaviour is avoided. The person modifies their beliefs about their risk of stroke because they cannot change their behaviour, rather than making the more difficult change, for them, of modifying their behaviour in line with their beliefs.

Changes in the healthcare system's response to TIA and minor stroke – towards treating it as a medical emergency and as a significant marker for future stroke risk - have, quite correctly, focused on initiating prompt investigation and treatment in order to reduce the incidence of disabling or fatal stroke (Royal College of Physicians, 2004a). Even so, many such patients still receive inadequate, ineffective, and delayed care (Royal College of Physicians, 2004b). The clinical benefit to patients in obtaining swift assessment and

treatment after TIA or minor stroke is undeniable, particularly since their stroke risk is highest in the first few days. However, this emphasis on the urgency of treatment also carries a drawback, in that the patient's awareness of their risk of stroke is thereby heightened. This awareness can be harnessed to good effect, and for some people is essential, in providing a catalyst for lifestyle change. Awareness of risk may, however, also be detrimental because it increases anxiety, particularly if the person is then unable to adhere to the recommended risk reduction measures. (Stress, although it is not an independent risk factor for stroke, may be a potential contributor to hypertension and to the persistence of detrimental lifestyle choices). The extent to which patients focus on healthcare interventions as a means of eliminating risk is a way for them to reduce the detrimental impact of this awareness of risk. They act in order to reduce their risk, so that they can then also reduce their anxiety about it, as much as reducing the likelihood of stroke per se. In this way, their knowledge of their risk of stroke becomes 'background noise' to their life, rather than the major preoccupation which it assumes in the earlier stages of diagnosis and investigation.

4) Carotid endarterectomy: surrogate symptoms and the worry-ectomy.

I will examine the role of CEA in some detail, because its effect on participants' perceptions of their stroke risk was quite different from the impact of other aspects of treatment.

Participants had a variety of interpretations of the purpose of CEA. Its aim, understood from the surgeon's perspective, was to reduce the individual's long-term risk of stroke by correcting the underlying carotid stenosis. Patients also demonstrated an understanding of this aim, in their discussions of their stroke risk with CEA and BMT.

'Well, I'm hoping that it (CEA) will take away a lot of the risk that was there regarding having a stroke' (Participant 12, preoperative).

However, some also viewed the purpose of CEA as the elimination of long-term stroke risk (not merely its reduction):

'He (surgeon) said if you don't have the operation there's a 35 to 40% chance that you'll have another stroke. If I do the operation, he said there's a 5% chance we could cause a stroke' (Participant 10 - preoperative)... 'and if I come through it, you're cured and that's it. You shouldn't have any more problems' (Participant 10 - postoperative)

For patients however, CEA had an additional purpose. It did not eliminate stroke risk, but their concern about that risk. The surgical removal of atheromatous plaque, performed to reduce stroke risk, had a beneficial side-effect: namely, the removal of anxiety. For the patient, the procedure was not an endarterectomy or even a risk-ectomy, but a 'worry-ectomy'. This alternative interpretation of the purpose of CEA is especially ironic when we realise that the anxiety itself was possibly iatrogenic in the first place:

'The worry (about a possible stroke) came all at once, because I wasn't thinking that I was going to have a, any sort of severe stroke at all (before the TIA)... (but) it was all explained to me, and I did become aware of it for a short time, but now that worry's gone, and I don't want it to come back' (Participant 12 – postoperative).

Unlike many other, but not all, other healthcare interventions, surgery has an immediacy of action (Tallis, 2004). Because of this, the success of surgery, and, even more so, its failure, are expected to be more quickly apparent than, for example, the effects of antihypertensive medication (Naylor, 2004a). This immediacy is one factor in the impact of CEA on people's perception of their risk. Another contributor to the personal impact of CEA is the undeniably dramatic nature of surgical intervention, when contrasted with the commonplace and (literally) everyday experience of taking medication or adhering to health promoting behaviours. A patient cannot take the drastic step of allowing a surgeon to take a scalpel to their neck without the expectation of a similarly dramatic benefit. But because patients undergoing CEA usually have no current physical symptoms, the benefit they derive from surgery cannot be evaluated in

terms of alleviation of such symptoms. Instead, their future stroke risk and their anxiety about it must play the part of surrogate symptoms. The alleviation of these surrogate symptoms then becomes the measure of the success of the operation. A reduction in a person's stroke risk is undoubtedly a benefit, but it is one which can only be recognized in hindsight. By contrast, anxiety about one's stroke risk is an unpleasant phenomenon which can be instantly alleviated by an uneventful CEA. This will confer an immediate benefit on the patient's psychological health. For participants in this study, this immediacy of effect meant that the function of CEA as a 'worry-ectomy' came to assume greater importance than its actual impact on their stroke risk. Therefore, one analysis of the purpose of CEA is that, in addition to the function of the operation as a reducer of stroke risk, the processes of consultation and investigation leading up to the operation themselves create the need for it, by heightening the patient's awareness of and anxiety about their stroke risk.

5) Minimising regret

I have argued that one of the major benefits which participants experienced from CEA was the reduction of their surrogate symptom of anxiety about stroke risk, as well as the intended effect of an actual reduction in that risk. However, there was yet another unintended effect, which could only be elicited by asking participants about two hypothetical situations; firstly, how they might feel if they were to have a stroke as a perioperative event, and secondly, if they were to have declined CEA and subsequently had a stroke.

Perioperative stroke was a potential complication of which all those having CEA were aware. Indeed, the prevailing approach to informed consent meant that clinicians were obliged to disclose this risk, as they should for '*material or significant risks*' relating to any treatment (Department of Health, 2001b). When I asked participants in preoperative interviews how they might feel if a perioperative stroke were to occur, their responses were surprisingly sanguine:

'Right from the beginning, they told me that it (surgery) could cause another stroke and another stroke can cause death...If I'm going to have it I'd sooner have it now while I'm still young; as for dying, everybody's got to go, so it doesn't make any difference you know...so I might as well take my chances now' (Participant 2 – preoperative).

Although participants acknowledged that surgery did confer a risk of perioperative stroke, several of them expressed that they had confidence in the surgeon (and perhaps also in the team). It seemed that a perioperative stroke was to be regarded as an unfortunate event, but was not usually one to which blame could be attached. One man felt that the surgeon himself would want to avoid complications because others (i.e. other professionals) might question his skill or judgement, but it was clear that the participants themselves would not attribute any blame. This is surprising in light of the recent increase in medical litigation cases. Perhaps, however, before surgery, patients must gain trust in the surgeon (and team) in order to consent to the procedure. In order to gain trust, the patient must believe the surgeon to be highly skilled, perhaps, even, infallible. The expression of any doubts (even if only to oneself) about the surgeon's abilities will also throw the decision to have surgery into doubt. So prior to the event, at least, the prospect of a perioperative stroke was viewed, if not with lack of concern, at least without regret or blame.

The alternative hypothetical situation was one where the person did not have the advised CEA and had then had a stroke whilst on medical treatment (or, indeed, on no treatment). In this scenario, participants believed that they *would* experience feelings of regret:

'I'd be kicking myself – if I could' (Participant 2 – post operative).

There was also an anticipation of self-blame, in that they felt they would have been at fault in declining the treatment which could have reduced their risk of stroke:

'I'd be stupid' (Participant 3 - preoperative).

The patient facing CEA chooses between two main options (CEA or medical treatment), both of which might result in regrets:

'You're damned if you do and damned if you don't. I mean I'd have a stroke if I didn't have it (CEA), and I might have the stroke under the operation, or I mightn't. You've just got to take that chance haven't you' (Participant 4 – preoperative).

Although both options could entail regrets, participants would, in fact, experience less regret with the outcome of a perioperative stroke, compared to having a (to them inevitable) stroke without CEA. This would be the less regrettable outcome and therefore was preferred. It was surely better to try – and fail - than not to have tried at all.¹

This theme reached its apotheosis with the participant who would be prepared to consider undergoing CEA even if the overall risks of stroke with and without surgery were identical:

(JG: How big would the surgical risk have to be for you to have second thoughts about having the operation? If I was to say 5 per cent, 6 percent, 7 per cent?) 'I think I would decide really on having the operation regardless, rather than it being at the back of my mind all the time afterwards.' (JG: so even if we said it's 10% and there's a 10% risk of having a stroke in the future if you don't have it, would you still go for it?) 'Yes, I think so, I think I would, yes.' (Participant 12 – preoperative).

This is not a situation in which CEA would normally be suggested, for example in patients with symptomatic moderate ICA stenosis. But this participant's response, at

¹ The belief that you are 'damned if you do and damned if you don't' is well expressed by Kierkegaard (1843): 'Yes, I perceive perfectly that there are two possibilities, one can either do this or that. My sincere opinion and my friendly counsel is as follows: do it/or don't do it -you will regret both.'

least, suggested that surgery might be acceptable to him in this scenario. It seems, therefore, that what is important to the patient is not just reducing the chance of having a stroke at all, but, if one does have a stroke, of having no regrets about the choices and actions that have led up to it, even if the stroke is the direct consequence of those choices.

6) Discussion

Healthcare is a probabilistic discipline (Tallis, 2004), in which there are no certainties in prognosis or treatment. However, after a TIA or minor stroke, patients contrive to reinterpret their situation in terms of certainties: that they were sure to have a stroke if they had not had medical intervention, and that they are now certain not to have one. This may enable people to simplify the process of decision-making about treatment options. If, instead, they were to acknowledge the inherent uncertainties in estimating their stroke risk with the different alternatives, opting for a particular course of action would be far less straightforward. But if one believes that one will ‘definitely’ have a stroke without the treatment in question, the argument to undergo that treatment is compelling.

What, then, is the purpose of medical and surgical treatment of carotid stenosis? It can be argued that the purpose depends on one’s perspective. For the epidemiologist, the aim is to reduce (as efficiently as possible) the incidence of stroke in the target population. For the health professional, it is to reduce the individual patient’s stroke risk (whether by medical or surgical intervention). But for the patient themselves, although they may agree with these two aims, the purpose of treatment appears to be the elimination of anxiety about their future stroke risk – not an endarterectomy, but a ‘worry-ectomy’. Patients also believe that this will reduce the potential for regret in the future about their choices. It can be argued that the ‘correct’ choice of treatment is the one which will avoid or at least minimise any ‘*retrospective chagrin*’ (Feinstein, 1985).

It is possible that these aims may come into conflict. For example, a patient whose anxiety about a potential future stroke leads them to opt for CEA when in fact, it will confer little or no benefit in terms of stroke risk, will reduce their anxiety but will not reduce (and may even increase) their risk of stroke. Similarly, medical treatment may confer risks of side effects with little corresponding impact on the person's absolute stroke risk (for example, if oral anticoagulation is commenced in a patient whose risk of stroke is low). In relation to CEA, there is an additional pressure on the surgeon, who may prefer to operate on patients with lower perioperative risk of stroke, so that the surgeon's personal and institutional records for perioperative mortality and morbidity are less likely to be blemished. However, this runs counter to the real purposes of CEA (whether from a public health, surgical, or patient perspective). In fact, patients with factors leading to a higher perioperative stroke risk (such as contralateral ICA occlusion, comorbidities, and older age) also have higher risk of stroke without surgery (Rothwell et al., 2004), and therefore, if we wish to maximise the benefit of CEA in terms of stroke risk reduction, these 'high risk' candidates for CEA are exactly the patients who have most to gain.

The prevailing wisdom is that to have a stroke today is a worse outcome than to sustain a stroke some months or years hence (Cina, Clase and Haynes, 1999). Treatments to reduce stroke risk, whether medical or surgical, are evaluated in terms of their effect on stroke-free survival. But the feelings of patients about stroke risk do not always match this strategy. Instead, some patients prefer to face a high short-term risk rather than live with a longer period of risk in the future. They will opt for a CEA to bring the risk 'upfront' rather than having to live with long-term risk and uncertainty. This approach has the potential to improve their long-term quality of life by reducing their anxiety, but at the risk of having an early stroke as a result of CEA. Patients may also feel that to sustain a stroke earlier in one's life is preferable, as they believe that they have better chance of recovery from it now than if they are older.

The effort to reduce one's uncertainty of an event does not necessarily, therefore, take the obvious form of the person's taking steps to try to eliminate or reduce risk. If one

wants to reduce uncertainty, rather than risk, this goal can be equally well achieved by reformulating the risk in order to reduce one's perception of it to zero, or to equate it to 100%. If someone believes that it is certain that an adverse event will happen if they take no action, it is then obvious that any step – even one which is itself risky – is worthwhile if it reduces the perceived risk from 100%. The experience of long-term anxiety about the prospect of a possible stroke can itself be considered to be an adverse event. It follows that courses of action with even a very small chance of stroke-free survival might be considered to be useful in achieving a reduction in the person's anxiety.

CEA is a major surgical procedure, which itself can be regarded as a risk factor for stroke. Therefore, it is necessary for people to reconceptualise the adverse effects of their current situation into a certainty of harm in order to accept this unpleasant, and potentially risky, treatment. One only seeks '*a traumatic remedy in the face of a serious threat.*' (Little, 2001). Since the risk of stroke, even with a high-grade carotid stenosis, is not a certainty, the patient's way of accepting the 'traumatic remedy' of CEA is to treat it as a remedy for uncertainty, as much as for its impact on their risk of stroke.

7) Chapter summary

In this chapter I have demonstrated how people aim to reduce their anxiety about stroke risk. The process of decision analysis which they undergo includes a number of processes: the reformulation of stroke risks into certainties; denial of stroke risk; the reconceptualisation of worry about stroke risk into a symptom in its own right; and the recognition of the desire to minimise retrospective regret. These processes, almost coincidentally, lead most people to make choices about their treatment which will also reduce their long-term risk of stroke.

In the final chapter I will revisit these themes and those discussed in earlier chapters, in order to place them firmly in the context of the scientific literature, current clinical practice and future research.

CHAPTER 11: SUMMARY AND RECOMMENDATIONS

1) Introduction

The relationship of the scientific literature to the subject matter of this thesis has two dimensions. It was intended from the outset to provide a conventional literature review, which would be a starting point for the design and setting of the study. But the literature also had a second, more intimate, relationship with the study. My research was, in part at least, about the literature itself, and about the participants' understanding of and response to it. Of course, none of the participants, as far as I was aware, had ever read any of the primary scientific literature relating to their clinical situation, nor did they have any but the most basic appreciation of the methodology of evidence-based medicine. None the less, the experiences and events that they discussed with me were derived from the application of the scientific literature which I described in Chapters 2 to 4. So the evidence base was not just a backdrop to the study; it (and especially the participants' interpretation of it) was also a central phenomenon under investigation. For this reason, I chose to introduce this part of the literature early in the thesis, as without it the study would never have happened. But the study has also resulted in the emergence of new themes, whose literature I had not previously explored. It makes sense to follow a chronological pattern and give an appraisal of these other emergent themes at this point, rather than fitting them into the conventional position earlier in the thesis. In this way I hope that my exposition of the literature relating to the study reflects the design and findings of the study.

Another reason for revisiting the literature in this chapter is that, in the tradition of grounded theory, the exploration of the literature should not be entirely or even mainly completed before data collection. There were many themes which emerged quite unexpectedly in my study, and with which I was relatively unfamiliar beforehand despite believing myself to have already reviewed the relevant literature thoroughly. I could not know fully what literature to review until I had analysed my data and identified the key concepts of the study. To present a literature review of these areas in

advance of the results would go against the exploratory nature of the study. By delaying the presentation of this material until the present chapter, I also hoped to emphasise the way in which the study developed. In this way I hope that the reader will be able to follow the process which I undertook in order to generate new knowledge, and to place it in the context of existing theory.

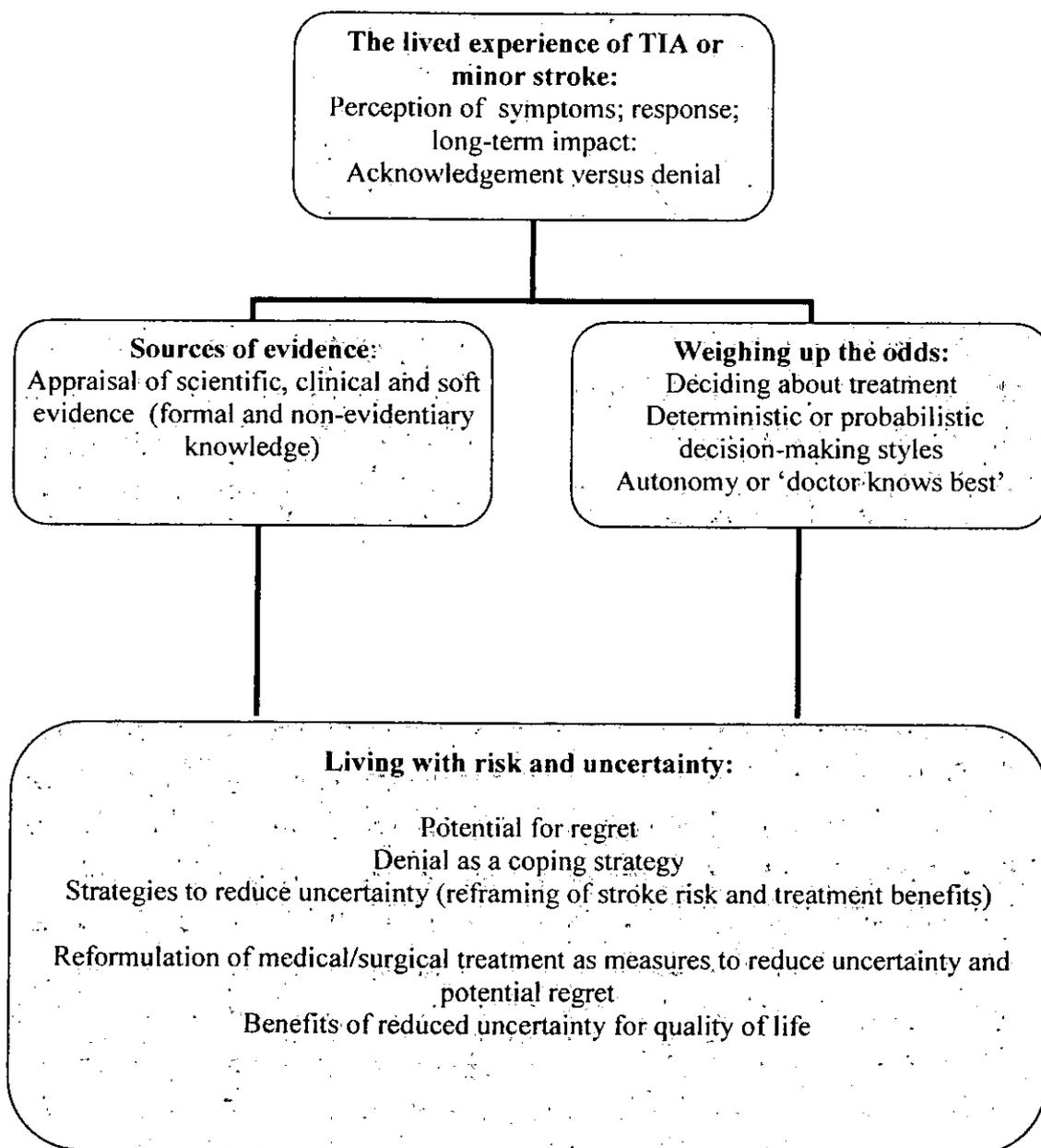
This final chapter therefore contains a synopsis of the key findings of the study in section 2, in relation to the four main themes already described and discussed in Chapters 7 to 10. As well as summarising the findings themselves, I hope to outline some of the literature which I have reviewed in relation to each theme, and to delineate the relationship between these areas of established theory to my research in a previously unexplored situation.

In section 3 I explore the reflexive nature of the study and its strengths, followed by a discussion of the study limitations and scope for generalisability. In section 4 I will present recommendations and possible directions for future research. Finally, section 5 is concerned with the implications of the findings for healthcare policy and practice, with reference to the changes in practice which have taken place since I conducted the study.

2) Synopsis and discussion of findings

The findings I have discussed in the previous chapters can be summarized in the following theoretical framework (Figure 1). The framework demonstrates that people interpret and reformulate their initial experience of TIA or minor stroke, in the light of formal and non-evidentiary knowledge, via a process of decision-making. This enables them to develop a personal strategy to enable them to cope with uncertainty in the context of their risk of stroke.

Figure 1: Framework for reducing uncertainty after transient ischaemic attack or minor stroke



a) The lived experience of TIA

My findings confirm those of other authors (Sorensen et al., 1989; Duncan et al., 1997) that TIA is anything but a trivial event, and that it can have a detrimental effect on people's long-term quality of life and physical health. My findings also support other work relating to the delayed impact of the event and the process of adjustment after mild to moderately disabling stroke (Kirkevold, 2002). Similar phenomena of adjustment, caution and concern about the unknown, have also been identified in people with angina (MacDermott, 2002). The loss of social roles and the limitations on their daily lives which are experienced by people after TIA are not, of course, uncommon in other chronic illnesses such as chronic obstructive pulmonary disease (Barnett, 2005; Fraser et al., 2006), arthritis (Kralik et al., 2004), and in peripheral arterial disease (Gibson and Kenrick, 1998; Wann-Hansson et al., 2005). What is surprising, however, is that after a TIA, these limitations occur in the absence of current symptoms (after what was, by definition, a transient event). The social and personal limitations and lack of adjustment which occur cannot be attributable to the physical manifestations of the condition, but are related to the psychological impact of having a chronic illness.

My findings indicate that many participants delayed seeking advice after a TIA or minor stroke. Similar delay has been identified in people with symptoms of acute coronary syndrome (Goldberg et al., 2002) and is a major barrier to the implementation of effective treatment, notably thrombolytic therapy. In these patients, delay appears to be related to older age and to having atypical symptoms (Grossman et al., 2003), and to female gender (Lockyer, 2005). Similarly, in people with stable angina who self-refer to their general practitioner, both patient and clinician (Gardner and Chapple, 1999) often misattribute symptoms. Referral for investigation of angina is hampered by delay, denial and self-management, with factors such as diagnostic confusion, lack of knowledge, and low expectations contributing to these problems (Tod et al., 2001). My findings suggest that attempts to promote early referral after TIA are likely to be hampered by similar problems as those in angina and acute coronary syndrome. Acknowledgement of the potential implications of the symptoms of TIA or minor stroke

is essential for self-referral and treatment, yet appears to be hampered by denial of these implications.

b) Sources of evidence

The literature of evidence-based health care mostly assumes that there is a hegemony of evidence derived from well-conducted experimental research and systematic review. Whilst it is certainly true that some research studies are more robust than others, the unquestioning translation of this hierarchy of evidence into clinical practice has been widely criticised. Some commentators (Tanenbaum, 1999; Tonelli, 2006) have expressed the view that the clinical acumen of professional judgement is not a lesser form of evidence when compared with the 'gold standard' of the RCT, but is a qualitatively different form of evidence. Therefore, they argue, clinical skill cannot be evaluated in terms of the hierarchical scale of EBM. Tonelli (2006) also goes further in arguing that the integration of 'non-evidentiary' forms of knowledge (such as clinical expertise and judgement) into clinical decision-making undermines the whole epistemological stance of EBM. I would also suggest that professional judgement can be subjected to its own hierarchy, for example, in the well-known "*novice to expert*" hierarchy of professional skills in nursing (Benner, 1984). This means that, just as not all forms of scientific evidence are of equal validity, so the quality of different clinicians' judgements is not necessarily equal.

I found, however, that the participants in my study had little awareness of the robust scientific and clinical evidence base which is well-known to clinicians in the field of stroke risk reduction. Instead, their 'sources of evidence' were dominated by what I have termed 'soft evidence'. This included: their experiences and beliefs about stroke, personal experiences of TIA, personal health beliefs and experiences, instinct or gut feeling, reputation of the healthcare team, implicit seriousness, and consistency of information. In relation to the use of 'non-evidentiary' knowledge (Tonelli, 2006), participants came to a judgement of the trustworthiness of the clinicians involved in their care and treatment. This included a judgement about the quality of judgements

made by clinicians, as well as matters relating to their technical knowledge and proficiency. Professional competence and skill can, as I have indicated, be evaluated and subjected to a hierarchy, for example by using competency frameworks and other evidence of levels of professional development. However, it seems that the participants assessed professional competency itself in an instinctive, heuristic fashion. Their subjective impression of the clinicians' trustworthiness was the key factor, rather than, for example, the level of experience and qualifications (although these were also considered).

The presentation of ever-more detailed and accurate data in relation to the scientific evidence about treatment options and their risks and benefits may, therefore, have little relevance to people after a TIA or minor stroke. Indeed, the provision of additional written and verbal information about CEA has been found to have no effect on patients' understanding of the procedure and its risks and complications, nor on patients' levels of anxiety (Stanley et al., 1998). Furthermore, it is known that the provision of more detailed information and options can overwhelm people's information-processing capabilities, and results in them resorting to strategies of simplification that may overlook much of the information and can lead to poorer decisions (Redelmeier and Shafir, 1995). Other researchers have recently found that patients' recall of postoperative stroke risk relating to CEA is generally poor (Middleton et al., 2006).

c) Weighing up the odds: Deciding about treatment after TIA or minor stroke

The evidence base relating to measures to reduce stroke risk after TIA is a robust body of evidence, especially in relation to CEA. Yet my exploration of participants' treatment decisions when they were faced with this situation demonstrated that the formal evidence base was barely considered by them. Although they mostly felt that the locus of decision-making should, and did, lie with them, almost without exception their decisions concurred with what they felt was the clinician's preferred option for them. I shall now discuss these two matters (the implementation of formal evidence, and the locus of decision-making) in the context of the literature of patient-decision making.

Much of the literature on medical decision-making focuses on the decisions made by professionals rather than on collaborative or patient-led approaches (SDM). There is little agreement in the literature on the concepts implicit in SDM, with a recent review identifying that only 'patient values and preferences', and 'options' are common features to more than half of the definitions in the literature (Makoul and Clayman, 2006). In order to have options, however, the patient must have access to information and evidence about those options. The two essential components of SDM could be better expressed as accessing the evidence, and making the decision itself. Patients' usages of these two components are not necessarily closely related. One patient may wish to have a great deal of information about their condition and the possible treatments, yet will prefer to adhere to a clinician-led decisional style. Conversely, another patient may choose to make a relatively autonomous decision, without necessarily seeking much in the way of information about the options available. My findings suggested that for most people for whom a surgical option of CEA was available, they felt that they made a choice themselves of undergoing surgery or not. This decision was intuitive or deterministic in nature, rather than being evidence-based or probabilistic. In so far as they did examine the evidence, this 'evidence base' also included unconventional sources of evidence (non-evidentiary knowledge), as detailed in Chapter 8 under the heading of 'soft' evidence. The rigorous, comprehensive and high quality scientific evidence about CEA scarcely figured in their decisions at all.

It seems that in the context of decision making after TIA or minor stroke, the availability and presentation of ever-more precise evidence about the risks and benefits of treatment options is not a particularly useful tool to promote SDM, no matter how useful it is to epidemiologists and clinicians. Patients do not appear to practise EBHC in the same way that clinicians do (or rather, are encouraged to do). This is not surprising, given that EBHC is based on the principle of 'the greatest good for the greatest number': that is, some people will be harmed by an intervention which will help others. The patient will rightly be concerned only with what is best in their individual case. No individual, only a population, can have a 5% risk of stroke (the individual will either have a stroke or not within a given timescale; they cannot have a fraction of a stroke). In

making a decision about treatment, therefore, it is understandable that patients give more credence to such factors as the trustworthiness and reputation of the surgical team, than to the figures put in front of them. To accept any treatment, especially one with serious risks, the patient must believe that they will personally benefit and will not be harmed. This belief cannot be engendered solely by an understanding of the probability of those risks, but entails a process of intuitive judgement.

There are, of course, medicolegal reasons why patients must be enabled to access whatever level of information they wish to have about their condition and its possible treatment, especially in the context of informed consent. The principle of self-determination which underpins healthcare implies that patients' decisions are theirs alone, as are the choices they make about information-seeking. However, people's wishes to be informed about their illness and possible treatment options, and their right to make their own treatment decisions, are not synonymous. It is over-simplistic to classify patients' preferred styles as tending towards an 'active' or 'passive' role in decision-making. It has been suggested that SDM entails four separate components: physician knowledge of patient history, physician disclosure of treatment choices, discussion of treatment choices, and selection of treatment choice. Most people want to be presented with treatment options and for their clinician to be well-informed about their medical history. However, there are wide variations in the other two components in this typology: the extent to which people want to participate in discussing treatment options, and in selecting treatment (Flynn, Smith and Vanness, 2006). It has been suggested that the effectiveness of SDM approaches should be evaluated in terms of patients' satisfaction with the decision and the decision-making process, and certainty about whether the best option has been chosen, rather than in terms of the traditional outcomes of patient comprehension and compliance (Edwards and Elwyn, 1999). In this context, effective SDM will rely in part on factors which I have described as 'soft evidence' or non-evidentiary knowledge, such as trustworthiness and consistency.

My study suggests that ever-greater access to more accurate 'gold standard' evidence is not necessarily a useful tool to promote patient self-determination. Within the field of

EBHC, and particularly in relation to SDM, there is a drive for researchers and clinicians to work together to develop and present ever more precise and specific evidence in order that patients can then base their decisions on such evidence. However, despite the use of CEA, along with many other treatment choices after TIA, having been validated by 'gold standard' evidence, my findings suggest that patients actually base their treatment decisions largely on other factors. From an epidemiological and clinical perspective, randomised trials are the method of choice to evaluate prospective treatments, but it seems that EBHC is of limited use in SDM, in terms of its usefulness in helping patients to reach decisions. It is possible, however, that this finding is itself due to the robustness of the evidence in this specific clinical situation. If patients recognise that the evidence in favour of either surgical or medical treatment relating to their individual situation is robust, they may not feel it necessary to question it or examine it further. Instead, they base their rationale for making a decision on the elements of 'soft evidence' I described earlier. Had they been facing a decision where the evidence was less robust, they might have questioned it more closely.

A central assumption of EBHC is that systematic or probabilistic approaches to decision-making are superior to, or more appropriate than, intuitive or deterministic approaches (Ubel and Loewenstein, 1997). The pursuit and implementation of ever-more accurate evidence is intended to ensure that the potential clinical benefits of new and existing treatments are maximized for the population of interest. The paradox of this assumption is that the provision of accurate evidence may have the potential to diminish patient autonomy, if patients then feel that there is 'no decision' for them to make. There is also evidence that people do not, in general, use information systematically in reaching decisions, but tend to employ simplifying heuristics in their judgements (Lloyd, 2001). For example, they may reinterpret risks categorically, or may be influenced by the framing of the situation, and they may also experience anxiety which would seem disproportionate to the actual numerical risk (Redelmeier, Rozin and Kahnemann, 1993). All these strategies were practised by at least some of the participants in my study.

In an attempt to make their interventions patient-centred and to promote SDM, clinicians may try to enhance patients' understanding of the scientific evidence relating to their condition. However, such attempts are, perhaps, more compatible with systematic, probabilistic approaches to healthcare decisions, rather than the intuitive or deterministic style (Tanenbaum, 2005) which appears to be favoured by patients. An approach to SDM which is exclusively underpinned by the philosophy and language of EBHC may therefore, in fact, alienate patients further from the decision-making process. If the information on which decisions are based is in an unfamiliar language and style, patients may find it hard to take ownership of the consequent decisions. It may be that the use of 'soft evidence', which is largely 'owned' and even defined by the patient, is a strategy to regain control and self-determination in a situation where patients feel powerless.

One way for health providers to promote SDM is for them to try to find ways of presenting data more and more clearly, so that patients' decisions are based on accurate and valid evidence. This approach does not appear to be a very useful one in the context of this study, both because of the risk of information overload which may lead to poorer decision making (especially for patients who are already in a stressful situation), and because many patients do not use a systematic, probabilistic approach to decision-making. More usefully, we can work to ensure that treatment decisions are congruent with the patient's wishes. This can be done by integrating the clinician's understanding of the evidence base, and its applicability to the individual's clinical situation, with the values and aspirations of the patient. It is also important to remember that the locus of decision-making is in itself a choice which patients should be able to make: whether patient-led, clinician-led, or a shared style. True patient self-determination is not necessarily promoted solely by maximizing the individual's autonomy and providing ever more detailed information, but by facilitating information sharing, support and decision-making in whatever way and to whatever extent the patient wishes.

It is important that we do not treat the provision of information about conditions and treatments as merely a means to an end; as a tool to aid decision-making. My work

suggests that in so far as patients seek to gain knowledge about their condition, they do so for its own sake, as much as to enable them to make decisions about their treatment. Much of their information-seeking takes place after they have already come to a decision, and acts as corroborative detail to reinforce their intended course of action. Conversely, patients also have the right to self-determination: to make a decision about their treatment, even if they do not wish to have detailed information about the risks and benefits of treatments. The aim of a philosophy of SDM should not be to achieve a certain level of comprehension, nor to promote an exclusively patient-focused decision making style. Instead, the goal should be to enable patients to reach decisions about their treatment in the style they choose, incorporating all the types of evidence which are important to them (Flynn, Smith and Vanness, 2006). They also have the right to choose not to choose.

d) Living with risk and uncertainty

It has been argued that the EBM movement is motivated by a desire for certainty and definitive solutions, aspirations which are at odds with the inherent uncertainty of the professional knowledge held by clinicians and the personal knowledge which patients bring to the healthcare setting (Tanenbaum, 1999).

The presentation of clinical trials data, and in particular, its extrapolation to an individual patient can sometimes be unhelpful in helping the patient to comprehend their own risk (Edwards, Elwyn and Mulley, 2002). Risk communication is usually best understood if absolute risks, rather than relative risks, are cited. Non-numeric terms such as 'possible' or 'rare' are also open to widely differing interpretations. For example, in consideration of treatment options in atrial fibrillation, quantitative rather than qualitative risk presentation has been found to make patients feel better informed, but only sometimes affects their treatment choices, and has no effect on overall knowledge of the condition and on most aspects of decisional conflict (Man-Son-Hing et al., 2002). Yet my findings showed that participants used non-numeric terms in discussing their attitude to risk and its effect on their treatment choices. Systematic

review of the use of decision aids relating to health treatment or screening has found that, while they improve knowledge and realistic expectations, they have little or no effect on anxiety or on satisfaction with either the decision or the process of decision-making (O'Connor et al., 2001). It has also been found in other contexts that medical evidence about risks and benefits is presented in such a way as to give an impression of certainty (Griffiths, Green and Tsouroufli, 2005), and many participants in my study also gained a spuriously certain impression of the likely outcomes of their treatment options.

My findings suggest that when people undergo treatment which is intended to reduce their risk of stroke, their personal motivation in doing so is not necessarily to reduce risk itself, but to reduce uncertainty. The risk reduction could be regarded as a beneficial side-effect of the treatment. My findings indicate that the process of reframing of the scientific and other evidence is used to support this desire to reduce their degree of uncertainty. For example, people believe that a treatment will 'prevent' a stroke, or that a clinician (who, however skilled, is also a fallible human being) can be trusted without reservation. The direct translation of scientific evidence conveys a spurious degree of precision in the context of the imprecise arena of healthcare. It seems that patients reframe the clinical problem. What matters to them is not so much that they are at risk of stroke, but that it is difficult to cope with anxiety about risk, and with uncertainty about a future unknown event. It is partly the desire to reduce the impact of this uncertainty that leads patients to have treatment after TIA and minor stroke.

The impact of living with risk and uncertainty has not previously been considered as a potential factor in choosing to undergo measures to reduce risk of stroke – especially the potentially stroke-inducing operation of CEA. However, Mishel's work (1981; 1984) proposes that uncertainty about symptoms, treatment and outcomes is a major predictor of stress in physical illness. Uncertainty has been found to be associated with depression in patients with atrial fibrillation (Kang, 2006). It is also associated with anxiety in abdominal aortic aneurysm (Patterson and Faux, 1993) and in patients awaiting forthcoming coronary artery bypass surgery (McCormick, McClement and Naimark,

2005): Communication is held to be essential to the resolution of uncertainty (Babrow, Kasch and Ford, 1998).

The concept of uncertainty incorporates several characteristics of the experience of illness: ambiguity, vagueness, unpredictability, inconsistency and lack of information (McCormick, 2002). People's desire to reduce uncertainty about stroke risk is expressed in their attempts to manipulate and alter these characteristics. The key attributes of the concept of uncertainty are held to be probability, temporality, and perception (McCormick, 2002). In the context of living with the risk of stroke, these attributes translate to the questions that patients may ask: "What is my risk of stroke? Over what time period? How might a stroke affect me?" People therefore take action relating to their perceived stroke risk, in order to partly resolve these questions.

It is likely that when patients make choices about treatment after TIA that will reduce their level of uncertainty, they may also gain psychological benefits such as reduced levels of anxiety and depression. However, when making decisions about treatments to reduce the risk of stroke, such psychological considerations, for example fear, anxiety and regret – the 'chagrin factor' (Feinstein, 1985) are difficult or even impossible to integrate into a systematic, probabilistic process of decision analysis. Regret theory proposes that people tend to avoid choices which may lead to retrospective regret if there is a negative outcome (Loomes and Sugden, 1982). Although rarely applied to healthcare decisions, this theory is an important element in healthcare decision-making (Smith, 1996; Brehaut et al., 2003). The theory may explain why people reframe their risk of stroke into certainty. If a patient believes that, without intervention, they are certain to have a stroke in the future, this belief will diminish the potential for regret if they do have a stroke as a result of CEA. In addition, patients' tendency to defer treatment decisions to clinicians might be partially explained by their desire to reduce future regret. In sharing treatment decisions, they may also share any possible regret.

It follows that the fear of a future stroke (regardless of the magnitude of risk) may outweigh any other consideration in coming to a decision about treatment after TIA or

minor stroke. Conversely, a patient may reframe their perception of the magnitude of their risk of stroke, and their anxiety about this outcome, in order to justify their intuitive decision to accept CEA. Some patients may undergo treatment such as CEA in order to reduce fear of stroke, the possibility of future regrets and their perception of uncertainty, rather than to reduce their actual risk.

3) Strengths and limitations of the study

The study I have described in this thesis is the first to explore the lived experience of TIA and its effects on quality of life from a reflexive and qualitative perspective. My description and analysis of people's evidence-seeking and decision-making processes is an attempt to convey the complexity for patients of using evidence in this clinical situation, even when the evidence base is robust. The study is also the first exposition of the concept of uncertainty, and of the measures which people use to reduce their perception of uncertainty, in the context of stroke risk.

My approach throughout this study was a reflexive, interactionist one. I sought to regard myself as a participant in the study, just as much as the participants who I had recruited. This was demonstrated in the flexible, interactive style of data collection, and in the use of note taking before and after interviews and during transcription and analysis. I feel that the participants' side of the interview process showed the interactionist philosophy well:

"When we talk with someone else about the world, we take into account who the other is, what that other person could be presumed to know, 'where' that other is in relation to ourself in the world we talk about." (Baker, 1982; cited by Silverman, 1993 p 90).

My role as interviewer and researcher was, not to gain access to 'objective' facts about the world, but to generate data which gave an authentic insight into people's experiences of the world in relation to the emerging themes of the study. It follows

from the use of an interactionist approach and a relatively unstructured interview style that the interviews I conducted were unique. This relates not just to the unique perspective of each participant, but because they would have engaged differently with a different researcher. The participant's perception of my professional role, my role as a researcher, my prior knowledge and even my personality would lead them to tailor their responses accordingly. Participants' experiences necessarily included their previous and ongoing contact with me, and with the context in which they engaged with me. Similarly, my interaction with each participant was unique. This related partly to the stage of the study I was engaged in at each interview, but also reflected my response to their individual perspective and character.

This thesis focuses on a study using qualitative interview-based methods of data collection and analysis, and therefore direct generalisation of the findings to other settings or other situations is not appropriate. This is, however, not a criticism of the study, but an inevitable consequence of the research approach I used.

There were also some specific limitations of the design and conduct of the study. Firstly, the participants were drawn from a limited geographic area in the North-West of England. Although in terms of their age and sex distribution the participants were not unrepresentative of the local population of people at risk of TIA and stroke, there were, for example, no participants who were of ethnic backgrounds other than white British. The study design itself also precluded the inclusion of potential participants who were not fluent English speakers, or who had other communication difficulties.

The participants were recruited only from one clinical caseload, but some of the experiences that the participants described are known to be commonplace (for example, delays in accessing services after TIA). The setting was fairly typical of a district general hospital in the British NHS, rather than a highly specialist or teaching hospital unit. Rather than try to establish generalisability to other settings, I prefer to argue that the findings were an authentic reflection of the experiences of these participants in this setting.

The interview data were also collected by only one interviewer (myself). Whilst this could be said to reduce the generalisability of the study, it also meant that I was able to use a consistent approach to data collection and analysis.

4) Directions for future research

The exploratory nature of this study immediately leads to many possible directions for further work in this field. Firstly, the theme of the lived experience of TIA warrants more detailed study, particularly as it was not originally intended to be part of this research programme. Further work on this theme could entail a larger-scale study of similar design, and analysis of measures of health-related quality of life after TIA. It would also be useful to study the experiences of people who had hemispheric and ocular symptoms separately, since the attribution and interpretation of these symptoms seems to be very different. It would be useful for further work to include participants from ethnic groups other than white British. It may be that the person's response to a TIA reflects their ethnic background and cultural health beliefs. Attitudes to risk, particularly in the face of transient symptoms, may be influenced by the person's cultural perspective. Minority ethnic groups may also experience greater difficulties in accessing healthcare, and people from black or Asian backgrounds are also known to have a high stroke incidence.

Further work needs to be considered on the factors associated with delays in seeking and gaining referral and treatment after a TIA. This may also give insight into the reasons why some people fail to seek healthcare after TIA. Again, patterns of referral and treatment may vary with ethnic background.

It would also be worthwhile to formally study the presentation of risk data and the framing of risk in the field of stroke risk reduction. Such a study could be carried out on healthy volunteers, involving hypothetical choices about treatment options with differently framed questions. Similarly, a study could be undertaken to explore patients'

preferred decision-making style, in the context of SDM and stroke risk. The use of vignettes may be a useful way of exploring these issues further. More detailed study of the impact of uncertainty on quality of life after TIA or minor stroke could also give insights into people's decisions about reducing the risk of stroke.

5) Implications for practice

a) Organisation of TIA and stroke care delivery

In the time that has elapsed since I started this study, many changes have, of course, been initiated in TIA and stroke care. Notably, the emergence of stroke and the reduction of stroke risk as a higher priority in the British NHS (DoH, 2001a) has led to the introduction of dedicated stroke units in most acute medical facilities. Although the level of in-patient access to such units remains patchy, the presence of such a unit will also reflect a greater concentration of expertise, allowing access to stroke physicians and specialist nurses, rather than having care provided by generalists. Even more significantly for people after TIA, the introduction of dedicated 'fast track' TIA clinics has been widely adopted, with such a service in most acute hospitals. Again, however, the quality and in particular the speed of referral and subsequent investigation which even a dedicated TIA clinic can provide is highly variable. However, it is now widely accepted that TIA (as well as stroke) should be regarded as a medical emergency, since the majority of excess stroke risk after TIA is in the first seven days, declining rapidly by three months (Rothwell and Warlow, 2005). Recent guidelines recommend immediate admission after TIA for those considered to have a greater than 20% risk of stroke. Patients at highest risk are those who have more than one TIA in a week, or those who have at least three of the following four characteristics: blood pressure greater than 140/90 mmHg, unilateral weakness or speech disturbance, symptoms lasting 60 minutes or more, and diabetes (National Pre-Hospital Guidelines Group, 2006). Yet significant delays have recently been identified in access to investigation and treatment after TIA and minor stroke, with waiting times of many weeks for carotid duplex scanning (National Audit Office, 2005) as well as for CEA itself. This period of

waiting reduces the effectiveness of CEA in reducing stroke risk, and also exposes all patients to a period of uncertainty and diminished quality of life in this period. Recent work also indicates that many people still fail to report their stroke or TIA symptoms at all (Howard et al., 2006), thus missing any opportunity for secondary risk reduction.

With respect to CEA, many changes have taken place in practice since I undertook data collection. These include the performance of CEA under local anaesthetic (which although still being formally evaluated [www.galatrial.com] is now widely performed, including at the site of my study), the greater availability of high-dependency (Level 2) facilities for postoperative care, and greater openness and availability of surgeons' and institutions' performance in this and other procedures via the National Vascular Database (Vascular Society, 2004). We also have a better understanding of the high early risk of stroke after TIA, and the corresponding benefit of early surgery (Rothwell, 2006). Similarly in the development of BMT, the effectiveness of therapies such as antiplatelet therapy, cholesterol-lowering treatment, and control of hypertension are better understood than when I commenced the study (Rothwell, 2006; Amarenco et al., 2006). As I also indicated in an earlier chapter, the emergence of treatments for acute stroke such as thrombolytic therapy have led to a change in the very definition of TIA.

The use of CEA as a procedure purely to reduce the risk of stroke has also come into question. Some recent studies have suggested that CEA may improve cognitive function, particularly in those patients with impaired cerebrovascular reserve before surgery (Fearn et al., 2003), and in those with mild vascular cognitive impairment (Borroni et al., 2004), although Aleksic et al. (2006) found that cognitive function was unchanged after CEA, and Lloyd et al. (2004) suggest that it may be reduced in some patients. It has also been suggested that people's quality of life is improved after CEA (Vriens et al., 1998; Dardik et al., 2001), although Lloyd et al. (2004) do not uphold this finding. These are, however, small-scale studies, and the primary intention of clinicians performing CEA (as well as healthcare purchasers and commissioners) remains to reduce the risk of stroke, rather than to relieve symptoms (whether those symptoms are related to reduced cerebral blood flow or to anxiety about stroke risk).

The delays in referral, investigation and treatment which were experienced by the participants in my study may be somewhat reduced today with current practice.

However, delays are likely always to occur to some extent, especially since people who experience a TIA or minor stroke do not always feel there is any great urgency in self-referring. After referral, the investigation and treatment trajectory will also be influenced by patient preferences. It appears that patient aversion to surgery is a strong predictor of failure to perform CEA in otherwise appropriate clinical situations, but that there is no association with gender (Horner et al., 2004). Although women are as likely to accept CEA as men, women have been shown to be less confident in their decisions about CEA and to prefer more information to assist with the decision-making process (Kapral et al., 2006). Aversion to surgery is associated with increased age, black race, no previous surgery, locus of control (lower level of chance), less trust of physicians, and less social support (Bosworth et al., 2004). Other work, however, has found no association with race (Oddone et al., 2002). Even if patients do agree to have a clinically 'appropriate' CEA, those who have a stronger aversion to surgery might be expected to experience greater anxiety in the pre- and perioperative period.

My study has also demonstrated some of the difficulties inherent in any attempt to help patients to access information about their treatment options, and to make choices which are congruent with their values and expectations. The impact of even a physically short-lived TIA on the person's quality of life is also potentially devastating. These aspects of care add to the complexity of diagnosis and treatment after TIA and minor stroke. My findings therefore add weight to the need for urgent access to specialist stroke services, for all patients who have experienced TIA or minor stroke. Stroke units have, traditionally, focused their energies and resources on acute care and rehabilitation after major disabling stroke, but the care of patients after less prolonged or disabling events also needs to be developed further.

b) Nursing practice

Shared decision-making is now assumed to be the prevailing and most acceptable style of decision making in UK healthcare. Official endorsement from the Department of Health indicates that it expects the nursing profession, which has advocated an individualized approach to patient care for some years, to be a key player in promoting the SDM approach:

'Patients are no longer the passive recipients of nursing care and expect to be involved in and informed about decisions regarding them and their family' (DoH, 1999).

Yet my study, along with others, suggests that a formalized SDM style of practice has limited applicability. There are two reasons for this. Firstly, there are inherent difficulties in establishing and using an evidence base which is comprehensible and has validity for patients and professionals. Secondly, despite the rhetoric of patient choice, it seems that many patients' and clinicians' preferred decision-making style is to defer decision making to each other.

My study has confirmed that increasing access to information about stroke risk after TIA and minor stroke cannot be assumed to be helpful in enabling people to reach decisions about their care which are congruent with their values and expectations. It may even be that the provision of ever-more detailed information may lead to increased anxiety, uncertainty, and possibly poorer decisions, or to diminished satisfaction with the decisions made.

It is possible, however, to make some suggestions about a number of ways in which the nursing care of patients after TIA or minor stroke could be improved (apart from the procedural changes which have already been discussed). Firstly, TIA and stroke - their aetiology, pathology, symptoms, treatment and prognosis - are poorly understood even by those patients who have recently experienced the condition. Nurses need to assess the patient's level of understanding and to have the skills and opportunity to provide

tailored information and support, both about the TIA itself and about possible treatment options. Secondly, the concept and magnitude of stroke risk after TIA does not appear to be well understood by patients. Nurses can play an important part in helping patients to understand this. The level of detail and the way in which stroke risk is expressed (framing) needs to be individually tailored. In general, absolute risks, expressed as percentages or in equivalent terms such as '20 out of 100 people will have a stroke' are the most appropriate numerical terminology to use. The use of non-numeric terms should be chosen carefully as some terms have emotive connotations ('severe' stenosis and 'high risk' of stroke, for example, are more emotive terms than 'significant' stenosis and 'high likelihood'; even the term 'stroke' itself may also cause distress.) The term 'stroke prevention' should be avoided completely, as it is incompatible with the uncertainties and imprecisions of clinical practice. Whichever terms are used, it is important that we do not attempt to imply that the existence of precise research findings in relation to the effectiveness of therapies in reducing stroke risk, translates into a similar precision in predicting the outcome for one individual.

TIA and minor stroke have the potential to reduce quality of life and to lead to uncertainty about one's health status, despite the swift resolution of physical symptoms. Perhaps the most important role for the nurse is to recognise the potential for this diminution of quality of life, and to work with the patient to reframe the TIA in order to view it as a positive event. It must not be forgotten that many patients suffer a major stroke without ever having experienced or having had the opportunity to pay heed to the warning sign of a TIA. Yet with careful treatment choices (whether as simple as commencing antiplatelet therapy or as complex as CEA), most patients can, in fact, reduce their long-term risk of stroke after a TIA. The nurse's role is to enable them to take such measures, and to appreciate that the TIA has given them the opportunity to access the health advice they need in order to reduce their long-term risk of stroke. The perception that one has had a warning of impending stroke can be reframed positively. In this way, the experience of having a TIA can lead to two desirable outcomes: a reduced risk of stroke, and a perception of enhanced quality of life.

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SEFTON HEALTH AUTHORITY
NORTH SEFTON RESEARCH ETHICS COMMITTEE
Pharmacy Office
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Town Lane, Southport, Merseyside PR8 6PN

Chairman: Dr M Abbott
Administrator: Mrs A Fossard
Vice-Chair: Mrs C Major

Tel: 01704 547471 Extn: 4165
Fax: 01704 502008

23 June 1999

Ms J Gibson
Vascular Nurse Practitioner
Southport DGH

Dear Ms Gibson

RESEARCH PROTOCOL (279) AN EXPLORATORY STUDY OF PATIENTS' PERCEPTIONS OF AND ATTITUDES TO METHODS OF REDUCING THE LIKELIHOOD OF STROKE AFTER TRANSIENT ISCHAEMIC ATTACK

Thank you for your letter of 16 June 1999. Acting under delegated authority from the committee, I am pleased to be able to grant you permission to proceed as per your revised protocol along the lines indicated in your letter.

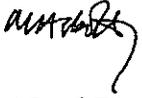
Please note that permission to proceed is granted on the proviso that the following points are noted and adhered to:-

1. No variation or deviation from this protocol is permitted.
2. Should it be necessary to amend the protocol in anyway, the research must be suspended and a revised protocol submitted to the committee for review.
3. Sometimes new information (particularly treatment advances) emerges during the course of a study that affects the ethics of continuing with the research. If your research involves different trial 'arms', you must advise the committee if it becomes apparent that one particular 'arm' is demonstrably more effective.
4. An interim report should be submitted at least once a year and a final report submitted on completion of the study.

You will no doubt realise that whilst North Sefton LREC has given approval for the study on ethical grounds, it is still necessary for you to obtain management approval from the relevant Clinical Director and/or Chief Executive of the Trust (or Health Boards/DHAs) under the auspices of which the work will be done.

Since the reconfiguration of trusts' locally an anomaly has arisen whereby research conducted in one trust may involve patients that come from geographical patches served by more than one ethics committee (particularly West Lancs). If you envisage recruiting patients from outside of North Sefton, the appropriate ethical committee should be informed. We will endeavour to work closely with our neighbouring LRECs to facilitate a co-ordinated response to you. This is the reason for my forwarding a copy of this letter to Mrs Howel.

Yours sincerely



M ABBOTT
Chairman
North Sefton Local Research Ethics Committee

Copy to: Mrs D Howel
Chairman
West Lancs. LREC
ORMSKIRK DGH



Mr E Chew
Executive Director (Medicine)
SOUTHPORT DGH

Dr M Abbott
Chair, Research Ethics Committee
Southport and Formby District General Hospital
Town Lane, Kew
Southport PR8 6PN

5/7/01

Dear Dr Abbott,

Re: Research Protocol (279): An exploratory study of patients' perceptions of and attitudes to methods of reducing the likelihood of stroke after transient ischaemic attack.

I am writing to ask for an extension to the ethical approval granted for the above study. I have been unable to complete data collection in the initial time period granted due to serious illness in my family, and had in fact suspended my PhD registration from May 2000-2001. I estimate that I will need another 6-9 months to complete the data collection. There have been no other changes to the protocol.

I look forward to hearing from you

Yours sincerely

Jo Gibson
Vascular Nurse Specialist

SEFTON HEALTH AUTHORITY
NORTH SEFTON RESEARCH ETHICS COMMITTEE
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Southport & Formby District General Hospital
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17 July 2001

Mrs J Gibson
Vascular Nurse Specialist
SOUTHPORT DGH

Dear Mrs Gibson

**RESEARCH PROTOCOL (279) AN EXPLORATORY STUDY OF PATIENTS'
PERCEPTIONS OF AND ATTITUDES TO METHODS OF REDUCING THE LIKELIHOOD
OF STROKE AFTER TRANSIENT ISCHAEMIC ATTACK**

Further to your letter of 5 July 2001, I am happy to take Chairman's Action and grant an extension to the above study as outlined in your letter. I will report my action to the committee when it next meets on 19 July 2001.

I would ask you to note that the conditions of approval are as indicated in our correspondence to you dated 23 June 1999.

Yours sincerely



DR M ABBOTT
Chairman
North Sefton Local Research Ethics Committee

Mr J. Brigg
Executive Director – Surgery
Southport and Ormskirk Hospital NHS Trust

21/7/99

Dear John,

Re: Research Protocol no. 279: An exploratory study of patients' perceptions of and attitudes to methods of reducing the likelihood of stroke after transient ischaemic attack.

I have recently received approval from the North Sefton Local Research Ethics Committee to carry out the above study. I am writing to request permission to recruit subjects from the Vascular Clinic at Southport and Formby District General Hospital. I have discussed the project thoroughly with Mr D.R. Jones and he is happy for me to proceed.

I enclose a copy of the protocol and related documents, and a copy of the approval letter from the Ethics Committee. If you need any further information please let me know.

Yours sincerely

Jo Gibson
Vascular Nurse Practitioner

Surgical
Clinical
Services
Group

Memo

To: Jo Gibson, Vascular Nurse Practitioner
From: John Brigg, Executive Director - Surgery
Date: 26 July, 1999
Subject: **NWLREC RESEARCH PERMISSION**

Many thanks for your letter of 21 July. I am delighted to support your research.



JOHN BRIGG

Southport & Ormskirk Hospital

Miss B. Strong
General Manager - Surgery
Southport and Ormskirk Hospital NHS Trust



NHS Trust

SOUTHPORT
& FORMBY
DISTRICT
GENERAL
HOSPITAL

TOWN LANE
SOUTHPORT
MERSEYSIDE
P R B 6 P N

TEL: 01704 547471

12/7/99

Dear Barbara,

Re: Research Protocol no. 279

I am writing to let you know that I have now obtained ethical approval for this study and will be starting recruitment and data collection in the next few weeks. I have also discussed the project thoroughly with Mr Jones and he is happy for me to proceed.

I have not enclosed a copy of the protocol as no doubt you already have a copy via the Ethics Committee. However if you need any further information please let me know.

Yours sincerely

Jo Gibson
Vascular Nurse Practitioner

INCLUSION AND EXCLUSION CRITERIA

Participant code:

Date:

1. Does the patient have symptomatic carotid territory stenosis? Y/N
2. Has carotid stenosis been identified by duplex scanning? Y/N
3. Is patient willing to give informed consent? Y/N
4. Is patient able to speak and understand English? Y/N
5. Has patient ever had a permanently disabling stroke? Y/N
6. Is patient undergoing treatment for acute stroke (in past 30 days), crescendo TIA's or stroke in evolution? Y/N
7. Is patient currently receiving treatment for mental health problems, other than night-time sedation? Y/N
8. Has patient ever received treatment from a specialist psychiatric unit, as inpatient or outpatient? Y/N
9. Has patient participated in another research study in the past 6 months? Y/N
10. Is admission to hospital planned in the next 48 hours? Y/N

(Answers to questions 1-4 must be Yes and 5-10 must be No for the patient to be eligible to participate in the study.)

PATIENTS' AND CLINICIANS' PERCEPTIONS OF AND ATTITUDES TO
METHODS OF REDUCING THE LIKELIHOOD OF STROKE AFTER TRANSIENT
ISCHAEMIC ATTACK: AN EXPLORATORY STUDY.

PATIENT INFORMATION SHEET VERSION 1: JANUARY 1999

What is the purpose of the study?

To explore how patients, and the health professionals caring for them, balance the pros and cons of treatments for carotid stenosis (narrowing of the carotid arteries).

Why have I been chosen?

You have recently been having investigations for carotid stenosis, in order to decide on the most appropriate treatment for you. You have been invited to take part in the study, along with other patients in a similar situation, in order to find out your views and feelings.

Who is organizing the study?

The study is part of a research degree which I am undertaking at Liverpool University. This part of the research will take about 12 months to complete.

What will happen to me if I take part?

The study involves either one or two interviews lasting about 30-45 minutes. The interviews will be audiotaped and transcribed by me. If you are interested in taking part in the study, I will arrange a convenient date and time for the first interview. It will take place in about two weeks, possibly with a second interview about 6 weeks later. The interviews will take place at your own home. I will, if possible, telephone you the day before to confirm the appointment. After the interviews, I will send you a copy of the transcript if you wish. Brief details about you and your condition will be taken from your hospital casenotes.

Are there any disadvantages in taking part in the study?

No – apart from giving your time for the interviews it will not affect your treatment in any way.

What are the possible risks of taking part?

There are no risks involved in taking part. It is up to you whether you want to take part. Even if you do, you may prefer not to answer specific questions, or to end the interview at any time without giving a reason.

What are the possible benefits of taking part?

There is no intended clinical benefit to you from taking part in this study. We hope that the information we get from this study will help us to treat future patients with carotid stenosis better.

Is my doctor or nurse being paid for including me in this study?

No.

What happens when the study ends?

Your hospital care will continue as normal, both during and after the study.

What if something goes wrong?

If you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are open to you.

Confidentiality- who will know I am taking part in the study?

All information collected about you during the course of the study will be kept strictly confidential. Any information about you which leaves the hospital will be anonymised so that you cannot be recognised from it. This applies both to details from your casenotes and to the content of the interviews.

If you have a query or problem which you mention to me, I may then need to refer you back to another health care professional. I will only do this with your express permission.

GP notification

I will let your GP know that you are taking part in this study. If this is a problem for you, please tell me.

Local Research Ethics Committee approval

The study has been approved by the North Sefton Local Research Ethics Committee.

Research results

A summary of the findings of the study will be sent to you if you request it.

Contact for further information

Jo Gibson, Vascular Nurse Practitioner

Southport and Formby NHS Trust, Town Lane, Kew, SOUTHPORT PR8 6PN

Tel 01704 547471

Thank you very much for your time.

DEMOGRAPHIC AND MEDICAL DETAILS

PARTICIPANT CODE:

DATE:

Date of birth

Sex

Marital status

Occupation

Age completed full-time education

History of cerebrovascular disease

Source of referral GP / Consultant physician / neurologist / other _____

Investigations and findings:

Date	Investigation	Result

Other illnesses:

Ischaemic heart disease Y/N

Hypertension Y/N

Diabetes mellitus Y/N

Current medication:

Planned management:

Centre Number:
Study Number:
Patient Information Number for this trial:

CONSENT FORM

Title of Project:
**PATIENTS' AND CLINICIANS' PERCEPTIONS OF AND ATTITUDES TO
METHODS OF REDUCING THE LIKELIHOOD OF STROKE AFTER
TRANSIENT ISCHAEMIC ATTACK: AN EXPLORATORY STUDY**

Name of Researcher:

Jo Gibson

Please initial box

1. I confirm that I have read and understood the information sheet dated
(version) for the above study.
2. I understand that my participation is voluntary and that I am free to withdraw at any time
without my medical care or legal rights being affected.
3. I am willing to allow access to my medical records but understand that strict confidentiality
will be maintained. The purpose of this is to check that the study is being carried out correctly.
4. I agree that my GP may be informed of my participation in this study.
5. I agree to take part in the above study.

----- Name of Patient	----- Date	----- Signature
----- Name of Person taking consent (if different from researcher)	----- Date	----- Signature
----- Researcher	----- Date	----- Signature

INTERVIEW GUIDE A (PATIENT SAMPLE A)

(Give verbal and written explanation of the study and obtain informed consent.)

"I would like to talk to you today about your feelings about the possible treatments which have been considered with you by the medical staff to reduce your likelihood of having a stroke.

If you don't understand a particular question or prefer not to answer, please let me know.

1) To go back to the beginning - how was the problem first noticed?

RISK

2a) What did the doctor/surgeon tell you about your chances of having a stroke with/without an operation?

2b) What were your feelings about this?

2c) What was the most difficult aspect of this situation for you?

INFORMATION

3a) What information were you given about the situation?

3b) When did you get this information?

3c) Who gave you this information?

3d) Was this information adequate?

3e) How would you have liked the information to have been given?

DECISION-MAKING

4a) How did you and the doctors/surgeons come to a decision about your treatment?

4b) At what point was this decision made?

4c) How did you feel about this decision at the time?

4d) How do you feel about this decision now?

5) Are there any other areas we haven't discussed which concern you?

Interview with participant no.3 (date) - preoperative.

JG What I'd like to talk to you about today is your feelings about the treatments that have been considered with you .. by you with the medical staff as a result of the investigations you've been having recently. If there's anything you don't understand or prefer not to answer then that's fine. So can we just go back to the beginning, tell me how the problem was first noticed, what happened?

03: um... Wednesday the, prior to Friday the 13th I had what I called a little wobble, in my kitchens. I took no notice of it, however on the Friday lunchtime I was in service and unfortunately felt this paralysis on my left hand side, the eye, vision going, and unfortunately left me on the floor. After that my wife was called and I was taken to the hospital (Name) ..um I was attended by a very young, helpful nurse, she observed that I was stammering, or slurring my speech, at which point she said do you normally speak with this impediment and I said no, so immediately they took me through to the ... inner sanctum as I would call it and er.. progressed to take blood from me, put me on these machines, um .. the attention was wonderful. The feelings were horrible, er the feelings I had personally, but I could at least explain what it was and um obviously they took a little bit of time to diagnose but um I had a fair idea of what was happening

JG so what, what was horrible about it?

03: um.. it left me feeling totally weak. Totally, um.. I couldn't concentrate, I felt as though all the strength particularly on my left hand side, the strength of my body had been taken away, and... I just wanted to sit there and not respond basically to anything. People were asking me questions, who's my doctor, and my date of birth, and I wasn't really capable, or not interested in responding positively to enquiries which was a little bit frustrating because I was so, obviously visibly physically, um, attentive

JG yes

03 I just couldn't put it all together

JG you just weren't quite there?

03 I wasn't there, no, and it was frustrating, because what had happened to me in the kitchen was something that I couldn't explain, it was, if somebody said how do you feel, I've got a headache, I've got a sore throat, my ankle hurts, I couldn't describe – I didn't have any chest pains, but all I had was this sharp pain in my eye, and then this draining of power on the left hand side

JG that was the previous

03 that was on the Wednesday, it was more intense on the Friday and at that point I literally fell, I crumpled to the floor and I was very nicely, er, put away from the kitchen into the rest area. And it was just um ... It was just a void. It was just a feeling of nothing, I was floating, I was, I didn't want to know anything. But obviously the mind was still conscious of my environment and um people were humming around

me. basically my inner thoughts, my inner feelings were .. I can't do anything, I just want to sit there, um, which was definitely the annoying part about it. But then when, when the doctors and nurses were coming round me and .. is it ECG, the .. ECG.. I was still not compos, to the fact that I wasn't answering, my wife was answering all the questions .. um, obviously the concern factor, um but generally yeah, the response from the medical team I felt was quite good, but I couldn't reciprocate it because I didn't have this, I had no feelings to respond with.. it was just negative... that's all I can say, it was negative.

JG yeah... so what happened after that?

03 um they were sort of, there was an interim period where I was again, blood was taken from me and, er, then the consultant I think came to see me it was? Or a young lady . Yes it was a young lady it wasn't the consultant at this stage, it was his assistant. and she went through the documentation and she said I think we, we need to have you, er, brought in onto a ward. At which point I was a little bit anxious about this, not feeling terribly ill but not feeling as though I wanted to be in hospital

JG right so a bit of

03 there was friction there and, I wasn't protesting, I wasn't screaming and shouting, but I was saying could we possibly do it any other way

JG 'do I really have to'

03 that's right ... bearing in mind that, um, even with the limited amount of knowledge that I had of hospital workings that being Friday afternoon I was, in my little bit of brain that was compos again, I was saying well, what are they going to do, examine me over the weekend or ... so, unfortunately for me um this young lady referred back to the consultant and he said that because you didn't have any blood tests back and because of what had typically happened with me they just described it then as a TIA, which was a mini-stroke in layman's terms er.. but they would like to have me in for observation over the weekend, and possibly do some tests and... so I was taken to a ward um.. given a gown and the bits, obviously... very kind people .. I was even offered something to eat which was a very nice gesture um.. I think something was plated for me .. I don't remember eating it .. but I still had this stress situation, where I felt that I didn't want to be in hospital .. at that particular time .. it was fear, a little bit of ignorance, I just felt as if I couldn't cope with being away from that situation

JG what was that fear about?

03: well.. of just being hospitalised .. um.. because I didn't know exactly what had happened to me .. um. It's possibly the.. without sounding too basic.. the survival instinct in me was a.. I didn't know what had happened - I knew something had happened to me, physically, I didn't feel correct totally mentally, but inside me somewhere I knew I could.. look after myself, away from hospital support. And I don't know why I came to that conclusion at that time, but these thoughts were spinning in my head, and it was a case of – not self-survival, but a case of well, I feel as though I could just go away, can I come back next week.. you know. Probably

trying to hide the problem or trying to push it away.. I don't, I can't even to this day er.. define my, my emotions, my feelings then, but that's the feelings I had at the time. I just wanted to be away from that situation

JG Partly perhaps that if you weren't there then it wasn't happening

03 well yes that's right, probably a little bit of escapism yes, somewhere along those lines ... with all this uncertainty, well, we were sat in this bed for some time, probably about an hour and a half, or something like that, and then this very nice gentleman came along, and in the meantime my wife had brought me a dressing gown in, I'd got the hospital robe, and then this consultant came round, pulled the curtains round again, examined me and gave me the reflex tests and he said well we've had some blood tests back, we feel as though we can treat you as an outpatient so, the minute he said that I was like, I'm not staying, well I wasn't even in bed and I said right, do you think I can go now, and he said yes, but I just want you to take it very easy, just sit down, and he said we'll treat you as an outpatient so with that I didn't even bother changing clothes or anything, I just put my dressing gown on and said to the ward sister, I'm returning the gown at a later date, and my wife took me in the car, came back home. The Friday evening I probably spent half an hour down here, and then I went straight to my bed and I was useless... for a few days at least

JG so it was a few days before things got back to normal for you

03 I would say back to normal in the fact that yes, I could stand up, but I didn't want to communicate, I didn't want to talk to anybody ... I found it very, um, frustrating if somebody tried to enter the conversation with me like, oh I've heard you were ill, I heard you've been in hospital - I couldn't actually physically sit there and tell them why I'd been into hospital er.. I felt very frustrated

JG was that, your speech

03 the speech was coming back after the, the Friday - the Saturday I spent most of the day in bed and I wasn't speaking at all. On the Sunday I got up for about an hour, maybe even longer, and I was - that was the frustrating thing because, I knew something wasn't quite right um.. so as I say, I didn't want to enter into conversation with people .. and this non-interest, it was very strange, because I'm a very perceptive person, I try to communicate, because I'm in retail anyway, so that's my job, but I just felt like saying to everybody, will you just leave me alone, just let me sit down

JG just wanting to sort of hide away

03 yes yes just leave me alone and .. I didn't want to read a book, have any media attention like the television or the radio or newspapers or anything, I just wanted to sit there and I didn't even want to analyse what's happening to me, or what had happened to me, um even though I was quite aware at the time that I felt this draining away in my arm, and it was a feeling of coming down, here somewhere and I know the feeling was there, and going back on it um.. it was like it wasn't me that was doing that, it was someone else

JG happening to someone else

03 that's right, um, very distant, very distant. And then progressively um I probably took about another two or three days to be more of a human being, than just sitting there not even trying to communicate or think. But the minute I did notice was .. if I wanted to do something, the stupidest thing like go and have a shave, um, in fact er I remember one day we had the decorators here and I said to this chap – I'd come down and my wife had gone to work - I'd come down and I said to him , I said I'll make you some tea later on your break and this was about half past nine, and I got downstairs and the foreman or whoever it was, oh I said you're ready for your tea and it's eleven o' clock, too late for tea and it had taken me nearly two hours to have a shave and shower .. but to me, I was just doing a normal everyday thing

JG so everything was slowed

03 slowed right down yeah. Um..

JG how long was it before you got back to what you would say was normal

03 Totally normal – I'm still not totally normal um you probably notice that although we're sat in a warm environment but you probably notice that I'm starting to sweat – perspire – Ladies perspire, gentlemen sweat -I've been doing an awful lot of this lately .. because I feel, I still feel a bit stressed, a bit tingly..

JG A bit edgy

03 yes that's the word and um

JG but physically..

03 physically it's, I'm getting stronger, I went and did some gardening um I can go for a walk, walk that little dog you met before um – not too far, try and measure myself to about a mile, mile and a half, but the first two weeks if I'd, I did try one morning I went from the front driveway to the local paper shop which is about a 2 - 2 ½ minute walk and I couldn't make it I had to sit on the wall. I wasn't out of breath but I was out of energy

JG right, yes

03 but from that point I've become much stronger, um, my appetite's come back, um fortunately I've put a bit more weight on because I was a little bit skinny at the time but that was purely due to pressure of work, I was under a lot of stress um but as I say I'm still not 100%, I wouldn't look forward to going back into my kitchens, at this particular time um... I've cooked 2 meals in the 10 weeks I've been off, I've cooked 2 meals for the family, and that consists of 4 people um.. In my kitchens we're doing 150 covers a day which is by comparison a lot so it doesn't , I couldn't do that – if I was put in that situation now I know I'd walk out, I'd have to walk out. I couldn't do it. So that's my level of normality, I'm OK in this environment but I'm now just looking – not forward to this operation but I'm just looking forward to having this done and hopefully after a small amount of recuperation going back to being a normal person

JG right

03 but not the person I was before because it has now taught me something

JG what has it taught you?

03 to slow down

JG right

03 because I think catering particularly at the sharp end where I am is – if it's done properly that is, which I think I've been doing for 20 odd years now, um if it's done properly it is very stressful, but.. I think I've learnt my lesson. I have learnt my lesson because I know I will not go back to the kind of situation. I'd go back to a situation because I can't say I'd retire at this particular point. I don't want to think I'd like to be able to retire um but I will certainly take things a lot easier and, er, look after me as opposed to looking after a lot of other people, namely my company, my employees and things like that

JG put yourself first for once

03 well yes, yeah. When you – when you have a family and you do all the things for them and give them an education which is very important, which I've done for three, for the three girls now so um – they're all away from the house, there's only (wife) and myself here and um - yes, I'll start looking after me for a change

JG so it sounds like you've had to, after you had that episode, um - what happened then

03 well this now goes on to become a little bit protracted, simply because I was under the er the wing of (physician) who I'd not actually seen simply because I was in the hospital situation, er, for less than 24 hours and then out of the situation. And um it was approximately 5 weeks ...now I think these dates will have to be verified by my wife, she keeps the diary um... where I actually said I think I'd better go and see somebody so I went to my local doctor and I explained what had happened, and he said well unfortunately we've not had any notes from anybody. So he got in touch with the hospital and um.. it became... not urgent but it became a little, that I'd not had any, anybody to see me, at that point. So then my practice nurse got professionally involved with us by discussing with (GP), who should we see, what should be done, and it was getting a little bit as I say, unacceptable, er, that I'd been kept this long. So um we then had an appointment to have an X ray which was the first one, which was the ... can I describe it to you and then

JG was that the echo

03 the echocardiogram, that's the one, yeah, that was done and then, there was no appointment made with (physician) at that point. Again (GP) got in touch with me and he said I think we need to speed this up a little bit, then the very next thing is we had, um, an appointment from the hospital for a carotid X ray is that right

JG yes

03 of which again we had no response from (Physician) there was just nothing there . But then (GP) then said to me would you like to see a (Surgeon) and I said indeed I would so what we did I, we planned and I made an appointment to go to (private hospital) so we had a private consultation

JG so the GP sort of speeded things up

03 the GP, that's right, got the wheels going – they were churning but they weren't moving as quickly as I think everybody thought they should, on my behalf, bearing in mind it's a 50 year old man, self employed, needs to do things in life and all the rest of it. So we went to see (surgeon) and the very next day I got an appointment from the hospital - oh sorry, no, (GP) asked had I had an MRI scan and I said no, so he said well just ring the hospital to see if there is one booked for you. So I rang the X ray department and they said sorry, no, you wouldn't have one until you'd had a referral from your consultant and I said well that's (physician) and she said well just let me look so she looked and she found my card in the file ready for.. and she said well we will be in touch with you within the next 6 weeks so I said right. And she said that's very strange. And I made the comment of saying well why is that strange and she said well normally you get a referral for these, she said I don't know how you got – but I think because we'd had this consultation, (Physician) had come in through communications with my doctor here and (surgeon). However, next thing we had this X ray. And I was not a happy puppy having that done. It was not a very nice one

JG which one

03 the er MRI ... claustrophobic, however, I didn't realise, that's the first time ever that I've felt that kind of fear and the nurse had to pull me out of the machine and explain to me and I said well it must be terrible to be having that fear all the time, because its panicky, it's frightening – anyway, we resolved the problem. From that point, then we finally got an appointment with (surgeon) at (hospital) coming through on the national health system now

JG was that after the

03 that was after the scan, the last scan was, I came out of the room, the young lady asked me oh, are you seeing (surgeon) here or are you seeing him at (private hospital)

JG can I just take you back to when you saw him at (private hospital) um.. what happened then, what did he say and what did you say

03 well right very simply he had the report from the two scans indicating that the carotid was um 80% blocked

JG right

03 of which I knew because (GP) had told me prior to us making this appointment. So he said we'll wait for this last scan just to confirm that, because if that is the case the

cut off point is 70% or 75%. Below that point we need to have.. an operation, he said but we'll wait for this, this X ray to go and then we'll confirm that with you. So we spent 10-15 minutes with him at my cost, I didn't mind that , I just wanted things to be rolling, and he said that he would make an appointment through his secretary to see me again at (NHS hospital) after the X ray so we left it at that. The following week there was an X ray appointment made and er we duly went to have this thing, and then the following week an appointment was made with (surgeon) but unfortunately on the day of the appointment his secretary phoned saying (surgeon) has had to go to surgery to do an emergency operation, he had to cancel it.. um, we then had to wait another 3 weeks for an appointment and then my wife got onto the hospital. Fortunately I think she must have got the right person at the right time, we finally got, we got an appointment made for the 13th October and we actually, the following day, we got an appointment made for the 3rd which was 2 weeks.. no that doesn't make sense.. I'll have to confirm these dates with my wife

JG you got it brought forward in other words

03 yes by a week, 10 days because by this time it was going into the 9th week

JG and what happened then when you eventually saw him again?

03 (surgeon) we spoke to him, and er he explained the intricacies, the percentages of having the operation, the risk percentages, and the non-risk percentages of not having the operation

JG and what did he say about that?

03 right, basically, you are in a position where the risk factor would be 5% of having another stroke under my hands.

JG uh huh

03 You are having a 20% risk of having another stroke without the operation. He said in the time he's been in charge or been in Merseyside, he has never had one person um had any, anything done unduly wrong to him in the theatre. He's had some colleagues unfortunately he's had known have had some problems, but um he said we do tend to take it a bit carefully, it's a delicate operation, um, so he reassured me that way

JG so what did you feel about – what were your thoughts about ..

03 Hesitant. Yes, hesitant, because, yes, because having had the percentages, because obviously not being um academically in full trim with the procedures in surgery, but to give you some percentages, um, as laymen you can relate to the risk levels. And I felt the risk of having the operation far, was – outweighed the risk of having another attack within the next 12 months. And my doctor indicated to me some time ago that um normally you can have three strokes, the first two you have, the third one you don't remember. So... yes that was hesitance, er, when I - he didn't go into real detail about the operation at (private hospital) but then when we saw him at (NHS hospital) he did explain how long the operation would be um and what kind of scar

you would have, any numbness I, any feelings I would lose, and the exact procedures about keeping the artery open while they dislodged all this um ...stuff.

JG so you had these two figures in your head, the 5% and the 20%, um.. what was it that made you hesitate about those?

03 The risk of actually being put up to an operation table and either coming out being unable to speak, talk, move, whatever, 'cos you hear of strokes, and people actually, since I've had this occurrence, we've had Stroke Week which was a few weeks ago, and I'm always reading things in the papers about strokes, I don't know whether it's become the fashionable thing to have these days, there seems to be more

JG as soon as you have a condition, you

03 you seem to be more aware of it, that's right, um, and you hear these horrendous stories about people having strokes and they can't talk, can't walk, um so obviously that was a factor. It's all imaginary but it looms into your imagination

JG so that 5% risk, um

03 it blows, it magnifies

JG it magnifies

03 it magnifies up to something really horrendous

JG what about the 20% risk

03 um... putting the fact that, in the long term, bearing in mind that I probably initially thought oh this isn't happening to me, but after that period of – it did happen to me, and how long it's taken me to recover from what I would call a warning stroke, a minor stroke, I would consider that 20% .. not a risk worth taking .. for the time factor.. if my doctor said to me yes, you might have another stroke in 20 years time, yes, I might possibly have said well what the hell, you know, I could be hit by a bus

JG so it's the fact that it's within the next year

03 within a year, brought it down, 12 months is a relatively short period of time, um.. and being young enough to appreciate another 12 months .. of life, yeah, the 5%

(END OF SIDE 1)

JG the 5% starts to

03 the risk that 5 % represents starts to reduce considerably, when you consider you've got such a man as (surgeon) with such an incredible reputation for being the man that knows exactly what he's doing

JG so his reputation

03 his reputation obviously, if you're going to go under the knife, you're going to be treated by anybody, you try and get some homework done on them, of which I have done, and he comes out a shining light

JG who recommended him?

03 well, you bounce these things off different people, academics, you talk about these things socially and you always hear about somebody that's had something done, and they always say, oh yes, I had my, something, done by him and he was very good and so you tend to say right, it's like, not in the same calibre as going to have your car fixed or this kind of thing, but yes, I believe you do your homework on somebody and if you get a few plusses that gives you the..

JG they've been recommended by a friend

03 that's right, yes, recommendation is everything

JG so ...you had these figures laid out in front of you, you knew that if you were going to have it done – he's the chap to do it

03 that's right

JG how did you, between you, come to a decision about .. having the operation or not?

03 well, um... we talked about it, we talked about the risk factor, we talked about our lifestyles, um.. as I explained to you earlier um.. when I've been doing such silly things like working so, too hard for so many years.. to have this 5% element of risk put before me, knowing that I can be cured - it's not a 5% risk that is, can be cured/can't be cured ..(surgeon) assures me that once I come out of this I'll be 100%

JG right

03 so again that's – the 5% becomes less and less and less. So this is how we ,um, we qualified it and um yes, I think the decision was made within less than half an hour, it was literally common sense

JG right ... who made the decision, was it up to you or up to him or

03 well no, I think it's obviously down for me, down to me initially, but er, when you're talking to a professional and you're sort of seeking um guidance , encouragement – and advice, (surgeon) came over so well that the decision was, well there was at the end of the day there was no decision, it was yes, we'll do it.

JG so it was clear cut once he'd laid out

03 once we'd gone through the procedures, how long I'd be in theatre, um, I'd be in intensive care for a night, um, everything was laid bare for me, there was nothing sort of hidden, even to the point where he said, er, you will notice for ever and a day now you'll have numbness, a slight amount of numbness, you'll probably notice it when

you shave, which, it relates down to me again, because he could have talked of something else couldn't he, but he said it'll be a numbness you'll feel. So - he wasn't hiding anything from me, he was just giving me exactly how it is, how it's going to be, and again this 5% was reducing down and down and down to the point of - not no return, but a case of yes, we'll have it done

JG you say it was reducing down, what ..

03 the confidence was building in me

JG so the 5% became ... less important

03 that's right, yes, it was reducing down, every time I was talking about (surgeon), his reputation, even to a lady that, she'd had her varicose veins done

JG yes

03 which er isn't associated with me, but he did the job and she was totally, um, emphatically satisfied with his surgery -he'd done that at (other NHS hospital) so even from out of town

JG from far and wide, yes

03 that's right

JG so that 5% as you said earlier, it sort of

03 it blew

JG blew up

03 because I didn't know anything about it

JG initially, and then as you talked to him it

03 that's right

JG came back down

03 because the encouragement, the information was all collated and formulated into a package that I could understand,

JG yes

03 yes, and then this 5% started to diminish to an acceptable fear rate of 5%. If somebody said to you right, I've got, there's a 5% chance I'm going to kill you in the next 10 minutes, that would

JG yeah, yeah.

03 but if the fear's taken away for that 10 minutes and replaced by something else, which is knowledge, that 5% fear

JG so the knowledge of - his reputation, what's going to happen,

03 the whole picture, yes, takes away that worry

JG so how do you feel about that, that risk now?

03 again I'm still apprehensive, I just now want to – just get it over with

JG yes

03 and just hopefully make a full recovery, yes. Um.... Yes, and just um.. pray that it will go OK, I'm not going to be the 1% of 100%, he's not had a success with, yes. But there's no guarantees in life anyway so (pause) it's got to be done, it's got to be done. That's the end of it. And just be thankful that they've found something that they can cure. Because if I'd had an illness where if I'd gone into hospital and then they'd said to me I'm sorry, you might as well go home – well that would be very very sad. But it does happen

JG so the fact that something can be done, even though as you say it's not 100% guaranteed

03 oh no, no. But that's the little carrot at the end of the stick isn't it, – not even a little carrot it's a big carrot, is the chance that you can be cured, you can be correctly done, um, and hopefully come back to a normal life

JG yes... it sounds like that 5% risk was a big big concern for you - were there any other aspects of it that – what was the most worrying thing about that possibility of having another stroke?

03 The possibility of, yeah, right. When you say the possibility of having a stroke in theatre, right, would be for me waking up and thinking what's gone wrong here, yes. The fear of having a more severe stroke, a severe stroke that was going to kill me. I know that sounds stupid because I wouldn't have the fear because I'd be dead. But I'd have the fear, consciously, now because I would be leaving a wife and family, all my bits and pieces. It makes you feel very um.. what's the word,.. it makes you very aware of what is your life, what – the quality of your life

JG it makes you aware of the things that are really important

03 that's right, yeah, yeah. So that 5% was, as I say it became a great big bubble

JG dominating everything

03 that's right, yeah. It was like, um, Windows on Microsoft, it was – I could open this one and this would pop up, or that would pop up, and all these questions had to be asked, and you know, and qualified, you know, what happens if I do have this operation and I came out with having a stroke – what would I do, where would I go,

what do I say – I can't say anything. What if I can't. and all the permutations, all the questions that your inner brain, your inner mind asks yourself before you start talking to other people, yeah. So it was quite a big 5% um..

JG holding a whole range of possibilities – minor, paralysing, possibly fatal

03 that's right yeah, – all sorts of equations, right from being successful through to being dead, you know. And those permutations when you're involving third persons like your wife and family and ... mother in laws, and all the things that are around your life, yeah it does, it makes you question quite a lot

JG a lot of things that you were concerned about – if you could just put your finger on one thing and say there was one thing you were most worried about what would it be

03 Of coming out dead. Yeah.

JG That would be the worst.

03 Yeah. Because if that was the paramount in my head going into theatre I don't know whether I would be able to overcome that fear. That was the initial one

JG but as you say things have come back down to a manageable sort of

03 yeah, again and talk to different people about your life and people who are going to do the surgery for you and people you've been to see – again permutations, I keep using these words but they are , yeah, options, ideas that are going around in your head and then you talk to your other people involved, and then you make a decision

JG and you gather the information from almost anywhere

03 well yeah you give people feedback, you get feedback from people, um... and then you evaluate their ideas, their responses and then you formulate it into making your own decision, making your own mind up

JG so everybody else has their opinion – including the professionals, is that right?

03 well yes because he says his opinion because that's his opinion and he gave it to me

JG so at the end you make the decision

03 well yes, it's up to me, because I can always say no to the operation (pause) because I'm not in a life-threatening situation now. I could be, at any given time, I could have another stroke next week, I could have another stroke tomorrow, nobody knows, but at this time sitting talking to you or prior to this conversation, um, I wasn't in a life threatening position where a doctor or surgeon wouldn't look over and say well do you want me to do this operation Mr (name) , he would do it to save my life, no questions about that

JG so you're not in that emergency type of situation

03 I'm not in that situation . Now I've made the decision, yes, it's taken me probably longer than it's taken me to decide on what I would have considered in priority a lot more detailed, a lot more important in my life. The operation, I wouldn't have considered that being a major issue as part of my life. But when I started to analyse all the aspects of it and all the involvements, all the consequences, it became quite a big part

JG so it was a

03 a decision making factor, it was a big one

JG it was a big big decision

03 a big decision yeah, because it would change my life if it didn't go right, and it would devastate my loved people's lives if it didn't go right. It would upset a lot of people if it didn't go right, so it is, it has become quite a big

JG but on the other hand if you didn't have the operation, then

03 Ah, I'd be stupid, absolutely stupid. And I would be putting not only me, my situation in jeopardy, I'd be putting everybody else's situation in jeopardy

JG because of

03 Because of my decision if I didn't have the operation. Yeah. So it becomes clear cut, the more you think about it, the more you analyse it, the more conversation you have, it becomes more clear cut

JG so it's a difficult thing to say, yes I will have this operation, but it's preferable to saying, no I'm not going to have it, is that right, it's difficult either way

03 oh yes, yeah. It just depends how you go about evaluating the problem, um , I'm sure that some people would say well no, let's risk it, let's risk not having anything medical done

JG but not in your case

03 not in my case, no . Not at all, no. Because I've got far too much to lose. Not just financially, but emotionally, spiritually, um

JG why do you think some people might say no, I'm not going to have it?

03 um... fear factor, um I think a lot of people aren't honest with themselves and they tend to hide behind something they don't know – bullies are the biggest cowards, this fear factor. People might do because of religion, um, some people might not feel the quality of their life warrants messing around

JG so they'd rather

03 forget it – just the conscious effort of making changes in their lives wouldn't suit some people. Some people like to smoke their heads off, some people like to eat all the incorrect things, there's so much to analyse isn't there, um you could talk all day saying why hasn't he accepted this operation, why hasn't he accepted that. People don't accept change easily, especially as you get older. But once you start putting the fear factor into it, some people just turn their eyes shut and

JG they'd rather not think about it

03 they'd rather not think about it, that's right

JG but it sounds as if you have done a lot of thinking about it and a lot of talking

03 I have, I've analysed it every which way, any way,

JG and how do you feel about this decision now, how do you feel about having made that decision

03 now just waiting to get to the gates to start the race. And the race is for me to have (surgeon) to have a very good lucky day and he can do the operation and come out of it and I'll just go and shake him by the hand. And that's how I feel now. I've got no more trepidation, I've got no more fear

JG so having made the decision, that's

03 that's it yes. It's final, it's absolute. There's no turning back. I feel strongly that if you do go down these avenues where people are going to treat you and going to test you, and the hospital have, I know it's taken a long time to get there, but that's political anyway, I know it's political, I won't go into that one, but what, once people have made the effort to do tests on you and give people results and you've seen somebody about it, I feel conscious that yes, I should do something and go ahead with their efforts, because everybody has made the effort

JG they've gone to the trouble to find out what's caused it so

03 that's right yes, so all their opinions and all their ideas have all suggested, yes OK you have a problem with this particular part of your anatomy, we can do it. Then I've done my little bit of analytical review and put the percentages, this 5% against the 20% and reviewed it and analysed it again and again and again and kicked it round and every type of aspect you can think of, and now I'm repeating myself, I'm at the starting gate, waiting to get it done

JG so, I think we've covered everything that I'd like to ask you about, is there anything that else that you'd like to bring up

03 no, no, I don't think so, um, when I said I don't want to get political, I don't want to get political but, I do feel that this hospital, it's a fairly new hospital. No, I won't – can I end the conversation now?

(END OF INTERVIEW)

JG so what I want to talk to you about today really is your feelings about the possible treatments that have been discussed with you about - to reduce your risk of having um a stroke, if there's any questions you don't understand or you'd rather not discuss then that's fine, just let me know, um but can we just go back to the beginning, and how was, how was the problem first noticed?

I1 well, I was watching television, and I always tend to lean, like that, always the weight on this arm, and all of a sudden it just - just went, just to the elbow,

JG right

(husband)

I1 so I said to ~~him~~, 'ooh, I've gone absolutely dead, I said ooh ~~him~~ I'm frightened' he said 'oh it's because you're leaning on the chair', so he was massaging it, and it was only minutes, and the feelings came back again,

reluctant / trivial cause

JG yeah

I1 it was as quick as that, but then again it was on my mind and I thought oh dear I'd better go to the doctors because I'm not one for the doctor's I'm afraid

premium good health

JG so what were your thoughts at that, that moment?

I1 well I did think it could possibly be a slight stroke

JG OK so that was something that immediately

(husband)

I1 you know that um, ... with ~~him~~ having had one

JG yeah

fear of stroke

I1 you know I thought, well you hope it's not, so there you are, I did

JG knowing what had happened to him it made it, made you more aware if it

I1 it did, it did. And then um on the Tuesday I went down to my daughter's at

~~home~~, and well you've met her, 'Mother what's wrong with you?' because I looked down in the dumps, so in the end I told her, so we rang the doctors, she said you must go and see the doctor, well we couldn't get in to see Dr ~~him~~ till a week on Thursday, and she said well you're not waiting that long Mum, so she whizzed me into ~~emergency~~ emergency OK,

waste / seriousness

(from daughter's perspective)

JG right

Would she have gone to Dr without her daughter

I1 and they tested me up and down and what have you, and they said they thought that it was a mild stroke and to see our local GP immediately

waste

JG so this was how many days from when it first happened?

(but why did they pass the buck?!)

fear of the sudden

fear

resolved rapidly - Anxiety still remains

stroke

small reference stroke

ing help - why not?

TIA - impact on mood - 'down in dumps' - anxiety