

# **PATIENT EXPERIENCES OF TRANSIENT ISCHAEMIC ATTACK**

MARGARET HEWETT

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## **Abstract: Patient Experiences of Transient Ischaemic Attack (TIA)**

The expanding field of stroke medicine lacks foundation if it fails to embrace the infrastructure of experiential evidence, instrumental in shaping future services by identification of need. Potential seriousness of fleeting illness, like transient ischaemic attack (TIA) a precursor for stroke with devastating health and social consequences may be underestimated. Lack of awareness leads to under-reporting and not accessing timely medical attention and the latter could obviate serious consequences of long-term disability. Informed choice and opportunity to avert these circumstances by lifestyle changes needs to be available to all to take responsibility for health.

The literature gap of lived experience of illness needs narrowing, particularly transient illnesses like TIA that comes under the umbrella of stroke yet is a discrete illness of very short duration and nonetheless alarming. Health and social care lifetime costs of stroke are immense. Implications for evidence-based clinical practice concern influencing lifestyle changes, a role that physiotherapists could take to help avert disastrous costly outcomes consequent upon modifiable risks. This lead to a research question of: **What is the lived experience of a TIA?**

The intention of this study was to position the research within current UK National Health Service (NHS) policy considering the historical and philosophical background and psychosocial theories of health and illness. A tension exists between increasing public awareness of health matters and improved health against unhealthy behaviours of sedentary lifestyles and poor diets leading to lifestyle diseases with budgetary implications. Multiple behaviour theories affect lifestyle change. One trigger is evidence-based information with sufficient impact to awaken a response to take responsibility for health. Influences are education, knowledge, patient-centred care, partnership, choice, empowerment, consumerism and professional roles and identity. Studies of other transient illnesses were considered.

Aims were to contribute to the stroke-related literature pertaining to secondary stroke prevention by understanding the subjective meaning of TIA; to contribute to evidence-based practice by highlighting the importance of narrative reasoning in clinical practice and to explore the factors impacting upon lifestyle change. An interpretive phenomenological approach employed semi-structured interviews. The purposive sample comprised seven participants with recent experience of TIA and the medical pathway, three females and four males, age ranged from 39 to 86 years, four were employed and three retired. All experienced stroke-like symptoms, as in Face, Arm, Speech, Time [FAST] (UK Stroke Association 2007).

Thematic analysis addressed facts of the data and narrative analysis embraced emotive aspects. Poetic representation allowed participant voices to be heard to maximum effect. Phases of experience were Disruption, Transition and Change. Eleven themes, of participants' words, included emotive aspects like —*Didn't know what was happening*”, facts of the *Medical Journey* to —*Moving on*” and —*What the future holds*”. A weakness of the study was that the sample was limited to clinic attendees.

This study makes contributions to knowledge under patient-centred care and secondary stroke prevention in relation to the experience of transient illness and TIA in particular including the medical pathway, factors impacting upon behavioural change after transient illness, self-management after transient illness and the importance of narrative reasoning in clinical practice. Raising stroke awareness needs to deliver strong preventive messages at an early age alongside other campaigns like reducing obesity. Expert patients could take supportive roles in clinical practice as an extension to support groups. Multidisciplinary one-stop-shops for patients following TIA need consideration. Longitudinal studies to track lifestyle changes need conducting and the physiotherapist's role in lifestyle change needs evaluating. Training programmes should place emphasis upon narrative reasoning, effecting lifestyle change and harnessing patient expertise, as part of patient-centred care.

*Key words:* Lived experience, Transient illness, Lifestyle

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23. UK Stroke Forum Conference 2008 poster
24. UOB Conference 2010 work-in-progress presentation
25. World Confederation for Physical Therapy WCPT Congress 2011 abstract submission

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## **Declaration**

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

## Chapter 1 Introduction

*I was alone.  
Changed into my swimming costume,  
Putting on my cap.  
I turned.  
A strange sensation  
A cold hand under the surface of my skin.  
Like a stroke  
Across the top of my head.*

*Right to left,  
Face,  
Neck,  
Across my shoulder,  
Left arm,  
Left leg.*

*God, I'm having a stroke!*

(Ann, 1, age 70)

## 1.1 Introduction

Transient Ischaemic Attack (TIA) is defined as sudden onset of clinical features suggestive of acute cerebral dysfunction that resolves within twenty-four hours (Royal College of Physicians RCP 2008). Such features could include numbness, weakness or paralysis in limbs or face, slurred speech, blurred vision, confusion and severe headache (Hatano 1976 in the National Institute of Clinical Excellence NICE clinical guideline 68-Stroke 2008). Persistence of clinical features over a more extended period leads to a more serious diagnosis of ‘stroke’ or ‘brain attack’ (NICE 2008). The swift resolution of TIA sometimes known as a ‘mini stroke’, means it is not associated with the prolonged motor or sensory disabilities consequent upon a fully evolved stroke. However, its potential as a portent of more severe disease —“...a taste of what could happen<sup>1</sup>” - underlies the rationale and design of this investigation.

In this chapter the reasons why a qualitative investigation into the subjective experience of TIA was considered timely are explained. Some aspects of personal experience that influenced the decision to embark on the research are outlined. Key policy-related and practice-based factors that provided further impetus for the research are introduced, and these are examined in more detail in Chapter 2. In Chapter 3 the aetiology and pathophysiology of TIA are described in detail and a list of medical terms is found in the Glossary. Subsequent chapters present the essence of the investigation.

## 1.2 Aspects of personal experience

Experiential accounts can reveal a level of knowledge that identifies needs and expectations that in turn, if heard in the relevant arena, can help to shape future services.

### 1.2.1 *Gap in the literature*

The lived experience (Husserl 1982) of TIA, including the subsequent medical journey and impact upon lifestyle, is not documented. Limited experiential accounts of stroke (Ripley 2006) exist in the literature (Doolittle 1991) but not in relation to TIA (Coull et al. 2004), as will be discussed in Chapter 2. Whilst TIA comes under the umbrella of stroke it is

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<sup>1</sup> Participant quotation

discrete on account of the very short duration of symptoms that completely resolve in comparison to the long-lasting effects of stroke; and they are highly heterogeneous clinical syndromes (Rothwell 2004). It is important to try to close this gap in the literature because:

*—In order to understand disruption caused by a stroke, it is necessary to understand the personal and social situation within which the stroke occurred. It is imperative to know what it means to the person”.* (Doolittle 1991)

An aim of this study was to make a contribution to the literature in terms of understanding the subjective meaning of TIA to those experiencing the phenomenon. Setting this in context of experiential accounts of other transient illnesses is discussed on page 48, where reference is made to international studies from the UK, other European countries, Australia, USA and Canada.

### 1.2.2 *Lack of Knowledge of TIA*

The knowledge of stroke amongst the general population is limited. A MORI poll commissioned by the Stroke Association in the UK in 2005 identified that only 40% of people could name three symptoms of a stroke, 50% of people knew what a stroke was and 25% of people did not think any specialised treatment or care could make any difference. It is acknowledged that with recent publicity campaigns about stroke, for example Facial and Arm weakness, Speech difficulties and Time [FAST] (Stroke Association 2007) advertised on bill boards, on public transport and in magazines and detailed in Chapter 3, knowledge may have increased since 2005. There is no evidence regarding peoples' knowledge of TIA but it might be assumed that this is even less than that of stroke since the incidence of stroke per year in the UK is 200 per 100,000 of population (Mant et al. 2004) as opposed to 35 per 100,000 for TIA (Coull et al. 2004). Therefore there is less likelihood of people having direct or indirect experience of TIA than of stroke.

The National Stroke Strategy (Department of Health DOH 2007c) identified problems of limited knowledge, for example:

*—Lack of awareness of stroke is a significant problem. People do not know what a stroke is; what the symptoms are, or that it is a*

*treatable disease that warrants the same response as a heart attack. Nor do they know what their own risk of having a stroke is, how to reduce that risk, or that stroke is largely preventable”.*

(DOH 2007c page 15)

The study herein also set out to find out how much participants knew about TIA and thereby make a contribution to stroke prevention. Service improvement cannot be influenced unless people are knowledgeable, nor are people empowered to take responsibility for their health without being informed (Darzi 2008).

### **1.3 Policy-related factors**

#### **1.3.1 *Patient needs influence future services***

Several health documents, mainly pertaining to services in England, illustrated below, mention the importance of identifying patient needs. The Darzi report (2008 page 42) mentioned the importance of recognising patients' experience and viewpoints as part of the measures to assess quality of care to help attract future finite resources with reference to the DOH document 'The NHS in England: Operating Framework' (2009). Likewise Choosing Health: Making healthy choices easier (DOH 2004b page 2) spoke of the importance of getting in touch with people's real concerns and NICE (2008) claimed that treatment and care should take account of peoples' expressed needs and preferences. Quality marker four in the National Stroke Strategy (DOH 2007c) concerned involvement of individuals in the development of services. The reason for supporting experiential accounts of illness is to promote the importance of patients' voices and of narrative medicine to assist arriving at an integrated clinical judgement (Lapsley and Groves 2004). With this in mind this study sought to explore the unique experiences of people who have suffered a TIA with the desired outcome of contributing to secondary stroke prevention.

Experiences of health, illness and illness behaviour are individual but influenced by multiple sociological factors (Gabe et al. 2004). Those who experience TIA are in the best position to understand and describe their needs and their views may be as important as research evidence on clinical interventions in shaping future services (Kelson et al. 1998). The Commissioning Framework for Health and Wellbeing (DOH 2007a) emphasised the need for peoples' voices to be heard. Once needs are identified and given a voice clinical

guidelines and National Health Service (NHS) policies could be viewed and influenced from an informed position. This in turn may inform clinical practice and ultimately effect change.

### 1.3.2 *TIA as a Further Risk for Stroke*

TIA is a risk in itself for a full stroke with residual symptoms. The risk of a stroke following TIA is high initially at up to 20% increased risk at one month diminishing to 5% at one year (Coull et al. 2004). It is likely that there is lack of awareness, as above, of the potential seriousness and despite complete resolution of symptoms in TIA, the implications are that cerebrovascular disease is present. This is an added reason to try to assess how much people know about these facts and there is a need for greater health literacy (Darzi 2008). Likewise

*—...some deaths could be prevented if people understood their own health status-----we want people to understand clearly what the risks are to their health and what they can do to prevent the onset of irreversible disease”*  
(Darzi 2008 page 35)

### 1.3.3 *Cost of Stroke*

The average cost of healthcare for a person suffering a stroke in the UK is £15,000 over five years (National Audit Office [NAO] 2005). This will include all primary and secondary care (hospital stays, investigations, medication, rehabilitation and ongoing care in the community). If this is multiplied by the numbers of those affected by stroke each year in the UK of 200 per 100,000 population (Mant et al. 2004) it is easy to see the enormity of the expense for the healthcare budget. However, it is estimated that one third of patients affected by stroke will die in the first ten days (UK Stroke Association 2009) and therefore the incidence quoted above will not incur quite the same expense over five years. Stroke costs the NHS and the economy approximately £7 billion each year. This is divided between £2.8 billion in direct costs to the NHS; £2.4 billion in care costs, for example nursing home fees and £1.8 billion in loss of productivity and disability (Mant et al 2004).

One billion pounds more is spent on stroke than heart disease (NAO 2005). One of the major costs is associated with long-term medication as 84% of patients with transient

ischaemic attack and stroke are now prescribed antihypertensive drugs, statins or non-aspirin antiplatelet agents in addition to any pre-existing medication (Rodgers et al. 1997).

Outcomes of stroke services in the UK, despite services being very expensive, are poor when compared internationally, in terms of long lengths of stay and high levels of avoidable disability and mortality (Leal et al. 2006). The National Stroke Strategy (DOH 2007c) suggests that:

*—Investing in services to diagnose TIA and minor stroke and manage subsequent risk of stroke will result in savings to acute care costs, as more strokes will be prevented”*

(DOH 2007c page 26)

An aim of this investigation was to make a contribution to the secondary prevention of stroke.

#### 1.3.4 *Why research this topic now?*

There has been a recent plethora of stroke-related documents published, informed by the latest evidence, designed to improve the care and attention delivered to those who have suffered a stroke or TIA. The particular emphasis has been around raising awareness and implementation of preventive measures. The driver for this has been the raising of the profile of stroke and the availability of improved medical treatments and prevention as said by Alan Johnson, Secretary of State for Health, writing in the National Stroke Strategy (DOH 2007c):

*—Many strokes are preventable, most are treatable, and the harm done by stroke can be greatly reduced if we can act quickly on important warning signs like transient ischaemic attacks”*

(DOH 2007c page 3)

The documents listed in Appendix 1, published between 2002 and 2009, attest to the timeliness of this study. Some are stroke-specific; others have sections dedicated to stroke whilst a third group are related to lifestyle change and health initiatives that are relevant to stroke prevention. Most of these references are cited within the text. A more detailed account may be found in Chapter 2. There is much overlap and repetition within some of the documents, for example the National Stroke Strategy (DOH 2007) precedes the NICE (2008) Clinical Guideline 68: Stroke which in turn is followed by the National Clinical Guideline for Stroke (RCP 2008). However, as the titles suggest the latter two documents

are guidelines that have been informed by the strategy publication and the publishing sources have determined their influence.

So to seek an understanding of TIA in terms of experience of the illness and the pathway through the medical management is also timely because the field of stroke medicine is rapidly expanding the scope of practice. The third edition of the National Clinical Guideline for Stroke (RCP 2008) has brought increased awareness of stroke-related issues and enhancement of services, in both primary and secondary care. In terms of secondary prevention, the lifestyle advice is the same for post TIA or stroke, that is stop smoking, take regular exercise, maintain a healthy diet, achieve satisfactory weight, decrease salt intake and avoid excessive alcohol intake.

The recommendation post TIA is that neurovascular clinics, with rapid access, should be available, where patients can be assessed within seven days of the incident, leading to risk factors being treated and secondary prevention advice given (RCP 2008). Whilst the field of cardiovascular medicine has, for some time, attracted resources and had a high profile, the field of stroke has been lagging behind and only recently had more prominence. Acute cerebrovascular syndromes warrant treatment as aggressive as cardiologists currently employ for the coronary equivalent (Muir 2004).

With the growth in the elderly population, there is an increasing recognition of the need to reduce the incidence of and the costs of treating health problems in older people (Cochrane et al. 1998). Stroke and transient ischaemic attack are largely associated with older age groups and resulting disabilities from stroke can be profound and are often compounded by other medical problems, particularly in the elderly. The health and social care costs of this problem have been outlined above.

## 1.4 Practice Related Factors

### 1.4.1 *Physiotherapy Practice and Lifestyle Change*

Lifestyle change, following TIA, is recommended to minimise risks of stroke, for example increasing physical activity levels (DOH 2008a, RCP 2008). Physiotherapists are considered, by some, to be well qualified to impart lifestyle advice concerning physical activity and exercise. However, this is only part of the advisory role within TIA clinics, where advice will need to include smoking cessation, dietary advice, alcohol limits and weight control. Clinical specialist positions, within TIA clinics, have been largely assigned to the nursing profession where the role is not only advisory but also health screening, liaising closely with medical staff and more recently ordering of urgent CT scans.

Achieving and sustaining behaviour change in relation to personal health is not easy and various models of action, behaviour and motivation can be applied (see Chapter 2, pages 43-50). For example, initially after TIA the protection motivation theory (Rogers 1983) may apply, where the health decision-making is related to the threat of a stroke which results in a short-term reactive change, for example attending a TIA clinic and heeding the lifestyle advice. However, sustaining changed behaviour may be more linked to theories of perceived behavioural control (Ajzen 1988) where decisions are founded upon perceptions of ease or difficulty of performing the behaviour, past experience and self-efficacy. Individuals often find it difficult to translate good intentions into sustained action (DOH 2004b). Choice and control issues may be influenced by the doctor-patient relationship and come into play in individuals' decision-making about their bodies, where embodiment directly concerns lived experience, associated with the rise of early phenomenology (Merleau-Ponty 1962). Physiotherapists can also have a positive influence in this change process in their relationships with their patients, for example:

*—With their specialist knowledge, physiotherapists play a unique role in wider efforts to improve the UK population's health, and give invaluable advice about exercising safely”*

(Chartered Society of Physiotherapy [CSP] 2009, page 3)

Hearing the patient narrative and lived experience creates an opportunity to see into a person's lifeworld and how lifestyle change might be facilitated. In terms of physiotherapy

the facilitatory role is likely to be enhancing self-management skills and promoting physical activity and exercise.

#### 1.4.2 *Contribution to Evidence-Based Practice*

Despite recent significant improvements evidence-based practice in physiotherapy remains limited (Ashburn et al 1993) and Standard 19.1.3 of the Core Standards of Physiotherapy Practice states that *“...new innovations in practice and technological advances---should be based on best available evidence and show a link bringing research/theory into clinical practice”* (The Chartered Society of Physiotherapy 2005). The evidence base will need to continue to expand if physiotherapists are to be able to demonstrate effectiveness and accountability in order to attract resources to maintain their professional standing, particularly in the current economic climate. One of the quality markers in the National Stroke Strategy (DOH 2007c) related to research states that:

*“Provision of evidence-based services and participation in the development of research evidence for practice are key tenets of high quality stroke service provision”*

(DOH 2007c page 57)

A key aim of this study is to make a contribution to evidence-based practice. In formulating the National Clinical Guideline for Stroke (RCP 2008) *“...recommendations drew on evidence from qualitative studies which were often powerful and informative”* (RCP 2008 page 9). These guidelines are frequently updated and, in drawing on new evidence, are increasingly recognising the value of qualitative studies alongside quantitative work.

#### 1.4.3 *Impetus for this Research*

The impetus arose from disturbances in the researcher’s personal life and clinical practice of witnessing and dealing with the devastating effects that a stroke can impose and the need to contribute to prevention. The researcher’s professional background as a neurological physiotherapist, particularly in the field of stroke, over many years laid the foundation for this line of enquiry. This was contributed to by personal experience of caring for a close relative, with multiple strokes preceded by TIA’s, for several years. Questions started to arise around what could be done to help avoid stroke and contribute

towards prevention?‘ It was evident that the literature was lacking in response to these questions. Hence there were multiple reasons driving the research in this direction and the next step was development of a clear research question.

#### 1.4.4 *Development of the Research Question*

Before finally settling on a qualitative study, the initial line of enquiry, as a physiotherapy researcher, had been to try to find out about physical activity levels in those who had experienced a TIA to see if there was any correlation between inactivity and then progressing to a full stroke. This was in line with an identified under-researched area of secondary prevention in the second edition of the National Clinical Guideline for Stroke (RCP 2004). This idea progressed to identification of validated standardised questionnaires to measure attitude to activity as well as activity levels and a small scale pilot study was carried out, following the required ethical approval. Details of these early ideas are found in Chapter 6.

Although the quantitative study was not discounted, it was put to one side. Then thinking and realisation rapidly moved on to the need for the starting point to be to try to understand what a TIA was from the perspective of those who had experienced it and had been through the ensuing medical journey. Formulated ideas finally settled upon the research question **‘What is the lived experience of a transient ischaemic attack?’** Then the best research paradigm, approach and method were chosen.

## Chapter 2 Literature Review

*Out of the blue  
Didn't feel very well  
Off balance, a bit odd  
Very weird, leant on a wall  
Couldn't really talk,  
Speak properly-speech slurred  
Side of my face pretty useless  
Unsure of myself on my feet-a bit wobbly  
Bit of a blow-no driving for a month  
Scary, worried  
A taste of what could happen!*

(Arthur, age 71)

## 2.1 Introduction

Following identification of a disturbance in clinical practice a literature search and review was undertaken. Initial literature searches related to ideas that were being formulated around a quantitative study before arriving at the definitive research question. These included databases of Amed, Cinahl, Medline, Pubmed, Science Direct, Sports Discus and UK Index to Thesis. Key words were:

Aerobic exercise and stroke Exercise, stroke and risk Obesity, fitness and stroke Physical activity and stroke incidence Stroke and diabetes Stroke and exercise Stroke and fitness Stroke and hypertension Stroke and obesity Stroke and secondary prevention Stroke, exercise and secondary prevention Transient ischaemic attack Transient ischaemic attack and exercise Transient ischaemic attack and physical activity Transient ischaemic attack, exercise and risk Transient ischaemic attack and secondary prevention
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Box 1. Key Words for Preliminary Literature Search

Subsequent searches pertaining to the definitive qualitative study were conducted using the key words in Box 2. Searches were also carried into experiences of other sudden onset illnesses to make comparison of methodologies, methods employed and impact of the illness.

Coping after stroke Lived experience of hip fractures Lived experience of myocardial infarction Lived experience of stroke Lived experience of transient ischaemic attack Stroke and coping Stroke and patient experience Stroke and patient journey Transient ischaemic attack Transient ischaemic attack and coping Transient ischaemic attack and emotions Transient ischaemic attack and patient experience Transient ischaemic attack and patient journey Transient ischaemic attack and phenomenological research Transient ischaemic attack and qualitative studies
--

Box 2. Key Words for Definitive Literature Search

One purpose of the literature review was to position the research in relation to current imperatives in UK NHS policy, the historical and philosophical background to those imperatives, and relevant psychosocial theory related to health and illness. The second purpose was to identify research literature related specifically to the experience of TIA and stroke. In the context of these two purposes, the research aims and questions are defined.

## **2.2 Key Imperatives in Current UK Health Care Policy**

Over two decades UK health care policy has evolved from a limited to a broader comprehensive perspective, largely driven by increasing challenges that are reflected in changes within society. These changes and challenges are global within developed health care systems and are broadly summarised as: rising public expectations, demand driven by demographics, the advancing technological age, advances in treatments, the changing nature of disease and changing expectations of the health workplace (Darzi 2008).

### **2.2.1 *Cost-Effectiveness and Value for Money***

As detailed in Chapters 1 and 3 recognising and treating TIA and stroke as medical emergencies is cost effective since stroke costs the annual UK economy £2.8 billion in direct costs and £1.9 billion in indirect costs to the wider community. The latter burden of care cost is associated with severe long-term disability consequent upon a stroke, and TIA presents a high risk for a stroke (NHS Institute for Innovation and Improvement 2006).

### **2.2.2 *Disease Prevention, Health Promotion, Lifestyle and Education***

Since the inception of the NHS in England in 1948, —...*a national institution that has made an immeasurable difference to millions of people's lives across the country*” (Darzi 2008 page 7), ever increasing resources have been spent on the treatment of illness and disease, with improved outcomes, leading to wellness and increased longevity. Developing in parallel with this, people have become more informed about health matters. This has been enhanced by access to internet websites and the NHS Direct helpline. This self help and searching for information has, by chance, coincided with the changing of general practitioner working hours with patients allegedly not having such easy access to their

doctor. The heightened awareness of health-related issues may have raised expectations for perfect health and a ‘cure all’ attitude (Institute for Public Policy Research 2007).

However, whilst becoming ‘*Our Healthier Nation*’ (The Stationery Office 1998), the UK has also become a wealthier nation, which has sometimes resulted in excesses, for example alcohol and fast fatty food consumption, sedentary lifestyles and an epidemic of inactivity (Rippe and Hess 1998). This has led to a mismatch. On the one hand, health has improved, particularly in terms of rapid progress being made on combating the most lethal infectious diseases (Choosing Health, DOH 2004c) through immunisation, the advent of screening programmes and improved medical treatments leading to increased longevity. On the other hand some of this progress has been offset by the result of excesses and inactivity leading to “...*more intractable conditions such as cancer and coronary heart disease*” (DOH 2004c page 1). So the burden of disease and “...*impact of ill-health on the population and the allocation of resources to meet health needs*” (DOH 1996 page 1) will continue to escalate. Resources will never match the rising demand for treatment (Choosing Health, DOH 2004c) particularly with the development of new costly technologies and treatments and increasing public expectations, despite increased investment. For example in 1996/7, the budget for the NHS in England was £33 billion, in 2008/9 it was £96 billion (Darzi 2008).

It is only relatively recently that “...*promoting good health as well as tackling disease*” (Darzi 2008 page 9) has come to the fore and more resources have been focussed in this area, for example in screening programmes. By preventing avoidable illness, funds can be re-directed towards treating conditions that cannot yet be prevented (Our Healthier Nation, DOH 1998). Included in preventable diseases are heart disease, stroke and related illnesses which cost the NHS £ 3.8 billion every year. The emphasis within prevention has been on empowering people to take responsibility for their own health and that “...*health is everybody’s business*” (DOH 2004d page 19). This can only follow on from informed choice from having “...*credible and trustworthy information*” (DOH 2004d page3).

Stroke, for example, affects between 174 and 216 people per 100,000 of population, in the UK, each year and the risk of recurrence within 5 years is between 30% and 43% (Mant et al. 2004). With increasing longevity comes increase in stroke, as stroke is associated with

older age groups. In a population of 100,000, thirty three people aged 35 to 44 will have a first ever stroke each year, whereas in the age group 75 to 84 the figure will be multiplied fifty-fold.

Whilst TIA represents less of a problem, in terms of numbers reported (35 per 100,000 of UK population) and length of time that disabling symptoms last, it can be a precursor to a stroke. The fact that symptoms in TIA are not long-lasting may engender a false sense of security in that patients rapidly return to normal, which may lead to under-reporting and not seeking medical attention. This is an education issue as —*..lack of awareness of stroke is a significant problem*” (DOH 2007c). This is particularly pertinent since stroke is now seen as an equal medical emergency to a heart attack (Muir 2004). The introduction of thrombolysis (clot-busting drugs) that has to be administered, following scanning, within three hours of the onset of symptoms may have been one of the drivers for this change of emphasis as detailed in Chapter 3.

It is argued that substantial savings could be made in terms of —*..burdens of disease*” (DOH 1996) costs by employing a preventive educational strategy (Our Healthier Nation 1998). This could be aimed at changing lifestyles to avoid behavioural modifiable risk-factors and could include patients who have experienced a TIA and who remain at high risk of stroke. Much has been written recently about the need to lead healthier lifestyles in a drive to prevent intractable diseases and reduce the burden of the same (DOH 1996). For example Darzi (2008) spoke of —*..supporting people to stay healthy*” (page19). Several documents are listed in Appendix 1 and some examples are mentioned here. Choosing Health: Making Healthier Choices Easier (DOH 2004c) spoke of informed choice, personalisation and working together. The Wanless report (DOH 2004d), —*Securing Good Health for the Whole Population*,‘ declared that everyone is to be fully engaged in health promotion, protection and care. Likewise —*Self-Care-A Real Choice*‘ (DOH 2005) has a self-management theme.

There have been various campaigns of late designed at increasing public awareness of healthy eating, for example —*Healthy Weight, Healthy Lives*‘ (DOH 2008a), reducing alcohol intake, smoking cessation and increasing physical activity (Darzi 2008).

*“Changes in lifestyle---requires changes in behaviour by the patient in areas such as smoking, exercise, eating and alcohol intake”* is stated in the secondary prevention section of the National Clinical Guideline for Stroke (RCP 2008 page 65).

This is the advice given at stroke and TIA clinics. Lifestyle change following TIA will be advised to reduce vascular risks (Darzi 2008, DOH 2004d and RCP 2008). Support and encouragement to maintain healthy lifestyle choices will be required and to this end it was proposed to support people with NHS health trainers (DOH 2004d). Informed choice precedes change and choice is influenced by *“...quality information and education, provided at the right time and in an accessible format can improve opportunities for choice”* (DOH 2007a page 19).

Allied health professionals such as physiotherapists and dietitians will have had training to be able to deliver advice on exercise and diet. However, it cannot be assumed that doctors will have had this training and therefore they may not be quite so practised or effective in stimulating behaviour change in, for example, exercise and diet. But Rotter et al. (1995) claimed that communication skills associated with improved outcomes such as adherence can be taught, learnt and put into practice by doctors. A study by Greenlund et al. (2007) found that receiving physician recommendations to make changes in activity or diet in order to protect health can provide a stimulus for change and motivation to sustain these changes. This was a large quantitative study across 20 states in the USA, employing a telephone survey asking people what advice they were given regarding diet and exercise and if they adhered to this advice. They were also asked to think back over 30 days and report on how many days they felt their physical and mental health was good and not so good. Potential weaknesses of this study were that people may have reported what they thought the researcher wanted to hear, and that it may be difficult for them to remember with any accuracy how they felt over the previous 30 days.

How adults learn, otherwise known as andragogy (Knowles 1998) is included here in relation to patients increasing their knowledge in order to effect lifestyle changes. Education is regarded as the agent of change and the learner is the person in whom the change occurs. *“Learning is the act or process by which behavioural change, knowledge, skills and attitudes are acquired”* (Boyd Apps et al. 1980 page 100), whereas Kolb’s

(1984) definition is of *—..learning is a process whereby concepts are derived from and continuously modified from experience*” (page 34).

Experiential learning *—..involves transaction between the person and the environment*” (Kolb 1984 page 34) and is the richest source for adults learning (Lindeman 1926) where *—..the student’s experience counts for as much as the teacher’s knowledge*” (Knowles 1998 page 39). In terms of medical consultations this infers shared authority and decision-making and the fusion of ideas from two experts, that is to say that the patient is the expert in his own illness and the doctor is the expert in diagnosing the disease or underlying medical problem.

The process of experiential learning has been described as a four stage cycle involving four learning methods, namely concrete experience, reflective observation abstract conceptualisation and as active experimentation (Kolb 1984 page 40). These relate to different learning styles and means of knowledge acquisition (Figure 1). Within a medical consultation it is unlikely that there will be enough insight into a patient’s lifeworld to assess their individual learning style but an awareness of differing needs will be important in the giving of information. Change in behaviour implies that learning is taking place or has done so as a result of experience.

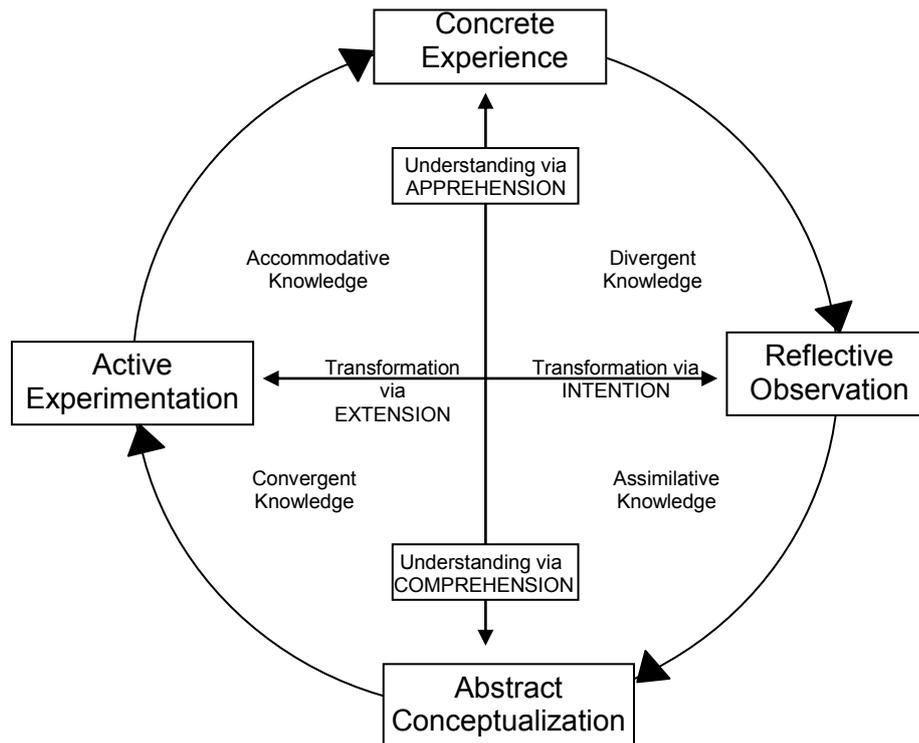


Figure 1. Adapted from Kolb's Learning Cycle (1984)

### 2.2.3 Health Care Delivery-Primary Care vs. Secondary Care

Increasing longevity resulting in large numbers of elderly people in society has increased demands upon both primary and secondary health care in the diagnosis and treatment of intractable diseases associated with older age groups, for example stroke-related illnesses. The average 85 year old is 14 times more likely to be admitted to hospital for medical reasons than the average 15 to 39 year old (The Information Centre 2006). However, increasing numbers of people with long-term conditions are managed at home with input from community teams. Only the most acutely ill are hospitalised with decreasing lengths of hospital stays with pressure upon beds, driven by targets. More resources have been poured into keeping people out of hospital and in their own homes (National Service Framework NSF for Long-Term Conditions DOH 2007b).

Patients as health care consumers are offered more choice about the time and location of interventions in both primary and secondary care. New technologies have brought greater levels of control, personalisation and connection (Darzi 2008). Patients have come to expect faster solutions to health problems and boundaries have been extended, for example in shortening hospital stays with the use of key hole surgery as opposed to more major

procedures that required a long period of hospitalisation. Satellite and polyclinics have been established where minor surgical procedures can be carried out in the community that previously would have meant an inpatient stay.

#### **2.2.4 *Partnership***

The essence of the doctor-patient relationship is the social space that exists between the two where participation of the patient in their health care is encouraged to arrive at joint decision-making. Patients have some control and responsibility for their health, and they should be active rather than passive recipients of health services. This includes power-sharing and negotiation leading to patient empowerment and improved self-management (Gallant et al. 2002). There are shifts in the powerbase when patients are empowered through information, knowledge and consumerism. The knowledge of the patient concerning his/her own illness may match or, at times, exceed that of the practitioner. The Expert Patient Programme (DOH 2002), explained on page 38, is an example of partnership.

The discursive practices both construct and are constructed by the discussion event called partnership and these could be viewed as power strategies but therapeutic relationships are always deemed to be power driven (Silverman and Bloor 1990). The practitioner is seen as the expert and allowing patient participation may just serve to extend the power base rather than being a collaborative venture (Paterson 2001). The patient experience is only seen as relevant if it fits within the frame of the directed discussion, otherwise it is sidelined, marginalised or disregarded (Laine and Davidoff 1996).

#### **2.2.5 *Patient Choice***

There have been several recent white papers written on the subject of leading healthier lifestyles. One of these, 'Choosing Health: Making Healthier Choices Easier' (DOH 2004c) spoke of informed choice, personalisation and working together. The Wanless report (DOH 2004d) 'Securing Good Health for the Whole Population' was a Treasury document on public health which declares that everyone is to be fully engaged in health promotion, protection and care. Likewise, 'SelfCare-A Real Choice' (DOH 2005) had a self-management theme. The advice was designed to increase public awareness of healthy

eating, reducing alcohol intake, smoking cessation and increasing physical activity. For example 'At least five a week' (DOH 2004a) detailed the advice given at stroke and TIA clinics about regular exercise.

There will be individual differences in peoples' needs and preferences (NICE 2008) regarding how much they wish to be involved in decision-making, or how much information they wish to give and take. The term concordance has been used to describe the degree of similarity or agreement between a characteristic or behaviour shared by patients and their physicians. Patients experience positive outcomes from receiving information, participation in treatment decisions and interacting with physicians whose interpersonal behaviours are low in control and high in affiliation. The congruence hypothesis described by Sandler et al. (1983) and Strickland (1978) inferred that patients are likely to respond more favourably to opportunities for medical information and involvement in decision-making that are congruent with their beliefs about personal control. For example a physician intervention that presents detailed information and shares decisional control would be expected to optimise outcomes for patients who have an internal locus of control whereas a more paternalistic physician style might be more facilitative for patients with an external locus of control (Auerbach et al. 1976).

## **2.3 Historical and Philosophical Background**

### ***2.3.1 Evolution of Models of Illness and Disease***

Improvements in healthcare in the prevention of infectious diseases and meeting the challenges of the treatment of more intractable problems of cancer and cardiovascular diseases has led to a shift within models of healthcare. The biomedical model dealt with the treatment of disease and a focus upon the body and not the whole person. This model was associated with medical dominance and paternalism where the power and autonomy of the medical profession predominated (Friedson 1970). The professional status of the doctors (Macdonald 1995) commanded authority and a respected standing in society. Patients were expected to know when to seek medical attention but then to relinquish any medical insight at the time of the face to face appointment. Very often those in most need

did not seek attention and conversely doctors complained of patients bothering them with trivial complaints.

The biopsychosocial model began to embrace more social aspects and widen the scope of healthcare in an attempt to explain causes of disease. This approach started to include opportunities for health promotion and modification of behaviours. Recognition that feeling ill and seeking help was not necessarily related to the severity of the illness was acknowledged (Mead and Bower 2000).

### ***2.3.2 Rise of Consumerism and Professional Accountability***

The rise in consumerism went hand in hand with that of professional accountability. Patients gradually became active consumers of healthcare and no longer passive recipients. They had rights to a standard of service that included full information and explanation, to be treated with dignity and respect and to be actively involved in decision-making. With better information they were able to assume more responsibility for their health (Grol et al. 1990).

Professional accountability within physiotherapy in the UK started to emerge in the 1970's with the appointment of district therapists in 1974 to manage service delivery. This was followed in 1977 with the breaking away of the remedial professions from the dominance of the medical profession. In 1971 the Chartered Society of Physiotherapy (CSP) registered as a trade union to protect the rights of the members. This rise in accountability was further consolidated in the 1980's with the establishment of specific and clinical interest groups, boards and local branches of the CSP, professional affairs, public relations and industrial relations departments at the CSP, the Physiotherapy Journal, introduction of CSP fellowships and the formalising of post registration education. In 1983 Korner reports, a method of collecting data on productivity and information systems, were introduced into physiotherapy. In 1986 the physiotherapy profession merged with the remedial gymnasts and in the early 1990's the profession assumed an all graduate status (Barclay 1994). The brief history of the profession is detailed above by way of illustrating the rise of accountability.

### ***2.3.3 Implications for Patient Empowerment, Individual and Collective Agency***

Patients as healthcare consumers have become more informed leading to empowerment to have a voice and make personal choices that best fit their individual needs. This not only affects individuals but has a wider implication in directing future services that meet collective needs.

The Expert Patient Programme (DOH 2002) is an example of patient empowerment and it was an initiative designed to modify peoples' adaptation to illness and enhance self-management strategies. It consists of a six week programme of two to three hours of weekly meetings lead by lay tutors who have experience of a particular illness. The tutor acts as a positive role model, peer support is provided as well as information on techniques for overcoming anxiety and uncertainty. The importance of self-efficacy is promoted. This particularly relates to this study where the patient experience may be invaluable in supporting others through the process of diagnosis and management. However, sceptics purport that the expert patient programme may not be as successful as first thought, in terms of momentum to sustain this initiative. Alternative ways need to be found that adapt meaningful professional practice to facilitate illness-related problem-solving (Taylor and Bury 2007).

### ***2.3.4 Patient-Centred Care-Key Dimensions***

How patient-centred care has evolved in parallel with changes in healthcare models will be presented first, followed by an exploration of the various attempts that have been made at definition and subsequently a discussion of some of the models available. Illustrations of patient-centred care emanating from the findings of this study linking into one of the models will be found in Chapter 7.

#### ***2.3.4.1 The Evolution of Patient-Centred Care***

The biopsychosocial model of healthcare did not take in the patient's own biography and embrace the unique experience of his/her illness. In order to understand illness and alleviate suffering there needs to be an understanding of the personal meaning of the illness to that patient. How people explain illness and act in response to it determines their attitude to illness and that in turn affects the outcome of their treatment (Balint 1964).

Patient-centred medicine conceives the patient as an experiencing individual rather than the object of a disease entity. Attending to the patient's story of illness involves exploring both the presenting symptoms and the broader life-setting context in which they occur.

Patient-centred care meant a move away from paternalism (Parsons 1951) but initially a competence gap between the expertise of the doctor and the lay patient was highlighted and patients were not regarded as experts in their own illness (Tuckett et al. 1985). Patients were not provided with adequate information and explanation (Korsch et al. 1968). There was no shared decision-making and no reaching of a consensus through negotiation (Stimson and Webb 1975). The move away from paternalism was gradual with patient consultations involving closed questioning and the giving of directions still prevailing. The patient experience was only seen as relevant if it fitted in the frame of the directed discussion (Laine and Davidoff 1996). The patient's voice in their lifeworld continued to be dominated by the voice of medicine. However, therapeutic relationships are always deemed to be power driven (Silverman and Bloor 1990).

#### 2.3.4.2 *Defining Patient-Centred Care*

Patient-centred care remains a nebulous concept that means different things to different people and may be contextual in association but underlying the concept is the notion of improving the patient experience. Fundamental to patient experience is care and this term in itself has multiple interpretations. Words that have been associated with care are respect, dignity, sensitivity, understanding, gentleness, kindness, welcoming, friendliness, comforting, smiling, compassion and communication. Terms that have been linked to patient-centred care are basic care, person-centred care, personalised care, dignity and respect, humanity and customer care. These words and terms have derived from the findings of qualitative studies by Goodrich and Cornwell (2008) where patients, families and staff were interviewed about the meaning of good care and hospital and trust staff were interviewed about terms and concepts associated with patient-centred care in parallel with the literature being reviewed. Eight patients, both male and female, undergoing various procedures, and two daughters (of patients) were interviewed at various acute hospitals in the UK. A broad spectrum of healthcare management staff, professionals and support staff were interviewed or took part in focus groups at one London teaching hospital. Thematic analysis was used to analyse data. The results of these studies were used to inform the

Point of Care Programme, an initiative set up by the Kings Fund to investigate the experience of care in UK hospitals from both patients and staff points of view. The report to launch the programme was a review paper ‘\_Seeing the Person in the Patient’ (Goodrich and Cornwell 2008). Although this study appeared to be an excellent piece of comprehensive work on the surface, there was no transparency about the thematic analysis and how themes were arrived at; and some specific ages of patients were given, others appeared only in an age range and there were no ages given for hospital personnel at all. Since attitudes, particularly in healthcare are influenced by age, this would have been useful information.

‘\_Basic care’ seems to imply minimal care but in terms of a hierarchy of needs model (Maslow 1966) getting the basics right is the foundation for improving the patient experience. This embraces a patient being treated as we would hope our loved ones would be treated, that is with kindness, consideration, empathy and respect and as individuals with their own needs and expectations (Goodrich and Cornwell 2008). ‘\_Personalised care’ has a definite ‘\_ing’ about it from White Papers including High Quality Care for All (Darzi 2008) and appears to be a politically correct contemporary healthcare term. ‘\_Customer care’ has only recently been associated with healthcare as a commodity, being previously thought of as linked to, for example, the retail industry. This shift in emphasis is also about empowering patients to have a voice and make their needs known. These examples are given by way of illustrating the difficulty of explaining patient-centred care. It seems that the more demands that are made upon finite healthcare resources the more terms are introduced that imply quality for individuals that cannot be delivered. Therefore it appears that they may be based upon ‘\_blue sky’ thinking and political propaganda and that they raise unrealistic expectations that, in turn, create further pressures. The latter comments are purely based upon reflection and speculation.

Accumulating pressures upon healthcare include rising provision costs, targets, changes in medical and nursing education and practices, increasing longevity and the inherent comorbidities of old age, European working time directive, technologies, retaining, recruiting and updating staff, increasing consumer expectations and the litigious society and the need to practice defensive medicine. This is the reality that has to be matched against such ideals as ‘\_personalised care’. Of all the terms used synonymous with this individualised care in mind, patient-centred care in the quality improvement literature was found to be the term

of choice and denoted seeing through the eyes of the patients and seeing their needs (Goodrich and Cornwell 2008).

Patient-centred care claims to embrace the whole person, both body and mind, and makes attempts to understand the meaning of an illness to an individual and how that may affect the treatment and outcome (Stewart et al. 2003). Within the shared decision-making the doctor needs to find the best fit solution for an individual patient's lifeworld. This then keys into lifestyle change and health promotion and where a patient is within the cycle of change (Prochaska and Di Clemente 1982).

The emphasis within patient-centred care is on power-sharing and negotiation leading to patient empowerment and improved self-management (Gallant et al. 2002) and Darzi (2008) spoke of giving *“...patients more rights and control over their own health and care”* (page 33). Terms used in recent public health documents are *“...informed choice”*, *“...personalisation”* and *“...working together”* (DOH 2004b page 3) with an inference that people could take more responsibility for themselves. A recent paper on patient-centredness in physiotherapy by Cooper et al. (2008) identified six key dimensions to this concept, namely communication, individualised care, decision-making, information, the physiotherapist and organisation of care, where communication was deemed to be the most important. This echoes findings from the literature pertaining to medical practice.

#### 2.3.4.3 Models of Patient-Centred Care

Various models or frameworks of patient-centred care have been described, the contents of which are essentially similar with slight variation in wording or emphasis. Shaller (2007) reviewed nine frameworks in the United States of America that included those from the Picker/Commonwealth Program for Patient-Centred Care, the Institute for Family-Centred Care and the Planetree Association and found that they all had six properties in common, namely:

- Education and shared knowledge
  - Involvement of family and friends
  - Collaboration and team management
  - Sensitivity to non-medical and spiritual dimensions of care
  - Respect for patient needs and preferences
  - Free flow and accessibility of information
- (Shaller 2007)

The above properties are very similar to those described by the Institute of Medicine (2001) but those contained in the latter are a little more expansive and explicit viz:

- Compassion, empathy and responsiveness to needs, values and expressed preferences
- Co-ordination and integration
- Information, communication and education
- Physical comfort
- Emotional support, relieving fear and anxiety
- Involvement of family and friends

(Institute of Medicine 2001)

The model from the Planetree Association will be alluded to in Chapter 7.

### ***2.3.5 Implications for Professional Role and Identity***

The clinician-patient relationship can have significant impact upon the patient experience and health and illness behaviour. A friendly sympathetic manner may increase compliance with treatment and vice versa (Rogers 1967). Important elements within the relationship are the patient's perception of the relevance of the treatment offered, the consensus over the goals of treatment and the feeling of empathy from the clinician (Bordin 1979).

The biomedical model failed to recognise the importance of the dynamics within the doctor-patient relationship in having any impact upon the diagnosis and treatment (Friedson 1970). Patients value empathy, respect, being given sufficient information and time, being treated as individuals and involved in decision-making and having trust in the doctor (Baker 1990, Hall and Dorman 1988, Wensing et al. 1998, Williams and Calnan 1991). Also, a doctor who takes the trouble to get to know the patient as a fellow human being (Evans 2003) is very much appreciated and this relationship fosters good information exchange and patient involvement in decision-making (Ong et al. 1995). There is increased recognition of the importance of patients' voices and of narrative medicine to assist arriving at an integrated clinical judgement (Lapsley and Groves 2004). As patients become better informed there will be a greater challenge to medical authority (Conrad and Schneider 1980) with the rise in consumerism and there will be encouragement to have increased control and choice (DOH 2010a).

## 2.4 Theoretical Background

A body of psychosocial research, related to health and illness, underpins changes in patients' and practitioners' attitudes and behaviour implicit in the sections above. In order for an individual to make changes in behaviour and sustain them they have to be meaningful, achievable and worthwhile. They may be triggered by an event or set of circumstances, for example a TIA. Some of the models involved in behaviour change will be explored here and illustrated in Figure 2, page 45.

### 2.4.1 *Health Beliefs*

Health may be defined in terms of the ability to engage in everyday tasks and with others in a fruitful and rewarding way that brings satisfaction (Gadamer 1996); whereas health outcomes are a product of individual choice and the constraints under which people make these choices. Terms used recently are —*...informed choice*” (Darzi 2008 page 39), —*...freedom of individual choice*” (DOH 2004c, page 2) and —*...choice gives patients power*” (Darzi 2008 page 38). This subject is very closely linked with quality of life that is associated with social, emotional and physical wellbeing which influences the achievement of personal satisfaction with life circumstances.

Illness may be seen as a normal part of daily life (Blaxter and Paterson 1982). Illness behaviour includes the way in which people perceive, define, evaluate and interpret their symptoms and the actions they take in seeking help (Mechane and Volkart 1960). This may be based upon beliefs in an attempt to reason through contradictory demands of illness and treatment (Robinson 1971). People tend to seek medical help when symptoms disrupt lives and are long-lasting and visible, which does not relate particularly well to fleeting symptoms in TIA. This will be highly influenced by sociological factors. The sick role that people take by seeking and taking medical advice puts the doctor in a position of authority. This is compounded by patients being seen on the doctor's terms and premises which links to paternalism, discussed above. However there should be guidance, co-operation, mutual participation and negotiation in an adult to adult way where the patient's views of their illness are valued and form part of the decision-making (DOH 2010a).

The meaning of being ill will be down to individual perception based on prior experience but could include not feeling as normal, having specific signs or symptoms of illnesses, suffering the consequences of illness or the length of time that the symptoms have persisted (Lau 1995). Perceptions of illness will be influenced by the name given to the problem, the cause, how long it persists, the consequences, the curability and the control that one has over the symptoms (Leventhal et al. 1997). The illness behaviour will be dependent upon interpretation of the problem, coping mechanisms and appraisal of the situation. Coping mechanisms will be based on self-worth, self-esteem, self-belief and self-efficacy and closely linked to learnt behaviours. The self-regulation model claims that an individual is coping with the emotional consequences of an experience (House 1987). Reactions to sudden health threats may give rise to a sense of loss and stages within the grief cycle (Kubler-Ross 2009) may be experienced.

The health belief model was introduced in the 1950's (Becker et al. 1977) to predict health behaviours particularly in response to the low uptake, of and adherence to, healthy lifestyles in disease prevention. It was based upon psychosocial theories and the model claimed that people will not seek preventive health behaviours unless they have minimal levels of health motivation and knowledge, they feel vulnerable and see their health status as threatening, they have faith in the treatment offered and they do not foresee any problems in carrying out the required action (Rosenstock 1990). This may relate to those who have experienced a TIA or other health threat in their contemplation of changing their lifestyles.

#### **2.4.2 *Locus of Control***

The locus of control theory arose from social learning theory (Rotter 1954) where motivation for change is based upon prior reinforcements for behaviours and the importance attributed to them. So the control is determined by the reinforcements for certain behaviours. Internal locus of control relates to a situation where the person can control events by his or her behaviour whereas with external locus of control the behaviour does not entirely determine the outcome as external factors are at play. This is relevant to behaviour change following TIA where motivation may be influenced by prior experience of the power of certain behaviours to generate rewards.

### 2.4.3 *Theories of Reasoned Action and Planned Behaviour*

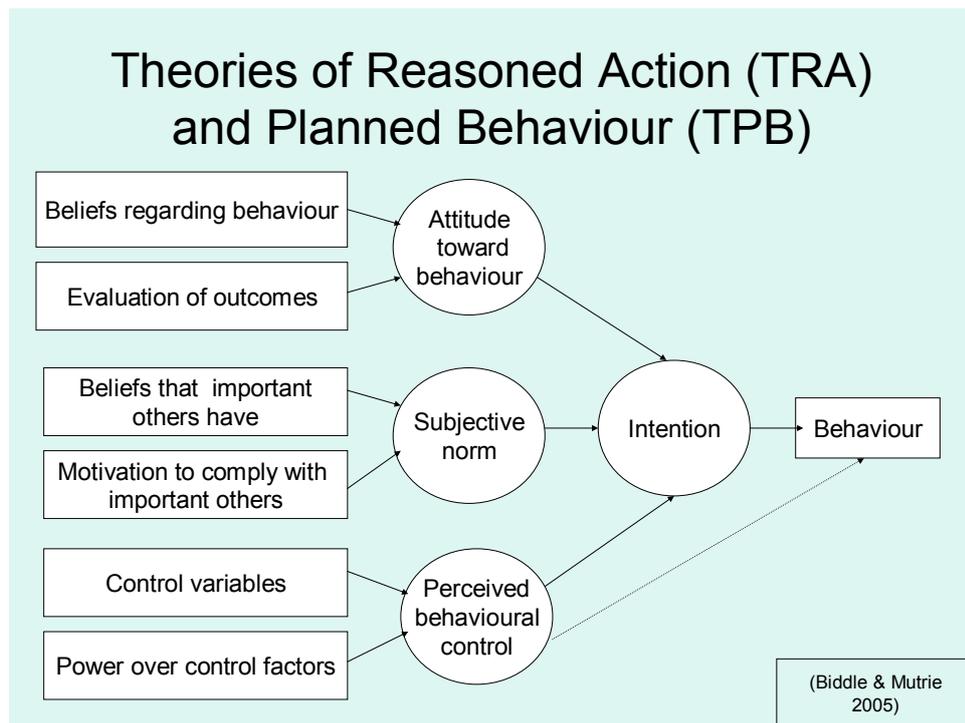


Figure 2. Theories of Reasoned Action and Planned Behaviour

(Adapted from Biddle and Mutrie 2005)

(Original in colour)

Theories of reasoned action (TRA) and planned behaviour (TPB), illustrated in Figure 2, are models that, together with social influences, have been used to predict intention and subsequent behaviour. Beliefs influence attitude which in turn gives rise to intention and resulting behaviour. Subjective norms are more important in, for example teenagers keeping up with peers, but they have a weaker effect upon intention than attitudes in predicting behaviour. Attitudes are more influential in adults. Perceived behavioural control (PBC) is the perceived ease or difficulty of performing the behaviour, partly linked to beliefs built on past experience, and has a strong effect on intention and behaviours (Ajzen 1988). Intentions have been shown to be better predictors than attitudes (Godin 1993, Sallis and Owen 1999).

### 2.4.4 *Protection Motivation Theory*

Protection motivation theory is a model of health decision-making that may explain the choices made when faced with health threats. For example TIA is a threat for a stroke but it is only short-term, so it does not support sustained changes in behaviour (Rogers 1983).

This might relate to a person with TIA attending a clinic and then only temporarily taking action on the lifestyle advice given, for example regarding physical activity.

#### ***2.4.5 Transtheoretical Model***

Motivation theories demonstrate that intrinsic motivation is linked to feelings of self control and self determination which equate with autonomy (Deci and Ryan 1985) and in turn lead to sustained behaviour often associated with fun, enjoyment and satisfaction (Csikazentmihalyi 1975). This linked closely with the lifestyle changes that are connected with prior behaviour (Bentler and Speckart 1981, Triandis 1977), for example engagement in physical activity before TIA. The trans-theoretical model (Prochaska and Di Clemente 1982, West 2005) was based on stages of change leading to behaviour modification and has been applied in addiction, for example smoking. These changes progress from pre-contemplation through to maintenance and termination illustrated in Figure 3.

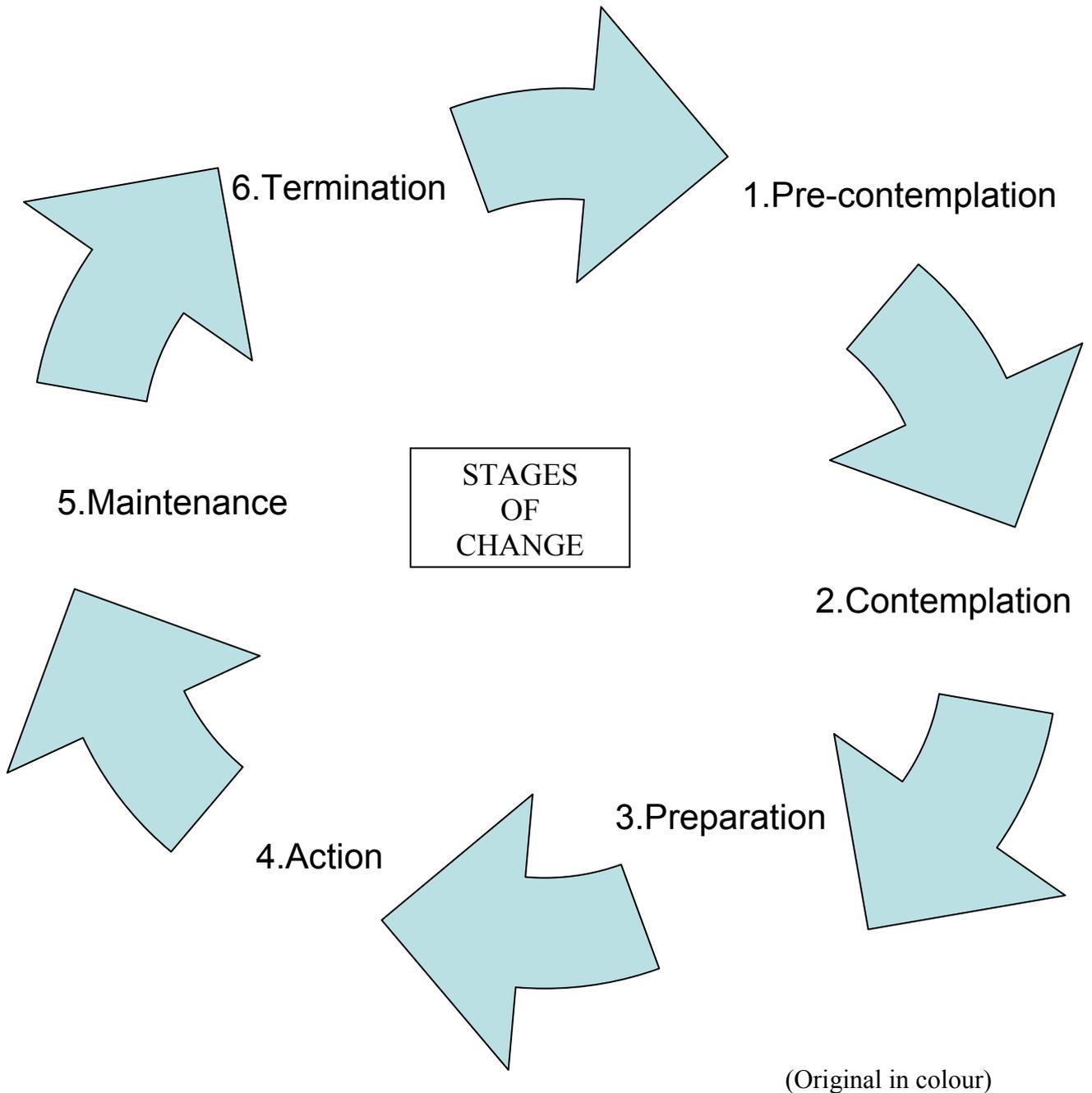


Figure 3. The Cycle of Change. Adapted from Prochaska and Di Clemente (1982)

There are several transitions through the lifespan that might influence change in lifestyle. These are generally biological or psychosocial, for example puberty, adulthood, work, marriage, parenthood, bereavement, occurrence of disease (this might be TIA), widowhood and earlier events might condition those that come later (Malina 1996). As TIA is generally associated with older age groups, it is likely that those affected will have already

experienced many of the life transitions mentioned and so there will be a wealth of life experience skills to draw upon.

There is a dearth of literature detailing the impact of TIA upon lifestyle but one can relate to studies of other sudden onset illnesses, for example myocardial infarction (MI) and hip fractures. The transience and fleeting nature of TIA is unique and cannot be directly compared to any other illnesses, however MI and hip fractures are considered as examples of the similarity of sudden and unexpected onset. Stroke is included because of the association with TIA and subsequently more insidious onset illnesses are included, such as rheumatoid arthritis and chronic pain by way of comparing and contrasting. Theobald (2008) described an acceptance of the need for lifestyle changes as well as crushing uncertainty, overwhelming emotional turmoil, anxiety being heightened by lack of information and the need for support following MI. This was a phenomenological study employing in-depth interviews with a sample of three; it had good transparency with the implications being closely linked to the findings that demonstrated the importance of managing spouses' emotions with support networks. Another study by Kerr and Fothergill-Bourbonnaire (2002) described themes of life being scattered, trying to make sense of it, learning to live with it and getting settled. The latter was a phenomenological study employing open interviews with a sample of seven. The findings revealed the contextual nature of recovery from illness, specific to how older women recovered. The analytical process and interpretation was not easy to follow. Svedland and Danielson (2004) spoke of 'looking to the future' and 'living in a changed situation' as themes. This was a phenomenological study with a sample size of nine, employing interviews at three months and a year after MI. The findings revealed that women and their partners may have specific individual and differing needs following MI. It was unclear about suggestions for further research.

A phenomenological study of experiences of hip fractures was considered, where themes identified included losing confidence in the body, taking one day at a time, and being uncertain about the future (Ziden et al. 2008). This was a phenomenological study with a sample size of eighteen, employing semi-structured interviews of participants one month after discharge from hospital. There appeared limited transparency in analysis and the implications for practice were not clear although findings revealed not just a broken bone but also multidimensional 'cracks' in life. Studies relating to patient experiences of stroke

spoke of the immense psychological impact and how unpredictable the human body is (Hafsteinsdottir and Grypdonck 1997, Kvigne and Kirkevold 2003). The former study was an overview of the research literature on the patient's experience of stroke that not only highlighted the psychological impact but also that patients rated their recovery in terms of return to participation in pre-morbid activities. The latter was a phenomenological study, employing three in-depth interviews with each of twenty five participants at eighteen months to two years after stroke focussing upon women's experiences of stroke. There were no suggestions for further research.

There may be a fear of causing another episode or for example, that exercise may interact with medications (Biddle and Mutrie 2005). This could equally apply to those following TIA. Confidence may need boosting to become, for example, more active and to sustain the behaviours. The TIA may have been a shock to the person experiencing it and to close associates. Initially protective behaviour as suggested by the protection motivation theory, such as taking on the dependent sick role might be apparent. The advice given at the TIA clinic regarding lifestyle changes might influence behaviour. There should not be a long wait for the clinic and then the scan to confirm the diagnosis (DOH 2007) but this might be a time of anxiety and uncertainty not knowing what is wrong and wondering if it will lead to a major stroke. Anxiety may be compounded by knowing someone who had a TIA and then a major stroke. So past experience will shape behaviours as discussed above. One cannot assume that everyone will associate changes in lifestyle with health benefits, for example over vigorous exercise has been shown to be contributory to stroke (Kurl et al. 2003). The advice given by public health documents is not always consistent and new evidence is constantly arising which can be confusing. Older age groups, that could include those at risk of stroke, may have become conditioned to unhealthy lifestyles and therefore will need encouragement to gradually change their behaviour. The latter relates to theories of motivation and sustained behaviours discussed above, including self-efficacy.

#### 2.4.6 *Self-Efficacy*

Self efficacy can be considered as the belief or confidence in one's ability to initiate and maintain the desired behaviour (Bandura 1977). Belief and confidence are related to a self assessment or judgement of potential to carry out a course of action with a desired

outcome. This judgement depends on the confidence one has that the skills one possesses can be applied to the task in question (Bandura 1986).

It might be assumed that any of the models of behaviour discussed above may apply to the person following TIA and it may be that the TRA and TPB will be most applicable in lifestyle change as they are based on intention being the immediate determinant of behaviour. However this was purely speculation at this stage. The protection motivation theory and the health belief model are both related to health decision-making but they only apply to short-term situations and not to sustained behaviours. The TPB includes PBC and in the older population there may be issues outside of control in co-morbidities, for example arthritic knees. People may make health-related decisions from information that is readily available to them, for example identifying family myths about disease or hereditary patterns and tendencies in families (Sanders et al. 2007). The latter related to a small qualitative study employing in-depth interviews. It demonstrated that having an awareness of health risks did not necessarily result in behaviour change and that information needs to be personalised to result in change. People extract what information they think relates to them from public health documents. Acknowledgement was given to the limited scope of the study in terms of numbers but this was compensated for by the amount of information accrued and the sample size reflected other similar qualitative studies of sudden illness events discussed on page 48.

### Chapter 3 Transient Ischaemic Attack (TIA)

*There was no pain.  
No loss of consciousness.  
I was not paralysed,  
Just struck dumb  
Didn't move for a while.*

*I could smile and speak aloud  
Didn't lose my balance or my strength  
Felt just as strong as normal  
The problem was  
I couldn't make my left leg  
Do as I wanted to do*

(Ann 1, age 70)

### 3.1 Introduction

This chapter details the medical aspects of TIA and an explanation of subject-specific terms is found in the glossary. Figure 4 illustrates the arterial circulation of the brain and the main arteries implicated in TIA are the basilar, carotid and vertebral.

### 3.2 Definition and Aetiology

TIA is a clinical syndrome with acute loss of focal cerebral or ocular function lasting less than 24 hours, sometimes called a mini stroke. It is caused by inadequate cerebral or ocular blood supply as a result of low blood flow, thrombosis or embolism associated with diseases of the blood vessels, heart or blood (Hankey and Warlow 1999).

#### 3.2.1 Risk Factors

Physiological risk factors for TIA are the same as for stroke, namely hypertension, hyperlipidaemia, atrial fibrillation and diabetes; and the behavioural risks are obesity, smoking, excessive alcohol consumption and inactive lifestyle. Other non-modifiable risks are age, gender, ethnicity and family history:

*-age* as vascular diseases are associated with older age groups, 50% of patients with TIA are over 70 years of age (Dennis et al. 1998).

*-gender* as women are more susceptible to stroke at certain time points in their lives and more women than men die of stroke; however stroke is more common in men compared with women by the age of 75 (World Health Organisation WHO 2004).

*-ethnicity* as African and Southern Asians have higher rates of stroke related to hypertension and diabetes

*-family history* of TIA or stroke, that is if a close relative was affected before the age of 65.

### 3.3 Epidemiology

The incidence, of TIA in the UK is 35 per 100,000 of population as opposed to 174-216 per 100,000 for stroke (Mant et al. 2004).

### 3.4 Clinical Features

The symptoms define the territory. The carotid artery will be implicated in 80 % of patients and the presentation will be unilateral motor or sensory symptoms, dysphasia or transient monocular blindness; and hemianopia may be present depending on where the optic tract is disrupted.

Image not available due to copyright restrictions

Figure 4. Arterial Circulation of the Brain (Adapted from [www.spectrum-health.org](http://www.spectrum-health.org) Original in colour)

The remaining 20% of patients will have vertebrobasilar territory involvement, and the manifestations will include vertigo, diplopia, hemianopia or bilateral motor or sensory symptoms (Dennis et al. 1998).

### 3.5 Medical Management

*—Any patient who presents with transient neurological symptoms suggestive of a cerebrovascular event should be considered to have had a TIA”*

(Royal College of Physicians [RCP] 2008 page 46)

#### 3.5.1 *Diagnosis*

The initial diagnostic screening may include the FAST tool (Face Arm Speech Time test-UK Stroke Association 2007). Patients should be referred to specialist services (RCP

2008) and for stroke prevention to be most effective, should be seen in the first few hours or days (Coull et al. 2004). Following TIA the recommendation is that rapid access neurovascular clinics should be available where patients can be assessed within seven days of the incident, and treatment of risk factors expedited, and secondary prevention advice given (Rothwell et al. 2007). Diagnosis is made provisionally on the presenting clinical picture, but patients are rarely seen whilst experiencing symptoms as they are so short-lived. Therefore, in the clinic provisional diagnosis is made by careful history-taking. However, with increasing public awareness that stroke is a medical emergency, and may be treated by the use of thrombolysis in specific patients, more people will present at accident and emergency departments and therefore be seen during the TIA.

### **3.5.2 Prognosis**

The longer the symptoms persist, beyond one hour, the greater the likelihood of a stroke evolving. Coull et al. (2004) reported the risk of stroke recurrence as 8% at seven days, 11.5% at one month and 17.3% at three months after TIA. Following TIA there is an increased risk of myocardial infarction (MI) and other vascular events. Other studies (Lees KR et al. 2000) quote 8% risk of stroke at one month, 5% at a year and a 5% risk of MI at a year. The risk at one week is 10% and at a month can be as high as 20% with the greatest risk being in the first 72 hours. There may be under-reporting of TIA (Dennis et al. 1998). Whilst 15% of patients with their first stroke have had a TIA, only 50% of these will have been detected and not many patients are examined during a TIA (Brain 1992). However, 30% of patients suspected with TIA and referred to TIA clinics, have other neurological diseases (Muir 2004).

There is no difference in the survival rates between the two different types (carotid or vertebrobasilar) of TIA, detailed on page 53. The most common cause of death post TIA is cardiac disease (50%) and a third will die of stroke (Whishnant 1993).

### **3.5.3 Investigations**

Patients will see their general practitioner GP or present at hospital Accident and Emergency A&E departments where a neurological examination will be carried out to assess motor, sensory and cognitive function with reference to the ROSIER (recognition of

stroke in the emergency room) screening tool (Nor et al. 2005). Patients presenting at A&E may have investigations, detailed below, initiated immediately.

In order to estimate the possibility that a TIA will be followed by a stroke a risk stratification formula has been established namely ABCD2 (Appendix 2); where A=age, B=blood pressure, C=clinical features, D=duration of symptoms and D2=diabetes (RCP 2008). Each of these factors is allocated a score, the most significant factors with the highest scores being unilateral weakness and duration of symptoms for more than one hour. The likelihood of a further event being rated as high, moderate or low is related to factors above. Having established level of risk patients will follow the TIA Referral Pathway (Appendix 2), high risk patients being assessed and investigated within 24 hours and low risk patients within seven days.

As already mentioned patients will be referred to a TIA clinic where they will undergo a further neurological examination. At the clinic appointment patients will be weighed, have their blood pressure checked and be asked about their lifestyle especially in relation to smoking, alcohol consumption and physical activity levels (RCP 2008).

Patients may be referred for the following investigations:

- Blood tests may include fasting lipids to test for hyperlipidaemia, triglyceride levels, blood sugar levels, abnormalities in blood clotting
- Carotid Doppler studies to assess for any occlusion/stenosis/loss of patency in the carotid artery
- Carotid Artery Angiography to further look at the carotid arteries
- Electrocardiogram ECG to assess for any cardiac arrhythmias
- Echocardiogram to assess for any cardiac conditions, especially any source of embolism
- Computerised Tomography CT scan to exclude other cerebral pathologies, for example stroke, tumour or haemorrhage

As manifestations of TIA may not be visible on the CT scan, the definitive differential diagnosis is made by excluding other causes. In the future, with the refinement of

scanning procedures, it may be possible to detect, with confidence, manifestations of vascular events resulting in a TIA or that these are seen as minor strokes, that is an area of infarction. There will be a follow-up clinic appointment at which patients will be given the results of all investigations and a definitive diagnosis. Medications will be started following the clinic if not already started by the GP or doctor in A&E.

### 3.5.4 *Secondary Prevention*

Secondary prevention, as described below, may be started prior to a definitive diagnosis, if a TIA is suspected.

#### 3.5.4.1 *Medication*

Medication prescribed following TIA will include anti-thrombotic treatments of antiplatelets or anticoagulants. If patients are already receiving antiplatelet medication additional therapy should be commenced (RCP 2008) and:

*—...all patients with suspected TIA or minor stroke who are not already taking regular aspirin should be given 300mg aspirin immediately”* (DOH 2007c)

Risk factors will also be treated. Hypertension may be treated with –angiotensin II receptor blockers, angiotensin converting enzyme inhibitors, beta blockers, diuretics or calcium channel blockers. Some of these classes of medications may benefit secondary prevention over and above their effect in lowering blood pressure. Hyperlipidaemia may be treated with statins or statins may be used as a prophylactic measure in the absence of hyperlipidaemia for the effect upon inflammation. Atrial fibrillation can be treated with cardioversion or medication to return the heart to sinus rhythm. The anticoagulant warfarin will be necessary because clots may form in the fibrillating heart and become dislodged, embolising to the brain as well as other organs.

#### 3.5.4.2 *Surgery*

If the carotid arteries are found to be significantly occluded or stenosed, carotid endarterectomy may be recommended to clear the occlusion in the artery caused by atheroma.

#### 3.5.4.3 *Lifestyle Advice*

The stroke related documents, listed in Appendix 1, for example RCP 2008, have brought increased awareness and improvements in secondary prevention. Lifestyle advice, as already explained, is the same following TIA or stroke namely stop smoking, take regular exercise, adopt a healthy diet, achieve satisfactory weight, decrease salt intake and avoid excess alcohol. This message is the same as that being given to the general population, for example in ‘Choosing Health’ (DOH 2004c). The advice, if not already given by the patient’s GP, will be given or reinforced by the clinic doctor or nurse, both of whom should be specialists in stroke medicine or neurology. TIA specialist nurse posts have recently been created and these have authority to triage patients and request investigations, including CT scans.

### 3.6 **Summary of Chapter**

The diagnosis and management of TIA has moved on and investigating and treating high risk patients with TIA within hours could produce an 80% reduction in the number of people who go on to have a full stroke (Rothwell et al. 2007). The person facilitating the flow through the TIA pathway in a timely fashion will be key to the effectiveness of the management and secondary prevention. Patient-centred care is essential to the service and the treatment and care provided should take account of peoples’ needs and preferences. People with acute stroke or TIA should have the opportunity where possible to make informed choices and decisions about their care and treatment, in partnership with their healthcare professionals (NICE 2008).

As the awareness of the potential seriousness of stroke-like symptoms improves more people will seek the urgent attention required. Improved awareness is an educational issue being tackled by the publications listed in Appendix 1 as well as publicity campaigns, for example FAST (Stroke Association 2007). The need for increased awareness and knowledge linked into the aims of the study and choice of methodology as only by hearing experiences can we find out the extent of peoples’ knowledge.

### 3.7. Aims of the Study

The literature reviewed supports the **aims of the study** outlined in Chapter 1 and relates directly to the purpose in Chapters 2 and 3 and summarised here:

1. To make a contribution to the body of stroke-related literature pertaining to secondary stroke prevention, in terms of understanding the subjective meaning of TIA to those affected by the phenomenon.
2. To make a contribution to evidence-based practice by highlighting the importance of the narrative aspects of clinical reasoning.
3. To explore the factors impacting upon lifestyle change.

## Chapter 4 Methodology

*I stretched,  
Arms towards back of head  
Suddenly, no feeling in right arm!  
Couldn't bring it down  
Strange feeling in arm-no sensation  
Not speaking properly  
Right side of mouth, they noticed  
Something was wrong  
—Are you alright?"*

*Lasted fifteen seconds and that was it  
Came and went so quickly  
Wife quite concerned  
Loss of control right side of body  
Purely speech and arm  
A total surprise!  
Slight worry, a concern  
Another tablet-more inconvenience!*

(James, age 59)

## 4.1 Introduction

This chapter presents the methodological basis of the study. It outlines the philosophical and theoretical perspectives that helped develop the research question and define the research strategy and methods. It also examines researcher positioning in relation to the research. The relationships and interactions with participants are considered, as well as the conceptual lenses through which data were gathered and interpreted. The chapter goes on to explain the research strategy, including rationale for the choice of method, and gives a detailed description of how data were collected and analyzed. The final part describes and justifies the strategies used to enhance transparency and trustworthiness of the data.

### 4.1.1 *Research Purpose and Question*

The purpose of the research was to contribute to the field of stroke prevention by addressing gaps in the literature relating to experiential accounts of TIA. Here experience identifies need which in turn helps to shape future services by embracing consumer views. Specifically it addressed the following research question:

#### **What is the lived experience of a transient ischaemic attack?**

The research did not set out to explore the experience of stroke but purely to uncover the experience and thereby meaning of TIA for those affected as they progressed through the medical pathway from onset, through diagnosis, and resumption of their life. The research question sits most comfortably within the qualitative paradigm.

### 4.1.2 *Research Paradigms*

The positivist paradigm is based on assumption of a single reality independent of any observer's vested interest, which operates according to immutable natural laws, many of which have a cause-effect relationship (Guba and Lincoln 1989). Thus, truth or reality is objective and measurable, observation and experiment can lead to results that, in turn, can be generalized and upon which predictions can be based (Higgs and Titchen 2001). According to this perspective, there are rules that can explain human behaviour. The role of researchers is to be as objective as possible, maintaining distance between themselves

and the data. In terms of this investigation it was evident that such a normative approach would impose a level of external form and structure on the research process that could obscure the lived experience of participants.

In contrast the qualitative research approach recognizes that truth and knowledge are related to meaning and the context in which they are produced. Thus in any given situation there may be multiple realities, truths, or perspectives (Higgs and Titchen 2001). Realities are local and specific in nature; nevertheless they may share elements across cultures and among individuals. *—The researcher observes and records events and relationships through text, dialogue, participant observation, photography and video*”, (Maggs-Rapport 2001, page 375). Four levels of understanding have been described in relation to qualitative research:

Level 1: Ontology – What is reality?

Level 2: Epistemology – What counts as knowledge?

Level 3: Methodology – How can we understand reality?

Level 4: Methods – How can evidence be collected about reality? (Porter 1996)

In the context of transient ischaemic attack and this investigation these levels might be expressed as:

Level 1: What makes up the reality of TIA for these participants?

Level 2: What should be counted or valued as knowledge of TIA?

Level 3: By what means can knowledge of the patient’s perception of reality, following TIA, be accessed?

Level 4: How can evidence be collected about the reality of the TIA experience?

## **4.2 Philosophical Framework**

### ***4.2.1 Ontological Perspective of the Research***

In the philosophical sense, ontology is concerned with the theory of fundamental existence. In other words, what kinds of things can exist in the world, and how they might relate to each other? Social constructionism has its roots in psychology and recognises that reality

and knowledge are socially constructed by and between the persons who experience them through interaction and interpretation (Gergen 1999). Therefore, although increasingly viewed as an epistemological perspective, it can still be viewed as an ontological position in terms of its focus on the nature of existence.

*—Constructionism is an ontological position that asserts social phenomena and their meanings are continually being accomplished by social actors. It implies that social phenomena and categories are not only produced through social interaction, but that they are in a constant state of revision”.*  
(Bryman 2001, page 18)

This notion of continuous construction and reconstruction of reality presupposes a pre-existent social reality that precedes individuals' current reality and acts as a reference point. At the same time current reality is in process of being changed as individuals act upon it through social interaction. From this perspective TIA might be viewed in terms of three dimensions, namely:

- Pre-existent social reality of participants and its impact upon them as social actors
- The active role of participants in social construction in the context of TIA
- The revision of participants' social reality through social interaction processes within the health care system.

#### **4.2.2 Epistemological Perspective of the Research**

*—Interpretivism is a term given to a contrasting epistemology to positivism....The study of the social world therefore requires a different logic of research procedure, one that reflects the distinctiveness of humans as against the natural order”.*  
(Bryman 2001, page 13)

From this perspective emphasis is on the local and situated, rather than the generalisable and "...knowledge should be concerned with these local and specific occurrences, not with the search for context-free general laws," (Polkinghorne 1992, page 149). In other words, the priority is to understand participants' subjective experience and to interpret the social world from their perspective.

### 4.2.3 *Interpretive Phenomenology*

–*Subjectivity is the first starting point of phenomenology*” (Levering 2006, page 455). Therefore this was an appropriate methodological approach for this investigation into the subjectivity of TIA. Phenomenology is identified as an approach within qualitative methodologies that seeks to uncover the real life experiences of individuals in terms of essence and meanings of knowledge by laying bare the intrinsic nature of that experience. The uniqueness of the individual experience is acknowledged and valued in describing a phenomenon. The founders of this theoretical perspective were largely philosophers of German extraction (Hans Georg Gadamer 1900-2002, Martin Heidegger 1889-1976, Edmond Husserl 1859 -1958). Each had his own viewpoint, adding something extra or disputing what had gone before by way of making his contribution identifiable and these points are outlined in Table 1. However, they were united in their recognition that everyday human life experiences were as important as contributions from the natural sciences. The importance lay in finding out the meaning of a given situation to an individual by delving into that person’s reality and seeing the first person subjective experience as paramount (Denzin and Lincoln 1998).

Lived experience could be interpreted in the shape of objectives, values and meaning. Experience needs to be captured in its immediacy, and the starkness is very real to those who live through it (Cresswell 2003). The research process needs to be able to preserve this raw state and be able to identify, understand, describe and maintain the subjective experiences of the respondents (Crotty 2004).

<b>Phenomenologist</b>	<b>Background</b>	<b>Distinctive Features</b>
Hans Georg Gadamer 1900-2002	Philosophy	Interpretation, Shared understandings, Acknowledgement of pre-understandings, Historicity, Hermeneutic circle, Fusion of horizons
Martin Heidegger 1889-1976	Theology	Hermeneutics, Co-created reality
Edmond Husserl 1859-1958	Mathematics	Description, Bracketing, Transcendental Phenomenology

Table 1. Contributions Made to Phenomenology

### Terms explained

-*Bracketing* is setting aside of the researcher's pre-understandings and historicity

-*Transcendental Phenomenology* is related to the uncovering of meaning and essence of a phenomenon to an individual through description by the researcher detaching himself from any preconceived ideas

-*Hermeneutics* is —..the philosophy of understanding and the science of textual interpretation” (Geanellos 1998a page 155)

-*Co-created reality* is that constructed between researcher and participant

-*Historicity* refers to the ability to be aware of our own past and incorporate that awareness into our present and current research process.

-*Hermeneutic circle* is the development of understanding of the parts to the whole and vice versa.

-*Fusion of horizons* is between the text and the interpreter where the horizon relates to cultural and historical awareness.

#### 4.2.3.1 *Implications of Phenomenology to this Study*

Initially the study objective was to hear the lived experiences of the participants lending itself to a Husserlian descriptive approach uncovering essence and meaning. However bracketing is difficult when working as a practitioner researcher in a specialist field. Data analysis implies interpretation, which is inevitable in making sense of transcribed accounts of experience. Both participants' and researcher's preconceived ideas and pre-understandings add to the co-created or co-constructed data as a whole. Therefore this study was informed by a philosophical hermeneutic approach embedded within phenomenology.

#### 4.2.4 *Critical Social Theory*

Critical social theory concerns itself with critiquing and changing society through investigation of how society came to be configured at a specific point in time. Understanding of society should be improved through critical social theory by integrating the major sciences including economics, sociology, history, political science, anthropology and psychology.

The concern is also with critique of domination in emancipatory terms and fusion of social and cultural analysis, as well as explanation for, and interpretation of, social and cultural issues. Critical social theory can be viewed as a form of self-reflective knowledge that involves both understanding and theoretical explanation. This reduces entrapment in systems of domination or dependence and obeys the emancipatory interest in expanding the scope of autonomy and reducing the scope of domination (Calhoun 1995). Jurgen Habermas's (late 1960's) epistemology concerned critical knowledge, enabling human beings to emancipate themselves from forms of domination through self-reflection and took psychoanalysis as the paradigm of critical knowledge (Habermas 1972). This led to an expansion in the scope of critical theory that focused on construction. Critical social theory sits within the philosophy of postmodernism that was heavily influenced by phenomenology of both Heidegger (1889-1976) and Husserl (1859-1958). Within this philosophy there is a celebration of a world of ever-changing relationships, among people and between people and the world. The postmodern world has been described as one where everything is possible and almost nothing is certain (Havel 1994). This recognised changes in society such as fragmentation of authority and commoditization of knowledge.

#### ***4.2.5 Combining Critical Social Theory with Interpretive Phenomenology in the Study***

Leading on from the ontological position of constructionism, critical social theory was included to explore issues of domination in social relationships. Here links are made with fragmentation of medical authority. Medicine has become an institution of social control within Western society although medical dominance and paternalism still exist (Coulter 1999). Historically the way medicine was practised served to promote and maintain the social and political interests of doctors. Illness became a social state constructed through the power of doctors to create labels and meanings for lay experiences. Disease categories reflect objective diagnoses whilst illness is a subjective state capable of manipulation by doctors with power to define illness and determine what counts as being sick. Disease categories are the result of social, political and professional power struggles (Friedson 1988). Constant change has become the status quo within the postmodern world and embedded in this there are claims that the notion of progress is obsolete (Lyotard 1979).

In the context of TIA the interface between doctor as professional and patient as layperson is the pertinent relationship where issues of power and dominance may prevail leading to either empowerment or disempowerment and dependence. Also critical social theory examines possibilities for change and societal changes. Following illness experience, that is TIA, empowerment through knowledge will take place within individuals and may collectively have an influence upon changes within society, for example impacting upon clinical practice.

Interpretive phenomenology is the key to the philosophical perspective of the study. This is underpinned by the ontological position of constructionism in embracing societal and psychological aspects of illness. Focusing on these human behaviours and social change, in the context of TIA, combining interpretative phenomenology with critical social theory has permitted this exploration. The hermeneutic approach seeks to go beyond description to explanation and interpretation; constructionism recognises that all knowledge is socially generated through interaction and interpretation; critical social theory addresses possibilities for change. In summary this study takes the form of an interpretive hermeneutic inquiry informed by critical social theory.

#### 4.3 Researcher's Role and Positioning

*—The relationship between interpreter and interpreted is wholly dependent on historical time, for in order to lay bare our own beliefs, we must first be aware of the historicity of understanding that governs all our prejudices”*

(Maggs-Rapport 2001, page 378)

The researcher came from a background career as a neurological physiotherapist working mainly in the field of stroke rehabilitation over many years. During this time preventive medicine expanded (see Chapter 2) including within the field of stroke. This was initially lead by investigations to identify risk factors, such as diabetes and hypertension, and developments in available medication, for example anti-hypertensives. Lifestyle advice was given less priority, and inconsistently delivered although it may be equally important to medications and the two should go hand in hand to be effective in managing risks. It could be argued that lifestyle advice is more important since if people lead healthy lifestyles and there are *—..better incentives for maintaining good health”* (Darzi 2008 page

37) they are less likely to require expensive medications. However, as already discussed, it may be that competence of the medical profession to deliver effective lifestyle advice may need improvement.

If physiotherapists are in a position to impart lifestyle advice and influence behaviour change pertaining to physical activity and exercise, this could have an effect upon the modifiable risk, for stroke, of lack of exercise, identified in the second edition of The National Clinical Guidelines for Stroke (RCP 2004). In the latter document lack of exercise was identified as an important risk for stroke but the degree of importance was not quantifiable. Obviously lack of exercise has close links with other more measurable risks, for example obesity. To this end the researcher, within her clinical work, established a stroke fitness programme of exercise and relaxation for secondary stroke prevention. This included an educational workshop programme of talks from representatives from other disciplines expert in managing other risk factors, for example a dietitian, a stroke specialist nurse and a lifestyle adviser.

I also had immediate experience as a stroke carer, witnessing both stroke and TIA. Improvements in stroke medicine lead to the setting up of TIA clinics to identify, treat and minimise stroke risks, although lifestyle advice was still limited and inconsistent. As the researcher I was left with the disturbance of ‘\_could more be done at the TIA stage to help prevent a full stroke occurrence through understanding more about the experience of TIA in order to inform practice?’

#### ***4.3.1 Managing the Research Process***

Within the research process there were several roles required of the researcher:

##### *4.3.1.1 Facilitator*

The role of the researcher was to facilitate the flow of interaction within the interview process, from thoughts through language to themes (Silverman 1997). This was achieved through an empathetic cathartic approach, taking a neutral stance with minimal questioning. Participants were put at ease by providing a safe comfortable environment (Maslow 1966) in which experiences could be exposed, explained and real meaning and essence uncovered.

#### 4.3.1.2 *Managing Historicity*

There was recognition of the influence of both the researcher's and participant's background biography impacting upon the whole emergent construction of reality, that is gender, social class, ethnicity, values and beliefs (Sword 1999). But this was seen as a positive contribution in shaping the research and providing a background to the interpretation in line with a hermeneutic inquiry. There was acceptance that at times the participants' stories were far removed from the reality of the researcher. I recognised that my experience of the healthcare system and that of the participants could influence the view and utilisation of the same in the concurrent medical pathway.

#### 4.3.1.3 *Managing Bias, Expertise and Power*

Participants knew that I was a physiotherapist from the patient information sheets (Appendix 8) which for some may have posed difficulty in separating clinical and researcher roles. This meant the researcher being seen as an expert at times and receiving some questioning, bringing about a shift in the focus of the interaction and powerbase. But this was accepted as a two-way sharing of information and understandings, and part of the co-construction process and the researcher giving something back. The importance of minimising power within the research interaction was recognised. Attempts were made to minimise bias in presenting a neutral stance by appearance, demeanour and environment by not wearing hospital uniform and providing comfortable chairs to reduce the clinical appearance of the surroundings.

#### 4.3.1.4 *Theoretical Sensitivity*

The background, literature and my personal experience influenced interpretation of the data (Strauss and Corbin 1990). But this theoretical sensitivity is important for having insight into the subtleties of meaning of the data as commented upon in participant feedback, for example: *“I am very impressed with your insight into my experience”*<sup>2</sup>. The awareness enhanced the possibility of uncovering multiple interpretations from a single data set (Ayres and Poirer 1996), improving the noticing (Mason 2002) and developing of ideas. It also sat comfortably with the notion of the contribution made by pre-understandings within a Gadamerian hermeneutic inquiry.

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<sup>2</sup> Participant quotation

#### 4.3.1.5 *Social Relationships*

It was important to engage the participants' interest, hold their attention and develop a rapport recognising that the development and maintenance of effective relations is central to the social experience and research endeavour. How I presented and introduced myself as the researcher and the topic affected the outcome by gaining entry into the participant's world and reality by successfully engaging her/him in the research process. The more interest shown by myself as the researcher, not solely in the research area but as a person as well, the more the data was enhanced.

#### 4.3.1.6 *Vision of the Future*

My role as researcher was to see the project through to fruition by maintaining the momentum and at all times keeping the aim in mind. It was important to have a vision and for the insider to be looking out and working towards a productive and original outcome at doctoral level that would contribute to practice. I became immersed in the data enabling the participants' voices and views to be heard. It was hoped to leave the participants feeling that something pleasant, interesting and worthwhile had been achieved (Oppenheim 2002). The interface with the supervisors helped with the developing and shaping of ideas and the momentum, through feedback on draft chapters and sharing of ideas and decision-making and suggestions. Their academic expertise, not least from seeing their own doctoral studies through to fruition, helped with keeping 'on track' and having a vision of where the endpoint needed to be and the rigorousness of the same. Reflection and reflexivity were employed throughout as was the respecting of confidentiality, as detailed in Chapter 6.

#### 4.3.1.7 *Acknowledging Emergent Feelings*

Feelings that arose in the interview for both the participant and myself were noted and acknowledged. These were communicated by body language, tone of voice, words and phrases, emphases and pauses. Likewise the same, excluding body language was noted from listening to the audiotapes. There was registering of anger, frustration, sadness, and threat to role at work or home. My first impressions, from reading the transcription, were initially based upon an immediate reaction and these were harnessed in the emergence of themes.

#### 4.3.1.8 *Making Meaning, Understanding and Interpreting*

Hearing about the experience of the TIA allowed meaning to be inferred in terms of what it meant to be ill, have a threat to health and a threat of a stroke. What this meant to individuals was closely linked to historicity. Meaning was identified through lived experience. What this meant for future clinical practice was explored.

As the researcher I was able to understand with theoretical sensitivity due to my own historicity. I was interpreting the data within an analytical framework and identifying commonalities across all transcriptions.

#### **4.4 Researcher's Theoretical Perspective, Epistemology and Ontology**

My theoretical perspective was that of hermeneutic philosophy of interpretivism, where there was sharing of understandings with others. The epistemology was subjective where the researcher and participant are interdependent. Here the constructionist ontology meant that meanings were co-constructed between participant and researcher that gave rise to knowledge through data analysis. There was a possibility of multiple realities being socially co-constructed. This allows for individuals to make sense of their world as they see it and experience it; and that backgrounds of researcher and participant are embraced as part of the whole.

#### **4.5. Ethical Issues**

In April 2006 approval for the study was gained from the Local Research Ethics Committee (Appendix 4). In October 2006 permission was obtained from the consultant stroke physician at the acute trust where the research was to be conducted (Appendix 6), to access patients and their medical records from the TIA clinics, in order to recruit to the study. In March 2007 research governance approval was gained from the Research and Development (R&D) department at the research site (Appendix 5). The title of the study changed during this time to reflect the move from the quantitative study (section 1.4.4 page 26) to the qualitative study. However, the titles on the ethics documentation (Appendices 4 and 5) did not although permission was gained for minor changes to the study and the new title (Appendix 6). Also the Patient Information Sheet (Appendix 8) and Patient Pathway (Appendix 9) include details of both studies. This was partly because the quantitative study

was conducted separately by another researcher. Further details regarding ethical approval are given in section 6.5 on page 147.

Confidentiality and anonymity were maintained throughout the process of interview, transcription, analysis and dissemination of findings. I was aware of the limitation of the clinical consulting room being used for interviews in terms of a neutral environment and therefore made efforts to minimise the clinical appearance. If the subject of physical activity was raised by the participant within the interview, as a physiotherapist, I was careful not to introduce bias or attract answers that the participant thought that I wished to hear. It was important and courteous to keep those who interfaced with the research appreciated and updated. Participants who gave feedback on analyses were thanked and informed of progress of the project. Annual updates were given to the Local Research Ethics Committee and the Research and Development Department at the NHS Trust sponsoring the research endeavour. Two funding sources for the research practicalities were kept informed of progress.

#### **4.6 Research Procedure**

The process from sampling through to data collection and analysis is described here.

##### **4.6.1 *Sampling Method***

Possible participants to recruit to the study were identified by a list of names and addresses of clinic attendees being handed to the researcher by the clinic nurse after each TIA clinic. The stroke or TIA nurse running the clinic had identified which patients were likely to be diagnosed with TIA from what the consultant had said in the clinic, by marking the list. The TIA clinics ran weekly with the stroke physician and monthly with the neurologist. Both clinics were run along the same lines. Patient invitation letters (Appendix 7), patient information sheets (Appendix 8) and consent forms (Appendix 10) were sent out to 52 clinic attendees with a provisional diagnosis of TIA, between March and October 2007. Twenty two (42%) consented to take part in the study. Participants were recruited over a seven month period because numbers were small at each clinic; although there were large numbers of clinic attendees many were not diagnosed with TIA. Also larger numbers of participants were required for the other researcher's surveys and we had the same recruiting documentation (Appendices 8-10). So I continued with recruiting for longer than I needed in the knowledge that if I did not require so many participants they would be

needed for the other study. Some participants would have taken part in both studies as explained in Appendices 8 and 9. Additionally it was not definitely decided at the beginning of the study how many participants would be required; although it can be seen from Appendices 8 and 9 that approval was for up to 15'. Recruiting was conducted in parallel to interviewing.

A purposive sample of seven participants was recruited from two consultant-lead TIA clinics at one acute hospital trust. Sample size relates to other phenomenological studies of experiential accounts of sudden illness onset discussed in Chapter 2, page 48 where depth of data content can be captured in relatively small sample sizes. In other words it is the quality and depth of data that is more important than quantity. For example in the studies of experiential accounts of myocardial infarction cited on page 48 (Kerr and Fothergill-Bourbonnaire 2002, Svedland and Danielson 2004 and Theobald 2008) the sample sizes were seven, nine and three respectively. A critique of these studies is given on page 48. Whilst exact correlations with TIA cannot be made, it was thought that myocardial infarction might be the closest in terms of sudden onset, albeit that the damage to the heart will be permanent (an area of infarction) as opposed to resolved effects upon the brain in TIA.

#### 4.6.1.1 *Background to the Sample*

Since this study was conducted practices in TIA clinics, at the researcher's hospital base, have developed in line with meeting the quality markers of the National Stroke Strategy (DOH 2007). When participants were recruited to this study the timing of medical attention was much slower reflected in some of the findings herein. So, for clarity the version presented is related to the experience of participants in this study but this is followed by the latest practice which is essentially the same but more timely.

Patients attended TIA clinics at the researcher's hospital base on two occasions following referral from their doctor with a suspected TIA. The first attendance was for clinical assessment and provisional diagnosis. Following investigations a subsequent appointment was for confirmation of diagnosis and recommendation of medication. Treatment may have been started after the first visit, that is provisional diagnoses were made from history taking and clinical assessment and later confirmed by investigations to exclude other

causes. Some lifestyle advice about minimising vascular risks was given by the clinic doctor or nurse.

*More Recent Practice (at the researcher's hospital base)*

Referrals for patients suspected with TIA are faxed to the TIA specialist nurse at the hospital by GP's, from A&E or the Medical Assessment Unit. The TIA specialist nurse will screen referred patients, using the ABCD2 scoring (Appendix 2), and send high risk patients for CT scans, carotid doppler studies and blood tests on the same day. After this patients will be seen by the clinic doctor and medication will be started as appropriate.

The TIA nurse is instrumental in identifying behavioural risks, for example obesity, smoking, excessive alcohol consumption and lack of exercise and will keep a record of these factors. She will advise patients about modifying their lifestyle and give patients information from the Stroke Association about TIA, driving after a stroke and avoiding a stroke. Sometimes she would follow patients up or refer them on to other agencies, for example smoking cessation clinics, lifestyle advisors or dietitians. Results of investigations, diagnosis, identification of risk factors and treatment recommendations are sent to a patient's GP. At subsequent GP appointments patients can have this information reiterated and regular medication regimes and monitoring of risks established and reviewed. Patients attend a follow-up hospital clinic at four to six weeks. However some patients with significant carotid artery stenosis may be referred for carotid endarterectomy as part of stroke prevention (page 56) and others may be sent for further investigations, for example MRI scans.

*4.6.1.2 Inclusion and Exclusion Criteria*

Participants had a diagnosis of TIA within the timeframe of a year from the clinics mentioned above. No evidence of stroke either before or after TIA was the only exclusion criterion.

*4.6.2 Data Collection Method: Interview*

The method utilised for data generation was a semi-structured interview approach with minimal questioning detailed in an interview guide (Appendix 11) to allow participants to

explore their experiences as they perceived them in their life world. This was to uncover the real essence and meaning of the experience to individuals where the phenomenon was the TIA (Kvale 1996). The interview guide (Appendix 11) was drawn up early on in the research process and was subsequently part of the paperwork approved by the Local Research Ethics Committee in April 2006, however, by the time interviews were commenced in March 2007 thinking had moved on. The questions contained in the interview guide, particularly the follow-up questions, were not only too numerous but also directional and somewhat closed. Therefore the follow-up questions were generally not used. Further detail is given below in section 4.6.2.1. Data were generated through the co-constructed process of the one-to-one interview that through analysis gave rise to new knowledge.

#### 4.6.2.1 *Interview Strategy*

The information sent out to recruit participants and the interview guide with prompts (Appendix 11 after Moustakas 1994) have been discussed in sections 4.6.1 and 4.6.2 above. Interviews were conducted in a non-directive manner avoiding formal and leading questions (Oppenheim 2002) and after putting people at ease by asking them about themselves and their lifestyle, they were asked about their experience of TIA and what it had meant to them and phrases like ‘\_tell me about what happened to you’ were used. This was usually sufficient to elicit a detailed account of the illness event, what immediately preceded it, what was felt to be the possible causes and all of the medical pathway and impact and consequences of the whole event. Prompts were used as required to encourage participants to expand on subjects that arose or to elicit more specific information (Janesick 2004, Rubin and Rubin 1995), for example medical knowledge of stroke and TIA, advice they might give to someone newly diagnosed with TIA and lifestyle changes. It was important not to have a pre-determined list of questions that would be very limiting and reductionist in approach but allow the interview to flow in order to explore the unique experiences.

A check list for field notes (Hammell et al. 2000) was used to cover administrative aspects and record overall impressions of the interview (Appendix 12). One participant was interviewed on two occasions, before and after the completion of the medical pathway to capture the evolving experience. This participant wished to make a contribution of the

story of her experience before and after investigations. Other participants were at different stages in the medical process and their experience was generally captured within one interview. However, it is recognised that in order to complete a hermeneutic inquiry it may be necessary to repeat interviews at different time points to see how thinking evolves and as in Appendices 8 and 9. This was the plan at the outset to interview ‘up to 7’ participants twice. However the decision was taken by my research team after seven interviews to call a halt as the breadth and depth of the data that had already been accumulated was deemed to be more than adequate for analysis as can be seen by the findings in Chapter 5.

#### *4.6.2.2 Interview Process*

Reflecting upon the first three interviews there appeared to be three distinct parts to the interview process, namely:

1. Setting the scene and revealing context, that is biographical narrative and establishing rapport
2. Experiential narrative, the main body of the interview which was the co-construction and key part
3. Reflection upon meaning and consequences

(Wimpenny and Gass 2000)

This could not have been pre-empted before commencing the interviews but subsequently emerged and evolved and so may not be reflected in the Interview Guide (Appendix 11) that had been drafted at a much earlier stage.

#### *4.6.3 Data Analysis and Interpretation*

##### *Analytical Framework*

From the literature review (Chapter 2) I drew up a framework to give some structural underpinning to the data analysis (Figure 5). The starting point for this was the four cornerstones from the literature. These included Preventable Disease, Health Behaviour, Patient-Centred Care and Patient Partnership. The experience of TIA was central to the research and Interpretive Phenomenology and Critical Social Theory were key to exploring the experience. Alongside Health Behaviour was ‘What does it mean to be ill?’ and

Illness Behaviour. Closely linked to Preventable Disease and Health Behaviour were issues of lifestyle change, psychosocial, socioeconomic and theories of transition (Hopson et al. 1976), change (Prochaska and Di Clemente 1982), behaviour (Ajzen 1988), motivation (Rogers 1983) and health belief (Rosenstock 1990).

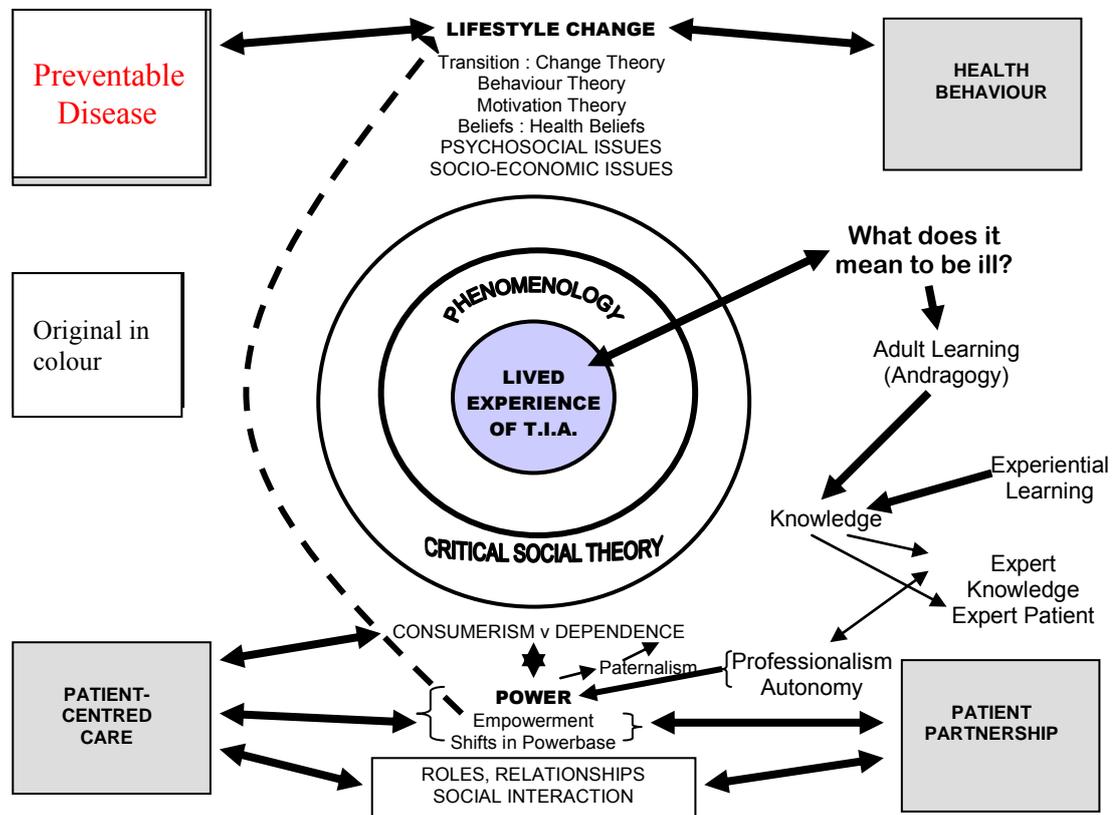


Figure 5. Framework for Analysis

From Figure 5 it can be seen that as experiential knowledge was gathered it led to shifts in the powerbase within the medical interaction and it was instrumental in empowering participants to take control through self-management to make lifestyle changes that represented preventive health behaviour. Further explanation is given below.

*Knowledge, Power and Empowerment*

The discursive social interaction between clinician and patient within a consultation is subject to issues of expert knowledge and resulting power. Paternalism and medical dominance have been discussed under Critical Social Theory above, but knowledge and power are mentioned here as an extension to, and important part of, the analytical

framework. Within patient centred care the patient as expert in her/his own illness is recognised and decision making is shared, leading to empowerment that enables patients to take control over their lives, making informed healthy lifestyle choices (Darzi 2008).

### *Data Analysis Methods*

Thematic analysis was used predominantly and addressed collective aspects emerging from the data. This was complemented by incorporating some elements of narrative analysis in order to capture the emotive impact for individuals. This combination allowed attention to fall on both factual and emotive aspects of the data to provide an enriched interpretation and foreground the participants' voices, commensurate with the philosophical approach. Poetic representation was used to allow maximum impact of participants' voices to be heard by connecting with the data, through the medium of words and language, in a different and creative way (Whyte 1994). The *...giving of attention to the rich and multifaceted dimensions of human experience can enhance research-----and through work with different forms of poetry access can be gained to deeper insight into the emotional texture of social interactions*" (Grisoni 2008 pages 108-109). The purpose of the poetic representation was to capture the intensity, to crystallize and condense the data into a form that represented a powerful narrative message of the experiential account that could be instrumental in achieving the aims of the study (page 58). This is further explored below in section 4.6.3.3.

#### *4.6.3.1 Thematic Analysis*

Simple thematic analysis (Burnard 1991) was used as a means to open up the data, identifying commonalities and differences in participants' stories. After reading and re-reading of the first three transcriptions a pause was made to take stock of happenings to identify key messages and potential themes emerging. This helped to orientate further analysis. Each transcription was read and re-read to gain a general impression and the main points noted. This was repeated with all transcriptions in turn and the salient points compared across all. There was continual movement and cross checking between individual transcriptions and the whole data set. The thematic analysis was further developed in terms of identifying topics that were evoked by the use of particular evocative words, connecting to narrative analysis. Having identified multiple topic areas these were

grouped into themes. There was continual re-configuring and re-naming of themes as the immersion in the data proceeded and the analysis developed.

#### 4.6.3.2 *Narrative Analysis*

Narrative analysis was then used to allow deeper involvement in individual subjective experiences. It was acknowledged that Gadamerian hermeneutics does not concern itself so much with individual meanings but more with collective textual aspects. However, it was decided to include this to capture the richness of experiences recognising that it is through language that understanding becomes possible (Gadamer 1989).

Narrative is the human means of making sense of an ever-changing world by rendering events into a story and the act of lapsing into story signifies importance of events. Stories have ontological status and we identify with and live through the stories told by others and ourselves. Narrative forges links between the exceptional and the ordinary and reality is constructed by bringing sense to something that is obscure or unusual (Ricoeur 1984).

One approach to narrative analysis is data reduction to core stories (Emden 1998b) where the core story takes a chronological journey through the participant data having first removed all of the researcher's narrative. The data is then broken down into sections, the first being *'call to adventure'* in terms of what happened. This is followed by *'crossing the threshold'* which is a period of realisation and change. Then the *'trials and ordeals'* are faced, for example the medical investigations and finally *'the road back'* concerning making adjustments in the light of knowledge (Daloz 1999, Vogler 1999). Central to the process of bringing order is *'enplotment'* where the sequence of events is organised into a plot (Ricoeur 1984). The concern with narrative elements of the interview allowed time for stories to be told about specific disruptive events that may be change-provoking experiences.

#### 4.6.3.3 *Poetic Representation*

Data analysis was refined further using poetic representation (Richardson 1997) in order to give maximum impact to the participants' emotive experience. Creative work supports the discovery of the not yet known, going beyond previously established knowledge and

challenging accepted thinking (Marshall 1990). Poems better capture the starkness and bluntness of the participant's delivery and the raw emotion. Also this avoids sanitising the research encounter and reactions (Harvey 2002). Within poetic structure, verses are an intrinsic part of the way people relate their experiences (Gee 1991) and they can cut through the superficiality.

However, the researcher recognised that to write poetry requires skill and that there was a risk of losing some of the essence of the data or that something could be missed through this representation if the poetry was poor (Whyte 1994). But as can be seen in Chapter 6 feedback from participants about this representation was very encouraging, recognising its strength. Also this was only part of the data reduction and analysis that complemented the thematic and other aspect of narrative analysis and therefore it was unlikely that anything would be missed between the analytical methods.

Methods of data analysis were used that were embraced under the headings of thematic and narrative analysis with various representation forms. Thematic analysis was dominant but augmented by elements of narrative analysis. Each method flowed from one to the other and made a contribution to the whole. This helped to ensure the nuances of participants' experiences of TIA were captured as fully as possible.

#### **4.7 Strengths and Limitations of the Method**

One-to-one interviews were deemed to be the appropriate method for data generation in this qualitative study. Exploring the experience of the phenomenon of TIA lent itself to a fairly open interview approach with minimum questions. As already discussed the interview guide submitted and accepted for ethical approval (Appendix 11) contained superfluous questions and the interview was directed rather by the co-construction and flow of the narrative than the questioning. As the researcher I had to be careful to minimise bias but at the same time recognising that the background of both the participant and the researcher was a valuable part of the whole co-construction that gave rise to knowledge through analysis. Meanings were explored collaboratively and interpretation informed by my assumptions and preconceptions and those of the participants.

Qualitative research seeks depth over breadth and attempts to reveal subtle nuances of life experiences as opposed to aggregate objective evidence. Whilst one cannot make claims to generalise from a qualitative study such as this there may be some transferability of insights to similar situations, which can be a valuable means to enhance practice and outcomes for patients.

#### **4.8 Summary of Chapter**

This chapter has set out the methodology for the research, outlined my role and perspective as the researcher, including epistemology and ontology. Issues of sampling and ethics have been discussed. Data collection method, analysis and interpretation have been described. Also included have been issues of rigour and possible strengths and weaknesses of the method.

## Chapter 5 Findings

*Hand and arm numb  
Hand in front of me-whose arm is that?  
Someone behind me-putting their arm around me  
Thought I was being attacked*

*Pulling it-it is my hand and arm after all!  
Really weird, really strange  
Pulling at my arm as if I was an idiot!  
Couldn't feel it-arm completely gone*

*I struggled, something not right, people  
Thinking I was drunk?, wobbly on my feet  
Right leg wouldn't move, started to go numb  
Drag myself to one side*

*Everything moving far away  
Space getting bigger and **bigger** and **bigger**  
Shaking and wondering what was going on  
Lost the ability to communicate-couldn't speak*

*Dizzy, arm gone, could hardly walk  
No feeling in right leg  
Know who I am but can't say  
Face dragging down, nothing, a complete black*

*Realised classic symptoms-a stroke.  
What extent? How bad?  
Panicky-looking like a mini stroke-don't panic  
What's going to happen to me?  
Less than 24 hours-put it into context*

*Out of the blue  
Coming through it, out the other end  
Feel better now  
Everything cleared*

*Starting to answer questions  
Couldn't get out,  
Grasp high level stuff  
Click, click, trying to find the word*

*Thirst for knowledge, know nothing about it  
Weight a bit of an issue, be more active  
No dietary or alcohol advice  
Know the limits, where slip down*

*Extremely lucky, life still goes on  
Thinking about it petrifying  
Feeling very down but give me a bit of time  
And go back full time*

*Thrown off your horse, get back on and carry on!*

(Sarah, age 39)

## 5.1 Introduction

The key purpose of the investigation was to examine how people who experience TIA try to make sense of the phenomenon. In this chapter findings of the research are detailed and interpreted. Thematic analysis is used predominantly and demonstrates collective aspects of experiential accounts. The analysis is flavoured by a complementary narrative approach to present the impact of the TIA upon individuals. The former, although not generalisable, could translate to other contexts and individual contributions are recognised to be of equal value in contemporary healthcare. Poetic representation is also used in data display to allow the maximum impact of participants' voices to be heard.

The process and stages of analysis are outlined in Figure 6. The findings are presented by progressing from the actualities of the illness event to the level of impact and finally to how participants coped as a result of the disruptive life event and threat to their health. Coping strategies, including self-efficacy, are considered. Quotations are annotated with name (pseudonym) and age of participant followed by line numbers; for example (James, age 59, 261). '\_Ann 1' and '\_Ann 2' denote her first and second interview respectively. Age is included in referencing quotations due to the relevance in this study. However, when there are several separate quotations from the same participant in close proximity on the page, age will only be mentioned once. Participant characteristics are displayed in Table 2, page 83, for example occupational status.

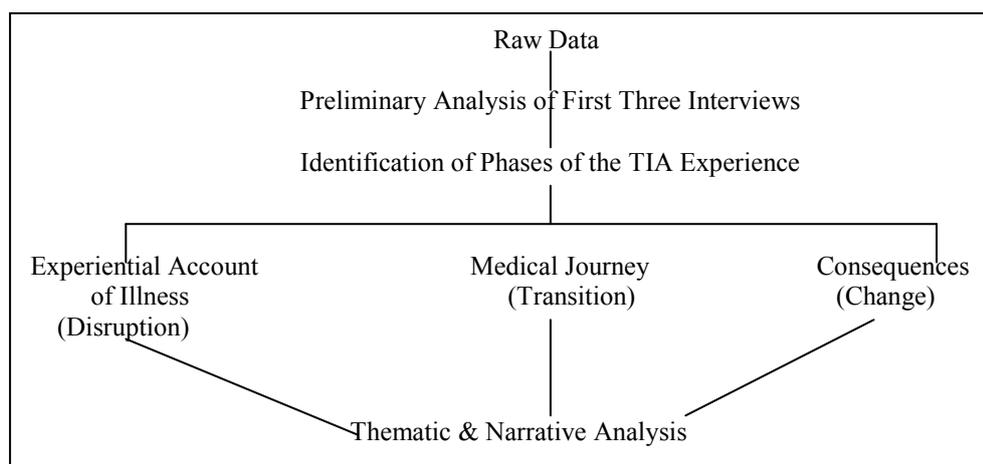


Figure 6. Analytic Process

## 5.2. Characteristics of Participants

Name	Age	Profiles
Ann	70	<b>Clinical:</b> First TIA, risks of hypertension & hyperlipidaemia, mother had strokes
		<b>Occupational:</b> Retired primary school teacher; education officer for local history museum post retirement
		<b>Social:</b> Lives with husband in a town, two unmarried children living away. Enjoys the arts, history, speaking French, swimming & walking. Role as housewife. Importance of balanced life
Sarah	39	<b>Clinical:</b> First TIA, risks of obesity, smoking, hypertension & lack of exercise
		<b>Occupational:</b> Works full time for lost property office of ---- Transport-manager 'behind the scenes'; work is very physical; involves long hours commuting.
		<b>Social:</b> Lives with partner and two children in a town. Does walking, role as housewife & mother. Works to pay bills
Megan	52	<b>Clinical:</b> First TIA ,risks of hypertension & hyperlipidaemia, mother had strokes
		<b>Occupational:</b> Works single-handed as a hospital cleaner doing shift work-cleans up to 8 theatres alone
		<b>Social:</b> Lives with husband, two children & one grandchild in a town. One other child lives away. Enjoys knitting, reading, crosswords & shopping. Role as housewife, mother & carer for grandchild
James	59	<b>Clinical:</b> First TIA, risks of obesity, lack of exercise, hypertension, hyperlipidaemia & AF; mother had a stroke
		<b>Occupational:</b> Sells furniture in UK & Europe-a lot of travelling
		<b>Social:</b> Lives with wife in a town .No children .Enjoys gardening, DIY, golf & walking. Role as breadwinner, DIY, gardener. Looks on life to be enjoyed
Esmond	86	<b>Clinical:</b> First TIA, risk of hypertension
		<b>Occupational:</b> Retired manager from wine trade, variety of previous jobs, army in second world war
		<b>Social:</b> Lives with wife in a town .No children .Enjoys gardening, crosswords & watching TV. Role as gardener, driver. Very laid back
Andrew	65	<b>Clinical:</b> Second TIA, risks of smoking ,heavy alcohol consumption ( now stopped smoking & reduced alcohol), hypertension & hyperlipidaemia
		<b>Occupational:</b> Retired Ofsted inspector, previously self-employed builder.
		<b>Social:</b> Lives with wife in a town. No children of own, one stepson living away. Enjoys caravanning, painting, building, gardening, watching TV & listening to music. Swims and walks .Role as driver, gardener & maintenance. Wishes to play an active role in life
Arthur	71	<b>Clinical:</b> First TIA, risks of hypertension & hyperlipidaemia, father had a stroke
		<b>Occupational:</b> Graphic designer-long hours
		<b>Social:</b> Lives with wife in rural location. Two unmarried adult children living away. Committed to enjoyable work

Table 2. Characteristics of Participants: Profiles

**Key:**

**Clinical**=history of present condition & predisposing causes

**Occupational**= occupational status, occupation & pre-retirement occupation

**Social**=marital status, dependents, residential location, hobbies, role in household & life philosophy

The participant profiles were collected mainly from the biographical narrative, when participants were talking about themselves and their lifestyles. Age was collected from participant details handed to the researcher by the nurse from the TIA clinics. The decision was made to include clinical details, occupational status and social aspects in the profiles in order to get a comprehensive picture of factors that could impact upon lifestyles. All participants in this study were white British Caucasian middle class (Her Majesty's Stationery Office HMSO 2004).

*Thematic analysis* is summarised in example boxes and tables showing links between the transcript data (Appendix 18) and identified themes. Illustrative quotations are used throughout the text to support the subsequent interpretation.

*Narrative analysis*, partly based on core stories, is presented with examples within the text.

*Poetic representation* of specific experiences depicts the emotional impact on individual participants. The poems or parts thereof lead into each chapter and the full text of the same can be found in Appendix 22. They are brought to life through contributions from an actor's voice on the compact disk inserted inside the back cover of the thesis, to be played using Windows Media Player. It was decided not to present the poetic representation in its entirety all together in the Findings chapter but rather distribute it throughout the thesis for maximum impact of participants' voices and to hear the intensity of their individual experiences.

Eight participants were interviewed, one of whom was interviewed twice at different times in the medical pathway. This participant wished to make a contribution of the story of her experience over two interviews, before and after receiving results of medical investigations. One interviewed participant was not entered into the study as she received an alternative diagnosis not apparent at the time of recruitment. Therefore seven participants were entered into the study, one of whom was interviewed twice making a total of eight interviews. The sample of seven consisted of three females and four males, age range 39 to 86 years with a mean age of 63 years. Four were employed and three were retired. Length of the interviews ranged from 20 to 50 minutes with a mean of 36 minutes. The longer interviews appeared to relate to psychological impact; some were more affected

than others and took advantage of the one-to-one situation as a cathartic experience. Pseudonyms were given to participants and others they referred to in order to preserve anonymity. A summary of participants' characteristics is presented in Table 2, followed by objective data pertaining to the nature and duration of symptoms experienced and the proportion of participants affected. Symptoms affecting participants were those commonly experienced by individuals suffering a stroke and there were several similar experiences (Figure 7).

### 5.2.1 *Nature of Symptoms*

Symptoms experienced by participants were predominantly those of facial weakness, speech difficulties and arm weakness which reflect those detailed in the FAST algorithm (Stroke Association 2007).

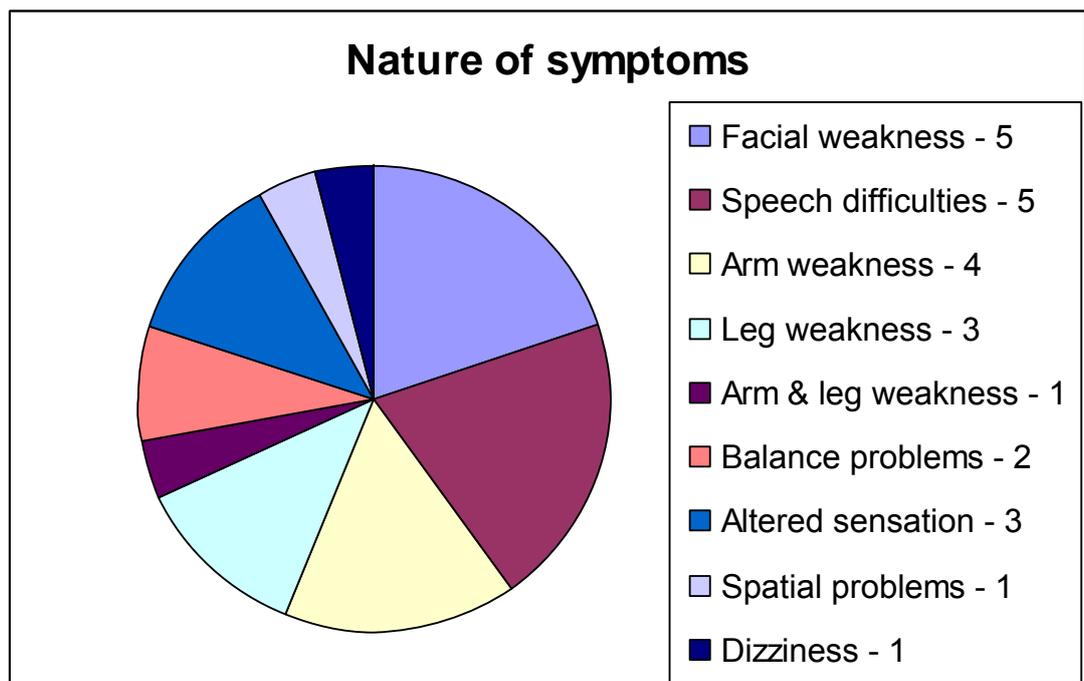


Figure 7. Symptoms Experienced and Number of Participants Affected  
(Total of 7 participants)

### 5.2.2 *Duration of Symptoms*

The attack was —...*short-lived*”, —...*so brief*” and —... *it came and went so quickly*”.

Symptoms were estimated to have lasted from 15 seconds to 4 hours, the longest period being experienced by the youngest female (Box 3).

— <i>Don't know that it was even 15 seconds</i> ”	(James, age 59, 34)
— <i>Within one minute I could walk normally</i> ”	(Ann 1, age 70, 98)
—... <i>2 minutes---and everything was back, speech, movement</i> ”	(Andrew, age 65,34)
— <i>Was like that for about 15 minutes before it got better</i> ”	(Arthur, age 71, 99)
—... <i>must have been about an hour</i> ”	(Megan, age 59, 36)
—... <i>after a couple of hours it sort of passed off</i> ”	(Esmond, age 86, 24)
—... <i>about four hours in total</i> ”	(Sarah, age 39, 206)

Box 3. Duration of Symptoms

### 5.3. **Preliminary Analysis of the First Three Interviews**

After three interviews preliminary inductive analysis, by way of data reduction, was undertaken to inform subsequent interviews. The audiotape of the first interview was listened to repeatedly and the transcript made verbatim. After reading and re-reading of the first transcript notes were made about perceived potential salient points of the evolving story being told, whilst identifying possible themes. This process was repeated with the subsequent two transcripts in turn. The purpose was to become familiar with the content of the data, to gain an initial overall impression, including the use of language, and to select and note the main messages. Then comparisons were made across the three for common elements emerging from the data.

The interviews comprised three main sections of experiential account, medical journey and consequences (Figure 6, page 82). As explained above, characteristics of participants (Table 2) were mainly elicited in the introductory part of the interview. Here participants were put at ease in talking about themselves before proceeding to the main body of the interview which invited them to recount their illness experiences including the medical journey. In a final section how participants perceived the consequences of those experiences was explored. There was no pre-set timeframe for each part of the interview

and neither were these sections discrete; participant narrative moved freely to and fro with the recounting of stories. The sections were in no way timed and some participants spent longer talking about themselves and their lifestyle than others; and interestingly the longer time taken on the introductory part the richer the data yielded from the subsequent parts of the interview (Appendix 14). The analysis of these preliminary interviews started to be shaped by three phases of experience apparent in participants' responses outlined in Figure 6, page 82.

### 5.3.1 *Experiential Account of the Illness Event.*

In describing the actual illness event (TIA) each participant told a story of sudden, startling disruption to normal function:

*—just stretched. I put my arms up towards the back of my head and stretched and just as I did that I suddenly felt no feeling in the right arm. I realised I couldn't bring it down, so I used the other hand to bring it down to the table. I've got this strange feeling in my arm. I have no sensation. I wasn't speaking properly out of the right side of my mouth. They noticed something was wrong. Are you alright? It only lasted 15 seconds and that was it".*

(James, age 59, 28-34)

*—suddenly had the most strange sensation. It felt as if someone had placed a cold hand under the surface of the skin and it was like a stroke or a wave of cold, it travelled across the top of my head from right to left. I felt it go down the side of the left side of my face, down my neck, across my shoulder, down my left arm and into my abdomen, into my left leg and my immediate reaction was God I'm having a stroke!"*

(Ann 1, age 70, 40-43)

*—my right leg was going and I just said to my wife I'm going again and I just propped myself up on a low wall and the whole of this side lost all sort of control and ability----my speech was slightly impaired"*

(Andrew, age 65, 28- 29)

### 5.3.2 *Medical Journey.*

The disruption immediately gave rise to a protracted medical journey during which participants were in transition between illness onset and definitive diagnosis, but before the

full impact of the consequences had been felt. This phase included initial clinic appointments, a programme of tests, follow-up visits to receive results and subsequent appointments with the general practitioner (GP) for a discussion:

*—I came up to the clinic and it was just a formality of checking blood pressure check and an arrangement for an MRI scan”.*  
(James, age 59, 73)

*—..the specialist put forward a programme of tests----- carotid which I know will assess the blood-flow in the neck, from the body to the brain and vice versa and I’m going to have a brain scan-----I know I will go back and see the specialist”*  
(Ann1, age 70, 250-261)

*—..the paramedics came in 3 or 4 minutes it felt like, but it was probably a bit longer than that, and put me on oxygen and then the ambulance arrived about another five minutes after that and they took over and again by the time I was in the ambulance, 10 minutes, 12 minutes perhaps, had gone something like that and everything was back, speech, movement and we chatted away from --- to --- in the back of the ambulance. They did an ECG, blood tests, the usual rigmarole in the hospital and they released me about 3 hours later”.*  
(Andrew, age 65, 31- 35)

Some of the differences in the medical experiences above can be explained by where participants were in their medical journeys but also how they accessed the service. Andrew was taken into hospital by ambulance whereas the other two presented to their GP’s and then had subsequent hospital referral.

James was relatively younger and the breadwinner in the household:

*—I’m really busy working--I’d rather do less but I can’t afford to”*  
(James, age 59, 8 &196)

so there was a great deal at stake in coming to terms with the health threat. Ann had been treated for stroke risk factors for 16 years as well as nursing a close relative with a stroke and seeing others:

*—I have been under the care of my GP and taking medication for hypertension----about 16 years-----also for a high cholesterol level”*  
(Ann,1, age 70, 24-26)

*—I’ve seen it happen to other people, elderly people, my mother died of a stroke”*  
(Ann 1,age 70, 89)

so the adjustment for her was influenced by prior knowledge from having *—..had a bit of experience*” (Ann 1, age 70, 91). Andrew had experienced a previous TIA and so had prior experience of adjustment:

*—..this is the second one and the experience in both cases was very similar except that for the first one I was at home”*  
(Andrew, age 65, 23)

### 5.3.3 *Consequences*

As a result of the disruptive event and medical interventions participants reflected upon where they thought things may have gone wrong in contributing to the health threat. This appeared to be their way of rehearsing change for the future, for example:

*—I’d rather do less but I can’t afford to----that’s not strictly true. We live in a nice house, we could consider down-sizing and I could semi-retire or retire”*  
(James, age 65, 196- 197)

*—I’ve modified my diet slightly. I’m drinking soya milk and taken up green tea, and I’m eating more highly coloured fruit and vegetables----and as far as my exercise is concerned, I’m trying to do more than I did before and make it more strenuous”*  
(Ann 2, age 70, 161-165)

*—..we’ve finally solved the problem by walking to the station, travelling very light with a rucksack instead of a suitcase. You can adapt”*  
(Ann 2, 178- 180)

*—I’m trying harder to relax more and just sit down with a glass of wine more, one a night, just so you really do unwind and relax”*  
(Ann 2, 281- 282)

*—I know I’ve done stupid things. I’ve decided I better get a sack barrow for things in the garden so that I can just slip it on and wheel them around and I’m not---I’ve finished the house, I’m not doing any more major building work. I shall do some landscaping which is just laying a few bricks”*  
(Andrew, age 65, 215- 217)

### 5.3.4 *Summary of the First Three Interviews*

It seemed that participants were at various stages in their journey. The TIA represented a disruptive life event that triggered a change process in which participants proceeded through a transition process in parallel to the medical journey.

Following this analytical pause, in looking at subsequent interviews, viewed through the lens of the three above, the research embraced what individuals said as well as how people said it. The three phases identified in their accounts provided an orientating framework for thematic analysis of subsequent interviews. Within each phase there were certain commonalities around what was salient. These appeared as themes or patterns in the data that would best represent the data chunks of meaning that were starting to emerge. An example of a coded transcript is shown in Appendix 14 that demonstrates how phases and themes emerged from the data.

The emerging essence of the data was captured under the three phases of disruption, transition and change and this is displayed together with themes relating to each phase in Table 3 and further breakdown of themes and subthemes is shown in Figure 8. Themes are illustrated with quotations followed by interpretation of what the data meant and represented. Themes were continually checked against the raw data and repeatedly both re-configured and re-defined as the process of immersion in the data progressed. These were labelled using, as near as possible, participants' words. Narrative analysis was interwoven where appropriate in looking at the language used to relay the impact within individual stories of experience as well as the content of evolving stories themselves.

<b>Phase</b>	<b>Themes</b>
<i>Disruption</i>	1. A surprise more than anything 2. I didn't know what was happening 3. A sense of disconnected body parts 4. Continuum of concern
<i>Transition</i>	5. The after effect 6. Medical journey 7. We're on a sharp learning curve 8. What is the right thing to do? 9. Unnerved because of the uncertainty
<i>Change</i>	10. Moving on 11. What the future holds

Table 3. Phases and Themes

Phases	Themes	Subthemes	Subsubthemes
D I S R U P T I O N	1. <i>A surprise more than anything</i>	Context	
	2. <i>I didn't know what was happening</i>	Feeling threatened How did participants talk about their reaction? A sense of disorientation	
	3. <i>A sense of disconnected body parts</i>	Limbs misbehaving	
	4. <i>Continuum of concern</i>	A sense of helplessness Panic-stricken A sense of fear Feeling angry Depressed	
T R A N S I T I O N	5. <i>The after effect</i>		
	6. <i>Medical journey</i>	Roles encountered First medical contact post TIA Programme of tests Medication → Compliant Concerned →	Limitations of medication A lot of tablets Prescriptive practice Wishing to find alternative Possible side effects
		Clinic appointments	
	7. <i>We're on a sharp learning curve</i>	Components of the learning curve →	Knowledge Skills Attitudes Values
		How did they know? →	Experiential learning Self-directed learning Taught by medical professionals
		What did they know? →	Stroke-related knowledge TIA-related knowledge Knowledge of pathophysiology Knowledge linked to investigations Knowledge of risks
		Power →	Empowered through knowledge Conferred power Disempowerment → Lack of info Labelling Paternalism
T R A N S I T I O N	8. <i>What is the right thing to do?</i>	Why has it happened? What were the causes?	
	9. <i>Unnerved because of the uncertainty</i>	Possible recurrence Effects of medication Imparting of info Awaiting medical advice Carry on as normal Strength from family support	
C H A N G E	10. <i>Moving on</i>	A sense of relief Improving diet Recognising working too hard Pacing and relaxation Modifying travel plans	
	11. <i>What the future holds</i>		

Figure 8. Themes and Subthemes

An illustration of a coded transcript is found in Appendix 14 that demonstrates how themes were identified and the formulation of ideas for the thematic analysis is shown in Appendices 18 to 21 when themes were being configured. The remainder of the findings will now be presented under the three phases of disruption, transition and change.

## **5.4 DISRUPTION PHASE**

*—I didn't know what was happening” (Megan, age 52, 36)*

## 5.4. Disruption Phase

The themes in the disruption phase are displayed in Table 3 and Figure 8 on pages 90 and 91 and detailed with quotations and interpretation below. The sudden surprise element of the onset is presented first, followed by the context of what individuals were doing at that time and just prior to the event. Thereafter the impact is detailed. The nature and duration of symptoms experienced is displayed in Box 3 and Figure 7 (pages 86 and 85).

### 5.4.1 Theme (1): “...a surprise more than anything”

All participants experienced sudden and surprising onset of symptoms, for example:

— <i>sudden had the most strange sensation</i> ”	(Ann 1, age 70, 63)
— <i>sudden felt no feeling in my right arm</i> ”	(James, age 59, 29)
— <i>all of a sudden</i> ”	(Sarah, age 39, 272)
— <i>a surprise</i> ”	(James, age 59, 271)
— <i>it’s a total surprise</i> ”	(James, 333)
— <i>a surprise more than anything</i> ”	(Esmond, age 86, 333)

Box 4. Theme (1): —. a surprise more than anything”

This typifies the nature of the sudden health threat of TIA —. *completely out of the blue*” (Arthur, age 71,176) with —. *no warning*” (Andrew, age 65,111).

#### 5.4.1.1 Context

Participants were engaged in various activities at the time of onset of symptoms, for example:

<i>— . a walk up to the cathedral”</i>	(Andrew, age 65, 27)
<i>— .. a walk-----around-----we had only just set out”</i>	(Arthur, age 71, 92)
<i>— I was walking underneath the rail bridge to go into-----station”</i>	(Sarah, age 39, 120)
<i>— I was on my way to work”</i>	(Sarah 113)
<i>— I was doing a bit of gardening”</i>	(Esmond, age 86, 24)
<i>— I d changed into my swimming costume”</i>	(Ann 1, age 70, 38)
<i>— I was driving along”</i>	(Megan, age 52, 34)
<i>— .. went out to a restaurant”</i>	(James, age 59, 28)

#### Box 5. Context of Illness Event

However it was interesting to note that three participants had engaged in excessive physical activity just prior to the onset:

*— I was doing (cleaning) eight theatres by myself”* (Megan, age 52, 130)

*— I d been down to the boat to get it ready for the summer. I d worked all day in the blazing sunshine without a hat on----the week end before----I can t remember what job we were doing but it was physical over about three days. I d just finished the decking in the house----so I d probably been burning the candle a bit”* (Andrew, age 65, 121- 123)

*— I d been heaving all my pot plants----I d laid a concrete floor---in two days, breaking up the old one in one and laying the other in a day”* (Andrew 132- 133)

*—I was doing a bit of gardening---in the dry weather and the ground was quite hard and I had to knock it up a bit”*

(Esmond, age 86, 24)

This issue is discussed in Chapter 7 on page 161.

#### 5.4.2 *Theme (2): “I didn’t know what was happening”*

There was a range of cognitive and emotional responses to the impact of symptoms expressed by participants. These were only communicated within the interviews in an initial limited time frame post TIA and so would need tracking over a longer period to see how attitudes changed through transition to adjustment and change. Some of this is illustrated in metaphor shifts below that demonstrated changing attitudes. It was interesting to note participants’ repeated use of the word *‘happening’* or *‘happen’* to convey that an event had occurred or could occur:

*—I didn’t know what was happening”* (Megan, age 52, 36)

*—What’s going to happen to me?”* (Sarah, age 39,195)

*—I think whatever happens, happens ultimately”* (James, age59, 201)

*—...a taste of what could happen”* (Arthur, age 70, 189)

*—...see what is going to happen”* (Esmond, age 86, 193)

*—I’ve seen it happen to other people”* (Ann 1, age 70, 89)

##### 5.4.2.1 *Feeling Threatened*

This not only included health threat or *—...a taste of what could happen”* (Andrew, age71, 189) but also two participants felt they were being attacked and *—...someone had placed a cold hand under the surface of the skin”* (Ann 1, age 70, 64) and *—...someone behind me putting their arm around me-thought I was being attacked”* (Sarah, age 39, 123). The latter experiences clearly related to sensory disturbances and were obviously very alarming.

The health threat was very real for most participants, especially for Andrew who was *—..frightened to death”* (Andrew, age 65, 266) as he had experienced a second TIA despite medication and apparently heeding lifestyle advice: *—I thought I was doing the right things”* (Andrew 270). Likewise Ann was also executing healthy lifestyle behaviours

and was questioning — *...why has it happened?*” (Ann1, age 70, 105). However it appeared that some participants did not experience so much of a health threat. Esmond was only — *...slightly concerned*” (Esmond, age 86, 74) and James — *...never really worried*” (James, age 59, 85). This may have influenced their decision to delay seeking medical advice. Possible factors influencing level of health threat are considered here; although some of these issues are subsequently presented in more depth.

#### 5.4.2.1.1 *What Influenced the Level of Health Threat Experienced?*

The following factors emerged from the data:

- 1) level of health motivation and knowledge
- 2) vulnerability
- 3) perceived efficacy of medication
- 4) self-efficacy

##### 1) Level of health motivation and knowledge.

Knowledge of stroke varied between participants. It was apparent that Esmond’s knowledge of stroke was minimal and he — *...didn’t think it was a stroke really* (Esmond, age 86, 177). Despite being 86 years old, he had never seen anyone who had suffered a stroke. Complacency was echoed in — *I’ve always been able to recover*” (James, age 59, 167) and — *I hope I don’t need to do anything*” (James 295) and — *I arranged to see her (doctor) in about ten days*” (Arthur, age 71, 103).

##### 2) Vulnerability

The perception of vulnerability was on a continuum reflected in the level of concern. Esmond did not appear vulnerable as he continued gardening whilst seeking medical advice: — *...tried to do as usual-still do a bit of gardening*” (Esmond, age 86, 76), resented his wife trying to stop him doing things: — *...she didn’t want me to do this and didn’t want me to do that*” (Esmond 76) and drove himself to the doctor’s surgery. When asked if he was able to drive to the doctor’s surgery, he replied emphatically — *...oh yes*” (Esmond 337). Arthur’s attitude was similar as immediately following the incident he — *...went back to work and did an afternoon’s work and quite a bit of the evening-----I’ll phone the doctor tomorrow*” (Arthur, age 71,100). Likewise, James carried on with his meal out

immediately following the event and went to see his doctor three days later: *—..we just carried on with the meal-----and I went to see the doctor on Monday* (James, age 59, 35). However vulnerability was expressed in different ways, for example: *—..a taste of what could happen”* (Arthur 189) and *—..a shot across the bows”* (Andrew, age 65, 161).

### 3) Perceived efficacy of medication.

Several participants had concerns about medication. Both James and Ann recognised the limitations of the medications in the scope of stroke prevention:

*—I think whatever happens, happens ultimately”* (James, age 59, 201)

*—..it prevents you from getting it as early as you might have done”*

(Ann 1, age 70, 29).

Esmond had been taking antihypertensive medication but he had not made any links between hypertension and stroke. When asked if there was a link between hypertension and stroke, he replied *—No I didn't really think so”* (Esmond, age 86, 199) but he recognised that his medication was controlling his blood pressure: *—..they seem to control it quite well with the tablets”* (Esmond 199). Sarah was re-assured by the medication: *—I'm being treated, I'm on tablets”* (Sarah, age 39, 463).

### 4) Self-efficacy.

Most participants had adjusted their lifestyle behaviours or expressed intention to do so but some were less committed, for example: *—I hope I don't need to do anything”* (James, age 59, 295) and *—I need to and would enjoy doing more exercise but it's finding the time”* (James 315). Also Sarah had several barriers to change, for example: *—..it is a lack of willpower and there's always time to find to do these things but I haven't made a conscious effort to that”* (Sarah, age 39, 419). Possible influences upon self-efficacy for these two participants will be discussed in the phase summary.

The above four factors seemed to influence the perceived level of health threat and thereafter the changes in lifestyle behaviours. The language used to express reactions to the event conveyed the impact.

#### 5.4.2.2 How did Participants Talk About Their Reaction?

Two participants exhibited a clear realisation that they were experiencing a stroke. Ann's immediate response to her symptoms was: *—.. to speak aloud and then to smile and then to move my left arm*" (Ann1, age 70, 71) and *—..my immediate reaction was God I'm having a stroke!*" (Ann1, 66). Likewise Sarah had awareness: *—..when he said smile, I realised---classic symptoms of face drooping---I thought straight away a stroke*" (Sarah, age 39, 190) despite claiming she knew *—..nothing at all*" (Sarah 322).

The use of emotive words and metaphors evoked the impact of individual experiences as illustrated below. Images of disaster and war were used to convey the immediate reaction to the experience, for example:

<b>Shaken</b> — <i>felt shaken</i> " (Ann 1, 99), <i>really did shake me up</i> "	(Andrew 272)
<b>Shook</b> — <i>shook me</i> "	(Andrew 270)
<b>Shock</b> — <i>it sbcked me</i> " (Sarah 121), <i>it shocked my daughter</i> "	(Sarah 383)
<b>Struck</b> — <i>truck dumb</i> "	(Ann 1, 68)
<b>Stroke</b> — <i>it was like a stroke or a wave of cold</i> "	(Ann 1, 64)
<b>Attacked</b> — <i>Tought I was being attacked</i> "	(Sarah 123)
<b>Electric Shock</b> — <i>lectrical discharge going off in the middle of your head</i> " (Ann 1,159)	
<b>Blow</b> — <i>It was a bit of a blow</i> "	(Arthur 105)
<b>Shearing</b> — <i>it feels more like something shearing</i> "	(Andrew 81)
<b>Knock</b> — <i>knocked me over</i> "	(Andrew 205)
<b>Shot</b> — <i>sbt across the bows</i> ", — <i>awarning shot</i> "	(Andrew 161 & 165)
<b>Sink</b> — <i>gt one (shot) below the water line and sink</i> "	(Andrew 162)
<b>Pulled up</b> — <i>pulled up quite sharply</i> "	(Andrew 13)

#### Box 6. Participants' Reactions: Images of Disaster and War

Andrew's use of seafaring images may have related to his sailing experience as he *—..gave up sailing about two years ago*" (Andrew, age 65, 17). Participants appeared temporarily out of control of their bodies and lives and were experiencing a health threat that was disorientating and gave rise to concern.

#### 5.4.2.2.1 *A Sense of Disorientation*

There was a sense of disorientation as a result of the sudden health threat. A step into the unknown was another way participants described how they felt. Expressions used in relation to the disruptive event were participants' attempts to provide meaning and make sense of the unfamiliar situation for example:

— <del>k</del> <i>knew it was something that shouldn't be</i> "	(Esmond 329)
—... <del>s</del> <i>omething was wrong</i> "	(James 33)
—... <del>s</del> <i>omething not right</i> "	(Sarah 139)
—... <del>s</del> <i>omething wasn't quite right</i> "	(Sarah 157)
— <del>h</del> <i>ad a strange turn</i> "	(Ann 1,101)
—... <del>r</del> <i>eaction to something strange</i> "	(Ann 1, 99)
— <del>s</del> <i>tarted to go a bit strange</i> "	(Andrew 24)
—... <del>b</del> <i>it strange</i> "	(Sarah 273)
— <del>f</del> <i>elt a bit strange</i> "	(Megan 34)
—... <del>b</del> <i>it odd</i> "	(Arthur 92)
—... <del>b</del> <i>it funny</i> "	(Sarah 122, Megan 34)
—... <del>b</del> <i>it weird</i> "	(Sarah 118)
—... <del>f</del> <i>elt vry weird</i> "	(Arthur 95)
—... <del>t</del> <i>at's really strange</i>	(Sarah 138)
— <del>h</del> <i>thought that was strange</i> "	(Esmond 30)

#### Box 7. A Sense of Disorientation

Repeated use of the word strange conveyed a new experience and in the immediacy not knowing what that was or meant, for example:

— <del>I</del> <i>didn't know what it was</i> "	(James, age 59, 263)
— <del>I</del> <i>didn't know what was happening</i> "	(Megan, age 52, 36)
—... <del>h</del> <i>at's going to happen to me?</i> "	(Sarah, age 39, 195)

### 5.4.3 *Theme (3): A Sense of Disconnected Body Parts*

Participants spoke of their failing body parts almost as if they had become disconnected:

- ..arm had gone*” (Sarah, age39, 160)
- ..my right leg was going*” (Andrew, age71, 28)
- ..my face had gone*” (Sarah, 176)

possibly unconsciously inferring pathways from their brains were interrupted. But conversely the image used to describe the resolution of symptoms was that —*..connections were made very quickly*” (Ann 1, age 70,125).

#### 5.4.3.1 *Limbs \_Misbehaving‘*

There was a sense of irritation that limbs were *\_misbehaving‘* and that participants did not have any control over this:

— <i>tried to write, pencil not doing what it should</i> ”	(Esmond, age 86, 24)
— <i>couldn‘t make thisleft leg do as I wanted to do</i> ”	(Ann 1, age 70, 77)
— <i>was trying to use the phone and with my right arm I couldn‘t really do anything</i> ”	(Megan, age 52, 56)
— <i>look my mobile out but I couldn‘t get it to do anything that I wanted it to do</i> ”	(Sarah, age 39, 234)
— <i>got to the cash point ... I struggled to get the card out of the slot of the purse ...I couldn‘t put the card in the card slot</i> ”	(Sarah 135 –137)
— <i>face wouldn‘t respond</i> ”	(Sarah 177)
— <i>the spade slipped out of my hand...I couldn‘t hold it up</i> ”	(Esmond, age 86, 24)

#### Box 8. *Limbs \_Misbehaving‘*

Participants were urgently assessing the situation that had been thrust upon them and their ability to cope and deal with the consequences. This required considerable cognitive effort that linked into the disorientation. The event had given rise to concern.

### 5.4.4 *Theme (4): Continuum of Concern*

Participants expressed their concern and that of others on a continuum from relative nonchalance to extreme fear, for example:

— <i>didn't worry at all</i> "	(Esmond, age 86, 179)
—... <i>it didn't worry me much</i> "	(Esmond 72)
— <i>we never really worried</i> "	(James, age 59, 85)
—... <i>slightly concerned</i> "	(Esmond 74)
—... <i>slight worry---a concern</i> "	(James 132)
—... <i>he (policeman) started getting a bit concerned</i> "	(Sarah, age 39, 161)
—... <i>she (wife) was worried</i> "	(Arthur, age 71, 211)
—... <i>they (colleagues) were worried</i> "	(Sarah 255)
—... <i>my wife was quite concerned</i> "	(James 105)
—... <i>they (children) are both very concerned</i> "	(Ann 2, age 70, 128)
—... <i>my husband was extremely concerned</i> "	(Ann 1, 120)
—... <i>she's (wife) taken it very seriously</i> "	(Andrew, age 65, 294)
—... <i>petrifying</i> "	(Sarah 484)
—... <i>it did frighten them (daughters)</i> "	(Megan, age 52, 182)
—... <i>it frightened the life out of her (daughter)</i> "	(Sarah 242)
—... <i>he (partner) was absolutely devastated</i> "	(Sarah 390)
—... <i>frightened me to death</i> "	(Andrew 266)

### Box 9. Continuum of Concern

The level of concern appeared to relate to their life philosophy (Table 2). For example the oldest retired male participant Esmond, who had a sanguine attitude to life, for example —...*we don't bother about things much*" (Esmond, age 86, 148), was least worried whereas the youngest participant Sarah who had a family and was in full-time employment was —...*petrified*" (Sarah, age 39, 484). It was important for her to continue as a breadwinner in her family, for example:

—...*it pays the way. I mean it pays my mortgage and it keeps the money coming in---it's a case of having to*" (Sarah 71)

Andrew was —*..frightened to death*” (Andrew, age 65, 266) by the second TIA as he was adhering to the lifestyle and medication advice following the first event: —*..I thought I was doing the right things*” (Andrew 270). This then had greater significance for him especially as he had a very full life despite retirement, for example:

*—I play an active role in life and always have done and to have that curtailed would make me very unhappy”* (Andrew, age 65,194)

#### 5.4.4.1 A Sense of Helplessness

The level of significance attributed to the event appeared proportionate to what was at stake, should participants be left with residual disability and incapacity that would affect their lifestyle, life plan expectations and longevity. There was a sense of helplessness, for example:

*—Id hate to lose even part of my mobility, or my means of communication, to have that impaired in any way ...I'd hate to impose it on, certainly my wife having to cater for somebody who couldn't get up and down stairs on their own or couldn't drive, we would be stuck”* (Andrew, age 65, 184-185)

*—..you can lose your power of speech, which is something that worries me more than anything else”* (Ann 1, age 70, 85)

*—How helpless you are...if you had another stroke ...couldn't do things for yourself ... fairly helpless in some respects, failing to communicate, apart from that, a burden to everyone else”* (Arthur, age 71, 189-204)

#### Box 10. A Sense of Helplessness

Here both Andrew and Arthur were showing social conscience in not wanting to burden others with significant disabilities.

Although both Esmond and Andrew were retired, their life philosophies differed widely. This could have related to age and length of retirement since Esmond was much older and had been retired for considerably longer and may have felt, in his twilight years, he had achieved his life goals and was contented:

*—..we don't bother about things much”* (Esmond, age 86, 148)

Those who expressed most concern were anxious to acquire more knowledge, for example:

*—‘I’d like to know what more I can do to help myself’* (Ann1, age 70, 113)

*—‘I had a thirst for knowledge’* (Sarah, age 39, 343)

The search for knowledge seemed key to the experience.

#### 5.4.4.2 Panic-Stricken

Feelings of panic were expressed by two participants:

*—..panic-stricken”* (Ann 1, age 70,108)

*—..getting panicky and thinking oh what’s going to happen to me?”*  
(Sarah, age 39, 195)

*—Charlotte (daughter) sort of panicked”* (Sarah 246)

#### 5.4.4.3 A Sense of Fear

Fear very much related to *‘threat’* and *‘panic’* above but specific expressions of fear were made, for example:

<i>— .frightened me to death”</i>	(Andrew, age 65, 266)
<i>—...it frightened the life out of her (daughter)”</i>	(Sarah age 39, 242)
<i>—...it did frighten them (daughters)”</i>	(Megan, age 52, 182)
<i>—...wondering what was going on”</i>	(Sarah 152)
<i>—...it was absolutely petrifying”</i>	(Sarah 484)
<i>—...what’s going to happen to me?”</i>	(Sarah 195)
<i>—do feel apprehensive”</i>	(Ann 1, age 70,127)
<i>—...scary”</i>	(Arthur, age 71, 189)

Box 11. A Sense of Fear

Reflecting on the significance of the disruption, fear for the future was expressed in these metaphors:

—...*a warning shot*” (Andrew, age 65, 165)

—...*a taste of what could happen*” (Arthur, age 71, 189)

#### 5.4.4.4 *Feeling Angry*

Anger was expressed towards the medical profession, particularly around the need for medication. Both Ann and Andrew were resentful that they had experienced a TIA as they were both apparently heeding the lifestyle advice and taking the preventive medication:

—*I felt resentful -----I am careful with my diet and my exercise and I do take my medication and I try to be a good girl and why has it happened?*” (Ann 1, age 70,105)

—*I thought I was doing the right things*” (Andrew, age 65, 270)

However, on reflection, Ann knew the answer to her question:

—*I’ve always been told by my GP that any kind of medication I’m given is going to help the situation but it won’t necessarily prevent heart attack or stroke but it prevents you perhaps from getting it as early as you might have done*” (Ann1, 29)

Likewise Andrew was able to reason cause as —...*overdoing it*” (Andrew 119)

Other minor expressions of anger or discontent were around:

1) Having to spend so long in hospital undergoing investigations when feeling fine:

—*I felt as right as rain*” (Andrew, age 65, 169)

—*I got so fed up that I almost discharged myself*” (Andrew 155)

—...*the consultant bogged off on Friday at 5 o’clock without coming back to say you’re all clear you can go home*” (Andrew 167)

2) Not having expectations met at the clinic and yet losing a day’s work to attend:

—*I was under the impression that I would be having an MRI scan. In fact it was just simply check the blood pressure and arrange a date for the future which annoyed me ----because I am busy, I have little time to spend on these things. It was the waste of the best part of a day really*” (James, age 59, 224- 228)

3) Having to wait for appointments and test results:

*—It took about eight days before I got confirmation of an appointment”* (Andrew, age 65, 48)

*—...the one personal niggle I had, was that I had to wait two months from the final scan test to the date when I actually saw the neurologist for the results-----I felt that if I could have been told sooner what those results were I would have been happier”* (Ann 2, age 70, 20- 26).

4) Having to work too hard:

*— .it makes me very cross”* (Megan, age 52, 132).

5.4.4.5 *Depressed*

Two participants admitted feelings of low mood:

*—I got very depressed”* (Megan, age 52, 86)

*—...feeling very down”* (Sarah, age 39, 489)

5.4.5 *Summary of the Disruption Phase*

The most prevalent symptoms of TIA that participants described were those associated with the FAST campaign (UK Stroke Association 2007), notably problems with arm and facial weakness and speech difficulties, as displayed in Figure 6 page 82. Emotive language was used in recounting the experience of limbs going and the struggle with the challenge of the sudden health threat.

Location when taken ill and the timing of seeking medical attention influenced the subsequent care received but this was also determined by factors in individual life philosophies. The timing of seeking medical attention was affected by levels of knowledge and understanding of the potential seriousness of the situation. It was interesting to note the levels of excessive physical activity that several participants had engaged in just prior to their illness event and this is discussed in Chapter 7 page 161. It appeared that some participants would have liked more timely information to meet their needs, which may in turn have alleviated some of the anxiety. Following the immediacy of the event and impact participants then moved into a transition stage starting with their medical journeys.

## **5.5. TRANSITION PHASE**

*—..waiting results from the medical profession to see what more they have to say”*

(Ann 1, age 70,122)

## 5.5. Transition Phase

Emergent themes, from the transition phase, displayed in Table 3 page 90, will continue to be illustrated with quotations followed by interpretation. Narrative analysis considering ongoing impact upon individuals will be woven into the findings where appropriate.

### 5.5.1 Theme (5): “The after effect”

Participants continued to talk about their ongoing reaction. The recovery from the TIA was a struggle, where the self-identity was being re-configured in the transition phase. Following TIA, unlike stroke, the physical recovery was almost immediate and complete:

—*...it came and went so quickly*” (James, age 59, 42)

—*...within one minute I could walk normally*” (Ann 1, age 70, 98)

However, the psychological aftermath was the ‘war’ and struggle to come to terms with the health threat:

—*...it really did shake me up quite badly, not physically but certainly mentally*” (Andrew, age 65,272)

—*...it’s much more severe on me psychologically than it is physically*” (Ann1, age 70,143)

—*...the after effect-----two or three weeks afterwards----I felt very down*” (Sarah, age 39, 489)

—*I got depressed* — (Megan, age 52, 172)

### 5.5.2 Theme (6): Medical Journey

Core stories were used to relate specific accounts of participants’ medical journeys. These were illustrative of transition, how individuals were moving towards a state of adjustment and change, and what had occurred along the way to influence that process by way of learning. Two examples are given below, from the youngest and oldest participants who had quite different experiences.

#### Sarah (age 39)

*It was a good 20 minutes before I had to alert somebody that I was having difficulties. The policeman said —I’ll call an ambulance”. The ambulance man was asking questions and the ambulance driver said —I don’t like this; lets get her across to hospital”. They took me into*

*hospital and I went into A & E. They said —askher to smile”. The ECG monitor was on and someone was talking to me. The doctor came down and assessed me; he’d done all the various tests.*

*I stayed in overnight. The doctor said —it’s looking at being a mini stroke”. Before I left the hospital he wanted to run the tests on the echogramme and he said —I can organise for you to have it all done today, all your tests, all your blood tests, all Dopplers”, all done within that period of time to save me coming back, so I couldn’t have been in a better place. On the day it happened, they had me at the scan pretty much straightaway, the Doppler later in the afternoon and blood tests were done throughout the day. I had that done (echogramme) next day. A hole between two chambers of the heart ---most probable cause was that I had a clot in my leg that had come up, gone through my heart, gone over through the chambers in the hole in my heart and then caused a stroke. I’ve been back to the doctor; he said I would be part of this research and study. My GP referred me up to the neurologist here who was in complete agreement with the other doctor and he said not to interfere, —you’re in the right hands”. Last week I was back to have---it was when you swallow the ultrasound thing so they do it from the inside. I’ve got to go back to see the doctor about whether they are going to operate on the heart to close it up. I’ve had excellent being looked after.*

### **Esmond (age 86)**

*I went the next day and saw my doctor---she thought it was a stroke. Then a few days after I’d seen the doctor I had a bloodshot eye and then I saw Dr-----, he said it’s nothing to do with that but he said I’ll get you into the stroke clinic. He checked and found that the first doctor had put things in for me to come up. I think it was about a month I had to wait, or three weeks, something like that. I had various tests and they seemed to think it was that.*

*I haven’t been for any tests yet. I’m due. I’ve got them with me, what I’ve got to do actually. Where am I? Friday I’ve got to come up and have an x-ray on my head. Then on Monday 2<sup>nd</sup> July I’ve got the carotid arteries in the neck is it? Then on 5<sup>th</sup> July I go back to see Dr----- .I’ve got a letter with the appointments and what will happen with the scan on the head and then the arteries will be, well similar to what a pregnant woman would have to look for any clots.*

*I was going to wait until I get the results of these tests and things and see what is going to happen. Both of us have got high blood pressure. They seem to control it quite well with tablets. The doctor prescribed some pills, including an aspirin a day and I asked her about driving and she said I’d be alright to drive. The doctor at the clinic sat and talked for a while and I’m taking the two pills he suggested.*

The experience differed on account of one participant presenting at A& E and the other visiting their GP with the latter resulting in time delays. However, the endpoint of receiving medical care was much the same. The medical journey for both involved interaction with various medical personnel and their roles. Core stories relating to two participants’ medical journeys have been presented above and now specific points in the medical journey will be considered.

The experience of TIA was a journey not only in terms of the medical journey but also a pathway to adjustment and change through the experience of a life-changing event. The

direction the journey took was influenced by the interaction with, and roles of, those encountered along the way; in particular the doctor-patient relationship and the balance of power therein. Power and paternalism are discussed below.

#### 5.5.2.1 Roles Encountered in the Medical Journey

The patient could have been seen as a student on a learning curve:

*—..the first thing I done was go on the internet---the stroke association site”* (Sarah, age 39, 331)

The hospital doctor could have been the lecturer as the supplier of information:

*—..waiting results—from the medical profession to see what more they have to say”* (Ann 1, age 70, 122)

The GP could have been the personal tutor:

*—..the information will go to my GP who will---have a discussion with me”* (Ann 1, 274)

The Expert Patient (Expert Patient Programme 2002) could be the mentor providing peer support:

*—..to relay one’s own experience-----I think that would be an excellent idea, because the more support you have around you the better it is”* (Ann 2,468)

This was part of participants’ *—..learning curve”* (Andrew, age 65, 211) and how, where and from whom they were acquiring the necessary knowledge and skills for adjustment.

#### 5.5.2.2 First Medical Contact Post TIA

Three participants were taken into accident and emergency (A&E) departments, two by ambulance and one by car:

*—..the ambulance driver said----let’s get her across to hospital----first went into the A&E department”* (Sarah, age 39,170-173)

*—..from ----- to ---- in the back of the ambulance”* (Andrew, age 65, 34)

*—They (family) came and picked me up and brought me to the -----(hospital)”* (Megan, age 52, 34)

The remaining four went to their GP within a few days:

*—I’ve seen my GP”* (Ann 1, age 70,109)

- I was able to see my GP within three days of the TIA”* (Ann 1,268)
- I went to the doctor on Monday (3 days later)”* (James, age 59, 35)
- I went the next day and saw my doctor”* (Esmond, age 86, 48)
- ...seeing the doctor a few days later”* (Arthur, age 71, 104)

#### 5.5.2.3 *—Programme of tests”*.

A programme of *—...all the various tests”* (Sarah, age 39, 202) was carried out during the short hospital stay for those who presented at A&E:

- ...have it all done today, all your tests---they had me at the scan pretty much straight away, then had the doppler and blood tests”* (Sarah, age 39,275-278)
- I did have a scan more or less straight away”* (Megan, age 52, 48)
- ...they did an ECG, blood tests----released me about three hours later”* (Andrew, age 65,34-35)

or following clinic appointments for those who saw their GP first:

- ...all these tests and a scan”* (Arthur, age 71, 139)
- ...a programme of tests----blood test, ECG---carotid---brain scan”* (Ann 1, age 70, 257)

#### 5.5.2.4 *—The medication”*

All participants commented on medication. Participants were compliant with medication but also had concerns.

##### 5.5.2.4.1 *Compliant*

All participants were taking their prescribed medications and those who had taken preventive medication for some time were more adjusted to this requirement:

- I do take my medication and I try to be a good girl”* (Ann 1, age 70,105)
- I take the pills and I wouldn't forget them”* (Megan, age 52,178)
- I take the advice, I take the medication”* (Andrew, age 65, 178)

Not forgetting them suggested an awareness of the need for and importance, of her medication but also the benefit that Megan attributed to the taking of medication. This

may have related to her experience of seeing both her husband and mother suffer recent strokes:

—*..my husband having it and my Mum*” (Megan, age 52, 68)

Four participants were already taking several medications:

—*..taking medication for hypertension---also for a high cholesterol*” (Ann 1, age 70, 24-26)

—*..another tablet to take from the doctors*” (James, age 59, 49)

—*I take the medication*” (Andrew, age 65, 178)

—*I'd had my blood pressure tablets changed*” (Megan, age 52, 32)

—*I've had my statins changed*” (Megan 78)

One participant, Sarah, made only a brief comment about medications related to stroke prevention in that she was taking medication:

—*I take Plavix-----the aspirin*” (Sarah, age 39,446-448)

#### 5.5.2.4.2 Concerned

Issues of concern regarding medication were:

##### 5.5.2.4.2.1 Limitations of Medication

Limitations of medication were noted. Ann and Andrew were resentful of the TIA having not been prevented by their prescribed medication, for example:

—*I thought I was doing the right things*” (Andrew, age 65, 270)

—*I feel resentful---I do take my medication---why has it happened?*” (Ann 1, age 70, 104-105)

Two participants recognised and seemed accepting of the limitations of medication in the scope of prevention:

—*I think whatever happens, happens ultimately*” (James, age 59, 201)

—*..it prevents you from getting it as early as you might have done*” (Ann1, age 70, 29)

Again this inevitability may have been linked to both participants seeing close relatives suffer strokes, and this is discussed further under ‘What is the right thing to do?’ below.

#### 5.5.2.4.2.2 *—A lot of tablets*”

Three of the participants did not normally take medication:

- I don't usually take tablets*” (Megan, age 52, 176)
- I'm not a great pill taker*” (Esmond, age 86,353)
- I was always anti taking any medicine*” (James, age 59, 86)

and there was concern about the amount of medication participants were required to take, for example:

- I've got a lot of tablets at the moment*” (Megan, age 52, 176)
- taking half an aspirin a day to my normal medication*” (Ann 1, age 70,113)

#### 5.5.2.4.2.3 *Prescriptive Practice*

Prescriptive practice caused concern for some participants, for example:

- ...another tablet to take from the doctors. It just means more inconvenience*” (James, age 59, 49)
- ...start taking the aspirin immediately*” (Arthur, age 71, 138)
- ...promptly put on Simvastatin for the cholesterol and Cavisol for the blood pressure*” (Arthur 142)

This linked to paternalism in issues of power, discussed below under section 5.5.3.4.3.3.

#### 5.5.2.4.2.4 *Wishing to —...find an alternative*”

Three participants were deliberating alternatives to medications in lifestyle adjustment, for example:

- ...if I could find an alternative medicine I would probably do it*” (Andrew, age 65, 51)
- ...my aim would really be to get off the medication and have a go at it the alternative way*” (Arthur, age 71, 149)
- ...leave it up to me and my personal situation*” (James, age 59, 174)

#### 5.5.2.4.2.5 *Possible Side Effects*

There was concern about the effects and side effects of the medication, for example:

—...*the problem is with not knowing the baseline and really what I'm achieving*" (Arthur, age 71, 146)

—*It's difficult to really know how much damage statins will do*" (Arthur 169)

—*I've had my statins changed because they were making me ache. I was very achey in the morning*" (Megan, age 52, 78)

—...*is the medical profession knowledgeable enough about what reaction there is from one drug to another?*" (James, age 59, 168)

This echoed issues of trust and faith in the medical profession, discussed in Chapter 7, pages 168-169.

Two participants commented on the effects they felt the statins may be having on their exercise tolerance, for example:

—...*sometimes---there's nothing left in my legs and I think that's the medication because I didn't feel like that until I took it*" (Arthur, age 71, 156-158)

—*I have just washed my car---that's it, I'll have to sit down--- normally I'm a busy person*" (Megan, age 52, 86)

#### 5.5.2.5 Clinic —appointments"

Appointments were made for all participants to attend TIA clinics. They were either seen by a neurologist or a stroke physician depending on to whom they were referred by their GP:

—*I saw a neurologist*" (Ann 1, age 70, 110)

—*I saw the specialist within a few weeks*" (Ann 1, 209)

—*It was quite a long time before I was actually given an appointment*" (Arthur, age 71, 119)

—...*a month before I saw the doctor*" (Arthur 132)

There was some inequality in provision in that the three participants who presented at A&E had more rapid attention and investigations than those who presented to their GP. However, there was further inequality in that these three were seen at three different

hospitals. One was seen by a leading stroke physician at a teaching hospital. A second participant was treated at a general hospital not near his home and the third person was seen at an acute hospital where she worked. So within this group of three, circumstances of location when taken ill determined their initial medical attention.

### 5.5.3 *Theme (7): “We’re on a sharp learning curve”*

The learning process evolved throughout all phases of the TIA as knowledge was accumulated by participants. The components thereof are illustrated below.

#### 5.5.3.1 *Components of the Learning Curve*

The experience was new for participants and therefore represented a learning event:

—*...we’re on a sharp learning curve”* (Andrew, age 65, 99)

##### 5.5.3.1.1 *Knowledge*

Knowledge was acquired about pathophysiology and pharmacology and the following terms were used:

—*...furring up of the arteries caused by fats and smoking”*  
(Esmond, age 86, 124)

—*...blood flow to the brain”*  
(Andrew, age 65, 81)

—*...a blockage of the arteries in the brain”*  
(Esmond 58).

##### 5.5.3.1.2 *Skills*

Skills were learnt about self-management, for example exercise and adjustment:

—*‘m not doing any more major building work. I shall do some landscaping which is just laying a few bricks”* (Andrew, age 65, 217)

—*...we have finally solved the problem by walking to the station, travelling very light with a rucksack instead of a suitcase. You can adapt”*  
(Ann 2, age 70, 180)

Participants were modifying their behaviour to accommodate healthier lifestyle practices.

##### 5.5.3.1.3 *Attitudes*

Attitudes were changed by the experience:

—*‘ve started to take stock on my priorities in life”* (Sarah, age 39, 424)

#### 5.5.3.1.4 Values

Values were reviewed in the light of the experience, for example family values:

- ...*a very supportive family*” (Andrew, age 65, 256)
- I’m very fortunate in that I have a good family*” (Ann 1, age 70,241)
- ...*my husband has always been very supportive*” (Ann 2,129)
- ...*my family has come to the fore---they will now do more than they have in the past*” (Ann 2, 95)
- ...*she (daughter) has been marvellous*” (Ann 2,121)
- ...*he’s (partner) been very very very supportive*” (Sarah 395)

The four components of the learning curve, namely knowledge, skills, attitudes and values, were demonstrable in all participants’ accounts to varying degrees. The variation related to where participants were in the medical pathway and at what stage in their transition. The four elements represented a curriculum for change that comprised subjects that each participant needed, in order to arrive at a stage of adjustment in dealing with the consequences of the event. This gave rise to the question: *How was contextual TIA-related knowledge acquired and what was the content therein?*

#### 5.5.3.2 How Did They Know?

Knowledge relating to the TIA was acquired through experiential learning from own TIA experience, common to all participants, and that of seeing others, self-directed learning and taught from medical professionals.

##### 5.5.3.2.1 Experiential Learning

Experiential learning was *“first hand”* for all participants in experiencing their own TIA and, for some, from seeing others. Four participants *“...knew about strokes”* (Andrew, age 65, 74) from seeing close relatives or associates with the same as illustrated below:

- I’ve seen it happen to other people*” (Ann 1, age 70, 89)
- I knew it was something, as I say with my husband having it and my Mum had one at my age*” (Megan, age 52, 68)
- ...*it is learnt from other people and their personal experiences*” (Ann 1, 95)

—...*he (father) would have lots and lots of mini strokes, so I've seen it first hand*" (Arthur, age 71, 201)

—...*she (mother) had a small stroke----I've had a small stroke*" (James, age 59, 100)

#### 5.5.3.2.2 Self-Directed Learning

Some of the self-directed learning had taken place prior to the event, for example:

—*I read bits but I didn't really take it in*" (Megan, age 52, 140)

—...*it's been on the telly at odd times and it sort of sinks in and you don't realise you've taken it in*" (Esmond, age 86, 62)

but for others this had been triggered by the disruption, for example:

—*I read it up*" (Esmond 60)

—...*the first thing I done was go on the internet----I read it up as much as I could*" (Sarah, age 39, 333)

Neither Esmond nor Sarah had much prior knowledge of stroke-related illness and so were trying to boost this and —...*had a thirst for knowledge*" (Sarah 343). Likewise Ann wanted —...*to know what more I can do to help myself*" (Ann 1, age 70,114).

#### 5.5.3.2.3 Taught by Medical Professionals

The GP and clinic doctors were the main sources of information, for example:

—... <i>sk (GP) thought it was a stroke</i> "	(Esmond, age 86, 48)
—... <i>tky (doctors) said it was a stroke</i> "	(Sarah, age 39, 320)
—... <i>tk doctor (GP) gave me more advice about it</i> "	(James, age 59, 222)
—... <i>tky (clinic doctors) gave me something on it</i> "	(Megan, age 52, 136)
—... <i>tk doctors were convinced it was a TIA</i> "	(Arthur, age 71, 188)
—... <i>Dr---said it's looking at being a mini stroke</i> "	(Sarah 249)
—... <i>tky (doctors) explained to me---it was where the speech area of the brain is</i> "	(Sarah316)
—... <i>sk (specialist) explained things very carefully</i> "	(Ann 1 age 70,261)
—... <i>iformation will go to my GP who will in turn have a discussion with me</i> "	(Ann 1,274)
— <i>have listened and taken advice</i> "	(Andrew, age 65, 102)

#### Box 12. Taught by Medical Professionals

### 5.5.3.3 What Did They Know?

Knowledge related to the illness event was varied amongst participants.

#### 5.5.3.3.1 Stroke-Related Knowledge

Participants had some prior knowledge related to stroke and made the association with their symptoms:

- “m having a stroke”* (Ann 1, age 70, 66)
- ...my first reaction was to speak aloud and then to smile and then to move my left arm”* (Ann1, 71)
- I realised classic symptoms of face dropping----a stroke”* (Sarah, age39, 190)
- I think I’ve had a stroke”* (Sarah 249)
- ...a taste of what could happen”* (Arthur, age 71, 189)

However, there was doubt in Esmond’s mind as he *—...didn’t think it was a stroke really”* (Esmond, age 86, 177) although he *—...had a rough idea”* (Esmond 54) what the term stroke meant.

#### 5.5.3.3.2 TIA-Related Knowledge

TIA-related knowledge was more limited, particularly the term TIA, for example:

<i>—I was not aware of the mini type at all”</i>	(Andrew, age 65, 79)
<i>—I was completely unaware of this”</i>	(Sarah, age 39,288)
<i>—...it meant absolutely nothing”</i>	(Sarah 327)
<i>—I knew nothing about it”</i>	(Sarah 343)
<i>—I didn’t (know anything about TIA)”</i>	(Megan, age 52,136)
<i>—I’m not fully aware of it but my mother had a slight stroke also”</i>	(James, age 59, 77)
<i>—I hadn’t really (heard of TIA)”</i>	(Esmond, age 86, 170)
<i>—I knew what I thought it might be, I mean the description of TIA I knew nothing about”</i>	(James 260)
<i>—I didn’t know what it was”</i>	(James 263)
<i>—I called it a mini stroke but it’s not a stroke”</i>	(James 265)
<i>—I kept calling it a mini stroke, so that makes sense less than 24 hours, so that actually puts that into context”</i>	(Sarah 328)

Box 13. TIA-Related Knowledge

Some participants claimed to know nothing yet later in the interview offered very accurate descriptions:

*—..if one has after effects it's a stroke, if it's a TIA there's usually no after effects"* (James, age 59, 267)

*—I kept calling it a mini stroke, so that makes sense less than 24 hours"* (Sarah, age 39, 327)

*—I know that with a TIA feeling and movement can come back within 24 hours"* (Ann 1, age 70, 93)

#### 5.5.3.3.3 Knowledge of Pathophysiology

Knowledge of pathophysiology was varied but fairly accurate:

*—I had a clot in my leg that had come up, gone through my heart, gone over through the chamber in the hole in my heart and then caused a stroke"* (Sarah, age 39, 282)

*—..furring up of the arteries caused by fats and smoking"* (Esmond, age 86, 124)

*—I know that with a TIA feeling can come back within 24 hours"* (Ann 1, age 70, 93)

*—..something wasn't connecting"* (Ann 1, 287)

*—..my knowledge of it now is that---there is a loss of blood flow to the brain and you get a minor stroke"* (Andrew, age 65, 81)

#### 5.5.3.3.4 Knowledge Linked to Investigations

Knowledge linked to investigations was part of the pathophysiological knowledge:

*—..the brain scan said---I think it was a front lobe---there was a small lesion there"* (Sarah, age 39, 314- 315)

*—I've got that ----carotid---to see if you've got a clot"* (Megan, 52, 196- 200)

*—..three arteries that supply the brain ---check on those to make sure there was no blockage"* (James, age 59, 144-145)

*—I've got the carotid arteries in the neck---to check if there was any blockage in the arteries"* (Esmond, age 86, 114- 120)

#### 5.5.3.3.5 Knowledge of *risks*

Knowledge of risks for stroke and TIA is mentioned here in the context of knowledge. Some were more aware of risk factors especially if they had already received medications prior to the TIA and were being monitored by their GP:

*—I know about risks*” (Megan, age 52, 154)

*—I have been under the care of my GP and taking medication for hypertension---about 16 years---I’ve also had medication for the same number of years for a high cholesterol---so I’ve always been aware of these factors in the background*” (Ann 1, age 70, 24- 27)

Others had gained awareness of risks:

*—I’m more aware of that sort of thing (dehydration) and the risks and things*” (Sarah, age 39, 407)

There was also awareness of genetic risks:

*—...they (children) know about their grandmother’s series of little TIA’s---they also know there are certain tendencies within families that can be carried on from generation to generation*” (Ann 1, age 70,136-137)

*—I suppose more likely to be genetics involved*” (James, age 59, 334)

*—...the only thing that made me think was when my doctor asked is there anyone else in the family that this has happened to? And this happened to my mother*” (James 355- 356)

This was not the end of the knowledge chain, setting aside lifelong learning, because participants wanted to know more:

*—I’d like to know what more I can do to help myself*” (Ann 1, age 70, 113)

*—...had a thirst for knowledge*” (Sarah, age 39, 343)

*—...we’re on a sharp learning curve*” (Andrew, age 65, 99)

This is further explored under *‘What is the right thing to do?’* below.

#### 5.5.3.4 Power

The whole medical experience gave rise to issues of power, largely linked to knowledge.

#### 5.5.3.4.1 *Empowered Through Knowledge*

Knowledge was gained from personal experience, from seeing others, from doctors, the internet and media:

- ...*learnt from other people and their personal experiences*” (Ann 1, age 70, 95)
- ...*he said I’d had a TIA*” (Megan, age 52. 48)
- ...*the first thing I done was go on the internet*” (Sarah, age 39, 331)
- ...*it’s been on the telly at odd times*” (Esmond, age 86, 62)

There was an element of seeking empowerment through knowledge and participants wished to be more informed so they could better self-manage and take control. They were questioning and searching for information:

- I’d like to know what more I can do to help myself*” (Ann 1, age 70,113)
- I had a thirst for knowledge*” (Sarah, age 39, 343)

#### 5.5.3.4.2 *Conferred Power*

Conferred power was about giving people authority and power partly through labelling, for example Ann referred to the junior clinic doctor as—...*the specialist*” (Ann 1, age 70, 261) with great reverence and respect. Equally Sarah was in great awe of the doctor she saw and she had —...*found out so much more about him (medical consultant) and his work and everything else he does*” (Sarah, age 39, 198), and the local neurologist compounded her view by saying —...*you’re in the best hands there*” (Sarah 302). The person referred to may have been deserving of this omnipotent image since he was an eminent stroke physician at a leading teaching hospital. The issue here was also about the faith and trust that participants put in the medical profession and this is explored in Chapter 7. Out of that faith sprung hope for the future. However there were some disempowering issues, detailed below.

#### 5.5.3.4.3 *Disempowerment*

Empowerment was important because participants had experienced a health threat and as a result they were in a state of transition within which change could be positively influenced. They did experience some disempowering aspects, for example:

#### 5.5.3.4.3.1 *Lack of Information*

—...*there doesn't seem to be any way of finding out what I'm achieving and what the drugs are doing*" (Arthur, age 71, 161)

—...*is the medical profession knowledgeable enough about what reaction there is from one drug to another?*" (James, age 59, 168)

#### 5.5.3.4.3.2 *Labelling*

Labelling was another source of disempowerment, and if participants felt disempowered it could have affected their learning to adapt. Arthur felt that, as stroke had been more associated with older age groups, he would now be seen in that category and —...*suddenly became classified as elderly*" (Arthur, age 71, 120). Arthur was still in full time employment and clearly did not wish to be viewed as elderly. This was probably representative of how people in that age group now feel with increasing longevity. Age related issues were also noted by three other participants:

—...*there was nothing to explain why I would have had a stroke and being my age----why has it come out of the blue?*" (Sarah, age 39, 272)

—...*she (mother) was a lot older*" (James, age 59, 80)

—...*he (GP) just said I was a little young to have experienced an attack like that*" (James, age 59, 357)

—...*she (mother) was my age when it happened*" (Megan, age 52, 146)

—...*for goodness sake, I'm now over 70*" (Ann 2, age 70,269)

—...*their (participant's children) grandmother's series of little TIA's in extreme old age*" (Ann 1, age 70,136)

#### 5.5.3.4.3.3 *Paternalism*

Having put their faith in the medical profession, the participants then succumbed to dominance and paternalism whilst they were still vulnerable in recovery. For example they were told what to do and some things they did not wish to do:

—...*start taking the aspirin immediately; you can't drive for a month*" (Arthur, age 71, 138)

—...*it annoys me that I have to take medication*" (James, age 59, 90)

—...*she's (wife) very annoyed that I'm taking medication*" (Arthur 212)

All power issues were linked to knowledge. Paternalism could have been challenged by those who were well informed and wished to take control and self-manage their lives, for example: —...*leave it up to me and my personal situation*" (James, age 59, 173)

—...*once you've got the advice make up your own mind*" (James 214)

—...*he said 'you're not doing enough exercise'. I said 'well I'm fairly active' and he said 'yes but it's not the right active, building, gardening and things'. Although I notice that gardening for half an hour is one of the things you can do to keep your heart happy*" (Andrew, age 65, 53- 55)

Issues relating to paternalism together with trust in the medical profession are discussed in Chapter 7 on pages 164 and 168-169.

#### 5.5.4 **Theme (8): "What is the right thing to do?"**

There may appear to be overlap between this theme and the previous in section 5.5.3 but here participants were at the next stage in searching for answers in order to 'move on' whereas in section 5.5.3 there was assessment of accumulated knowledge and how that had been accrued and facilitated or hindered. In trying to rationalise and come to terms with what had happened participants posed several unanswered questions.

##### 5.5.4.1 "Why has it happened?"

Two participants were questioning why this had happened to them because they were already on the preventive medication and lifestyle:

—*I am careful with my diet and my exercise and I do take my medication and I try to be a good girl and why has it happened?*" (Ann1, age 70, 99)

—*I thought I was doing all the right things?*" (Andrew, age 65, 270)

Two were questioning because of their age:

—...*there was nothing to explain why I would have had a stroke and being my age, why has it come out of the blue, all of a sudden with no history?*" (Sarah, age 39, 272)

—...*he (GP) said I was a little young to have experienced an attack like that*" (James, age 59, 357)

#### 5.5.4.2 *What Were the Causes?*

Causes in terms of modifiable and non-modifiable risk factors, to include behaviour, medical risks and genetics are shown in Table 2 page 83 as they occurred before the event and not as a result of the TIA. However the TIA itself meant an increased risk of a further event. A summary is given here as a background to the subsequent participant awareness of causes and risks.

All participants had raised blood pressure; three had high cholesterol; two were overweight; one had atrial fibrillation (irregular beating of the heart); two were smokers and one consumed excess alcohol. Four had stressful working conditions and four had a close relative (parent) who had experienced a stroke.

Although participants were surprised that a TIA had occurred:

*—..it's a total surprise”* (James, age 59,333)

*—..it's a surprise more than anything”* (Esmond, age 86, 333)

and were questioning causes:

*—..nobody has actually been able to explain cause”* (Andrew, age 65, 74)

*—..find out what on earth it would mean”* (Arthur, age71, 140)

most were aware of their own risk factors as they spoke of them in the interviews:

*—I know about risks”* (Megan, age 52,154)

*—..taking medication for hypertension----and high cholesterol-  
---so I've always been aware of these factors”* (Ann 1, age 70, 24- 27)

Several had modified their unhealthy behaviours:

*—I was certainly drinking too much----I've cut right back”*  
(Andrew, age 65, 67)

*—..cut out smoking----more conscious about what I'm eating”*  
(Sarah, age 39, 403)

However, participant commitment and motivation to change lifestyle was not apparent in all aspects. For example when speaking of the need to exercise more Sarah said:

*—..unfortunately I haven't made a conscious effort to that yet”*  
(Sarah, age 39, 419)

and James was hoping to not to have to make changes:

*—I hope I don't need to do anything really”* (James, age 59,295)

Sarah was giving several reasons why she perceived this change of behaviour to be difficult for her: *—..with the housework and everything else that's got to be done during the week, I find it very hard”* (Sarah 416) and yet she recognised *—..it is a lack of will power and there's always time to find to do these things”* (Sarah 418). So this suggested a shift in her thinking.

Esmond was in the high risk category for stroke on account of his age and duration of symptoms of his TIA. Sarah and Ann had a moderate risk, Sarah due to clinical features and duration of symptoms and Ann due to clinical features and age. Andrew, Arthur, James and Megan had a low risk, James and Megan due to age and duration of symptoms and Andrew and Arthur despite being over 60 years of age due to duration of symptoms. Additionally Arthur only had speech disturbance and not unilateral weakness as a clinical feature.

As already discussed the response for those accessing the medical service via their GP was slow and protracted, which could have represented a further risk:

*—..a month on until I saw the (hospital) doctor”* (Arthur, age 71,132)

*—..it was about a month I had to wait”* (Esmond, age 86, 64)

Having deliberated causes and risks in the transition phase, participants were then in a position to move on to consider lifestyle adjustments that could be sustained as beneficial changes, as discussed under the Change Phase.

#### 5.5.4.3 *What More Could be Done by Self-Management?*

Three participants were looking for answers as to what more they could do to help themselves:

*—I'd like to know what more I can do to help myself?”* (Ann1, age 70, 112)

*—What is the right thing to do?”* (James, age 59, 184)

*—I don't think there is anything else I can do?”* (Megan, age 52, 208)

#### 5.5.4.4 *What Were the Effects of the Medication?*

Both Arthur and James wanted specific advice about the effects of the medication as already illustrated, but mentioned here in the context of participants searching for answers. Below is a flowchart demonstrating that, collectively, participants had answered several of their posed questions whilst travelling on their medical journey.

#### 5.5.4.5 *What to do for the Best?*

The chronological journey is relayed from key points, taken from all transcriptions in Figure 9. This could be used as a guide or part of a workbook for those with a new experience of TIA and it had answered several of the participants' posed questions, for example about causes, lifestyle and self-management. Here participants were demonstrating advancement towards adjustment and consolidating changes that will be further discussed under the Change Phase. As a result of some unanswered questions there was a need for participants to —*...get back on and carry on*” (Sarah, age 39, 522) with their lives whilst accepting a degree of uncertainty about the future having experienced —*...a taste of what could happen*” (Arthur, age 71, 189).

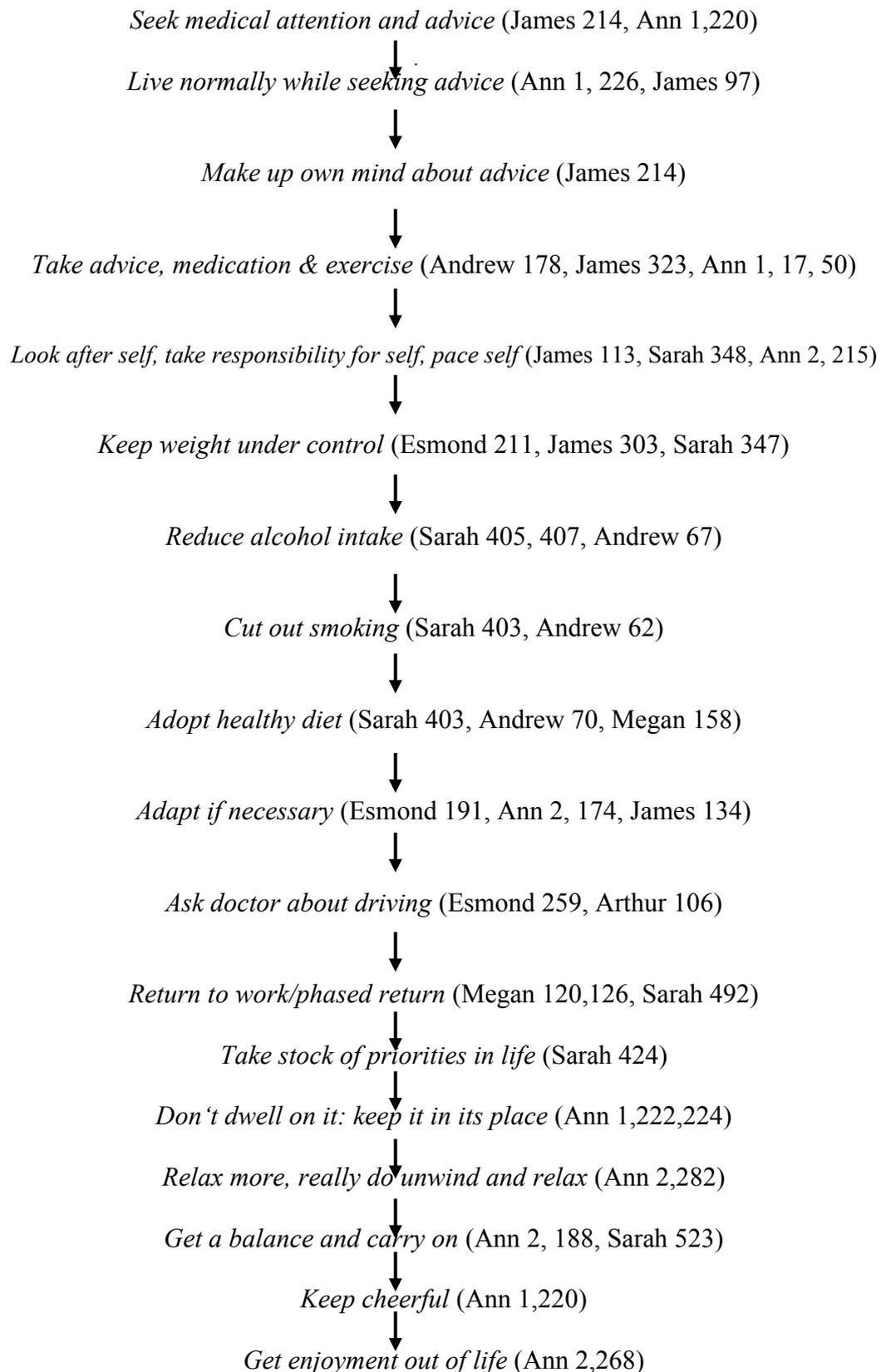


Figure 9. What to do for the Best

### 5.5.5 *Theme (9): “Unnerved because of the uncertainty”*

Anxieties about the future were expressed as well as coping mechanisms to deal with this uncertainty.

#### 5.5.5.1 *Possible Recurrence*

Five participants were concerned about the possibility of a future recurrence or that it could lead to a stroke, for example:

—...*is this the start?*” (Ann1, age 70,108)

—...*a taste of what could happen* — (Arthur, age 71, 189)

—...*it does worry me that it could happen again at any time*” (Sarah, age 39, 458)

#### 5.5.5.2 *Effects of Medication*

There were several unanswered questions regarding medication, as illustrated above.

#### 5.5.5.3 *Imparting of Information*

Not all participants may have wanted the same level of detailed information about their health depending on issues of locus of control and health belief. Some were happy with the paternalistic approach, at least in part:

—*I have listened and taken advice*” (Andrew, age 65, 102)

—*I do take my medication and I try to be a good girl*” (Ann 1, age 70,105)

Also participants’ receptiveness to new knowledge was dependent upon where they were in their transition. An example is given here of James: when asked how much interaction there was with the clinic doctor, he initially said —...*none*” (James, age 59, 247) but then added —*I can’t remember now exactly word for word but I was asked questions about how I felt at the time but I can’t remember now 100% what was said to be honest*” (James 249-250). This suggested that people only hear what they are ready to hear and that some might go to a clinic with their own expectations and agenda. For example: —*I was under the impression that I would be having an MRI scan. In fact it was just simply check the blood pressure and arrange a date for the future*” (James 224-225). Other important messages may also have been missed.

This points to the need for the same information to be given on more than one occasion and may be in written as well as a verbal format, in order to meet different learning needs and styles with consideration of timing of where participants were on the cycle of change. One participant expressed satisfaction with the information, for example: —...*she (doctor) explained things very carefully*” (Ann1, age 70, 261). Also, it is always helpful to be accompanied to medical appointments so that two people can hear important messages and remember to ask relevant questions:

—...*she (neurologist) was very happy to have my husband in with me-----he heard the story as well*” (Ann 2, 69)

Although both Arthur and James were very resentful of the need for medication, both were committed to doing whatever was necessary to avoid a recurrence:

—*I'm going to do what I can to avoid it*” (Andrew, age 65, 85)

—*I wouldn't want things to get worse and I would do whatever is necessary to avoid that*” (James, age 59, 134)

Mixed messages were echoed in other issues. For example, as discussed above, participants claimed to know —...*nothing at all*” (Sarah, age 39, 323) but they subsequently revealed considerable knowledge that was mostly accurate. Participants heeded the medical advice:

—*I'm quite happy taking the medical advice*” (James 176)

—*I have listened and taken advice*” (Andrew 102)

albeit reluctantly at times, but recognised that doctors are only human beings and that the human body is complex so cannot be treated in black and white terms:

—...*there's always grey areas isn't there?*” (James 161)

#### 5.5.5.4 Awaiting Medical Advice

Hopes were being pinned on the awaited advice and information:

—...*waiting results from the medical profession to see what more they have to say*” (Ann 1, age 70, 122)

—...*there is a slight feeling of being in limbo until I get some positive results*” (James, age 59, 289)

—*I was going to wait until I get the results of these tests and things and see what is going to happen*” (Esmond, age 86, 193)

#### 5.5.5.5 *“Carry on as normal”*

Participants were trying to keep cheerful and live as normally as possible during the uncertain time:

- “...try to keep cheerful”* (Ann1, age 70, 220)
- “...try to do as usual”* (Esmond, age 86, 76)
- “...get back on and carry on”* (Sarah, age 39, 522)
- “I’m just carrying on as normal”* (James, age 59, 97)
- “...did everything and felt normal”* (Arthur, age 71, 105)

#### 5.5.5.6 *Strength from Family Support*

Ann, Andrew and Sarah gave particular emphasis to the strength they gained from family support:

- “I think the family, a very supportive family, we are all supportive of each other”* (Andrew, age 65, 257)
- “I’m very fortunate in that I have a good family”* (Ann1, 241)
- “...my family has come to the fore”* (Ann 2, age 70, 92)
- “I had the whole family in at some point”* (Sarah, age 39, 266)
- “...he’s (partner) been very very very supportive”* (Sarah 395)
- “...the more support you have around you the better it is”* (Ann 2, 468)

Living with uncertainty gave rise to concerns that lead on from searching for answers, but also unmasked coping strategies and revealed how participants were dealing with unresolved issues. This will be further explored in the Change Phase.

#### 5.5.6 *Summary of the Transition Phase*

Participants were empowered by the accumulation of knowledge, gained by means of experiential and self-directed learning and teaching from medical professionals. However, they were disempowered by their unanswered concerns and, for some, paternalism of the medical profession. Living with the uncertainty and threat of a possible stroke in the future

was unnerving but most participants were adapting and starting to make, or contemplate, lifestyle changes.

The inequality of provision of care and inconsistent advice from some GP's did not meet the standards and guidelines of the National Stroke Strategy (DOH 2007c) for some participants. Generally participants were resourceful and were getting on with their lives.

## **5.6. CHANGE PHASE**

*—I am carrying out these little rules with regards to exercise and diet---  
although I had to think about them initially, with time they become  
automatic. That enables you to keep the original reason for your change in  
it's place.”*

(Ann 2, age 70,383-386)

## 5.6. Change Phase

Throughout the process from disruption through transition to change there was a noticeable shift in the use of metaphors. Ann who initially spoke of being *—..struck dumb*” (Ann 1, 68) moved to *—..get your mind tuned*” (Ann1, 150) and finally to *—..keep it in it’s place*” (Ann 1,222). The latter phrase seemed to indicate that her resolve was strengthened and she was getting on with her life despite the event and health threat:

*—..keep cheerful and forget about it if you possibly can*”  
(Ann 1, age 70,220)

*—I don’t want it sitting on my shoulder*” (Andrew, age 65, 285)

Change was taking place in all participants depending on where they were in their own pathways and transitions. Changed lifestyle behaviour was particularly apparent in Andrew’s account.

Reduced alcohol intake:

*—I used to drink quite a lot ---up until this first TIA----I’ve cut right back*”  
(Andrew, age 65, 65)

Stopped smoking:

*—I don’t smoke, I used to*” (Andrew 62)

Improved diet:

*—..we eat fresh food, I eat a lot of fruit, a lot of veg*” (Andrew 70)

Increased exercise:

*—I now religiously exercise----I enjoy long hearty walks*” (Andrew 105)

Adhering to medication regimes:

*—I’ve been sent away with my medication which I take religiously*”  
(Andrew 88)

Taking more leisurely holidays:

*—..we’ve decided that our holidays would be using a caravan*”  
(Andrew 147)

Reducing stress and commitments:

*—..if the grass grows long, it grows long*” (Andrew 196)

*—I’m not doing any more major building work*” (Andrew 216)

Andrew was more advanced in adjusting his behaviour and sustaining these changes because he had experienced a second TIA and his philosophy now was: *—I shall do anything necessary*” (Andrew 179). It was Andrew who used such vivid war images, for

example: —...*a shot across the bows*” (Andrew 161) to relate his experience which, in Boylstein’s study of metaphor shifts in stroke recovery (Boylstein et al. 2007), indicated an indomitable fighting spirit. However, it also meant that if recovery was not achieved that those with such a fighting spirit could easily be crushed and become quite depressed. This was indicated in Andrew’s comment:

*—I play an active role in life and always have done and to have that curtailed would make me very unhappy”* (Andrew 194).

Emergent themes that arose from the change phase of the TIA experience are presented in Table 3, page 90 and illustrated with quotations and interpretation below. The findings concerning behaviour change are placed critically in a thematic framework illustrated by a vignette below, pertaining to one participant’s story of lifestyle change.

### 5.6.1 Vignette of Behaviour Change

This core story, relating to behaviour change, has been crafted directly from participant narrative and was taken from Ann’s (age 70) first interview before she had received the results of medical investigations. The story is codified in the margins where the text illustrates knowledge or relates to a particular model of behaviour change. K= knowledge, TT = transtheoretical theory, PMT=protection motivation theory, HBM=health belief model, SE=self efficacy, PBC=perceived behavioural control and LOC=locus of control.

*I do walk everywhere and my husband and I enjoy walking whenever we can; we also swim once a week; we enjoy movement. It is essential to lead a balanced life between relaxation and enjoyment and work and exercise. I’m so aware of the importance of exercise. What I would like to know from someone is whether the amount of exercise and type of exercise that I take and have taken in recent years is considered by the medical profession to be sufficient for someone who is perhaps more at risk than others for stroke or heart attack. I need advice as to whether I should have more aerobic exercise.*

*I’ve continued with my normal routine. I haven’t cut down on anything, cut back, just continued as normal. I do try to walk between three and five miles five days a week and I do go swimming once a week. I’ve had a sensible diet, I don’t drink, well I drink a little yes, perhaps two glasses of wine at the week-end and I don’t smoke and I do take care that I exercise. My husband and I are active in the house, I have no help. We do all our own maintenance, decorating and gardening. So I would call myself an active person but I’m not I think very active aerobically.*

*I don’t know what it is I could change, except alter my exercise, maybe have more, I don’t know. I’m open to advice and suggestions and depending upon what advice I’m given I’d act upon it. I’d like to know what more I can do to help myself or what the professional advice might be.*

TT

K  
K

K  
K

The core story below relating to Ann’s subsequent interview, after the receiving of results of medical investigations, illustrates some behaviour changes.

TT	<p><i>I'm trying to do more exercise than I did before and make it more strenuous. I'm trying to walk more and relax more and just sit down with a glass of wine more, one a night, just so you really do unwind and relax. You have to take it into consideration (that you've had a TIA) when planning anything like an especially adventurous holiday. It wouldn't stop me doing what I normally enjoy doing but I'm aware of it from time to time and it'll never go away. I've got accustomed to a pattern of activity that's automatic. I had to think about them (changes) initially, with time they become automatic and that enables you to keep the original reason for your change in it's place. The neurologist said 'go and enjoy your retirement'. My husband has always been very supportive and friends understand. The more you have support around you the better it is.</i></p>	PMT
TT		
HBM TT	<p><i>As a result of the lifestyle session that I came to I've modified my diet slightly but I've only changed the fringe bits and my husband has altered his diet. I'm drinking soya milk and have taken up green tea and I'm eating more of the highly coloured fruit and veg. We were given such comprehensive written material to refer to. I've got to be really flexible, so that I fit that exercise in and I don't stray too far from the diet despite outside pressures which I get, which are perfectly normal. We're walking to the station and travelling very light with a rucksack instead of a suitcase. You can adapt but it's a pressure really but if you don't use it you lose it! I've got a pedometer, my husband has bought one as well, just a guide really to see how much I do. I try to do up to 10,000 steps at least three to four times a week but I don't keep to it sometimes.</i></p>	K
TT SE PBC		
LOC	<p><i>We need to take quite a bit of responsibility for ourselves. My initial feeling was resentment when this first happened but I can't resent it, because I'm still getting so much enjoyment out of life and as far as I can tell, if I'm sensible, I shall for some time. You just accept it and particularly being old it helps. We went through the Second World War and that is where my mother established a well balanced diet for us. She learnt a lot through that war to have gotten that advice and that has stayed with me through life.</i></p>	LOC
K		HBM
K		
LOC	<p><i>The health advice from the government is constantly changing but you do the best you can with the advice that is available at the time. But the advice I've received since my TIA, has been constant from all the experts. I would prefer to rely on the expertise of the specialists than look on the internet. Now I want to get on with the positive side of my life.</i></p>	

The model of behaviour change that was most closely aligned to lifestyle change issues in this core story was the transtheoretical theory or cycle of change, illustrated in Figure 3 page 47 (Prochaska and Di Clemente 1982). Ann was reflecting upon her lifestyle and contemplating what she could change, putting this into action and sustaining these changes. However the cycle of change model appears to be a closed circuit that does not take account of external influences, for example knowledge and only flows in one direction in a set order. The reality of peoples' lives, as demonstrated in the core story, is that change is very much influenced by external forces, for example support networks—*My husband has always been very supportive and friends understand. The more you have support around you the better it is*". Equally searching for answers—*I would like to know-----*", *I need advice*" and knowledge play a large part—*As a result of the lifestyle session that I came to I've modified my diet*" and *We were given such comprehensive written material to refer to*". Also the stages of change are more fluid than the model suggests in that people move

from one to the other in any order and direction before the change is consolidated or they have become —...*accustomed to a pattern of activity that's automatic*”.

Other models of behaviour change are echoed in Ann's story but to a lesser extent. For example the protection motivation theory, discussed on pages 45-46, was evident in her decision-making about modified travel plans—*You have to take it into consideration (that you've had a TIA) when planning anything like an especially adventurous holiday*”. In other words she had perceived the health threat and recognised and accepted the need for moderation and taking care of herself. However, the indication with this model is that it applies more readily to short-term changes in behaviour linked to a very recent health threat whereas as demonstrated in Ann's account her behaviour changes are sustained.

There is resonance in Ann's account with the health belief model, discussed on pages 43-44, in that the lifestyle behaviours that she spoke of are, in her mind, good measures for enhancing her health, particularly when she says —*As a result of the lifestyle session I've modified my diet*”. In other words not only did she believe that what she was doing would help prevent another TIA but she had had this reinforced by medical professionals. This model also embraces the importance of knowledge in that people will not contemplate changes in behaviour unless they have some knowledge about their illness and the implication of making changes (Rosenstock 1990) and Ann set out to find out more—*I would like to know---*”.

There was a sense of self-efficacy, discussed on pages 49-50, in Ann's story, in that she displayed confidence and belief in her ability to change her lifestyle, for example—*We're walking to the station and travelling very light with a rucksack instead of a suitcase. You can adapt*”. However, perceived behavioural control (page 45) was also demonstrated in her behaviour changes because she recognised that —*You can adapt but it's a pressure*” and —*I had to think about them (changes) initially*”. In other words she had perceived the effort required and accepted that level of commitment.

Loci of control (page 44) issues were evident in the core story. Ann's comment —*We need to take quite a bit of responsibility for ourselves*” demonstrated an internal locus of control in that she recognised that she was in control of her destiny, at least in part, by how she behaved. Also —*Now I want to get on with the positive side of my life*” illustrated an

internal locus of control in that she felt she had made the required changes and was now able to move on in her life. But there were also external locus of control issues as well, for example —*The neurologist said ‘go and enjoy your retirement’*” and —*My husband has always been very supportive*”.

### 5.6.2 Theme (10): "Moving on"

There was a sense of relief that a full recovery had been made and there had been no recurrence. It was against this background that participants were able to move on‘ with a measure of reassurance despite an element of uncertainty, for example:

#### 5.6.2.1 A Sense of Relief

—... <i>think myself lucky it was very mild</i> ”	(Megan, age 52, 90)
— <i>It’s not paralysed further and that it hasn’t affected anything ...I’m grateful for that</i> ”	(Ann 1 age 70, 146)
—... <i>it could have been much worse</i> ”	(Andrew, age 65, 277)
— <i>I am extremely lucky</i> ”	(Sarah, age 39, 457)
—... <i>it could have been a hell of a lot worse</i> ”	(Sarah 483)
—... <i>you’re so lucky to have this far and to be enjoying apparently good health</i> ”	(Ann 2,81)
—... <i>thank goodness there has been no repeat</i> ”	(Ann 2, 333)

#### Box 14. A Sense of Relief

Participants were getting on with their lives and had returned to work and were speaking of —...*going back full time*” (Sarah, age 39, 511). Some demonstrated a fairly philosophical attitude in —...*life still goes on*” (Sarah 477). Part of the moving on‘ process had involved making changes in adapting lifestyle or at least intentions had been expressed as illustrated in the summary of individual adjustments below.

**Sarah (age39)** felt that as she was being treated for an identifiable cause that she could move on:

—*I’m ok and we’re moving on and I’m being treated*” (Sarah 398)

She had —...*cut out smoking*” (Sarah 403) and reduced her alcohol intake:

*—I've been more aware of---how much I'm drinking”* (Sarah 405)

She had dietary awareness:

*—I'm more conscious about what I'm eating”* (Sarah 403)

as well as knowledge of risks:

*—I'm more aware of----the risks”* (Sarah 407)

She was *—...taking stock of her priorities in life”* (Sarah 424) and considering stopping her long daily commute:

*—...is it worth me keep travelling up to ----- and the stress and strain?”* (Sarah 426)

She was contemplating the need to increase her exercise although she had made no commitment to this:

*—I haven't made a conscious effort to that yet”* (Sarah 419)

**Esmond (age 86)** recognised that he might need to adjust his lifestyle and was prepared to do so:

*—I'm prepared to adjust if necessary”* (Esmond 191)

He was considering getting help with his garden:

*—I shall have to get somebody in to do it if I can't”* (Esmond 231)

**Arthur (age 71)** was concerned that his medication may be damaging:

*—I was just worried about kidneys and things-----taking Simvastatin and so on”* (Arthur 147)

**Megan (age 52)** was returning to work and considering talking to her manager about her workload:

*—I'm planning on coming back to work”* (Megan 120)

*—I've got to see her (manager)”* (Megan 134)

**James (age 59)** was taking stock of his possible genetic predisposition and therefore the need to *—watch* other risks:

*—...a degree more likely to be genetics involved ---because of the make up---I'd have to watch it”* (James 334)

and contemplating the need to increase his physical activity:

*—I'd like to get back to doing that (cycling)-----I need to”* (James 315)  
and recognising that he was *—...overweight”* (James 303).

**Andrew (age 65)** had become aware of the need to pace himself and acknowledge that he was getting older:

*—...what I could do when I was 20, 30, I can't do now I'm 65  
and I have to face that fact”* (Andrew 128)

*—I will not be working 9 to 5 flat out”* (Andrew 126)

He was accepting of the need for medication and exercise:

*—I take the medication and I take the exercise”* (Andrew 178)

He was swimming twice weekly and walking four times a week and allowing himself a rest day on Sundays:

*—...since then I've been swimming twice a week and walking  
the four other days with Sunday off for the newspapers”* (Andrew 56)

and was not undertaking any more major building work:

*—I'm not doing any more major building work”* (Andrew 216)

and using a sack barrow to move heavy objects in his garden:

*—I've decided I better get a sack barrow for things in the garden”*  
(Andrew 215)

**Ann (age 70)** was living as normally as possible:

*—I've continued with my normal routine”* (Ann 1, 125- 126).

She was doing more exercise generally and aerobic exercise in particular:

*—I do try and walk between three and five miles five days a  
week and I do go swimming once a week”* (Ann 1, 185-186)

*—I'm trying to do more (exercise) than I did before and make it  
more strenuous”*  
(Ann 2,165)

She was open to advice:

*—I'd like to know what more I can do to help myself”* (Ann 1, 114)

and wished to keep things in perspective:

—...*keep it in it's place*” (Ann 1, 222)

The two participants who had worked in education (Ann and Andrew) seemed to be making the most commitment and effort to adjust. This was particularly pertinent for Andrew because he had experienced two TIA's:

—...*this is the second one*” (Andrew, age 65, 23)

and Ann because of her genetic predisposition:

—...*my mother died of a stroke*” (Ann 1, age 70, 58)

and length of time requiring medication to treat risk factors prior to the TIA:

—...*taking medication for hypertension-----16 years----same number of years for high cholesterol*” (Ann 1,24-26)

Adjustment included psychological adaptation to change, as well as practical issues of planning ahead. Participants were engaging in a process of mental rehearsal of the changes they might need to make to their lifestyle:

—*I could probably work reduced hours---maybe 10 to 3*” (Sarah, age 39, 509)

—...*we could consider downsizing and I could semi-retire or retire*” (James, age 59, 197)

In looking to the future with some anxiety:

—...*a bit apprehensive not knowing what the future holds*” (Ann 1,148)

several adjustments had been made or were intended. This overlaps with What to do for the best? above and so only additional issues not already discussed are illustrated here:

#### 5.6.2.2 *Improving Diet*

—*I'm more conscious about what I'm eating*” (Sarah, age 39, 405)

—...*we eat fresh food, I eat a lot of fruit, a lot of veg*” (Andrew, age 65, 70)

—*It's very rare that we eat anything that's bad for us*” (Megan, age 52, 158)

#### 5.6.2.3 *Recognising Working too Hard*

—...*more than I can cope with*” (Arthur, age 71, 8)

- It's a stressful job. There's a lot of work and it got on top of me"*  
(Megan, age 52, 112)
- I'd rather do less"*  
(James, age 59, 196)
- I will not be working nine to five flat out with only half an hour  
break for a sandwich and a cup of tea while still working"*  
(Andrew, age 65, 127)
- ...my work taking up so much time"*  
(Sarah, age 39, 408)
- I'm doing long hours commuting"*  
(Sarah 423)

but enjoying work:

- I enjoy it and I'm really keen to do it"*  
(Arthur, age 71, 8)
- I can't wait to come back (to work)"*  
(Megan, age 52, 222)
- I love working"*  
(Megan 130)
- I enjoy what I do. I still get a buzz out of and a satisfaction about  
being successful in what I do"*  
(James, age 59, 198)

#### 5.6.2.4 Pacing and Relaxation

- I'm trying harder to relax more"*  
(Ann 2, age 70, 281)
- I will not be working from 9 to 5 flat out"*  
(Andrew, age 65, 126)

#### 5.6.2.5 Modifying Travel Plans

- I don't know if we shall go (drive to Cornwall) this year"*  
(Esmond, age 86, 164)
- I'm not going to do it (drive to South of France) in a day, I'm  
not going to do it in two days, I'm going to do it in at least two  
and a half days and I'm going to stop every couple of hours"*  
(Andrew, age 65, 141)
- You have to take it into consideration when planning anything  
like an especially adventurous holiday"*  
(Ann 2, age 70, 88)

#### 5.6.2.6 Modifying Heavy Physical Work

- I shall have to get somebody in to do it (gardening) if I can't"*  
(Esmond, age 86, 231)

*—I'll probably put it down to grass”* (Esmond 233)

*—I'm not doing any more major building work”* (Andrew, age 65, 216)

Concerted efforts were being made to adopt healthier lifestyles in line with latest evidence and government guidelines as well as advice given at clinics. Although there was recognition that *—...health advice ---from government departments is constantly changing”* (Ann 2, 420). Self management was evident so participants were empowered by their newly acquired knowledge. Consolidated changes had taken place:

*—I had to think about them (changes) initially, with time they became automatic----that enables you to keep the original reason for your change in it's place”* (Ann 2, age 70, 386).

Changes for this participant appeared more advanced but this may have related to the timing of the second interview post investigations and receiving of results.

### 5.6.3 *Theme (11): “What the future holds”*

The health threat had given rise to anxiety to be lived with:

*—...a bit apprehensive not knowing what the future holds”*  
(Ann1, age 70,148)

whilst living under the threat of a possible stroke in the future:

*—...a taste of what could happen”* (Arthur, age 71, 189)

but had also unmasked coping strategies:

*—I will not be working from nine to five flat out with only half an hour break for a sandwich and a cup of tea while still working”*  
(Andrew, age 65, 127)

*—...we take things very quietly and steadily”* (Ann 1,199)

Living with uncertainty and *—...not knowing what the future holds”* (Ann 1,148) has been discussed above in relation to the transition stage when participants were embroiled in the medical journey:

*—...in limbo until I get some positive results”* (James, age 59, 289)

*—I really feel in limbo at the moment”* (Ann 1, 113-114)

but equally applies thereafter to living with the potential health threat of a future stroke:

*—...a taste of what could happen”* (Arthur, age 71, 189)

at the stage of change:

—...*slightly unnerved because of the uncertainty*” (Ann 2, age 70, 79)

However participants were —...*getting on with the positive side*” (Ann 2, 475) of their lives, —...*getting back on and carrying on*” (Sarah, age 39, 522) and —...*still getting so much enjoyment out of life*” (Ann 2, 268), —...*enjoying long hearty walks through the country park*” (Andrew, age 65, 105) and not allowing the threat to be —...*sitting on my shoulder*” (Andrew 285).

#### 5.6.4 Summary of the Change Phase

It was evident that most participants were making beneficial changes to their lifestyles as a result of the health threat.

### 5.7. Summary of Chapter

This chapter has detailed findings largely through thematic analysis with some complementary narrative analysis, each contributing to the final tapestry. Narrative analysis has highlighted individual contributions to healthcare, including addressing the interaction between medical professionals and that of expert patients, where power and control issues are at play. Power issues were linked to knowledge and learning and having the awareness to recognise stroke is paramount in prevention.

The rich descriptions have been embellished by recognition of the importance of researcher and participant historicity. The terms that participants used to describe the impact of the event were very evocative. This valuable contribution of narrative analysis has supplemented the thematic analysis by adding another dimension to hearing the essence of participants' stories described through emotive language and metaphors. The second interview of one participant permitted insight into a more advanced state of change and gave further ideas for future research, discussed in Chapter 8. The stages in the participant journey overlapped but generally each participant progressed through these phases as a result of the health threat, eventually arriving at a state of recognisable change that appeared acceptable to them. Multiple issues have been revealed to take forward to the subsequent Discussion chapter. Ideas will continue to be developed in relation to policy

and practice with particular reference to issues of knowledge and learning and the resultant impact upon peoples' lives.

## Chapter 6 Reflexivity and Trustworthiness

*Started to go a bit strange  
Right leg going—"I'm going!"  
Propped myself up on wall  
Side lost control and ability  
Speech slightly impaired  
Face collapsed  
Everything back within minutes  
Speech and movement-we chatted  
Talked about taking pills—"do I have to?"  
Don't mind the exercise.  
A minor stroke-pin prick in the brain  
Feels like something shearing  
No warning, a shot across the bows  
Frightened me to death!*

(Andrew, age 65)

## 6.1 Introduction

This chapter will describe chronological stages in the journey through the research process by way of an audit trail. Issues of trustworthiness will be included that support the quality and rigour of the study by making the research practice and process transparent and visible. The term trustworthiness is most commonly applied to qualitative studies and embraces credibility, dependability, transferability and confirmability (Guba and Lincoln 1989, Maggs-Rapport 2001, Rolfe 2006 and Sandelowski 1993) and all of these elements are demonstrated in this study as illustrated below.

## 6.2 Literature Searches and Review

Details of the literature searches undertaken are found in Chapter 2. Review of the literature is found in Chapters 2 and 3. In parallel to searching the literature contact was sought with experts in the related field.

## 6.3 Networking

Contact was made with expert multidisciplinary colleagues, both academic and clinical, working in the field of stroke and TIA medicine nationally. This was to accrue as much information as possible about the latest clinical work being carried out in the field as well as any relevant research projects being conducted. Examples of contacts made are shown in Box 15.

Stroke Association (UK) Five physiotherapy lecturers from 4 universities Two consultant stroke nurses One stroke research nurse Chartered Society of Physiotherapy Two academic medical professors from 2 universities Stroke co-ordinator Physiotherapist researching TIA Two physiotherapists in stroke medicine Three medical consultants in stroke medicine
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Box 15. Contacts Made

Direction was given from the professional doctorate programme regarding literature searches as well as encouragement to network with expert colleagues.

#### **6.4 Professional Doctorate Programme**

The professional doctorate programme included attendance at lectures, provided by internal and external speakers, relevant to the research process. This was also supplemented with attendance at extracurricular lectures at the University of Brighton and the University of Sussex related to the study. Part of the programme involved action learning sets where ideas were shared and developed in the company of peers on the same study path. Academic supervision was ongoing and this included a second supervisor in the last two years who was a methodological specialist linking into the study methodology.

Three assignments were undertaken in the preliminary part of the programme:

- A practice-based assignment identifying a researchable problem relevant to enhancing the quality of clinical practice.
- Critiquing Research Methodologies.
- Undertaking a small scale research project to inform the main study.

These had to be passed in order to progress to the next stage of thesis approval. Thesis outline approval application had to be made and approved at interview.

#### **6.5 Application for Ethical Approval and the Small Scale (Pilot) Study**

Application was made to the University of Brighton ethics panel for approval of the small scale study that did not involve patients. This small study was carried out at a local branch of Women's Royal Voluntary Services WRVS Age Concern, where a convenience sample of four participants took part in semi-structured interviews. Although this did not relate directly to the definitive study, experience was gained in the process of gaining ethical approval, recruitment of participants, interviewing and speaking to older people about their lifestyles. So some knowledge was gained that helped to inform the main study.

Application to the Central Office for Research Ethics Committees (COREC) was made online for the definitive study and attendance, together with one supervisor, at the Local Research Ethics Committee (LREC) panel meeting was undertaken. The letter of ethical approval is found in Appendix 4 that bears the title of the preliminary project yet relates to the definitive study. Minor amendments were required to be made and the amended form

was submitted and approved. In parallel to this approval was sought and gained from the local Research and Development department (Appendix 5) and the Director of Therapy Services of the acute trust where the research was to be carried out. Sponsorship for the research was also acquired from the University of Brighton (Appendix 3).

### **6.6 Preparing for the Interviews**

Observation was made of TIA clinics at the NHS Hospital trust where the research was to be conducted, by permission of the consultant running the clinics (Appendix 6). This was to get a feel for the experiential accounts that were being given in the medical clinics, albeit very briefly within the time limit of the consultation and to observe the interaction. Some preliminary thoughts were recorded and set aside about what might emerge from the interviews (Appendix 13). These were based purely upon clinical experience and knowledge base.

### **6.7 Feedback**

Feedback, as part of dependability, was given from one supervisor on performance, technique and content by direct observation of one early interview, by consent of the participant and suggestions informed subsequent interviews. All verbatim transcripts were sent to supervisors for comments and the latter continued to positively influence the ongoing research.

Participant feedback on transcripts was collected by sending transcripts out, inviting comments on accuracy of content, asking if it was a true reflection of what was said or intended and initial themes identified, by way of verification. These corrections to the transcripts were incorporated and any ideas about themes were considered. Participants also gave feedback on poetic representation, for example:

—...*unusual, novel*”

—*Refreshing, unstuffy*”

—*Sounds like me but more eloquent*”

—...*to the point. I thought it was excellent*”

—...*it was refreshing and delightful. It was a surprise*”

—*As you have selected the salient points emerging from the interview I can still hear my voice emanating from your representation*”

—*Your perceptive selection of material has been faithful to my narrative and has succeeded in retaining my essential voice and identity*”

—*A piece of work with much more powerful impact*”

—...*the impact of the poem was very strong---it's like reducing a stock---right down*”

—*I am very impressed with your insight into my experience*”

#### Box 16. Participant Feedback on Poetic Representation

Participants either sent feedback by post or via e mail.

### 6.8 Reflection and Reflexivity

In terms of reflexivity I was critically evaluating my own positioning within the research in terms of historicity to include professional and personal background, research interests and setting this against the expectations and needs of the participants. There was an awareness of acknowledging the weaknesses of the study and that the research was co-constituted and that the result was a joint product of the participant, researcher and their relationship.

Five variants of reflexivity have been described namely Introspection, Inter-subjective Reflection, Mutual Collaboration, Social Critique, Ironic Deconstruction (Finlay and Gough 2003). All of these will be explored in relation to this study as there are elements of relevance within each.

### 6.8.1 *Introspection*

My background experience laid the foundation for the research area. Therefore on some levels there was a shared story within the interview and the co-construction had a shared voice.

*—..those researchers who begin their research with the data of their experience seek to embrace their own humanness as the basis for psychological understanding”.*

(Walsh 1995 page 335)

As the researcher I was aware of possible power issues within the interview. Preliminary thoughts about possible themes that might arise (Appendix 13) were considered before commencement of the participant interviews and set to one side for subsequent reflection. These ideas were partly echoed in the emergent themes, particularly around the impact issues and importance of the doctor patient relationship but in no way did they directly influence the analysis. However themes from the interview transcriptions were easily identified with my background knowledge and pre-understandings as commented on by one participant: *“I am very impressed with your insight into my experience”* (Sarah, age 39). However care was taken to not miss other issues which may have been equally important. My background historicity provided a springboard for the interpretation.

### 6.8.2 *Inter-Subjective Reflection*

There was acknowledgement of the emotional investment in the research relationship for both parties. As the researcher I reflected upon why the participants had agreed to participate and what was in it for them and what were their expectations; in other words what it meant that some had agreed to take part and others had not. For some participants it seemed a cathartic experience whilst others appeared to want to give something back by way of thanking those who had helped them through the medical process. Some saw it as another way of gleaning more information about their medical condition. This is discussed further in Chapter 7.

It appeared that the female participants were more inclined to feel comfortable talking about their experience than the males. This may have been related to gender issues such as stoical attitudes in Western males or interpersonal dynamics of female researcher with

male participants. The longer the time spent on the initial biographical narrative element of the interview the richer the data provided. When I could identify with things that were being said, for example working life, interests, background of stroke carer, knowing the locality referred to and experience of seeing people following TIA or stroke, this affected the relationship in a positive way and more data was generated, in terms of expanding on topics. Also the longer spent on getting to know the participant and building up a rapport and showing interest in what was said, the more information was yielded. This skill developed further as the interviews progressed and the researcher gained in confidence.

### **6.8.3 *Mutual Collaboration***

Whilst the participants were not essentially co-researchers they were co-constructors with multiple voices and some sharing of realities.

### **6.8.4 *Social Critique***

There was a social construction of power issues within the interviews and a shifting of power and positioning which hopefully lead to some empowerment for the participants in allowing them space and safety to explore their experiences. Their expertise in their own illness matched that of my own expertise as the interviewer and in that way power issues were shared and levelled.

### **6.8.5 *Ironic Deconstruction***

Creative efforts were made in representation of analysis of the data. Poems allowed the participants' voices to be heard, sometimes called textual radicalism in postmodern researchers (Harvey 2002). This involves breaking down or deconstructing the data or language to such an extent to reveal multiple stories and meanings, some with ambiguity.

During the data analysis stage various concept maps, for example Appendices 19-21, were drawn up to help clarify thinking about emergent themes and these were later compared with Figure 5 page 76 \_Framework for Analysis. Throughout the whole of the professional doctorate programme and all stages of the research process, a record was kept in a reflective diary. The latter was illustrative evidence of reflective processes and

development of ideas and thinking and of standing back with a critical analytical gaze (Schon 1983). The importance of reflection is increasingly recognised in clinical reasoning processes within professional practice (Taylor 2000).

#### ***6.8.6 Reflecting Upon My Journey as a Researcher***

Setting out with a line of inquiry and searching for answers lead to much being learnt on my research journey, particularly relating to the requirements of the research process. I have improved insight into the carrying out of specific literature searches and identifying gaps in the literature, formulating a research question, making application to ethics panels, reflecting upon what is known and critically appraising what has been achieved and how that was achieved and the implications. Skills of reflection and reflexivity have improved and been applied, for example in continually evaluating the research process and the re-configuring of ideas relating to my study. Much has also been learnt about research methods, methodologies, paradigms and research perspectives and ontological and epistemological positioning. When embarking upon this line of study it was not immediately obvious about my positioning and research perspective and a lot of reading and thinking was required. Some skills have been learnt about talking about and disseminating the research and defending the work and findings without being defensive, for example through conference presentations, speaking with colleagues in the same field and the doctoral viva.

Working full-time in clinical practice whilst conducting the research and writing the thesis has been challenging but that is the nature of the professional doctorate in facilitating the translation of research findings into practice. Sustaining the momentum to complete the research has probably been enhanced by being in the clinical environment and surrounded by the subject matter of the research, for example being clinically involved with patients following stroke. Personal and professional growth has taken place during the research process, noticed by a shift in practice and even possibly influencing the practice of others and acknowledging that something worthwhile has been achieved. An example of professional growth is the increased awareness of hearing the patient narrative as a crucial part of clinical reasoning and being sensitive to the needs of individuals in goal-setting and facilitating lifestyle changes. These improvements have been demonstrated in improved

treatment outcomes and patient satisfaction. The latter was evident from a recent patient satisfaction survey within the researcher's work area.

### 6.9 Dissemination

Throughout the whole process various conference presentations have been carried out to both disseminate the work and gain further feedback in the development of ideas, illustrated in Box 17 with examples in Appendices 23-25. These include an abstract submission for the World Confederation for Physical Therapy WCPT Congress 2011 that has been accepted for a poster presentation.

University of Brighton Annual work in progress presentations 2005-2010

Surrey & Sussex Integrated Research Network (SIREN) Primary Care Research Conference Presentations 2005 & 2006

Sussex Association of Chartered Physiotherapists Interested in Neurology (ACPIN) evening lecture 2008

UK Stroke Forum Conference poster 2008

WCPT 2011 abstract submission accepted

#### Box 17. Conference Presentations

The Stroke Association (UK) has shown interest in participants' accounts of their illness experiences. This will need careful consideration in terms of ethical issues. Further dissemination strategy is discussed in Chapter 8.

### 6.10 Summary of Chapter

The trustworthiness of the study has been represented in a transparent audit trail that supports the substantiveness of the qualitative study. The findings may be transferable to similar situations, not only related to the field of stroke and TIA.

## Chapter 7 Discussion

*Spade slipped out of my hand  
Dropped the spade  
Couldn't control it, grip anything, hold right hand up  
Tried to write-pencil not doing what it should  
Slightly concerned  
It was a surprise more than anything else  
But tried to do as usual  
Do a bit of gardening*

(Esmond, age 86)

## 7.1 Introduction

This study, with the research question of ‘What is the lived experience of a TIA?’ aimed to make a contribution to narrowing the gap in the literature pertaining to the experience of TIA. By exploring these experiences needs were identified and behaviour modifications to lifestyle noted, in line with motivation theories outlined on pages 43-50. Identification of needs, that are given voice and heard on the right platform and arena, helps in the shaping of future services. Hearing this narrative as part of clinical reasoning makes a contribution to evidence-based clinical practice. The purpose was to contribute to secondary stroke prevention and thereafter have an effect upon healthcare costs. The timing of the research coincided with an expansion and a rising of the profile of the field of stroke medicine in terms of awareness, improved treatments and prevention. This chapter brings together pertinent issues from the findings in a discussion. Policy and practice implications will be considered and finally limitations to the study discussed.

## 7.2 Prevention: “...a warning shot”, Opportunity for change

The sudden illness event was shocking as identified in studies of illnesses of similar onset discussed on page 48 and the subsequent uncertainty was echoed in a study by Haggstrom et al. (1994). The latter hermeneutic phenomenological study, with a sample of twenty nine, of experience of living with stroke sequelae, illuminated by means of stories and metaphors, identified participant recognition of the interviewer’s sensitivity to hearing the messages relayed. This was also noticed within this study where participant feedback on poems expressed: *“I am very impressed by your insight into my experience”* (Sarah, age 39). This helps to affirm the relevance of both participant and interviewer historicity within the co-construction.

Living with uncertainty is echoed in other studies of more chronic complaints where, on a day to day basis, those affected are unsure how they will cope and feel and how that might impact on their social activities. A study by Sofaer-Bennett et al. (2007a) explored the impact upon social lives of older people living with neuropathic pain. This was a qualitative study using semi-structured interviews of sixteen participants over the age of 60, who attended pain clinics. The study had good transparency and highlighted the social isolation of pain sufferers and a suggestion for further research was for future studies to focus upon pain and the social impact. Conclusions were drawn that treatment and

management needed to be more holistically focused, embracing interpersonal and social needs and quality of life outcomes for those within the supportive family network as well as the patient. Within the study herein all participants had supportive family networks that were greatly valued and they noted that—*...the more you have support around you the better it is*” (Ann 2, age 70, 468) but by contrast there was not quite the same emphasis as with ongoing chronic conditions.

A longitudinal predictive study of perceived control, coping and recovery from disability following stroke in 71 patients by Johnston et al. (1999) employed various standardised questionnaires in structured interviews at intervals of three weeks post stroke, and one month and six months after discharge from hospital. The results confirmed the association between perceived control, emotional state and recovery also identified in another study by House (1987) that reviewed the evidence for mood disorders after stroke. This relates to the study here, where two participants who were alarmed by the event and felt out of control with comments like *—I didn't know what was happening*” (Megan, age 52,) and *—...what's going to happen to me?*” (Sarah, age 39) went on to have mood disorders such as *—I got very depressed*” (Megan 86) and *—I felt very down*” (Sarah 489). This then may have affected their initial coping and recovery. Bury (1982), in a qualitative study of the biographical disruption for patients with rheumatoid arthritis, noted that participants experienced great uncertainty and did not know what was happening at the onset of the disease. The latter study that employed semi-structured interviews of thirty patients who were attending a rheumatology clinic for the first time lacked transparency at times.

Bandura's (1989) social cognition theory applies to the findings of the study herein, in that the experience of control results in greater expectations of control which leads to further successes. The participants who were empowered by information and knowledge to successfully change their lifestyles appeared more likely to sustain these behaviours for example: *—I am carrying out these little rules with regards to exercise and diet---even though I had to think about them initially, with time they become automatic*” (Ann 2, age 70, 383-385). However, these behaviours would need tracking over a longer period to see if they were sustained.

The warning event in this transient illness represented a window of opportunity for change for participants to do their best, in conjunction with medical intervention and advice, to

avoid experiencing a full stroke. This concerted effort needed to be immediate in order to obviate the threat of stroke that is initially high following TIA. The health threat was very concerning for some participants and they lived in fear of another recurrence or a ‘fully evolved’ stroke. The threat of potential helplessness was echoed in a study by Ellis-Hill and Horn (2000) that explored change in identity and self-concept following stroke. Although the latter study was a cross-sectional study employing standardised questionnaires, it revealed the same sense of fear experienced by the participants in this study. This anxiety was indicative of their insight and knowledge of “...*what could happen*” (Arthur, age 70,189), also noted in the study by Jones et al. (2008) addressing reasons for recovery after stroke that identified issues of personal control and fears of dependency as in this study. The latter qualitative study employed in-depth interviews with 10 participants who had experienced a recent stroke; the study had good transparency and the implications for practice were explicit. A study addressing the bereavement model, stroke and rehabilitation by Alaszewski et al. (2004) also highlighted the impact, feeling of helplessness and disruption to life plans. This was a qualitative study employing semi-structured interviews and self-report diaries with a sample of 25 patients following stroke. Suggestions for further research were unclear.

Participants in the study herein were assessed by either their GP or the A&E doctor and referred to a TIA clinic. Although this met quality marker 5 “*Assessment and referral to specialist*” of the National Stroke Strategy (DOH 2007c page 23) the timing of this varied across the sample of participants. Those admitted to hospital had immediate investigations but others who went via their GP waited up to a month to be seen at the clinic, after which they had investigations. The latter was not timely as the highest risk for stroke following TIA is within a month (Coull et al. 2004). This should improve with increased awareness, encouraging people to seek urgent medical attention via A&E and the use of the TIA pathway (Appendix 2) described in Chapter 3. Indeed, at the researcher’s hospital base the issue of timeliness has already improved since the completion of this study.

The FAST ‘tool’ had been effective in early recognition of symptoms of stroke in two participants and two others knew what their symptoms meant from prior experience. However the remaining three did not immediately react to the situation and seek early medical attention and this delay could have had serious consequences. This would suggest that the education message about stroke needing prompt attention is still not heard by

everyone. Taking this back one stage, before the TIA, all participants had risk factors for stroke, including genetic risks and yet only two participants had awareness that they were vulnerable to stroke. It would seem that people who have risk factors for stroke of hypertension, hyperlipidaemia, obesity, diabetes, lack of exercise, smoking and excess alcohol intake, identified at GP surgeries, should be made more aware of the risks in specific terms. This would allow them to have more of an informed chance and choice to avert the serious consequences. It may be that the FAST campaign does not go far enough in terms of prevention as the message is directed at early treatment of stroke and not prophylaxis. Considerable healthcare cost savings could be made if TIA and stroke were prevented.

Lifestyle change was partly based on issues of perceived behavioural control (Ajzen 1988) where decisions were founded upon how much effort was required in terms of the ease or difficulty of executing change. But also very much related to self efficacy and efficacy expectations (Bandura 1977) where expectations of personal mastery affected the initiation and persistence of the healthy behaviours, as discussed on pages 49-50. In terms of persistence, a qualitative study of 63 participants by Sofaer-Bennett et al. (2007b), employing in-depth interviews and grounded theory, explored perseverance in older people in their management of chronic pain. The study had good transparency, implications for practice and suggestions for further research. Findings were that older people persevered despite adversity and kept going. This reflects the findings of this study where the older participants made light of their health problems and were carrying on as normal and *“...try to do as usual”* (Esmond, age 86, 76). Bandura’s social cognition theory (1989) may apply to the findings of this study in behaviour changes in that people are partly in control of their own destiny and can effect changes in themselves with effort. This is echoed in the results of this study where there was recognition that *“...we need to take quite a bit of responsibility for ourselves”* (Ann 2, age 70, 215) and *“... you can adapt”* (Ann 2, 180) and several participants had made considerable changes. Where participants were in the cycle of change (Prochaska and Di Clemente 1982) was also pertinent and related to transtheoretical theories discussed on page 46. Barriers to change were postulated by two participants, for example in the need to increase exercise, again reflecting the theories of perceived behavioural control discussed on page 45.

The level of perceived threat appeared to largely determine the changing lifestyle behaviours for example two participants who were very alarmed by the event were well advanced at the maintenance stage in the cycle of change; whereas others who were less concerned were only at the contemplation stage of change. Pound et al. (1998), in a study about the impact of stroke, noted that this was nothing much to those who had already experienced hardship. The latter study that employed in depth interviews with a sample of 40 participants at ten months after stroke lacked clarity in the methodology but found different responses to illness that inferred the need for individualised care. One of the participants, in the study herein, who was less concerned, had been involved in the Second World War and for him to have a slight weakness in one hand for two hours was nothing relative to previous experiences and a stoic ‘stiff upper lip’ attitude prevailed. A study by Sofaer-Bennett et al. (2007b), alluded to above, demonstrated that older people appear more stoical and persevere in difficult circumstances. Interestingly one of the participants in that study had experienced the Second World War as did two participants in this study that appeared to have enhanced their coping skills in adversity.

Learning involves change and discovery in relationship to our environment (Knowles 1998) that empowers us to cope better with our life crises. The health threat had given rise to a focus upon health matters and health as a way of life (DOH 2004c) with all participants involved in the process of change, albeit at varying stages. The participants as learners were those in whom changes had occurred, where learning embraced the acquisition of behavioural change, knowledge, skills and attitudes (Boyd et al. 1980), reflecting self-efficacy. Change was closely linked to knowledge which had been acquired from various sources and this had been the catalyst for change as illustrated in Figure 10.

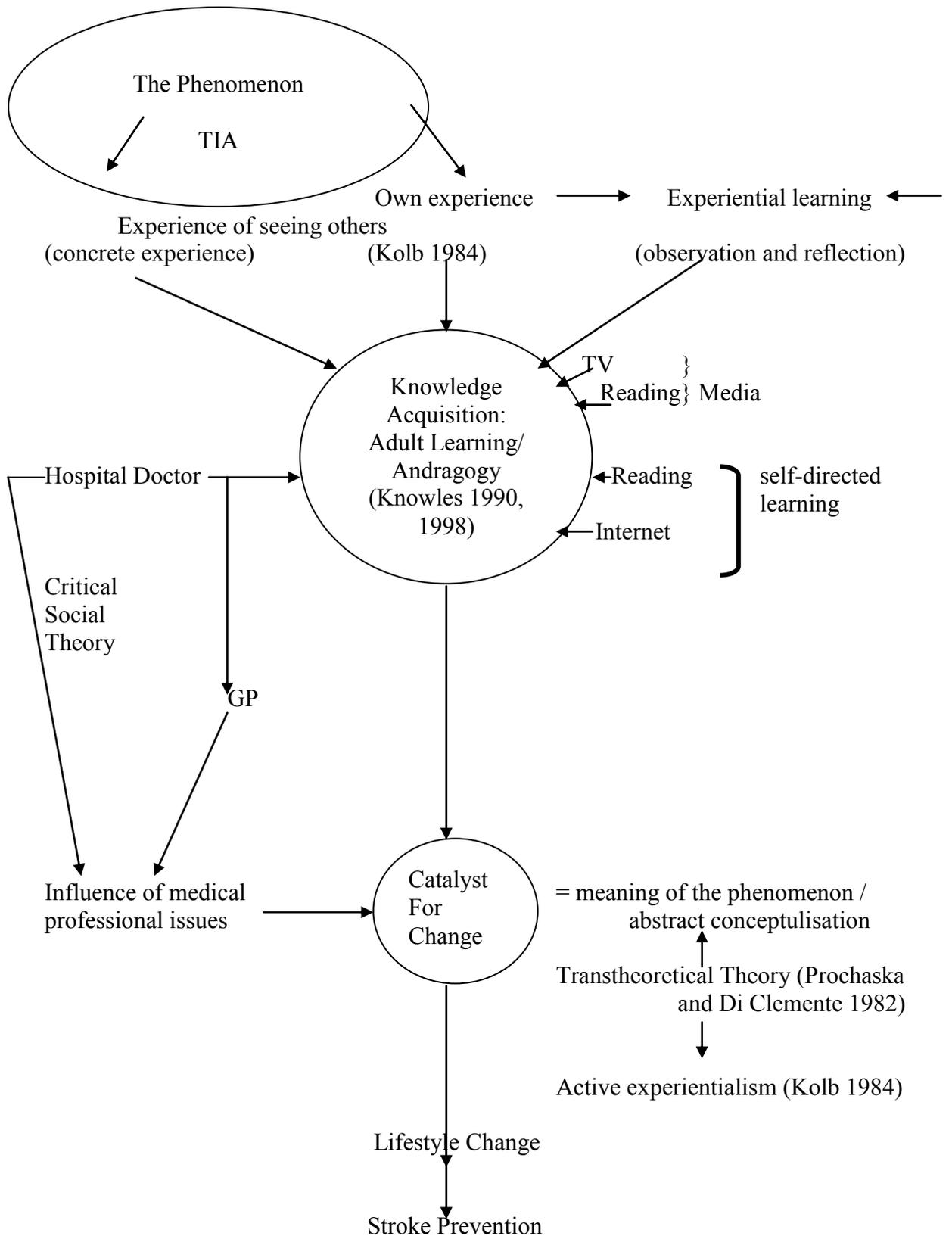


Figure 10. Knowledge and Change

Two participants' commitment to lifestyle changes keyed into normalisation theory (Kelleher 1988) where people changed their routines to adapt to their condition and did not complain of the effects upon their lives. This commitment to change had spilled over to supportive family members where relatives were also adapting their lifestyle behaviours. This was the ultimate support for participants to make and maintain lifestyle changes (DOH 2007a).

Recommended lifestyle changes need to reflect the reality of peoples' lives today (DOH 2004d). Taking physical activity as an example, four participants had recognised that they needed to exercise more, two of whom were retired and had made commitment to that and were enjoying it. The other two, in full-time employment and breadwinners in their households and both of whom had cardiac problems, were contemplating increasing exercise and considering how they would make time in their busy life routines. Both were ostensibly putting up barriers to change, inferring that they would need to make major changes, even retire, to accommodate more exercise in their lives, reflecting theories of perceived behavioural control. This goes against Black's advice in 'Working for a Healthier Tomorrow' (DOH 2008e) that expounds the health benefits of staying in employment. There appeared to be no lateral thought about building exercise into something they were already doing, as noted with other participants. However exercise that is fun and enjoyable is more likely to be sustained (Csikazentmihalyi 1975). Although one participant who had previously enjoyed dog walking, playing golf and riding his mountain bike, more recently felt he was too busy. There seemed to be the need for a life coach or "NHS health trainers" (Choosing Health DOH 2004c, page 13) or at least a role for the expert patient to mentor, or a physiotherapist to give exercise advice and facilitate behaviour change.

Reflecting upon the physical activities that participants had engaged in just prior to the TIA revealed that some changes had been made post TIA, but that generally there was still enjoyment in preferred pre-morbid hobbies. Although only one participant had engaged in extreme exercise just prior to TIA and had since modified that behaviour, others had engaged in excessive pastimes as detailed on pages 95-96. Extreme exercise was found to be a risk for stroke in a study by Kurl et al. (2003). The latter was a large population-based cohort study of 2011 men addressing the relationship between cardio-respiratory fitness, as

measured by V02 max, and stroke. Participants were monitored over an eleven year period and findings were that a low V02 max was comparable to other risks for stroke of hypertension, obesity, smoking, excessive alcohol intake and hyperlipidaemia. A weakness of the study appeared that V02 max was only measured once at baseline.

Without exception all participants in the study herein were still getting enjoyment out of life and had moved on and the motto was that —*..you can adapt*” (Ann 2, 180). It appeared that all participants were able to enjoy a reasonable quality of life and engage in rewarding social activities (Bluvol and Ford-Gilboe 2004). A diagrammatic representation of the hierarchical elements of quality of life is shown in Figure 11 that relates to participant behaviour in this study where autonomy that permits choice in decision-making is the foundation for moving on and getting on with the positive side of life.

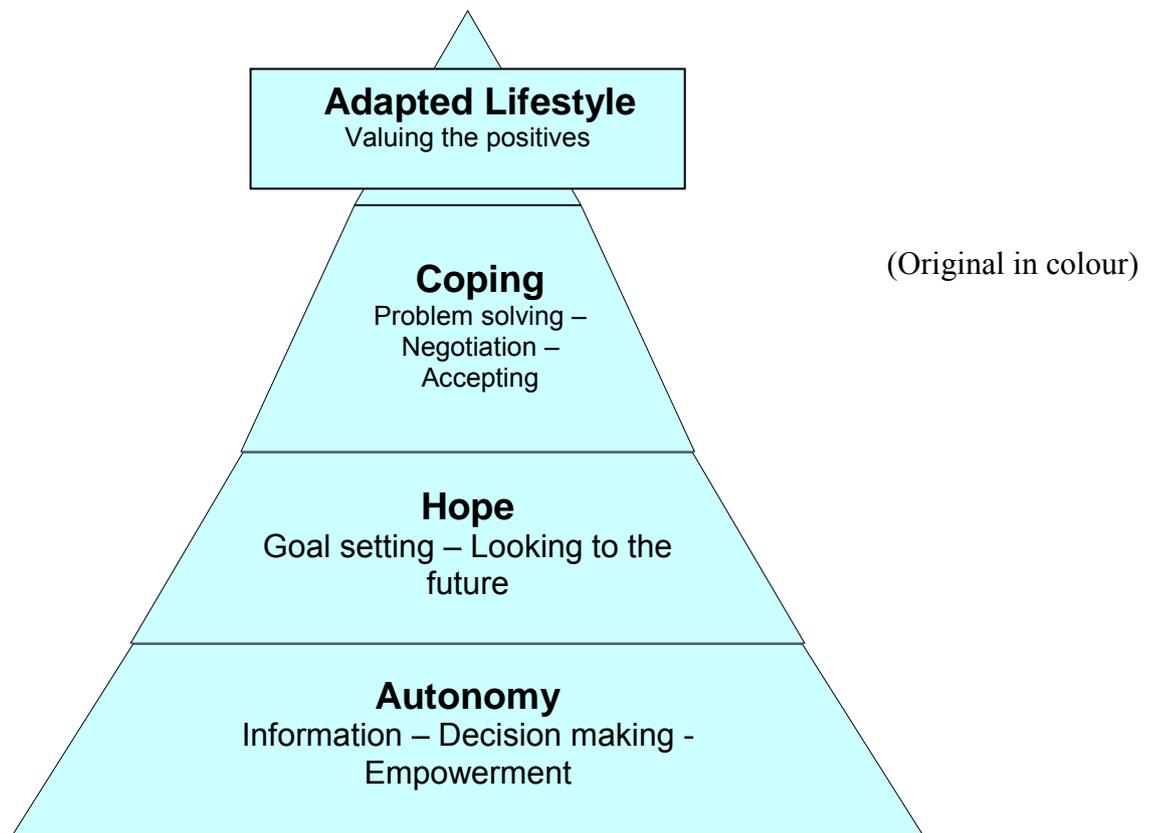


Figure 11. Achieving Quality of Life as Changes Occur (Adapted from Jaracz and Kozubski 2003)

### 7.3 Patient-Centred Care and Beyond

Debate still exists about the meaning of the term 'patient-centred care' that is dismissed by some as political correctness with no substantive origins (Coulter and Ellins 2007), as has been discussed on pages 38-42. However, in this qualitative study the essence of patient-centred care has been revealed in embracing the uniqueness of individual experiences of illness as opposed to the focus upon disease within a medical model (Stewart et al. 2003). The biomedical model claimed that doctor subjectivity did not impact on diagnosis and treatment (Friedson 1970) and this has been challenged including in the findings of this study. Patients value warmth, respect and empathy, sufficient information and time, being treated as individuals, being involved in decision-making and having mutual trust in the doctor (Baker 1990, Hall and Dorman 1988, Wensing, Jung, Mainz, Olesen and Grol 1998, Williams and Calnan 1991).

Empathy, shared understanding and mutual respect are of paramount importance in effecting behavioural change in patients (Rogers 1967) as well as the patient's perception of the doctor as caring, sensitive and sympathetic (Bordin 1979). One of the participants who had made several sustaining lifestyle adjustments reported a very good empathetic clinic experience that had been empowering and led to consolidated change and —...*still getting so much enjoyment out of life*” (Ann 2, 268). Others had less positive experiences and as a result were less committed to lifestyle changes. One had experienced a paternalistic attitude at his clinic appointment that was disempowering; the lack of feeling in control had resulted in reluctance to change and low mood. Johnston et al. (1999) in their study of coping strategies following stroke, identified the relationship between perceived control and emotional state as discussed above. Bordin (1979) and Squires (1990) noted that the patient's perception of the relevance of the planned interventions to be critical in the doctor-patient relationship and outcome of treatment. This equally applies to other therapies, including physiotherapy and the issue of perceived relevance is echoed in a qualitative study by Sokunbi et al. (2010) that addresses experiences of chronic low back pain, employing focus groups with nine participants. The findings drew attention to the importance and empowering effects of informatory education packages in the treatment of low back pain where participants acknowledged the need to employ self-help strategies. These factors were also found to be important in the study herein. One participant in this

study was particularly dissatisfied with his experience of the medical encounter in terms of relevance and as a result showed little intention to make lifestyle changes.

Moving away from the biomedical and biopsychosocial models of healthcare has permitted understanding of the personal meaning of the TIA to individuals. There has been acknowledgement of the importance of hearing the patient's story of illness that involves exploring both the presenting symptoms and the broader life setting in which they occur (Mead and Bower 2000). In so doing an opportunity has been created to see into individual lifeworlds and how health promotion and beneficial lifestyle changes could be and have been effected.

Whilst the biopsychosocial model went part way in addressing opportunities for health promotion and modifying behaviours (Mead and Bower 2000) it did not embrace the patient as a person (Balint 1964). It did not take in a patient's own biography and unique experience of illness and in order to understand the illness and the impact it is necessary to appreciate the personal meaning of the illness to an individual patient as a whole person. This study has endeavoured to embrace all of these elements that give depth and meaning to experiential accounts of illness. The rich descriptions that participants gave that included use of emotive language signified the impact. This is particularly captured in the poetic representation. Some participants appeared to welcome the cathartic opportunity to share their stories and have time dedicated for this exposition. Lapsley and Groves (2004) postulated that giving patients the time and space to talk about what had happened to them may improve their experience of the illness and, in a study by Sofaer-Bennett et al. (2007b) the interviews were found to be a positive experience. This was a desire in this study to leave participants with a positive feeling about having shared their stories. It is well recognised that patients' stories bring experiences to life and that they can be powerful and informative as alluded to on pages 38-39.

Relating some specific aspects of patient-centred care, both positive and negative, that arose from the findings of this study to some of the properties of the Planetree model of patient-centred care (The Planetree Organisation 2008) is illustrated below, by way of identifying commonalities. Other models of patient-centred care have been discussed on

pages 38-42. The Planetree model brings together philosophy of care and more practical aspects and has a resonance to the findings of this study:

- A patient is an individual to be cared for, not a medical condition to be treated:  
*—I received full explanations as to what was going to happen and why and they made sure I was comfortable. So I was impressed by the staff who conducted both scans, they were splendid. I also had an ECG in addition to two scans and again I couldn't fault the staff and the procedures they were all fine”* (Ann 2, age 70, 15-20)  
  
*—So the treatment from the hospital, considering it was such a short-lived attack, I can't praise too highly”* (Ann 2, 70-71)
- Each patient is a unique person, with diverse needs:  
*—The staff treated me as if I were there first ever patient to escort through the procedures that I was going to have to undergo”* (Ann 2, 14-15)
- Each staff member is a care-giver, whose role is to meet the needs of each patient:  
*—I felt that if I could have been told sooner what those results were I would have been happier”* (Ann 2, age 70, 24-26)  
  
*—I was under the impression that I would be having an MRI scan. In fact it was just simply check the blood pressure and arrange a date for the future which annoyed me----because I am busy, I have little time to spend on these things. It was the waste of the best part of a day really”* (James, age 59, 224-228)
- Our patients are our partners and have knowledge and expertise that is essential to their care:  
*—...make up your own mind about the advice”* (James, age 59, 214)  
*—...we have finally solved the problem by walking to the station, travelling very light with a rucksack instead of a*

*suitcase. You can adapt, but it's a pressure really"*

(Ann 2, age 70, 178-180)

- Our patient's family and friends are also our partners and we welcome their involvement:

*—She (doctor) was very happy to have my husband in with me and so*

*he heard the story as well, that was helpful"* (Ann 2, 68-69)

*—...they (son and daughter) wanted to be fully informed"* (Ann 2,101-102)

- Access to understandable health information is essential to empower patients to participate in their care and it is our responsibility to provide access to that information:

*—...we were given such comprehensive written material to refer to. Now that wouldn't have been nearly so good had you not given me that material to refer to at leisure and I can use it now for reference---so that was excellent in two ways, the information I thought was good and the written material was good"*

(Ann 2, age 70, 207-211)

(here the participant was referring to a lifestyle session that she had attended following TIA)

*—She (doctor) explained things very carefully and I was very impressed how thorough she was, very calm and friendly and explained everything she was doing and why, answered my questions and gave me plenty of time. It was excellent, excellent".*

(Ann 1, age 70,261-264)

- The opportunity to make decisions is essential to the well-being of our patients. It is our responsibility to maximise patients' opportunities for choices and to respect those choices:

*—...he (doctor) and I have both come to a decision, a mutual decision..."*

(Ann 2, age 70, 276-277)

*—...make up your own mind about the advice"*

(James, age 59 214)

These examples demonstrate elements of patient-centred care as well as unmet need but with the pressures upon healthcare, discussed on pages 34-35, it is very unlikely that it will be possible to get everything right for an individual but to strive for ideals may be commendable. It appears that underpinning all of the ‘properties’ are the basics of communication and information and knowledge, much of which equates to quality of life, discussed on page 162 and illustrated in Figure 11. The part that knowledge plays in lifestyle change cannot be underestimated as illustrated in Figure 10 on page 160; and this is a contribution that this study makes to other models of behaviour change discussed on page 185 and illustrated in Figure 14, page 184.

### ***7.3.1 Entering the Patient’s Lifeworld***

At hospital appointments, following TIA, it is likely that the clinic doctor will be unfamiliar with the patient’s lifeworld, most pertinently that pertaining to health matters, and unaware of the whole person, probably only seeing him/her on one or two occasions. At the first appointment the patient may be very anxious and alarmed at receiving the diagnosis of a stroke-like illness that requires the taking of medication and monitoring of risk factors. Yet it is here that possibly unpalatable messages of diagnosis, need for investigations and medications and future risks and prognosis are given often in a paternalistic way. Subsequent appointments may not be so anxiety provoking and patients may be re-assured by being monitored and followed-up. There may be a lack of appreciation of the potential for health which is essential in the decision-making process when considering the role of prevention in an individual’s health. The patient’s historicity is a major component in the understanding of how an individual might be receptive to change thereby embracing the knowledge of the expert patient. It would seem better to be imparting lifestyle advice at follow-up appointments when some rapport has already been established that can help with shared decision-making. However, it is acknowledged that the greatest risk for stroke following TIA is within the first month and therefore behaviour changes need to be commenced immediately.

### ***7.3.2 Paternalism***

Some messages may have been relayed to participants in this study without sufficient explanation and shared decision-making. This could have undermined mutual trust, instilled lack of confidence and resulted in resentment and non-compliance, for example in

the taking of medication. It has long been understood that the patient's attitude to illness will be disclosed by the way people explain the illness and act in response to it and this affects any therapeutic measures and success of the same (Balint 1964), including in physiotherapy. The notion of patient centred-care spanned the three phases of disruption, transition and change where better information at each and every stage gave rise to greater self-efficacy and responsibility for health (Grol et al. 1990). There needs to be recognition that *—..we need to take quite a bit of responsibility for ourselves*” (Ann 2, 215) but also have awareness to be able to recognise potential serious illness in others and be able to act accordingly (Darzi 2008) and provide support. Within medicine the word paternalism is gradually being replaced by partnership and the key to successful partnership is to recognise that patients are experts as well (Coulter 1999). However, some older patients or those who are seriously ill will still look to doctors to make the decisions based upon the concept of *‘in the patient's best interest’* (Charles et al 1998). There is recognition amongst the medical profession that training is required to improve communication skills in effective shared decision-making and dealing with the informed patient (Towle et al 1999).

### **7.3.3 *What Practices Dominate Practice?***

It is important to understand what *‘goes on’* in the dynamics of a one-to-one clinic appointment between the expert doctor as professional and the expert patient (in their own illness) as lay person. Issues of power, domination and paternalism in the seeking of medical attention and attempts to get an illness labelled have been discussed above. Patients are vulnerable in relinquishing partial control and autonomy if they are not informed. Vulnerability of the participants in this study was recognised for example all immediately sought help and support from family members. Issues of locus of control applied both internal and external.

The doctor as an expert practitioner should be adhering to the framework of professional standards and practising against a body of knowledge and evidence-based practice.

But it has been noted that many patients are better informed than clinicians about certain aspects of their own illness, through readily available information from increasingly reliable websites (Darzi 2008). The participants in this study were generally well-informed, albeit after the event. This challenge to medical or health professional dominance should

help address the balance of power within the interaction, in favour of acknowledging that the patient knows what is best for her/his own body. So to have a workbook designed by expert patients (‘What to do for the best’ pages 126-127) makes a lot of sense since experiential knowledge is paramount. Only by really knowing can we address needs, preferences and choices.

Getting to know the patient as a person is important in order to meet individual needs and deliver personalised care. Health care delivery is a service industry where the patient as consumer should be in a position of authority and not as a passive recipient. In other industries the customer holds the powerbase and directs changes according to demand, need and satisfaction. The health care industry has been slow to change and acknowledge patients as experts and active consumers, hiding behind medical dominance and the vulnerability of people when they are ill. The increasing costs of healthcare and finite resources make it even more important to meet specific consumer needs in a personalised way.

Personalised care will include assessment, treatment, risk assessment and advice, all of which should be delivered in a joint decision-making way. In the interaction there will be a merging of two lifeworlds and within this fluidity an acknowledgement of each person’s historicity that results in a sharing of information. The components of a one-to-one clinical practice interaction are listed in Figure 12a and illustrated in Figure 12b.

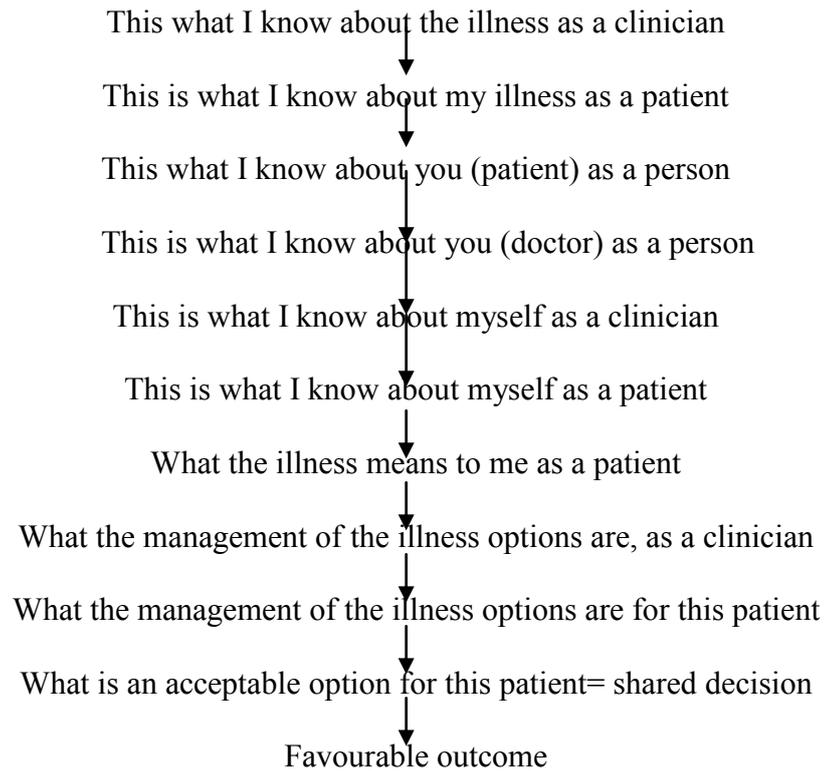


Figure 12a. Flowchart of Components of One-to-One Practice

The above flowchart (Figure 12a) presents a summary that could represent any clinician and patient encounter, including in physiotherapy. This has arisen from this study and makes a contribution to knowledge. Figures 12a and 12b demonstrate the importance of self-awareness in the understanding of others and being open to acknowledging that patients may know a considerable amount about their illness and what is best for them. This, combined with the clinician's medical knowledge, gives rise to shared decision-making that has the best chance of leading to a favourable outcome (Coulter 1999).

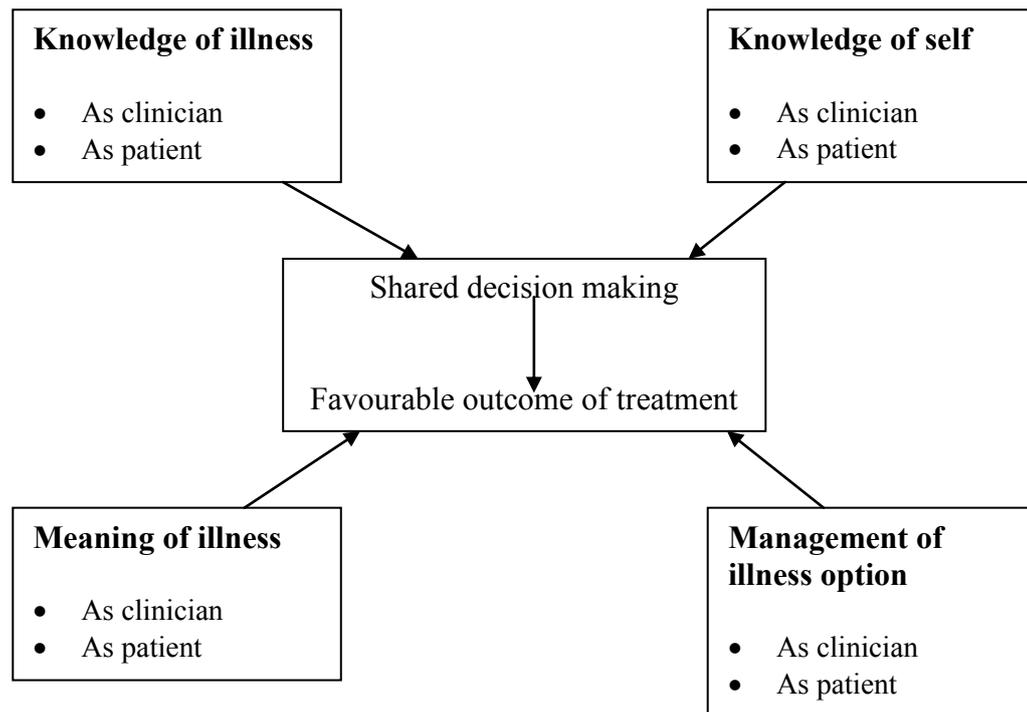


Figure 12b. Dynamics of One-to-One Clinical Practice

The above equates to holistic management of patients, embraced under patient-centred care and it demands being sensitive enough to recognise the impact of illness upon an individual and the consequences and best ‘fit’ solution for that person. This comes back to the importance of the narrative in clinical reasoning and really hearing the patient’s message.

#### 7.4 Expert Patient

Insight needs to be matched with an acknowledgement of the expertise of the patients in their own illness, self-management and adjustment. So within a medical consultation the sharing of information and the finding of common ground (Stewart 2001) needs to be a two-way process that acknowledges issues of power and responsibility (Parsons 1951) between two experts (Tuckett et al. 1985) who each have a common goal of health attainment. A consensus needs to be reached through negotiation (Stimson and Webb 1975). Lindeman (1926) in his writing about the way adults learn noted that individual differences increase with age and in this study the average age was 63 years. Therefore there needs to be provision to accommodate differing learning needs in terms of style, time, place and pace. By providing timely information that meets individual needs a

contribution can be made towards further empowerment in this vehicle for change through mutual trust and shared decision-making, where education is the agent of change (Knowles 1998). During the immediate disruptive crisis following sudden onset of illness, where patients are questioning ‘what is going on’ in a state of confusion and uncertainty, (Bury 1982) will not be an optimum time to impart too much information as it will not be retained. A study by Sokunbi et al. (2010) exploring experiences of low back pain during and after a specific exercise programme, in a sample of nine, that employed focus groups, noted the empowerment through the giving of pertinent information. In the latter study participants recognised the importance of self-help echoed in this study where there was also acceptance of the —...*need to take quite a bit of responsibility for ourselves*” (Ann 2, age 70, 215). This is about handing the control and responsibility to patients to manage themselves and empowering them through giving them the ‘tools’ or the required credible and trustworthy information (Darzi 2008). Jones et al. (2008) in a study of factors affecting recovery from stroke found that there may be a shortfall in some clinical practices in acknowledging and valuing the resourcefulness of patients in their recovery from illness.

### **7.5 Knowledge and Empowerment**

The UK Stroke Association website has excellent information on all aspects of stroke including experiential accounts that can be listened to, for example ‘It happened to me’ and ‘Share your story’ under ‘Talkstroke’ (Stroke Association 2009) and participants found it —...*extremely helpful, especially the Stroke Association site*” (Sarah, age 39, 335). However these relate directly to stroke and not TIA and people need to understand that very fleeting stroke-like symptoms of TIA are potentially serious so accounts of these would also be helpful. The emotional impact of something so fleeting is brought to life in the poetic representation (lead into each chapter, Appendix 22 and the compact disc attached to the back cover of the thesis) within this study and makes a novel contribution to knowledge of the same.

It was the level of knowledge and vulnerability (Rosenstock 1990) that had also fuelled perceived threat. Those who understood the potential seriousness of the event were more committed to change. Two participants indicated that their jobs were more important than their health and they were the most resistant to change. This seemed to indicate being stuck in a denial stage (Kubler-Ross 2009) because terms were used like —...*scary*”, —...*a taste*

*of what could happen” and “...it’s not a nice thought”*. So the threat had been perceived, although this participant was stuck in the pre-contemplation stage of change (Prochaska and Di Clemente 1982), relating to transtheoretical theories discussed on page 46. But this is an example of the importance of understanding the historicity because there was prior experience of prolonged illness within this participant’s family. Therefore this participant may have been unable to face up to the threat of another disruptive illness within his family unit. This was compounded by his genetic risks and seeing the profound impact of stroke in a close family member. So the experiential awareness here had possibly not been a factor for change but rather left him caught in a state of denial (Kubler-Ross 2009), which may have implied that he needed help to move on.

Most participants knew about healthy lifestyle behaviours and *“...really what I should be avoiding”* (Sarah, age 39, 365) and when faced with a health threat were able to reason in part why this has occurred, with their expertise about their own illnesses, for example: *“I was certainly drinking too much”* (Andrew, age 65, 67). They also knew a fair amount about stroke-related illness and specific causes partly from recent publicity campaigns (RCP 2008).

Initially saying they knew *“...nothing at all”* (Sarah, age 39, 322) but then revealing considerable knowledge gave mixed messages. This may be related to the bargaining phase in a bereavement type process (Kubler Ross 2009, Figure 13) where participants were coming to terms with the shock and health threat and were still in partial denial. The inference for patient-centred care here was that participants were at different stages in transition and therefore the information given would need to be timely and repeated to meet individual needs, as discussed above. There was a dogged determination to find out *“...what was happening”* (Megan, age 52, 36), for example:

*“I wanted to know and if I hadn’t have got it off the internet, I would have gone to the library---I would have got the information one way or another and the history, whys and wherefores”* (Sarah, age 39,343-345)

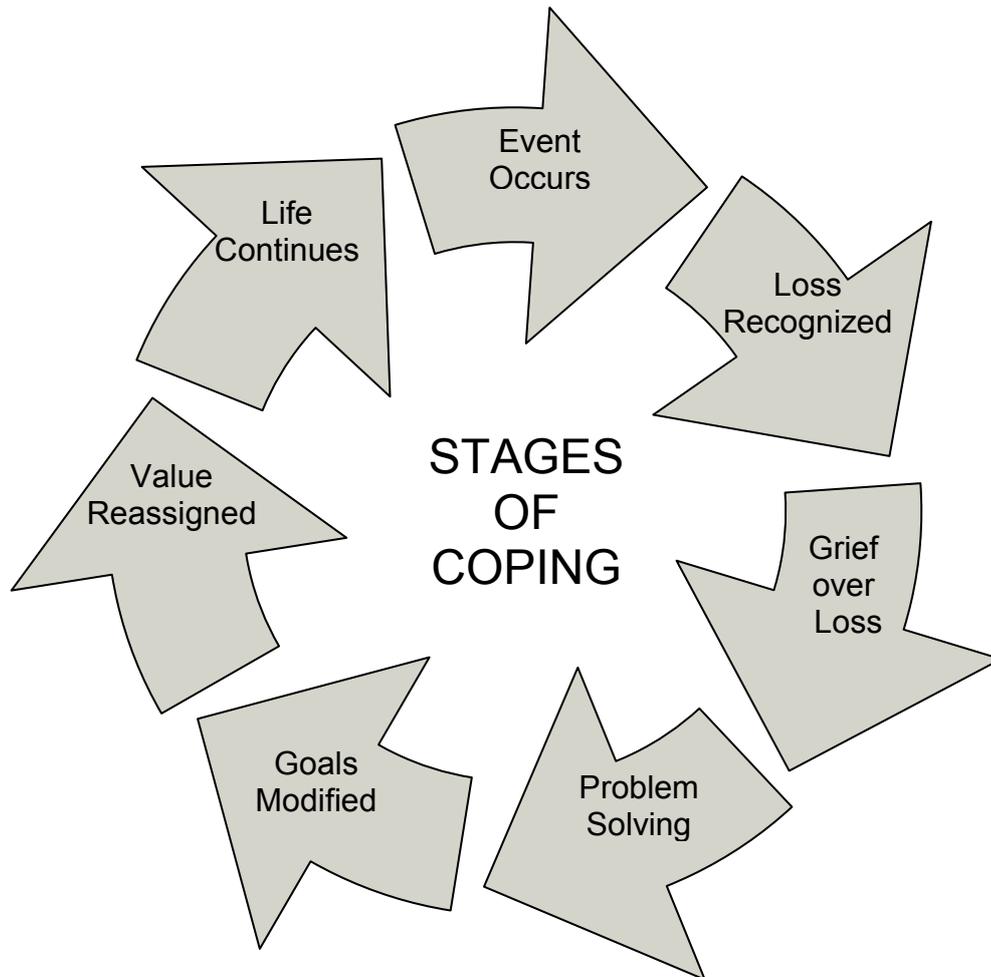


Figure 13. Cycle of Coping. Adapted from Kubler-Ross's (1969) Grief Cycle  
(Original in colour)

Participants reported finding themselves in a disorientating crisis situation where they —...*didn't know what was happening*” (Megan, age 52, 36) that gave rise to anxiety around: —...*what's going to happen to me?*” (Sarah, age 39,195). This had resulted from the biographical disruption of illness (Bury 1982). Several participants described past life events that appeared to serve the purpose of making the current illness event more intelligible and they were encouraged to set the scene with some life history. For example Esmond gave a colourful account of his experience in the Second World War and his enjoyment of playing cricket. This appeared to infer distraction as a way of coping (Weiten and Lloyd 2006). The event was threatening and frightening and most participants knew what it was and it occurred whilst participants were engaging in daily routines (Pound et al. 1998) as discussed in Chapter 5. A study by Backe et al. (1996) exploring patient conceptions post stroke in a sample of six noted the feelings of unreality and confusion

echoed in the findings of this study. Also in the study by Backe et al. (1996) the use of expressions was similar to this study. For example there was indignance that the illness event had occurred, signified in *“I followed all the rules”* (page 289) reflected in *“I thought I was doing all the right things”* (Andrew, age 65, 270). Likewise in Backe’s study participants spoke of *“...bodies---not obeying signals”* and a limb *“... was just gone”* (page 289) that was echoed in *“Limbs Misbehaving”* in this study which also included expressions of *“limbs going”*. The similarities in language and expressions support the importance of having included narrative analysis in capturing these emotive aspects, although the study by Backe et al. (1996) lacked transparency at times.

However, participants had revealed their own way of coping and problem-solving as illustrated in the flowchart in Figure 9 page 127 that presents a chronological list of practical advice or *“what to do for the best”* taken from the experiential accounts. This supports the notion of the expert patient. Whilst Kubler-Ross’ *“Cycle of Coping”* (2009) is general and could relate to any life crisis, the flowchart mentioned is specific to patients who have experienced a TIA and makes a contribution to new knowledge.

At the onset of stroke-like symptoms it is important that everyone is able to recognise the meaning of this as 95% of strokes occur within the community (RCP 2008 page 45) and then to treat this as an emergency as indicated in the FAST campaign (Stroke Association 2007). Once within an acute hospital environment personnel are equally required to promptly recognise this as in ROSIER (Nor et al. 2005). A measure of success of the quality marker of awareness in the National Stroke Strategy (DOH 2007c) is increased numbers seeking medical attention within two hours of symptom onset. In this study three participants met this requirement, two of whom had a quick response from ambulance crews. One participant immediately recognised the problem from a previous event for example: *“I’m going again”* (Andrew, age 65, 28) and his family called an ambulance. The other person was attended to by a policeman who *“...called an ambulance”* (Sarah, age 39, 161). The third person was taken to hospital by two of her family members, one of whom had recent experience of stroke himself, for example *“...they came and picked me up and brought me to the hospital”* (Megan, age 52,34). So these three participants got prompt attention due to their own knowledge or that of those around them demonstrating the paramount importance of raising awareness.

### 7.5.1 *Significance and Coping*

A longitudinal study, exhibiting good transparency, of 57 participants interviewed at intervals over a two year period following stroke by Faircloth et al. (2004 page 242) proposed that the *“...lives of people who have a particular illness that is notably marked by sudden onset are not inevitably disrupted”* inferring that some will take this in their stride and see it as part of life’s pattern. This was evident in this study where the level of concern was on a continuum with some participants exhibiting very little concern. In the case of stroke-related illness associations with the ageing process may be made and this was apparent in the accounts of three participants. Here participants might have seen the event as part of the trajectory of old age, for example: *“...you just accept it and particularly being old it helps”* (Ann 2, age 70, 391). However studies of other illnesses of sudden onset, discussed on page 48, revealed a definite sense of disruption.

This was a way that participants were softening the *“...blow”* (Arthur, age 71,105) for themselves by justifying what had happened. Two of the participants had co-morbidities of heart problems, for example *“...a fluctuating heart rate”* (James, age 59, 51) and they spoke at length about this almost as a projection out in order to not to have to face the reality of the threat of a stroke that was a *“...petrifying”* (Sarah, age 39, 484) thought. One of the participants, Arthur, appeared in denial and not addressing the issues, employing avoidant coping, as he was not contemplating any changes to his hectic lifestyle and when questioned about the impact of his illness experience he quickly moved off the subject with comments like *“...scary”* (Arthur, age 71, 189). Different coping strategies were being employed across the sample. Those with better self-efficacy were demonstrating active coping (Johnston et al. 1999) for example: *“...you do the best you can with advice available at the time”* (Ann 2, age 70, 422); whereas others were employing distraction as a way of coping (Weiten and Lloyd 2006). Ann was one of the participants in whom resources had been mobilised and she put this down to exposure to previous exacting circumstances, also echoed in Esmond’s account, for example:

*“...we went through the Second World War and that is when my mother established the good, a well balanced diet for us. She learnt a lot through that war---that has stayed with me through life”*  
(Ann 2, age 70,401).

The minimising of the significance of the event demonstrated by some participants may have been their way of coping (Kelleher 1988). Older people cope better in a crisis (Pound et al. 1998) as evident in the older participants Esmond (age 86), Ann (age 70) and Andrew (age 65). Weiten and Lloyd (2006) described three strategies employed by people dealing with stressful situations that can be recognised in the behaviours of participants in this study, for example:

*Appraisal-focused strategies* where individuals change the way they perceive the situation either in denial or distancing themselves from the reality as evident in the case of Arthur discussed above.

*Problem-focused strategies* where individuals acquire more knowledge in order to best manage the situation as demonstrated in both Ann and Andrew with their commitment to recommended lifestyle changes.

*Emotion-focused strategies* where individuals manage their emotional responses to the situation by distraction, venting of feelings, managing anger and relaxation strategies as evident in Esmond with *“I do enjoy gardening”* (Esmond, age 86, 14) and Ann with *“I’m trying harder to relax more and just sit down with a glass of wine more, one a night, just so you really do unwind and relax”* (Ann 2 age 70,282).

### 7.5.2 *Whose Life is it?*

The Darzi report (2008) stresses that *“...most people recognise their health is their responsibility”* (page 33) and that people should be empowered to *“...take control over their own health”* (page 33). Part of the medical management of stroke is the identification of risks to individuals and empowering people *“...to take responsibility for monitoring and treating their own vascular risk factors”* (DOH 2007c page 26) having first given advice and information on smoking, alcohol, diet, driving and exercise. Participants realised that they needed *“...to take quite a bit of responsibility for ourselves”* (Ann, age 70, 214-215). In this study considerable effort had been made in this direction by some participants but they had experienced inconsistencies in the advice given. But having received the advice there was recognition in maintaining control and autonomy in *“...make up your own mind*

*about the advice*” (James 214). These issues of control relate to the locus of control model of behaviour discussed on page 44. Here participants may have felt rewarded for example losing weight, lowering their blood pressure or cholesterol levels through exercise and healthy eating; seeing the improvement in these objective measures in terms of rewards or reinforcements for changed behaviour.

### 7.5.3 *What Information?*

Within this study advice given to participants by their GP or at clinics was inconsistent, for example Arthur was told that he *—..couldn't drive for a month*” (Arthur, age 71,106) whereas Esmond was told it was *—..alright to drive*” (Esmond, age 86, 259). Andrew was given specific advice about exercise and told *—..you're not doing enough exercise*” (Andrew, age 65, 53) whereas others either did not report exercise advice or were looking for advice for example: *—I would like to know whether the amount and type of exercise ---- is considered to be sufficient for someone who is more at risk?*”(Ann 1, age 70, 33-35). This exercise advice could well be given by a physiotherapist, possibly within a multidisciplinary workshop for people following TIA. Some of these inconsistencies linked into the position of participants in the cycle of change (Prochaska and Di Clemente 1982) and to how advanced they were in the medical journey. However, to give inconsistent advice is not helpful and a workbook based on *\_What to do for the best?*‘ discussed in Chapter 5 might ensure that the right information is available to all.

### 7.5.4 *Who Gives Information?*

In most cases the patient’s GP will have more insight into individual lifeworlds through a more established relationship. Having first received specialist reports, the GP is in a better position to give information in a way that is more patient-centred and patients feel more comfortable with:

*—..the information will go to my GP who will in turn have a discussion with me”* (Ann 1, age 70,274).

However, it was apparent from this study that participants had faith and confidence in *—..the specialist*” (Ann 1, 109) so it might be that initial information is best given at hospital appointments but later clarified and reinforced by a patient’s GP. Again

information concerning exercise could be given by a physiotherapist or on diet by a dietitian suggesting a multidisciplinary approach is optimal.

#### 7.5.5 *Awareness*

Patients need to understand the importance of prompt diagnosis in TIA and that this cannot be made by their GP without investigations. One of the participants Arthur who had a long-standing patient-doctor relationship with his GP had *“...arranged to see her in about ten days”* (Arthur, age 71, 103) following the event which was obviously not timely. The impact of sudden illness *“...out of the blue”* (Sarah, age 39, 201, Andrew, age 65, 244) is always shocking, *“...really did shake me up”* (Andrew 272) and comes as *“...a total surprise”* (James, age 59, 333). However, on reflection later, participants did *“...know about risks”* (Megan, age 52, 154) and their own specific causes, for example *“...overdoing it”* (Andrew 119). Yet initiating positive lifestyle changes was, for most participants, a protracted process, based upon a variety of motivational and behavioural theories discussed in Chapter 2, pages 43-50.

The fact that some patients consented to this study and others did not cannot be fully explained, as in any research study, but it may relate to awareness issues. Whilst it cannot be linked to under-reporting in TIA as the people invited to take part were all clinic attendees and therefore had sought medical attention. It could be speculated that following the first clinic appointment there were several required hospital attendances for various investigations and to attend again for a research interview was too much all at once for some people. This could have been attributed to the protection motivation theory in that patients were looking after themselves by attending clinics and investigations but not doing anything extra.

#### 7.5.6 *Empowerment*

It was evident from this study that participants did have a working knowledge of stroke-related issues, though less so specific to TIA, including their own risk factors and consequent lifestyle changes that they needed to make. Though tapping into, releasing and unlocking that knowledge and translating that into action for lifestyle changes by mobilising resources (Bury 1982) was hard. This linked to empowerment and acknowledging patients as experts in their own illness as Darzi (2008) said *“...empowering*

*people ---enables them to use their personal knowledge, time and energy for solving their own health problems”* (page 40). It is important that the *---credible and trustworthy information”* (DOH 2004b page 3) given to patients builds on what they already know. This is empowering and results in shared decision-making and informed choices (NICE 2008). Fifty per cent of stroke patients are dissatisfied with the information received (Healthcare Commission 2006). This was echoed in concerns expressed by three participants in this study. James and Arthur wanted more information about what their medications were trying to achieve and Ann wanted more exercise advice. This may have inferred that they needed empowering to ask these questions at clinic appointments because they felt intimidated by medical dominance and paternalism. The physical activity advice could be given by a physiotherapist in a patient-centred timely fashion.

As Darzi (2008) said patients need to be *---partners in decisions about their own care, shaping and directing it with high quality information and support”* (page 40). It takes time to get to know patients as fellow human beings (Evans 2003) and find out what they already know and in most busy GP surgeries and hospital clinics this may not be seen as a priority at the time. However, this is time well spent to allow patients to take some control over their health decisions as this will result in better outcomes and ultimately reduce healthcare costs. The knowledge gathered through all of the phases built on any prior relevant learning and was instrumental in laying the foundation for change, where *---learning is a process by which behaviour is changed”* (Knowles 1998 page 13).

## **7.6 Summary of Chapter**

This chapter has highlighted the paramount importance of awareness of stroke-related symptoms and, once identified, the necessary immediate action required. This equates to knowledge and a need for all to know, not just taking responsibility for our own health but others as well. Introduction of the vascular risk programme ‘*Reduce your Risk*’ (Darzi 2008) has led to people having knowledge of their cardiovascular risk in terms of percentage chance of a myocardial infarction within ten years. This would suggest that a similar assessment could be made about stroke risk, particularly since there is overlap of the risk factors. Having this knowledge could empower people to take control, employing locus of control and self-efficacy issues, and lower their risk profiles, especially if they have some objective marker to aim for. However, it is recognised that it is not so

simplistic in that risk factors for stroke may not be so easy to control, as discussed on pages 182-183.

It is evident that the message of the FAST campaign is not reaching everyone and may need revitalising in order to raise awareness further. Although the publicity initially appeared striking, for example graphic images on prime time television, the emphasis needs to be sustained as in anti-smoking campaigns. It may be that individuals do not relate to the collective message unless it awakens meaning for them personally. Since it is likely that everyone will have vascular risks to a greater or lesser degree, that is no one will have perfect arteries, it seems that the message needs to be about keeping our arteries in as good condition as possible for as long as possible. Therefore the images need to be of atherosclerotic arteries as well as what could occur if we do not pay attention to this. The two messages need to be linked. Likewise, the heart attack posters, from the British Heart Foundation, show graphic images of someone experiencing crushing chest pain but nothing about cause and prevention. People need to be empowered at an earlier stage that enables them to make the association between cause and potential outcome.

Seeking medical attention following experiencing stroke-like symptoms within two hours of onset is recommended but the reality in most peoples' lives is that this is probably not attainable, especially if the event occurs at night. The emphasis is on treatment of residual symptoms as part of secondary prevention and yet the thrust of health policy documents is upon the need to pro-actively anticipate challenges and deal with them before they arise.

The FAST campaign is only reactive and infers the use of costly investigations and medications. Whilst this is infinitely less expensive than the treatment of someone with residual disabling life-long symptoms of stroke, it would be more cost-effective to pro-actively target the vascular risks pre-morbidly with greater emphasis. Increasing longevity continues to present challenges for the finite resources of the NHS budget, not only in terms of numbers of people making demands upon the service but also the fact of the escalating elderly population with the cumulative health problems or co-morbidities of old age. This makes it essential to proactively identify and mitigate health risks to minimise the drain on resources. Realistically this can only be achieved by individuals being

empowered through knowledge to take responsibility for minimising their own health risks.

The word FAST infers a reactionary response whereas self-inflicted vascular risks do not suddenly arise but are cumulative over a long period of practicing unhealthy behaviours that may be started in childhood or possibly even in utero. The reversing of the damage that we do to ourselves in terms of vascular risk is very hard and may not be possible, setting aside genetic risks that we cannot change. This is probably the message that people need to hear. However, if our parents had cardiovascular or cerebrovascular disease at a young age, it is estimated that this factor influences our future risk. We do not know if their unhealthy lifestyle behaviours were major contributory factors and that if we practice healthy behaviours we could offset this familial risk. But it may be with the future developments in the study of genetics and personal genomes relating to a wide variety of illnesses, that individuals will have personalisation in medical care and preventive measures in the future (Ashley et al. 2010).

Nevertheless it is likely that the behaviours of our parents are embedded in us or that the self-inflicted vascular risks are established in childhood and it requires a very determined effort to make major required changes measured by the strength of our self-efficacy and perceived behavioural control. Also the perceived level of health threat is influential and if we witnessed our parents with a particular illness, with experiential knowledge we may think this is our ‘fate’ as did some of the participants in this study. Despite this fatalistic attitude efforts were made to adopt healthy lifestyles and move through the cycle of change but goals could have been tempered by —*..what ever happens, happens ultimately*” (James, age 59, 301). Some of this attitude may be offset by having objective goals to attain that are meaningful and motivating by demonstrating achievement and change, employing theories of reasoned action and planned behaviour discussed on page 45.

It is likely that not everyone will want to know their future health risks that could pose a threat, in terms of personal genome, but this might be part of choice and personalisation (Darzi 2008). GP’s currently calculate percentage risks of myocardial infarction and use this to inform prescription of statins in the management of hyperlipidaemia (high cholesterol). So by giving this information to patients they are empowered with

knowledge to make changes and they know that statins are available in future should the percentage risk rise over an acceptable level. But to give a percentage risk of a stroke within a certain time period, to all patients at risk, would be quite different as multiple factors are at play and some may not be changeable or treatable. If this information were available, some patients may choose not to be informed and medical practitioners may withhold this information in the patient's best interest or just use it to make clinical judgements. However, this information, if used selectively, could be effective in promoting recommended lifestyle changes or adherence to medication regimes in non-compliant patients. This would be at the discretion of the practitioner in relation to knowing the lifeworld of individual patients.

Patient-centred care infers entering the patient's lifeworld in order to meet individual needs of learning styles, gaps in knowledge, addressing concerns and 'what to do for the best' for that person in his or her situation. There needs to be mindfulness of the patient as the expert in his own illness in the shared decision-making and that control and autonomy are essential ingredients of quality of life (Jaracz and Kozubski 2003). Patients may be better informed than clinicians and the latter are considered to be slow at exploiting the potential of new information services, for example the internet (Darzi 2008). However, some websites may be unreliable and information needs to be credible and trustworthy (DOH 2004). Patients should be seen as active consumers of health care and not passive recipients. Learning is a lifelong process and experiential learning is the richest source for adults learning (Lindeman 1926) and as said by Knowles (1998) —*..in an adult class the student's experience counts for as much as the teacher's knowledge*” (page 39).

The information given to quench the —*..thirst for knowledge*” (Sarah, age 39, 343) and reduce the steepness of the —*..learning curve*” (Andrew, age 65, 99) needs to be tailored to individual needs and ideally imparted in a timely manner by someone with an insight into the whole person. There needs to be recognition that during the crisis period of onset of symptoms, immediate investigations and diagnosis, is not the best time to be giving too much new information. During this time the focus of attention is upon the immediacy of the health event, the causes and possible consequences. Therefore the potential to assimilate new information is considerably diminished (Backe et al. 1996). This points to the need to be given the advice at this time by the 'specialist' but for it to be reiterated at a

later calmer date at the GP surgery by someone who has insight into the patient's lifeworld. Additional peer support could be provided by an expert patient based upon the flowchart 'What to do for the best' (Figure 9, page 127).

Mobilisation of all patients' resources (Faircloth et al. 2004) should be possible if the advice and information is timely, accurate, consistent and most importantly keys into individual needs and therefore is pertinent and meaningful. In other words, that the interaction is patient-centred. This means taking time to get to know patients and not just handing out a general advice leaflet with no explanation. It is important to get this right because "...this warning event provides an opportunity to prevent stroke" (Coull et al. 2004 page 326) with all the inherent health and social care costs that stroke implies. All of this points to the importance of understanding the influence of historicity on lifestyle behaviour changes and taking time to get to know patients. Factors impacting upon lifestyle change are shown in Figure 14.

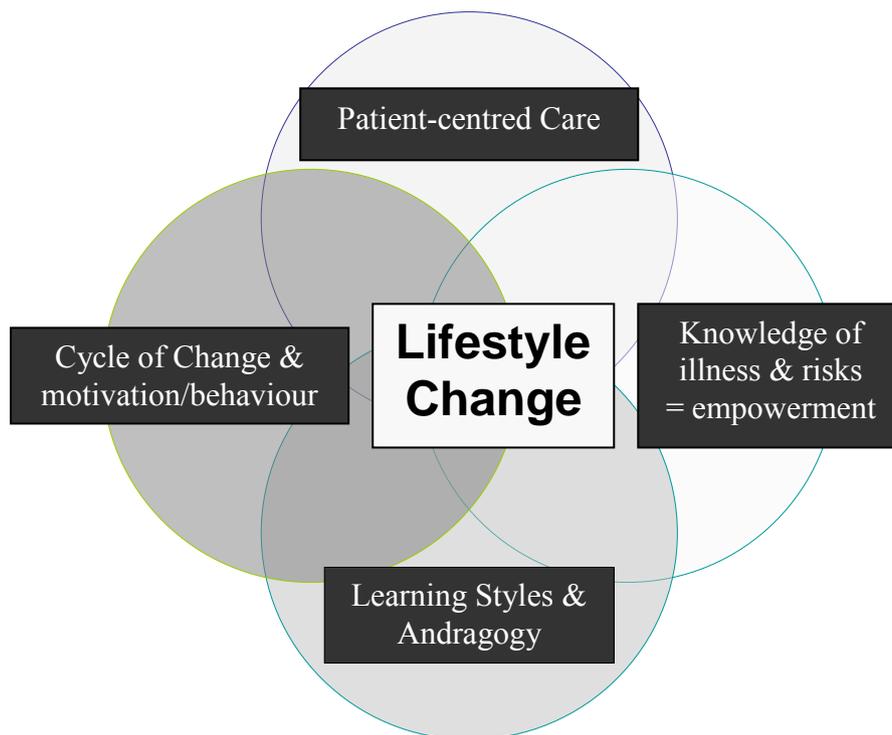


Figure 14. Factors Impacting on Lifestyle Change

(Original in colour)

The importance of the influence of knowledge on behaviour change cannot be underestimated as illustrated in Figure 10 page 160. Application of several models of behaviour change, explored on pages 43-50, to the findings of this study have been discussed with direct reference to the vignette of behaviour change presented in the findings on pages 134-135. In summary, although there is some resonance with several behaviour change models within the findings of this study, none of them are quite comprehensive enough. Behaviour change is so complex and of the models discussed, only the health belief model mentions the importance of knowledge in influencing change. Knowledge was found to be of paramount importance as a catalyst for change in this study as illustrated in Figure 10 page 160. Also some of the models, for example the transtheoretical model, are very fixed in their representation as following a set pattern and only flowing in one direction. This does not take account of the need for fluidity and moving back and forth whilst engaged in a decision-making process which might be better represented in a diagrammatic form that allows for some blurring of the stages. Also this model does not appear to allow for any outside influences, such as knowledge.

### **7.7 Limitations to the Study**

The study was conducted in one acute hospital trust in South East England where there was a developing TIA service run by a stroke physician and TIA specialist nurse. Whilst most acute hospitals will have a TIA service this cannot be assumed. The sample of seven participants comprised all white British Caucasian middle class, as identified in the 2001 census categories (Her Majesty's Stationery Office HMSO 2004), who may not be representative of the population drawn from or other areas. All participants had access to a TIA clinic with follow-up. There was no way of capturing the population of patients experiencing TIA who did not seek attention, possibly through lack of awareness, and who represented an under-reporting element. Only one participant was interviewed on two occasions, which was her choice, and to interview participants more than once does better complete the hermeneutic circle in order to see how thinking develops.

It would have been interesting to have had feedback from participants on the impact of the interview and if they valued that. For several it appeared to be a cathartic experience. It was the first time following the illness event that they had one-to-one attention when they

could speak at length about what had happened to them in a fairly neutral situation. Comments like —*...it's much more severe on me psychologically than it is physically*” (Ann 1, age 70,143) may not have been said or heard in a busy medical clinic and were important to be voiced in order for participants to move on. Therefore it would have been valuable to have conducted second interviews with all participants and track progress over time, possibly in a longitudinal study to see how many go on to have a full stroke.

The study has looked at the medical management and pathway including all doctor-patient interactions with limited direct reference to physiotherapy practice. However, the implications for patient-centred care have resonance for other care professions and those for physiotherapy practice have been considered.

Cornwell (1984) noted that the depth of information provided by interviewed participants is directly related to the relationship with the interviewer and the context in which the research takes place. One of the participants worked in the area in which the research was conducted and was known to the researcher and this may have limited some responses, from this individual. Additionally the interviews were carried out in the clinic rooms where participants would have attended medical clinic appointments following the TIA. However this point could be seen as positive as the interviews were within the context of the TIA experience. Attempts were made to minimise the clinical appearance of the room with use of armchairs and pot plants to diminish any negative effects of the above two points.

The field of stroke medicine is rapidly expanding and initiatives and documents are being frequently published or updated and —*...the health advice coming from the government departments is constantly changing*” (Ann 2, age 70, 419-420). At the time of writing the latest evidence is incorporated. However at the time of evaluation and examination it is possible that further developments will have occurred that one needs to be mindful of.

## Chapter 8 Conclusions and Recommendations

*Feeling unwell  
Strange, a bit funny.  
Driving along, couldn't chew gum  
Face numb, eye and mouth drooped  
Pinched my face-couldn't feel anything  
Couldn't speak properly  
They couldn't understand me  
Crying, didn't know what was happening  
Lost strength in my arm  
Couldn't squeeze doctor's hand  
Really horrible  
Think myself lucky, it was very mild*

(Megan, age 52)

## **8.1 Introduction**

This study aimed to explore the lived experience of transient ischaemic attack to address the related gap in the literature, thus contributing to secondary stroke prevention. By entering the lifeworld of the participants, multiple realities have been exposed that impact on practice under the umbrella of patient-centred care that could equally well apply to pathologies other than within stroke medicine, particularly other sudden transient illnesses. Key conclusions and then recommendations for clinical practice relating to specific topics will be presented below and the latter illustrated in Table 4. This embraces the essence of the professional doctorate in addressing practical applications of new knowledge (Scott et al. 2004) transferred from the academic setting, thereby contributing to evidence-based practice. This will be followed by suggestions for further research; a summary will include contributions made to knowledge and finally a dissemination strategy will be outlined and lastly a closing statement made.

## **8.2. Key Conclusions Emanating from the Research Findings**

Key conclusions may be summarised as follows:

- The power of the narrative in giving voice to patient experiences is undervalued. Only when it is fully acknowledged as an essential part of clinical reasoning, can truly patient-centred goals be set. Meaningful patient-centred goals lead to better outcomes and are empowering for patients to take control, undertake self-management and maintain changed lifestyle behaviours.
- Patient expertise in mobilising resources to self-manage (what to do for the best) following TIA needs recognition and facilitation through patient-centred care.
- The importance of information and knowledge as key factors in effecting lifestyle change need to be seen as adjuncts to theories of behaviour change

### 8.3 Recommendations

Recommendations for clinical practice will be summarised in Table 4 and detailed thereafter.

<b>Subject Areas</b>	<b>Recommendation</b>	<b>Action Plan</b>
<b>Meaning of Illness To Individuals</b>	Hearing the patient's voice and story, identifying expectations and needs are essential components of clinical reasoning in recognising the importance of the narrative	1. Check physiotherapy curriculum re narrative reasoning with CSP/UOB BSc and MSc 2.? Input to UOB BSc/MSc
<b>Informed Patient</b>	Information and advice given to patients at TIA clinics may be key in effecting behavioural change	1. Approach Stroke Association re patient stories on the website 5. Review info & advice at TIA clinics with stroke physician & TIA specialist nurse
<b>Expert Patient</b>	1. Make more use of expert patients in clinical practice 2. Experiential accounts of TIA need to be heard	1. Contact expert patient programme 2. Contact Stroke Association re TIA workbook (What to do for the best) 3. Poetic representation put to good use re emotional impact via Stroke Association as above 4. Contact ESHT physiotherapy managers re using expert patients in clinical practice
<b>Knowledge &amp; Learning</b>	Expert patients available at TIA clinics	1. Approach stroke physician/TIA nurse re expert patients at TIA clinics 2. Consider how effectiveness could be measured
<b>Self-efficacy &amp; Lifestyle Change</b>	1. TIA support groups affiliated to stroke support groups	1. Approach local stroke support group 2. Check local lifestyle change initiatives re how could benefit those post TIA
<b>Expert Practice</b>	1. Increase clinician awareness re factors impacting upon lifestyle change behaviour in TIA/transient illness 2. MDT 'one-stop-shop' for patients post TIA	1. Find out PT curriculum re factors affecting lifestyle change-contact CSP/UOB BSc 2. Approach community stroke rehab team/TIA nurse re MDT 'one-stop-shop' post TIA

Table 4. Recommendations for Clinical Practice

#### 8.3.1 Meaning of Illness to Individuals

Investing time in entering patients' lifeworlds with empathy is time well spent in clinical practice as part of clinical reasoning. It is within this patient-centred interactive relationship opportunity that health promotion and lifestyle changes could be triggered and effected with favourable outcomes leading to cost savings in both healthcare and burden of

social care. It is only through the understanding of the meaning of illness to individuals that potential for health can be fully appreciated. Here shared understandings can result in collaborative decision-making for realistic health attainment goals with favourable outcomes. It is essential to hear the patient's voice and tailor treatments and advice that embrace individual expectations and needs.

It would be worth checking how much emphasis is given to the importance of hearing the patient narrative in clinical reasoning within undergraduate Physiotherapy training. This is the intention to check with both the Chartered Society of Physiotherapy and the University of Brighton (UOB) BSc and MSc programmes. It would be possible for the researcher to input to the latter two programmes and other related UOB modules. Input to an MSc module 'Contemporary Issues in the Health and Wellbeing of Older People' at UOB has already taken place with good feedback.

### **8.3.2 Informed Patient**

Information given following TIA needs to be timely and meaningful to individuals. This might mean repeating information on more than one occasion and providing written as well as verbal information. Patients need to be quite clear about the implications of their illness, why they are being sent for investigations, what these tests will entail and how long they will need to wait for these to be carried out, and then to obtain the results. If patients are required to take medication they need to know what effect this will have and then to be kept informed of any measurable objective effect that it is having that can demonstrate to them that it is worth continuing, in line with theories of perceived behavioural control. An example of this is in the taking of statins in hyperlipidaemia and patients seeing an improvement in their low-density lipoprotein levels.

Likewise, with any lifestyle changes embarked upon patients need to know that it is worth the effort if it is to be sustained since behaviour is directly related to outcome in terms of successful performance (Bandura 1977). Knowledge of percentage risks of certain illness outcomes such as stroke, MI or death may be useful for some patients to know, in order to motivate behaviour change, that is they have some control over the factors or that they could be offered medication if the situation is not changeable. This links into a recent NHS white paper 'Equity and Excellence: Liberating the NHS' (DOH 2010a) and a

subsequent supporting document – ‘Transparency in Outcomes: a Framework for the NHS’ (DOH 2010b) that claim that services will be developed in partnership with patients and the public and therefore voices will be heard. The key messages from the former document, that have overwhelming resonance with the findings of this study are patient choice, informed choice, patient-centred care (‘no decision about me without me’), empowerment and control and valuing patient experience.

It is the intention to approach the Stroke Association about the possibility of publication of patient stories of the experience of TIA on their website in order that others might learn from this. The researcher also intends to review the information and advice given to patients at clinics following TIA at her place of work, in conjunction with the stroke physician and TIA specialist nurse.

### **8.3.3 Expert Patient**

Acknowledgement of patients as experts in their own illness and health problem-solving is undervalued. The shift away from the biomedical model of healthcare and paternalism has, in part, led to increased empowerment for patients to take greater responsibility for their own health matters. However, implicit trust and faith in the medical profession still exists and patients look towards doctors to provide solutions as part of their expert practice and patients have high expectations. To this end patients put more trust in information provided by specialists although it is likely that GP’s will have more insight into patients’ lifeworlds. Specialist advice can be reiterated within GP consultations where individual needs can be addressed.

Within this study expertise amongst participants in managing their own health needs was identified in arriving at a pathway through the medical phase to guide others on their journey. Much of this included healthy lifestyle advice, based on recent DOH guidance on exercise, diet, alcohol, smoking and weight issues that applies to the general population. There were more emotive issues about making up one’s own mind once medical advice had been acquired, staying cheerful in adversity and uncertainty, keeping things in perspective and continuing to enjoy life. This pointed to the contribution that could be made to the Expert Patient Initiative (DOH 2002). In practice generally, including physiotherapy practice more exploitation of this experiential knowledge could be put to

more productive use. On the UK Stroke Association website there are experiential accounts of stroke but not of TIA and the latter could be helpful, as discussed above.

It is the intention, for the researcher, to contact her local Expert Patient Programme to see how TIA patient expertise could be harnessed for the benefit of others. The Stroke Association is to be contacted regarding the possibility of publishing or contributing to a workbook for patients following TIA \_What to do for the best'. Poetic representation of the emotive aspects of the TIA experience may equally be useful to publish for the benefit of others. Physiotherapy managers at the researcher's work base are to be contacted about the practicalities of increased use of expert patients in physiotherapy practice.

#### **8.3.4 Knowledge and Learning**

From the experience of TIA, experiential learning (Kolb 1984) took place in line with how adults learn, known as andragogy (Knowles 1990 and 1998) giving rise to knowledge. The knowledge gap between the doctor as professional and patient as layperson was narrowed through the experiential knowledge and acquisition of further information from other sources such as the internet. However, the doctor as professional (McDonald 1975) was seen as having expert knowledge which conferred power and autonomy (Friedson 1970), but the patient was empowered through knowledge and consumerism leading to shifts in the powerbase. The Expert Patient Programme (DOH 2002) where a patient, who has experienced a particular pathology, following training, can mentor other patients with similar health experiences is an example of lay empowerment. It might be that each patient diagnosed with TIA could be asked if they would be prepared to mentor another patient who is starting out on the pathway by way of peer support. The experience of lifestyle change in patients who have been through the medical pathway could be instrumental in facilitating change in others via modelling enhancing self-efficacy expectations (Bandura 1977). This study makes a valuable contribution by making available a language and vocabulary of metaphors and analogies that patients use to communicate their experience of TIA.

Expert patients should be available at TIA clinics and it is the researcher's intention to approach the stroke physician and TIA specialist nurse, at her work base, to see how this

could be incorporated and the effectiveness measured. This has now been explored with a TIA clinical nurse specialist and some thought is being given to this.

### **8.3.5 Self-Efficacy and Lifestyle Change**

With improved self-efficacy, influenced by empathic clinic experiences, patients are likely to take control through empowerment and motivate themselves towards realistic goals in achieving lifestyle changes. The stronger the self-efficacy the better the outcome expectations will be; that is the belief held that a particular course of action will produce certain outcomes (Bandura 1977). This was demonstrated in the behaviour of some participants in this study and also keys into theories of reasoned action and planned behaviour discussed on page 45. The efficacy expectations will be the patient's confidence about whether the outcome is achievable for him/her. This sense of personal mastery affects initiation and perseverance of behaviours as identified in one of the participants in this study who had never been athletic and was not committed to increasing her physical activity levels. However, this could be overcome with encouragement and rewards of achieving small goals designed to boost a sense of efficacy and personal mastery. Two other participants, who related having successful, rewarding, yet very demanding occupations with a sense of personal mastery, were reluctant to change their lifestyle behaviours. It appeared that any new lifestyle behaviours would not render equal rewards and that contemplation of change appeared threatening and was a foray into the unknown. This would support the initiatives of lifestyle advisors and NHS personal trainers. Patient support groups have a part to play in effecting change in behaviours as in stroke support groups and may be TIA support groups could be established and affiliated to these.

The researcher intends to see if TIA support groups could be established alongside Stroke support groups by contacting her local Stroke support group; and to check with any local lifestyle change initiatives to see how they might benefit patients following TIA.

### **8.3.6 Expert Practice**

Clinicians need an awareness of all the factors impacting upon lifestyle change, as part of patient-centred care, particularly behaviour theories and knowledge when trying to influence change. These include where a person is in the cycle of change, what knowledge they have related to their illness and risk factors, and the nature of their learning style. To

be competent in this comprehensive role not only requires a healthcare background but also knowledge of theories of behaviour, motivation and change as well as andragogy or how adults learn. To bring all of these skills from health, psychology and education together in one clinical practice role might be challenging and some of this could be done by lifestyle advisors, personal trainers or a multidisciplinary team. For example physiotherapists would have the medical knowledge and competency in effecting change in physical activity behaviours that impact upon other healthy lifestyle changes. This supports the idea of a multidisciplinary ‘one stop shop’ for secondary prevention where a dietitian, physiotherapist and specialist stroke or TIA nurse could deliver a healthy lifestyle programme to patients who had experienced a TIA.

Clinician awareness needs increasing in relation to factors impacting on lifestyle change behaviours in TIA/transient illness and development of multidisciplinary ‘one-stop-shops’ for patients following TIA could be helpful.

It is the researcher’s intention to check the curriculum for physiotherapy training at the Chartered Society of Physiotherapy and the University of Brighton (UOB) MSc and BSc programmes to see what is included in the syllabus regarding factors influencing lifestyle change. It would be possible for the researcher to input to these training programmes. Also the researcher will approach the Stroke Association, to find out if multidisciplinary workshops for patients following TIA are established, and find out about the content of these. The researcher will contact her local community stroke team and TIA specialist nurse about the possibility of establishing a multidisciplinary ‘one stop shop’ for patients following TIA. (The researcher has been previously involved in such an initiative but this had to be curtailed through lack of supporting evidence for cost-effectiveness. The findings of this study support the re-establishment of this practice).

#### **8.4 The Future**

There are some components of the findings of this study that do impact upon policy and practice but the researcher is not in a position to drive these changes. However, they will be mentioned here so as to be highlighted. It would seem essential that the vascular risk message needs addressing within primary schools in terms of making the links between, for example obesity, inactivity, hypertension, smoking and stroke in more specific terms.

Health education needs to start early and be quite explicit about risks and potential serious outcomes, as in teaching about drug and alcohol dependency alongside sex education. For example, obese children who are encouraged to exercise more as recommended in *Healthy Weight, Healthy Lives* (DOH 2008a) should be made aware of specific serious health outcomes if they do not change this modifiable risk. This knowledge is empowering to make changes and take control and be responsible for own health. The power of emotive language, from the findings of this study, could also be harnessed in health campaigns to emphasise the important message.

The emphasis of the FAST campaign does not go far enough in terms of prevention, only on the rapid recognition of stroke-like symptoms in terms of seeking early management. It needs linking to modifiable lifestyle factors that increase vascular risks and the threat of a stroke in particular. The message needs to be *'this is what could happen to you if you do not do this'* as in anti-smoking campaigns.

## **8.5 Suggestions for Further Research**

Leading on from the findings of this study ideas for further research are listed in Table 5 and outlined thereafter without specific detail.

### **8.5.1 *Advice at TIA Clinics***

The value and outcome of the health advice given to patients following TIA needs evaluating to see how many then go on to have a future stroke and in what time-period. This could be conducted in a longitudinal study, interviewing and tracking participants over two years. Adherence to improved lifestyle changes and medications may be difficult to accurately measure. People may only report what they think should be said in terms of compliance with healthy lifestyle behaviours and medication regimes.

<b>Research Ideas</b>	<b>Possible Methods</b>
How can the value and outcome of advice given at TIA clinics be evaluated?	Mixed methods
Where and in what roles are physiotherapists employed in giving exercise advice?	Survey
Is there a role for a physiotherapist in a TIA clinic?	Mixed methods
How do lifestyle changes evolve in patients after transient illness?	Longitudinal study
What is the experience of the TIA clinic for staff and patients? Does it match the ideals of the National Stroke Strategy?	Interviews
How can we demonstrate that hearing the patient narrative and employing a patient-centred approach leads to better outcomes?	Mixed methods
What is the value to the participant/patient of the research interview? Why do some consent to take part and others do not?	Interviews

Table 5. Suggestions for Further Research

### 8.5.2 *Physiotherapists Imparting Exercise Advice*

Physiotherapists may be considered, by some, to be competent in the giving of exercise advice and effecting lifestyle changes. If this is so, where are they employed in this role and how effective is this advice? This could probably be carried out through a large survey but to evaluate the effectiveness may require a qualitative element interviewing a variety of recipients from different spheres of practice.

### 8.5.3 *The Role of the Physiotherapist in a TIA clinic*

Leading on from section 8.5.2 above, a physiotherapist could probably give exercise advice in a TIA clinic but currently this role is fulfilled by a TIA clinic specialist nurse whose role will embrace the giving of lifestyle advice generally. Is there any value in a physiotherapist in this role where a clinic nurse is probably employed in a multi-function role liaising closely between the clinic doctor and patient? This could be evaluated in a mixed methods approach through a survey and possibly a focus group of staff.

### 8.5.4 *Lifestyle Changes Following TIA*

It would be useful to know how lifestyle changes, following TIA, evolve over time and are shaped by external influences, for example knowledge. This might appear to overlap with section 8.5.1 but the emphasis here is upon specifics of changed behaviour. To interview patients on more than one occasion following TIA, at different time points in their medical

journey would throw light on how lifestyle changes evolve and what factors come into play. Patients could possibly be tracked over two years by being interviewed on three separate occasions about their lifestyle changes and this information could be matched against how many have progressed to experiencing a stroke in that time frame. There might also be scope for and mileage in seeing where these individuals were scored on the ABCD2 risk stratification initially and comparing this with outcomes of lifestyle changes and possible stroke in the time frame above.

#### ***8.5.5 Experience of the TIA Clinic for Staff and Patients***

From the study herein findings have revealed patient clinic experiences but not included those of staff members that might be helpful to have a balanced view. For example in this study findings alluded to some discontent about clinic experiences for some individuals but this needs matching against the views of staff members as well. Also this could be compared with the ideals of the National Stroke Strategy. This piece of work would require interviews plus focus groups of patients and staff separately and together to get a complete and comprehensive data set.

#### ***8.5.6 Hearing the Patient Narrative and Enhanced Outcomes***

It appears that really hearing the messages from the patient narrative, employing a patient-centred approach, can lead to better health outcomes through identification of needs and expectations and the setting of realistic goals. How could this effectiveness be measured? Allowing people to expose and explore their needs, expectations and anxieties takes time and therefore has a cost element when thinking of the financial implications of units of healthcare. Whilst outcome measures demonstrate changes in physical functioning, the subjective elements are exceedingly valuable and underpin the objective, yet are given scant regard and are difficult to measure.

It may be possible to employ a mixed method approach, in a comparative study; of collecting objective data about outcomes from individuals who have been allowed extra time to explore needs and set goals and this could be compared with another data set from others who were given the ‘\_standard’ time. In many busy outpatient physiotherapy clinics only half an hour is allowed for a new patient assessment and establishing a treatment plan. This limited time means the session is very ‘\_directed’ by the physiotherapist and the focus is upon the objective measurable elements that might demonstrate change and

effectiveness of a physical intervention. Participants in both groups could be interviewed about their experiences of their first appointment and findings could be compared with the outcomes and how soon patients are referred back with the same problem. The latter would give an idea which group were better empowered to self-manage. In other words the cost element of initially spending more time with the patient could be more than nullified by the outcome.

#### **8.5.7 *Value of the Research Interview***

It appeared from the findings of this study that the interview experience was valued by participants in that it was the first time that they had unlimited one-to-one attention to be able to talk about what had happened to them and the impact and consequences. However, there was only a 42% response rate to consenting to take part in the study and it would be useful to evaluate why those in the sample consented, if it met their expectations based on the information provided and what it meant to them. This would need to be attached to a study and not a ‘stand-alone’ project and the information could inform other studies or subsequent interviews within the same study. It might reveal some influence in the contemplation of lifestyle change and if the experience made them feel ‘special’ as they had been selected to take part.

#### **8.6 Summary**

This study has made a contribution to the narrowing of the gap in the literature pertaining to experiential accounts of illness, particularly transient illness that represents living with the uncertainty of a future recurrence. More specifically it has added to the body of knowledge within secondary stroke prevention. Multiple issues have been uncovered that impact upon health care policy and practice, particularly in relation to the need for early prevention. Clinical practices need a more holistic approach to patient care that values the patient’s experience and expertise in their own illness and recovery. A summary of specific contributions to knowledge is given in section 8.6.1 and illustrated in Table 6.

### 8.6.1 *Summary of Contribution to Knowledge*

<b>Area of contribution</b>	<b>Contribution to knowledge</b>	<b>Relevant literature</b>
<b>Experience</b>	1.Experience of TIA	-Experiential stroke-related literature -Experiential transient illness literature
	2.Experience of TIA medical pathway	-Patient satisfaction/patient-centred care literature  -Matched against TIA pathway (National Stroke Strategy DOH 2007)
<b>Lifestyle Change and Secondary Stroke Prevention</b>	1.Factors impacting upon behavioural/lifestyle change in TIA/transient illness	-TIA and secondary prevention of stroke literature  -Transient illness literature
	2.Self-management post TIA	-Secondary prevention of stroke literature  -Expert patient literature
<b>Clinical Reasoning</b>	Importance of narrative reasoning	-Clinical practice literature -Patient-centred care literature - <u>Language of illness literature</u>

Table 6. Summary of Contribution to Knowledge

#### 8.6.1.1 *Experience*

Stories of patient experiences of TIA, that embraced all aspects of the illness event, what preceded it, the impact and consequences including the medical journey, have been told. This has made a contribution, not only to the body of knowledge that comprises the experiential stroke-related literature but also adds to that relating to other transient illnesses. This is particularly pertinent to the unique experience of a fleeting transient illness that results in living with uncertainty for the rest of one's life with something that *—...will never go away*” (Ann 2, age 70, 263) and could recur at any time. More specifically the experiences of the medical pathway, particularly the attending of TIA clinics, may be useful information in service development, in terms of identification of patient satisfaction. Additionally the matching of patient experiences of the medical pathway against the TIA pathway (Appendix 2) throws light on any shortfalls in terms of meeting the quality requirements of the National Stroke Strategy.

#### 8.6.1.2 *Lifestyle Change and Secondary Stroke Prevention*

A contribution to knowledge has been made by the identification of factors impacting upon behavioural lifestyle changes, especially knowledge, in people who have experienced transient illness and specifically TIA. This makes a contribution to the secondary prevention of stroke literature. Also contributing to the same source, by way of a ‘recipe’ for self-management following TIA was the identification, by participants, of ‘What to do for the best’. The latter also makes a contribution to the expert patient literature.

#### 8.6.1.3 *Clinical Reasoning*

A contribution is made to clinical reasoning within patient-centred care in recognising and acknowledging the power of the narrative elements and the importance of hearing the patient’s story in guiding decision-making processes. This is particularly pertinent to physiotherapy practice, where assessments and clinical reasoning processes have historically been largely based upon objective measures with little time spent on subjective elements. There needs to be more emphasis upon what we hear to match what we see and feel (palpate). Also relating to the narrative, the study makes available a language and vocabulary of metaphors and analogies that patients use to communicate their experience of TIA.

#### 8.6.2 *Dissemination Strategy*

A dissemination strategy is presented and set out in Table 7. This comprises what has already been done, publication ideas, conference presentation/poster ideas, undergraduate and postgraduate lectures and other avenues. Examples of possible journals under consideration for publications are listed in rank order according to impact factors. An outline of time frames over a two year period is also given. The plan for dissemination over this period is to publish within peer reviewed, professional and lay journals and present at conferences and to colleagues. The latter is a short-term objective and the remainder is to be spread out, aiming for a dissemination point at three months, nine months, a year, eighteen months and two years post doctorate. Some activities are already planned for 2011 as can be seen from Table 7.

The items listed under ‘Other’ in Table 7 will be explained. The researcher will make contact with the Royal College of Physicians to see how evidence from qualitative studies

is being collected for the next edition of the National Clinical Guideline for Stroke and if a contribution could be made from this study, specific to patient-centred care in TIA. Contact has been made with the Stroke Association about publishing patient stories on their website under ‘It Happened to Me’ and possibly the poems as well as ‘What to do for the best’ within a workbook as has been detailed in Table 4. A meeting has taken place with a TIA clinical nurse specialist at ESHT to share ideas about information and advice that is given to patients at TIA clinics and look at the feasibility of setting up a multidisciplinary one-stop-shop for patients following TIA and using expert patients as a peer support resource.

Already done	Publication/journals	Impact factors	Conferences	Undergraduate/postgraduate lectures	Other
See Box 17 page 153 with examples in appendices 23-25	-Synapse	2.557	WCPT June 2011	-UOB masters module lecture Feb 2011	-National Clinical Stroke Guidelines -Stroke Association -TIA clinic ESHT Feb 2011
	-Sociology of Health & Illness	2.041		-UOB MSc in Rehab Science lecture TBA	
	-Qualitative Health Research	1.659		-UOB BSc in Physiotherapy lecture TBA	
	-Qualitative Research Journal	pending		-Sussex ACPIN lecture 2012	
	-Health Communication	1.344		-Sussex Stroke Network lecture 2011	
-Physiotherapy	0.773	-ESHT in-service training to colleagues 2011			
-Stroke Matters					
-Stroke News					

Table 7. Dissemination Strategy

### 8.6.3 *Closing Statement*

This study, which started with something seemingly as small and trivial as a very fleeting momentary illness, has resulted and grown into a research project with much larger ramifications and implications for practice. It might appear that this inverse relationship did not warrant such an in-depth piece of work but this assumption would be wrong because TIA can be a portent of the more serious event of stroke. With the increasing elderly population and stroke being associated with this age group, despite prevention and treatment of stroke improving, it is likely to remain a large burden on finite healthcare resources. Therefore it is important that the findings, of this study, gave rise to contributions to knowledge relating to experience, lifestyle change and secondary stroke prevention and clinical reasoning, all of which are embedded within patient-centred care. However the term patient-centred care is interpreted, it would appear that it is here to stay

in contemporary healthcare and that it embraces the essence of the findings of this study that makes a valuable contribution to the same.

**Word count** 61,040.

*Slightly unnerved, uncertainty*  
*So lucky, **put it in perspective***  
*Family to the fore, to do more than in past*  
*Very concerned, husband very supportive*

*Modified my diet, doing more exercise*  
*Walking to the station, travel light with*  
*rucksack*  
*Can adapt but it's a pressure but*  
*If you don't use it you lose it*

*Incidents like TIA create a pressure*  
***Get a balance and carry on***  
*Take responsibility for self*  
*Encouraged to by medical profession*

*Small shock faded, no longer sharp edge*  
*With time accept things, don't stop doing*  
*what enjoy*  
*Initial resentment but still*  
*So much enjoyment out of life*

***Put it in perspective***

(Ann, age 70)

## Glossary

**ABCD/ABCD2**-a prognostic score to identify those at high risk of stroke after TIA; A= age, B=blood pressure, C= clinical features, D=duration of symptoms. ABCD2 includes diabetes.

**Angiotensin converting enzyme (ACE) inhibitors**-a group of medications that reduce the production of an enzyme required to produce a chemical (angiotensin 11) that causes blood vessels to constrict. ACE inhibitors decrease vascular resistance thereby reducing blood pressure.

**Angiotensin 11 receptor blockers (ARBs)**-a group of medications that block the chemical angiotensin 11 that causes blood vessels to constrict. ARB's decrease vascular resistance thereby reducing blood pressure.

**Anticoagulant** -medication to reduce the risk of thrombosis or embolism e.g. warfarin.

**Antiplatelet** -medication to prevent embolism or thrombosis e.g. aspirin.

**Antithrombotic**-medications to reduce risk of thrombosis or embolism.

**Arrhythmia**-a disorder of heart rhythm.

**Atheroma**-plaques of fatty deposits on the artery walls.

**Atrial fibrillation**-ineffective contracting of the atria of the heart, an example of an arrhythmia.

**Beta blockers**-medication to reduce the work of the heart by slowing the heart rate and reducing blood pressure.

**Calcium channel antagonists/blockers** –a group of medications that block the passage of calcium into the muscles that control the size of blood vessels. The dilating of blood vessels lowers blood pressure.

**Cardioversion**-the heart is electrically shocked to try to establish sinus rhythm in e.g. atrial fibrillation.

**Carotid angiography**-a radiological study of the carotid artery to assess for occlusion and sources of emboli.

**Carotid Doppler**-an ultrasound study of the carotid artery to assess occlusion.

**Carotid endarterectomy**-a surgical procedure to remove the occlusion caused by atheroma in the carotid artery.

**Cerebral**-relating to the brain.

**Cerebrovascular**-relating to the blood vessels within the brain.

**Computerised tomography (CT)** of the brain-a radiological study of the structures within the brain.

**Diplopia**-double vision.

**Diuretic**-medication that increases the excretion of urine by the kidneys.

**Dysphasia**-difficulty expressing or receiving information.

**Echocardiogram**-an ultrasound study of the heart to assess function.

**Electrocardiogram**-a study of the electrical activity of the heart.

**Embolism**-a clot or fatty deposit that has moved from another part of the body.

**FAST** (Face, arm, speech & time-Stroke Association 2007)-an assessment tool for out of hospital recognition of stroke, assessing facial & arm weakness, & speech problems and identifying the time-critical emergency.

**Focal lesion**-a specific local lesion, not widespread.

**Hemianopia**-a disturbance of vision in half of both eyes in seeing to one side i.e. the medial half of one eye and the lateral half of the other.

**Hyperlipidaemia**-raised blood fats e.g. cholesterol, triglycerides

**Hypertension**-high blood pressure.

**Infarct**-area of the brain or heart that has been starved of oxygen resulting in permanent damage to that area.

**Monocular**-relating to one eye.

**Myocardial infarction (MI)**-coronary thrombosis, heart attack.

**Neurovascular clinic**-clinic specialising in diseases of the blood vessels within the nervous system.

**Ocular**-relating to the eye.

**ROSIER**-Recognition of Stroke in the Emergency Room (Nor et al. 2005).

**Sinus rhythm**-the heart is beating normally and efficiently.

**Statins**-medications that lower blood cholesterol levels (they may also act on inflammation).

**Thrombolysis**-use of intravenous antithrombotic medication to dissolve a clot in the first few hours after a stroke or MI. Can be given as an injection or guided procedure.

**Thrombosis**-a clot.

**Stenosis**-narrowing e.g. narrowing of carotid artery.

**Vertebrobasilar** –the territory in the brain associated with the vertebral and basilar arteries.

**Vertigo**-dizziness.

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DOH (2008a) Healthy Weight, Healthy Lives

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## Appendices

1. Stroke-related documents
2. TIA referral pathway and risk stratification\*
3. University of Brighton UOB sponsorship of the research
4. Central Office of Research Ethics Committee COREC approval
5. Research and Development R&D East Sussex Hospital NHS Trust ESHT approval
6. Consultant approval to access his patients for research at ESHT
7. Letter of invitation to patients
8. Patient information sheet
9. Patient pathway
10. Consent form
11. Interview guide
12. Check list for field notes
13. Expectations of the interviews
14. Example of coded transcript
15. Reflection upon three interviews
16. Phases of the TIA experience
17. Flowchart of stages in process from data through analysis
18. Example table of thematic analysis
19. Flowchart of thematic analysis
20. Development of ideas for thematic analysis
21. Concept map of thematic analysis
22. Poetic representation
23. UK Stroke Forum Conference 2008 poster\*
24. UOB Conference 2010 work-in-progress presentation\*
25. World Confederation for Physical Therapy WCPT Congress 2011 abstract submission\*

\*Permission to reproduce appendices 2, 23, 24 and 25 has been granted by a Consultant Stroke Physician at East Sussex Healthcare NHS Trust, the UK Stroke Association, Director of Research at the Clinical Research Centre for Health Professions at the University of Brighton and the Chair of the Scientific Committee of the World Confederation for Physical Therapy respectively.

## Appendix 1

### Stroke-Related Documents

Stroke specific documents	Documents with sections on stroke	Documents re lifestyle change & health initiatives
<p>DOH (2007) National Stroke Strategy</p> <p>DOH (2006) ASSET 2-Action on Stroke Services</p> <p>DOH (2006) Delivering Quality and Value Focus on: Acute Stroke</p> <p>DOH (2006)Improving Stroke Services: A guide for Commissioners</p> <p>Healthcare Commission (2006) Survey of patients, caring for people after they have had a stroke</p> <p>National Audit Office (2005) Reducing brain damage: faster access to better stroke care. London: The Stationery Office</p> <p>NICE (2008) NICE Clinical Guideline 68 Stroke</p> <p>RCP (2009) National Sentinel Audit for Stroke</p> <p>RCP (2008)National Clinical Guideline for Stroke</p> <p>Scottish Intercollegiate Guidelines Network (2008) Management of patients with stroke or TIA. Edinburgh: RCP</p> <p>Stroke Association (2005) MORI poll</p>	<p>DOH (2008) Technical Consultation on Economic Modelling of a Policy of Vascular Checks</p> <p>DOH (2007)NSF for Long Term Conditions</p> <p>DOH (2006)Mending Hearts and Brains</p> <p>DOH (2006) NSF for Older People</p>	<p>CSP(2009)Move for Health (www.csp.org.uk/moveforhealth)</p> <p>DOH (2009) The NHS in England: Operating Framework</p> <p>DOH (2008) Healthy Weight, Healthy Lives</p> <p>DOH (2008) High Quality Care for all</p> <p>DOH (2008) Putting Prevention First</p> <p>DOH (2007) Commissioning framework for health and wellbeing</p> <p>DOH (2007) Putting People First.</p> <p>DOH (2006) Best Research for Best Health</p> <p>DOH (2005) Our health, our care, our say</p> <p>DOH (2005) Self-Care. A Real Choice</p> <p>DOH(2004) Better information, better choices, better health</p> <p>DOH (2004) Choosing Health</p> <p>DOH (2004)The Wanless Report: Securing Good Health for the Whole Population</p> <p>WHO (2002) The WHO report: Reducing Risks, Promoting Healthy Life</p>

**TIA Risk Stratification**

ABCD <sup>2</sup> score	
<b>A</b> ge	≥ 60+ 1 point
<b>B</b> P	≥ 140/90 (at presentation) 1 point
<b>C</b> linical features	- Unilateral weakness 2 points Speech disturbance without weakness 1 point
<b>D</b> uration	≥ 60 mins+ 2 points 10 - 59 mins 1 point 0 - 9 mins 0 points
<b>D</b> iabetes	1 point
<b>Total Score:</b>	

- Low risk = 0 - 3 points
- Moderate risk = 4 - 5 points
- High Risk = 6 - 7 points

**Action:**

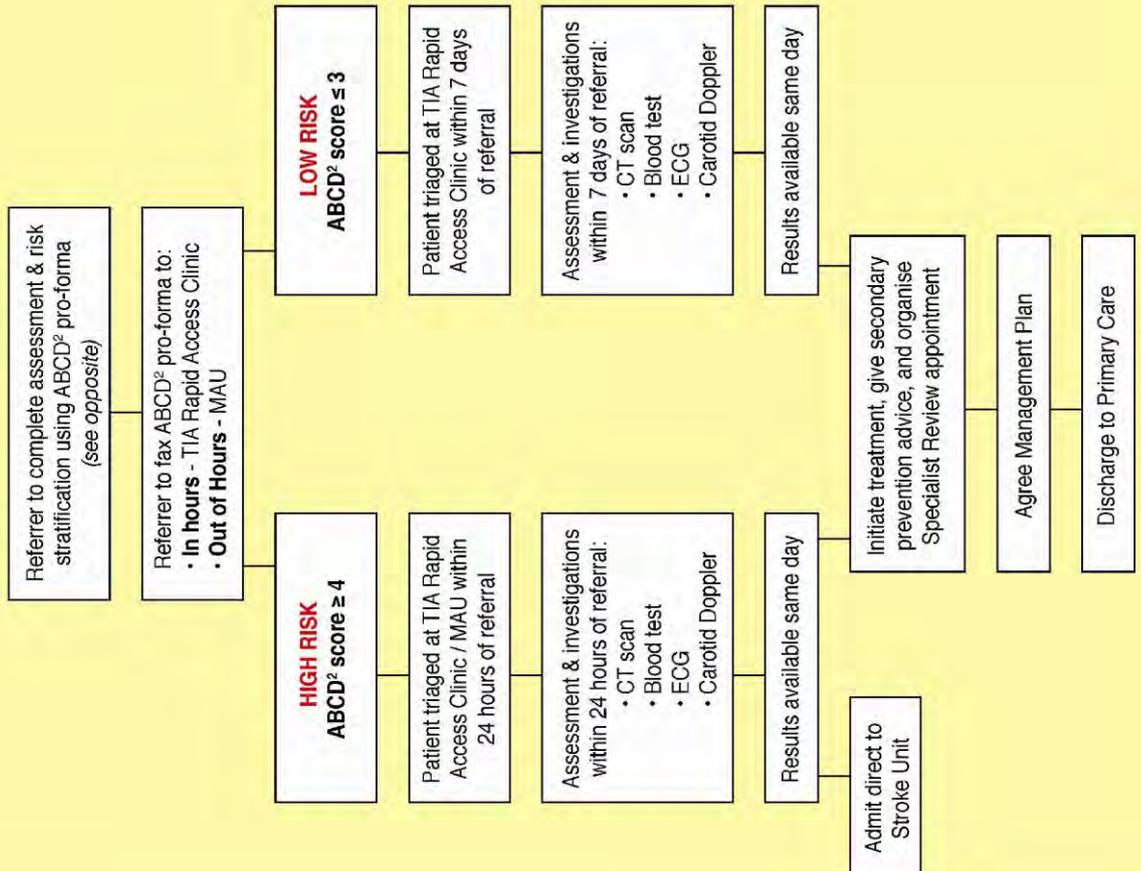
All patients with minor stroke and all high-risk patients with TIA (ABCD<sup>2</sup> score equal or more than 4) **need to be assessed by a specialist and treated within 24 hours.**

All other patients with minor stroke and all low risk patients with TIA (ABCD<sup>2</sup> score equal or less than 3) **need to be assessed by a specialist and treated within 7 days.**

Patients with crescendo TIA (two or more TIAs in a week) should be treated as being at high risk of stroke, even though they may have an ABCD<sup>2</sup> score of 3 or below.

People who have had a TIA but who present late (more than 1 week after their last symptom has resolved) should be treated as though they are at low risk of stroke.

**TIA Referral Pathway**



Faculty of Health



University of Brighton

Appendix 3  
UOB Sponsorship of the Research

Direct line:

Michelle Roman  
Ethics Committee Administrator  
East Sussex Local Research Ethics Committee  
6<sup>th</sup> Floor, Vantage Point  
New England Road,  
Brighton BN1 4GW



Clinical Research Centre  
for Health Professions  
Professor Ann Moore PhD GradDipPhys  
FCSP DipTP CertEd FMACP  
Director of Centre

19 January 2006

Aldro Building  
49 Darley Road  
Eastbourne BN20 7UR  
Telephone 01273 643647  
Fax 01273 643644

[www.brighton.ac.uk/sohp/research/index.htm](http://www.brighton.ac.uk/sohp/research/index.htm)

Dear Ms Roman

**University of Brighton research sponsorship**

I am writing to confirm that the University of Brighton will act as research sponsor as required under the Department of Health's Research Governance Framework, for the project entitled "*Physical activity following Transient Ischaemic Attack (TIA), and risk for stroke: an exploratory study*" to be carried out by Margaret Hewett.

If there are any general questions about the university's approach to research governance, please contact Ronnie Boyce-Stevens, Academic Research Officer on 01273 644184 or [V.Boyce-Stevens@brighton.ac.uk](mailto:V.Boyce-Stevens@brighton.ac.uk)

Yours sincerely,

Professor Ann Moore PhD, GradDipPhys, FCSP, DipTP, CertEd, FMACP  
Director of Research

**Appendix 4**  
COREC approval

**Brighton and Mid Sussex Research Ethics Committee**  
**East Sussex Research Ethics Committee**

Brighton and Hove City Teaching PCT  
6th Floor  
Vantage Point  
New England Road  
Brighton  
BN1 4GW

12 April 2006

Mrs Margaret Hewett  
Clinical Specialist Physiotherapist  
Conquest Hospital  
The Ridge  
St Leonards-on-sea  
TN37 7RD

Tel: 01273 296437  
or 01273 296588  
Fax: 01273 296578  
Email: kerry.longhurst@bhcpct.nhs.uk  
or: michelle.roman@bhcpct.nhs.uk

Dear Mrs Hewett

**Full title of study:** Physical activity following transient ischemic attack (TIA)  
and risk for stroke: an exploratory study.  
**REC reference number:** 05/Q1905/143

The Research Ethics Committee reviewed the above application at the meeting held on 10 April 2006.

**Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

**Ethical review of research sites**

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to complete Part C of the application form or to inform Local Research Ethics Committees (LRECs) about the research. However, all researchers and local research collaborators who intend to participate in this study at NHS sites should notify the R&D Department for the relevant care organisation and seek research governance approval.

**Conditions of approval**

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

**Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	Part A & B	22 January 2006
Investigator CV		22 January 2006

**Appendix 5**  
R & D East Sussex Hospitals  
Trust Approval

East Sussex Hospitals   
NHS TRUST

Research & Development  
Room 2.1 24, Ground Floor  
Eastbourne District General Hospital  
Kings Drive, Eastbourne  
East Sussex, BN21 2UD

Telephone 01323 417400  
Extension 3042

Mrs Margaret Hewett  
Dept. Physiotherapy  
Conquest Hospital

7<sup>th</sup> March 2007

Dear Mrs Hewett,

**Re: Physical activity following transient ischaemic attack (TIA) and risk for stroke:  
an exploratory study (Ref T07-05).**

Thank you for your application for R&D approval of the above study. I confirm that the Trust would be happy to support this study.

It is important that the protocol is adhered to and that no additional costs are incurred other than those stated within the application.

I wish you well in your study.

Yours sincerely

**Dr Guy Lloyd**  
Chairman of the R&D Committee

Experience of TIA Oct 06 version 3

**Appendix 6**  
Consultant Approval  
**East Sussex Hospitals**   
NHS Trust

**Physiotherapy**  
Conquest Hospital  
The Ridge  
St Leonards-on-Sea  
East Sussex  
TN37 7RD  
Tel: 01424 758122  
Fax: 01424 758107  
Website: [www.esh.nhs.uk](http://www.esh.nhs.uk)

October 2006

**To Whom it May Concern**

I agree to Margaret Hewett, Clinical Specialist Physiotherapist and Elaine Faulkner, student Physiotherapist having access to the patients from my Stroke Clinic at the Conquest Hospital for the purpose of their study '**The Lived Experience of Transient Ischaemic Attack and the Impact upon Physical Activity**'.



Dr. M.J.H. Rahmani  
Consultant Physician in Stroke Medicine

**Appendix 7**  
Letter of Invitation to Patients

**Letter of Invitation**

Name  
Address

Date

**The Lived Experience of Transient Ischaemic Attack and the Impact  
upon Physical Activity**

Dear

Following your recent attendance at the TIA/Stroke clinic at the Conquest Hospital, you are being invited to take part in the above research project. Please find attached information (Patient Information Sheet, Consent Form and stamped addressed envelope) to help you decide if you would be interested.

If you would like to take part, please return the consent form in the stamped addressed envelope by\_\_\_\_\_.

Yours Sincerely,

Margaret Hewett

Clinical Specialist Physiotherapist

Study no:  
Patient Id: no:

## **Patient Information Sheet**

Study title: **The Lived Experience of Transient Ischaemic Attack and the Impact upon Physical Activity**

Dear

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

I am a physiotherapist and chief investigator for this study and for part of my doctoral studies I am interested in finding out about peoples' experience of transient ischaemic attack. In parallel the student researcher (physiotherapy student) will be looking into the relationship of attitude and physical activity following transient ischaemic attack (TIA/mini stroke).

### **Why have I been chosen?**

You have been selected because you may have had a TIA (the term for symptoms like a stroke that resolve within 24 hours) as identified at your recent clinic appointment. We are contacting up to 100 people to take part in this study.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive in any way.

### **What will happen to me if I decide to take part?**

After filling in the consent form you will be invited to attend the hospital to complete a 5 minute questionnaire about attitude to physical activity and take part in a 20 minute structured interview, with the student researcher about your level of physical activity. Initially you will be asked a few simple questions to assess your ability to recall. Your answers will be recorded in a questionnaire and be audiotaped. This appointment will be arranged at a convenient time for you as far as is possible and you will be able to claim travel expenses. Both of the questionnaires will be anonymised with coding to ensure confidentiality. Your name will not appear on the questionnaire or any other documents apart from the consent form.

## **Appendix 8** Patient Information Sheet

- Up to 15 of those completing the above 2 stages will be invited to attend for a second interview of approximately 60 minutes to talk about their experience of transient ischaemic attack. Up to seven (of the 15) may be
- invited for a further 60 minute interview. Appointments will be arranged at a convenient time for you as far as possible. The interviews will be audio-taped for accurate recording and analysis of the discussion. Confidentiality will be assured at all times and the data from the interview will be transcribed in such a way that there will be no way of linking comments to individuals. You will be able to claim travel expenses for all appointments.
- You will be given a copy of the consent form and this information sheet to keep.

### **What do I have to do?**

You will need to attend the hospital on one occasion to complete a 5 minute questionnaire and take part in a 20 minute interview. Up to 15 of those completing the above 2 stages will be asked to attend for a second longer interview of 60 minutes and up to seven(of the 15) may be invited for a further 60 minute interview. Whether you decide to take part or not will in no way affect your treatment.

### **What are the possible side effects and risks of taking part?**

There are no side effects or risks of taking part and you do not need to make any lifestyle changes.

### **What are the other possible disadvantages of taking part?**

You will need to spend a maximum of 85 minutes of your time, in total, completing a questionnaire and attending interviews (for most people this will be only 25 minutes).However for up to 7 there may be a further 60 minute interview. Travel time for interviews will be on top of this (most people will only have 1 interview). You will be able to claim travel expenses.

### **What are the possible benefits of taking part?**

There are no direct benefits to you but you might have a heightened awareness of issues related to physical activity, particularly within your own lifestyle, although you are not required to make any lifestyle changes .By taking part you may benefit others in the future. If you would like to attend sessions on ‘ Healthy Living Advice After TIA ‘ you can ask for information.

### **What happens when the research study stops?**

Your identifiable information will be destroyed .You will be sent a summary of the results of the study if you have requested this. The results may be used for training purposes at the hospital to improve clinical practice or presented at

**Appendix 8**  
Patient Information Sheet

conferences or published in scientific/professional journals. You will not be identified in any publications/presentations.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any concerns that you have will be addressed

Contact number for complaints is myself as the chief investigator 01424 755255 blp 595 or through the hospital complaints procedure.

**Will my taking part in the study be kept confidential?**

Yes. All the information about your participation in this study will be kept confidential. The questionnaires will be anonymised with coding and kept on hospital premises. The taped interviews will be transcribed in such a way that no comments made can be linked to named individuals, and audiotapes will be kept on hospital premises. Access to the data will be by the researchers, academic supervisors and nominated statistician. All identifiable data will be destroyed on completion of the study.

**What will happen if I don't want to carry on with the study?**

You can withdraw from the study at any time and the data will be destroyed at this point. There will be no adverse effect on your treatment as a result of your withdrawal.

**Who is organising and funding the research?**

For the chief investigator the study is part of a professional doctorate programme at the University of Brighton which is supported by East Sussex Hospitals NHS Trust. For the student researcher the study is part of a Master of Science degree in Physiotherapy at the University of Brighton.

**Who has reviewed this study?**

This study has been reviewed by academic supervisors and the East Sussex Research Ethics Committee.

**Contact for further information**

If you have any questions or concerns about this study, please contact:

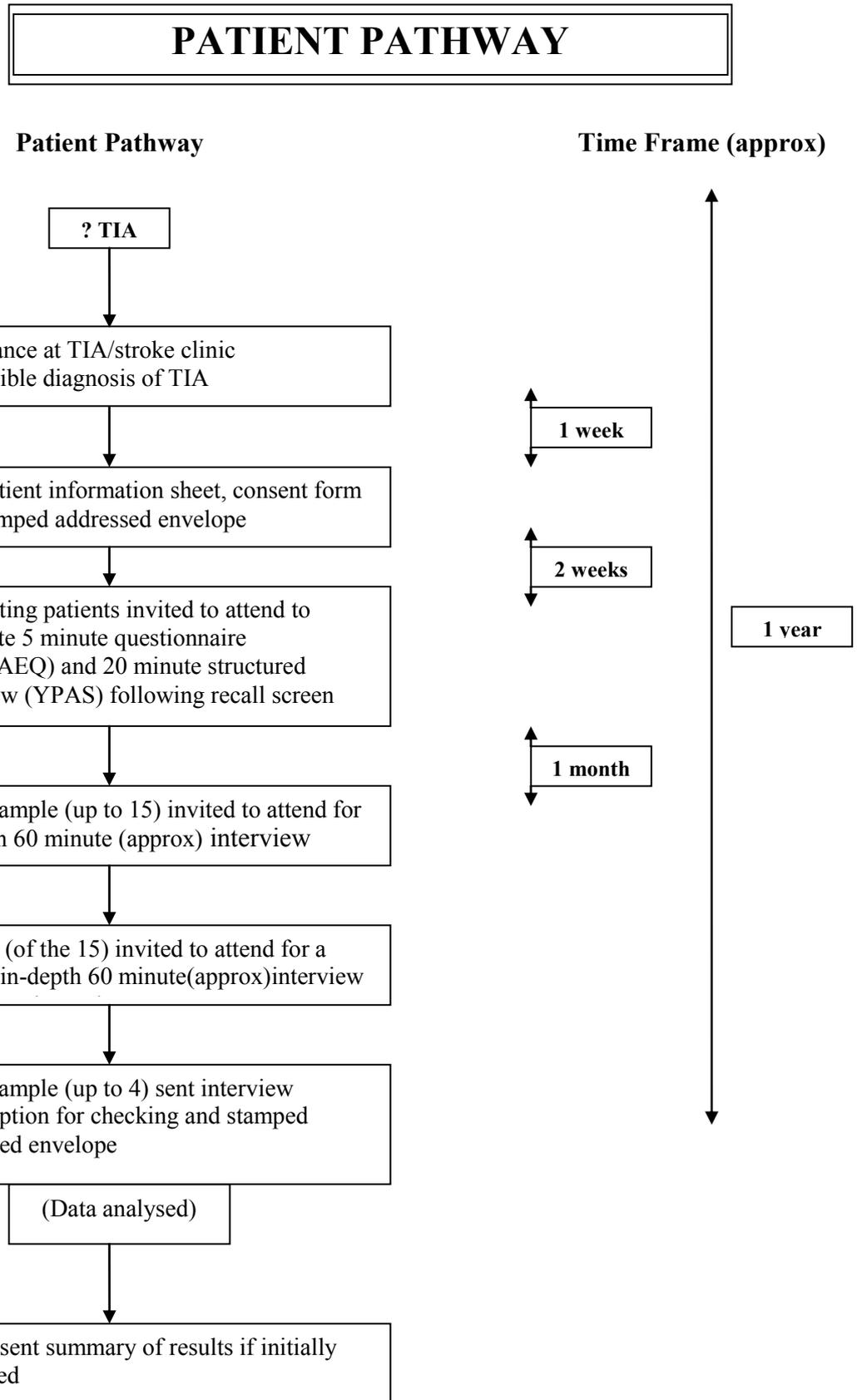
The R&D Office  
East Sussex Hospitals NHS Trust  
Eastbourne District General Hospital  
Kings Drive  
Eastbourne BN21 2UD

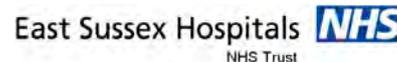
or myself at **Conquest Hospital**  
01424 755255 bleep 595  
or the academic supervisors:-  
Dr R.Kuisma [r.kuisma@bton.ac.uk](mailto:r.kuisma@bton.ac.uk)  
01273 644198  
Dr V.Cross [v.cross@bton.ac.uk](mailto:v.cross@bton.ac.uk)  
01273 600900

**Thank you for your time**

Yours sincerely

Margaret Hewett MA MCSP Cert Ed (chief investigator)  
Clinical Specialist Physiotherapist





CODE	
------	--

Study Number:.....

Patient Id.: No:.....

## CONSENT FORM

Title of Project: **The Lived Experience of Transient Ischaemic Attack**

Name of Researcher: **Mrs Margaret Hewett**

**Please initial box**

- |   |   |
|---|---|
| <p>1. I confirm that I have read and understand the information sheet dated:..... (version:.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>  | <div style="border: 1px solid black; width: 60px; height: 40px; margin: 0 auto;"></div> |
| <p>2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.</p>  | <div style="border: 1px solid black; width: 60px; height: 40px; margin: 0 auto;"></div> |
| <p>3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my medical records.</p> | <div style="border: 1px solid black; width: 60px; height: 40px; margin: 0 auto;"></div> |
| <p>4. I agree to my GP being informed of my participation in the study.</p>   | <div style="border: 1px solid black; width: 60px; height: 40px; margin: 0 auto;"></div> |
| <p>5. I agree to take part in the above study.</p>  | <div style="border: 1px solid black; width: 60px; height: 40px; margin: 0 auto;"></div> |
| <p>6. I would like a summary of the results of the study sent to me.</p>  | <div style="border: 1px solid black; width: 60px; height: 40px; margin: 0 auto;"></div> |

Name of Patient	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Name of Researcher	Date	Signature

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

Experience of TIA October 06 version 3

Appendix 11  
Interview Guide

Code \_\_\_\_\_

Date \_\_\_\_\_

### Questions to Guide the Interview Process

(Moustakas 1994)

*Main, Follow-up and Probing Questions (Rubin & Rubin 1995)*

Main Question-open introduction (Janesick 2004)

Can you tell me about your experience of transient ischaemic attack, what it has meant to you?

Follow-up Questions (according to themes that arise from the main question answers, linked to experience, feeling and knowledge –Patton 1987, non-directive and not pre-determined)

Examples:-

- What happened and **how did you feel?**
- Was it a **frightening experience**, can you tell me more about that?
- What was your **knowledge of TIA** before your own experience?
- What was your **experience of the medical help** that you received/are receiving in relation to the TIA?
- Did the TIA **impact upon your lifestyle?**
- Has the TIA affected your **level of activity?**
- Has the TIA changed your **attitude to physical activity?**

Probing Questions (according to what arises in the two sections above)

Can you tell me more about-----describe in more detail-----? (Kvale 1996)

Conclusion

I have no further questions; do you have anything to add to what we've already discussed?

NB

**Second Interview Guide** to clarify and develop issues that have arisen from the first interview-questions not pre-determined but related to themes from the previous interaction.

**Appendix 12**  
Check List for Field Notes

**Code** \_\_\_\_\_

**Check List for Field Notes**

(Hammell, Carpenter & Dyck 2000)

Interview date, start time, end time	
Location of the interview	
Pre – interview goals	
Description of the environment (physical space, equipment etc)	
People present	
Content of interview (key words, topics, focus, what stood out?)	
Researcher’s impressions (discomfort with any topics? Emotional responses?)	

**Appendix 12**  
Check List for Field Notes

Technological problems? (did the tape recorder work?)	
Impact of researcher positioning (positive or negative)?	
Analysis (questions, hunches, familiar themes, data trends, emerging patterns?)	
Was the amount of structure right for this interview?	
What would I do differently next time?	

## **EXPECTATIONS OF INTERVIEWS**

### **The Lived Experience of TIA-7/02/07**

Some thoughts about possible themes prior to commencement of interviews.

#### **Fear.**

Could lead to stroke, knew someone who had a stroke. I lost my speech-does that mean if I had a stroke that the temporary symptoms that I had, could become more permanent? What can I do to prevent it happening again?

#### **Vulnerability**

So sudden, out of control, not aware of what was happening to me. The effect on those around me-shock and anxiety for them-fear of the unknown -my husband thought I would die or I was having a major fit”.

#### **Significance**

By the time I saw the doctor I had no symptoms-would he/she think I was malingering?-even I felt a fraud now-do I really need medical attention now that I have nothing to show for it-out of sight, out of mind-making a fuss about nothing. Put it behind me and get on with my life, sweep under the carpet. If I get attention, could it become a recurrent reality through knowing about what might/could happen?

#### **Doctor-patient relationship**

The doctor never gave me chance to ask questions and when I did he seemed annoyed that I was deviating from the set topics that he seemed to focus upon. He never said what was wrong with me and I didn't like to ask-it all seemed so scientific and above my head-he wasn't interested in me as a person, only as another diagnostic statistic.

#### **Regret**

I realise now about the importance of the lifestyle changes I should have made previously, that the government has been banging on about in various healthy living drives. I wish now I'd taken the advice.

**Appendix 14**  
Example of Coded Transcript

AE	After Effects
BC	Barriers to Change
BD	Biographical Details
C	Context
CA	Cause
CC	Contemplating Change
CH	Change
CO	Concern
CP	Conferred Power
D	Disorientation
DE	Depression
DU	Duration
F	Fear
FS	Family Support
IM	Impact
IN	Investigations
K	Knowledge
L	Lifestyle
LM	Limbs Misbehaving
LU	Living with Uncertainty
M	Medication
MO	Moving On
P	Panic
R	Risk
RE	Relief
S	Symptoms
SL	Self Directed Learning
SO	Sudden Onset

**Key to Appendix 14**

BD

1. R Right so thanks very much for coming along and helping us with the research project today and it's all to do with trying to prevent  
 2. people having a stroke. We're trying to find out what happened to people but before we start I'd like to know a little bit about you and your  
 3. lifestyle before we get into the main questions. Do you want to tell me about what you do and your home life that sort of thing?  
 4. P Basically I do work full time in ----, I work for the -----  
 5. and the ----- .It's a fairly active physical job, I'm on my feet shifting and sorting the property as it come in. That  
 6. keeps me going through the day .Obviously the travelling is a bit of a bugbear .I have to leave at six in the morning and I don't get home  
 7. until 7.30 at night and that's on a good running day you know that's on a good running average day. As soon as there's any problem with  
 8. trains that's it , it goes completely out the window  
 9. R Yes  
 10. P Uhm I've got 2 teenage children and my partner. As far as physical activity, I walk but I don't do any form of sports as my job itself  
 11. keeps me fairly active , it's active during the hours I'm at work during the week .And the rest of the time outside of work it's taken up with  
 12. housework and all the usual life things kick in .So that's it in a nutshell  
 13. R yes. It sounds quite a busy job .So where are you based for that?  
 14. P ----- in -----  
 15. R Yes so do you have a lot of other people working with you?  
 16. P Yes in the actual ----- office itself there's 40 members of staff all told that's from management right down to the lowest level .So  
 17. we all work, that's including all the customer service team that deal with the customer enquiries, telephones and the people coming into the  
 18. environment. Then you've got the behind the scenes staff which is where I work .I'm a manager for behind the scenes so as the stuff comes  
 19. in. We take from about 800 to 1000 items a day from all the sources  
 20. R Goodness!  
 21. P They come in, we have to categorize them ,sort them out, get them on the system ,the computer system, identify them .Then store them  
 22. away in all the stores and that  
 23. R So there's quite a bit of admin and organising in all of that  
 24. P Yes it's an absolute nightmare!  
 25. R How many people do you manage?  
 26. P Uhm there's 15 in my part. There are more that work behind the scenes .There's 15 I'm responsible for. There's 2 managers there and  
 27. we tend to oversee all parts of it .Of course you've got the part where all the stuff goes out for auctioning as well .Because after 3 months  
 28. if it hasn't been collected or claimed we've got to move it on .So we're slightly self-funding so then we have to sell it on and some of it  
 29. goes on e bay if there's anything like the laptops and mobile phones .There's a subsidiary of e bay that we use

**Appendix 14**  
Example of Coded Transcript

- BD
30. R Oh right
31. P So there's a lot of internet auctioning and we use-----which is an auctioneers that we use and they usually take the main bulk of the
32. stuff. Then there's charities as well that gets all the clothing and stuff like that
33. R Big business in a way
34. P It's huge, it's absolutely huge
35. R So people could pick things up quite cheap on e bay?
36. P Yeah, I mean they don't advertise where they come from so unless you know what you're looking for on e bay you wouldn't know it's
37. actually coming from the ----- but there are specialists that come in. They assess what the price would be and they put it on
38. and they know what they're looking for .It's all a bit beyond our control as none of us have the specialist knowledge to say what some
39. things would sell at
40. R of course
41. P So there's other people that do come in and make decisions on our behalf about how much to sell at
42. R You say it's all -----?
43. P Yes -----
44. R Right
45. P So it's those 3
46. R So how did you get into that sort of line?
47. P I've been with, as it was, ----- many years ago .I've been working for them for 20 years now ,not always at -----
48. -----, I've only been there for 5 years now, but I was redeployed from another department that was closed down and sold off as it
49. would be and so had to move on
50. R Right. So you've always lived here in ----- have you?
51. P No I actually lived in ----- when I first started there but I've moved several places since and I ended up in ----- for a while
52. then we made the move down to here and that was at the time when we thought I know what we'll do ,I can give up work and I can work
53. locally but it never quite happened .You know I was relying on the ----- wages, the money I was earning there so could never quite give
54. it up
55. R It must cost quite a lot to travel doesn't it?
56. P You get subsidised rates because I've been with the company .Before when you was with ----- you used to get a quarter rate
57. on what was the ----- at the time because it was all part of the same inter-linked transport system but then of course it became
58. all privatised and it all changed but people that were entitled to that quarter rate on the ----- retained that quarter rate .So new people

- BD
59. going in in the last 15 or so years don't receive it .So I only pay a quarter rate so it's not as bad as it could be
60. R It's still a lot of travelling time, how much time do you spend on the train on an average day?
61. P Average day I leave home about 5.50 am that's to get me to work for 8.45am .The actual journey time sitting on the train from -----
62. to ----- is about one hour 45/50 minutes but then I've got the tube journey the other end and obviously getting from where I live
63. to the station plus giving yourself time. So going there takes a little longer. Coming home I leave at 4.30pm but I have to wait ¾ hour for a
64. train until 5.15pm but then I'm usually back indoors by 7.30pm.So it's a couple of hours each way
65. R So do they let you do flexi hours?
66. P No, no they used to but it was one of the things that was stopped about 5 or 6 years ago. I used to do a 4 day week which made it slightly
67. easier. It meant extremely long days but then I was only doing 4 days but then they stopped all that flexi time and now I just have to do 9
68. to 5, 5 day week
69. R Mm but you enjoy it do you?
70. P Not so much enjoy it but it pays the way. I mean it pays my mortgage and it keeps the money coming in especially with working more
71. locally I would have to take a drastic cut in wages .So it's a case of having to but the actual people there and the environment , even though
72. it can be a bit mucky, a bit dirty and not very pleasant, it's actually quite a good team of people .It's quite a laugh doing the job itself
73. R Oh that's good
74. P Can be a bit monotonous
75. R I bet you get a whole range of things handed in don't you?
76. P You're not kidding! I mean the most popular things are mobile phones now .It used to be umbrellas but it's mobile phones now and you
77. get thousands of those
78. R Do you ever get a package that you're a bit suspicious of?
79. P Yeah but what usually happens because they get left on stations ,buses, trains, everywhere else, they're investigated long before they
80. come to us because obviously the station , if it's left on a station, the station's got to assess the danger of the package .So normally it's
81. already opened or sorted before it actually gets to us. But we have had occasions where we've had to have our own evacuation through
82. suspect packages and things
83. R Mm scary
84. P Yes it's not very good. I mean with 7/7 when all that went up it was absolutely horrendous around that time
85. R So you said you've got teenagers, are they at school or college or are they working or what do they do?
86. P One's 15 in December, he's at school, he's doing fairly well. I can't really say much about him to be honest! He's a 14 year old lad ha ha
87. ha-you know, he's a good lad, he is a good boy, he doesn't cause me any grief or anything. He's just a typical, I don't get more than 2

- |    |  |
|----|--|
| BD | 88. grunts out of him a week! But you know he doesn't cause me any grief ha ha   |
|    | 89. R usual then!  |
|    | 90. P Yes, He's doing well at school and he's never in any trouble   |
|    | 91. R And your other one?  |
|    | 92. P The other one oh a teenage girl, she's 17, well she's nearly 18. She's caused me a bit more grief but she's actually working now. She was            |
|    | 93. in college ,she dropped out of college about 6 months ago .She was working part-time in ----- in town as a sales assistant as a Saturday               |
|    | 94. job in with college and she decided she actually preferred the working side than staying on at college   |
|    | 95. R A lot of them do   |
|    | 96. P That's it. I did try to beg her and stop her dropping out .She done very very well in her GCSE's and she got through those with A's and              |
|    | 97. B's all the way through so she was an ideal candidate to go on to college and go further but she decided it wasn't for her. When she                   |
|    | 98. dropped out she decided to go full time at ----- and do NVQ's there. So she's already done a couple of NVQ's already and sh'e already                  |
|    | 99. been promoted to a supervisor so in a very short period of time and now they're looking at fast-tracking her   |
|    | 100. R She's done alright then!  |
|    | 101. P She's done absolutely well, I can't knock it at all after having a go at her for wasting her life away about dropping out of college!               |
|    | 102. R She lives at home does she?   |
|    | 103. P Yes she does  |
|    | 104. R Your partner works does he?   |
|    | 105. P He's self-employed, so yes he works in the building trade. He's not at work at present, it's dried up these last couple of weeks but yes he         |
|    | 106. will be going back. It's self-employment so it's swings and roundabouts which is usual with that sort of work   |
|    | 107. R Right well thanks for that. So that tells me a little bit about your lifestyle and family and everything. Are you quite warm in here? I'm           |
|    | 108. going to open the window as it seems quite warm   |
|    | 109. P It is ,typical hospital   |
|    | 110. R Right so now I'm going to ask you a bit more about what happened to you and your experience of your illness and why you came up to                  |
|    | 111. the hospital. So do you want to start by telling me what happened to you?   |
| C  | 112. P Right so I've not actually been involved with the ----- before because all this happened while <u>I was on my way to work</u> so                    |
|    | 113. everything was based in -----   |
|    | 114. R Ah ok yes   |
| C  | 115. P <u>I got off the train</u> at ----- <u>to go to work in the morning</u> , it was Monday 2 <sup>nd</sup> July .I came out the back entrance of ----- |
|    | 116. that leads down to ----- station and there's like a little bridge-way stairs that go down and I was coming down those and my right                    |

S	117. <u>hand and arm started to go numb</u> and I thought I'd fallen asleep as where I'd been dosing on the train .I was on that side, I thought I'd
IM	118. fallen asleep on my arm a bit . <u>I thought it was a bit weird</u> and I was sort of shaking it as I was walking down the stairs and I was thinking
C	119. oh God come to ,wake yourself up, you're going to work, it's Monday morning and as <u>I was walking sort of underneath the rail bridge</u> to
IM	120. go into ----- station and I looked down and I saw my hand in front of me here but <u>it shocked me</u> because I thought my hand was
IM	121. by the side of me or my arm was hanging by my side .So when I looked down I thought whose arm is that? I actually, <u>it shocked me</u> and I
D	122. thought oh crikey! I don't know why ,whether it was all starting to go <u>a bit funny</u> but <u>I thought someone had come up behind me and was</u>
D	123. <u>putting their arm around me</u>
D	124. R How weird!
S	125. P and I thought I was being attacked or something so I swung round and thought what's the hand doing there because I thought the hand
↓	126. was just by the side of me and then of course the first thing I done was I kept pulling it and it was as I was pulling it, I felt it pulling at the
↓	127. shoulder and then I thought well it is my hand and arm after all! I was thinking God this is really weird, I must have really laid on this for it
↓	128. to go as numb and I do suffer from migraines and uhm sometimes very very rarely I do get like a numbness but not complete no feeling but
D	129. sometimes you know you need to get the blood pumping when I've got migraine coming on and so I thought oh don't say I <u>m</u> coming
D	130. down with a migraine .I thought <u>this is really strange</u> and I was still pulling at my arm as if I was an idiot!
D	131. R You couldn't feel it that well?
S	132. P Couldn't feel it at all , couldn't actually feel it to touch. I could obviously feel what I could feel with this hand, and as I pulled at it I
↓	133. could feel it pulling at my shoulder, but the actual arm itself was completely gone. So I walked into the station, and I thought this is really
↓	134. strange, but I thought it will come back in a minute. I went to go to the cash point, on the station, get a few pound out, for the week, and
↓	135. uhm, I got my purse out the bag ok, but I struggled to get the card out of the slot of the purse, so I sort of struggled a bit with that, and I
↓	136. thought, oh I'll try and I got it out, and I got to the cash point, and there was a man in front of me who had already gone through, I had a
↓	137. couple of bags with me, so I shuffled forwards and I couldn't put the card in the card slot, and I started thinking to myself, that's really
↓	138. strange, the man in front of me has glued the slot, so I can't get the card in. That's what I was thinking at the time, you know, thinking this
S, D	139. is not right, there is <u>something not right</u> . And uhm, so I tried again, but there was a couple of people now, Monday morning, rush hour,
S	140. people saying... they were all like <del>huff</del> huff" at me, thinking I was probably drunk or something because I'm a bit wobbly on my feet, as
↓	141. it would be. And, uhm, so I thought I'd better move to one side, so I bent down and dragged my bags across so I could stand to one side
↓	142. and let the other person in the line in, and as I went to move, my right leg wouldn't move with me, so now it was like my right leg had
↓	143. started to go numb and I sort of had to physically drag it over, even though I hadn't lost my balance, I had to physically drag myself over
↓	144. to one side. Then I realised something was definitely not right. And things started to look, uhm, I can't explain how, but <u>everything</u>
S, D	145. <u>seemed to be, to be moving far away, as in, as I'm looking round, the space seemed to be getting bigger and bigger and bigger</u> in front of

- |    |   |
|----|---|
| S  | 146. me, it was really hard to sort of, the actual feeling I got at that moment.  |
|    | 147. R Have you had that -----?   |
| S  | 148. P No, nothing like that, nothing like that at all. And I thought, oh, everything seems sort of like far away in the station, even though it's          |
|    | 149. actually very busy. But at the time, it was the weekend after the, they've done the car bombs at -----, the nightclubs, what                           |
|    | 150. happened sort of thing was the high alert on the stations, just after 7/7, it became very high alert, so they had a lot of the police on the           |
|    | 151. stations, and armed police and high vi jackets, so there was loads around -----, and in the station. I managed to catch one of                         |
| IM | 152. their eyes, because I was standing there and I started shaking and <u>I started to wonder what was going on</u> . It wasn't the best feeling in the    |
|    | 153. world, but I'd managed to catch the eye of one of the policeman and he came over and he said, oh it's alright love, you know, you're                   |
|    | 154. probably just having a bit of a panic attack. He said, you know, usual things, have you eaten this morning, are you pregnant, you know,                |
|    | 155. are you sure..... come outside for a bit, so I was sort of in the station, so he said come to one side, get a bit of fresh air, you'll probably feel   |
| S  | 156. a bit better. At this point, I've <u>lost the ability to communicate</u> . I was saying to him... yeah, hm, ur, hm, oh, yeah..... and he got me to one |
|    | 157. side, and he was looking at me and you could see, he could see something wasn't quite right. So he got me to sit down, got a chair and I               |
|    | 158. was sitting down, and he kept saying what's your name, what's your name. And even though part of me was saying just tell him your                      |
|    | 159. name, just tell him your name, I couldn't, couldn't get it out, couldn't speak to him. I was feeling sort of, getting more sort of dizzy and           |
|    | 160. <u>my arm had gone</u> , and I spent the whole time doing this with my hand, moving my hand, to try and, to try and get the feeling back in it.        |
| CO | 161. Then he was, uhm, he <u>started getting a bit concerned</u> and he said I'll call an ambulance. And that's when an ambulance was called, and           |
| S  | 162. they managed to get me from one side of the station to the other. By now, I could hardly walk, I was sort of hopping, but I was being                  |
|    | 163. helped by two other policemen across the station, so I had no feeling at all in my right leg. And got to the other side, and the ambulance             |
|    | 164. man come along and he was asking the same questions. I could understand what they were saying to me, I just couldn't communicate back                  |
|    | 165. in any way, uhm, and he was asking me what my name was, do I have any children, where do I work, where do I live, could I remember                     |
|    | 166. anything. And I can remember myself thinking I know who I am, but I can't say who I am and then I'd think what question did he just ask                |
|    | 167. me, and then, and then, it would come and say oh, yeah, I know who I am, my names ----- . Why didn't you tell me your names -----?                     |
|    | 168. And it just wouldn't come out but they understood to the fact that they went through my bag to get my purse out to find my name. And                   |
|    | 169. they pointing at my credit card, asking me if that was my name, and I was nodding, so I was sort of, sort of aware what they were saying to            |
|    | 170. me but I just couldn't communicate a thing. And then the ambulance driver just said, you know, he said, I don't like this, he said to the              |
|    | 171. actual driver, there was a paramedic, he said to the actual driver, come on, let's get her across to hospital, and that's when they took me            |
|    | 172. just across the bridge into ----- hospital. So I was over in ----- and uhm, went to the A&E there. And the first time I'd                              |
|    | 173. realised roughly what I'd had, I didn't know to what extent, was when I went into the, first went into the A&E department. I was in a                  |
|    | 174. wheelchair, they wheeled me in and the paramedics said my peripheral vision, he said to the doctors, <u>ask her to smile</u> , so get her to smile,    |

- S 175. and as I went to smile, I felt the left hand side of my face rise, no problem, but the right felt like it was dragging down on the floor. I
- S 176. hadn't even realised I'd lost any, you know, that my face had gone, uhm, but I felt as soon as I smiled, the left hand side all light up, but
- S 177. the other side, just nothing. Just nothing, wouldn't respond.
178. R Could you feel the face to touch?
- S 179. P To touch, well, with that hand, I mean remember touching my face and I remember not feeling any different, but I don't know whether
180. my face was actually numb. That's something I can't remember. I remember, sort of, putting my hand up with, I couldn't feel with this
- S 181. hand, the right hand, but the left hand, I could feel my face, but whether if I touched it that side, whether I was feeling what I could feel
182. with my fingers or whether I was feeling my face I don't know, I don't know, I can't remember.
183. R Your main concern seems to be the arm...
- S 184. P Yeah, that was the main focus, because that was the only thing I kept thinking, and even in the ambulance I was shaking it and squeezing
185. my hands together to try and, to try and get it...
186. R Are you right handed?
187. P Uhm, I am, yes.
188. R So you use it more?
- S 189. P Yeah, and uhm, of course when he said smile, I realised that, then, the classic symptoms of face dropping and that, I thought straight
190. away a stroke, but I didn't know to what extent, or how bad I was going to be, and then uhm, I was, I can remember going, there was a bit
191. of a complete black, not a complete black out, but I can't really remember what happened between me first going in and then I was, uhm,
192. on the couch, in the emergency, A&E ward, with the heart, the ECG monitor things on and that sort of, I had someone talking to me. And
193. said uhm, its going to be ok, but I can't remember getting to that point, and they said its going to be ok, its going to be ok, and I was trying
- P 194. to talk to them, and couldn't, I couldn't and I remember getting very upset at that point. To actually getting panicky, and thinking, oh,
- CO 195. what's going to happen to me, and they said, you know, don't worry, it will come back, you'll be ok, it will come back, don't panic. And
196. then the neurologist, Dr -----, at er.....
197. R He's a top -----
- CP 198. P Yeah, so I've found out since. Obviously at the time, I didn't know him from adam, but now I've found out so much more about him
- CP 199. and his work and everything else he does. And Dr -----, he came down and assessed me, by then, I was actually coming through it, I was
200. actually coming through and out the other end, and I remember him being in the room and me going, sitting up and going, oh, I feel so
201. much better now. Just out of the blue, from going, not being able to answer questions or anything to sitting up going, oh feel so much
- IN 202. better, it was like everything had just cleared. And he'd done all the various tests, and I did have, the right hand side was affected, with the
203. various tests and what not. That's when I stayed in over night.

204. R How long did it last then, before you were back to normal?
205. P Uhm, I would say, by mid day, this happened about 8 o'clock in the morning, by mid day, I would say I was 100%, no different, about
- DU 206. four hours in total. Uhm, it was about ten, quarter past ten when I actually sat up and said, I feel a bit better now and I could start
- S 207. answering questions. But I know they were asking me stuff that I couldn't quite get out, and the usual things they ask you about, the
- S 208. watch, the watch face and strap, and I couldn't for the life of me think of the buckle. So it was the high level of stuff that I couldn't, I
- S 209. couldn't quite grasp for a couple of hours. And then, I'd say, by mid day.....
210. R Did everything come back all at once? Which came back? Was it the speech, the arm, or everything back all at once?
- S 211. P Uhm, the, do you know what, I can't remember, but I'd say, do you know, I can't remember whether, it must have been all pretty much
- S 212. at the same time because I have no recollection of my arm still being numb when I sat up and said I feel better now. I know speech, or the
- S 213. power to communicate took a little while to actually get there. I remember for a couple of hours trying to talk to people and I was like that
- S 214. ~~e~~lick, click" trying to find the word I mean, to actually get it out and then carry on the sentence. But by then, my arm, I had all the feeling
- S 215. back in my arm, so I don't know whether it was before or after the speech, or what come through first, but it would have been roughly
- S 216. around the same time, I should imagine.
217. R But when it started, you started with the arm you said
218. P Yes
219. R But you didn't need to speak to anyone at that time, did you, because you were at the station. Do you think your speech might have
220. gone then?
221. P It might well have
222. R Because you don't know do you.
- S 223. P It might well have, because it was a good twenty minutes before I then had to alert somebody that I was having difficulties. So, the
- S 224. speech could have gone at that time. And it's the same with the arm, getting the feeling back in the arm, it could have come back at the
- S 225. same time as when I felt, I could sort of communicate, but I can't be 100% sure.
- S 226. R No. That's interesting because the last person that I interviewed, she was driving and the first thing she noticed was her face.
227. P Right.
228. R But when she went into A&E, then she noticed her arm. But she doesn't know if the arm might have been a problem beforehand. She's
229. not sure. But its interesting how people describe their symptoms. But everyone is describing similar, but the rate that they come on differs
230. in the way they describe.
231. P Yeah, that is interesting, yeah. That must have frightening if she was driving, oh...
232. R She managed to pull over. Then she wanted to get her mobile out to call her husband and obviously she couldn't -----

S	233. P Couldn't -----. I had that problem as well with the mobile, because all during this time, when they were trying to ask me, is there
LM	234. anyone they can call, I had my mobile in my pocket, <u>so I took my mobile out, but I couldn't get it to do anything that I wanted it to do</u> , so I
	235. even handed it to the policeman, but without being able to communicate to him, he was looking, he didn't know what to do with it or what
	236. to look for. But yeah, I did have the same problems with my mobile.
	237. R How did they alert you family?
	238. P Well, it was a bit of both, what happened was, just as it was coming to quarter past, half past ten, by a freak chance, which my daughter
	239. very rarely does, she phoned my work. Now she will phone me a lunchtime if she wants to speak, but she for somehow reason, it was
	240. something and nothing as well, but it is weird, but she phoned work looking for me, and work actually said, well she's not turned up yet.
	241. R Gosh, that was worrying for her then, wasn't it?
F	242. P Well it did, <u>it frightened the life out of her</u> . And they said, well, she's not actually turned up, and she said, well she left as normal this
	243. morning. She was gone on time. And they said, well don't worry, you know, because of where I travel from, there's often been occasions
	244. where I've been caught up. They checked on the internet and everything to see if there were any major delays, there were no delays. They
	245. thought it was strange I hadn't rung in because every time I had been caught up on a train, I'd give them a quick call to say I'm going to be
P	246. late in, uhm, they said they hadn't heard. And then of course ----- <u>then sort of panicked</u> , and they said, don't panic, you know, it's ok,
	247. she'll turn up, and then the next thing she done, was put the phone down and rang my mobile, and it was just when I was talking to Dr ----,
	248. that my mobile rung, and it was my daughter, and this was at half past ten, and I had to say to her then that, don't panic, but I am in A&E.
	249. I think I've had a stroke, Dr ----- has already sort of said, its looking at being a mini stroke, you know, so I said don't panic. Of course,
	250. she took over then, you know, she called my partner, she ----- my brother, and my family and what not.
	251. R She was responsible then
	252. P Yeah, that's it, let her deal with that.
	253. R Did they come up?
	254. P Well, yeah, uhm, what she done, she rang work straight back. Now work was uhm, of course they, I mean, I work up in ----- and all
CO	255. my family are down in ----- . <u>They were worried</u> obviously being on my own, so they sent one of the other managers straight away.
	256. R That's kind
	257. P Yeah, to come up straight from work, straight up to the hospital to make sure I was ok, they said I may not be safe to be on my own in
	258. case I needed to get a taxi anywhere, like home, or wherever. And they raided everything to get some money together to make sure I had
	259. enough.
	260. R It's nice to have colleagues like that, isn't it.
	261. P Exactly, I can't fault them at all. It was lovely. So one of the other managers came up and as she walked in, my daughter had phoned

262. one of my other friends that lives in -----, not knowing, she travels a lot for her job, not knowing whether she would be there and as it  
 263. happened, she happened to be in ----- at the time, so she jumped on a train and come up. Those two came in together. By the end of  
 264. the day.....  
 265. R You were alright...

FS 266. P Yeah, I had the whole family in at some point or another. They were all coming up to the hospital at some point. My daughter made her  
 267. way up to -----, -----, so yeah, it was her that organised everything in the end.

268. R I'm going to stop this tape and turn it over. It's a really good story, thanks! Ok, off we go. I'm just going to ask you now what  
 269. happened after, after you left the hospital you came home obviously the next day, and then what happened?

IN 270. P Before I left the hospital, Dr ---- wanted to run the tests on the echogramme, just to see if there was a connection between the heart and  
 CA 271. what, because there was no, no uhm, reason, there was no family history, there was nothing to explain why I would have had a stroke.  
 SO 272. And being my age, they were a bit sort of like, well, hang on, why has it come out of the blue, all of a sudden with no history. So, he said  
 273. he just wanted to, he said then, it was a bit strange, but he wanted to check my heart out before I went home, and it during that time that  
 IN 274. uhm, I was going to go back and have the echogramme done, but because I lived in -----, because I was up at -----, he said well  
 275. I can organise for you to have it all done today, all your tests, all your blood tests, all Dopplers, all everything, all done within that period  
 276. of time to save me coming back, so I couldn't have been in a better place. Had the scan, I had the scan about midday on the day it  
 277. happened, when I first went into ----- they had me at the scan pretty much straight away, then had the Doppler later in the afternoon  
 278. and blood tests were done throughout the day. Uhm, and the next day, they said we will make an appointment to come back to the  
 279. echogramme, then they said no, we've got to do it now, you're here, we're going to keep you, we're going to get it through now. So, I  
 280. went, went, so I had that done and that's when it was, I had this uhm, this PFO, -----, have I got the right pronunciation? It's a  
 281. hole, between two chambers of the heart, and they reckoned, they established that most probable cause was that I had a clot in my leg that  
 282. had come up, gone through my heart, gone over through the chamber in the hole in my heart, and then caused a stroke.

283. R Right, so you knew you had a heart problem, did you?  
 284. P I knew I had a heart problem, and that particular, no I didn't know anything, no...  
 285. R So you didn't know off hand...  
 286. P No, I was a complete clean bill of health. I'd never been ill in my life. The only time I'd ever been in hospital was for the children, to  
 287. have them, otherwise I've never had any problems, I've never had any heart problems, any breathing problems, nothing at all. So I was  
 288. completely unaware of this, so it came out when the echogramme was done. So that was when that was established, and of course then Dr  
 289. ---- then said, right obviously you've got to go back to -----, so everything can be done.... Then sorry, before that, he mentioned that  
 290. at ----- hospital, there was a Dr -----, that was doing a study between the TIAs and PFOs. So he said would I be, would I want to

291. be part of the study, and of course I said yes, no problem.
292. R I heard him talk about his study on Monday.
293. P Oh right
294. R Dr ---- came down to -----
295. P Oh did he?
296. R So I know what you're talking about
297. P Yeah, and I saw Dr ----- a couple of weeks ago. I've been back to ----- since, but uhm, and so uhm, he said would I be part of
298. this research and study, and I said yes, no problem. He said, well, I'll refer you, you can go from there, so of course, I then came back
299. home, uhm, obviously through my own GP, he referred me up to Dr -----, here, just to speak to him and me to be assessed here at
300. the ----. Dr ----- was in complete agreement with Dr ----- and Dr ----- that I was in the best place for me and not interfere
301. with the -----, as if they want anything done locally, they will let them know. But otherwise, just carry on the way I'm carrying on
- CP 302. because he said, you're in the best hands there. So, I was completely happy with that and uhm, I then went to see Professor ----- on,
303. uhm, about three weeks ago and agreed to be part of his research, and that's now sort of all on going. Last week, I was back at -----
- IN 304. to have uhm, I don't know the full technical term, but it was when you have the echogramme that you've got to swallow the ultrasound
305. thing, so they do it from the inside. That's an experience I never want to go through again, but they needed to assess the heart fully. So
306. uhm, and so I had that done, so that's basically all the follow ups so far. I've got, then I'll be, because its gone over to another doctor
307. called Dr ---- at -----, that deals with the cardiology department, I'm now, I've got to go back and see Dr ----- about
308. whether to, whether they are going to operate on the heart to close it up, ----- from what I understand. So they have to close the hole
309. up or not, but I'm going to see him on the 5<sup>th</sup>. So that will be my next follow up appointment.
310. R So it's all happened quite well, the way it's come together, the doctors and the medical cover?
311. P Yeah, absolutely, it's very quickly, very fast and you know, I've had excellent, you know, excellent uhm, being looked after, I can't
312. knock it in any way.
313. R So what was the scan result? Did you get a result from the scan, the brain scan?
- IN 314. P The brain scan said that I had, uhm, I should have brought all the paperwork up so you could have seen it, uhm, the brain scan said that I
- IN 315. had had a, now I think it was a front lobal -----, there was a small lesion there, and when they explained to me at -----, I think they
- IN 316. said it was, it did go to where the speech area of the brain is, so uhm...
317. R You've made a complete recovery though, haven't you?
318. P Yeah.
319. R Did they say it was a TIA?

K	320. P Yeah, they said it was a TIA.
	321. R So did you know much about stroke and TIA?
	322. P Nothing at all, I've had no family history of it, I don't know anyone, I've known of people who have had them, uhm, but its more been
	323. distant, relatively distant friends, its never been close to home.
	324. R You never really knew much about it
K	325. P No, didn't know much at all.
	326. R So, TIA didn't really mean...
K	327. P It meant absolutely nothing. I mean, <u>I kept calling it a mini stroke</u> , so that makes sense <u>less than 24 hours</u> , so that actually puts that into
	328. context, so what's actually happened to me.
	329. R So that made sense.
	330. P So, it did make sense but then one of the first things I did do when I came out of -----, and I spoke to Dr ----- about this, and he
SL	331. said be very careful what you google, was <u>the first thing I done was go on the internet</u> , but went into the stroke association site, so
↓	332. recognisable sites that were not going to fill me full of, you know, dread or worry, you know, of stuff that you think has gone wrong
	333. somewhere, and uhm, I read up as much as I could to er...
	334. R Was that helpful?
	335. P Oh, it was extremely helpful, especially the stroke association site. I managed to get a lot on women with TIAs, migraines and TIAs,
	336. driving and TIAs, and there was all these different bits of information that started making a lot more sense to me, and yeah, it was
	337. extremely helpful.
	338. R So you wanted to know?
	339. P Yes.
	340. R It didn't scare you looking it up?
	341. P No. I would say I had to be very selective on where I went, because I was, I know what the internet is like -----
	342. R Some people have come here and have said they are scared to look on the internet and they couldn't face it.
SL	343. P Couldn't face it. <u>I had a thirst for knowledge because I knew nothing about it, so I was a bit, I wanted to know and if I hadn't have got it</u>
SL	344. <u>off the internet, I would have gone to a library, you know, I would have got the information one way or another and the history, whys,</u>
SL	345. <u>wherefores...</u>
	346. R Of course. So have they given you any advice about anything you've got to do?
	347. P Uhm, my weight is a bit of an issue, they are looking for feasibility of dieting, they didn't say out and out categorically you've got to go
	348. on a diet tomorrow, looking for feasibility for that. Uhm, and being more active and generally looking after yourself, uhm, but when they

- IN 349. had done all the blood tests, everything came back fine, even my cholesterol was only 4, so that came back as normal. All my functions  
 350. and of all my organs, my liver and everything else. When I got the tests back, they said everything is functioning perfectly well and  
 351. there's no trigger area or point, so there was nothing really, I mean, there was, the other thing that was said straight away was actually on  
 352. the combination pill at the time...
353. R Right. Did they think that was a...
354. P They said get off that straight away, yeah. Dr ---- said that, said I should come off it straight away. He said we will find, there are  
 355. other ways and means, just stop it. He was a lot happier about, with my age and now with this happening and I think he said, he said, I  
 356. would recommend you come off that, which I did do.
357. R Would that make you put on weight anyway, being on that....?
358. P Yeah, it could well have, it could well have, I mean, I've always been fairly big, but it has fluctuated over the years.
359. R Did they give you any advice about a diet, I mean, types of things that you should and shouldn't eat?
360. P No, nothing at all. I've had no dietary information. They did, when they spoke to me at ----- at the very beginning, they said if  
 361. you are having problems, if you want to lose weight, if you have problems, ask the speech or dietician, or someone at the hospital that  
 362. could give you more information. As it so happened, up until now, I have been, I don't know all there is to know about nutrition, but I  
 363. know where my problems lie, in what I eat and where I go wrong and it's just a case of addressing it myself.
364. R Most people know about dietary ----- don't they, but you should do really.
- K 365. P Yeah, I know really what I should be avoiding and what I should be eating more of, but we do make a conscious effort, the whole  
 366. family eat more fresh fruit and vegetables, rather than processed food and we've been cutting that out for a while now. So, its, I know  
 367. there's a lot of areas where I slip down and it's personally my own will power addressing that more than anything. And the other was, I
- CH 368. was a social smoker, I did smoke, I did smoke uhm, well I stopped when I had my children for about ten years, started again for about five  
 369. years, but then unfortunately my mum died 2 years ago of cancer and at that point I went, that's it, cigarettes, I'm not going to, I said no.  
 370. the problem was, if I'd been out socially with friends, it would still be tempting and I'd have the odd cigarette and I was smoking, maybe  
 371. 3 or 4 maximum in a week, in a week, just on a Saturday or a Friday, they'll all be smoking, all people around me smoking and I'll have,  
 372. I'll have one, just to crave that, you know, get rid of the craving. And it wouldn't worry me because I was thinking, well its only the one,  
 373. or only two on that day, or whatever. So, but as soon as this happened, that was it, I've not touched any at all, you know, there's  
 374. absolutely no way, you know.
375. R Did they give you any advice about alcohol or anything like that?
376. P No, nothing said about alcohol. No, they didn't say what I should be drinking, or what I shouldn't be drinking. They asked me what my  
 377. consumption was, but they weren't concerned over what I told them.

	378. R You probably know what your limits are.
	379. P Limits are, yeah, the fourteen units and that, you know, half a glass of yeah, that's right. I do know the limits on that, but er, yeah, I
	380. mean, they do occasionally like to have a drink and to go out, when I go to a party, but I'm not a, I don't sit and drink 20 pints through the
	381. weekend, or something, so...
	382. R So, did it frighten your family, your children and your partner? Was it a frightening experience for them?
IM	383. P It was, it was extremely, for, I think <u>it shocked my daughter</u> probably more than it did my son, my son is very very quiet, and him in his
	384. own way, uhm, was dealing with it. He didn't get overly protective or want to be around me or anything, but he would just go very very
	385. quiet, and you could see he would be thinking about it. So, I got him to sort of, talk a bit more, and he, but he's been ok. My daughter,
	386. she's fine now, she sort of like realised that I'm ok, but -----, the first, for about six weeks after she wouldn't leave my side, everywhere I
	387. went. She still now comes to, if I've been up to -----, to visit the hospital, she wants to come with me. She's ringing home a lot more,
	388. or ringing me a lot more.
	389. R Is that nice for you in a way, to have that support?
IM	390. P Oh, it's lovely, it's lovely, because my partner, <u>he was absolutely devastated</u> , he was devastated that he couldn't be there, that he wasn't
	391. there, that he couldn't be there at the time, it took him ages to get there, you know, that's it. He was stuck in Hastings, or he wasn't, he
	392. was actually over in ----- or something at the time, and at work, and he was, he couldn't get out because -----, and he was going,
	393. pulling his hair out, he's got no hair to pull out but...
	394. R I know what you mean. It's hard sometimes when you need to get somewhere and you can't.
FS	395. P <u>He's been very very supportive.</u>
	396. R So they've adjusted to it now then?
	397. P Yeah, they seem to be a lot, they're lucky they're old enough, to sort of, the children are old enough to know or realise, that yes, it's
MO	398. happened, but <u>I'm ok, and we're moving on and I'm being treated, so everything's alright.</u>
	399. R Your in a good position aren't you? It's great.
	400. P If they were a bit younger, it may have been a bit of a problem, with them understanding, but they seem to be ok with it now.
	401. R So what do you think about, will you be changing anything in your lifestyle? Obviously you cut out smoking, and thinking about the
	402. diet...
CH	403. P <u>Cut out smoking, yeah, I'm more conscious about what I'm eating</u> , uhm, whether I actually go on a strict diet remains to be seen, but
	404. uhm, I'm more aware of when, especially since this has happened, I've been more aware of when I do go out and I'm having a drink, to
	405. how much I'm drinking and, yeah, I have actually, what I have done is I've had glasses of water in between, rather than yet another top up.
	406. R So you don't get dehydrated as well.

407. P Dehydrated, things like that. So there's, I'm more aware of that sort of thing and the risks and things. But uhm, exercise is a bit of a  
 408. difficult one because of my work taking up so much time and it is very physical, so it's sort of...
409. R How is your work physical, what...?
410. P Lifting things, I'm on my feet and moving the whole time, and all the ----- comes in in like huge mail sacks, completely full of  
 411. all items of -----, and then you've got to pick them up and shake them out, lug them from one place to another, sort them out.
412. R You get quite a lot of activity in your job then.
413. P Job, yeah, so there's, so I'm not, I've not made any conscious decisions to say, right, I'm going to take up swimming or, I mean, I love  
 414. swimming in the sea when it's warm enough, but er, I hadn't because I find when I'm off work, by the time I get home, I'm so tired  
 415. anyway.
416. R You just want to crash out.
- BC 417. P And with the housework and everything else that's got to be done during the week, I find it very hard. I mean, it sounds like a good  
 BC 418. excuse but it's not, it's not, it is a lack of will power and there's always time to find to do these things, but unfortunately, I haven't made a  
 BC 419. conscious effort to that yet.
420. R Not yet.
421. P It may be something that comes with time.
422. R Your thinking about it?
- L 423. P Yeah, I'm also looking, I've been at this job for 20 years, I'm doing long hours commuting, and uhm, my children are now a lot older,  
 424. and I've started to take more stock on, on my priorities in life. So, you know, thinking...
425. R It's made you sit back and take stock...
- CC 426. P Yeah, it has, it certainly has. Now I think, well is it worth me keep travelling up to ----- and the stress and the strain and everything  
 CC 427. else I've been going through. I've been doing the commuting for eight years now, from ----- to -----...
428. R It's a lot isn't it, on your body?
429. P Yeah.
430. R Did they say anything about high blood pressure, or anything like that?
- R 431. P I have got high blood pressure. It's, every time they've done it since, I didn't know about this beforehand...
432. R Right.
433. P I was not aware of it. Every time I've been to the doctors previously for the birth control, it had never been a problem, uhm, but  
 434. obviously after I had the TIA, it was all over the place. While I was being assessed over the first 24 hours, they weren't overly concerned,  
 435. it dropped back down and...

436. R Back down to where it started...

437. P They weren't overly concerned with it, but it did have a bit of a rollercoaster. All the times I've been back, uhm, it has been high, uhm,  
 438. the doctor was, my GP was waiting on a report from Professor ----- and his team, there was a Dr ---- I actually saw there as well,  
 439. before he was going to make any decisions on what was the best thing to do about the high blood pressure.

440. R Right.

441. P So, I'm not on any tablets at the moment, but it might be looking that I might be needing to go on that. But when I went up the hospital  
 442. the last time, it was fine.

443. R Oh right.

444. P There was no problems. And now they might say, well actually, you've had a bit of a rollercoaster, but it seems to have settled.

M 445. R So did you have to take any medications as a result of this?

446. P I take the, I can't pronounce it, but it's the ----plavix ----- gel", or something, you know...

447. R Yeah, I know what you mean.

448. P The aspirin.

449. R Yeah.

450. P And I'm on the mini pill now, which they deemed as acceptable. So they're the three mains things that I'm on. So, there is a possibility  
 451. of going onto the high blood pressure, but unless it becomes an ongoing problem, my GP was very reluctant to start me on anything.

452. R Because you are quite young aren't you?

453. P Yeah.

454. R What about uhm, have you faced up to the fact that, you know, it was like a warning wasn't it, for a stroke? Is that how you saw it?

455. P Uhm...

456. R You were lucky in a way, is that how you saw it?

R 457. P I actually think I am extremely lucky. I don't tend to dwell on the fact that it was a warning. It does worry me that it could happen again

LU 458. at any time.

459. R Is that what they said to you?

460. P No.

461. R Is that what you think?

LU 462. P That's what I think, you know, it's never been said to me at any point, but it does worry me that there, that it could happen again,

LU 463. because it happened that time that morning. But I also look at it as I'm being treated, I'm on tablets, uhm, I've got to look at this logically,

M 464. I'm on tablets...

465. R You've got to think positively...
466. P Yeah, and I'm being treated, and if anything, the problem with the heart is, was the problem for the stroke, then they find that, then the
467. likelihood of me having another one, it should be cancelled out. But that's more of a worry but not so much, I don't tend to dwell on the
468. lack of warning as such, you know, getting off the train and it just happening. I just tend to think the only thing that more worries me is
469. the, could I be walking down the, or could I be driving a car.
470. R Yeah, and it would happen.
471. P And it would happen.
472. R But we can't live like that really. You have to just get on with your life, don't you?
473. P After going through the 7/7 and being on the underground when, I wasn't in any of the trains, don't get me wrong, I was on the system at
474. the time and I was at -----, one stop from -----, and as I got off at -----, was when the bomb went off at -----
475. Road and you start looking, my god, if I was three minutes earlier, I would have been on that train, or if was going one stop extra, you just
476. can't, or if they decided to detonate at -----, which would have been a bigger place to do it, rather than ----- . And you go
477. through all the what ifs at the time, but then you say, well life still goes on, you've still got to carry on, and yeah...
478. R On a scale of 0 to 10, 0 being it's a slight worry for you, or it was a slight worry, and 10 being... somebody said to me they were
479. frightened to death by the experience, where would you sit with how it was for you? Was it slightly concerning or very concerning?
480. P Uhm, when it actually happened at the time, I would say no more than a 2 or a 3. I wasn't particularly over, I was, at the time it was
- AE 481. happening, I was more... what is happening, rather than it... the after affect, the 3 or 4 weeks, maybe not even that long, the 2 or 3 weeks
- AE, R 482. afterwards, when you get all the what ifs, and everything, and you start thinking about it, and you think, it could have been a hell of a lot
- R 483. worse, this could have happened, that could have happened, la la la la. Then, it went right up off the Richter scale, it went to 11, 12, you
- F 484. know, it was absolutely petrifying that, what I went through. At the time, I would say I was no more, I was more concerned that I was
485. losing the feeling in my arm than anything else. But not that I was, it didn't register that I was having a stroke until I was in A&E.
486. R The bulk of it really caught up with you later on.
487. P Later on, definitely.
488. R And did you get depressed, some people said they got a bit depressed afterwards, because, you know, it really hit them?
- DE 489. P Yeah, I felt very down, I felt, you know, a bit down in the dumps, but no, I don't think I would put any form of depression on it.
490. R So how long did you have to have off work?
491. P Uhm, I am technically off work now, at the moment, because that's because of the heart, to do with the heart problem. So I've not
492. actually, I did go back, but then, once I went back to ----- . So I was off for... originally... 4 weeks, and then I had another 1 week
493. because an appointment fell in with it, so they said get that appointment out the way, so I had another 1 week, went back to work, had the

494. appointment. They got the results back and that's when the doctor said, my blood pressure was very high as well, I went back, my blood  
 495. pressure was high and he said, I'm not happy with what's going on. He said, I'll write you back off work, so he wrote me back off work  
 496. for originally another, I think, 4 weeks...
497. R That was the GP?
498. P The GP, and then the second time I went back, and I said right, am I ready to go back to work now, just to keep going back to get my  
 499. blood pressure tested and everything else and I said, am I ready and he said, I've still not heard from ----- at the moment, I want to  
 500. hear from -----, once I've heard from -----... then he said, I'm not going to muck about this time, and he wrote me off for  
 501. another 8 weeks. He said, until this is sorted, because otherwise, I'm travelling to and from ----- as well...
502. R It's a lot isn't it?
503. P And I think he, with the blood pressure and the travelling and everything else, he just said, I'm not happy with this until we know exactly  
 504. what's going on. Once he gets all the stuff back, he said then he, I can, make decisions and I can go back to work.
505. R So, would you go back slowly, so part time? Or would you go back all at once?
506. P Probably not, I think, I've got an option to go back, not necessarily part time, but reduced hours, you know, maybe phase it in, maybe,  
 507. and they will, I know, the way transport fund work, they've got the occupational health system there, which I know I have to go and see  
 508. when I go back. But when I go back and see them, then I could probably work reduced hours, as in, I would still work Monday to Friday,  
 509. but maybe 10 \_til 3.
510. R Yeah, that would be easier.
- MO 511. P And then with the travelling, I'm outside the rush hour, give me a bit of time, and then I can go back full time afterwards. So, it all  
 512. depends on what they decide. I'm not overly worried if I have to go back full time. I wouldn't think that I don't feel that I'm not  
 513. particularly ready, but I do want to make sure that I am ready, you know, physically that I am ready and it's not going to cause any  
 514. problems.
515. R So, what did it feel like, going back and going through that station?
516. P It was quite disconcerting when I went through the first time, but funnily enough, I came back through there the other day, coming back  
 517. from ----- hospital, I got off ----- to come back to -----, and I didn't even register I was going through the, going  
 518. through that, following the same footsteps.
519. R You're over that now, aren't you?
520. P So, it's not er...
521. R It's like when you get thrown off a horse, you have to get back on...
- MO 522. P Get back on, and carry on.

523. R You have to get on with it, don't you.
524. P It didn't cross my mind until I was actually outside and walking up ----- ----- to -----, that I thought...
525. R You've done it.
526. P Oh, it didn't even register that I'd come back through the station, so the first time I came off the train and went in there, I did feel a bit,
527. oooo...
528. R Strange...
529. P Bit strange, and I thought, I kept looking around, I kept looking around for the policeman that helped me. And I knew he wouldn't be
530. there, logic dictates he wouldn't be there, but I kept looking around for the policeman, I was standing there for a few minutes trying to see
531. if I could see him, you know, why I thought he would still be on the station, I have no idea. But, no main bad feelings or anything with it.
532. R Oh, that's really helpful, is there anything else I've missed out or you haven't told me about? I normally ask people about their lifestyle,
533. what happened to them, their medical experience and how they feel about it all, so... is there anything else you want to say about it all?
534. P No, no, I think I've covered everything. I've been chatting away, nineteen to the dozen.
535. R No, that's really helpful, it's a rich story and...
536. P It's silly really
537. R No, that's just what we want, and uhm, compare it to what other people have said and then get something out of it, that's really helpful.
538. Well, thanks very much.
539. I hope it's been a help anyway.

## **Reflection upon 3 Interviews June 2007**

### Interview Format

1. Biographical narrative-get to know the participant/put them at ease
2. Experiential narrative-the story of their experience
3. Reflection upon meaning, consequences

### 3 Key Stories

#### 1. **Vignettes of the TIA experience** (what happened to you?)

- Descriptors/metaphors e.g. Ann/63 the most strange sensation. It felt as though someone had placed a cold hand under the surface of the skin, James/31 I've got this strange feeling in my arm, James/123 Loss of control of the right side of the body, Andrew/24 I started to go a bit strange, Andrew/81 It feels like something shearing (in the brain)
- Transience e.g. Ann/98 within one minute I could walk normally, Ann/123 one minute of incapacity, Ann/125 the connections were made very quickly, James/34 it only lasted 15 seconds, James/42 it came and went so quickly, Andrew/24 it was all over by the time the ambulance got there, Andrew/33 by the time I was in the ambulance 10 minutes, 12 minutes perhaps---everything was back speech, movement
- Psychological Impact & Uncertainty e.g. Ann/68 I was just struck dumb, Ann/98 I was shaken, Ann/66 my immediate reaction was God I'm having a stroke, Ann/113 I really feel in limbo at the moment, Ann/107 I felt cross and panic-stricken, James/100 I just thought I've had a small stroke, James/132 it is a slight worry, James/85 I just felt frustrated, James/289 there is a slight feeling of being in limbo until I get some positive results, Andrew/178 serious part of the situation that I'm now in, Andrew/272 this one really did shake me up quite badly, Andrew/266 the second one frightened me to death, Andrew/270 the second one shook me because I thought I was doing the right things, Andrew/161 it's a shot across the bows  
Future Ann/127 I do feel apprehensive because it's brought the future into my mind, Ann/148 not knowing what the future holds, Andrew/249 I would like to enjoy a few more years

#### 2. **Lifestyle and Lifestyle Change**

- Family e.g. Andrew/256 very supportive family, Ann/241 I'm very fortunate in that I have a good family, Ann/237 a good loving husband, 005/105 my wife was quite concerned, James/108 she was obviously worried for me personally, Ann/120 my husband was

extremely concerned

- Hobbies e.g. Ann/116 swim once a week, Ann/15 I enjoy walking, Ann/14 my interests are largely cerebral, James/9 I enjoy --- gardening---DIY,Andrew/191 if I couldn't paint, if I couldn't garden
- Adapting to change/reducing risks/negotiating/changing roles/accepting health is no longer perfect e.g. Ann/106 it can happen whatever you do,Ann/150 when it's not happened to you before in 70 years it takes a bit of getting used to,Ann/190 I don't know what it is that I could change,James/133 I wouldn't want things to get worse and I would do whatever is necessary to avoid that,Andrew/249 I'd like to enjoy a few more years and I would not knowingly jeopardise that,Andrew/272 I will not give up on the exercise and the diet---
- Physical Activity e.g. Andrew/53 you're not doing enough exercise,Andrew/55 I've been swimming twice a week and walking the other 4 days, Andrew/58 I don't mind taking exercise, James/315 would enjoy doing more exercise but it's finding the time, Ann/15 I do walk everywhere,Ann/16 swim once a week

### 3. The Medical Experience

- GP v Hospital Doctor e.g. Ann/27 I've always been told by my GP that any kind of medication I'm given is going to help the situation but it won't necessarily prevent heart attack or stroke, Ann/112 neither my GP nor she could suggest doing anything further, James/222 I think the doctor(GP) gave me more advice about it, Ann/274 I know that the information will go to my GP who will in turn have a discussion with me
- The Clinic & the Tests: the hospital experience e.g. Andrew/34 they did an ECG, blood tests, the usual rigmarole in the hospital,Andrew/42 the doctor down there would only release me if there was a TIA clinic here, Andrew/46 asked him to see me within 2 weeks of the date of the letter,Andrew/48 I came in and saw one of the doctors, had another ECG, blood prick thingy, just went through again what had happened,Andrew/83 nobody has been able to explain the cause, Andrew/1523 I went in the doughnut the first time,Andrew/155 I got so fed up that I almost discharged myself( inpatient stay),Ann/250 it was very good. I have seen the specialist once and she has put forward a programme of tests, Ann/250 blood tests,Ann/256 carotid,Ann/257 brain scan,Ann/261 she explained things very carefully and I was very impressed how thorough she was Ann/263 very calm and friendly--- explained everything---answered my questions and gave me plenty of time. It was excellent, excellent.Ann/273 she may well explain more,James/73 it was just a formality of checking blood pressure and---arranging an MRI scan,James/144 I think the doctor explained James/218 it was literally walk in, have a blood test and out again,James/220 I can't really say it was an experience, James/228 it was the waste of the best part of a day really ,James/233 simply a

blood test, a blood pressure check and a little bit of form filling ,James/234-236 that could have been done on the day of the scan, James/247 None( interaction

- between clinic doctor and patient),James/249 I can't remember 100% what was said James/140 checking on the carotid arteries
- Knowledge-where from? What to do for the best? e.g. Ann/27 I've always been aware of these factors in the background (knowledge from GP),Ann 85 I know people who've had strokes,Ann/89 my mother died of a stroke,Ann/93 I also know that in a TIA feeling and movement can come back within 24 hours,Ann/95 it is learnt from other people and their personal experiences, Ann/136 they ( children) know about their grandmother's series of little TIA's ---They also know there are certain tendencies within families, James/77 my mother had a slight stroke, James/144 there are 3 arteries –that supply the brain, the 3 main arteries to the brain---,James/150 I've not looked on the internet,James/260 I knew what I thought it might be ,I mean the description of TIA I knew nothing about----I recognised the terminology, James/267 if one has after effects it's a stroke , if it's a TIA there's usually no after effects,Andrew/74 I knew about strokes,Andrew/79 I was not aware of the mini type at all,Andrew/81 my knowledge of it now is that somehow or other there is a loss of blood flow to the brain and you get a minor stroke,Andrew/99 we're on a sharp learning curve,Andrew/183 I'd hate to lose even part of my mobility or my means of communication
- Medication e.g. Ann/24 medication for hypertension, Ann/26 medication for high cholesterol, Ann/105 I do take my medication---- why has this happened?,Ann/113 taking half an aspirin a day to my normal medication, James/65 I'm taking Warfarin and I came off that , went on to half an aspirin,James/90 it annoys me that I have to take medication and things now,James/158 the chemist wouldn't give them(tablets) to me because he said that it would react with one of the other sorts of medication that the doctor had prescribed ,James/167 the more tablets one takes ----is the medical profession knowledgeable enough about what reaction there is from one drug to another----there's a lot of errors that are made, James/173 there are times when mentally I just think if I packed it all in and just lived my life,Andrew/51 talked about taking pills, God do I have to take any more? Because I absolutely hate taking pills ,if I could find an alternative medicine I would probably do it,Andrew/88 I've been sent away with my medication which I take religiously,Andrew/178 I take the advice, I take the medication,Andrew/268 I didn't fall down on medication

### Transition Theory applied to the 3 participants' journeys

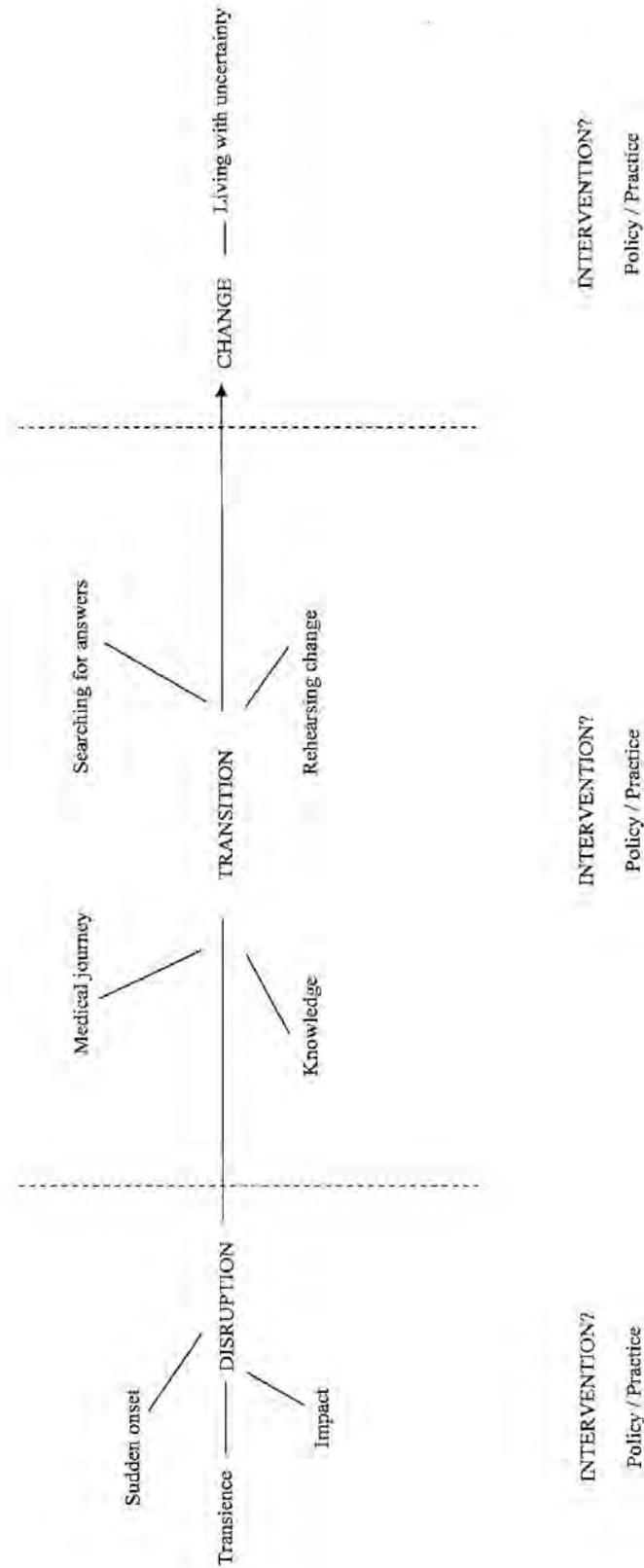
The 3 participants are at different stages in transition post TIA and adapting to change. One (Andrew) has experienced 2 TIA's and is well on the road to adapting lifestyle i.e. proactive decisions have been made following the first event which are now being re-evaluated again in a pro-active way-as the initial event 'came out of the blue', it could have been a reactionary situation. Ann for some time recognised stroke risks pre TIA and so post TIA responded in a proactive way which had already begun but at the same time is procrastinating further change until more information is available. James is not so advanced in transition and is in a state of planned proactive decision avoidance /procrastination until more information is available.

### My Experience/reflection

*Even if my interview style has a long way to go, I've got masses of information/data to work with so I must be doing something right! I'm still caught up in the interview process, trying to use similar questions to the previous interview and research purpose, whilst retaining the interviewee's interest and attention, rather than hearing the content of what is said at the time and reacting to it on the spot. This is improving and will continue to do so with experience. The first and third interviews were particularly good experiences and a lot of this is lost in the 'dry/clinical' transcription e.g. empathy is not only conveyed through the words but emphasis, tone, body language, pauses etc. The preliminary 'crude' analysis is based upon what I felt, as the interviewer, to be valuable and to be a starting point but I recognise that those with more experience may have other ideas and that I may need to further narrow my focus.*

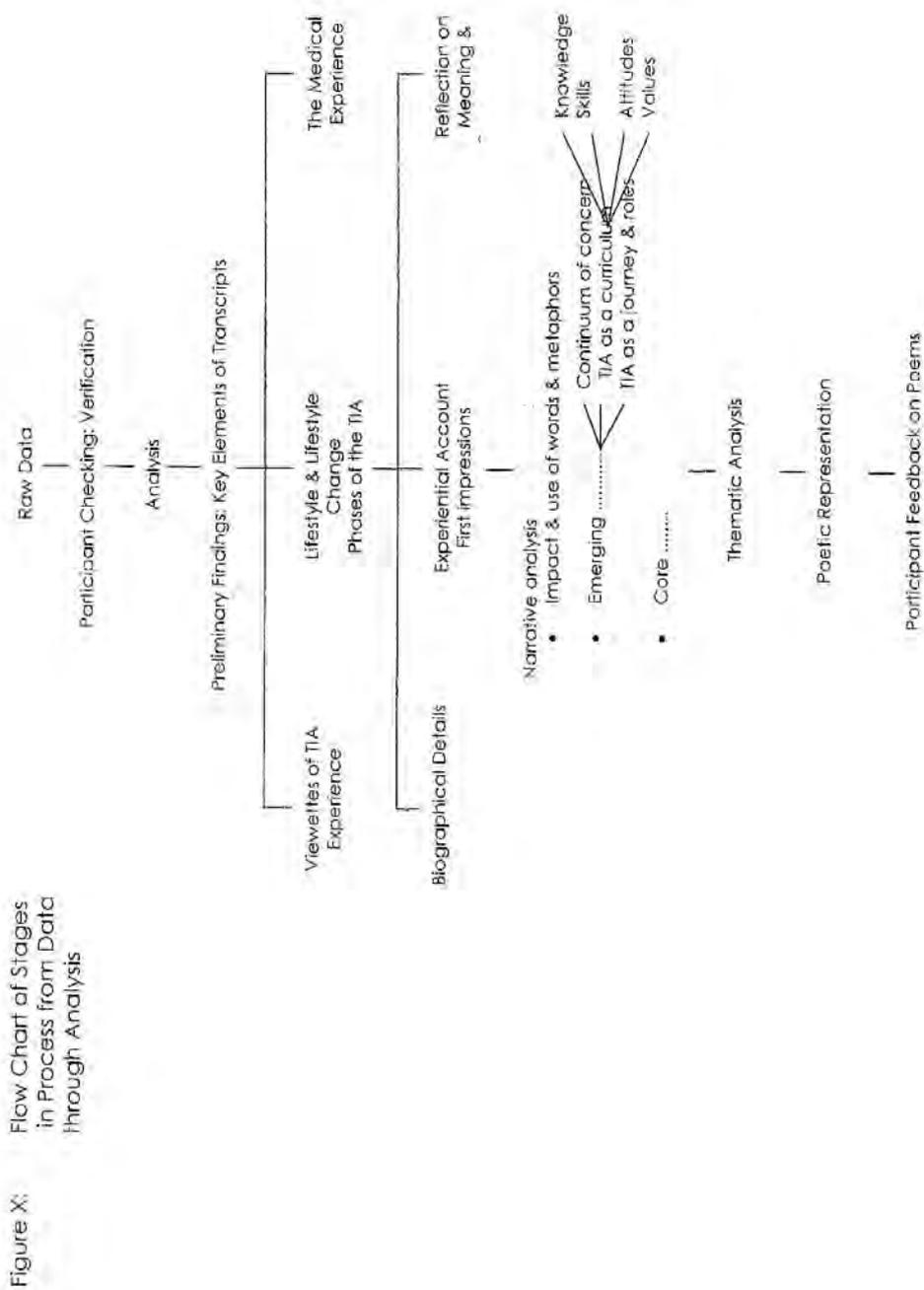
**Appendix 16**  
Phases of the TIA experience

**PHASES OF THE TIA EXPERIENCE**



Appendix 17

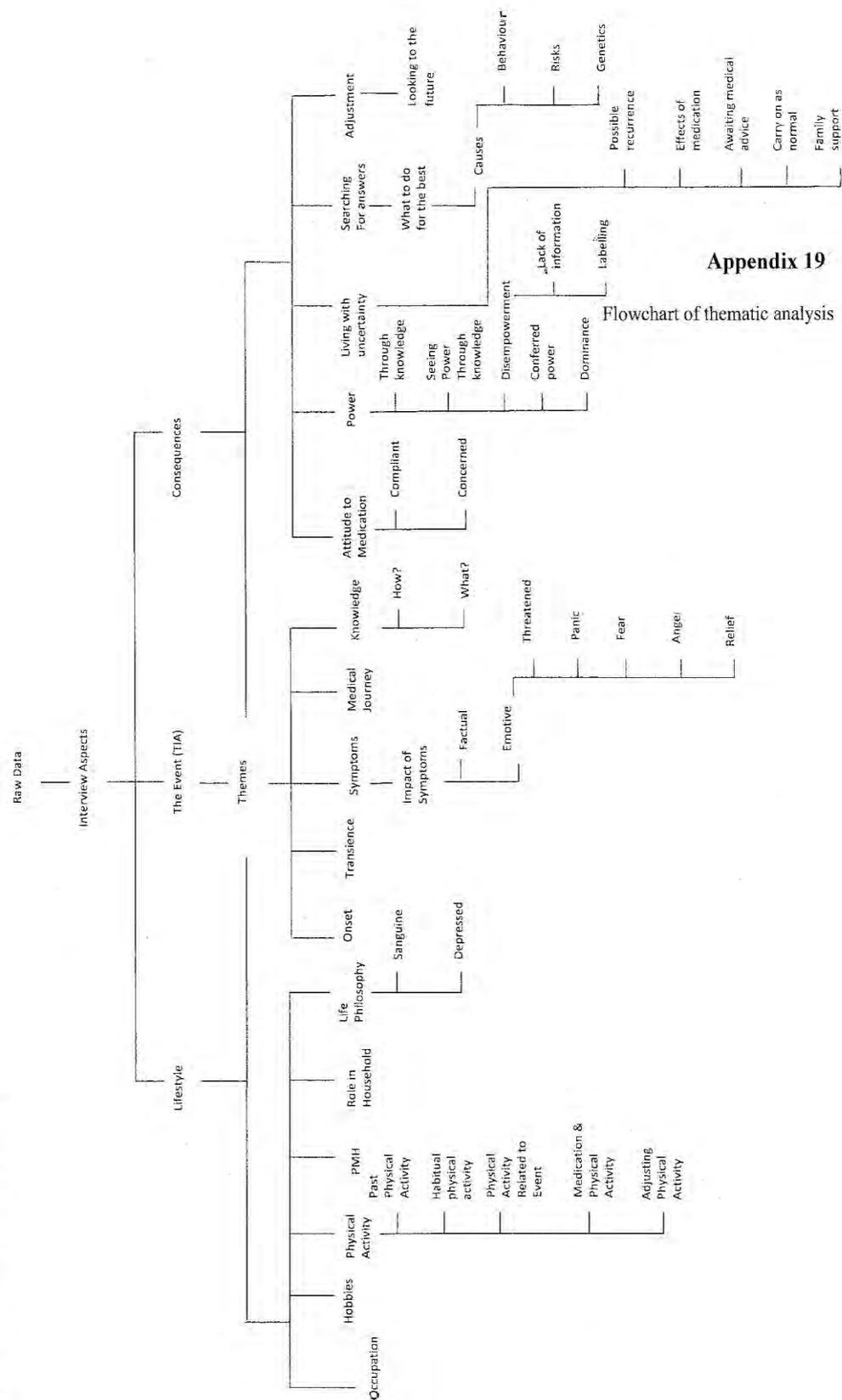
Flowchart of stages in process from data through analysis



**Appendix 18**  
Example Table of Thematic Analysis

<b>Emergent Theme</b>	<b>Interview Extract-Ann</b>	<b>Interview Extract-Arthur</b>	<b>Interview Extract-Esmond</b>	<b>Interview Extract-James</b>	<b>Interview Extract-Sarah</b>	<b>Interview Extract-Andrew</b>	<b>Interview Extract-Megan</b>
<u>Sudden onset.</u> <u>No warning</u>	I suddenly had the most strange sensation 63	completely out of the blue 176	the spade slipped out of my hand 24 I just dropped the spade 30	I suddenly felt no feeling in the right arm 29 a surprise 271	right hand and arm started to go numb 117	there was no warning, there didn't seem to be any cause. I wasn't doing anything unusual 111	Got a bit of chewing gum and popped it in my mouth and realised I couldn't chew it 34

Figure X: Flow Chart of Thematic Analysis



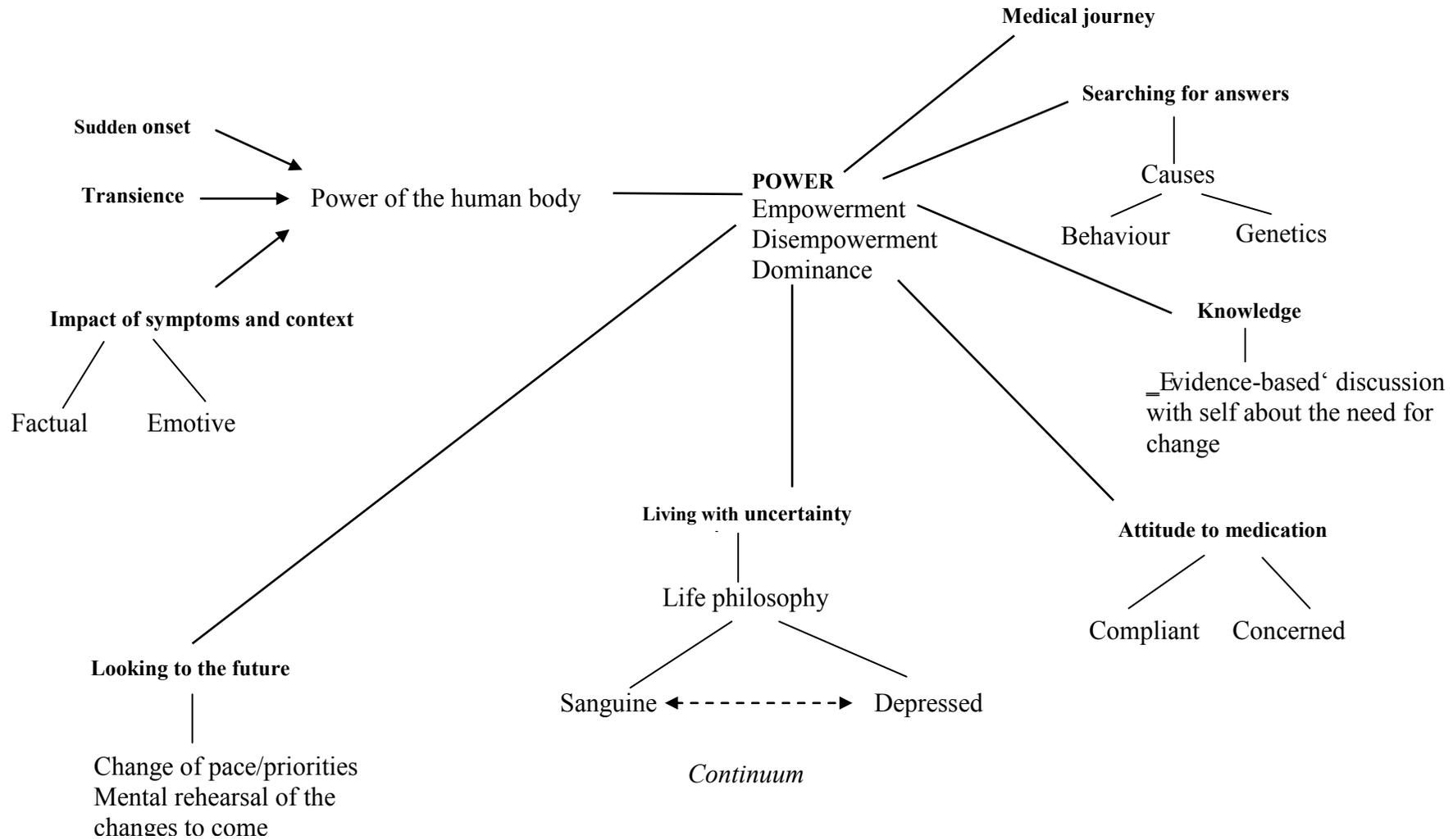
Appendix 19

Flowchart of thematic analysis

**Appendix 20**  
Development of Ideas for Thematic Analysis

	<b>Emergent Themes</b>	<b>Collective Theme</b>
<u>Lifestyle</u>	Social history Occupation Hobbies Past medical history Role in household Life philosophy	Learning
<u>The event (TIA)</u>	Sudden onset, no warning Transience Symptoms and context Medical journey Knowledge	Learning
<u>Consequences</u>	Resentment re medications Empowerment: disempowerment Living with uncertainty Searching for answers Adjustment	Learning

**Appendix 21**  
 Concept Map of Thematic Analysis



## Appendix 22 Poetic Representation

### Sarah

Hand and arm numb  
Hand in front of me-whose arm is that?  
Someone behind me-putting their arm around me  
Thought I was being attacked

Pulling it-it is my hand and arm after all!  
Really weird, really strange  
Pulling at my arm as if I was an idiot!  
Couldn't feel it-arm completely gone

I struggled, something not right, people  
Thinking I was drunk?, wobbly on my feet  
Right leg wouldn't move, started to go numb  
Drag myself to one side

Everything moving far away  
Space getting bigger and **bigger** and **bigger**  
Shaking and wondering what was going on  
Lost the ability to communicate-couldn't speak

Dizzy, arm gone, could hardly walk  
No feeling in right leg  
Know who I am but can't say  
Face dragging down, nothing, a complete black

Realised classic symptoms-a stroke. What extent? How bad?  
Panicky-looking like a mini stroke-don't panic  
What's going to happen to me?  
Less than 24 hours-put it into context

Out of the blue  
Coming through it, out the other end  
Feel better now  
Everything cleared

Starting to answer questions  
Couldn't get out,  
Grasp high level stuff  
Click, click, trying to find the word

Thirst for knowledge, know nothing about it  
Weight a bit of an issue, be more active  
No dietary or alcohol advice  
Know the limits, where slip down

Extremely lucky, life still goes on  
Thinking about it petrifying  
Feeling very down but give me a bit of time  
And go back full time

Thrown off your horse, get back on and carry on!



**Appendix 22**  
Poetic Representation

What advice I'm given  
I'll act upon  
I've just continued as normal  
And tried to forget it.  
I shall get accustomed to not knowing  
What the future holds,  
Given time.

I would say, don't ignore it.  
Get professional advice.  
Try to keep cheerful.  
That's my first thought.

And keep it in its place.

**Ann (2)**

Had brain and ultrasound scans  
Treatment excellent  
Full explanations, comfortable  
Impressed, splendid

Saw neurologist for results  
One small niggle  
Could have results sooner  
Very critical, but the real story

Nothing wrong of any significance  
TIA through process of elimination  
Re-assured,  
Go and enjoy retirement

Slightly unnerved, uncertainty  
So lucky, **put it in perspective**  
Family to the fore, to do more than in past  
Very concerned, husband very supportive

Modified my diet, doing more exercise  
Walking to the station, travel light with rucksack  
Can adapt but it's a pressure but  
If you don't use it you lose it

Incidents like TIA create a pressure  
**Get a balance and carry on**  
Take responsibility for self  
Encouraged to by medical profession

Small shock faded, no longer sharp edge  
With time accept things, don't stop doing what enjoy  
Initial resentment but still  
So much enjoyment out of life  
**Put it in perspective**

**Appendix 22**  
Poetic Representation

**James**

I stretched,  
Arms towards back of head  
Suddenly, no feeling in right arm!  
Couldn't bring it down  
Strange feeling in arm-no sensation  
Not speaking properly  
Right side of mouth, they noticed  
Something was wrong  
—Are you alright?"

Lasted fifteen seconds and that was it  
Came and went so quickly  
Wife quite concerned  
Loss of control right side of body  
Purely speech and arm  
A total surprise!  
Slight worry, a concern  
Another tablet-more inconvenience!

**Andrew**

Started to go a bit strange  
Right leg going—"I'm going!"  
Propped myself up on wall  
Side lost control and ability  
Speech slightly impaired  
Face collapsed  
Everything back within minutes  
Speech and movement-we chatted  
Talked about taking pills—"do have to?"  
Don't mind the exercise.  
A minor stroke-pin prick in the brain  
Feels like something shearing  
No warning, a shot across the bows  
Frightened me to death!

**Esmond**

Spade slipped out of my hand  
Dropped the spade  
Couldn't control it, grip anything, hold right hand up  
Tried to write-pencil not doing what it should  
Slightly concerned  
It was a surprise more than anything else  
But tried to do as usual  
Do a bit of gardening

**Appendix 22**  
Poetic Representation

**Megan**

Feeling unwell  
Strange, a bit funny.  
Driving along, couldn't chew gum  
Face numb, eye and mouth drooped  
Pinched my face-couldn't feel anything  
Couldn't speak properly  
They couldn't understand me  
Crying, didn't know what was happening  
Lost strength in my arm  
Couldn't squeeze doctor's hand  
Really horrible  
Think myself lucky, it was very mild

**Arthur**

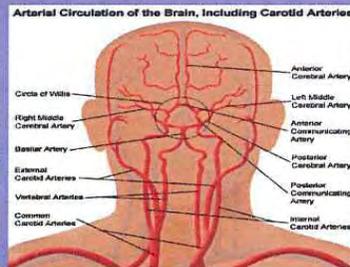
Out of the blue  
Didn't feel very well  
Off balance, a bit odd  
Very weird, leant on a wall  
Couldn't really talk,  
Speak properly-speech slurred  
Side of my face pretty useless  
Unsure of my self on my feet-a bit wobbly  
Bit of a blow-no driving for a month  
Scary, worried  
A taste of what could happen!

# Secondary Prevention: The Lived Experience of Transient Ischaemic Attack

Hewett M., Cross V. & Kuisma R. Conquest Hospital, St Leonards-on-Sea, East Sussex & University of Brighton

## Introduction

The incidence of stroke continues to grow in line with increasing longevity despite improved preventative measures (National Audit Office 2005). TIA as a precursor for a stroke is well known (Rothwell et al 2007). Experiential accounts of stroke exist in the literature (Ripley 2006) but not relating to TIA. Experience is closely related to need and is invaluable in shaping future services designed to embrace consumer views (Coulter & Ellins 2007, DOH 2005, DOH 2007, Kelson et al 1998).



www.spectrum-health.org

- Aims:** 1) To explore the lived experience of TIA  
2) To examine the impact of TIA upon lifestyle

**Purpose:** to contribute to secondary prevention

### Research Questions:

- 1) What is the lived experience of TIA?  
2) What is the impact of TIA upon lifestyle?

## Background

**Preventable Disease** Improvements in preventative medicine have developed in parallel with therapeutics. Increased wealth has led to excesses and inactivity (Rippe & Hess 1998) despite initiatives to offset this (DOH 2004)

**Health Behaviour** People better informed about health matters to make choices about lifestyle changes. Influences of socio-economics and psychosocial aspects of health impacting upon behaviours. The application of motivation (Rogers 1983) and behaviour (Ajzen 1988) theories.

**Patient-Centred Care** Responding to individual needs within the doctor-patient relationship.

**Patient Partnership** The informed patient and the rise in consumerism and decrease in paternalism (Frankel 2004) leading to shifts in the powerbase and empowerment.

**Stroke Medicine** has a raised profile with stroke being seen as a medical emergency, the use of thrombolysis and 24 hr CT scanning.

**Stroke Prevention** Improved management of risk-factors and public awareness.

**TIA within stroke medicine and prevention** The introduction of TIA clinics and lifestyle advice

With thanks to East Sussex Hospitals NHS Trust, the Association of Chartered Physiotherapists Interested in Neurology (ACPIN) & Sussex ACPIN for their sponsorship towards the professional doctorate in physiotherapy

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## Methodology

### Interpretative phenomenology and critical social theory

Subjectivity as the first starting point of phenomenology (Levering 2006) determined the methodological approach to explore the subjective experiences of those affected by TIA. Critical social theory complemented this due to the concern with theories of power and domination in social relationships (Habermas 1972) to explore issues within the doctor-patient relationship.

### Method



Semi-structured 1:1 interviews

**Sample** Purposive sample of 7 participants from two consultant-led TIA clinics

**Inclusion Criteria** TIA within a year, attended TIA clinics

**Exclusion Criteria** Those with stroke either before or after TIA

**Data Analysis** Thematic Analysis (Burnard 1991), Narrative Analysis (Ricoeur 1984), Poetic Representation (Richardson 1997)

This is a 'work-in-progress report' for the UK Stroke Forum Conference December 2008 and no conclusions have been presented as the data-analysis has yet to be completed

Margaret.hewett@esht.nhs.uk



TIA Clinic

## Findings

### Key Stories

- Vignettes of Experience
- Lifestyle and lifestyle change
- The medical journey

### Themes

Sudden onset, transience, vivid memory, prior knowledge, protracted medical journey, uncertainty, resentment of medications for life, and searching for answers.

### Themes and words

- TIA as a battle – blow, shaken, shock, shock, shot across the bows
- Continuum of concern – 'slight worry' to 'frightened to death'
- TIA as a journey – transition theory, roles
- Doctor-patient relationship – influence, power, the 'specialist'

### Poetic Representation

"Hand in front of me-whose arm is that?  
Someone behind me putting their arm around me  
Thought I was being attacked"

## Discussion

From the data-analysis to date the following issues have arisen for discussion:

- Patient knowledge acquisition – meeting different needs
- Expert Patient Programme (DOH 2002)
- Empowerment through voice – making needs known to shape future services
- Informing guidelines
- The role of the Physiotherapist in the TIA Clinic

Appendix 24  
UOB Conference 2010 Work-in-Progress Presentation

Original in Colour

## Patient Experiences of Transient Ischaemic Attack

Margaret Hewett  
Clinical Specialist Physiotherapist  
East Sussex Hospitals NHS Trust  
Professional Doctorate 2004  
July 2010

Margaret Hewett Professional Doctorate in Physiotherapy 2010

### Introduction

- Aspects of personal experience—gap in literature, lack of knowledge
- Policy-related factors—needs influencing services, TIA as a risk for stroke, cost of stroke, why research this now?
- Practice-related factors—physio practice & lifestyle change, evidence-based practice, impetus for research

Margaret Hewett Professional Doctorate in Physiotherapy 2010

### Literature Review

- Key imperatives in current UK health care policy—cost effectiveness & value for money, prevention, lifestyle & education, health care delivery—primary vs secondary care, partnership, patient choice
- Historical & philosophical background—models of illness & disease, consumerism & professional accountability, patient empowerment, patient-centred care, professional role & identity
- Theoretical background—models of behaviour, motivation & change

Margaret Hewett Professional Doctorate in Physiotherapy 2010

### Methodology

- Ontological perspective of social constructionism
- Epistemological perspective of interpretivism
- Hermeneutic enquiry through interpretive phenomenology
- Critical Social Theory—concern with issues of domination & dependence in social relationships

Margaret Hewett Professional Doctorate in Physiotherapy 2010

### Method & Sample

- Semi-structured interviews
- Participants (7) with recent experience of TIA & attending TIA clinics

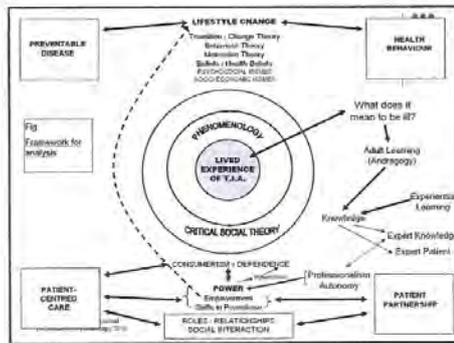
Margaret Hewett Professional Doctorate in Physiotherapy 2010

### Analysis

- Thematic analysis (Burnard 1994)
- (Narrative analysis)
- Poetic representation (Richardson 2003)

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Original in Colour



### Findings-phases & themes

- **Disruption**-a surprise more than anything. I didn't know what was happening, sense of disconnected body parts, continuum of concern
- **Transition**-the after effect, medical journey, learning curve, what is the right thing to do?, unnerved because of the uncertainty
- **Change**-moving on, what the future holds

Margaret Hewett Professional Doctorate in Physiotherapy 2011

### Discussion

- Window of opportunity for change: change theory
- Patient-centred care & beyond
- What practices dominate practice?
- Expert patient
- Knowledge/awareness & empowerment
- Significance & coping
- Whose life is it?
- What information?/Who gives information?

Margaret Hewett Professional Doctorate in Physiotherapy 2011

### Conclusion

- Meaning of illness to individuals
- Knowledge of illness and self-shared decision-making, favourable outcome
- Informed patient e.g. FAST campaign doesn't go far enough-control
- Expert patient under-valued
- Knowledge-empowerment
- Expert practice
- Future longitudinal study

Margaret Hewett Professional Doctorate in Physiotherapy 2011

### White Paper- DOH (2010) Equity & Excellence: Liberating the NHS

- Patient choice
- Informed choice- "information revolution"
- Patient-centred care- "no decision about me without me"
- Empowerment & control
- Valuing patient experience

• (meeting demands of increased consumer expectations, increasing technologies, increasing medical costs, ageing population)

Margaret Hewett Professional Doctorate in Physiotherapy 2011

World Confederation for Physical Therapy WCPT Congress 2011  
Abstract Submission

Category of Presentation: Research reports

Primary topic: NEUROLOGY: Stroke

2nd topic: LIFESTYLE DISEASES

Title: 'A TASTE OF WHAT COULD HAPPEN': LIVED EXPERIENCE OF TRANSIENT ISCHAEMIC ATTACK

Author(s): Hewett M,<sup>1</sup>

Institute(s): <sup>1</sup>University, Clinical research Centre, Brighton, United Kingdom

**Text Purpose:** To contribute to the field of stroke prevention by exploring the experiences of transient ischaemic attack (TIA) identifying needs that are instrumental in shaping service developments. To explore the experience of sudden onset illness, the essence of clinical practice and effects upon lifestyle change.

**Relevance:** This study contributes to both practice and policy developments within the current rapidly expanding field of stroke medicine. It exposes the critical essence of clinical practice, sudden onset illness and implications for lifestyle changes.

**Participants:** A purposive sample of seven participants with recent experience of TIA and the subsequent medical pathway took part in this study. The sample comprised of three females or four males with an age range from 39 years to 86 years, four of whom were in employment and three were retired. All participants experienced stroke-like symptoms echoed in the Face Arm Speech Time (FAST) campaign (UK Stroke Association 2007) lasting from 15 seconds to 4 hours.

**Methods:** An interpretive hermeneutic phenomenological approach was applied employing semi-structured interviews.

**Analysis:** Thematic analysis (Burnard 1994) was used to address factual elements of the data together with narrative analysis to focus upon the more emotive aspects relating to the impact. Poetic representation (Richardson 1997) was used to allow participant voices and stories to be heard to maximum effect.

**Results:** Findings revealed three phases in the experience namely Disruption, Transition and Change. Eleven themes were identified across the three phases using participants' words as far as possible that included emotive aspects relating to the impact for example "I didn't know what was happening" and more factual accounts about the 'Medical Journey' and then to 'Moving On' and 'What the Future Holds'. Weakness of the study includes limited participant group to those attending clinics.

**Conclusions:** The dynamics of clinical practice need to be fully understood to be effective in effecting lifestyle change. Raising stroke awareness needs to be more pro-active in delivering preventive messages earlier, for example in schools possibly alongside other campaigns like reducing obesity. More use could be made of the expert patient not only as in the Expert Patient Programme (DOH 2002) but also in clinical practice generally. Support groups for patients following TIA would be helpful and possibly affiliated to stroke support groups. The role of the physiotherapist could be expanded in exercise advice not only for this patient group.

Multidisciplinary one-stop-shops for patients following TIA could be beneficial. Clinician awareness needs increasing in relation to collective factors that impact upon lifestyle change. Longitudinal studies to track lifestyle changes could be helpful.

**Implications:** The importance of understanding the dynamics within clinical practice and the effect upon lifestyle change could be incorporated into training programmes. The content of stroke awareness campaigns needs changing via for example the UK Stroke Association. Preventive health messages within schools need to be more comprehensive to include more information about vascular risks which could be addressed via education authorities. Such initiatives as the Expert Patient Programme could be expanded into clinical practice, including physiotherapy not just within this field. The role of physiotherapists in effecting lifestyle change should be exploited more.

Key-Words: 1. lived experience  
2. transient illness  
3. lifestyle

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Ethics approval: Ethical approval from East Sussex, Brighton and Hove Ethics Committee(UK)

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