LIFE AFTER STROKE: PERSONAL, SOCIAL AND CULTURAL FACTORS - AN INNER CITY AFRO-CARIBBEAN EXPERIENCE

Calvin Moorley

A thesis submitted in partial fulfilment of the requirements of the University of East London for the degree of Doctor of Philosophy

May 2012

ABSTRACT

There is a prevalence of stroke amongst ethnic minority groups in the United Kingdom. Whilst a body of work explores chronic illness experience, less attention has been paid to life after stroke. To investigate the experience of life after stroke and the needs of individuals living within a diverse inner city community, everyday activities were analysed. A functional, psychological and social approach identified the effects of stroke on daily living, and the lived experience of life after stroke examined how Afro-Caribbean women managed on a daily basis. Using a specially designed electronic database, data from 213 patients attending an outpatient clinic was analysed within four groupings (White, Afro-Caribbean, Asian and Others). The men were significantly more dependent on support than the women. Asian men (n = 21) reported significantly ($p<\cdot013$) lower Barthel Indices, dressing difficulties ($p<\cdot05$), feeding ($p<\cdot007$), sleeping ($p<\cdot017$), required more carer support ($p<\cdot04$) and had low health ratings ($p<\cdot001$). For the women, the only difference was that the Asian women needed significantly ($p<\cdot016$) more help with bathing.

Six semi-structured interviews with Afro-Caribbean women were analysed using interpretative phenomenological analysis. The master themes encapsulating participants' experiences of life after stroke that emerged were 'understanding my health', 're-telling the stroke attack: the knowledgeable body - a medium for sense making' and 'the journey: identity and negotiating a new life'. Most of the interviewees had firm religious beliefs and viewed their health as granted and justly deserved. After a stroke, the body has to adapt to new ways of performing. This involves negotiating a post-stroke identity. Cultural upbringing and Caribbean heritage influences and shapes the way participants would like their health service to be administered. This mixed methods approach has led to understandings of benefit for both healthcare practitioners and clients, and to a greater cultural sensitivity in care planning with respect to ethnic groupings.

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Acknowledgements

I would like to express my gratitude to my supervisors Professor Oona Scott, Dr Sharon Cahill and Dr Aneta Tunariu of the University of East London for their guidance, support and untiring encouragement during the course of my study. I would also like to thank Professor David Humber for his initial support and guidance.

I am grateful to my partner, family, friends and colleagues at the University of East London, including my Head of Department, Professor Neville Punchard, for their support, understanding and shoulders to lean on in matters both philosophical and practical.

For specialist academic advice, motivation and inspiration I particularly want to thank Paul Armstrong, Nova Corcoran, Mary Cramp, Jane Culpan, Wendy Drechsler, Barbara Goodfellow and Germain Mesureur. For bottles of wine and banter I would like to thank Geoff Webb and the Friday QUIET committee.

My thanks go to John Spelman of Avalon Associates for his help in the final proof reading and presentation.

Finally, I would like to acknowledge the assistance and co-operation of the following who made this work possible:

- The Research and Development Department at Newham University Hospital Trust.
- Dr Khalid Darawill and the Stroke Team at Newham University Hospital Trust.
- All the participants who willingly gave their time and shared their lives with me, for without which this work would not have been possible.

List of Abbreviations

ADL/ADLs	Activity/Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
BME	Black and Minority Ethnic
BI	Barthel Index
CoD	Coefficient of Determination
COREC	Central Office for Research Ethics Committees
CVA	Cerebral Vascular Accident
DDO	Data was Deliberately Omitted
EDAL	Extended Activities of Daily Living
EPR	Electronic Patient's Record
FIM	Functional Independence Measure
GOS	Glasgow Outcome Scale
GP	General Practitioner
HRQOL	Health Related Quality of Life
IPA	Interpretative Phenomenological Analysis
IR	Incidence Rate
IT	Information Technology
LREC	Local Research Ethics Committee
MBI	Modified Barthel Index
MM	Mixed Methods
mRS	modified Rankin Scale
NIHSS	National Institute of Health Stroke Scale
NUHT	Newham University Hospital NHS Trust
PCT	Primary Care Trust
SSL12-I	Social Support List Interaction
SIS	Stroke Impact Scale
TIA	Transient Ischaemic Attack
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

1.1 Introducing the Researcher, Research Setting, the Organisation of the Thesis and a Personal Reflection

This chapter provides an introduction to the thesis, author and associated research.

1.2 Personal Introduction and Rationale

I grew up on Trinidad, one of the most southerly isles in the Caribbean forming the twin Republic of Trinidad and Tobago. In most Trinidadian homes, the hub of activity is in the kitchen where we all gather to talk, argue, laugh and, of course, eat. Outside the home, the hub of activity is 'down d road, on the junction or round d corner' liming (means to hang out) or in the market.

Contrary to popular belief, not all people from the Caribbean are of African descent. Trinidad is a cosmopolitan nation and my ethnic/racial heritage is Asian Caribbean. I attended school with Indians, Chinese, Africans and whites, and we all shared the commonality of 'drinking coconut', 'liming on the corner' and 'going down to the river or seaside catching river fish or pulling sane' (sea fishing).

After my secondary school education in Trinidad, I moved to London to undertake my training in adult nursing. I qualified as a nurse at the University of Essex in 1995, and went on to specialise in cardiac intensive care, working at Guy's and St Thomas' NHS Hospital (1995-1998), King's College NHS Hospital (1998-2000) and Barts and the Royal London NHS Hospital (2000-2005). While working at Guy's Hospital I returned to higher education and completed a B.A.(Hons) in Social Policy at Goldsmiths College, University of London. I then went on to gain my Postgraduate Certificate in Teaching from Canterbury Christ Church University.

My professional concern and interest in culture and health stemmed from the first year of my nursing training and education. During that period I lived in Colchester in Essex. Colchester is the oldest recorded town in Britain; it has a castle, an army garrison accommodation and training centre, as well as parks, museums and art galleries (1990 Census Online National Statistics, 1990). In the 1990s, Colchester was a predominantly white populated town. I was fortunate to have a fellow nursing trainee from the same country as myself, someone who shared a common dialect, social practices and understood my facial expressions and other gestures within a cultural context; it was with this friend that my awakening for cultural identity and sensitivity was roused.

One day on the high street my friend asked "tell mih wot yuh see when yuh look roun yuh?". I looked up and down and described what I saw; the castle park, the shoppers bustling with their shopping, the buses and people old and young, some with baby buggies and children. She asked me what type of people I saw, and I replied "old, young, male, female, people with babies or children". She responded "and they are all white, we are the only two black people here", but she was wrong (this was an observation on one particular day). That day we were probably the only two black people there, but I had seen a few other black people on previous occasions. My friend sadly left Colchester and transferred her training to London, where she felt she belonged to a more familiar community.

Our conversation haunted me on the wards throughout my training. I thought that if I am from a different culture and don't understand my patient's culture, how can I fully understand their needs and offer culturally sensitive care? In nursing classes, we were taught about religion, but this predominately focused on observances in death and dying. This, in my opinion, did not constitute how to offer care to an Afro-Caribbean, Asian or Caucasian patient based on their culture and religious practices. It was really to do with respect for a dead body. I was acutely aware of gestures, phrases, body language, practices (such as drinking hot water in the morning, taking half of the prescribed medication, not allowing men to touch women) and how they make up part of the person's cultural identity

and how to interpret these gestures while caring for patients. Today I work and live in London and I am even more aware of the role of culture in nursing care.

My personal interest in stroke developed when my mother suffered a stroke. While looking after and caring for her in Trinidad, I became aware of how an individual's life can be shaped by stroke. Some of these are changes in the body and daily routines, including the struggle to negotiate a new routine and accept illness. As I began to make mental notes, my personal interest became overshadowed by a professional and academic one.

1.3 The Research Setting: London Borough of Newham

The London Borough of Newham is one of the most culturally diverse of all London boroughs (Newham Public Health Report, 2009). It contains people with various ethnic backgrounds and a wide diversity of religious, cultural and linguistic heritage, largely stemming from migration into the United Kingdom. More recently, the development of the Thames Gateway Project and the 2012 Olympic Games has contributed to this melting pot of cultures. The breadth of ethnic diversity is illustrated by the fact that there are over 150 different languages spoken in this borough (London Borough of Newham, 2006; London Health Observatory, 2008).

East London has traditionally been the first point of arrival for many refugees and asylum seekers, and is known for its social and economic deprivation and poor health. Newham ranks as the 11th most deprived and 13th most populous borough in London (London Health Observatory, 2008; Online National Statistics, 2005). Newham residents display many features that are indicative of disadvantaged communities, including low income, low level of qualifications, low skills base, poor housing and poor health (Congdon, 2008).

The Newham Household Panel Survey (2007), modelled on the British Household Panel Survey, reports that 44% of the local population live in poverty. Examples are households

comprising of large numbers of children and those from Bangladeshi, Pakistani and black African ethnic groups (London Borough of Newham, 2006).

The resident population of Newham in 2005 (according to the mid-census report) was about 246,200 people: 49% male and 51% female. The indigenous white population is outnumbered by the combined ethnic minority populations. The black population distribution is black/black British 23% (including Afro-Caribbean), Asian 35%, mixed 3% and white 39% (Online National Statistics, 2005). In the 2001 Census, 10% of the Newham population reported that their health was 'not good' and 17% reported a lifelong limiting illness.

Cardiovascular disease is a high priority for the borough (Newham Public Health Report, 2008). Stroke falls under the umbrella of cardiovascular disease. In 2004, 512 people died in Newham as a result of all circulatory diseases, including coronary heart disease and stroke. There are variations such as type of stroke, age and response to treatment, based on both ethnic and racial backgrounds (Markus, Khan, Birns, Evans, Kalra, Rudd … Jerrard-Dunne, 2007) and Newham reported that 12% black and 9% Pakistani men were recorded as having had a stroke. This is well above the 5% in the general population, and the borough also then had the highest death rate for stroke in London (Newham Public Health Department, 2009).

1.4 Organisation of the Thesis

This thesis is made up of 2 phases consisting of 7 chapters. Phase 1 uses a quantitative approach and Phase 2 a qualitative approach.

The author of this thesis (a Registered Nurse Adult part 12 of the United Kingdom Nursing and Midwifery Council) and other professionals working in health or health research (e.g. Engel, 1981; Illich, 1976; McKeown, 1976; Nettleton, 2006) argue that in order to fully understand how an individual perceives his own health and illness, attention needs to be

paid to the biopsychosocial facets that contribute to health and illness. Phase 1 of this thesis analyses self-reported performance of activities of daily living (ADLs) by gender and ethnicity. The analysis also includes aspects of psychological and social care, such as care support, mood, memory function, behaviour and levels of social engagement over a 12 month period from an outpatient follow-up clinic. Quantitative analysis of the data collected produced a mapping of life after stroke for the clinic attendees. This analysis helps to better understand how groups based on gender and ethnicity are affected after stroke.

This information was then used to help guide the qualitative phase of the thesis. The Phase 1 report was used to help design questions for the semi-structured interviews carried out in Phase 2 when exploring life after stroke. The second phase of this thesis was concerned with exploring how social relationships and everyday interactions and activities impact on the health of Afro-Caribbean women, taking into consideration the cultural influences of 'identity', 'sickness', 'health' and 'well-being'. This exploration was achieved through the interrogation of these Afro-Caribbean women's talk using interpretative phenomenological analysis (IPA).

The structure of the thesis focuses on health, culture, illness representation and the body, being analysed in the context of:

- the literature review;
- phase 1 - a quantitative analysis of the functional, psychological and social assessment of stroke outpatient clinic attendees; and
- phase 2 - a qualitative analysis of transcribed data (semi-structured interviews) using IPA.

1.4.1 Chapter 2: Literature Review

The chapter begins with a review of the literature on health and how it is understood from both lay and professional perspectives. It examines the World Health Organisation's

definition of health and how those in the field of health have responded to this definition (Clarke, 2001; Kleinman, 2006; Wikman, Marklund & Alexanderson, 2005) . The chapter focuses on how the lay individual reports their health, drawing on the work of Blaxter (1990; 1995; 1997; 2001). It explores health, illness, culture, identity and gender and how they inform each other and are woven into the fabric of an individual's life (Helman, 2001). It also draws from the researcher's own experience as a nurse, where patients are seen and looked after in a structured way using models of health (such as the biopsychosocial and medical models) (Borrell-Carrió, Suchman, & Epstein, 2004; Engel, 1980, 2002; Tyreman, 2006). The individual's definition of health is also considered against their experiences, based on models of health (Alonso, 2004; Nettleton, 2006).

The process involving constructing a health identity and the literature around the body are reviewed (James & Hockey, 2007; Jenkins, 1996; Lupton, 2003), as well as work relating to stroke and the body (Corbin, 2003; Kvigne & Kirkevold, 2003; Roberto & McCann, 2011).

The embodiment and examination of interpersonal relationships and how they are validated through others (such as doctors, family members and friends) is then discussed. This chapter also explores some of the cultural formulations that can be absorbed and individualised, with a focus on the internal (feelings, thoughts and assumptions) and external (work, family and significant social relationships, local communities and the environment) life world. Usually, people take their body for granted (James & Hockey, 2007) and how culture influences the identity of individuals when they are ill or well, and how theses are formulated (Hall, 2003; Helman, 2001; Kessing, 1998; Woodward, 2002) is then considered.

As part of culture, the literature review looks at folk illnesses as culturally constructed (i.e. causes and treatment of illness), drawing on the works of Desmangles (1992), Klienman (1980), Sontag (2001) and Woodward (2002). The review also examines women's health and how it has been viewed (Annandale & Hunt, 2000; Doyal, 1995; Hunt & Annandale,

1999) and reported (Arber & Cooper, 1999; Arber, Davidson & Ginn, 2003; Bartley, Popay & Plewis, 1992).

There is a focus on life after stroke, which covers the incidence and prevalence of stroke (Rosamond, Flegal, Furie, Go, Greenlund, Haase … Hong, 2008) together with works that identify the racial disparities in stroke (Markus *et al*., 2007; Stewart, Dundas, Howard, Rudd & Wolfe, 1999; Wolfe, Corbin, Smeeton, Gay, Rudd, Hennis … Fraser, 2006; Wolfe, Smeeton, Coshal, Tilling & Rudd, 2005). The uses of stroke assessment are discussed (Brott, Adams, Olinger, Marler, Barsan & Biller, 1989; Kasner, 2006; Lyden, Lu, Jackson, Marler, Kothari, Brott & Zivin, 1999) with a focus on the Barthel Index (Wade, 1995). Functional, psychological and social recovery after stroke is reviewed and discussed. Life after stroke is reviewed and discussed via the work of various researchers using both quantitative and qualitative methods (Anderson, Carter, Brownlee, Hackett, Broad & Bonita, 2004; Clarke, 2009; Doolittle, 1992; Hackett, Yapa, Parag & Anderson, 2005; Kwok, Lo, Wong, Wai-Kwong, Mok & Kai-Sing, 2006; Radomski, 1995; Strudwick & Morris, 2010; Wood, Connelly & Maly, 2010).

The chapter closes with a discussion on mixed methods (MM) studies (Creswell, 2009; Creswell & Garrett, 2008; Morse, 2008; 2009, 2011; Tashakkori & Creswell, 2007) and typologies (Leech & Onwuegbuzie, 2007; Onwuegbuzie & Leech, 2007). The analyses of MM studies (O'Cathain, 2009; O'Cathain, Murphy, & Nicholl, 2010) and the advantages (Clarke, 2009; Hanson, Creswell, Plano-Clark, Petska, & Creswell, 2005; Tashakkori & Teddlie, 2003) and disadvantages (Bryman, 2006; 2007; Stewart, Makwarimba, Barnfather, Letourneau, & Neufeld, 2008) are then discussed. At the end of the chapter, the research questions and basis for the Ph.D. project are put forward, drawn from the arguments and discussions within the chapter.

1.4.2 Chapter 3: Quantitative Methods

Chapter 3 presents the methodological rationale and decisions undertaken in Phase 1 of the study. It discusses the use of an MM approach in health and the challenges faced when trying to integrate two methodologies. The theoretical decisions undertaken in order to carry out the research are discussed, with particular reference to the works of Bryman (2006), Clarke (2009), Morse (2009), Hanson *et al.* (2005) and Creswell and Tashakkori (2007). This is followed by a section on the study design, discussing the MM typology of Quan →QUAL. This chapter sets the scene for Phase 1 and outlines the aims and objectives of Phase 1 as well as Phase 2. The ethical procedure for both phases is then presented.

The scene for the study and how the data was collected in Phase 1 at the Newham University Hospital NHS Trust (NUHT) are explained, along with how the stroke outpatient clinic is operated. The instrument used to assess life after stroke for the clinic attendees is then discussed. This information is followed by the rationale to design a new electronic database for collecting such information, as well as the process involved in undertaking this task.

Finally, this chapter describes the collection and preparation of the data, together with how the distribution was tested. The data was analysed using descriptive statistics, which included analysis of variance (ANOVA) and non-parametric tests (the Kruskal Wallis test and Mann Whitney U) to produce an overview of the stroke community attending the stroke clinic at NUHT, ending with a reflection by the researcher on data collection.. The chapter presents the stages the researcher undertook in order to arrive at a sound dataset and the use of appropriate statistical analyses.

1.4.3 Chapter 4: Phase 1 - Stroke Related Phenomena: a Descriptive Analysis of Data from a Group of Inner City Stroke Clinic Attendees

The key focus of this chapter was to arrive at a descriptive and interpretative account (Tabachnick & Fidell, 2007) of the contributing factors that affect patients' overall quality of life after stroke. The intention was to provide more than a simple snapshot of the physical functioning, social activities and behaviour of those affected by stroke. Rather, it was to open up an epistemic space and examine the relationship between the social, psychological and physical patterns that emerge in life after stroke. This was done by gender and ethnicity for the four ethnic groups: Asian, Black, White Caucasian and Other. Through the use of self-assessment, the functional and physical, psychological and social presentation after stroke was analysed and presented using statistical description and tests. Systematic analysis of the data enabled trends to be identified and analysed in terms of demographic data, together with the identification of important factors such as dependence and independence based on gender and ethnicity.

The results are presented in the order of description of the research subjects and provide data analysis on age and stroke incidence by postcodes which are cross-referenced to a map of the borough. The lived experiences of stroke (via clinical reporting) are presented through quantitative analysis, by domains of functional and physical variables (including bathing, bowels, urinary continence, dependency and dressing), followed by the variables (behaviour, memory, mood, orientation, etc.) that fall into the psychological domain of life after stroke. The final domain, social (carer support and type of carer), is then presented. A summary of the statistical findings is given and this is followed by a discussion of the findings on life after stroke from an inner city population.

1.4.4 Chapter 5: Phase 2 - Qualitative Methods

This chapter outlines the methodological framework used in Phase 2, which is qualitative in design and uses semi-structured interviews analysed through the use of IPA. It seeks to

understand how life after stroke is portrayed in the day-to-day lives of Afro-Caribbean women and explores the personal meanings attached to their illness.

It explains how the researcher applied the criteria for reporting qualitative research using the work of Tong, Sainsbury and Craig (2007) for guidance. It informs the reader how the researcher arrived at the decision to use IPA by examining phenomenology. There is a presentation of how IPA was used in the study, together with the schedule of questions and the importance of interviewing. A brief description of the participants for Phase 2 is provided. The stages of analysis of the collected data are discussed, taking guidance from Smith (2004), showing step-by-step how the findings were derived. The chapter ends with a reflection on data collection and analysis, which embodies the criteria Tong *et al*. discuss.

1.4.5 Chapter 6: Life After Stroke - Findings from the Qualitative Phase

Chapter 6 reports on the qualitative findings of Phase 2. It produces an analytical report of the participants who were interviewed and is concerned with how life after stroke is acted out in everyday life. It focuses on the lived experiences of individuals as a collective and a subjective. The collective shows the patterns of shared experiences, while the subjective identifies the singular experiences of the participants.

The chapter looks at the meaning making repertoires of the chosen group and how their life worlds (Husserl, 1936; 1970) are shaped by their experiences of health and illness. The analytical results produced in this chapter were derived using IPA as the guide and tool for analysing the participants' accounts. IPA helped to examine how the participants made sense of their world. It also guided the researcher in making sense of the participants' sense making process.

The three master themes and cluster themes are then presented, with a summary provided at the end of each master theme. The master themes are (1) understanding my health, (2)

re-telling the stroke attack: the knowledgeable body, a medium for sense making, and (3) the journey: identity and negotiating a new life.

1.4.6 Chapter 7: Discussion, Conclusion & Reflexivity

This final chapter brings together the work carried out and discusses the findings of both phases of the study. It begins by restating the research questions and providing a summary of the research findings, then moves on to discuss the findings in terms of life after stroke. It looks at how Afro-Caribbean women with stroke view their health, as well as the role and impact of ethnicity and culture on health. Key findings on culture, knowledge and practices surrounding stroke are also presented. It discusses the interaction with health professionals, then the social roles of the stroke survivor and how the individual reacts to these.

The phenomenologically grounded self and the role of the body in life after stroke is discussed. Individualised views of life after stroke, which include interpersonal relationships, physical loss and control, identity and the role of spiritual beliefs on health are presented. Throughout the discussion, the findings of both methods are present at times side-by-side to complement each other, and at times are integrated where possible. The chapter ends with recommendations, the conclusion, strengths and limitations of the work, and a reflection on the research journey.

1.5 Contribution to Knowledge

It is hoped that theory concerning the perspectives and models of health, together with illness representations, the embodiment of illness and the awareness of cultural identity, will inform application to practice:

- The theoretical discussion elicited by the findings will be beneficial to stroke care and interprofessional practice through (i) the development of an electronic database

that allows easy sharing of information, (ii) an understanding of the subjective assessment of the individual will help in prioritising and planning care of the individual, and (iii) an understanding of meaning of illness may lead to a more sensitive manner in approaching stroke care.

- The analysis and interpretations of data from Phases 1 and 2 will lead to a fuller and more holistic understanding of the care needs of life after stroke. Secondly, understanding the lived experiences of stroke patients will benefit those who are core to providing care for this group in planning and allocating resources.
- This study will demonstrate the repertoire of needs of stroke patients. It will expose the social, emotional, psychological, as well as medical and physical effects of stroke and how individuals construct their world by adapting to hypertension and life after stroke.
- The integration of quantitative and qualitative findings has the potential of delivering theoretical claims that will lead to understanding that will benefit both practitioners and clients. For example, patterns of physical, social and psychological effects of stroke can be understood in terms of social and cultural practice, leading to greater cultural sensitivity in care planning for the affected group.

Knowledge from the study has already been disseminated via both informal and formal means. Informal sharing of knowledge included talks and workshops for staff and patient groups. Formal means included in publications and conferences, as below:

- Clinical Research Nursing Association Annual Conference, 2006 (Pisa, Italy), winning the award for best presentation.
- Newham University Hospital Trust 2007 Annual Research Conference (London), winning the award for best presentation.
- The group under research was a 'hard to find group', which led to a co-authored chapter "Reaching unreachable groups and crossing cultural barriers in communicating health promotion" in *Communicating Health Strategies for Health Promotion*, edited by Corcoran (2007).
- Accepted abstract for presentation at the International Conference on Qualitative Inquiry into the Caribbean 2009, University of the West Indies, Mona, Jamaica.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This review considers the perspectives and models of health, together with the embodiment of health and illness. It addresses culture in respect of folk illnesses and illness metaphors, along with their impact on identity and understanding of the body. It includes a gender perspective of health, looking at the health of women and men leading to the incidence and prevalence of stroke. An overview is then presented of three commonly used stroke assessments and the qualitative literature that evaluates the experiences of living with stroke in terms of functional, psychological and social domains. Finally the importance of mixed methods in health research is discussed and then the literature review concludes by outlining the aims and research questions addressed in the study.

2.2 Understanding of Health

Inherent to all meanings of health, there is a widely held default view of illness, meaning that people hold specific ideas of illness - usually having the opposite meaning of their definition of health. The current World Health Organisation (WHO) definition of health, formulated in 1946, describes health as a state of complete physical, social and spiritual well-being, and not merely the absence of disease or infirmity (WHO, 1946). Because of its breadth and ambition, this definition was groundbreaking (Huber, Knottnerus, Green, Horst, Jadad, Kromhou ... Smid, 2011). It overcame the negative definition of health and included the physical, mental and social domains, and although it has often been criticised it has not yet been adapted. More recently, criticism has intensified as life expectancy and patterns of illness have changed, and it is now generally accepted that the definition has become counterproductive. But even if the understanding of health and illness has evolved over time, and more recently has moved from a view of health as an absence of disease to one that incorporates a state of complete physical, social and spiritual well-being, and not simply the absence of illness and infirmity (Godlee, 2011), neither definition is seen as

being sufficient in the present era which is marked by new understanding of disease at molecular, individual and societal levels (The Lancet, 2009).

A need has been identified to extend this framework in two further directions (Wikman *et al*., 2005). Firstly, that human health cannot be separated from the health of our total planetary diversity and human beings do not live in a biological vacuum. Rather, we live an independent existence within the totality of the living world. The second dimension lies within the realm of the inanimate. The living world depends on a healthy interaction with the inanimate world. The science of climate change has shown how contingent our human well-being is on the 'health' of the Earth's systems of energy exchange. Clarke (2001), a medical sociologist, propounds the view that in order to provide comprehensive healthcare to all, providers need to understand that the definition of health has developed into a much more subjective and dynamic dimension, where health is a state (discussed further in section 2.4) dependent on the complex inter-relationships between the cultural and structural (i.e. the built environment), aspects of the healthcare system and personal variables at any given time.

One of the unhelpful upshots of the WHO definition is that health can be conceived as a static state. In reality, there is of course little about life or factors associated with living that are static. Institutional or lay definitions of health hold a conceptual reality rather than an actual reality. Based on Helman's (2001) work with migrant groups (West Indians and their engagement with the National Health Service in England), it may be considered that institutional definitions are based on perceived current healthcare needs; whereas for individuals belonging to different cultural groups, these definitions may vary depending on each group's value system. What each group sees as 'truth' (i.e. their acceptance and belief of health and contributory factors of good and ill health) can change over time and may be reworked by successive generations, involving external influences such as education and greater integration into society. It is generally now recognised that communities change as a result of acculturation, or as Dressler (2004) explains, the risk of disease minimises as individuals adapt to the current setting and their perceptions and meanings of health

change, allowing a broader perspective on health and the prevention of disease. Building on the work of earlier studies into the biological, psychological and social dimensions of health, many health professionals have been concerned with capturing the 'wholeness' of each individual's health status and the implications for living within their own community (Giddens, 1991; Helman, 2001).

The stated aim of the Department of Global Health and Social Medicine at Harvard University is to apply social science and humanities research to improve the practice of medicine, the delivery of treatment, and the development of healthcare policies locally and worldwide. Focussing on this aim, Kleinman (2006) has demonstrated how concepts derived from anthropologic and cross-cultural research may provide an alternative framework for trying to solve major healthcare problems such as patient dissatisfaction, inequality of care and spiralling costs, identifying the fundamental distinction between disease and illness, and the notion of cultural construction of clinical reality. Kleinman defines illness as a process that begins with personal awareness of a change in the body's feelings and continues with the labelling of the individual by family and friends as being 'ill'. Evidence from three selected case studies show that illness represents personal, interpersonal and cultural reactions to disease or discomfort, based on the experience of the individual. For each individual, illness is shaped by cultural factors such as belief and attitudes towards disease, medicine and healthcare that govern the way we label, explain and value the experience. Individuals define disease by referring to abnormalities in the structure and functions of the body's organs and systems, which physicians diagnose and treat, stating that disease is the malfunctioning or failure to adapt of biologic and psychophysiologic processes in the individual (Annandale, 1998). In contrast, the disvalued feelings and changes in states of being and social function are captured in the term 'sickness'. Sickness is the explanation for how individuals perceive, experience and cope with disease.

The recent editorial on "what is health" (The Lancet, 2009) referred to earlier in this section focuses on the work of a French physician, Georges Canguilhem (see Horton,

1995), who views health as the ability to adapt to one's environment rather than something that can be measured statistically or mechanistically. He notes that we should not look at health as a fixed entity, but as defined by the person based on his functional needs and that health is "being able to fall sick and recover" and by contrast "to be sick is to be unable to tolerate change". Thus, health becomes complex in its definition, as it relies on personal constructs which are influenced by culture, personal experience and time.

Blaxter (1990) studied 9000 individuals in England, Wales and Scotland, asking them to describe someone they thought was healthy and to consider "what makes you call them healthy?" and "what is it like when you are healthy?" The responses received were that health simply meant not being ill; health was seen in terms of a reserve (i.e. to have the capacity to perform). Other responses included: a healthy life filled with health behaviours, such as physical fitness; having energy and vitality; social relationships with others; being able to function effectively; and an expression of psychosocial well-being. She notes a high level of agreement in all contexts and among all social groups that health is, to a large extent, dependent on behaviour: "the responsibility for health and illness is in one's own hands" (Blaxter, 1990:748). Deterioration in health is seen to be caused by better or poorer diet, smoking, alcohol and drug consumption, and more/less exercise - and this is seen to be especially true for deterioration in people's health. Medical advances and increased knowledge are offered as the background to improved health and, although older people mentioned aspects of improved standards of living (Blaxter, 1997), little reference is made to structural or environmental causes.

In a review of published research, Hughner and Kleine (2004) sought to understand how lay people think about health and its meaning and place in their daily lives. Most of their participants defined 'health' as meaning an absence of illness or disease, although as participants aged they defined health in different ways. For example, older participants defined health as the ability to function and do things, while for younger people it was more about physical and mental well-being, and self-realisation.

It is reasonable to conclude that health is highly subjective and holds a personal meaning to each individual in the context of their own life. Healthcare delivery through organised frameworks can impact on the way an individual responds to care or treatment. The next section focuses on how the biopsychosocial model of health developed.

2.3 Towards a Holistic Approach: the Biopsychosocial Model

Collective understandings of health and illness have been captured within theoretical frameworks or models, each varying in their emphasis on biomedicine, cultural and/or psychosocial determinants of health. These models have served various purposes and provide different approaches towards defining health. For the purpose of this thesis, three key models, each with differing roles, have been identified. The 'biomedical' model identifies the needs of the patient in terms of their immediate medical and nursing care, the 'social' model aims to address the social needs of each individual and the longer term rehabilitation and delivery of healthcare, and finally the 'biopsychosocial' model attempts to acknowledge the health perceptions of each individual and that of their carers in the context of their individual circumstances.

In the researcher's personal experience of working as a registered nurse in a cardiothoracic intensive care unit, the biomedical model is often the model of choice of the multi-disciplinary team. One reason for this is that within intensive care we speak primarily in medical terms of supporting failing cardiovascular and neurological systems and organs. In this setting, the biomedical model is of considerable advantage in diagnosis and planning the patient care which traditionally underpins medicine (Engel, 1980). However, Engel argues for a biopsychosocial approach, stating that the biomedical model leaves little room for the psychological, social and behavioural dimensions in illness; thereby hindering an apparent holistic avenue as to how the individual and their illness is treated.

Engel, a psychiatrist from the University of Rochester, wrote that health and illness is a consequence of the physical/biological, psychological and social/cultural variables which

should underpin the blueprint for health action, treatment and research. More recently, Suls and Rothman (2004) and Engel (2002) have advocated that the components of the biopsychosocial model (i.e. biological, psychological and social), together with determinants of health, need to be considered when reviewing an individual's health or illness status. Tyreman (2006), considering the causation of illness, acknowledges that the biomedical model incorporates scientific knowledge (especially the pathological, biological and physiological sciences), and that it has explanatory and technical applications for establishing the correct diagnosis and subsequent clinical care. He explains that in this model, health constitutes freedom from disease, pain or defect, depicting the normal human condition in terms of cellular processes functioning optimally.

The social model of health considers wider determinants, such as how a person's culture and belief system contributes to their health. This model considers aspects such as levels of relative income, access to housing, education attainment and opportunities, as well as the wider environmental, political and socio-economic conditions in which people live. Seedhouse (1991) recognises that people's social and community networks and individual actions have an impact upon health. He acknowledges that illness may also be contributed to by government policy or industrial actions (such as the disposal of chemical waste which can lead to disease).

In a similar approach, Clarke (2001) identifies that physical structures such as the built environment and biological factors such as genetical pre-determinants interact with social factors, leading to inequalities of health, so that people from lower income groups living in poor housing are more susceptible to illness (such as asthmatic attacks and depression). The social model aims to improve health through reducing the health inequalities that lead to illness. Carlisle (2000), considering health inequalities and conceptual frameworks, acknowledges that this model challenges injustices that cause ill-health by assessing determinants that contribute to illness. The cornerstone of this model is the belief that illness can be understood by taking into consideration the wider social, psychological and cultural contexts.

Alonso (2004) performed a systematic literature review on the change towards biopsychosocial health concepts among medical researchers over the last two decades. She studied a series of papers published in *The Lancet* between 1978 and 1982, and then from 1996 to 2000. She found that none of the 52 papers she reviewed set out a positive and replicable definition of health, and that no differences were found between the two periods that were studied in terms of the psychological dimensions in measures of 'healthy status', although there was a change towards more holistic concepts of health. She found that there had been a greater number of papers written by both nurses and allied health professionals. She concluded that those from the nursing and allied health professions used a biopsychosocial (holistic) definition of health as they deal with the ill person as a whole and take responsibility for the patient's well-being. This was compared to physicians, who have traditionally dealt with the ill part of the patient, which means focussing on the medically relevant symptoms and treatments.

When an individual presents with a medical problem (for example, stroke), cultural formulations (i.e. beliefs and value systems) about normality and health, together with social practices (such as diet and family roles) that sustain them, are nonetheless paramount in the prevention of disease and should not be sidelined. In *Sociology of Health and Illness*, Nettleton (2006), a medical sociologist, discusses the work of Rene Descartes (1641) on the philosophy of the Cartesian dualism. Descartes identified the mind with consciousness and self-awareness and distinguished this from the brain. He formulated mind body dualism, suggesting that they had no interaction with each other. Descartes held that the brain (along with the rest of the body) was purely mechanistic in its principle of operation. This was a view that the body can be seen as a machine and any dysfunction can be repaired by medical doctors who act as engineers to mend the broken parts (Amoroso, 2010). Nettleton argues that this approach has led to the ideology that every disease is caused by a specific identifiable agent, a view also challenged by Engel (1980, 2002) in his work on the biopsychosocial model. Engel argues for a biopsychosocial approach, stating that the biomedical model leaves little room for the psychological, social and behavioural

dimensions of illness; thereby hindering a holistic approach as to how the individual and their illness is treated. He argues that the mind and body interact and that they should be treated together rather than as separate entities. McKague and Verhoef (2003), looking at the determinants of health from health providers' and community dwellers' perspectives, found that both parties described 'health' based on the biopsychosocial model. Participants linked psychosocial influences (such as the ability to cope and function) to the physical complaint, illness or event. Pertinent to this thesis, Hartigan, O'Connell, McCarthy and O'Mahony (2011) used a qualitative approach to investigate first time stroke survivors' perceptions of their health status and their goals for recovery. All participants were optimistic about returning home and regaining control over their lives. They noted that while progress (health) is often evaluated using benchmarks of functioning, stroke survivors themselves framed their health based on activities that have a wider meaning. The ten participants (5 men and 5 women whose ages ranged from 70-83 years) compared their health to expectations that often accompany old age. Two key themes emerged: firstly of 'sudden fear and helplessness' and secondly 'regaining control in life', giving clear accounts of how they perceived their recovery and their health post-stroke. They described health as being more than just physical. The importance of well-being was elaborated by six of the ten participants, health being evaluated in terms of ability to engage in personal care and social activities.

In my opinion, the three models do not compete with each other, but in reality co-exist as three compatible approaches to exploring the differing dimensions of health and illness. The biomedical model explores the underlying diagnosis and treatment of disease or biological systems malfunctions, while the social or biopsychosocial models can work alongside in addressing the other pertinent issues (such as social environment and levels of deprivation) as wider determinants of health. This type of approach can be particularly useful when looking after people with stroke, as the biomedical model is crucial particularly in the early days of care, while the biopsychosocial model addresses those factors that contribute to stroke well-being and recovery post-stroke. This view is supported by Frank (1990), who describes illness as a medicalised body that contains

disease and the social body as one that contains the inscriptions of everyday living. It is this body that contributes to the construction of health identities, as it bears feelings of illness and sickness within its parameters.

The next section of the review focuses on the construction and embodiment of health identities.

2.4 Constructing a Health Identity

In order to understand how health identities are constructed, a focus on 'the body' is needed. Earlier, in section 2.3, the Cartesian idea of the body as a machine was introduced. Helman (2001) describes the body as having mechanical qualities similar to a plumbing system. This Cartesian view of the body as a machine stemmed, Helman believes, from the idea that the body can be divided into bounded organs (such as liver, heart and lungs) or discrete systems (such as the endocrine, immune and cardiovascular systems). This mechanistic view of the body was identified by James and Hockey (2007), when they reviewed the work of Watson (2000). Watson studied men's perspectives of health, where he noted how one participant's way of making sense of the body and how it operated was to align the body to a car - once you make improvement to it, it has an equal and opposite effect in that it upsets another part. Both authors note that the body has become an index for individualised identity (i.e. using different parts to attribute meaning to outcome or circumstances - for example, someone with a well-rounded abdomen is a sign of wealth or someone with a walking impairment is seen as disabled). This is based on cultural notions, such as the body is a shrine, and this has moral functions. Therefore, the body should be treated with respect (e.g. individuals should refrain from some foods or alcohol which can lead to behaviour that may bring the body into disrepute). Some groups may hold ideas that certain parts of the body may bring prosperity or demise. Alternatively, that oppositions of hot and cold are needed for managing and maintaining balance in the body, as cited by Helman (1978) where 'feed a cold, starve a fever' was the result of folklore treatment based upon early ideas of the body and how it operates.

Kvigne and Kirkevold investigated women living with bodily strangeness after a stroke, proposing that changes in the body express an index for identity because it is "socially stigmatising and degrading" (2003:1307). For example, to be unable to control the flow of urine (as in the case of Lucy in their study) or walking, gait and balance (as in the case of Marie, who falls over in public, or when Queenie relates to walking with a limp or the use of a walking cane). The authors conclude that these types of stroke affect the order of the body (i.e. the functions that occur 'normally', such as to walk, talk or manage toilet independently) to perform without drawing attention or stigma, and the order of interaction (i.e. what is considered by society to be normal and accepted).

The importance of acknowledging the body in physiotherapy was investigated by Nicholls and Gibson (2010), where they explained the expanded view of Nettleton, O'Malley, Watt and Duffey (2005) that the body extends beyond the biological and physiological boundaries, to encompass the idea that the body is socially constituted and that cultural, economic, political and social forces shape how individuals view and use their bodies. The authors note that individuals use their bodies to express a unique identity and recognise the challenge for professionals, such as nurses, doctors and physiotherapists, who may view the body in terms of the biomedical model. The challenge is offering a remedy to a view that values diversity and inclusiveness (e.g. race, gender, age, body size and disability) and to understand what constitutes 'normal' by the individual and society in which they live.

Jenkins (1996) explains that an individual's health status contributes to his identity (e.g. disabled). In his opinion, health identities are not fixed but are part of the ongoing interactions of everyday life - through socialisation and social interaction, the individual is forced to constantly define and redefine himself. Therefore, the body is of great significance for creating and developing a health identity. The body is not solely a medium through which individuals experience health and illness, but also where conditions gain social meaning. For example, an individual may have a stroke and as a result become disabled. The social meaning gained from this stroke experience could be a disabled

identity or loss of social status, where the person retreats to his inner self, reducing contact with wider societal structures and agencies. Alternatively, the individual may take the challenge of adhering to a rehabilitation programme that may then lead them to become a leader in a fitness programme or to set up a self-help or support group for those with similar illness experiences (as in the case of Queenie in this study).

Roberto and McCann (2011) investigated how older women with chronic health conditions managed their everyday health and identity. The participants reported that social roles (e.g. mother, grandmother or carer) often influenced an individual's description of their health. If there was great emphasis or expectation of the role and the individual can perform that role, then they had a positive identity, and the opposite was also true.

Corbin (2003), a nurse known for her work in grounded theory, chronic illness and quality of life, demonstrated that illness identity construction derives from a fear of (i) losing control over the body, (ii) inability to do previous tasks, (iii) inability to understand the body's language, or (iv) inability to trust the body to act as it should. These identifications link to the findings of Phase 2 of my study - for example, Lucy had problems with urinary incontinence; Queenie could no longer cook her rice and beans and do her housework; Jenny's inability to understand her body so she rests; and Doris not being able to trust her body as she learns to cook again.

Lupton (2003) focuses on illness, disease and the body. She states that the body, although obvious, is an ambiguous point of reference for external labels such as crippled or deficient, and can become the attention of the social world. The attention the body draws has led to its stigmatisation. Connell (1983) and Goffman (1968) describe a diseased or traumatised body as one that is often noticeable or stigmatised - thus, a person suffering from a stroke may have to come to terms with having a body that departs from the cultural norms in terms of gender and social roles that are no longer considered acceptable. For example, in the previously mentioned narrative of Queenie in Phase 2, she attests that

having had a stroke stopped her from being a woman, because she was unable to function as a wife in performing household tasks due to her physical disability.

James and Hockey are both sociology professors whose academic interests focus on life courses, feminism, health, illness and health identities. They posit that the ways in which individuals experience illness and health are dependent on the cultural contexts within which the disease is viewed (James & Hockey, 2007). One view is how the individual circumscribes to the illness. They used the example of Jane Thomlinson, a 40-year-old mother, radiographer, marathon runner, long distance cyclist and cancer sufferer. The multiple identity descriptions, they argue, are placed in the contexts of time, place and people that Jane is with (for example a fundraiser for cancer care, an athlete when competing, or someone with a life limiting illness when she is in care). The individual takes on the identity that others most attribute to them when they are in that group's company. This is in contrast to view that multiple identities exist due to deserving or undeserving health identities. Sontag (1988; 2001) notes that people with Acquired Immune Deficiency Syndrome (AIDS) are seen by some groups in America as being punished by God for sinful behaviour. She also cites that similar views were held for those affected by cancer and that they were seen as evil or committing acts against God. Such individuals, as a result of cultural ideations, can be ostracised by their communities, leading them to embody an identity of not being valued and accept their illness as punishment.

Embodiment refers to how people experience and interpret their bodies (Roberto & McCann, 2011). Based on their study of older women's management of their identity while living with chronic illness, they argue that this is dependent on the way the body acts or experiences the world, with particular reference to the influences of biological, social and psychological factors. Frank (1998), a sociologist also with an interest in the body and identity, believes that participation in the social world helps to shape our bodies. In the context of health and illness, participation can take the form of medical appointments and interaction with health systems, medical personnel and other organisations and structures

that influence an individual's health. Following these contacts, the individual takes meaning from the experiences and exchanges the information gained with other people (Corbin, 2003).

Becker (1993), in her study on stroke as an interruption in old age, reported that personal expression is vital in the way by which chronically ill individuals attempt to repair their loss and cope with their illness. In the case of stroke rehabilitation, it is not about regaining functional ability or capacity (i.e. the ability to carry out activities as per pre-stroke) that excites the individual, but the ability to perform as such (i.e. to be able to try and achieve a task, even if it is not done to perfection or fully). The ability to perform signifies the individual as an ordinary person without stigma.

The body plays an important role in assigning meaning from experiences of illness (i.e. it guides the individual on what actions they can undertake or when they need to find alternatives). Corbin (2003), reporting on chronic illness, explains that the body speaks through sensations which are anchored in meaning, derived through experience in both the cultural and social world to which they belong. It can be seen that in terms of health and illness, individuals may challenge their bodies to respond to messages of disease by either taking positive steps to combat it or resign to its message. Kirmayer (1992) writes that the body may be understood as the basis for action (where the individual can take preventative measures), agency (the medium by which actions can be accomplished) and as the foundation of experience (container for action and agency encounters). The body can be described as a central agent through which the individual constructs their health identity; another strong influence is the cultural community to which an individual belongs.

2.4.1 Culture and Identity

Kessing (1998), a professor in linguistics and anthropology with interest in kinship, religion and politics from his fieldwork on the Kwaio people of Malatia and the Solomon Islands, concludes that the dividing lines that exist between societies are sometimes vague.

Each society has its own territorial marking (such as land boundaries), social structure (including education, health and economic provisions) and political identity (the practice of the elected government), all contributing to its culture. His findings show that societies provide a way for members to organise themselves into various groups, hierarchies and roles. There are rules that underpin the organisation of societies, and the ways they are symbolised (for example, through behaviour, values and dress codes) and transmitted become part of a particular society's culture.

Helman (2001) defines 'culture' as a set of rules that are implicitly and explicitly used to govern individual group members. These rules are inherited and learnt through sharing and the passing of beliefs, customs and practices. People belong to cultural groups; a cultural group is one where individuals share common beliefs, attitudes, values and behaviours. Their attitudes, beliefs and behaviours all contribute to how individuals within the different groupings view their health and the actions that they take towards preserving health.

It can be considered that three levels exist within cultural groups (Hall, 2003). The first is a tertiary level culture which is concerned with the explicit (i.e. culture manifested and visible to the outsider). This includes social rituals, traditional dress, national food dishes and festive occasions - it is the public appearance of the culture presented to the world. Under the public face lie more implicit assumptions, such as rules and beliefs, which form the group's cultural grammar. The second level is the cultural grammar of the group, which gives rise to what Hall terms the secondary level culture. Here, underlying rules and assumptions of the group are known to group members, but rarely shared with outsiders. This secondary level is concerned with the unwritten rules, practices and expectations that are 'passed on' through primary socialisation. Hall's third level is considered to be the deepest level, where rules are known and obeyed by all within the particular cultural group. However, these rules are seldom ever stated and because of their embodiment, it becomes impossible for the average individual to identify the underlying provenience. In Hall's view, it is this level of culture that is ingrained into group members and becomes the most resistant to change in the context of health and illness. Spivak (2006) explains that when an

individual encounters the different cultures that exist in society, the subsequent interplay can lead to the adoption of other cultures and acceptance of certain practices retaining elements of their own cultural ideology. This process is called acculturation, where the individual becomes accultured to practices and beliefs other than their own.

Identity is a production of representation (Woodward, 2002). Representation takes the form of symbols, and these symbols are usually within a context of language and the culture of the person. Symbols used for representation are not elaborate or ritualistic practices, but are often attributed to the person's everyday practices. An example is the way individuals identify themselves, such as 'I am black Caribbean'. This statement is not simply descriptive, but lays claim to a particular culture. It carries positive or negative values, depending on who is speaking and to whom they are speaking. Such symbols give meaning to individuals and position them within or outside societal groups and situations. Cultural identity, linked to the work of Hall (2003), is a form of representation that signifies differences which are relational, in that individuals, based on their practices and beliefs, can be different to each other. It is a way of making meaning to ourselves and of the world to us, or as Woodward (2002) states, the positioning of ourselves within or outside of society.

Identities are based and formulated on both individual and collective variables. Examples of the former are age and gender, while collective variables are factors such as the group, culture, or sub-culture to which the individual belongs. There are different ways in which a group may identify itself to society. For example, by dress, language, social activities, practices and beliefs (Giddens & Held, 1982). Crucial to any collective identity is the way in which a particular group is identified and defined by others in society. Part of the collective identity on health and illness pertains to how a group interprets and addresses illness, through folk practices, beliefs and rules.

2.4.2 Folk Illness

Folk illnesses are culturally constructed diagnostic categories (e.g. causes and treatments of illness) commonly recognised by an ethnic group. An ethnic group is a group of people whose members identify with each other, through a common heritage such as ancestry, history, kinship, religion, language, shared territory, nationality or physical appearance (Woodward, 2002). Kleinman (1988) states from his two decades of anthropological and psychiatric research within multi-cultural societies such as Great Britain, that the prevalence of folk illness varies as it depends on key factors such as ethnicity, national origin, regions and levels of acculturation. He further explains that folk illness occurs when members of particular cultural or ethnic groups claim an illness or suffering for which their culture provides treatment. This approach includes a diagnosis, aetiology, preventative measures and regimens of healing. Based on Kleinman's explanations, folk belief can impact on clinical care and the embodiment of such beliefs can also impede preventative efforts and/or delay or complicate medical care.

Health and illness is further moulded by the nature of the cultural label that is applied to a person's condition. Cultural labelling assigns the language which the group uses to describe illness (Blumhagen, 1980). As a result of this labelling, illness as metaphors develop, where illness is seen to occur from a moralistic nature and human suffering from such illness is seen to have developed as a result of deviant behaviour. An example of the late 1980s and 1990s in Britain is that of AIDS, which was seen as a plague from God bestowed upon homosexuals; homosexuality being seen as an immoral act (Sontag, 1988; 2001). Metaphors for illness are not new concepts and have been used in earlier times - for example, the bubonic plague was attributed to moral and religious breakdown and social disorder between 1563 and 1666 (Totaro & Gilman, 2010). Cancer has also been aligned to demonic possession, a close link and association to folk illness attributing disease to a negative spirituality (Sontag, 2001).

Helman (2001) examined culture and health among West Indian migrants living in the UK. He viewed folk illness as a form of cultural expression that excludes clinical (or psychological) frames of illness and is instead reflected in cultural structures, such as hierarchy within a group and religious structures and standards pertinent to their community. An example of folk illness is based on the view of hypertension and stroke that is held by people from the islands of Trinidad and Tobago in the West Indies (Caribbean), a culture and heritage I share. The people of these twinned islands are multi-cultural, as they belong to different ethnic groups each with their own cultural practices. There are various ethnic groups: Indians, Africans, Chinese and whites, giving rise to people of mixed racial heritage who hold and share particular beliefs and practices.

In the case of hypertension, the illness itself is not referred to as hypertension, high blood pressure or raised blood pressure, but simply as 'pressure'. It is common for individuals to speak to each other and make referral that either 'they have pressure', 'the pressure is high' or 'the pressure is killing me'. For some, 'pressure' may be viewed as being related to physical or psychological stress, but for people of Caribbean origin it is an accepted way of expressing physical illness. In an earlier study of hypertension among 117 Americans of multi-cultural origin attending an outpatient hypertension clinic, Blumhagen (1980) using semi-structured questionnaires reported that 72% of the participants used the term 'hypertension' to characterise social stress and nervousness.

In Trinidad and its neighbouring islands (including Guyana and St Lucia), 'pressure' is communicated to group members as one of illness; however, practices do not always conform to medical guidelines. For example, symptoms and the lay diagnosis of 'pressure' is derived from pain at the back of the neck, seeing black spots and light headedness. The treatment involves (i) 'taking it easy' or 'chillin' (a West Indian term for relaxing), (ii) using local herbs and remedies in order to bring the 'pressure' down, (iii) the individual at some level re-assessing their lifestyle to try and reduce their pressure, or (iv) the passing on of practices within the wider cultural group (i.e. what the individual should do in the sense of medicines and social practices). Blumhagen (1980) notes that a group's belief system is

often revealed by the way the social structures are used for dealing with illness. He outlines the following captured from the example above. The illness is culturally constructed as a psychosocial experience. There is a general criteria to guide the healthcare seeking process and to evaluate treatment approaches prior to and independent of individual episodes of sickness. There is a system of management of particular illness episodes through communicative operations, such as labelling and explaining. Healing activities exist in various forms, which include types of therapeutic interventions from drugs to surgery to psychotherapy, supportive care and healing rituals. Finally, within the group's belief system, there is management of therapeutic outcomes including cure, treatment failure, recurrence, chronic illness, impairment and death.

Desmangles (1992), in his study of Voodoo as a religion in the Caribbean, notes that people look to religion for restoration of health, guidance and hope of survival. He reports that in terms of health, some followers believe that hypertension (pressure) is the result of a spell and conclude that stroke is one of the consequences of uncontrolled 'pressure'. He found that individuals of different ethnicity aligned themselves to a form of spirituality as a way of cultural bonding. Spirituality to the inhabitants of the islands is viewed from two perspectives: (i) positive, as the individuals engage with a religious organisation to try and bring healing and restore health to their bodies inclusive of the self, or (ii) as negative, when some individuals hold the belief that illness (for example, stroke) occurs as a result of jealousy from a friend, family member, work colleague or neighbour. This jealousy is in the form of black magic, referred to in the Trinidadian dialect as 'obeah'.

Fernandez-Olmos and Paravisini-Gebert (2003) looked at Creole religions in the Caribbean, investigating the role of black magic in health and healing. They report that those individuals who had had a stroke made statements such as 'dey do mih bad'(they do me bad) or 'dey put ah obeha on mih' (they put a spell on me). In folk illnesses, it is well documented that affected individuals seek the help of the 'obeah man' or 'obeah woman' - cultural healers, who may replace the role of medical professionals.

Both of the above studies report that the focus of restoration and healing rests on folk practices. These findings illustrate how folk illness is part of culture and its customs, practices and beliefs. They are not only shared but learnt, and are part of the socialisation process. Children growing up within the families of these groups are first socialised to customs, practices and beliefs. Secondary socialisation takes place when these learnt rules and guidelines are reinforced by people of the same cultural group or challenged by those outside. This was described as Hall's third level of culture. Folk illness, in terms of Western societies based on the work of Kleinman (1988) and Helman (2001), affects not only how the individual utilises the available treatments but also on how well the individual takes on the cultural role of being the patient and engages with medically prescribed regimens.

Illness metaphors may become a barrier to any assessment of the individual's health and the ways, means and strategies for dealing with the presenting disease. Most notable in folk illness is that different practices and behaviours may stem from the same underlying cause (Helman, 1981, 2001). All concerned with the care of those holding such views should acknowledge that there is a cultural view of the body and that this view can affect the way in which the individual accepts and receives treatment and care.

2.5 Cultural Understanding of the Body

Restorative health depends on how the body is viewed culturally. Just as metaphors for illness exist, metaphors for the body also exist. Examination of the WHO's (1946) definition of health can be seen as a metaphor of the human body that reflects social, emotional and spiritual harmony to produce a 'whole' person. Any imbalance (illness) suggests lack of harmony with the body and an incomplete person. Historically, the body has been viewed as a metaphor for balance. The Hippocratic theory of four humors (developed by Galen, AD129-200), views the body as being made from four liquids or humors: blood, phlegm, yellow bile and black bile; and that too much or too little of these humors creates an imbalance (Porter, 1985). Helman (1978) described body metaphors as a

system of balance when his participants described their beliefs of hot and cold as balances within bodily systems.

Moss (2005) states that for Christians, the body is viewed as a holy temple (see Corinthians 1, Holy Bible). To some groups, the body holds a specific religious meaning and illness may signify punishment by God for deviant behaviour. For some Christians, illness is a form of punishment from God for not keeping the body as a shrine (Hunt, 2002). Hunt contrasts this with the medical metaphor that considers the body as a machine which, when broken, can be fixed or the individual may have to accept a broken body. The metaphorical ways in which bodies are viewed can impact on how individuals seek treatment (as the narratives of Doris, Margo and Queenie in Phase 2 of the present study show) and how they identify with certain practices that they believe in will help the restoration of the body and ultimately health.

2.5.1 Contributions to Women's Health and Illness

A growing body of literature demonstrates that women's health problems are not always directly related to biological characteristics, but reflect the discrimination and disadvantage they experience performing gender-related activities such as child rearing, caring for others and contributing to 'running a home'. Doyal (1995) believes that these roles can have a physical and mental impact which may negatively affect women's health. The study of women's health has mainly been the study of women's illnesses, emphasising specific risk factors and health behaviours such as heart disease, cancer, menstrual and reproductive disorders, and behaviours such as smoking, drug use, along with medical screening, mental health and hysteria (Lee, 1998). While the researcher does not dispute the importance and validity of these topics, it should be noted that women's position in society and the value placed on female health, together with identity and representation, is based on complex social, economic and cultural factors. It is their identity and position, based on these factors, that makes women susceptible to illness such as heart disease, cancer and mental disorders.

Kawachi, Kennedy, Gupta and Prothrow-Stith (1999) investigated women's status and the health of women in 50 American states. The status of women was assessed based on political participation, economic autonomy, employment, earnings and reproductive rights. The main outcome measures were taken from total male and female mortality rates. They found that higher political participation correlated with lower female mortality rates (r=0.51). A smaller wage gap between women and men was associated with lower female mortality rates (-0.30). Their study suggests that women's status may reflect general underlying structural processes associated with material deprivation and income inequality.

In 1999, *Social Science and Medicine* dedicated the whole of one issue (volume 48 issue 1) to gender and health. From the series of articles published, there appears to be an axis that divides males and females into two distinct categories (e.g. stronger/weaker, breadwinner/homemaker, resistant towards illnesses/susceptible towards illness) with allowances and restrictions. Depending on which side of the axis individuals fall, there are fundamental differences in (for example) patterns of morbidity and mortality, and differences in roles and responsibilities. Hunt and Annandale (1999) and Annandale and Hunt (2000), researching social patterns of health and gender inequality, argue that this type of axis presents gender hazards such as 'men die more quickly' or 'women get sicker'. The phrases are laden with meaning pertaining to the gender inequalities of health that exist and have been argued by many researchers and writers (such as Arber & Cooper, 1999; Hunt & Annandale, 1999; MacIntyre, Hunt & Sweeting, 1996). Research on longevity and mortality conducted by Baum and Grunberg (1991) and McDonough and Walters (2001) found that although women live longer than men, they report higher levels of mental illness, including depression, alongside a wide range of chronic illnesses across their lifespan.

Emslie, Hunt and Macintyre (1999), in a study of 1,112 men and 1,064 women all working for the same bank, found that there were statistically significant gender differences in health which was attributed to the type of activities in which men and women were

engaged. They conclude that the gendered nature of much of adult life, which includes paid work, shapes the experiences and health of men and women. They identify key periods, ranging from puberty to adulthood (e.g. pregnancy, marriage, work), to mid- and later life (e.g. menopause, retirement and chronic illness) within the life course, when women's health comes into focus. Ross and Bird (1994), in response to a telephone interview study in 1990 which reported the health of men to be better than women, argue that women are likely to occupy different structural locations; they may be less likely to be in paid employment, work in different occupations or have lower incomes and perform more domestic labour than their male counterparts.

Data from the Canadian National Probability Sample was used to investigate the vulnerability of health and social determinants among women and men (McDonough & Walters, 2001). They found that women reported higher social levels of stress in respect to child (parenting), environmental and family health stressors. High-income, working full-time whilst caring for a family and having a good social support network were high predictors of good health for women. They conclude that women, as a result of the position they occupy in society generally, react differently to stress than men. They argue that stressors form part of the contribution to women's long-standing health conditions; as women's illnesses become more gender specific, reflecting on the embodiment of life events.

Exploring data derived from the British General Household Survey 1992-1994 from over 14,000 men and women aged 60 and above, Arber and Cooper (1999) examined gender differences in health and later life. They found that there were few differences in the reports of self-assessed health and limiting long-standing illness, but that older women are more likely to experience functional impairment in mobility and personal self-care than men of the same age.

Shilling (1993, 2005) writes that, historically, women's health has been defined through their 'unstable' bodies, which were viewed by medical practitioners as dominating and

threatening to their minds. This view was captured in *The Yellow Wall Paper* (Perkins-Gilman, 1892), where Charlotte was ordered by her doctor to have little mental stimulation in terms of work and to rest, only seeing her newborn baby for set periods of the day. Perkins-Gilman (1892), writing on post-natal depression, illustrates how medicine dominated the sexes and exerted power where gender was concerned. This also shows how an important event (the transition to motherhood) is not recognised as meaningful but as an illness if it is not done in a manner as stipulated by society (albeit a male dominated society at the time of Perkins-Gilman's writings). Kalima (2001) focuses on how midwifery can help to overcome some of the reproductive health problems encountered by women (for example, moving away from a medicalised birth to achieve a safe and satisfying experience). She firmly believes that, through education, women's health can be improved (e.g. the menopause should not be viewed as a deficiency state that requires replacement of hormones and management, but rather as a natural process common to all women as a transition into mid-life).

Although much debate on women's health has focused on the inequity between male and female, Doyal (2000) discusses the dilemmas in addressing gender equity in healthcare. She argues that, in pursuit of gender equality policies, the focus should not be on health outcomes themselves but on the inputs that provide the basis for human flourishing. Doyal argues that biological influences (such as reproductive healthcare) are only part of the story and that we need to look further at the society constructed inequalities or gendered differences between males and females. Social construction has given rise to what is 'maleness' and 'femaleness', and that the former is valued higher than the latter, thus giving rise to health inequalities. These definitions shape the health of the individual (i.e. male = strong and resistant to illness and female = weak and susceptible to illness). Doyal reflects that gender identities are negotiated and the way forward is to have policies that will enable individuals to shape their own identities and actions in a healthier way.

This section of the review has shown how the health of men and women differ, based upon societal structures, and some of the differences in health between males and females. As a

result of women's position in society (e.g. homemaker, career worker, family carer) they are more vulnerable than men. Based on their ethnicity and cultural practices, Afro-Caribbean women are affected in similar ways. When illness strikes, they may become more disadvantaged compared to their Caucasian counterparts. One such illness is stroke and the sequelae it presents.

2.6 Health After Stroke

2.6.1 Incidence and Prevalence of Stroke

Stroke or a cerebral vascular accident (CVA) is a rapid development of the loss of brain function as a result of interruption of the blood supply to the brain. It occurs when a blood vessel to the brain becomes blocked by a clot (an ischaemic stroke) or there is a break or burst in the vessel and a bleed occurs (a haemorrhagic stroke) (Rosamond *et al.*, 2008). Loss of cerebral function results in unilateral loss of movement on one side of the body. Additional focal neurological deficits include an inability to formulate words or loss of speech (Chopp, Chan, Hsu, Cheung & Jacobs, 1996) and associated loss of vision from one side of the visual field (Smeltzer & Bare, 2004). The level of damage or impairment to the brain is reflected in the level of disability experienced by the stroke survivor. Some individuals may experience a mini-stroke, commonly referred to as a transient ischaemic attack (TIA). This is a limited episode with no persisting harm, compared to a stroke which may cause death or permanent disability (Marieb, 2001).

Wolfe *et al*. (2006), from the South London Stroke Register, write that stroke represents a substantial and increasing global health problem and that it is the third leading cause of death and the single greatest cause of disability in most Western countries. The WHO Stroke Statistics (Rosamond *et al.*, 2008) show that, worldwide, some 15 million people suffer stroke each year. Of this population, they estimate that 5 million die and another 5 million are permanently disabled. More recently, the British Heart Foundation (2009)

reported that, in the UK, stroke accounts for approximately 53,000 deaths every year (approximately 9% of all deaths in men and 13% in women).

In England, there is a higher prevalence of stroke among ethnic minority groups (Department of Health, 2000). The figures show that Afro-Caribbean and South Asian men had a 40-70% (age adjusted) higher prevalence of conditions that make them more vulnerable to stroke than any other group in the general population. Data obtained from the South London Stroke Register (1995-6), reported by Wolfe *et al*. (2005), and further work by Markus *et al*. (2007) show that there is a 2.2% higher prevalence of stroke among the black community compared to the white population.

One possible outcome of stroke is death. *Stroke Statistics 2009*, a report jointly produced by the British Heart Foundation and The Stroke Association (2009), classifies premature death as death occurring under 70 years of age. This report indicates that the mortality rate for stroke in England and Wales is higher among migrant populations when compared to indigenous groups. The difference is most marked among Bangladeshi men born in Bangladesh, then living in England or Wales, for whom the stroke mortality rate is more than three times higher than for Bangladeshi men born in England or Wales. Similarly, men born in West Africa have a stroke mortality rate over two and a half times those born in England and Wales. Stroke mortality in the Afro-Caribbean group for men and women born in Jamaica and living in England is nearly double those born in England or Wales. Balarajan (2000) draws attention to the excess of stroke deaths from the older (65-74 years) Afro-Caribbean community, which he states tend to be 50% higher that the norm for England and Wales. He urges further exploration into contributing factors such as race, age, socio-economic status and ability pre- and post-stroke; some of these are captured in the various stroke assessments available for use.

2.6.2 Use of Stroke Assessments - National Institute for Health Stroke Scale, Modified Rankin Scale & Barthel Index

Kasner (2006), introducing the clinical interpretation and use of stroke scales, observed that no single outcome measure describes or predicts all the dimensions of recovery and disability after acute stroke. For example, the Glasgow Comma Scale is applicable in the first 24-48 hours after stroke, as it measures the level of consciousness and motor deficits. Similarly, a CT scan, which is not a scale as such but which serves to identify the nature and location of the lesion, can aid in treatment options at stroke onset. Kasner identifies five particular scales with proven reliability and validity in stroke trials which are currently used to monitor the effect of intervention. These are the National Institute of Health Stroke Scale (NIHSS), the modified Rankin Scale (mRS), the Barthel Index (BI), the Glasgow Outcome Scale (GOS) and the Stroke Impact Scale (SIS). He differentiates between them, suggesting that the NIHSS is useful for early prognostication and serial assessment, whereas the BI is useful for planning rehabilitation strategies. As possibly being more relevant to clinicians and patients, he observes that the mRS and GOS provide summary measures of outcome and the SIS is particular in that it was designed to measure the patient's perspective on the effect of stroke. The GOS is a 5-point scoring system and provides an assessment of the general functioning of a person who suffers a head injury or stroke. It should not be confused with the Glasgow Coma Scale, which is used acutely to grade the severity of a patient's trauma and mental function after head injury (Collin, Wade, Davies & Horne, 1988).

The NIHSS is a 15-item impairment scale now widely used in stroke centres to assess the severity of acute ischaemic stroke within the first hours after stroke (see Fischer, Arnold, Nedeltchev, Brekenfeld, Ballinari, Remonda, Schroth & Mattle, 2005; Kasner, 2006). It was originally designed as an aid to non-specialist neurologists in their initial assessment of stroke severity (Brott *et al*., 1989). Patients with a low NIHSS score tend to have more favourable longer-term outcomes compared to those with higher scores on questions such as 'level of consciousness', 'gaze', 'motor leg' and 'neglect' (Fischer *et al.*, 2005).

Kasner (2006) writes that many of the items incorporated in the NIHSS require the patient to be alert, and so the scale may not differentiate impairment in the most severely affected strokes where patients may have fluctuant levels of consciousness. As with any impairment scale, by restricting its focus to physical functioning, the NIHSS is less appropriate for assessment in the longer term. At 90 days post-stroke, many patients may have recovered motor function in their limbs, but few will have returned to work or previous pastimes. The NIHSS is very useful in its predictive long-term functional outcome of stroke. The predictive value of the scale can also aid in planning a patient's rehabilitation or long-term care needs. In terms of clinical practice, the NIHSS provides a sensitive tool, with advantages for serial monitoring of patients after stroke who are at risk of neurological worsening.

In a review of functional outcome measures in contemporary stroke trials, Quinn, Dawson, Walters & Lees (2009) found that the Barthel Index was the second (40.56%) most used measure. The Barthel Index is a well established ordinal scale and includes ten most common areas within activities of living scales. It comprises a number of items associates with functional ability. The assessment scores the ten functions with varying weights (0-1; 0-2; 0-3) regarding: (1) bowel function, (2) bladder function, (3) grooming, (4) toilet use, (5) feeding, (6) ability to transfer, (7) mobility, (8) dressing, (9) negotiating stairs, and (10) bathing (Wade, 1995) (see Appendix 1). The credit for each functional category ranges from independent to dependent; a patient scoring 0 is able to manage the assessed functions without attendant help. The assessment is overall scored out of 20. This scoring directly compares to a score of 100 which is more commonly reported in North American studies (Duncan, Jorgensen & Wade, 2000). A difference of 4 out of 20 (or 20 out of 100) points is likely to represent a real difference (Collin *et al.*, 1988). Wade (1995) strongly recommends the BI as an assessment tool for ADLs. His arguments in support of this scale can be summarised as follows:

- The validity of the BI has been well established.

- The clinical impression of scores correlates with motor loss after stroke and with scores on other ADL indices.
- Excellent reliability (on test retest in various settings of observers and observed) has been established.
- It is simple to use and takes between 2-3 minutes to complete.
- The scale can be used to provide a baseline level of functioning and a measure for ADL over time.

Wade (1995) acknowledges that the BI is limited in two aspects. The index has floor and ceiling effects, and there is a lack of sensitivity to small changes in performance. Consequentially, the stroke survivor may make improvements in recovery which are not recognised and can lose out on additional treatment options, such as physiotherapy or occupational therapy. These observations were recognised by Kasner (2006) in his review of scales, but overall he acknowledges the value of the tool in establishing the effectiveness of rehabilitation therapies. The BI, despite well documented limitations (especially associated with ceiling effects), continues to be used by many stroke clinics, including the clinic at Newham University Hospital Trust, which is the setting for this study.

Lyden and Hantson (1998) describe the mRS as a specific measure of functional independence, incorporating the WHO components of body function, activity and participation This categorical scale has seven different grades ranges, from 0 (no symptoms) to 5 (severe disability) and 6 (dead) often added if the patient dies from stroke. A 1-point shift in scale 0-5 is often identified as being clinically significant (Kasner, 2006). The mRS includes constructs such as the ability to return to work, so it represents a measure of societal participation. The mRS offers an easy and rapid assessment in clinical practice of the effect of a patient's stroke on their activities and participation in a social context.

The functional independence measure (FIM) is often used as an indicator of what resources stroke survivors will need post-discharge. The FIM assessment determines levels of physical disability based on assessment of self-care, transfers, locomotion, sphincter

control, communication and cognition. The Short Form 36 (SF36), a subjective measure of quality of life based on physical, mental and social composites, is used in community settings as survivors reintegrate into society. Quality of life scales such as the SF36 build on measures of societal participation and attempt to assess physical, mental, societal and spiritual aspects of a patient's condition. These are useful in assessing the stroke patient and provide a comprehensive overview of the individual's ability in terms of neurological deficits, functional outcome or health related quality of life (well-being) - each being valuable at specific stages of stroke recovery.

In an earlier review of stroke assessment, Lyden and Hantson (1998) highlight that stroke survivors are not assessed by one health professional but by a variety, each performing an assessment relevant to their area of practice relating to the stage of recovery. For example, cognition may well be assessed by a psychologist or an occupational therapist trained in screening patients in cognitive and perceptual deficits. Similarly, mobility may be assessed by a physiotherapist or a nurse with specialist training. Other areas that are assessed by different health professionals include mood, depression, functional ability, pain and quality of life.

2.7 Functional, Psychological and Social Recovery After Stroke

2.7.1 Functional and Psychological Recovery

Functional activity and level of performance may be reduced after a stroke, due to the location and type of stroke. Other factors that contribute to low functional outcome are the experience of depression and social integration after a stroke. Kwok *et al*. (2006), in a one year follow-up of 303 stroke survivors found that overall only 46% of participants achieved independence in all basic ADLs and had a maximum BI score of 20. They measured participants' functional status at two points in time: 3 and 12 months. They found that recovery improved with time; survivors had increased (0-1) Barthel scores and using Mini Mental State Examination were less cognitively impaired on reassessment at 12

months. In terms of survivors' psychological well-being, they found that depression was strongly correlated ($p < 0{\cdot}02$) with ability to maintain mobility, independence, occupation, social activities and orientation. In a systematic review of the literature on depression post-stroke, Hackett *et al*. (2005) indicate that a third of stroke victims report depression. Thomas and Lincoln (2005) examined factors relating to depression post-stroke and report that the first six months is a crucial period, when the individual struggles with accepting the effects of stroke as well as disappointment at loss of function. A limited locus of control is contributory, which could lead to feelings of helplessness and depression. This conclusion could contribute to the findings of the Kwok *et al*. (2006) study.

Looking at possible gender differences in 1,136 older stroke survivors, Petrea, Beiser, Seshadri, Kelly-Hayes, Kase and Wolf (2009) note that when compared to men, women were significantly more ($p<0{\cdot}01$) disabled in the acute phase of stroke (first 3 months) in the following activities: dressing, grooming and transfer from bed to chair. Reviewing longer-term quality of life of stroke survivors, Anderson *et al*. (2004) from an earlier study of 680 patients (the Auckland 1981 study) found that 52 of these had survived 21 years after their stroke. Of these, only 12% were institutionalised and 19% required some help with their ADLs. They concluded that one of the long-term effects of stroke is that as stroke survivors get older, the effects of a stroke lead to further reduction in function. Using the Modified Barthel Index (MBI) and the WHO's Health Related Quality of Life (HRQOL) questionnaire, Pan, Song, Lee and Kwok (2008) interviewed 247 stroke survivors at 3, 6 and 12 months. They found that the HRQOL was independently related to ADL and depression. In a systematic review of epidemiology and treatment of post-stroke depression, Paolucci (2008) concluded that depression is identified as a common and serious complication, affecting quality of life and functional recovery.

In a mixed methods study of 89 participants, Townend, Tinson, Kwan and Sharpe (2010) found that one month post-stroke depressive disorders were diagnosed in one third of the participants (28 of the 89 - 33%). Gender was significantly associated with depression (0·021), as well as Barthel ADL (0·01) and Nottingham EDAL (Extended Activities of

Daily Living) at 0·001. A comparison at nine months showed that less than one third were now depressed (24 of 81 - 30%) and the Barthel ADL and Nottingham EDAL were not statistically significant. They concluded from the qualitative findings that this was due to non-acceptance of disability and being labelled as disabled. Similarly, in a one year study of 73 post-stroke patients, Srivastava, Taly, Gupta and Murali (2010) reported that depression was related to functional disability, but was not statistically significant ($p<0·05$). However, when evaluated as per different grades of independence in ADL (BI score), post-stroke depression showed higher prevalence in moderately (BI score <80) to severely (BI score <60) dependent patients compared to those who had mild dependency (BI score >80).

The above studies and those reviewed within them stress the importance played by depression post-stroke; however, close attention needs to be paid to the way in which the studies were carried out. To determine the nature of depression, some studies focused on type, location and lesion, while others focused on functional assessments. In terms of assessment, many different participant criteria and scales of depression were used and each yielded a different result, which can muddy the waters. We need to be mindful that there are a growing number of reports that identify depression after stroke as being prevalent. Worthy of note is that these studies show the close relationship between functional outcome and the link to depression.

2.7.2 Social Recovery

Apart from depression, social integration can also have an effect on functional outcome. Wood *et al*. (2010) reported on 'getting back to real living', as their participants described the role of physical functioning as a major factor to community reintegration. They charted the process as gaining physical function (related to the ADLs), establishing independence (described as transition from feeling overwhelmed to gaining control), adjusting expectations (adjusting expectation of self relative to own capacity) and getting back to real living (the strive towards community reintegration).

Quantitative studies (such as Clarke, 2009; Clarke, Lawrence & Black, 2000; Glass, Matchar, Belyea & Feussner, 1993; Simon, Kumar & Kendrick, 2008) have helped in the better understanding of some of the social problems encountered after a stroke. A consistent finding from all the studies reviewed is that both social support and educational resources act as buffers in the recovery of functional status and overall well-being. Another crucial aspect is that family, carers and social relationships are key in the recovery process. Simon *et al*. (2008) investigated 44 couples using the Caregiving Strain Index and found caregiver stress to be strongly correlated ($p > 0{\cdot}005$) with functional outcomes and depression. Green and King (2010), in their recent study of 38 patients and their spouses or caregivers, found that biopsychosocial characteristics such as age, marital status, employment, mental status and social support all contributed to the individual's psychological and social health post-stroke. For example, they found that survivors were more motivated in the recovery process if they were in employment and if returning to work could be conceived as a goal. Later, in Chapter 6 of this thesis, the narratives of Margo and Marie reflect this finding.

Collectively, the studies reviewed above demonstrate the crucial interplay between functional abilities, social support and psychological well-being, focussing on mood and depression, and the recovery process. They demonstrate that this interplay is an important determinant of health related quality of life. What they are unable to demonstrate is how it feels, nor do they capture the experience and how this experience and feeling is constructed by the individual as part of a dynamic, ongoing, 'messy' journey of transition from stroke to living life after stroke. Physical, social and psychological outcomes following illness among patients via an exercise programme have been reviewed by Stern and Cleary (1981). They conclude that functional status and well-being are not always closely correlated, as a participant's ability to perform a task is valued as much as performing the task correctly. Likewise Radomski (1995), an occupational therapist, stresses that functional recovery is not necessarily an indicator of well-being, and the challenge is to identify the other contributing factors and to understand them from a survivor's

perspective. Similarly, Kvigne and Kirkevold (2003), in their study of living with stroke 'bodily strangeness', conclude that loss of social roles, lower self-confidence or troubled personal identity (such as the fear of being viewed as less when compared to pre-stroke life) have all been identified as being more important for a subjective sense of well-being rather than functional independence alone.

2.8 Experiences of Living with Stroke

The qualitative studies reviewed in this section are concerned with emphasising stroke survivors' experiences and the strategies used in their personal stories of recovery. While quantitative studies provide evidence in terms of numbers and appropriate statistical analysis, Gubrium, Rittman, Williams, Young and Boylstein (2003) explain that qualitative studies capture the 'how' of the individual's constructions of their own recovery in order of importance, relevance and meaningfulness alongside individualised views of health, illness and well-being. Writing on qualitative methodologies in psychology, Smith and Osborn (2008) emphasise that the focus is on participant-defined meanings, which ignore the objective but focus on the subjective. Qualitative research takes a bottom-up approach to data collection, analysis and interpretation. It sets out to unravel key dimensions of the psychosocial dynamic process, such as a stroke survivor's trajectory. Radomski (1995) presented participants' feelings and ways of engagement in physical activities, rather than evaluating their exclusion by reasons of their physical disabilities. For example, a stroke survivor might not be able to play a game of golf, yet being able to turn on the television and watch a game delivers an important sense of continued engagement with the game. Her study shows that there is the possibility of mixing both quantitative and qualitative approaches to provide a better understanding of life after stroke.

In this section, a series of qualitative studies will be reviewed, looking at the methodologies used, the insight they provide in terms of evaluating life after stroke and the issues that are identified by stroke survivors in the immediate and longer term.

2.8.1 Physical Functioning and Appearance

Becker (1993), in a five year study of 216 stroke survivors recruited from an inner city community hospital, adopted a qualitative approach. The study shows that descriptions of experiencing a stroke are expressed in terms of a deep personal sense of loss and a range of individualised definitions over what was, is and is becoming meaningful to them, including statements such as "I can't wear high heels any more" or "my handwriting is not as good as it was" and "sometimes I can't get the right words out". Becker reflects the notion that individuals make sense of their stroke according to items of personal importance in their life, which provide a template for their recovery. Dowswell, Dowswell, Lawler, Green and Young (2002) qualitatively examined physical functioning after stroke and mapped out how individuals readjusted their views of the world and their physical place within it to achieve a sense of autonomy. These views are similar to those in Becker's (1993) study, giving light to an emergence of how physical functioning affects the rest of the survivor's life. Stroke survivors tend to adjust to their disabilities and impairments in order to maintain some sense of well-being post-stroke (Clarke, 2003). The uncertainty of this recovery process and survivors' experiences has been examined (Clarke & Black, 2005; Clarke *et al.*, 2000; Green & King, 2010; Kaufman, 1988). These studies provide a narrated interpretative voice to the frustration elicited by an inability to perform functions such as grooming, dressing oneself or making a cup of tea. They also use these feelings to map the path of frustration onto the despair of not ever being able to regain such functional abilities.

2.8.2 Adjustment and Social Engagement

Kirkevold (2002) followed nine stroke survivors during the first year of their stroke, conducting interviews at three, six and twelve months. Her analysis describes a process of adjustment, where the individual moves through different intervals of stroke recovery. Common across these intervals, she argues, is recognition by the survivors that recovery pivots around adjustment across the physical, psychological and social dimensions of

living. Her work shows how individuals recreate themselves so that their views of the world, values and life projects are based on what is important to them. Participants identified social identity, roles and agency as key to the recreation of a stroke survivor's life.

Doolittle (1992) focuses on living with an impaired body after stroke. Her participants describe benefits from choosing to use and direct their minds to exert control of their body. She concludes that positive thinking can help increase resilience capacity and strengthen personal ways of coping with stroke (this is discussed later in Chapter 6, in Jenny's narrative). Similarly, Clarke and Black (2005) show how, by focusing on what was now important to have a good quality of life, stroke survivors are able to adapt to illness and disability in order to reconstruct meaning to their lives. Both studies show how stroke survivors recreate themselves while adjusting to life after stroke, although one important area they did not explore was how individuals who cannot recreate a new identity adjust to life after stroke.

One early study to follow a qualitative paradigm was that of Kaufman (1988), which utilised a case study approach involving participant observation and open-ended interviews. She found that the post-stroke experience largely involves re-establishing a sense of identity, noting that stroke survivors search for ways to build links between their post-stroke life and their former selves. They often find ways to accommodate their disabilities rather than become overwhelmed by them, thus giving new meaning to their life. This new meaning of life is linked to identity and the value placed on these roles, as Kvigne and Kirkevold (2003) reveal. They conducted in-depth interviews with 25 women suffering first-time stroke, exploring how female stroke survivors experience their life following stroke and how they manage their altered situation. They report that these women struggled to continue life in familiar ways to preserve the self, relating to their valued roles being closely tied to their identity as mother, wife, grandmother or housewife.

The role and transactional nature of social support and care given in families with stroke survivors needs more attention, as it is pivotal to the recovery process in many cases (O'Connell & Baker, 2004). Lynch, Butt, Heineman, Victorson, Nowinski, Perez and Cella (2008) examined quality of life after stroke, using focus group interviews with nine long-term stroke survivors and six care givers. Their participants identified themes emphasising social relationships, such as social support, coping mechanisms, communication, physical functioning and independence. Carers reported the effects of role changes in participants. The authors conclude that measures of stroke related to quality of life should include assessment of social factors and support.

More recently, Strudwick and Morris (2010) studied the mechanisms of relations and the benefits gained through familial support, exploring the experiences of Afro-Caribbean stroke survivors, together with information from their informal carers. They report that the stroke patients' contributions to meeting daily care is crucial and rests on the back of a cultural expectation that family members will care and nurse each other in the event of illness (in Chapter 6 of this thesis, accounts by Doris, Lucy and Jenny of their strokes convey similar expectations and form part of the discussion in Chapter 7). Social support from family members and outside agencies is important for stroke survivors, as stroke can become a chronic illness and is likely to add friction and stress to the relationship between the informal care giver and the stroke survivor unless there is additional outside support given to buffer the stresses and strains.

Boosman, Schepers, Post & Visser-Meily (2011) support Lynch *et al.* (2008), investigating life satisfaction three years post-stroke. Of the 165 participants, 67.9% reported that they were satisfied with life as a whole. Socially inactive patients were significantly less satisfied (50%) than socially moderate (74.4%) and socially highly active (81.5%) patients. Social activity was measured using Social Support List Interaction (SSL12-I), where the score ranges from 12 to 148 (higher scores indicate that more support is needed). Their study shows that social ADL functioning (e.g. contact with friends, sexual relationships,

partner relationships and leisure) and, to a lesser degree, social support and cognitive functioning, are related to life satisfaction.

2.9 Towards a Mixed Methods Approach

Creswell and Garrett (2008) and Morse (2008) write on the development and coming together of quantitative and qualitative methods and researchers to address complex problems. They define mixed methods (MM) as an approach to inquiry in which the researcher links in some way (e.g. merges, integrates or connects) both qualitative and quantitative data to provide a unified understanding of a research problem. Dures, Rumsey, Morris and Gleeson (2011) have examined the legitimacy and associated problems of MM in health psychology, identifying key characteristics of an MM study: firstly, utilising both qualitative and quantitative methods in the same project; secondly, having a research design that clearly specifies the sequencing priority given to qualitative and quantitative elements of data collection; and thirdly, that the researcher needs to provide an explicit account of the manner in which the qualitative and quantitative aspects of the research relate to each other.

The typologies of MM research design (mixing partially fixed vs. fully mixed; time orientation-concurrent vs. sequential; equal status vs. dominant status) is discussed by Leech and Onwuegbuzie (2007). They identify MM characteristics as collecting, analysing and interpreting both qualitative and quantitative data in a single study (or a series of studies) that involve the same underlying phenomenon. They describe the 'mixed' sequential dominant design. In the sequential dominant design, the quantitative and qualitative phases occur sequentially at one or more stages, or across the stages. In this design, the qualitative or quantitative phase is given more weight. Examining the challenges and opportunities for using MM in rehabilitation research, Kroll and Morris (2009) outline different types of MM designs (similar to Leech & Onwuegbuzie, 2007) and concurrent or sequential priority (that is, which study takes precedence or is of greater

importance), whereby this design refers to the relative weight assigned to the qualitative or quantitative research components.

Integration can occur at different stages of the research process (Kroll & Morris, 2009), such as at the point when data is collected (e.g. combined survey and qualitative in-depth interviewing) or later during data analysis (e.g. when cross tabulation of interview codes is linked back to survey variables such as demographics) and interpretation (convergence, divergence or complementarity of findings). For example, in this doctoral study the data was collected sequentially, whereby quantitative data was collected first [Phase 1] to present a clinical description of how life after stroke can be subjectively reported via a stroke outpatient clinic using the Barthel Index. This data was analysed using descriptive statistics and common patterns that emerged were followed up by in-depth interviews providing qualitative data [Phase 2] and the data was then analysed using the 'following a thread' technique.

'Following a thread' takes place at the analysis stage of the MM research process (O'Cathain *et al*., 2010). It begins with an analysis of each component to identify key themes and questions requiring further exploration. The researcher selects a question or theme from one component and follows it across the other components – they call this the thread (ibid.). In this present study, an example of a thread are the ADLs, which were analysed in Phase 1 and followed up in Phase 2 to try and develop a better understanding of life after stroke. The intention was to maximise the combined results by seeking the ways in which the two sets of findings expand, collaborate or contradict their respective empirical findings.

Both methods must be clearly articulated in the design and each should illuminate how they answer the research question, ensuring that equal weighting is given to each component (Morse, 2009). This is not in terms of dominant/less dominant, but refers to the rigour with which each component is constructed, giving credit to each method. In their guidelines for medical research, Schifferdecker and Reed (2009) advise that researchers

must decide on the prominence of each data type and then adhere to the guidelines of the methods chosen. They should decide on when and how data are to be collected, analysed and integrated or compared. Researchers should explore tools or methods to integrate qualitative and quantitative data analysis and review MM research articles to generate ideas reporting and displaying data.

In terms of advantages, an MM design can be seen to enrich a study, as it uses more than one form of data collection and analysis (Brewer & Hunter, 1989; Hanson *et al.*, 2005; Tashakkori & Teddlie, 1998). Clarke (2009) states that the approach is particularly useful when the methods used are similar (such as a scaled quantitative questionnaire combined with semi-structured qualitative interviews) and when the methods examine different facets of the same phenomenon. It may also allow researchers to test theoretical models based on participants' feedback to adapt and fine tune them. Working with both forms of data allows the researcher to generalise results from a sample to a population, thus gaining a deeper understanding of the phenomenon under investigation (Hanson *et al*., 2005).

The use of an MM design poses some difficulties and disadvantages for researchers. In an independent systematic review of published MM design studies, it was noted that a common shortcoming for many of the works was the failure of the researchers to integrate their findings comprehensively, thus limiting transferability of the MM approach (Bryman, 2006). Bryman (2007), Clarke (2009), Sale, Lohfeld and Brazil (2002) and Stewart *et al*. (2008) all comment that the integration of MM findings remains a challenge for MM researchers. Perhaps we need to accept that MM findings do not always need to be integrated but can illuminate each area under investigation separately, as the chief concern is to use the method most appropriate to the research question.

Health service researchers tend to focus on healthcare provision rather than causes of diseases, and their research questions address issues such as access to care and the effectiveness of both established and new interventions (O'Cathain, 2009). In an analysis of MM research in the UK health services, O'Cathain reports that there is a growth from

17% of research commissioned before 1995 using MM compared to 30% funded between 2000 and 2004. Doyle *et al*. (2009) shares her view that MM research can be responsive to healthcare research, as it can respond to and provide the concrete data needed to form decisions by policy makers and also report on the context of those decisions made (e.g. that all stroke patients on admission must have Magnetic Resonance Imaging and thrombolytic therapy, and understand why this decision was made). By acknowledging the strengths and limiting the weaknesses of current practice, MM researchers can address complex health problems in a creative and imaginative way (Doyle *et al*., 2009).

2.10 Summary

This research aims to arrive at a useful and transparent presentation of both quantitative and qualitative findings. The quantitative findings comprise descriptive analyses of the clinical assessments undertaken and recorded by medical and health professional staff of selected Afro-Caribbean women after stroke. The qualitative findings are in the form of a narrative interrogation of women's talk generated via semi-in-depth interviews.

While there is a wealth of studies on the stroke experience from both philosophical and clinical perspectives, there are few studies concerning stroke which have used an MM approach. Those studies using MM have focused on the delivery of health services or treatments (Clarke, 2003; Dowswell *et al.*, 2002; O'Connell & Baker, 2004). Although the experience of stroke is an area of interest crosscutting both quantitative and qualitative literature, there are still relatively few studies examining the stroke experience among different cultural groups.

The empirical intention did not lie with a preoccupation over which of the research paradigms elicits the best evidence, but with the use of the findings of one methodology (Phase 1) to inform the issues addressed in the other (Phase 2). In the case of this thesis, questions on functional abilities, psychological issues and social practices in Phase 1 were followed up by the interviews in Phase 2 to gain a deeper understanding of how life after

stroke is acted out. Quantitative data was used to reformulate the issues for the qualitative study.

Few stroke studies combine both quantitative and qualitative evaluations. There is a need for studies that report on the factors that will affect life after stroke and associated aspects such as functional ability, with social engagement, social support and cognition. The particular contribution would be towards a better understanding and explanation of how these issues affect stroke survivors' sense of well-being and recovery following stroke. The process of trying to link findings from one study to another can become cumbersome and provide false results, and limit our knowledge and understanding of the experience of life after stroke. Gaugler (2010), at the end of his systematic literature review of stroke care, concluded that the MM approach may help us better understand the stroke experience from (a) identification of the relationship between selected stroke variables, such as those concerned with ADL and (b) the patterns of relationships among these areas (i.e. how a particular phenomenon may impact on life).

One of the reasons for conducting research within health sciences is to raise understanding and inform practice. The greater the power to generalise results, from the study's sample to the rest of the population (of which the sample is representative), the greater the impact of the study (Pallant, 2007). On the other hand, in qualitative research, sample selection is not driven by an interest in its statistical representativeness, but by the experiential relevance of participants' stories. Here, an interest in generalising findings is maintained and needs to be addressed in terms of transferability and the extent to which the emerging interpretative (qualitative) story can be extended to explain, in a meaningful way, the world of others in a similar context. This begins to indicate a useful way of integrating empirical knowledge generated through the application of quantitative and qualitative paradigms; namely, see the two as being able to offer different insights about a common phenomenon. Each can render important yet separate contributions towards a better understanding of the experience of stroke. This thesis thus employs an MM design, seeking to attain a comprehensive understanding of the stroke experience.

Earlier sections in the review examined models of health (e.g. Clarke, Engel, Seedhouse and Kleinman) and their contribution to how we interpret and treat illness. These models contribute to the way in which we view and define health and how these views are represented and embodied within the individual (e.g. Corbin, Frank, James, Hockey and Sontag). The representation and embodiment of illness relies on the cultural values (e.g. Helman and Hall) together with factors identified by the South London Stroke Register team. Alongside these, concepts such as folk illness and illness metaphors (e.g. Helman and Sontag) were explored and the manner in which they contribute to the individual's identity (e.g. Hall, Hunt and Woodward). The concept of the body and its centrality to identity and how we make meaning of illness has been presented (e.g. Shilling). These, together with the person's gender, provides an intricate perspective of the internal and external views of health, identity and representation (e.g. Annandale and Hunt, Arber and Cooper, and Doyal).

This thesis is guided by the contribution of the work reviewed to investigate life after stroke among an inner city Afro-Caribbean female community, as there is less published work using an MM approach in this area. The influence of inner city living and health provision services can impact on the way each individual views and is viewed by the community they live in, and this includes cultural constructs, identity and representation. I developed an MM study where subjective clinical reporting using an extended Barthel Index was collated and analysed, then patients from this database as well as patients attending day centres (not part of the database) were contacted and interviewed to investigate their lived experience of stroke.

2.10.1 Aims and Research Questions

The overarching aim of the study is to investigate the experience of life after stroke. A more comprehensive understanding of the concept and phenomenon of health can be arrived at through the lens of a biopsychosocial model. This lens values all components of

health and places the spotlight on the interplay between the concrete reality of a physical (medically diagnosable) condition, 'stroke', and how this is assimilated into the biopsychosocial aspects of living. The thesis considers this interplay within the context of a sub-culture of first generation Afro-Caribbean women, exploring the relationship between reports of life after stroke in clinical assessments and the narratives from open-ended interviews. The intention was to generate an informative, participant-defined map of the lived experience of life after stroke in an inner city population, to document the evidence and provide recommendations for supportive stroke care.

The analytic aim of the thesis follows an MM approach to address the research question: exploring self-reported experiences of life after stroke, with a focus on Afro-Caribbean women.

There are two research questions. The first question addresses what are the functional, physical, psychological and social changes following a stroke. Phase 1 examines reports of clinical assessments generated at a stroke outpatients' clinic in the London Borough of Newham and explores differences within four racial groupings. The second question is rooted in the area of health, culture and illness, and centres on what the meaning and embodiment of stroke is for Afro-Caribbean women. Based on the findings of Phase 1 and the previously reported literature, Phase 2 of the thesis takes a qualitative approach, exploring narrative accounts through one-to-one interviews with Afro-Caribbean women, some of whom attended the clinic. Chapter 7 brings together the findings from both empirical studies and relates them to the stated aims and research questions.

CHAPTER 3: QUANTITATIVE METHODOLOGY

3.1 Introduction

This chapter outlines the process and rationale underlying the methodological decisions involved in investigating the functional and social effects of stroke in patients attending the outpatient Stroke Clinic at Newham University Hospital NHS Trust (NUHT) from 1 January to 31 December 2004. The MM approach will be discussed and the methodology used in Phase 1 of the study presented. The methodology for Phase 2 will be outlined in Chapter 4.

Phase 1 sought to identify how life after stroke is reported via clinical assessment (subjective patient). Phase 1 aimed to identify gender and racial differences with respect to issues raised by patients attending the NUHT outpatient stroke clinic. This information was then used to structure the questions that were used when interviewing the Afro-Caribbean women in Phase 2. A hoped-for outcome was to be able to identify participants for Phase 2.

An electronic database was created using existing information on patients held in the Stroke Clinic at NUHT. Analysis of this data allowed identification of the underlying problems that the patients encountered after stroke. Phase 2 was concerned with exploring the lived experience of life after stroke, with a focus on how participants made meaning of their illness. Phase 2 involved semi-structured in-depth interviews of six participants (Jenny, Queenie, Doris, Margo, Marie and Lucy) following a stroke.

3.2 Mixed Methods Design: Theoretical Issues and Decisions

The MM approach involves the collection and analysis of both quantitative and qualitative data within a single study. Both methods must be clearly articulated in the design and each should illuminate how they answer the research question (Morse, 2008). Morse stresses that equal weighting should be given to each component. This is not in terms of dominant

or less dominant, but refers to the rigour with which each component is constructed, giving credit to each method.

In my study, data was collected sequentially (Creswell, 2009). Quantitative data was collected first, followed by qualitative data. The intention was to maximise the combined results by seeking the ways in which the two sets of findings expand, collaborate or contradict their respective empirical findings. An MM design can be used when a study presents methodological challenges. For example, qualitative investigations are used to explore quantitative data and results, and to add value to existing results. This approach is becoming more common in clinical trials and some forms of health research (Crawford, Weaver, Rutter, Sensky & Tyrer, 2002).

In terms of advantages, the use of MM is particularly useful when the methods used are similar (such as scaled quantitative questionnaires combined with semi-structured qualitative interviews) and examine different facets of the same phenomenon (Clarke, 2009). It may also allow researchers to test theoretical models based on participants' feedback and to adapt and fine tune them. Working with both forms of data allows the researcher to integrate findings or use them to complement each other, thus gaining a deeper understanding of the phenomenon under investigation (Hanson *et al*., 2005).

However, the use of an MM design also poses some difficulties and disadvantages for researchers. A common shortcoming can be the failure to integrate findings comprehensively, thus limiting transferability of the MM approach (Bryman, 2006). Bryman (2007), Clarke (2009), Sale *et al*. (2002) and Stewart *et al*. (2008) all comment that the integration of MM findings remains a challenge for MM researchers. Perhaps we need to accept that MM findings do not always need to be integrated, but can illuminate each area under investigation separately, as the chief concern is to use the method most appropriate to the research question (Morse, 2008). However researchers using this approach will need to bear in mind that they need to present their findings in such a way that the value of each component used is visible to all.

The choice of adopting an MM design as a medium for arriving at triangulation is highlighted by Creswell and Tashakkori (2007), who urge the researcher to move away from such practice as it devalues the MM approach. Similarly, researchers may need to move away from the idea that findings need to be integrated. Both sets of data should be used to complement each other, rather than corroborate each other. Triangulation is a research practice whereby the researcher employs more than one approach to ensure confidence in the study findings (Bryman, 2006). In their definition of MM, Creswell and Tashakkori offer a viable alternative theoretical positioning, adopting an MM design where the "investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry" (2007:4).

My research aims to arrive at a useful and transparent presentation of both quantitative and qualitative findings. The quantitative findings comprise the electronic documentation of the clinical assessments undertaken on patients after stroke, as recorded by medical and health professional staff. The qualitative findings are in the form of a narrative interrogation of spoken interviews with women after stroke.

While there is a wealth of studies on stroke experience from both philosophical perspectives, there are few studies concerning stroke which have used an MM approach. Those studies using MM have focused exclusively on the delivery of health services or treatments (Clarke, 2003; Koops & Lindley, 2002). Although the experience of stroke is an area of interest crosscutting both quantitative and qualitative literature, there remains a dearth of studies examining the stroke experience using an MM approach.

The final chapter of this thesis demonstrates how both facets of the study are interwoven into an analysis of the findings. The empirical intention does not lie with a preoccupation over which of the research paradigms elicit the best evidence, but with the use of the findings of one methodology (Phase 1) to inform the issues addressed in the other (Phase

2). In the case of this thesis, questions on functional abilities, psychological issues and social practices in Phase 1 were followed up by the interviews in Phase 2 to gain a better understanding of how life after stroke is acted out.

Whilst acknowledging the differences between quantitative and qualitative paradigms, the MM approach accommodates the use of numeric data as 'diagnostic mapping' (Tunariu & Reavey, 2007). This approach coincides with my own ontological and epistemological perspective that reality is something that is unique to each person. By approaching the study of life after stroke from both methodological perspectives, a greater depth of knowledge can be acquired about the stroke experience. As Bryman concludes, "when quantitative and qualitative research are jointly pursued, much more complete accounts of social reality can ensue" (1998:129).

3.2.1 Study Design

Based on the typology of the MM research designs outlined by Leech and Onwuegbuzie (2007), my study uses a partially sequential dominant status design. The distinction between a partially and fully mixed sequential design is that in a partial design the method is used only once (e.g. QUAN → QUAL) rather than in a fully mixed sequential design (QUAL → QUAN → QUAL). In both partial and fully mixed designs, the status can be dominant (QUAN → Qual or vice versa) or equal (QUAN + QUAL or vice versa).

I approached data collection sequentially (i.e. Quan → QUAL), whereby numeric data from clinic attendees helped to answer the question on how the physical, psychological and social functions of life are affected after stroke (by gender and ethnicity among an inner city population). The data collected in Phase 2 helped to facilitate understanding of the lived stroke experience from an Afro-Caribbean female population perspective. Areas identified in Phase 1 were followed up in Phase 2 following the thread technique (O'Cathain *et al*., 2010) discussed earlier in section 2.9. In essence, the Quan → QUAL approach helps to gain data on the same facets of the phenomenon under investigation.

Figure 3.1 shows how both quantitative and qualitative methods were utilised in this study design.

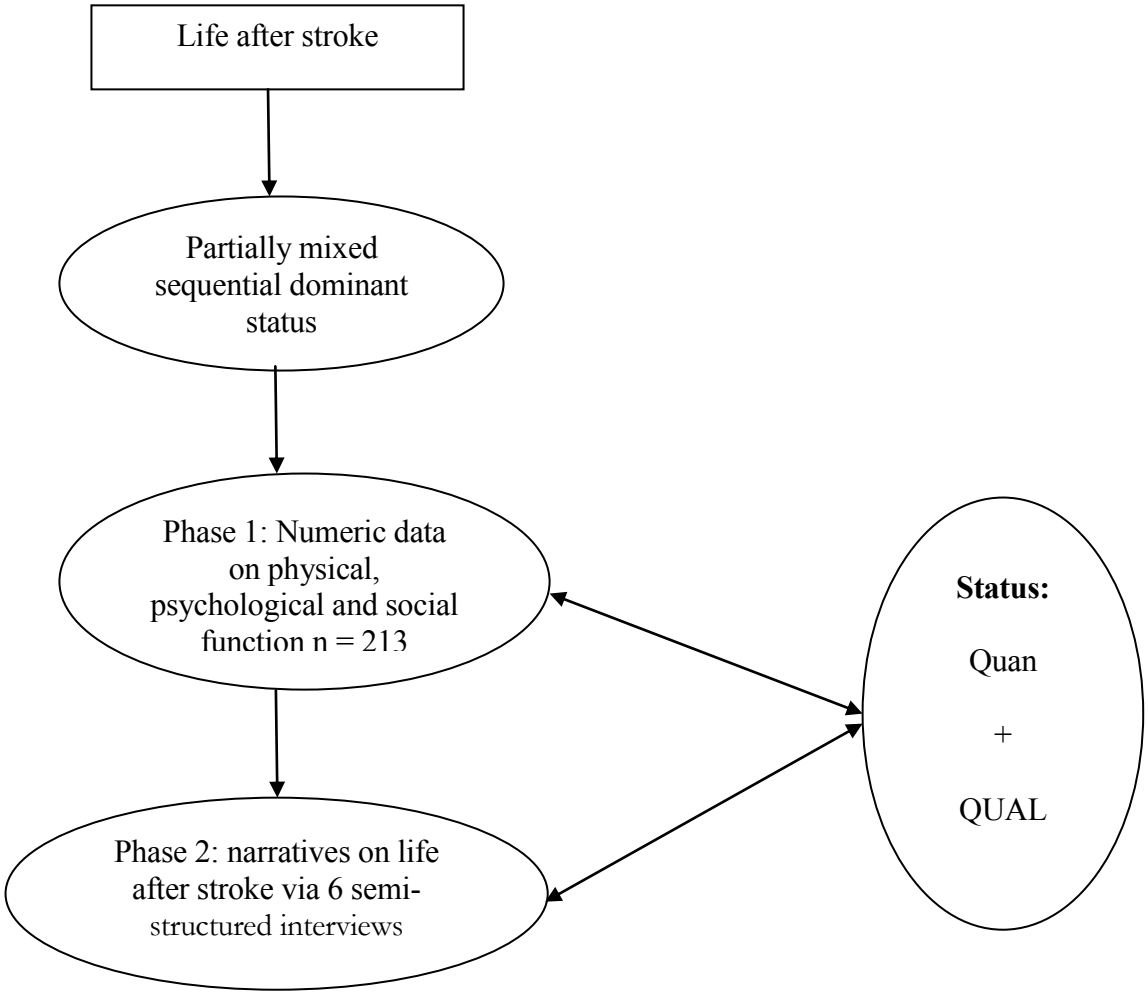

Figure 3.1: Status of Methodological Study on Life After Stroke

3.3 Phase 1

Having been awarded funding by the NUHT Pump Priming Project Scheme,[1] access was given to the hard copy records of the NUHT Stroke Clinic's assessments on stroke. These

[1] A successful application was made for an award by the researcher under the Pump Priming Project Scheme from the Research and Development Department of NUHT. A total of £5000 was awarded. Professor Allan Brimicombe of the University of East London was contracted to assist with the practical and engineering aspects of the electronic tool.

included the medical notes and assessment data collected by the Health Visitor for Older People (see section 3.7).

Within Phase 1 of the study, both a biomedical approach (i.e. index measurements) and a cultural perspective worked in symbiosis to produce insights into how the ability to perform daily tasks may lead to more internalised effects affecting an individual's quality of life. For example, in Phase 1 it was established that Afro-Caribbean women experienced few problems with bathing after stroke; this was followed up in Phase 2 where participants provided explanations for this phenomenon based on cultural practices.

3.3.1 Objectives of Phase 1

Each method should answer specific questions (Morse, 2009). The quantitative method used in Phase 1 helped to identify the problems experienced after stroke pertaining to the physical, psychological and social aspects of daily living that affected the lives of an inner city group of clinic attendees. Any differences in terms of ethnicity or gender on these personal matters after stroke were analysed statistically.

3.4 Phase 2

A qualitative approach was used to answer the question on social practices and how life after stroke is lived on a daily basis. Semi-structured in-depth interviews were analysed in terms of the subjective and personal meanings of health and life after stroke. Meaning making repertoires regarding illness and health were examined using IPA (Smith & Osborn, 2004). IPA allows participants to be viewed as both subjective and as a collective. The meanings and practices elucidated were able to be viewed from the perspectives of individuals who hold their own subjective meaning of illness, as well as from the practices that constitute a group (Afro-Caribbean women). The subjective view focused on how the collective shapes what may constitute the subjective. A group's perspective can influence how an individual views their own illness and vice versa. The collective analysis focused

on cultural formulation, popular ideas and dominant accepted views of the world. For this thesis, aspects shaped by the collective were explored. These included cultural identity, representation and symbolic markings. Phase 2 then explored how identity fits into culture, seeking to understand how signifying practices and symbolic systems produce meaning through representations such as 'my ill body' and health identities. The views of the women interviewed were assessed and analysed to illustrate how culture can shape identity and give meaning to experiences, making it possible to opt for one mode of subjectivity based on the collective.

3.4.1 Objectives of Phase 2

The main objectives of Phase 2 were:

- To identify and analyse the subjective and collective meaning of life after stroke among Afro-Caribbean women.
- To examine how social practices are represented in everyday life and are integrated into a cultural identity in life after stroke.

3.5 Ethical Approval

Ethical approval for both phases of the study was obtained from the University of East London (see Appendix 2). Approval was also obtained from the Central Office for Research Ethics Committees (COREC), the governing body for any research taking place in the National Health Service. The process of obtaining ethical approval from COREC was multi-staged. Firstly, an application was made to COREC, which was then referred on to the Local Research Ethics Committee (LREC). After the LREC (see Appendix 3) approved the proposal, it was referred to the local study centre (Newham University Hospital NHS Trust and Newham Primary Care Trust - see Appendix 4) for final ethical approval, which was granted by the hospital's Research and Development Office (see

Appendix 5). All participants in Phase 2 were given an information pack and full consent was obtained prior to any data collection (see Appendix 6).

3.6 The Impact of Stroke on Daily Function

Key to understanding the impact of stroke on daily functioning is the correct assessment of the complexity of the physical, psychological and social consequences of the disease (Wood-Dauphinee, Williams & Shapiro, 1990). In recognising the need to determine the amount of assistance needed to perform everyday functional activities, the validity of the Barthel Index (BI) was established by Mahoney-Barthel in 1965 (see section 2.6.2). This scale covers ten of the most common ADLs, including bowels and bladder. Despite the passage of time and the development of subsequent more comprehensive scales such as the FIM (Van der Putten, Hobart, Freeman & Thompson, 1999), the BI continues to be widely used (Kwon, Hartzema, Duncan & Lai., 2004).

3.6.1 The NUHT Assessment

To address these issues, Dr Mike Hill (now Medical Director for NUHT) and his colleagues in their assessment included scored assessments for physical and functional categories of bathing, bowel continence (urinary), dependency, dressing, eyesight, feeding, feet, food preparation, hearing, maintenance, mobility, pain and sleep. Scored psychosocial categories included memory, mood, orientation, level of carer support, overall health rating, social engagement and status of carer.

The designed NUHT assessment tool takes into consideration important aspects of functional and physical independence, emotional and social health, and quality of life. As far as can be ascertained, none of the scored assessments have been investigated for validity or test-retest reliability, so all responses were thus subjective and based upon patient responses and the assessor's clinical judgment.

3.7 The NUHT Stroke Clinic

The NUHT Stroke Clinic holds a weekly outpatient session for new and existing patients who have had a stroke or mini-stroke (TIA). The Stroke Clinic patients in this study were first seen by the Consultant Physician or the Associate Specialist, and then by the Health Visitor for Older People.

The Health Visitor for Older People interviewed each patient, collected the demographic information and undertook the NUHT assessment. Using this assessment tool, she manually recorded on paper the responses to a series of questions associated with the patient's lifestyle, family circumstances, medication compliance and tolerance to others around them. She also completed the sections on anthropometric data, ADLs, mobility and behaviour and mood changes. Exploring this data, it became apparent that the Health Visitor for Older People used her judgment and did not necessarily ask all the questions on the paper assessment. However, information on ADLs was collected for all of the patients in the survey.

All the information collected, together with any data concerning community referrals, formal advice on lifestyle changes, referral for benefits (social security, housing, council tax) and any written reports associated with regular home visits gathered over the past five years was systematically filed. This was subsequently accessible to me from individual patient files.

3.8 Designing the Electronic Database

Inner cities have diverse populations, including differences in age, gender, race, illness, employment, housing, transportation, built environment and access to health services. These can be seen in reports such as the *General Household Survey* or the *National Census Neighbourhood* reports. Within inner cities, there is a tendency to have pockets of wealth, poverty and ethnic groups, leading to health disparities (Baggott, 2000). There is minimal

documented evidence available of between group differences of outcome measures with respect to racial groupings for either men or women following a stroke. Designing and developing the database provided a basic profile of the functional, physical and psychological limitations experienced by stroke patients living in a deprived and ethnically diverse inner city population. Lack of such information can contribute to complexities in how data is collected and reported, as well as service provision and uptake among the inner city population.

One example of the complexity of service provision is that this Health Visitor for Older People works for the local Primary Care Trust (PCT). Once her assessment is completed, she files these in the PCT offices (which are different to the NUHT offices), while the medical assessments and reviews are held in the patient notes at NUHT. Thus, a situation developed where hard copy information on one patient is held in two different places. This may present problems in identifying and addressing healthcare needs, as the service is not 'joined up'. In order to collate and begin to analyse the data collected on stroke patients by the Health Visitor for Older People, it was decided to attempt to establish an electronic database.

To decide what information was most relevant and to whom within the team it should be available, each section of the proposed database was discussed in detail with members of the Stroke Team. For example, the Health Visitor for Older People was more concerned with the general patient assessment, while the consultant placed greater emphasis on medically oriented data assessment.

To achieve this, and to ensure compatibility with the hospital's present electronic patient's records (EPR) system, the first step was to consult with the hospital's information technology (IT) managers. This was important in order to design a database with the ability to import and export information and to provide a comprehensive overview of each of the various networks and drives within NUHT departments. The aim was to build on the positive aspects of sharing patient information across disciplines and different departments,

while remaining in line with the government's guidelines on IT and health (House of Commons, 2009).

In addition to deciding how to translate sections of the hand-written assessment into an electronic format, the researcher suggested that the current assessment might benefit from including some additional information. Following consultation with the team, the following areas were agreed to feature in the NUHT assessment:

- Demographic details: including postcode and other relevant information.
- Diagnosis: this section includes a description of the 'type of event' (e.g. stroke or TIA), allowing documentation of stroke sub-type. There was an added facility within this section to allow magnetic resonance imaging or carotid Doppler scans to be uploaded directly onto the database.
- Medical notes: this section allows medical staff to document their examination and assessment and to record any notes or case summaries.
- Clinical information: information on blood pressure measurements and other clinical results (such as blood sugar and cholesterol levels) can be entered. There is a section to record the patient's medical history.
- Drugs: medication received by a patient is shown under informative labels or categories; for example, cardiac medicines are broken down into beta blockers, ACE inhibitors, statins, calcium and potassium channel blockers and anti-coagulants.
- Anthropometric measures: body mass index is a contributing factor to stroke, and also a means of monitoring possible effects of a health promotion weight loss programme.
- Self care: includes numerical scales to assess bowel and bladder continence, bathing, dressing and grooming, feeding and food preparation.
- Mobility: includes numerical scales to record transfer from bed to chair, use of toilet, walking and climbing stairs.
- Psychosocial aspects: included in this section are aspects of psychosocial health (for example, dependency levels and the need for carers), as well as rating health status and the ability to engage in social activities.

Additional questions included in the NUHT assessment concerned dexterity, speech, memory, bereavement, pain, pattern of sleeping, condition of skin, hearing and eyesight, mouth and oral hygiene, difficulty in breathing and condition of feet. All the available scores were entered into the database. For some of these questions, answers had not been recorded for any of the patients, while for other questions only a limited number of patients had recorded answers (see section 3.7).

3.9 Piloting the New Electronic Database

Piloting work was carried out from September to November 2005. All data was collated and entered by the researcher. Piloting was carried out by the researcher and involved transferring the data from the current paper assessments into the electronic database. Second stage piloting involved members of the Stroke Team using the tool to perform dummy assessments. Piloting the electronic database was important and illustrated the compatibility of the database with the Trust's IT system, whilst also identifying areas of personal and professional development required for members of the team to enable them to input data and subsequently use the database.

Following an early review of the electronic database, the medical staff requested that the following six standardised scales were included:

- Barthel ADL Index.
- Glasgow Coma Scale: this assesses levels of consciousness.
- Glasgow Outcome Scale: a crude measure of handicap and quality of life.
- Hunt Hess Scale: a five point scale used as a predictor of a patient's outcome/prognosis. Mortality is minimum at grade 1 and maximum at grade 5.
- Modified Rankin Scale: a mixed measure of impairments and disabilities.
- National Institute for Health Stroke Scale: a scale that attempts to summarise all the disabilities associated with stroke into one scale.

Completion of one or all of these scales allows comparisons to be drawn with other published data. However, it is now important, following completion of the present study, to revisit the database and consider which records should be maintained and identify those thought to be of most benefit to both patients and those concerned with long-term care following a stroke.

3.10 Data Preparation

Information from the paper assessments concerning demography, diagnosis, functional psychological and social assessments were transferred onto a Microsoft Office Access database. This process allowed for the identification of faults within the design and construction; for example, to ensure that two screens could be open at the same time and to be able to link into the hospital's IT system. This process also helped to identify any viruses present which could cause adverse effects to the system (none were identified). The data analysed in the present study was derived from the first assessment made for each patient attending the NUHT outpatient Stroke Clinic from 1 January to 31 December 2004. All of the data collected on patients was coded and transferred manually onto the Access database by the researcher. To address the need for comparison with similar studies undertaken elsewhere, each item in the BI was scored retrospectively (i.e. the researcher used his nursing knowledge, together with patient information both in the NUHT assessments and the medical notes) and a total score for the BI was calculated. This information formed the data used to profile the clinic attendees and to identify the problems encountered after stroke.

Data for Phase 1 (n=213) was entered into the database, of which 185 were stroke patients and 28 were TIA patients. Those patients with a TIA (n=28) were not included in the final analysis, therefore n=185. Data for ethnicity were collapsed into four main groups: White Caucasian (including white British, Irish and white European) Afro-Caribbean, Asian (including British born Asian, Indian, Pakistani, Bangladeshi and Bengali) and Other (including Chinese, Jewish, black African, black British and mixed race). The reason for

this was that this was a small dataset (n = 213) and keeping to just four main ethnic groups facilitated better analysis.

Data cleaning was performed by reviewing the collected information and identifying any missing data; for example, date of birth, details of past medical history, ethnicity or postcode were not always recorded on the assessment. The patient's medical notes were then reviewed in an attempt to identify such missing information. Unaccounted missing data was excluded from the dataset by using a dummy code (999 was used to replace the missing data).

3.11 Data Analysis

The scored data in this study was, by definition, ordinal data, with one score being in some way better or worse than another. Group descriptions were undertaken using box and whisker plots. These are summary plots based on median, quartiles and extreme values of the data. The box length represents the inter-quartile range which contains 50% of the values. A line across the box indicates the median value and the whiskers are lines that extend from the box to the highest and lowest values, excluding outliers and extremes. Outliers are cases with values between 1.5 and 3 box lengths from the upper or lower edge of the box. Extremes are cases with values more than 3 box lengths from the upper or lower edge of the box (SPSS 15 version).

During the analysis, eight patients were identified as having extreme scores in at least one of the variables; these included three white males (subject numbers 1, 7 and 38) and three white females (nos. 121, 123 and 137), plus two males (nos. 106 and 109) in the mixed ethnic group. There was one female outlier in the Asian group (no. 192). These patients were identified and the possible reasons for falling into these two categories will be discussed later in Chapter 4.

In order to provide a comprehensive view of the population in Newham and the extent of stroke within the borough, the incidence of stroke for the borough and individual wards was calculated. This calculation was based on the available information for stroke admission by the hospital (not clinic attendance) and incidence rates based on the population from the National Census 2001 data. Incidence rates were calculated using the following formula taken from Moon, Gould, Brown, Duncan, Iggulden, Jones and Twigg (2009).

Incidence = number of new cases ÷ total population at risk × multiplier (e.g. 100,000)

Note: the multiplier is used simply to avoid fractions and then the incidence is expressed as a figure per multiplier value (for example, incidence per 100,000).

3.11.1 Testing Data Distribution

The One-Sample Kolmogorov–Smirnov Test procedure was used to compare the cumulative distribution function with a specified theoretical distribution, which may be normal, uniform, Poisson or exponential. The One-Sample Kolmogorov–Smirnov Test is a goodness-of-fit test (Field, 2009).

3.11.2 Kruskal-Wallis and Mann-Whitney U test

These tests are non-parametric analogues of the independent two-sample t-test and one-way ANOVA respectively. The Kruskal-Wallis test for two groups tests whether two or more independent samples are from the same population, and assumes that the underlying variable has a continuous distribution with at least one ordinal measurement. The Mann-Whitney U test is equivalent to the Kruskal-Wallis test for two groups, and is useful in determining whether the mean of two groups are different from each other (Pallant, 2007).

3.12 Statistical Analysis

Data was grouped into three main domains - demographic (including clinical profile), functional and psychosocial. Descriptive statistics (mean, mode, median, standard deviation, skewness and kurtosis) were used to summarise the data. These, together with histograms, box and whisker plots, were used to determine which of the variables showed differences. A decision was taken not to perform further analyses on the variables that showed little or no difference. The variables that showed differences were then further analysed using the Kruskal-Wallis test and Mann-Whitney U test (*post hoc*). Corelational studies were performed using Spearman's Rho to explore the relationship between certain variables.

3.13 Reflexivity

3.13.1 The Journey from Practitioner Assessment to Data in a Study

Reflection is an important act that enables researchers to examine their practices and how such practices impact on others, themselves and the findings they produce. Reflection can be an introspective and retrospective process, and can be carried out where the individual reflects on the situation as it occurs or after the event. At first, when I arrived at the NUHT Stroke Clinic and was faced with the challenge of transforming and redesigning a paper assessment into an electronic database, it sounded simple. The challenge was in understanding what different practitioners wanted from the assessment and how to design a new database to address these varying needs. I learnt that stroke assessment was incredibly comprehensive and each area of the affected individual's life needed particular attention that, with great effort and team meetings, was a challenge that could be achieved.

The database was now designed, but needed to be trialled in action. It was during this period of entering the assessment information into the database that I saw a picture emerging from the data. Here, I was further challenged with the idea of creating Phase 1 of

the Ph.D. study. I had access to valuable data which could explain part of the phenomenon I was interested in - life after stroke. On reflection, Phase 1 and the database were needed in order for me to be able to understand how patients from different ethnic groups reported their life after stroke.

Transferring information from a paper assessment into an electronic database where the collected information was viewed in terms of variables that could produce statistical evidence of the experience of life after stroke was not a straightforward task. I had to adjust the way I viewed the data (from clinical readings to statistical data) in order to work with it. Among the many tasks I had to undertake was to read through medical notes for missing information and learn how to handle empirical numerical data. In the end, moving from practitioner assessments to data in a study, I learnt that while the stroke assessment was good practice, it was even better to use the stroke assessment scales and using these electronically enhances and enables better data collection. Finally, it was crucial for those using stroke assessment scales to understand the nature of the data in order to interpret and effectively summarise the results of the investigations and to apply appropriate statistical tests.

3.13.2 The Journey: Thoughts on how to Develop an Improved System of Recording Information to Outlining a Methodology for an Empirical Study

Information concerning a patient's health should be collected in a systematic and coherent manner. Firstly, to get a good overview of the patient's condition through the assessment process that can help with planning and implementing care; and secondly, to be able to provide meaningful data on treatment and recovery which can be used to chart progress. Developing such a system can be confusing, time consuming and exhausting (some of the feelings I experienced while designing the electronic database). However, by designing, developing and trialling this electronic database, I was able to move towards formalising a methodology for this empirical work.

At the design stage, I had to listen to what members of the Stroke Team wanted and then conceptualise how this could be achieved. The next stage was to develop the database, ensuring software and hardware compatibility and, finally, to trial the database which gave rise to the data in this phase. This step-by-step process allowed the creation of an electronic database that provided the platform for developing the methodology for the quantitative phase of this study. The information entered into the database became a separate database from which tests and analyses could be undertaken to answer the research questions centred on the interplay of gender, culture and ethnicity on life after stroke.

3.14 Chapter Summary

This chapter has presented the rationale for using a mixed methodology, and explored why this approach best suits the research question that seeks to understand the extent to which culture, gender and ethnicity influence health and life after stroke among Afro-Caribbean women. The data collected was examined to establish any links or identifiable patterns between culture, gender and ethnicity among clinic attendees' functional, psychological and social abilities post-stroke. It was hoped that the data would provide knowledge and information on the interplay of gender, culture and ethnicity on life after stroke. This was then used to amplify the research for the qualitative phase, by exploring the phenomenon that had been identified.

The purpose of the retrospective analysis was to investigate and produce descriptive statistics reflecting demographic details of patients who attended the clinic over a 12 month period. Further analysis was performed to document post-stroke related phenomena in terms of functional, psychological and social categories. Within these categories, activities on preparing meals, feeding, bathing, dressing and using the toilet were assessed on a scale from dependence to independence. Other categories also included sociability (i.e. engaging in social activities), social mood and behaviour, and the patients' self-reported ratings of their own health status.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter examines stroke-related phenomena and provides a descriptive analysis of the data obtained from a group of inner city stroke clinic attendees.

Phase 1 of this study explores the demographic data associated with the attendance of patients at the NUHT. It presents a detailed analysis of clinical reports in terms of the gender and ethnicity of these patients who attended the stroke outpatient clinic. This analysis takes into account the age of stroke occurrence and differences in gender. The concern was firstly to determine the influence and prevalence of stroke within the London Borough of Newham, and then to relate these figures to those reported by the London Health Observatory for Inner City Populations.

The second part of Phase 1 provides a detailed description of the clinical assessment of the patients attending the stroke outpatient clinic at the NUHT. The assessments record the functional, psychological and social positioning reported by the patients as they were interviewed by the Health Visitor for Older People on their first assessment at the clinic.

As stated in Chapter 3, the aim was to evaluate any differences in these variables in terms of ethnicity in both gender groups, and to try to determine how these personal matters impact on their respective lifestyles after stroke. The results led on to a further qualitative exploration in Phase 2 of the study, where issues and, in particular, social barriers identified as influencing life after stroke of one specific group of patients (Afro-Caribbean women) are presented.

4.2 The Subjects and their Groups

4.2.1 Subjects

Two hundred and thirteen patients attended the NUHT Stroke Outpatient Clinic between 1 January 2004 and 31 December 2004, of whom 185 had suffered a stroke (108 male, 77 female). There was little difference in the mean ages of the male and female stroke patients (68.7 ± 12.9 years and 68.2 ± 11.7 years respectively) and similarly an equal distribution of right and left handed strokes were recorded, with 48 men and 38 women having had a right handed stroke and the remaining 99 having left handed strokes. The remaining 28 patients (12 male, 16 female, with mean ages of 68.4 ± 11.97 and 66.1 ± 12.95 respectively) had been diagnosed as having sustained a TIA. Because these patients did not have assessments, they were excluded from the analyses, but were included in the original dataset.

4.2.2 Stroke Groups

In order to investigate any differences reported in life after stroke, the subjects were divided into four groups based on ethnicity. For the purpose of this study, these groups were 'White Caucasian', 'Afro-Caribbean', 'Asian' and 'Other' ethnicity.

Table 4.1 compares the mean ages across the four groups of stroke patients on assessment. There was a mean difference of 15 months between the onset of stroke and full assessment in the outpatient clinic for both male and female groups.

Table 4.1: Age of Stroke Clinic Attendees on Assessment by Ethnicity and Gender

Group		Age at Assessment Years	
Male	**n**	**Mean**	**SD**
White Caucasian	57	71.8	12.5
Afro-Caribbean	14	68.4	10.2
Asian	23	67.0	12.8
Other	14	61.4	14.9
Female			
White Caucasian	40	72.0	11.2
Afro-Caribbean	10	67.6	9.1
Asian	12	64.3	10.7
Other	15	61.6	12.0

The White Caucasian males were the largest group of attendees, having a mean age of 71.8 ± 12.5 years. The corresponding female group was slightly older (72.0 ± 11.2 years). The males and females in the Other (or mixed racial) group were younger (males 61.4 ± 14. 9, females 61.6 ± 12.0 years). Analysis of variance using a one-way ANOVA and Tukey *post hoc* test showed that there was no significant difference in the age distribution of the male groups. There were significant differences in mean age between the White Caucasian and Other (p = 0·01) female groups of 9.91 ± 2.51 years.

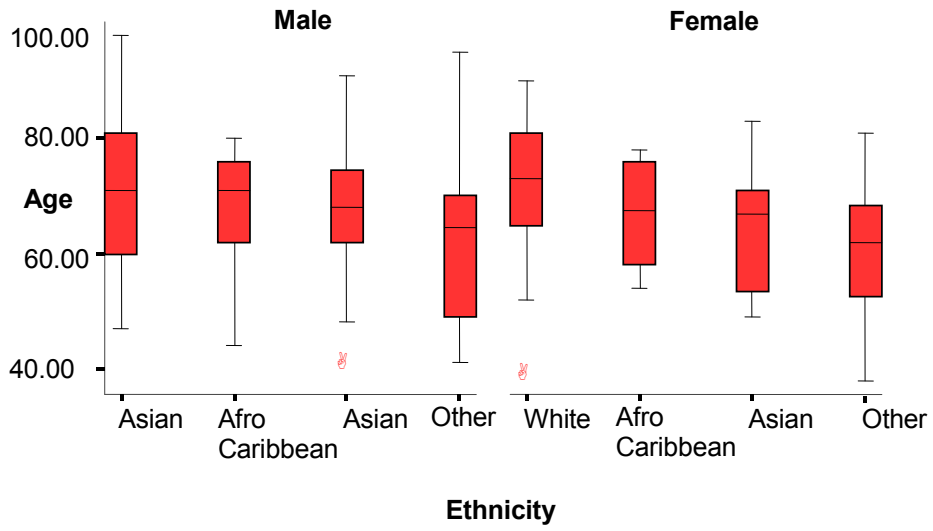

Figure 4.1: Median Ages for all Four Groups by Gender and Ethnicity

Box and whiskers plots (Figure 4.1) show there were two extremes in age, a 38 year old Asian male (no. 163) with a right handed stroke and a 46 year old female (no. 187) with a left handed stroke of Asian origin who, because she came from the Caribbean, had been placed in the Other group. Both extremes had limited mobility as assessed by the BI, which will be discussed later (see section 4.4.14).

Both male (n = 57) and female (n = 40) groups of White Caucasians had the highest range of age (from 47 to 98 years and 40 to 90 years respectively), whereas the Afro-Caribbean male (n = 14) and female (n =10) patients were younger (ranging from 44 to 80 years and 54 to 78 years respectively). Of the White Caucasian patients, three males (nos. 67, 132 and 202) and two females (nos. 135 and 145) were over 90 years of age. One Asian male (no. 152) and one Jewish (no. 25) male in the Other group were over 90 years of age. The overall age profile of patients points to them being over 65 years. This is similar to the ages of stroke patients presented in other studies (Department of Health, 2001; Health, 2001; Lawrence *et al.*, 2001; Leatherman, Sutherland, Airoldi & Health, 2008; Wolfe *et al.*, 2005).

4.3 Incidence Rates For Stroke Patients Attending the Clinic

In order to determine whether the patients attending the stroke outpatient clinic were representative of the national figures reported by the London Health Observatory (2004) for incidence of stroke in Newham, the postcodes of the patients' home addresses were investigated.

The Census for 2001 showed that the Newham population reported a total 98,535 residents (47,163 males, 51,372 females) aged 35 to over 90 years. Stroke admission for those over 35 years of age at the hospital in 2004 (London Health Observatory records) totalled 150 patients, of these 137 (78 males, 59 females) came from Newham and the remaining 13 (10 males, 3 females) came from areas outside the borough.

Table 4.2: Stroke IR by Ward and Ethnicity Based on the 2001 Census and 2004 Stroke Admission for NUHT

Area	IR per 10,000	Area	IR per 10,000
Beckton	5.1	Green St East	5.3
Boleyn	9.9	Green St West	11.9
Canning Town North	1.7	Little Ilford	5.8
Canning Town South	3.8	Manor Park	4.9
Custom House	6.5	Plaistow North	7.6
East Ham Central	16.4	Plaistow South	13.2
East Ham North	6.7	Royal Docks	5.6
East Ham South	10.1	Stratford & New Town	8.3
Forest Gate North	6.1	Wall End	8.4
Forest Gate South	6.6	West Ham	8.7
		Whole Borough	***32.8***

Table 4.3: Percentage and Number of Stroke Patients From Each Postcode Attending NUHT Clinic

Postcode	White Caucasian (m/f)*	Afro-Caribbean (m/f)	Asian (m/f)	Other (m/f)	Total (m/f)	Patients at ward level	Ward population	Stroke IR** per 10,000
E12 Little Ilford, Manor Park	48 (7m, 6f)	11 (2m, 1f)	19 (2m, 3f)	22 (4m, 2f)	(15m, 12f)	13	8,784	3.2
E13 Custom House, Plaistow	65 (7m, 12f)	14 (3m, 1f)	7 (1m, 1f)	14 (3m, 1f)	(14m, 15f)	15	15,274	4.9
E15 Stratford, West Ham	50 (10m, 5f)	17 (2m, 3f)	10 (3m, 0f)	23 (3m, 4f)	(18m, 12f)	15	10,247	3.4
E16 Canning Town, North Woolwich, Royal Docks	76 (16m, 4f)	12 (1m, 2f)	-	12 (1m, 2f)	(18m, 8f)	12	12,574	4.8
E6 Beckton & East Ham	46 (15m, 14f,)	5 (0m, 3f)	36 (16m, 6f)	13 (2m, 6f)	(33m, 29f)	31	19,197	3
E7 Forest Gate, Upton Park	43 (4m, 8f)	19 (4m, 1f)	19 (3m, 2f)	19 (1m, 4f)	(12m, 15f)	13	10,766	3.9
Non Newham	55 (6m, 0f)	27 (3m, 0f)	-	18 (0m, 2f)	(9m, 2f)	5	**Total**	**23.2**

* m = male, f = female
** IR = Incidence Rate, subdivided into postal codes (e.g. E12) and wards (e.g. Little Ilford).

Incidence rates for stroke (see page 70 for formula) were calculated based on these figures. The Newham incidence rate was 32.8 per 10,000 (Table 4.2). The stroke incidence rate for Newham based on clinic attendance was also calculated at 23.2 per 10,000 (Table 4.3). Tables 4.2 and 4.3 respectively show the incidence rates at ward and borough level based on clinic attendance and stroke admission for 2004.

4.3.1 Location of Stroke Patients by Postcode

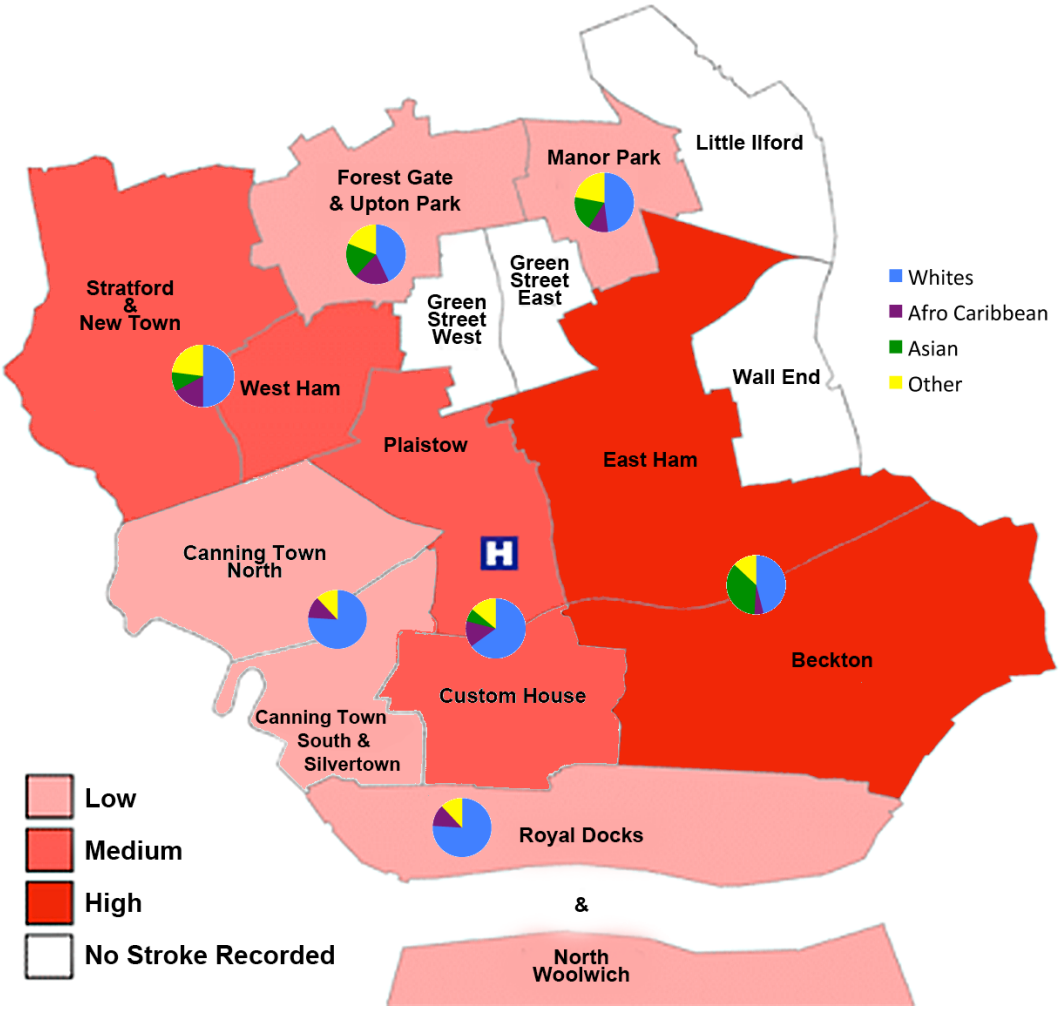

Figure 4.2: Map of The London Borough of Newham

Source: Newham Town and Country Planning 2005

The small coloured pie charts within Figure 4.2 show the proportion of ethnic groups for each Newham postcode and the colours of the postcode areas reflect the percentile of stroke patients attending the NUHT, where high is over 30%, medium between 30-15%

and low less than 15%. NUHT is based in Plaistow, London E13. Figure 4.1 shows the wards by main postcodes together with the percentage distributions as pie charts of the four ethnic groups of the patients who had attended the Newham Hospital Stroke Outpatient Clinic in 2004. Out of a total of 213 attendees, a large number of patients (n = 62, being 33 male, 28 female) (colour coded deep red) came from Beckton and East Ham (E6) from a total population of 19,197 persons. The pie chart indicates that 46% of these patients were White Caucasian, 5% were Afro-Caribbean, 36% were Asian and 13% were in the Other group.

The numerical data for Figure 4.1 can be seen in Table 4.2. It shows that the overall distribution of ethnic groupings was comparable across the postcodes, although no Asian stroke patients came to the clinic from E16. There were no subjects from Green Street East or West, Little Ilford or Wall End.

4.3.2 Public Transport

I looked to see whether there could be some underlying association between the number of patients attending from the different parts of the borough and transport. An examination of the maps of local buses to the hospital shows that there are three bus routes (nos. 262, 276 and 300) that serve the hospital from Beckton and Stratford, from Stoke Newington through West Ham and then Canning Town to East Ham respectively, but only one direct bus (no. 376) with no interchange operates from the Green Street area, and finally one other (no. 147) with only one bus interchange that serves Little Ilford and Wall End (for bus map see Appendix 7). It seems possible that the impact of the more difficult bus journeys influences clinic attendance and may account for the smaller numbers attending from E16 (Canning Town, North Woolwich and the Royal Docks) and for the large number of patients from E6 (Beckton and East Ham).

4.3.3 Incidence Rates Within Newham

Consulting the London Health Observatory records for 2004 (see section 4.3), the incidence rates for stroke with clinic attendance was calculated for Newham over the study period. The incidence rate (IR) was calculated per 10,000 persons based on the records of the 137 NUHT stroke admissions in 2004 for each of the 20 wards within the borough, for stroke admissions recorded for that ward (see Table 4.3) where IR = (Population at risk/Disease population) x 10,000. To determine if patients attending the clinic were representative of the IR calculated for each of the main postcodes in the borough the IR for clinic attendance was calculated; but this time using the number of patients attending the Newham Hospital Stroke Outpatient Clinic.

Table 4.3 earlier (see section 4.3) shows that the incidence rate for Newham based on clinic attendance was 23.2 per 10,000 persons, considerably less than the 32.8 per 10,000 calculated from the stroke admission data (Table 4.2). In our clinic population of 213 outpatients, 185 had had a stroke and 28 had sustained a TIA. There is a disparity in the figures between clinic attendances and hospital admissions, but possible explanations could include death as a result of stroke or other causes and unwillingness to attend an outpatient clinic. There is, however, sufficient evidence to allow the findings from this study to be seen as representative of a wider inner city stroke population.

4.4 Functional and Physical Variables

Explorative analysis of all variables grouped by physical and functional abilities can be seen in Tables 4.4 to 4.17. Box and whisker plots (Figures 4.2 to 4.5) show median values and quartiles together with any outliers and extreme values of the physical outcome variables: bathing, continence, dependency, dressing, eyesight, feet, feeding, food preparation, hearing, mobility, maintenance, pain, sleep and Barthel index (BI).

4.4.1 Bathing

Table 4.4 and Figure 4.3 show the median and range of scores of ability to bathe (where 1= independent, 2 = bathes with assistance, 3 = can wash only and 4 = totally dependent). Analysis of the differences between the four male groups of patients by ethnicity using the Kruskal Wallis test showed no significant differences, but for the female patients there was a significant (p = ·016) difference between the four ethnic groups. Further post hoc analysis using the Mann Whitney U test showed significant differences (p = ·013, ·003 and ·010) between the female Asian group and the other three female groups respectively.

Table 4.4: Scores for Bathing by Ethnicity and Gender

Bathing	Whole Group			White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
n	181	104	77	56	40	14	10	22	12	12	15
Median	2	2	2	2	2	2	2	2	3	1.5	2
Min	1	1	1	1	1	1	1	1	1	1	1
Max	3	3	3	3	3	3	3	3	3	3	3
Missing	4	4	0	1	0	0	0	1	0	2	0

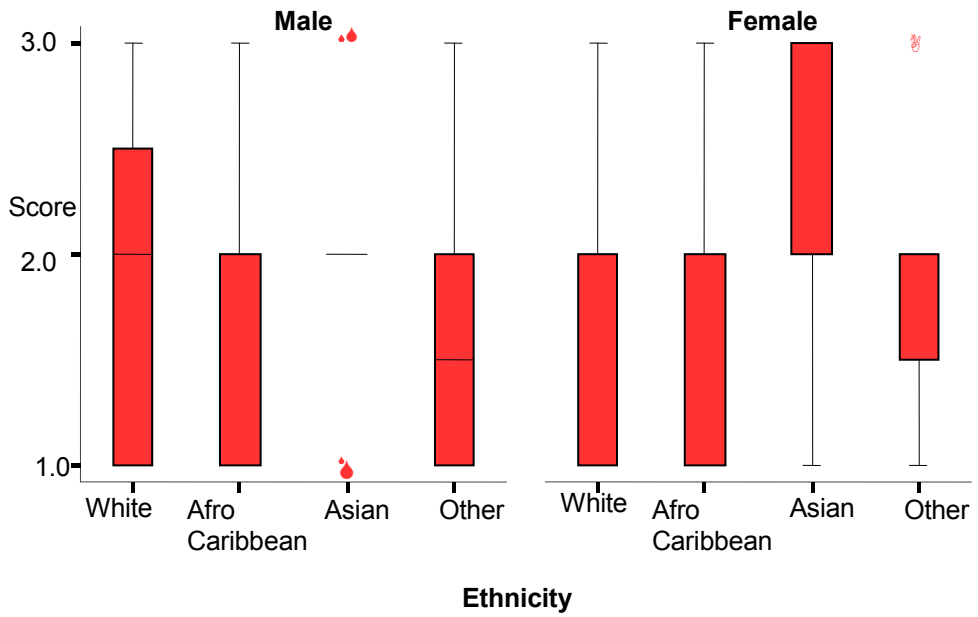

Figure 4.3: Median Scores for Bathing by Gender and Ethnicity

The scale used to assess bathing was limited, in that the median score was 2 indicating some help was required with bathing, but in the case of the Asian females the median score was 3 which indicated that significantly more Asian females preferred to wash themselves rather than undertaking bathing with supervision.

4.4.2 Bowel and Urinary Continence

The assessment of bowel function focused on the need for medicinal intervention to aid bowel movement (where a score of 1 indicates normal function and a score of 4 indicates that the patient requires support and/or enemas). Urinary and bowel continence was assessed on a range of five scores (where 1 = full continence and 5 = double incontinence). For the assessment of bowels, a median score of 1 indicates that 78% of patients were continent. Of the remainder, 2% indicated being 'incontinent or needed to be given an enema' and 20% reported constipation or diarrhoea, or needing to take laxatives or anti-diarrhoeal medication. In respect of urinary function, 83% reported 'continent' for over seven days and 17% reported 'occasional accident max once per 24 hours'. For these 17%, the occasional incontinence is likely to have impacted on their social engagements and limited their self-confidence in a wide variety of circumstances, as seen in Lucy's narrative in Phase 2.

4.4.3 Dependency

This scale assesses levels of dependency upon domestic assistance required to ensure maintenance of hygiene (assessed on a scale of 1 to 5, where a score of 1 indicates independence, 2 needs help with shopping, 3 needs domestic help, 4 needs help with personal hygiene and 5 indicates total dependence). Twenty patients scored 5, indicating they were totally dependent. The results for dependency (Table 4.5 and Figure 4.4) show the differences in median and range scores.

Table 4.5: Scores for Dependency by Ethnicity and Gender

Dependency		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	180	103	77	54	40	14	10	22	12	13	15
Median	3	3	3	3	3	3	3.5	3.5	4	3	3
Max	5	5	5	5	5	5	4	5	5	5	5
Min	1	1	1	1	1	1	2	1	1	1	1
Missing	5	5	0	3	0	0	0	1	0	1	0

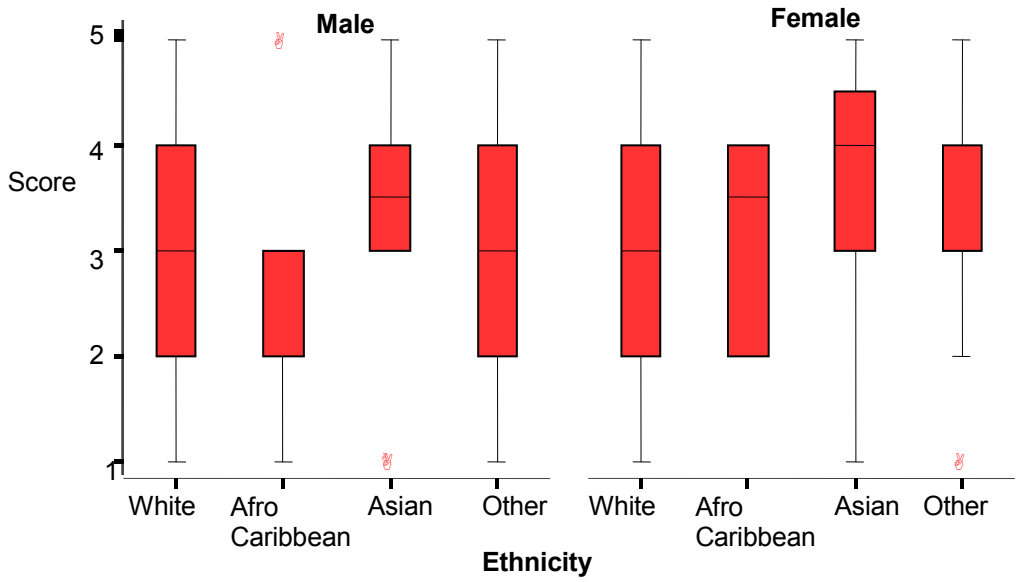

Figure 4.4: Median Scores for Dependency by Gender and Ethnicity

It can be seen that there was a wide range of scores for all four groups. The mean rank for dependency for Asian males was 63.75, while Afro-Caribbean males had a mean rank of 40.46, indicating that the Asian group reported needing more support where assessed. Within the female ethnic groups, the ranking ranged from a maximum of 50.67 for the Asian women down to a mean rank of 34.94 for the White Caucasian female group. However, analysis using the Kruskal Wallis test showed no significant differences of scoring within the male or female ethnic groups.

4.4.4 Dressing

A score of 1 indicates the ability to dress independently, 2 with difficulty, 3 able to wash only and a score of 4 indicates that the patient requires total assistance with dressing. Table 4.6 shows that the majority of patients within all four groups (with the exception of the males in the Other group) required some help with dressing. The Kruskal Wallis test results showed that there were significant differences between the mean ranks in the male group (White Caucasian 52.12, Afro-Caribbean 46.43, Asian, 66.52 and Other 41.0), but there were no significant differences in the amount of help needed by the four groups of females. Post hoc evaluation using the Mann Whitney U test of the male group showed that the Asian group required significantly (p = ·014) more assistance than those patients in the Other and Afro-Caribbean groups.

Table 4.6: Scores for Dressing by Ethnicity and Gender

Dressing	Whole Group			White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	181	105	76	56	39	14	10	22	12	13	15
Median	2	2	2.5	2	3	1.5	1.5	2.5	3	1	2
Min	1	1	1	1	1	1	1	1	1	1	1
Max	4	4	4	4	4	3	3	4	4	3	4
Missing	4	3	1	1	1	0	0	1	0	1	0

4.4.5 Eyesight

Eyesight was assessed on a score of 1 to 4 (where 1 = good eyesight, 2 = uses spectacles, 3 = poor with spectacles and 4 = blind). There were no significant differences within the male and female groupings. Two male patients (1 White Caucasian, 1 Afro-Caribbean) were blind (Nos. 196 and 69). Forty four patients (23 male, 21 female - equally distributed across the groups) had poor eyesight even when wearing spectacles.

Table 4.7: Scores for Eyesight by Ethnicity and Gender

Eyesight		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	181	105	76	56	39	14	10	22	12	13	15
Median	2	2	2	2	2	1.5	2.5	1	2	2	2
Min	1	1	1	1	1	1	1	1	1	1	1
Max	4	4	3	4	3	4	3	3	3	3	3
Missing	4	3	1	1	1	0	0	1	0	1	0

The effect of impaired eyesight on the functional, physical, psychological and social variables was investigated further. Looking at the inter-relationship across both gender groups, analysis using Spearman's rho showed a significant positive correlation with eyesight and dependency (p =·012) and that the positive correlations with both mobility and maintenance (see sections 4.4.10 & 4.4.11 for mobility and maintenance respectively) approached significant levels of p = ·056 and p = ·063.

In terms of racial groupings, Table 4.8 shows that there was a medium correlation between impaired eyesight and both maintenance and mobility in the Afro-Caribbean and Other groups. There were no significant correlations between eyesight and the selected variables in the female groups.

Table 4.8: Significant Correlations Between Eyesight and Maintenance, Mobility and Barthel Index in the Male Groups

Gender & Ethnicity	Maintenance				Mobility				Barthel Index			
Male	n	rho	CoD	p	n	rho	CoD	p	n	rho	CoD	p
Afro-Caribbean	14	·62	62	·017*								
Other					13	·07	70	·008*	13	-·73	-73	·016*

*Correlation is significant at 0·05 level 2 tailed.
CoD = Co-efficient of determination

4.4.6 Feet

There were no apparent differences in the condition of the subjects' feet (where 1 = normal, 2 = regular chiropody (no pain), 3 = discomfort, no chiropody, 4 = painful, no chiropody, and 5 = painful with chiropody in the male and female patients across all four groups). Only one 54 year old Asian female (no. 190) with a left sided stroke scored 4, indicating that her feet were painful and she had not been to a chiropodist.

Table 4.9: Scores for Feet Condition by Ethnicity and Gender

Feet		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	181	104	77	56	40	14	10	21	12	13	15
Median	1	1	1	1	1	1	1	1	1	1	1
Min	1	1	1	1	1	1	1	1	1	1	1
Max	4	3	4	3	3	3	3	3	4	3	3
Missing	4	4	0	1	0	0	0	2	0	1	0

4.4.7 Feeding

Feeding was assessed on a score of 1-4, where 1 indicates independence, 2 minimal assistance, 3 constant assistance and 4 unable to feed self. One hundred and seventy two (94%) of the patients were able to feed themselves or needed minimal assistance (see Table 4.10).

Table 4.10: Scores for Feeding by Ethnicity and Gender

Feeding		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	1	1	1	1	1	1	1	1	1	1	1
Max	4	4	4	4	4	2	1	4	2	4	2
Min	1	1	1	1	1	1	1	1	1	1	1
Missing	3	3	0	1	0	0	0	1	0	1	0

Nine (8 male, 1 female) patients (nos. 16, 17, 41, 96, 98, 111, 199, 165 and 202) scored 3 or 4, indicating that they were unable or needed constant support to feed themselves; three males and one female were in the White Caucasian group, four males were Asian and one male was in the Other group. All (except for no. 111) rated their health as being poor and all nine had low BI scores ranging from 12 to 2, with a median value of 6. The inter-relationships between these findings will be discussed later.

Analysis using the Kruskal Wallis test showed that there were significant ($p = \cdot 007$) differences in mean ranks of the four male groups in respect of feeding, but there were no apparent differences within the female groups. Comparison of all four male groups using the Mann Whitney U test showed that the Asian males needed significantly more help with feeding than the White Caucasian or Afro-Caribbean males ($p = \cdot 001$ and $p = \cdot 05$ respectively).

4.4.8 Food Preparation

A score of 3 indicates that the person is able to heat a prepared meal and make a cup of tea, while a score of 2 indicates that the patient is unable to cook a meal independently. A score of 4 indicates only being able to make tea and 5 that the patient is unable to prepare meals or make tea, while a score of 1 indicates the ability to independently prepare meals and drinks. Of the total number of patients, 24 (13%) were able to prepare and cook their own

meals and 156 patients (87%) needed some level of support. It would appear that after having had a stroke, a high percentage of patients could feed themselves, but were unable to prepare their own meals.

Table 4.11: Scores for Food Preparation by Ethnicity and Gender

Food preparation		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	1	3	3	3	3	3	2	5	5	4	4
Max	5	5	5	5	5	5	4	5	5	5	5
Min	1	1	1	1	1	1	1	1	1	1	1
Missing	3	3	0	1	0	0	0	1	0	1	0

Table 4.11 illustrates that in both male and female groups there were differences in median and range scores. Kruskal Wallis testing showed that the differences were not significant.

4.4.9 Hearing

There were no differences in median scores when subjects' hearing was assessed (where 1 = no problems with hearing, 2 = some difficulty, 3 = good with aid, 4 = difficulty with hearing aid, and 5 = total deafness). None of the subjects were totally deaf, but six subjects (nos. 15, 41, 92, 99, 105 and 132) had difficulty hearing even with an aid.

Table 4.12: Scores for Hearing by Ethnicity and Gender

Hearing		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	1	1	1	1	1	1	1	1	1	1	1
Min	1	1	1	1	1	1	1	1	1	1	1
Max	4	4	4	4	4	2	2	3	4	2	4
Missing	3	3	0	1	0	0	0	1	0	1	0

4.4.10 Mobility

The Kruskal Wallis test results showed that there were no significant differences in mobility between the groups (where 1 = walks independently, 2 = walks with difficulty, 3 = wheelchair bound, 4 = transfers unaided, and 5 = transfers with help/mainly bedridden). Table 4.13 shows that the median score for mobility was 2, indicating that most patients walked with assistance and/or with an aid. Maximum scores of 5 were recorded for six White Caucasian females (nos. 91, 92, 119, 176, 198 & 200), all of whom used wheelchairs when they were able to get out of bed.

Table 4.13: Scores for Mobility by Gender and Ethnicity

Mobility	Whole Group			White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	2	2	2	2	2	2	2	2	2	2	2
Max	5	4	5	3	5	4	3	3	3	3	3
Min	11	1	1	1	1	1	1	1	1	1	1
Missing	3	3	0	1	0	0	0	1	0	1	0

4.4.11 Maintenance

The ability of the patients to maintain themselves was measured on a scale of independence to dependence (where 0 = can manage to do odd jobs, 2 = can manage with help, 3 = cannot manage without help and 4 = total dependence). Table 4.14 shows that the median score for maintenance was 2. The Kruskal Wallis test showed no significant ($p = .337$ & $p = .386$) differences in maintenance within either the male or female group. As similarly observed in the scores for food preparation, 75% of the subjects were able to manage their daily activities with some help, while 25% (47) of the patients scored 3, indicating that they could only manage with help.

Table 4.14: Scores for Maintenance by Gender and Ethnicity

Maintenance		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	2	2	2	2	2	2	2	2	2	2	2
Max	1	3	3	3	3	3	3	3	3	3	3
Min	3	1	1	1	1	1	1	1	1	1	1
Missing	3	1	2	1	0	0	1	0	1	0	0

4.4.12 Pain

The experience of pain post-stroke was assessed on a rating of none, mild, moderate or severe using a score of 1 to 4, where 1 = none and 4 = severe.

Table 4.15: Scores for Pain by Gender and Ethnicity

Pain		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	2	2	2	1	1.5	1.5	1.5	2	2	1	2
Min	1	1	1	1	1	1	1	1	1	1	1
Max	4	4	4	4	4	3	3	4	4	3	4
Missing	3	3	0	1	0	0	0	1	0	1	0

Table 4.15 shows the median differences and range scores for pain experienced after a stroke. The Kruskal Wallis test showed that there were no significant differences in either gender groups in mean ranking for pain in respect of ethnicity. Out of a total of 182 patients, 47% reported that they had no pain, 28% had mild pain and 17% had moderate pain. Severe pain was reported by 6% (11) of the patients (5 male, 6 female). The association between pain and sleep is presented in the following section.

4.4.13 Sleep

The effect of stroke on sleep is seen in Table 4.16. Sleep disturbance was scored from 1 = 'normal' sleep pattern, 2 = disturbed occasionally, 3 = disturbed regularly (required night sedation), and 4 = severely disturbed.

Table 4.16: Scores for Sleep by Gender and Ethnicity

Sleep		Whole Group		White Caucasian		Afro-Caribbean		Asian male		Other	
		m	f	m	f	m	f	m	f	m	f
N	179	103	76	54	39	14	10	22	12	13	15
Median	1	1	1	1	1	1	1	2	2	1	2
Min	1	1	1	1	1	1	1	1	1	1	1
Max	3	3	3	3	3	3	3	3	3	2	3
Missing	6	5	1	3	1	0	0	1	0	1	0

The Kruskal Wallis test scores showed significant differences (p = ·017) between the four male ethnic groups, but no apparent differences within the female ethnic groups. The Mann Whitney U test showed a significant (p = ·014) difference between the mean ranks (10.80 and 12.08 respectively) for the Afro-Caribbean and Asian males. The Asian males reported experiencing more difficulty than the Afro-Caribbean males in sleeping after a stroke. For the whole group, Spearman's rho test showed there was a significant (p = ·005) correlation for the female patients between pain and sleep, but there was no comparable significant correlation found within the male group.

4.4.14 Barthel Index (BI)

Table 4.17 and Figure 4.5 show the median and range scores for the total scores of the BI. The Kruskal Wallis test showed a significant (p = ·003) difference within the male group. The mean ranks for the male White Caucasian and Afro-Caribbean groups were 54.60 and 57.86 respectively, whereas the mean ranks for the Asian group was 33.98 and the Other

group was 52.35. The Mann Whitney U test showed significant (p = ·013 & p = ·005) differences respectively between Asian and both Afro-Caribbean and White Caucasian males. Although the Kruskal Wallis tests found that there were no significant differences between the female groupings, it can be seen that there was a tendency for the Asian women to need more assistance.

Table 4.17: Scores for Barthel Index by Ethnicity and Gender

BI Total		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	175	100	75	55	39	14	9	21	12	10	15
Median	15	15	15	16	15	18	17	12	10.5	15	14
Min	2	2	2	2	2	7	8	4	7	6	3
Max	20	20	20	20	20	20	20	20	20	20	19
Missing	1	8	2	2	1	0	1	2	0	4	0

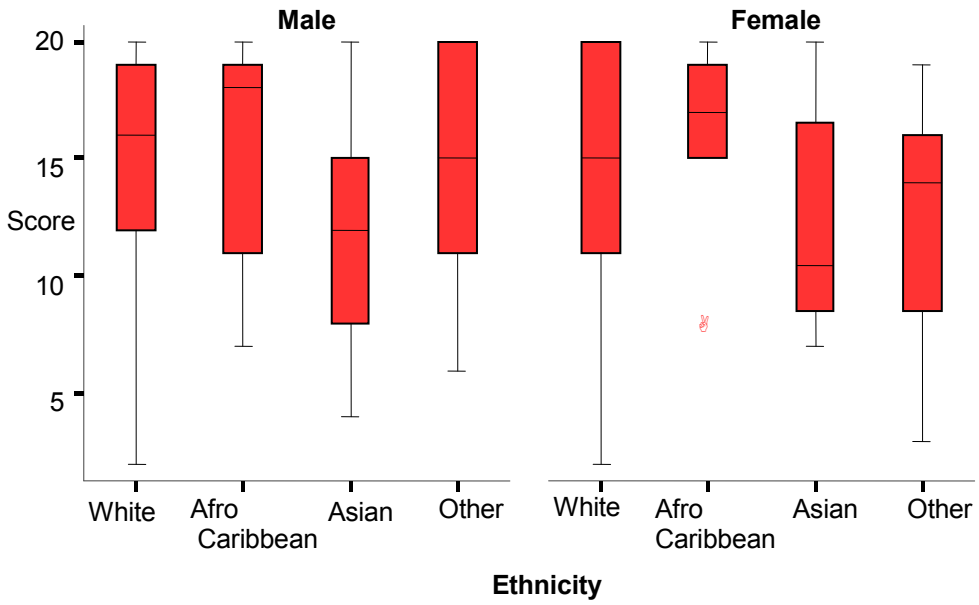

Figure 4.5: Box and Whisker Plot for BI by Ethnicity and Gender

Figure 4.5 shows that in each ethnic group of male patients there were ceiling scores of 20 and scores of 20 in all but the Other female group. The Afro-Caribbean males had the highest median score of 18, with three males scoring 20 (21.4%). The White Caucasian male group had lower median scores of 16, with thirteen (24%) patients scoring 20. In contrast, the Asian males had a median score of 12, with one (5%) scoring 20. Their low median score supports the earlier findings that the Asian patients required greater support in all activities of daily living. It should be noted that nine out of ten Afro-Caribbean females had high BI ratings, with the exception of one patient who scored a BI of 8.

4.5 Psychosocial Variables

Analysis for the psychological variables by gender and ethnicity can be seen in Tables 4.18 to 4.25.

4.5.1 Behaviour

This variable was assessed on a scale of 1 to 5 (where 1 = fully co-operative, 2 = verbally aggressive occasionally, 3 = verbally aggressive frequently, 4 = physically aggressive occasionally, and 5 = makes physical attacks on other people). There were no apparent differences in behaviour scores between the male and female groups. Most patients were scored as being fully co-operative, although a few were occasionally verbally aggressive and three male subjects (2 White Caucasian and 1 Asian) were reported as being frequently verbally aggressive.

4.5.2 Memory

This function was assessed on a scale of 1 to 6 (where a score of 1 = the ability to retain information, 2 = forgets recent events [short-term memory affected], 3 = long-term memory functioning, 4 = moderate impairment [short-term memory affected, but long-term

memory good, or vice versa], 5 = severe impairment [difficulty with both long-term and short-term memory], and 6 = total memory loss).

Table 4.18: Scores for Memory by Ethnicity and Gender

Memory		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	181	104	77	55	40	14	10	22	12	13	15
Median	1	1.5	1	1	1	1	2	2	1.5	1	2
Max	4	3	4	3	4	2	4	3	2	3	4
Min	1	1	1	1	1	1	1	1	1	1	1
Missing	4	4	0	2	0	0	0	1	0	1	0

The Kruskal Wallis test showed that there was no apparent difference in either gender groups in respect of ethnicity. Half of the patients (n = 91, 50%) scored 1 in that they were able to retain information and just less than half (n = 78, 43%) that they tended to forget recent events, while the remaining nine (5%) either had long-term memory problems, and three women had scores of 4 for moderate memory impairment.

4.5.3 Mood

Table 4.19 shows the findings for the assessment of mood post-stroke. This assessment looked at depression and was assessed on a score of 1 to 4 (where 1 was assessed as 'normal' self, 2 = mildly depressed, 3 = intermittently depressed and 4 = severely depressed).

Table 4.19: Scores for Mood by Ethnicity and Gender

Mood		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	1.	1	1	1	1	1.50	1	1	2	2	2
Max	3	3	3	3	3	2	2	3	2	3	3
Min	1	1	1	1	1	1	1	1	1	1	1
Missing	3	3	0	1	0	0	0	1	0	1	0

The Kruskal Wallis test showed that there were no differences in mean ranks within the gender groups in respect of ethnicity. Many (n = 103, 56%) patients stated that they were their normal selves and not depressed. Some (n = 62, 34%) were mildly depressed and a few (n = 17, 9%) were intermittently depressed. None of the Afro-Caribbean patients and none of the Asian females scored 3, indicating that no-one in these two groups reported that they were intermittently depressed.

4.5.4 Orientation

This variable was assessed on a scale of 1 to 5, focusing on orientation to time and place (where 1 = completely orientated, 2 = does not always remember time, 3 = does not always remember time and place, 4 = oriented only in familiar surroundings, and 5 = completely disoriented). The results are shown in Table 4.20.

Table 4.20: Scores for Orientation by Gender and Ethnicity

Orientation		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	182	105	77	56	40	14	10	22	12	13	15
Median	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Max	4	3	4	3	3	2	4	3	3	2	3
Min	1	1	1	1	1	1	1	1	1	1	1
Missing	3	3	0	1	0	0	0	1	0	1	0

The Kruskal Wallis test showed that there were no differences in orientation scores in either gender. Most (n = 148, 81%) patients appeared to be well orientated in respect of time and place, although some (n = 27, 15%) did not always remember the time and a few (n = 6, 3%) did not always remember time and place, and two females appeared to be orientated only in familiar surroundings.

4.5.5 Overall Health Rating

Table 4.21 and Figure 4.6 record the median differences for health rating (where 1 = very good, 2 = good, 3 = fair, 4 = poor and 5 = very poor).

Table 4.21: Scores for Health Rating by Ethnicity and Gender

Health Rating	Whole Group			White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
N	180	103	77	55	40	14	10	22	12	12	15
Median	3	3	3	3	3	3	3	3	4	3	3
Min	1	1	1	1	1	2	3	3	1	2	2
Max	5	5	4	4	4	4	4	5	4	4	4
Missing	5	5	0	2	0	0	0	1	0	2	0

Figure 4.6 shows the findings for health rating for each of the four ethnic groups within the male and female groupings.

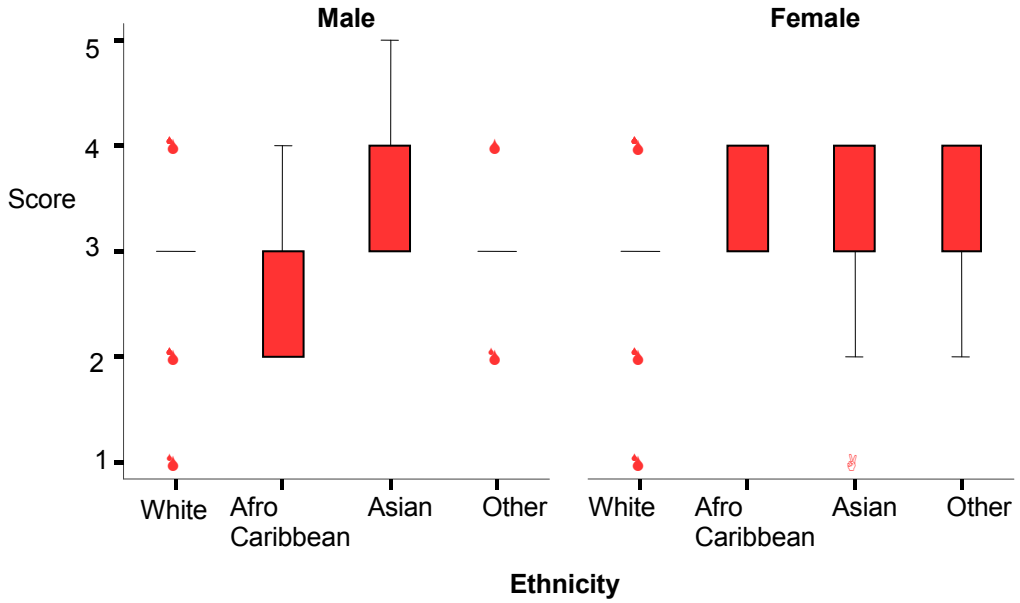

Figure 4.6: Box and Whisker Plot for Health Rating by Ethnicity and Gender

The Kruskal Wallis tests showed that there were significant (p = ·001) differences in the mean ranks in the four male ethnic groups, but no significant differences in the mean ranks of the four female groups. Only two White males, three White females and one Asian female scored their health as very good. All ten Afro-Caribbean females scored their health as either fair (3) or poor (4). Further analyses using the Mann Whitney U test indicated a significance (p = ·002) within this group. The Asian males (rank = 70.61) rated their health significantly worse than the Afro-Caribbean males (rank = 41.32). Three of these Asian males (nos. 4, 5 and 189) rated their health as being very poor. These three patients had BIs of 9, 8 and 7 respectively.

4.6 Social Variables

The variables explored in the social category (Table 4.22) showed no differences in the median scores for social engagement (where 1 = initiates and accepts social contact, 2 = accepts social contact only, 3 = avoids social contact and 4 = mute/inactive and no social contact) in either of the two gender groupings.

Table 4.22: Scores for Social Engagement by Ethnicity and Gender

Social Engagement		Whole Group		White Caucasian		Afro-Caribbean		Asian male		Other	
		m	f	m	f	m	f	m	f	m	f
n	182	105	77	56	40	14	10	22	12	13	15
Median	2.00	2.00	2.00	1.00	2.00	2.00	1.00	2.00	2.00	2.00	2.00
Min	1	1	1	1	1	1	1	1	1	1	1
Max	4	4	3	3	3	2	3	4	3	4	3
Missing	3	3	0	1	0	0	0	1	0	1	0

Eighty one (44.5%) patients initiated and accepted social contact, while 88 (48%) of patients only accepted social contact, eleven (6%) avoided social contact and four males were mute and apparently had no social contact. One Afro-Caribbean female (no. 177), a 66 year old who rated her health as poor and was wheelchair bound with a BI of 8 also assessed herself as avoiding social contact.

4.6.1 Care Workers

Care support was assessed based on provision by either (1) a professional or (2) a non-professional carer. The resulting data was nominal, meaning that the numbers assigned had no meaning other than denoting the professional or non-professional background experience of the carer. Table 4.23 shows that for all groupings, a greater percentage (71%) of patient care was provided by non-professionals and family members rather than by professionally trained individuals.

Table 4.23: Status of Carer by Ethnicity and Gender

Carer Type		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
	n	m	f	m	f	m	f	m	f	m	f
	166	97	69	50	33	12	10	22	12	13	14
Professional	48	24	24	17	13	1	3	3	3	3	5
Non-professional	118	73	45	33	20	11	7	10	9	10	9
Missing	19	11	8	7	7	2	0	1	0	1	1

Figure 4.7 shows the distribution of respective different professional and non-professional care within the male and female ethnic groups. Within the male grouping, 34% of White Caucasian males received professional care, the Other group received 23%, the Asian group received 13.6%, while only 8.33% of Afro-Caribbean males received professional rather than non-professional care. It is possible that the non-professional care was provided by members of the family, but these details were not documented.

Figure 4.7 shows that the female stroke patients received a higher percentage of professional support, but that the percentage differences were not so marked. 39% of the White Caucasian females received professional care, while similarly 35.7% of the Other group, 30% of the Afro-Caribbean group and 25% of the Asian group received professional help. The figures suggest that the Afro-Caribbean and Asian men received the most non-professional care and possibly family support. This hypothesis is supported by the following section on carer support.

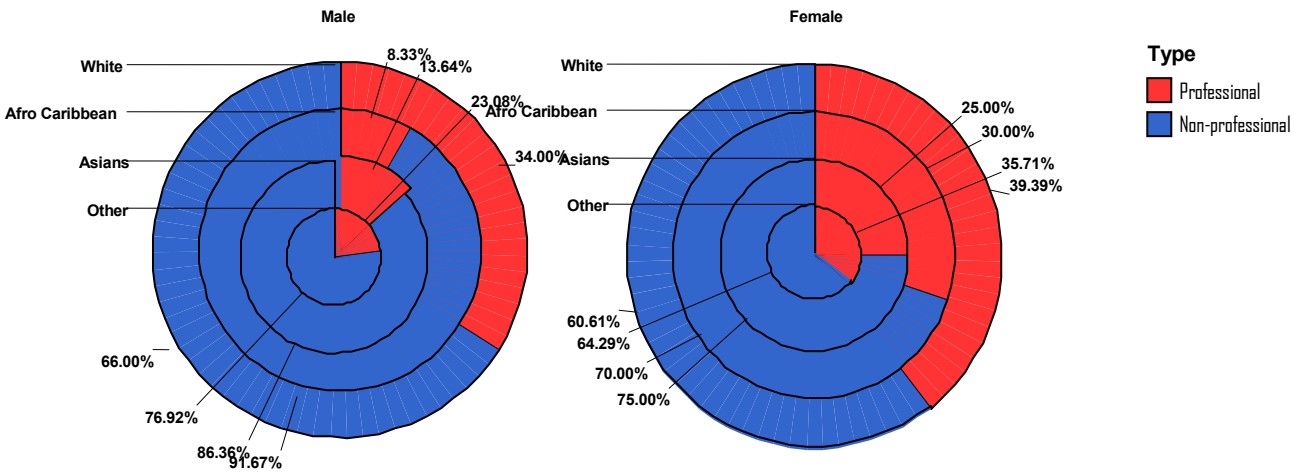

Figure 4.7: Percentage of Care Support by Gender and Ethnicity

4.6.2 Carer Support

Table 4.24 presents the assessment of carer support (0 = not applicable, 1 = lives in same house, 2 = nearby, regular visits and 3 = irregular visits). Further investigation shows that

119 (64%) of the patients had carers living in the same house, 40 (21.6%) had carers living nearby and the remaining 26 (14.1%) patients reported that their carer visits were irregular.

Table 4.24: Scores for Carer Support by Ethnicity and Gender

Carer Support		Whole Group		White Caucasian		Afro-Caribbean		Asian		Other	
		m	f	m	f	m	f	m	f	m	f
n	185	108	77	57	40	14	10	23	12	14	15
Median	1	1	1	1	1	1	1	1	1	1	1
Min	0	0	0	0	0	1	1	0	1	0	0
Max	3	3	3	2	3	3	2	2	2	2	3
Missing	0	0	0	0	0	0	0	0	0	0	0

The Kruskal Wallis test results show a significant (p = ·043) difference between the male groups. Further analysis using the Mann Whitney U test showed that the Asian male patients received significantly (p = ·015) more carer support than the Afro-Caribbean males.

4.7 Summary of Findings

This section presents a summary of the Kruskal Wallis tests (Table 4.25) used to determine differences in ranking and the divergences in ranges and median scores for each of the outcome variables. This table is based on the functional variables.

4.7.1 Physical and Functional Variables

In summary, there were significant differences between the male ethnic groups in the areas of dressing (p = ·047), feeding (p = ·007), sleep (p = ·0017) and BI total (p = ·03), and with the female grouping in respect of bathing (p = ·016). These significant findings were then further explored using the Mann Whitney U test (see Table 4.27). Overall, the Asian group were shown to have needed the most support when tested against the Afro-Caribbean

group and the White Caucasian group. In terms of dependency, the Kruskal Wallis test showed no significant differences in the female group; however, mean ranks indicate that Asian women (50.67) and Other (40.30) were more dependent than their Afro-Caribbean (39.30) and White Caucasian (34.94) counterparts. Afro-Caribbean women (32.9) indicated that they needed the least amount of support in dressing and the ability to walk (32.95) across the four female groups. The Barthel Index showed that the Afro-Caribbean women (47.72) required the least amount of support in terms of activities of daily living.

Table 4.25: Kruskal Wallis Test for Physical and Functional Variables by Ethnicity and Gender

	Bathing		Dependency		Dressing		Eyesight		Feeding		Mobility		Pain		Sleep		BI total	
Groups	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**
Male																		
White Caucasian	56	51.90	54	50.96	56	52.12	56	56.96	56	48.25*	56	53.30	56	50.53	54	49.55	56	54.60
Afro-Caribbean	14	48.96	14	40.46	14	46.43	14	51.71	14	49.43*	14	51.90	14	48.96	14	43.46	14	57.86
Asian	22	60.80	22	63.75	22	66.52*	22	41.91	22	66.36	22	56.10	22	64.82	22	66.95*	22	33.98*
Other	12	44.00	13	48.85	13	41.00*	13	56.08	13	54.69	13	47.80	13	48.00	13	40.08*	13	52.35*
p value	0·35		0·093		0·047		0·198		0·007		0··849		0·17		0·017		0·03	
Female																		
White Caucasian	40	36.18	40	34.94	39	36.97	39	34.69	40	40.31	40	40.95	40	35.74	39	33.27	39	41.32
Afro-Caribbean	10	34.10*	10	39.30	10	32.9	10	47.95	10	34.50	10	32.95	10	36.55	10	40.20	9	47.72
Asian	12	56.25*	12	50.67	12	48.00	12	38.54	12	37.67	12	38.92	12	46.42	12	45.08	12	28.63
Other	15	36.00	15	40.30	15	38.6	15	42.07	15	39.57	15	38.87	15	43.40	15	45.70	15	31.03
p value	0·016		0·173		0·315		0·282		0·639		0·763		0·356		0·112		0·089	

**p is significant at 0·05 level 2 tailed*

4.8 Summary of the Psychological and Social Variables

There were no apparent differences in behaviour and orientation scores in either of the gender groups with respect of ethnicity. Few cases of aggression were reported in behaviour and most patients appeared to be well orientated in respect of time and place.

There were no significant differences in the female ethnic groups in respect of the psychosocial variables. Table 4.26 presents the mean ranks by ethnicity and gender, along with the level of significance determined for carer support, health rating, memory and mood.

Table 4.26: Kruskal Wallis Test for Psychological Variables by Ethnicity and Gender

Groups	Carer Support		Health Rating		Memory		Mood	
Male	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**	**n**	**Mean rank**
White Caucasian	57	56.59	55	48.43	55	52.67	56	49.95
Afro-Caribbean	14	66.14*	14	41.32*	14	43.82	14	55.25
Asian	23	46.24*	22	70.61*	22	58.55	22	55.05
Other	14	47.93	12	46.71	13	50.88	13	60.27
p value	108	0·04	103	0·001	104	0·45	105	0·58

It can be seen that there were significant differences in mean ranks within the male groups for carer support ($p = \cdot 04$) and health rating ($p = \cdot 0001$).

4.9 Mann Whitney U Tests for Physical, Functional and Social Variables

Mann Whitney U tests were performed on those variables that had a value of $p < \cdot 05$ (see Tables 4.27 and 4.28) to determine where the significant differences in gender groupings between ethnic groups occurred.

Table 4.27: Mann Whitney U Test for Physical and Functional Variables

	Male					Female				
	Mean ranks (n)	∑ mean ranks	Mann Whitney U	Z	sig 2 tailed	Mean ranks (n)	∑ mean ranks	Mann Whitney U	Z	sig 2 tailed
Bathing										
Afro-Caribbean						7.95 (10)	79.5	24.5	-2.52	0·013
Asian						14.46 (12)	173.5			
Asian						18.13 (12)	217.5	40.5	-2.61	0·010
Other						10.70 (15)	160.5			
Dressing										
Asian	21.25 (22)	466.5	72.5	-2.52	0·014					
Other	12.58 (13)	163.5								
Asian	21.25 (22)	466.5	93.5	-2.06	0·014					
Afro-Caribbean	14.18 (14)	467.5								
Dependency										
Afro-Caribbean	13.29 (14)	186.0	81.0	-2.52	0·010					
Asian	21.82 (22)	480.0								
Feeding										
Asian	20.86 (22)	459.0	102.0	-2.02	0·043					
Afro-Caribbean	14.79 (14)	207.0								
Sleep										
Afro-Caribbean	13.50 (14)	189	84	-2.5	0·014					
Asian	21.68 (22)	477								
Barthel Index										
Afro-Caribbean	23.21 (14)	325	74	-2.5	0·013					
Asian	14.52 (21)	305								
Barthel Index										
White Caucasian	42.81 (55)	2354.5	340.5	-2.8	0·005					
Asian	27.21 (21)	571.5								

Table 4.28: Mann Whitney U Test for Social Variables

	Male				
	Mean ranks (n)	∑ mean ranks	Mann Whitney U	Z	sig 2 tailed
Carer Support					
Afro-Caribbean	23.21 (14)	325	102	-1.7	0·015
Asian	16.43 (23)	378			
Health Rating					
Afro-Caribbean	41.32 (14)	175	69.5	-3.0	0·002
Asian	70.61 (22)	492			

4.10 Discussion

As stated, the aim of Phase 1 of this study was to evaluate if there were any differences in functional, psychological and social aspects of life after stroke variables in both male and female clinic attendees in terms of ethnicity and gender, and to try to determine how these personal matters impact on the lives of both groups of patients as they recover after having had a stroke. Systematic exploration of the reported data showed that there were indeed differences within both the male and female groups in terms of functional, psychological and social aspects in their recovery after stroke in the four different racial groups.

Demographic analysis showed the composition of an inner city stroke population and their access to healthcare services by attending an outpatient stroke clinic. Analysis of the data allowed identification of the age of stroke occurrence and differences in the findings in both males and females for the four ethnic groupings. The concern was firstly to determine the influence and prevalence of stroke within the London Borough of Newham discussed in the next section, and secondly to extend this analysis to investigate any differences in functional, physical, psychological and social outcomes.

4.10.1 Stroke Clinic Attendees

There were more stroke (185) than TIA (28) clinic attendees. This is not surprising as a TIA is a warning sign for stroke (Wolfe, 2007) and if the TIA is caught in time, treatment of modifiable factors such as diet, stress management and exercise can reduce the risk of stroke (Department of Health, 2001; Mant, Winner, Roche, & Wade, 2005). Therefore, if effective health promotion is already in place in Newham, which relies on patient compliance (Corcoran, 2007), then this finding should ideally be the reverse (i.e. less stroke patients and more TIA patients). A possible explanation for the higher level of stroke is that some strokes occur without any warning signs. A TIA, as the name suggests, is transient and recovery is usually within 24 hours (Rosamond *et al.*, 2008). Secondly, those with TIA (based on more men with stroke) may not have understood the need to attend a clinic for what is considered a warning sign. The body is often used to assess health severity by those experiencing illness (Shilling, 1993). This concept of the body as a compass is also captured in the qualitative phase of the study under Master Theme 2, 'Re-telling the stroke attack: the knowledgeable body, a medium for sense making' (see Section 6.3). A final possible reason may be the developing practice in the NHS where primary physicians now have a special interest[2] (GPwSI) and hold clinics within their practice. This may account for reduced TIAs recorded in this dataset.

4.10.2 Age and Ethnicity

The mean age for onset of stroke of these clinic patients was 66.8 years (SD 12.64) with an equal number of left and right sided strokes. More males (n = 108) than females (n = 77) attended the outpatient stroke clinic over the period of the study. The preponderance of

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[2] A GPwSI is a GP with additional training and experience in a specific clinical area, who takes referrals for the assessment/treatment of patients who may otherwise have been referred directly to a secondary care consultant, or who provides an enhanced service for particular conditions or patient groups. GPwSIs are generally appointed to meet the needs of their local Primary Care Trust/Primary Care Organisation and typically undertake two sessions per week in their specialty (Royal College of Physicians, 2001).

male patients could have been due to the positive effects of health campaigns targeted towards men resulting in a behaviour change (Corcoran, 2007). Within the London Borough of Newham, the Neighbourhood Renewal Scheme (funded by Saving Lives Our Healthier Nation 1999) ran special health promotion campaigns for older people, with a focus on men. Calculations concerning the population at risk in Newham (total population at risk = 142,862) showed that from the age of 35 years to 90+ years, 96,000 (67%) were White Caucasian, 8,553 (6%) were Afro-Caribbean, 23,643 (16.5%) Asian and 14,666 (10.3%) were in the Other group. In my study (inclusive of TIAs), there was a distribution of 115 (54%) White Caucasian people, 26 (12.2%) Afro-Caribbean, 37 (17.4%) Asian and 35 (16.4%) Other. I was able to show (see Table 4.2) that these figures, to a considerable extent, reflect the 'at risk' population within the borough. In terms of age, there was a difference between the four female ethnic groups; White Caucasian women recorded a mean age of 72.0 ±11.2 years, Afro-Caribbean 67.6 ± 9.1, Asian 64.3 ± 10.7 and Other 61.6 ±12.0. This is similar to the work of Lawrence *et al.* (2001) and Wolfe *et al.* (2005), as identified earlier in section 4.2.2.

Most studies looking at incidents of stroke have shown that ethnic minorities, mainly blacks, tend to be prone to strokes (Hajat, Tilling, Stewart, Lemic-Stojcevic & Wolfe, 2004; Kelaher, Paul, Lambert, Ahmad, Fenton & Smith, 2003; Stewart *et al*., 1999). Interpretation of differences in disease among ethnic groups is often difficult depending on the classification of ethnicity. Using the South London Stroke Register and grouping Afro-Caribbeans and Africans together, Wolfe (2006) found that black Caribbeans had a higher stroke incidence than white people. In this present study, Africans and Afro-Caribbeans were separated and, as already described, the information gathered from the last national census and the London Health Observatory showed that in the inner city population of Newham there were more White Caucasian people (46%) in the at risk population for stroke.

Moorley and Goodfellow (cited in Corcoran, 2007), writing on hard to reach groups, suggest that patients from a white ethnic background are more likely to attend clinics and

to appreciate their long-term health benefits, based on the existing literature concerning this area. Previous studies (Lorenzo *et al.*, 2002; Sacco *et al.*, 1989; Williams, 2008) have found that the cultural positive attitude (trust in scientific medicine) towards the medical profession motivates white populations to adhere to follow-up appointments, while ethnic minorities may choose other avenues such as their own cultural and religious centres for guidance. Other studies have suggested that ethnic minority groups tend not to access health services as regularly as other groups (as noted by Curtis & Lawson [2000] in their research on ethnic minority health with a particular focus on East London). This remains an area of concern, especially for health promoters who have noted the following as contributing factors: transport (Davis & NHS Health Development Agency, 2005), carers' support and disability access (Keer, 2004).

4.10.3 Postcode Areas

For this study, I identified from the postcodes where each of the patients lived and established the percentage of patients from each ethnic grouping who lived in each postal area. The highest number of subjects came from E6. Exploring the relative distances from each postcode area to the NUHT in E13, I found that most areas of E6 are within a 2.5 km radius of the hospital. Three patients came from outside of the borough and it may be that they fell into the category of referral to a specialist clinic and service which the NUHT provides, or that their family lived nearby and they chose to return to the hospital for follow-up appointments. There were no patients attending the clinic from Green Street East or West. One hypothesis is that transport links are a key factor regarding the ease of assessing the Stroke Outpatient Clinic at NUHT. It is possible to assume that those who have had a stroke went to other hospitals, such as The Royal London Hospital Whitechapel or Hackney Homerton University Hospital, all of which are within geographical range of their homes. Alternative reasons for differences between the prevalent rates in the borough and clinic attendance may be death following stroke. The standard mortality ratio for stroke in Newham for 2004 was 157 per 10,000 and it is reasonable to suppose that otherwise they might have sought outpatient care. Additionally, some patients, and possibly those

with more severe impairments, may have preferred that their aftercare was managed by a local GP surgery.

4.10.4 Functional and Physical Abilities

Stroke can be described as a catastrophic event affecting all aspects of an individual's life. Bonita and Beaglehole (1988) looked at recovery of motor function after stroke; in their study, 88% of their sample who had experienced a stroke suffered a motor deficit. The present findings indicate that overall the male patients were significantly more dependent on professional and personal support than the female patients (see Figure 4.6). Overall, female groups received more professional care than the male groups. Within the male group, 34% of the White males received professional care, 23% for the Other, 13.64% for the Asian group and 8.3% for the Afro-Caribbean group, while in the female group 39.4% of the White caucasian females received professional care, 35.7% of the Other, 30% of the Afro-Caribbeans and 25% of the Asian group. The most marked difference in percentages of professional care received occurred in the Afro-Caribbean group, where a higher percentage of the women required professional care compared with the male patients. This suggests that, in the Afro-Caribbean community, more non-professional care is given to male patients following a stroke than to female patients.

There were significant differences within the ethnic groups in respect of dependency and maintenance. In the case of dependency, which measures the assistance required for both domestic and hygiene care, it was found that overall both groups of patients had a median score of 3, indicating that they needed domestic help, but as already stated there was a wide range of scores. In respect of maintenance (the ability to do things about the house) and mobility (needs assistance with walking), most patients reported that they needed some level of support (median score = 2).

A recent paper by Rowe *et al.* (2009), looking at visual impairment in 501 patients following stroke, found that only 8% of the patients referred with visual difficulty had

normal vision status on examination. They stressed the need for a full eye assessment following a stroke, which should be offered together with targeted treatment and/or advice. My study was interested in assessing the impact of self-reported visual impairment on functional activities. 24% of the subjects (21 male, 23 female) scored 3, indicating that they had difficulty seeing despite wearing their glasses. Further analysis within the male group using Spearman's rho showed that there was a positive correlation in the Afro-Caribbean group between eyesight and maintenance ($p = \cdot 017$), in the Other group between eyesight and mobility ($p = \cdot 008$), and the Barthel index ($p = \cdot 016$). These findings highlight the importance of visual assessment and onward referral of those with visual impairment for assessment and appropriate intervention by orthoptists.

Feeding and food preparation are key aspects of independence and self-preservation. It was interesting that the majority of subjects said that they were able to feed themselves independently or needed minimal support, but that in contrast only 24 people (13%) could prepare and cook their meals independently. Of particular note was the significant difference in the support for requirements in feeding within the Asian male group. This finding suggests that Asian men in the early stages of rehabilitation need to be encouraged to feed themselves and to regain independence in feeding themselves.

Jonsson, Lindgren, Norrving and Lindgren (2008) assessed the prevalence and intensity of pain in stroke patients over a one year period. They found that predictors of pain were younger age and sex (female), and that greater pain levels were reported by their female patients and this pain disturbed their sleep. In this present study, the Kruskal Wallis test showed significant differences within the four male ethnic groups, with the Asian males experiencing significantly ($p =\cdot 014$) more difficulty than the Afro-Caribbean males in sleeping after a stroke. For the female patients, there was a significant correlation ($p =\cdot 005$) between pain and sleep. This finding suggests that clinicians need to pay attention to patterns of sleep following stroke, consider the underlying causes and the possible need for medication.

The Barthel Index (as discussed in sections 2.3 and 3.5) has problems with the sensitivity of the scoring (Mayo, Wood-Dauphinee, Cote, Durcan & Carlton, 2002). Patients who remain limited in their ability to perform functional activities can score the maximum score of 20, suggesting that their scores may not reflect their true functional ability. In this study, subjects self-reported their assessment of each activity to the Health Visitor, which was then converted into a BI score (see Chapter 3). This present study showed that the male Asian group had significantly lower BI scores than the Afro-Caribbean and White Caucasian male groups ($p = \cdot 013$ and $p = \cdot 005$ respectively). These differences were not found in the female groups, all of which had lower median scores than their male counterparts.

Using the 1991 census data for London, Curtis and Lawson (2000) found that black Caribbean females were more likely than black Caribbean males to report illness. They considered that the reported illnesses might be due to the pressures of fulfilling social roles and reflecting stoicism among Caribbean females. In contrast, Nazroo (1997), in his study on the health of ethnic minorities in Britain, noted that African Caribbean respondents were less likely to report the limiting effects of illness. This is supported by the findings in this present study. Both Afro-Caribbean groups had the highest BI median scores of 18 and 17 and the highest minimum scores of 7 and 8 respectively, where a minimum score of 8 in the female group was an extreme value (see Table 4.17). The concept of underreporting due to pride is captured in the qualitative phase of the study (see Queenie's narrative on why black Caribbean females are difficult to find in hospital clinics, despite having had a stroke).

Markus *et al*. (2007), using the South London Stroke Register, found that black patients with stroke were significantly younger than white people and had a higher prevalence of hypertension, diabetes and obesity, all of which can contribute to stroke. All their black stroke patients were either first generation migrants from Africa or the West Indies. This present study did not have access to information on socio-economic status or pre-stroke activity of the subjects and risk factors, but in the male patients there are substantial ethnic

differences in the functional levels between the Asian patients and both the White Caucasian and Afro-Caribbean groups as assessed by the BI. The ability to execute basic functional tasks is often seen to be a strong indicator of how well the individual will be able manage their life at home (Eriksson, Appelros, Norrving, Terent & Stegmayr, 2007; Lo *et al*., 2008). In view of the differences that were identified within the gender groups, it would seem appropriate to implement increased rehabilitation efforts and social support for the male and female Asian patients and their carers.

4.10.5 Psychosocial and Social Outcomes

Physical impairment can have an adverse psychological effect on stroke survivors. Stroke affects not only physical functions but also emotions, memory, thinking and communication, therefore both physical and psychosocial functions play a major part in a person's quality of life. In this study, mood was assessed by questions pertaining to depression. An individual's perception of such a sensitive question will influence their answer, and the manner in which the question is asked can also contribute to the response (Nazroo, 1997).

Stroke can often affect the memory of the individual. There were no significant gender differences for memory in this study; approximately 50% had good levels of memory retention. However, mean ranks showed that within the gender groups, Afro-Caribbean males and White Caucasian females had better memory compared to the other groups. 52 males and 39 females reported that they were able to retain information compared to 52 males and 38 females who could not retain at some level. In this study, 34% of the subjects reported being mildly depressed and 17% intermittently depressed. Lai, Perera, Duncan & Bode (2003) found that memory and mood functions can have far reaching effects on the functional recovery of stroke patients.

As indicated in the literature review in Chapter 2, to a great extent health is determined by biological, psychological and social influences. These influences also contribute to the lens

through which the individual views their health status. On a national level, the *Household Survey for England* captures such individual rating/perception. The *Household Survey for England*, published by the Department of Health, is an annual survey of private households; within it, one of the themes surveyed is health and well-being (Department of Health, 2007; Health, 2007), where more than half of men and women aged 65 and over claimed that their health was 'good' or 'very good' (57% of men and 55% of women).

Those surveyed in this study were different to the national findings; this could be due to the compounded factor that Newham is acknowledged as one of the most deprived boroughs in England (Newham Public Health Department, 2009). The level of rating for health in this study ranged from 1 = very good, 2 = good, 3 = fair, 4 = poor and 5 = very poor. The fact that only 3% of the patients reported that their health was very good and the finding that overall subjects reported their health on the lower rating of the scale was not surprising, as Newham has been reported in the literature as possessing contributing factors to poor health.

There were significant differences ($p = \cdot 002$) between the Afro-Caribbean and Asian males for health rating, and both the Asian males and females had the highest mean rank in their respective gender groups, indicating that overall they rated their health as worse than the patients in the other ethnic groups. This may have some relation to cultural values and practices within this particular group. Kelaher (2003) posits that this type of reporting can be due to actual difference in health status, or a methodological artefact as a result of a different understanding of the question. The Center for Disease Control (2011) came to a similar conclusion after reporting in their study that blacks and Hispanics are more likely to report their health as poor and limiting their activities of living. This could be true for the Asian group in this present study. The Department of Health (2000) reported in the *1999 Health Survey for England* that African Caribbeans had lower global health ratings than the general UK population. Therefore, there may have been some under-reporting by Afro-Caribbeans in this study, or there has been an improvement in the health of Afro-Caribbean people due to health promotion efforts and positive engagement by this group.

It is generally accepted that the impact of stroke and loss of motor function leads to the need for formal or informal care support (Clarke, Lawrence & Black, 2000; Rudd, Hoffman, Down, Pearson & Lowe, 2007). The Institute of Health Care and Support (2009) recognise the amount of care and support that is provided by family members. The present study supports this finding, showing that Asian male patients received significantly ($p = \cdot 015$) more carer support than the Afro-Caribbean male patients. Analyses also showed that 64% had carers living in the same home, while 71% reported that their care was provided by non-professionals, indicating family, friends and neighbours as their primary carers.

At a more qualitative level of experience, Hunt and Smith (2004) and Mant *et al.* (2005) report the impact of stroke and how the individual depends on members of their family for support. Both studies conclude that stroke not only affects the individual but also has a direct impact on care giving from immediate family members, indicating the informal care that people with stroke require and subsequent stress upon these care givers.

In this present study, it was seen that more men than women required professional care, and that Afro-Caribbean and Asian men and women had more non-professional care while White Caucasians had more professional care.

Evaluating the nature of this carer support, in terms of whether the carer lived in the same house or nearby making regular visits, the Asian men received significantly ($p = \cdot 015$) more carer support from people living within the same house than the Afro-Caribbean men. One possible explanation for this could be the cultural concept of care and care giving, which is captured in Queenie's narrative in the qualitative phase. Stansbury, Jia, Williams, Vogel and Duncan (2005), in their review of stroke data across the USA, concluded that a cultural construct is crucial to understanding stroke among ethnic minority groups. This understanding includes the way care is perceived by the stroke patient and how they understand care to be delivered.

Women may underreport their need for assistance, carers or use of carers due to their role and function in maintaining a home and household, and therefore retain their stoicism (Curtis & Lawson, 2000). Fulfilling such roles can be viewed as role salience, as these can be salient to the individual's sense of identity; this concept is captured in the qualitative phase of this thesis through the narratives of many of the participants.

4.11 Conclusion

This chapter gives an in-depth view of the functions associated with everyday living and how these affect the health and impact on the lives of patients post-stroke.. This was achieved by gathering data held on paper assessments, which were then entered into an electronic database and analysed using descriptive statistics. Throughout this chapter, the effects of stroke have been presented via different dimensions of health, interpreted as physical (functional ability), psychological influences (which cover depression and behaviour) and social, including engagement and level of carer support and type of care utilised.

Demographic profiling reflected representativeness of stroke prevalence similar to that of the London Health Observatory figures, based on the 2001 census figures. Careful analysis of both attendance of the clinic and calculations concerning the population at risk in Newham showed that the clinic attendance figures to a large extent reflected the at risk population within this inner city and that the findings can be applied to similar inner city populations. The findings also suggest that public transport plays a key role in clinic attendance.

Phase 1 of the study showed in terms of demographic profile that there were more males than females, and White Caucasians outnumbered the other ethnic groups. There was little difference in mean ages between the genders (male 68.7±12.9 and female 68.2 ±11.7 years). One-way ANOVA showed no significant differences in age between the genders;

however, it did show a statistical difference (p = ·013) between the older White Caucasian women and the younger women in the Other group.

Phase 1 findings in terms of male gender groups showed significant differences between Afro-Caribbean and Asian males regarding care support (p = ·015), sleep (p = ·014), Barthel Index (p = ·013) and health rating for Afro-Caribbean and Asian males (p = ·002). Significant differences (p = ·005) were established for the BI between the White Caucasian and Asian male groups. These findings show that the Asian male patients found it more difficult to live with stroke than the Afro-Caribbean or White Caucasian males. There were fewer significant differences within female groups. However, it was shown that the only significant (p = ·013) difference was in the choice of bathing between the Afro-Caribbean and Asian women. But, in particular, it was shown that the female groups required more professional care support than the male groups. This was particularly noticeable in the Afro-Caribbean group, suggesting that Afro-Caribbean men receive more non-professional care support, possibly from their own community. Phase 2 will seek to ascertain to what extent culture and gender shape the experiences of female Afro-Caribbeans in their lives after stroke.

The next chapter will introduce the methodology for the qualitative phase (Phase 2) of this study, which will serve to complement this quantitative Phase 1.

CHAPTER 5: QUALITATIVE METHODOLOGY

5.1 Introduction

This chapter presents the qualitative methodology used in Phase 2, outlining the rationale for the data collection techniques used. It explains how the data was collected, managed and analysed using the Interpretative Phenomenological Analysis (IPA) principles and practice (Smith, 2004; Smith & Osborn, 2008). The chapter focuses on using methods appropriate to investigating cultural meaning and significance attached to stroke by Afro-Caribbean women living in the London Borough of Newham.

This qualitative second phase set out to explore the participants' subjective accounts about life after stroke, the meaning of health and how this shapes their private and social lives. The research question underpinning this second empirical phase of the thesis is rooted in the overlapping theoretical area created by a combined focus on health, subjective well-being and the interaction between culture and illness. The participants were selected from one particular ethnic group (Afro-Caribbean women) and those who participated were between 47 and 85 years of age. The analytic focus of the qualitative framework adopted here allows the researcher to unpack some of the important ways through which experiences of a major cardiovascular disease (stroke) are narrated, understood and embodied in the everyday lives of Afro-Caribbean women. The rationale for choosing this group is that Afro-Caribbean people are highly represented in stroke data (see the works by Balarajan, 1991; Markus *et al*., 2007; Wolfe *et al*., 2005; 2006, covered in Chapter 2) and an exploration of cultural meaning may help to better understand their healthcare needs.

5.2 Criteria for Reporting Qualitative Research

Tong *et al*. (2007) published a criterion in which they identified three main themes for reporting qualitative research: (1) research team and reflexivity; (2) study design; and (3) analysis and findings. The theme of 'research team and reflexivity' is subdivided and concerns the personal characteristics of the researcher and their relationship with the

participants. I informed the participants that I was a nurse and explained why I had an interest in stroke and Afro-Caribbean women. I did not make clear my training or experience as a researcher. In various reflexivity sections throughout this thesis I acknowledge my bias for interest in stroke and Afro-Caribbean women. I had little prior knowledge of my participants, apart from the fact that they had experienced stroke. Participants were given an information letter, so that they were aware of my goals and reasons for undertaking the research.

The study design is divided into three sub-sections. The first, theoretical framework, is concerned with methodological orientation (see sections 2.9, 3.2 and 5.3) and participant sampling (see sections 3.7 and 5.5). The second sub-section covers the setting, and focuses on areas such as where the data was collected and a description of the sample. Sections 3.7 and 5.6 cover the setting and section 5.7 provides an overview of the participants' characteristics. The final sub-section focuses on data collection, discussing information on the interview guide and providing information on audio or visual recordings, return of transcripts to participants and the use of field notes. The interview schedule used in this phase of the study is then provided (see section 5.6.4), highlighting that I returned the transcripts to Margo and Queenie for verification. Finally, the use of the field notes made to help in the analysis is discussed (section 5.8).

Analysis and findings is the final domain, and this is sub-divided into two sections: data analysis and reporting. When analysing data, a researcher is urged to report the number of coders used in the data analysis, derivation of themes, software used and details of participant checking. As this is a Ph.D. study and I was the only coder, I presented my final mapping of themes to my research supervisor for discussion and guidance as appropriate. All data was coded manually, as I felt that the use of computer analysis would detract from my 'doing' an IPA study. Section 5.7 on data analysis indicates how I engaged in this process and arrived at the master and sub-themes. The second sub-section concerns reporting, and this looks at how quotations are presented, the consistency of data and the findings, as well as the clarity of the master and sub-themes.

Chapter 6 then presents and discusses the findings of the master and sub-themes, locating them to extracts from the interviews with participants.

5.3 Qualitative Research – An IPA Decision

The qualitative approach adopted in this second empirical phase of the thesis is informed by the principles of phenomenology, as captured by IPA (Smith & Osborn, 2004). A common assertion of qualitative research is that the researcher and the participants are co-authors in the process of knowledge production and the knowledge claims emerging (Flick, Von Kardorff & Steinke, 2005). In this way, participants' voices are represented - in my study this was achieved via narrative accounts. This co-authorship can possibly serve to facilitate greater clarity and awareness of participants' situations, as well as a sense of empowerment.

Once healthcare staff gain an awareness of the potential of IPA they can easily value the real contribution such research makes to understanding healthcare and illness from the patient's or service user's perspective (Biggerstaff & Thompson, 2008). It is possible for healthcare workers to develop a deeper understanding of not only patients' experiences, but also carers', students' and colleagues' experiences, which in turn may facilitate reflection on current practices and lead to changes that improve or enhance healthcare service provision and training. IPA is rooted in psychology and has emerged as a methodological approach that can be used for exploring in depth how individuals experience and ascribe meaning to a specific phenomenon (Smith & Osborn, 2008). It acknowledges that there is a central role for the analyst in making sense of the participants' personal experiences (Smith, 2004). It is this facet that distinguishes it from the more descriptive phenomenological approaches described by Husserl (1925).

The philosophy of phenomenology was developed by Hurserl and later extended by philosophers such as Heidegger and Gadamar. Hurserl's transcendental phenomenology

places a focus on the individual's 'life world' - here, experience is regarded as the fundamental source of knowledge (Dowling, 2007). This phenomenological variant argues that the 'essence' of a phenomenon can be understood by returning a person's immediate conscious experience of it prior to imposing any reflections or explanations (Clarke, 2009). It is clear that Husserlian phenomenology has influenced IPA in its aim of understanding the individual's experiences. However, it does not seek to 'bracket' the researcher's beliefs and values; instead, it views these as vital in understanding and making sense of the individual's experiences (Shaw, 2001).

Heideggerian phenomenology focuses on 'being' and 'being in the world', which places considerable emphasis on understanding rather than description (Wilding & Whiteford, 2005). Unlike Husserl, Heidegger (1927) emphasises the constant element of personal engagement that emerges from being 'thrown into the world'; here, some events, objects and experiences have more meaning and purpose than others. It is these that create the basis for interpreting and making sense of our experiences. IPA acknowledges that it is not possible to have direct access to someone's 'life world'. The main reason for this is the influence of the researcher's own experiences, values, beliefs and prior knowledge and understanding, all of which are viewed as necessary in interpreting and making sense of a person's experiences. This is viewed as a double hermeneutic, where a "participant is trying to make sense of their world, [and] the researcher is trying to make sense of the participant trying to make sense of their world" (Smith and Osborn, 2008:53).

IPA, when viewed in relation to other forms of phenomenology, interprets participants' beliefs and accepts their stories. This is different to the critical interpretative framework advocated by Koch (1999), as IPA uses a degree of questioning which can be beneficial to the depth of analysis (Smith, Flowers & Larkin, 2009). IPA can be described as a variant of phenomenology whose aims are concerned with exploring individuals' perceptions and experiences (Finlay & Ballinger, 2006). To this end it uses an idiographic approach, whereby the focus is on individuals' cognitive, linguist, affective and physical being; while

Malim, Birch and Wadeley (1992) view ideographic research as addressing the wholeness and uniqueness of the individual, which presents a complete and in-depth picture.

Accounts analysed using IPA privilege the individual, as IPA offers a different perspective from approaches such as grounded theory, which tend to use larger sample numbers to substantiate a theory (Barbour, 2007). The ideographic emphasis of IPA means that the focus is not on large quantities of data, but on gathering quality data that allow a deeper understanding of participants' experiences. IPA recruitment can comprise individual case studies and the researcher should use small sample sizes (Smith & Osborn, 2008).

IPA is not concerned with making generalisations and sample groups should be as homogenous as possible to allow the researcher to explore the phenomenon under investigation, as a specific group shares it. Smith *et al.* (2009) advocate that researchers should use small numbers in IPA studies, while at the same time acknowledging that some researchers may consider smaller sample sizes a limitation. They argue that larger sample sizes could inhibit the richer depth of analysis that smaller participant numbers allow. A potential problem for IPA studies is that the small numbers used means that generalisations are not always feasible. Commonalities across accounts and analytic commentary could lead to useful insights that may have wider implications (Reid, Flowers & Larkin, 2005). IPA researchers should think of and view their research findings in terms of theoretical transferability rather than empirical generalisability (Smith *et al*., 2009).

IPA therefore needs to be firmly rooted in what the participants are actually saying, with direct quotes being used to substantiate findings. These should be used to illustrate and inform master themes, which are firmly anchored thorough direct participant quotes. Participants' quotes and metaphors may also be used in themes, titles or descriptions to further anchor the analysis in their words. By so doing, IPA goes beyond a 'standard' thematic analysis (Brocki & Wearden, 2006). Thematic analysis is a method that provides core skills for other forms of qualitative research analysis. However, the theoretical roots attached to IPA add a sense of depth and purpose that thematic analysis may lack (Braum

& Clarke, 2006). Willig (2001) asserts that IPA allows more room for creativity and freedom compared to other approaches (such as grounded theory). This may have particular relevance to healthcare research for groups that are difficult to reach or where beliefs and expectations may be outside the perceptual field of healthcare staff (Biggerstaff & Thompson, 2008).

5.4 Doing IPA: A Brief Rationale

IPA was chosen for the qualitative phase of the thesis because it allows the researcher to explore a chief research question of the thesis (a concern with participants' gendered, culturally indebted meanings), as well as key dimensions of the embodied experience of life after stroke. IPA is interested in capturing individual, subjective accounts, as well as more global patterns of collectively shared accounts of private experiences. It makes the basic ontological assumption that when trying to make sense on their experiences, people offer narratives that are structured into reoccurring patterns of interpretations (Brocki & Wearden, 2006). The interpretations of the individuals concerned may reflect the context of how they are experiencing a particular phenomenon at the present time in their life cycle. Therefore, interpretations become relative to the experience within the context and time of the individual's life.

> "The approach is phenomenological in that it is concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself" (Smith, Jarman & Osborn, 1999:218).

As with any other qualitative research, IPA acknowledges the active participation of the researcher in the generation of analytical findings, yet allows the researcher to arrive at a map of prevalent meanings across a body of data and present them as themes; a label given by the researcher to express interpretations of meaning. This is known as the 'double hermeneutic', where he makes interpretations about the participants' interpretations.

> "[Access to the participants' personal world] depends on and is complicated by, the researcher's own conception and indeed these are required in order to make sense of that other personal world through a process of interpretative activity. Hence the term interpretative phenomenological analysis is used to signal these two facets of the approach" (Smith *et al*., 1999:51).

IPA uses an ideographic approach where each case study is examined individually in order for the researcher to be able to comment in detail about the preconceptions and understandings of the group (Osborn & Smith, 2006). There are key analytic steps that the researcher needs to follow when making sense of participants' experiences and reflections. The process of IPA not only (as its name indicates) uses phenomenology, but also it incorporates a hermeneutics inquiry (Eatough & Smith, 2006).

5.5 Participants

Participants for the qualitative phase of the study were recruited from three different locations: the Newham University Hospital Trust Stroke Clinic, the Health Visitor for Older People's client list and the various Afro-Caribbean day centres located within the borough. The initial intention was to recruit participants from just the stroke clinic database. Of the ten women within the database, one had died and one had moved away, leaving eight prospective participants. These eight women who matched the criteria (i.e. had suffered stroke for more than six months and classed themselves as Afro-Caribbean) were identified and contact details (which included a postal address and telephone number) were noted. After numerous attempts to contact these women, only two of those contacted volunteered. The decision, taken following discussions with my academic supervisors, was made to recruit from the local Afro-Caribbean day centres. All potential participants were initially contacted by telephone and given a brief description of the study, which included its aims and the approximate amount of time the interview process would take. Once participants had agreed to take part in the study, a written information pack including a Consent to Participate form and an Information to Participants letter (see Appendix 6) was posted to their home address. The information pack (approved by the Ethics Committee at UEL, as discussed in Chapter 3, section 3.2) contained the study advertisement, the

participant information sheet which included contact details for the researcher (participants were advised that they could contact the researcher if they had any further questions) and a consent form. During the first telephone contact call it was agreed that the researcher would telephone in one week's time to confirm an interview date and attempt to answer any questions or concerns that the participant may have after receiving the information pack. Therefore, one week from the initial call, participants were contacted a second time to arrange an interview date and time. This was based on each participant's availability rather than around the researcher's schedule, owing to the fact that most participants had specific days when they attended clinics, rehabilitation appointments and day centres. In addition, the researcher needed the information and acknowledged that a partnership was important between participant and researcher. In order to gain data and contribute to new knowledge, I saw this flexibility as a crucial part of the research process. Once a date and time had been agreed, the researcher formally informed the academic supervisors of the interview arrangements. Twenty-four hours prior to their interview, participants were called to confirm the appointment. After confirmation, the interviews were conducted as planned. The main reason for confirmation was due to the fact that some participants may have forgotten the arrangement, become unavailable or unwell.

Participants who were not contactable by phone were sent a letter with all the information about the study, including a self-addressed stamped envelope with a tick box form to ask participants if they were willing to participate. Any participant who declined the offer to participate was asked for their reason, so that any barriers to future recruitment of this particular client group could be noted. Recruitment from this particular group was difficult, as most of those identified and contacted simply refused to participate. A decision to recruit six participants was made after discussions with my academic supervisors. Qualitative research does not seek to generalise to a power. In particular, IPA aims to understand how a phenomenon is experienced from a personal perspective via (in this case) narratives of those concerned. Although just six participants may sound small, the level and depth of information collected from each was vast and has transferability potential to the group under investigation. Here, I also found guidance from Smith *et al.* (2009) and Smith and

Osborn (2008) from their discussions regarding sample sizes in IPA. Below is a brief description of the research participants utilised for this phase.

- Lucy: an 80 year old Afro-Caribbean woman from St Lucia. She had a right sided stroke six years ago and lives with her husband and two sons.
- Jenny: a 72 year old Afro-Caribbean woman from Jamaica. She has a history of TIAs and she had a right sided stroke three years ago. She lives with her second husband. She has three children and although none of her children live at home they are all within driving distance.
- Doris: a 65 year old Afro-Caribbean woman from Jamaica. She has had a left sided stroke for more than five years. She now lives on her own, but her children are all within driving distance.
- Margot: a 47 year old Afro-Caribbean woman originally from Trinidad. She suffered a single stroke attack seven years ago. She is a single parent and lives with her teenage daughter.
- Marie: an 82 year old Afro-Caribbean woman from St Lucia. She had a left sided stroke five years ago. She is single and lives in sheltered accommodation, with no close family or relatives.
- Queenie: a 49 year old woman from Jamaica. She had her first stroke in 1994 and then subsequent strokes in 1998 and 1999. She lives with her husband and has three children.

5.6 Mode of Data Collection

5.6.1 Design

This study used semi-structured interviews as the mode of data collection. Several authors (such as Flowers, Duncan & Knussen, 2003; Flowers, Smith, Sheeran & Beail, 2002; Osborn & Smith, 2006; Willig, 2001) have discussed the suitability and conduciveness of semi-structured interviews as a favourable medium for collecting data when IPA as an analytic tool is employed. An interview schedule was developed and used to guide rather than restrict the conversation. The questions were open-ended, tapping into the world of the participants and the phenomenon under investigation. The questions were designed

with prompts, as recommended by Denzin and Lincoln (2005). These were only used when the researcher felt that questions were not being answered, or to gain a greater insight or clarity into a particular area. In carrying out semi-structured interviews, I acknowledged the participants as experts, for they had knowledge and experience of living with stroke. During the interviews, questions were not asked in the order of the schedule; instead, they were used as a guide or check list which prompted participants to discuss their lives and experiences. There were times when the researcher felt that participants were navigating away from the phenomenon under investigation, and had to make the judgement call whether to pursue the avenue or bring the participant back to the original question.

Another area of high importance was the physical environment of where the interviews were conducted. After being contacted, participants were given the choice of where they would like the interviews to be conducted. Most participants chose to remain within the comfort of their own home. The chief reason for such decisions was that some participants were disabled and housebound as a result of their stroke, so that mobility and transport would have presented practical problems. Some participants lived in sheltered accommodation and were under the direct care of their home manager. Finally, most participants felt more at ease in their own environment. The interviews were audio tape recorded, with each participant's permission, as this ensured that all aspects of the interview were captured for full textual analysis.

5.6.2 Procedure: Collecting IPA Data

The semi-structured interview is an exemplary method for IPA, as it allows the researcher to tap into the world of the participant and the interviewer can move freely across the topic using the interview schedule as a guide rather than prescription (Smith & Osborn, 2008). All interviews were carried out either in the participants' homes or a private room in the day centres that they attended. Prior to commencing each interview, the researcher reminded the participant of the reasons of the study (aims) and gave the participant time to ask any questions they may have had. The next step included collecting the signed consent

form from the participant and explaining what happens to the data and the participant's right to stop at any time during the interview. The researcher explained to participants that the conversations would be recorded via a dictaphone. If participants had any questions concerning (i) the reasons why the researcher was interested in women and (ii) seeking medical/nursing advice during the interview, the researcher assured them that these questions would be answered (but at the end of the interview) so as to (a) for (i) above not cause any bias as participants may see me as a nurse and withhold information and (b) as for (ii) above that I was there in a research capacity as a researcher and not as a health professional. I felt that sharing my professional background with participants was good practice and allowed transparency, which enhanced my credibility.

5.6.3 The Interview as a Social Encounter

In human sciences, objectivity cannot be achieved in the way the natural sciences model has invited us to believe. In fact, instead of the participants' actions and subjectivity as a confounding variable, their co-authorship in the knowledge production needs to be embraced and seen as a key component of the research process. Oakley's (1981) paradigm illuminates this position in her discussions on the interview technique for data collection, where she seeks to minimise objectification of the research subject as data by viewing the interview as an interactional exchange. Oakley believes that if the interviewee 'talks back' and the researcher engages with this conversation it will lead to a personalised, humanised interaction, placing both the researcher and the subject on an equal footing. "Personal involvement is […] the condition under which people come to know each other and to admit others into their lives" (Oakley, 1981:58). In this way it is hoped there will be richer, more authentic voices of interviewees and the result will be better quality data (Jaffe & Miller, 1994; Kayser-Jones & Koenig, 1994) Similarly, Tong *et al*. (2007) advocate for transparency between researcher and interviewee, claiming that openness from the researcher on why they are interested in the subject matter and their professional training and background will enhance credibility.

Oakley concludes that interactive interviewing is an approach which not only documents women's own accounts of their experiences, allowing the researcher to garner knowledge not simply for the sake of knowledge itself, but it is central for the women who are providing the information. Emphasis is placed on the quality of the interviewing. The researcher seeks to open boundaries for topics and aspects of experience salient to the participants by creating a space for respondents to provide accounts rooted in the realities of their lives. For example, during the interviewing process this was conveyed to begin with in clear, simple non-verbal communication (such as the nod of my head demonstrating understanding), hand gestures and facial expressions that brought about a common place for talking. In adopting Oakley's interactional approach, participants 'found out' that I held a professional nursing qualification and aligned this to a softer male persona, one who performs a predominantly and historically female profession - caring and nursing. I communicated that I was a man interested in understanding the lived experiences of women and the daily ins and outs of their lives, so they were also happy to share. By answering their questions such as 'why women' against the tide of literature, these women accepted my interest in their lives.

In keeping with the philosophy of interviewing, I prepared for the task that lay ahead of me. I carefully negotiated with participants the venue for the interviews, prepared an interview schedule, armed myself with a digital dictaphone - in essence, the guidelines were followed in detail. I needed to be careful when finding the balance between what may be seen as a professional interview, free of infection, or one that is infected by bias, corrupting the pure process (Oakley, 1981).

In one of the interviews in this study, after 10 minutes the participant ended the interview. The interview was being conducted in a day centre that she attended. However, during the interview we were interrupted by the coordinator of the day centre coming into the room that we were using, busying herself by looking at papers in a filing cabinet. These interruptions made the participant feel that she was being monitored and she was fearful that she may lose her place at the day centre, which caused her to end the session as she

indicated ‘sister was listening’. Two lessons were learnt from this encounter. Firstly, it may help to actually go and visit where the interviews will be held and ensure that privacy and quietness is assured. Secondly, there was a need to be aware of the power of ‘gatekeepers’; those that allow access to participants. The researcher was also responsible for creating a space in which the participants felt free to talk and thus should acknowledge his role as a catalyst in participants revealing very private and unhappy experiences – capturing the unheard voice, a process that is largely dependent on the researcher’s interpretative skills. I was new to conducting interviews in research - this was only my second interview. I also learnt all I needed to do was to put a simple ‘do not disturb’ sign on the door.

It became apparent that the utmost care was needed to be given to interviewing, as it was important to avoid leading the participants into making certain responses (this must not be confused with probing). I had to be aware of my own biases and how these can affect (if not infect) the interview. Advocates of qualitative research have recognised that the interview is a unique type of social relationship. This may involve disguise or create differing aspects of social interaction such as friendship, power, reciprocity and shared understandings (De Vault, 1990; Douglas, 1985; Holstein & Gubrium, 1995).

As a social meeting, the interview process largely depends on how the participant decides to answer each question (Burch, 1999). The decision is not concerned with whether the participant answers truly or falsely, but on their varying aspects of perception and experience in relation to the research question. Replies can be grouped into two responses: public or private responses (Cornwell, 1984). Public responses are gained through directly asked questions. For example, one of the questions in this study was “Can you tell me when you had your last stroke?”. This type of question allows a direct answer, but a private response emerges later on in the interview once a rapport is established and the participant is allowed to tell her story in her own words by recounting in detail her experience from the days preceding her stroke to the actual stroke occurrence. On the whole, responses become more detailed (data rich) as a ‘confiding’ relationship became established between the interviewer and the participant. As the interview relationship establishes a rapport and

confidence, the private world becomes revealed. In this study, participants were more than willing to share their experiences, but seemed mindful that they wanted to please the researcher. This was evident when the researcher conveyed his thanks at the end of the interview and on more than one occasion he was asked "Did I do alright?" or "Did I answer everything right?". Such comments serve to illustrate the sometimes artificial and hierarchal nature of the encounter, while demonstrating that a concept of 'correct' answers may be held by participants (Burch, 1999).

5.6.4 The Interview Schedule in IPA

Within the context of IPA, the interviewer enters the interview bearing in mind that the participant is the expert and that there is no successful or unsuccessful interview, as even the most un-producing interview can serve as a learning process (as discussed earlier). The interview schedule was used as a guide during the interviews rather than as a prescription. The questions were open-ended, which created an opportunity for the participants to tell their story. An advantage of this was that the researcher did little talking apart from when clarification or probing was needed, while the participant to a greater extent did most of the work. The interview style adopted was non-directive, as the aim was to let the experts (participants) give their accounts. Alexander and Clare (2004:82) describe their interview process as "collaborative emphasising that the participants were the primary experts", an approach that is certainly in keeping with the aims of IPA. A premise central to IPA is that the interview schedule should be used to facilitate the participants' abilities to tell their own stories in their own words (Smith *et al*., 1999)

In creating the interview questions, prompts were devised to help the researcher gain access to the more private world of the participant (see Table 5.1). These were also used to help return the participant to the point of focus if they had strayed away from the research topic. When there is movement away from the schedule, it is the responsibility of the researcher to decide how much movement is acceptable, whilst acknowledging that novel areas can be the most valuable and enlightening (Osborn & Smith, 2006). There is a role

for the interpretative facet of IPA in data generation as well as analysis. The schedule of questions was divided into four parts and comprised a total of five main questions. Each part ran in parallel with the post-stroke phenomena discussed in the empirical findings of Chapter 3 of this thesis - physical, psychological and social practices.

Table 5.1: The Interview Schedule

PART I - BACKGROUND/WARM-UP This part of the interview was concerned with placing the participant at ease and started off with a general conversation question such as:
(i) **Question: What do you remember of your stroke attack?** ***Prompt 1:*** When did it occur? ***Prompt 2:*** How old were you when this happened?
PART II - CONCEPTS OF GOOD HEALTH This part of the interview was concerned with finding out what participants perceive as good health and uses questions i & ii of the interview schedule.
(ii) **Question: Can you tell me what you understand by good health?** ***Prompt 1:*** How do you think absence of illness may affect your health?
(iii) **Question: What factors would you say threaten good health?** ***Prompt 1:*** A disease (acquired or genetic)? Our lifestyle? Ageing? ***Prompt 2:*** How does good health influence quality of life?
PART III - FEELINGS, MEANING & UNDERSTANDING OF THEIR OWN ILLNESS This part of the interview was concerned with gaining information surrounding the participant's own understanding of their illness. It aimed to elicit data on how they interpret their body and feelings of illness and what they attribute this to.
(iv) **Question: What cues/symptoms suggested to you that you were at risk of stroke?** ***Prompt 1:*** What do you think causes stroke? ***Prompt 2:*** How does it feel when you get the symptoms?
PART IV - THE LIVED EXPERIENCE This final part of the interview schedule looked at participants' experiences of living with stroke and the other avenues they may explore to help with making the experience a more endurable or positive one.
(v) **Question: What feeling do you associate with stroke?** ***Prompt 1:*** How does having a stroke affect your daily life? ***Prompt 2:*** Has having a stroke stopped you from doing anything?
(vi) **Question: What things can make a difference to your health?** ***Prompt 1:*** What medicines, other remedies, or physical exercise techniques might be useful to reduce your blood pressure? ***Prompt 2:*** What changes in your lifestyle might affect your health?

5.7 Approaching the Analysis

5.7.1 The IPA Protocol: Phases of Analysis

In order to analyse the data, the researcher followed a systematic protocol that allowed the data to be deconstructed to facilitate developing themes and interpreted to illustrate the meaning of the phenomenon under investigation. This process helped in contextualising the meaning of the lived experiences of those who were interviewed.

Table 5.2: The Phases of Analysis in IPA

PHASE 1 - FAMILIARISATION

- All interviews were listened to, then transcribed into a Microsoft Word document (this made it easy to cut and paste themes at a later stage of analysis).
- Lines in each transcript were numbered to link participants' own words with the emerging themes.
- Each transcript was read individually several times, until the researcher was comfortable and familiar with the transcript.
- All notes made during the interviews and reflections on the interviews were also read in conjunction with the transcripts to help with clarity.

PHASE 2 - SENSE MAKING

- Each transcript was attended to individually and, after familiarisation, themes were identified for each transcript.
- A handwritten summary of notes on each transcript was made, identifying meaning making repertoires.
- A meaning making repertoire grid was made for each transcript.
- This was presented to my supervisors for feedback and discussion of how I analysed the data.

PHASE 3 - THEORY BUILDING

- From the list of themes, a cluster of themes was created reflecting the idiosyncratic singular to the general (where possible), connected with line numbers.
- A master list was created from the cluster list.
- Themes were grouped together and linked to psychological and health theory.
- A master theme grid was created with/from each transcript and line numbers to illustrate location of the data.

PHASE 4 - DATA REFINEMENT & ANALYSIS

- Each individual transcript was read again, with a view to extracting each participant's own words to support themes, providing the richness IPA adds to analysis.
- All texts were checked against original transcripts to ensure accuracy of themes (this provides rigour of inductive reasoning).
- Reflections of the researcher on each transcript were read, to help guide the process of interpretation.
- An initial write-up and review was created to weed out unnecessary extracts.
- A final write-up of the narratives linked to psychological and health theory supported by 'rich extracts' of the transcripts provided support for the data analysis.

Table 5.2 captures the phases of data analysis the researcher underwent in order to make sense of the participants' sense making and to present a coherent narrative of their experiences of hypertension and life after stroke. The following sections provide a more in-depth account of this process. Before this process began, I sent a transcript of their own interview to two of the participants (Margo and Queenie) for verification, as advocated by Tong *et al*. (2007).

5.7.1.1 Phases of analysis – familiarisation

Once the interviews were transcribed, the next stage was to familiarise myself with the data. Osborn and Smith (2006) suggest that the researcher reads and re-reads the transcripts one at a time in order to gain familiarity with the data. Each reading should throw new light on the transcript; it should reflect the researcher immersing himself into the data. It is like stepping into the participant's shoes (Eatough & Smith, 2006). This type of familiarisation process enabled me to identify themes which emerged during the interviews. I included a research journal in the study design, because it would contribute to establishing the audit trail necessary in qualitative research (Koch, 1994). I always made my reflections and notes within two hours of conducting each interview. Clarke (2009) recommends the use of a research journal to help establish rigour in qualitative research. To this end, it helped me to clarify my thoughts and feelings. One added value in keeping a research journal was that I became more familiar with the interviews.

5.7.1.2 Phases of analysis - sense making

Each transcript was divided into three sections: (i) a left hand margin (ii) the transcription, and (iii) a right hand margin. The left hand margin was used for making initial notes and comments of significant interest as identified by the researcher. The right hand margin was used to transform and catalogue the comments into phrases and emerging themes (Eatough & Smith, 2006; Smith & Osborn, 2008; Willig, 2001). Making sense of the data involved using the logic of inductive reasoning. This was achieved by creating a series of analytical codes, which was twofold. Firstly, it captured the nature of the participants' experiences (for example, positive or negative). Secondly, it provided answers to the research question.

At this stage caution was needed, to ensure that I did not lose the link between the participant's own words and my interpretation. To achieve this, I made memos in my research journal and reviewed the notes that I had made directly after each interview; this process involved going back and forth in order not to lose the essence of what participants were saying. The use of field notes assisted me in making sense of the participant's sense making process, as after each interview I made notes on my initial thoughts and reflected on the process itself. I also made field notes such as when participants gesticulated rather than described their feelings.

5.7.1.3 Phases of analysis – data refinement

One of the facets of IPA is that it offers a way of identifying a relevant participant-defined understanding of the data gathered. This facet assists in refining the data, establishing connections between the preliminary themes and formulating a superordinate theme. In performing this analytical task, the researcher gains an in-depth understanding of not only the idiosyncratic or subjectively singular, but also develops an insight into how a participant's life-world is culturally constructed by systems and institutions (such as the family and healthcare providers). Once this was completed, I sent a second letter to Queenie, this time with a mapping of the study findings. Her comments were that the transcript was a true record of the interview; she felt that the findings represented the stroke experiences of Afro-Caribbean women.

5.1.7.4 Phases of analysis – writing up the IPA study

The formal processes of the study involved producing a written account of the participants' experiences and the meanings attached to those experiences. This narrative account can be viewed as an interplay between "the interpretative activity of the researcher and the participant's account of her experience in her own words" (Smith & Osborn, 2004:338).

My aim at this stage was to produce each participant's account in a textual format. This takes the reader between different descriptions and levels of interpretation, maintaining transparency at all times between the participants' words and the researcher's analysis.

> "IPA's iterative process means that the interpretative levels acquire more depth as the researcher moves beyond the description of the phenomenon to interrogating the participant's sense making" (Smith & Osborn, 2004:339).

The process of analysis involved interpreting the data at a more conceptual level, thereby moving from a 'cluttered' participant account to a more coherent narrative. Core to the process of IPA is that the narrative reflects both the subjective (i.e. the unshared aspects of the experience) and the collective experiences, where shared understandings are constructed via social processes and interactions which depend on culture, sub-culture and group culture.

Once this process was completed, two presentations were available. The first was a section which contained the narrative accounts, which included my interpretations with verbatim extracts from the transcripts to serve as proof of my interpretations. The second was a 'discussion' section, which was concerned with examining the analysis in light of the existing literature to illustrate how the experiences of the participants contributed new insights into existing knowledge on the meaning of hypertension and the lived experience of life after stroke.

5.8 Reflexivity

A research journal was started from the day I registered for my doctorate. I have used this journal throughout all the research stages including the interview process, transcription and analysis. I continued recording thoughts and reflections as I worked towards the completion of my thesis. Jasper (2005) recommends recording all ideas that a researcher generates along the way, so it can be considered coherently once an idea is committed to paper and then developed or discarded.

An important aspect of doing qualitative research is commitment to remaining aware of an ongoing contribution to the process of generating knowledge. This involves being accountable for the interpretative readings offered as findings and the theoretical claims that they generate. This practice is referred to as reflexivity. It can be described as a constructive (self) inspection which involves the researcher stepping back and observing their own engagement with all the aspects of doing research. In doing so, the researcher adds to their understanding of the phenomenon under investigation as well as the research process itself (Hanrahan, Cooper & Burroughs-Lange, 1999). It creates a medium and a means for continuously becoming a better researcher. Reflexivity is a position which the researcher adopts; one that involves looking at the research process from conceptualisation, design and interviews, through to data handling and analysis (Macbeth, 2001). In the spirit of adopting a reflexive stance, I kept a research journal throughout the entire course of this Ph.D. study, where I recorded thoughts, concerns, dilemmas and epistemological turning points with regard to self-positioning, conducting interviews, managing and analysing the data, and then the writing up process. The research journal documents my attempts to monitor the ways in which my epistemological stance, including the journey of developing and owning this stance, shaped this research project.

Epistemology is generally referred to as the relationship between the knower and the known. Cook and Fonow (1986:71) define it as not only “theories of knowledge” but also as “theories of knowledge production”. Typically, epistemology follows the concept of a

double consciousness, allowing the researcher to be fully engaged in the research process (i.e. the relationship between the knower [researcher] and the known [nature of things/ontology]). In my case, I was constructed outside the dominant paradigm. I was a man investigating a female phenomenology. I also hold a professional health qualification with a specialism in cardiovascular disease and critical care nursing. Thus, in this situation I was positioned from the service provider perspective and the participants from the service user perspective - I had specialist knowledge and they had lay knowledge.

In order to enter / hear / open up / tap into the world of my participants, I needed to move away from the traditional responses of social researchers where a participant is objectified, resulting in dividing the subject and the object in research. When all of the concepts and arguments were weighted, I made a firm decision to move away from the traditional schools of thought and strategies of enquiry in order to achieve the best possible results. I took guidance from Letherby (2003), when I acknowledged and embraced the experiences of women with stroke and focused on how women embody an illness in response to a traditional male treatment approach within the umbrella of cardiovascular disease. As the study progressed, I began to understand that within the social political economy of health, women's worlds are organised differently and their experiences of disease are different to those of men.

When I was conducting the interviews I thought that as I was from the Caribbean and naturally 'chatty', this would stand me well in interviewing the participants. However, an excerpt from my journal shows differently, as I was questioning what I was not doing right:

> *"I cannot believe that my first interview lasted only 31 mins, what happened? When I play this interview there are so many opportunities to probe and yet I failed. Is my voice and tone ok? I am a nurse, I am from the Caribbean. What am I not doing right?"* (Journal entry, 5 June 2006).

I was developing good practice, I was listening to my tape recording soon after the interview, and I was open to and examining issues that could potentially affect a good interview, such as my tone and pace. I was keen to apply this learning to maximise future

interviews, in terms of creating a medium where the participants would feel comfortable and interested to share their experiences with me. I also learnt that reflexivity is not about beating oneself up when something does not go to plan; instead, it is a practice which relies on noting, accepting and integrating learning as a way of moving forward:

> *"While running and thinking this morning I realised that I am beating myself up for something that the participant can be responsible, as she has had a stroke and there may be cerebral/neurological problems with concentrating and speaking"* (Journal entry, 6 June 2006).

What strikes me most about my response to the fact that the first interview only lasted 31 minutes is what I took for granted; namely that I had expected the participants to all want to talk to me simply on the basis that we shared some similarities:

> *"I have come to realise that if I use my Caribbean heritage, I could lose my objectivity in this interview, therefore I need to be aware of the fine balance that exists"* (Journal entry, 16 June 2006).

It was in striking this balance that I was able to successfully carry out six semi-structured in-depth interviews that provided an insight into the social life world of the participants.

By returning to the research scene through writing this reflection, I was able to chart some of my own learning related to interviewing and realise that it was only when I was faced with a concrete interview situation that I was better able to understand how knowledge is negotiated and dependent upon the interview context. Data analysis involves organising what has been seen, heard and read, so that sense can be made of what is learned (Silverman, 2005). I needed to be clearly submerged in the data analysis and, in doing so, generate a particular reading of the text. Only when I was faced with undertaking the data analysis did I fully understand the significance of reflexivity in qualitative research. This stepping back involved the knowing and ownership of personal views, expectations and so on. The early draft of the analysis documents my struggle with telling the participants' stories rather than my own:

> *"I felt I have written a good interpretation of Jenny's story but Sharon does not think so! According to her I am telling what I want to say rather than what the participant is saying"* (Journal entry, 15 August 2006, Trinidad).

I returned to my notes. I realised that the analysis began the same moment that the study began, and I started making notes and memos in my journal. Once again, field notes helped not only to analyse the data but also with my own struggles and development as a researcher. I understood that "[d]irection can and will be offered but the final destination remains unique for each inquirer" (Silverman, 2005:242). Returning to my research journal at this point in time, I now understand that this kind of learning is an ongoing process; not least since it is intertwined with a journey of personal development as both a Ph.D. scholar and researcher.

The next chapter presents the narrative findings from this qualitative phase and how my interpretations of the narratives developed into an account that accurately charted the participants' experiences.

CHAPTER 6: LIFE AFTER STROKE: FINDINGS FROM THE QUALITATIVE PHASE

6.1 Introduction

This chapter presents the findings that emerged from the IPA of the interview transcripts with six Afro-Caribbean women (aged from 42 to 82 years) who had experienced stroke for more than six months. This second empirical phase set out to examine in depth the nature of life after stroke alongside dimensions of functional, psychological and social living, in a way that goes beyond the picture painted by the findings of the quantitative study. The first empirical phase offered measurements across a population attending an outpatient stroke clinic and showed the outcome of stroke on functional abilities (e.g. mobility, self-care), psychological (e.g. subjective health perceptions, mood) and social aspects (e.g. engagement with the community, carer support). This chapter will show how these measurements unfold in everyday life and are negotiated by the participants on a daily basis. The reader is cued to the following format being adopted in the descriptive figures used in this chapter:

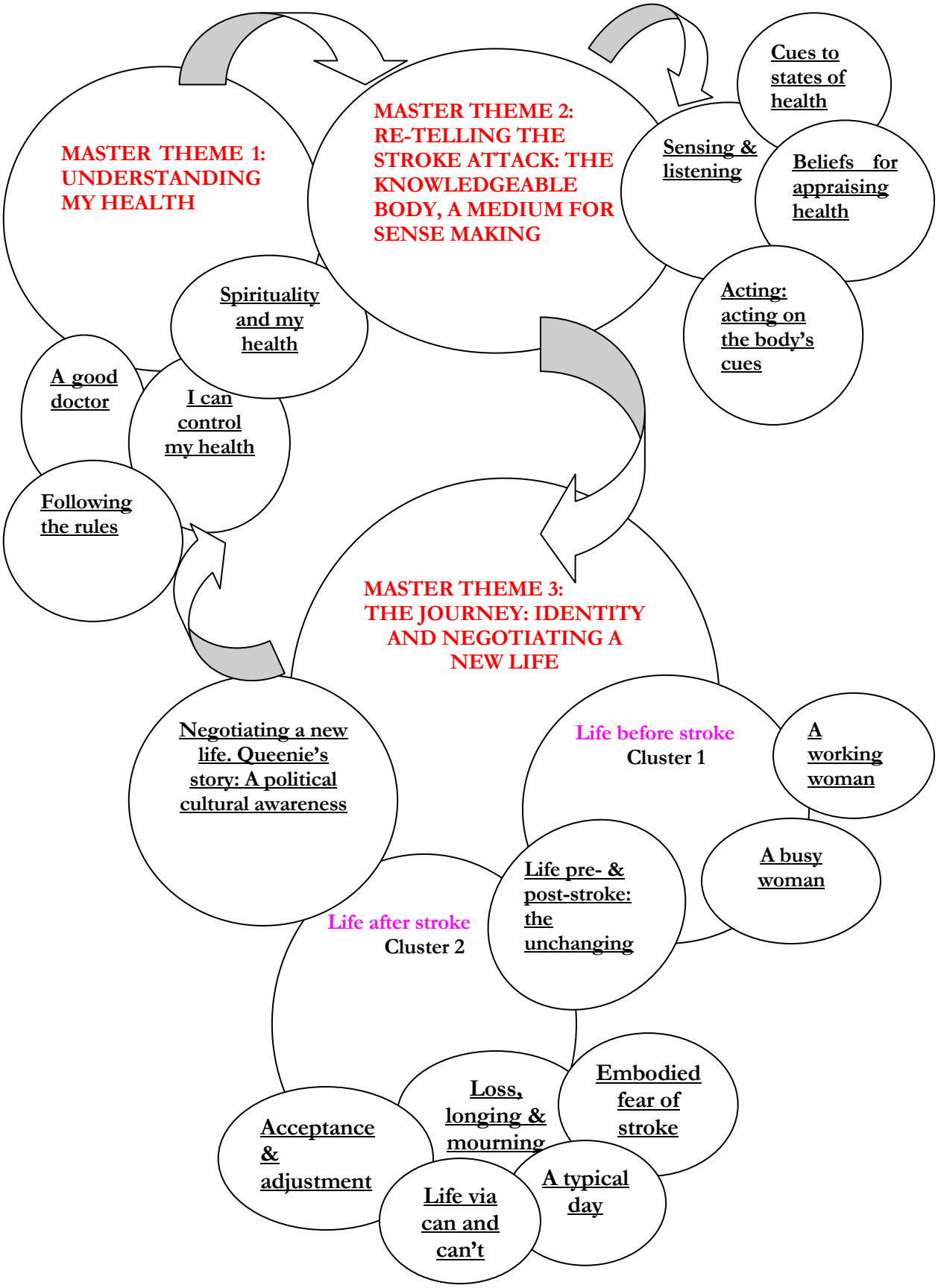
- All master themes in the figures are presented in **CAPITALS, red** and **emboldened** type.
- All sub-themes in the figures are presented in **bold and underlined** type.
- In the text, where 'DDO' is used in an extract it means that data was deliberately omitted [DDO], in order to capture the full essence of the text.
- In extracts where text is underlined it shows verbal emphasis by the participant.

At times the work is written in the first person. This is the style of the researcher and in so doing I aim to show ownership of my work - the interpretative, subjective facet of the study (Green & Thorogood, 2004; Smith, 2004). In some of the sub-themes I have used one participant's story. However, this does not mean that the other participants did not tell or share the same experience; the extract of the participant used is the most eloquent. In this chapter there is an introduction to each master theme in the form of a narrative and

then the sub-theme followed by supporting extracts and a discussion. There is a summary at the end of each master theme.

6.1.1 Introduction and Theme Development

Figure 6.1 presents the themes which emerged from the analysis of the six semi-structured in-depth interviews; it also shows the complexities and overlapping nature of the commonalities and variations identified. The interpretative story that follows is about the subjective experiences of life after stroke. Three master themes emerged as pivotal to these participants' accounts. Master Theme 1, 'Understanding my health', refers to the women's sense of agency and degree of control they can accomplish over their own health. Component sub-themes feature the role of 'a good doctor' alongside spirituality as the base for understanding health. Master Theme 2, 'Re-telling the stroke attack: the knowledgeable body, a medium for sense making', refers to an attunement to their own body seeking out cues, appraisal of success and further treatment actions. The final master theme, Master Theme 3, 'The journey', maps out two interdependent aspects of coping with life after stroke; being loss and mourning of an old self and the structure of, and the process involved in, negotiating a new life where a re-adjusted identity can flourish.

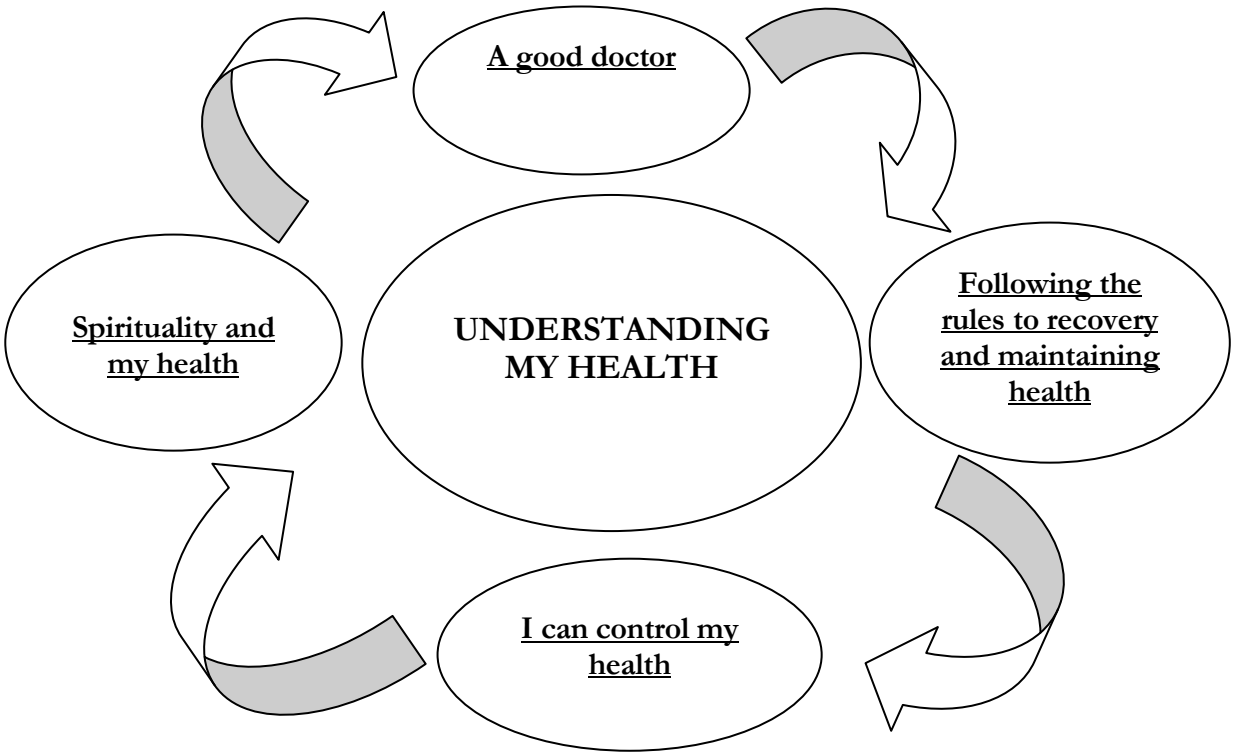


Source: Author

Figure 6.1: An Interpretative Mapping of Life After Stroke

6.2 Master Theme 1: Understanding my Health

Features that were common to the participants' understandings of their health were intricately developed from their engagement with the healthcare system and the treatment offered to them. As illustrated in Figure 6.2, this was shaped by the following interpretations relating to aetiology, risk and agency: (1) a good doctor, (2) following the rules to recovery and maintaining health, (3) I can control my health, and (4) spirituality and my health.



Source: Author

Figure 6.2: Understanding My Health and Sub-themes

The ways in which participants understood their health were captured through interpretations from their talk. Important here were emergent relationships with their doctors and exertion of personal control, which entailed following certain rules in order to maintain health and the influences of spirituality on health.

6.2.1 Understanding my Health: a Good Doctor

The relationship the women shared with their physician or General Practitioner (GP) was crucial in their own understandings and awareness of their health and how they contributed to it. The relationship reflected the high positive regard they held for their GP. Lucy, for example, introduces this by letting us know that her GP is always happy to hear of her progressive health maintenance and recovery. This positive regard is expressed as 'my doctor likes me', 'he knows me'. It seems to be very important that the patient is seen as an individual and not a clinical object. Lucy expresses confidence in her doctor and this confidence relies on patient/doctor boundaries being conceived in a personalised way (i.e. 'he knows who I am', and 'what my conditions are'; 'I am not just someone in the system, he treats me like a friend'). This echoes the view of a doctor as someone who is intimate with their community and the individuals within it; a doctor who has a whole picture of the patient, which includes their family and background. It is this view of the doctor that gives these women the confidence to hand over their lives to him.[3] This handing over should not be confused with a lack of agency, but a deliberate choice informed by their views of who and what constitutes a good doctor.

> **Extract 1. Lucy:** *"I remember that day from coming from Dr B. I had my blood pressure and he said: "Oh Ms *** I am so happy to see how the pressure has gone down."*

In these women's experiences of healthcare, a key facet was having a doctor who listens, advises, guides and takes care of them – a 'good' doctor. Important here is that the doctor listens to her, shares her pain and tries to understand what she is going through. As a result of this close relationship, participants feel able to discuss personal life issues. This type of conversation and interaction with the doctor makes the participants feel that as a result of

[3] In this study, for consistency doctors are always referred to being male, albeit some may have been female. All participants were given pseudonyms to maintain confidentiality.

sharing closeness with their doctor he is better able to understand their health. Lucy's relationship with her doctor tells of such a story, as seen in the extract below.

> **Extract 2. Lucy:** "*It is ah bit hard I don't know fuh everybody coz everybody does suffer de stroke differently; but I know for mihself that things were said to me years ago and ah had it in my mind all de time and it* [gesticulates hands upwards – possibly meaning high BP] *but I explain to mih doctor and then he start to give me de tablets although yuh know de same tablets he was giving me before it was not working but when I* <u>*expressed*</u> *myself then everything settled and I say thanks God."*

Once she had confided in him she felt better; her doctor became her confidant. The closeness shared with her doctor was seen when Lucy attributes various roles to him of being a father, son, Godson, friend and earthly God. In having such roles, the doctor was able to understand her pain as the roles identified shared closeness.

> **Extract 3. Lucy:** *"And I tell you sir Dr G….. he cried."* **CM:** *"That meant a lot to you".* ***Lucy****:* [Shakes head in agreement] *"And I'll never forget it I knew Dr. G 34 years now* [gives address of surgery] *and up to now mister I am looking at him. … You are my doctor, you are not God, because the God we cannot see he is hearing what I am saying, but I am looking at him as my earthly God, my father, my husband, my brother and my best friend…* [DDO] *So one day I sat down and told my doctor he said madam you are a strong, strong woman. Otherwise other woman will just turn white, suddenly turn white."* **CM: "***Do you mean grey hair?"* **Lucy:** "Y*es or drop dead."*

The doctor in this situation is not only viewed as a healer, but also as someone more powerful, as he is described as an earthly God, someone who can be confided in, someone who will listen and someone who will not turn away. In such a relationship, a brother is someone that looks after you and shares secrets. A Godson is someone whose care is entrusted to you, a father will nurture and protect his child, a husband is someone more intimate as he knows your moods, your thoughts and understands you when others may not. A God is someone who encompasses all of these roles who is omnipresent, omnicompetent and omniscient. However, she is keen to tell us that he is not omnipotent (discussed further in spirituality and health governance), but he is her 'earthly God'. He is her shelter in the time of storm and she can go to him for refuge, knowing he will do his

best for her and not turn away but remain longstanding. The relationship (with her doctor) shapes the way she seeks help and healthcare services.

> **Extract 4. Lucy:** *"I ring at that time* [DDO] *...I said I cannot come to the surgery I cannot walk, I cannot see and I have a palsy he said alright then 10-20 minutes then in 10 minutes I hear the door ring, I try and get up and open the door, before doctor come in he said oh God it is a stroke that is what my doctor G….. said before he enter you know he said if it was in St Lucia it hit you, you would be paralysed he come in and he had medicine in his suitcase, then he give me tablets* [DDO]. *He said I will not send you to the hospital, I'll treat you here, and Dr G…. did not send me to the hospital, he came three times a week to visit me at home."*

Her relationship with her doctor is one where she knows she can call on him and he will do his best to attend to her. Lucy presents her doctor as her saviour; he can look after her and save her from deteriorating. In order to do this, he decides to treat her at home and the bond of a strong and trusting relationship with her doctor is again exhibited when she agrees with him not to go to hospital and to be treated at home. Her faith in her doctor is paid off when she explains that during the critical phase of her illness he used to visit three times a week, interpreted as he cares, "*I trusted him not to go to hospital and he came to my home and looked after me"*.

A firm sense of trusting the GP emerges as crucial for these participants' development of a view of their health. Harbouring such trust facilitates a positive engagement with either good or bad news from their GP. For example, Marie's trust in her doctor means that she is more willing and able to comply with medical guidance. She listens to him and accepts his prognosis. She believes he will help her and accepts his word, and is boastful of him looking after her in the following extract.

> **Extract 5. Marie:** *"He* (her doctor) *just said to me you have a stroke and you cannot work again, you cannot work but we will look after you, we will give you something to satisfy yourself you want to work but you cannot work again. And look how it turned out I get everything from my doctor."*

Faith in the doctor pays off by him getting her 'everything'. Again, the doctor could be interpreted as an earthly God, one who will supply all her needs; she got everything she needed from him.

For some of these participants, the relationship with their doctor or the health professional within the team is not a familial one as described here but more medicalised (ill) - I attend the surgery and you should be able to repair me (treatment and recovery). Their perception of the doctor is based on how they (doctors) perform. Experiences of health and healthcare services may not always be positive and have left some of the women holding a low positive regard towards their doctor or healthcare team. Margo, for example, values her doctor based on his professional ability and her experience of his treatment, therefore she judges him in a more pragmatic way:

> **Extract 6. Margo:** *"...*[DDO] *Yes, but he is useless, I don't have any faith in him, especially since he told me my blood pressure was fine and then I collapsed two days later."*

One possible reason for this is that she is of a different generation (younger), and although she is from the Caribbean she came to the UK as a child and therefore she holds a more Westernised view of the role of the doctor. The other participants came during the Windrush era and perhaps remain grateful and subservient to the system in which they live. Immigrants of the Windrush era were from the British colonies and may hold a belief that they are not at liberty to obtain free healthcare and gratefully accept whatever level of care they receive despite their entitlement.

The positive regard the women in the study held for their doctor thus emerges as paramount in their understandings of their health. One of the reasons why the women felt close to their doctor could be because he is part of the local community, someone they see in a shop or at a bus stop. As stated earlier, one of the other contributing factors for a high positive regard is that participants were part of the Windrush immigration scheme, and hence they may have an internalised gratitude to Queen and country which translates into

the concept 'I am not British and I am not entitled to this but he (the doctor) is giving me all this support'. In most societies, the doctor is seen as a healer and because of the socio-political and economical positions the women are in, they are drawn even closer to him. Culturally, West Indians hold their doctors in high esteem (Kelleher & Hillier, 1996), as he is seen as the one who can restore their health and make them whole again. The women's relationship with their doctor is one of trust, where the doctor can do no wrong (with the exception of Margo). The women see their doctor as the person who cares for their well-being and can give them what they need, as in the case of Marie. He is not only a health provider but a guardian, but despite their belief in the doctor the women also believe that they can control their own health.

6.2.2 Following the Rules

There are existent rules that pertain to maintaining good health. Some of these rules are universal (endorsed by the government and society) such as smoking is bad for you, eat at least five portions of fruit and vegetables a day, and engage in regular exercise (Department of Health, 2007). Other practices include following the rules set by health professionals, such as a prescribed pharmacological regime. In Queenie's life this involves a strict medication regime, voiced below.

> **Extract 7. Queenie:** *"...I have to take a whole barrage of drugs, to keep my blood pressure to what is an acceptable level coz I have what is called malignant hypertension and also my blood pressure has a tendency to suddenly shoot up. So let's put it this way I could take my drugs in the morning but for some reason unknown it would shoot up past the barrier where it should be set at, so I have to take* (.)[4] *a heavy regime of medicines."*

There is an unpredictable element and Queenie is aware that the drugs do not always work. The embodiment of stroke provides an awareness of how her body performs and responds.

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[4] (.) indicates a pause in the narrative.

She has to adhere to the rules and take her prescribed medication as a means of maintaining her health.

Most of the women in this study commented on worrying, an act that is interpreted as stress which can lead to high blood pressure and stroke. Therefore, one of the rules from the medical team is to try not to worry, or reduce the level of worrying, as Marie relates.

> **Extract 8. Marie:** *"…because if you let it worry you or let yourself go you will not be alright as the doctor say"* [again she talks of her medical team's advice] *"They speak to me they say you must not worry about anything, you are carrying on good you are alright"* [and again Line 37 p.3] *"Doctor tell me you should not worry too much. Well I am healthy and living and doing everything I want to do and I listen to what my doctor have to say. So I am ok I am fine I'm alright."*

Marie follows the advice of her medical team and the reward for this is she is healthy and able to do everything she wants. The belief in Marie's medical team is one of trust. She follows the rules and the result is that she is 'alright', a cultural expression meaning she has nothing to worry about and her health is good.

Doris breaks the rules in order to follow the rules. These are her rules as opposed to the rules set by health professionals. In her own rules, she is willing to take a risk in order to maintain her mental and physical health. However, she is quick to state you cannot do this practice regularly. She understands her body and how it operates.

> **Extract 9. Doris:** "*Ah just get up in the morning and I say chuts, give it ah break. Every day, the same ting, de same ting, I must cah skip ah day, sometimes taking all these tablets is not easy.* [DDO] *Chuts man I say enough is enough and I must can skip one day, so I skip ah day***.** [DDO] *I don't do it regular, ah doh* (I don't) *do it regular, me just get up an say chuts.* [DDO] *I have been taking these tablets for years day in day out, day in day out. You must can skip one day, at least one in ah month, I is not saying you have to do it regular."*

Adhering to the rules of taking medication is not easy for Doris; it is a monotonous tiring routine. Therefore, as with most tedious routines, taking a risk makes it exciting. This is a calculated risk that she is willing to take only because she understands how her illness and

her body works. She is in tune and aligned with her body and, as a result of knowing her body, she is able to break some of the rules. Doris learns how to live with stroke and part of this entails taking risks such as omitting medication, reflecting an attunement to her body.

6.2.3 Summary of Sub-theme: Following the Rules

In order to maintain and achieve good health status, the women follow rules that are given by health professionals. However, they make their own rules as in the case of Doris. Following the rules is one way to maintain and contribute to their health. Another way of maintaining health is through spirituality, presented in the next sub-theme.

6.2.4 I Can Control my Health

> **Extract 10. Doris:** *"Yuh have to just make your mind up and try and not to make it a hindrance to you and take one day at a time."*

The WHO's initial definition of health in 1946 has attracted some level of criticism for being physically orientated and utopian (Blaxter, 1995; Senior & Viveash, 1998; Whittaker, 2004). Social factors (such as family responsibilities, relationships, employment and support networks embedded within culture) play a crucial part in the definition of health and how the individual comes to view their own health. As a result of these social factors, together with economic and other attributes such as spirituality and religiosity, the individual develops ideas of health as well as controls aspects of their health. Most individuals possess some control over their own health that ranges from choices such as the types of food consumed, the amount or level of exercise they do and lifestyle habits such as smoking and alcohol consumption. Some individuals also take actions such as weight management and exercise programmes, or vitamin and mineral supplements, to improve their health after illness or disease.

This sub-theme on controlling health shows how the women contributed to their health through a physical approach that was achieved by exercise, walking, dieting and

physiotherapy. The women also used a psychological approach to maintaining their health by reducing and trying to control anxiety and acts of worrying. Positive thinking was used by participants to maintain good health. Afro-Caribbean women believe that they can use mind control to advance or maintain good health. For example, Doris believes that recovery to independence is partly due to making your mind up. Her belief is that you need to try and help yourself, and part of controlling your health is to be independent and make it work for you by trying as much as you can.

> **Extract 11. Doris:** *"Yuh have to just make your mind up and try and not to make it a hindrance to you and take one day at a time, that is the way I look at it and try and help yourself...* [DDO] *I had the goal and determination to recover, because if you don't have the determination, you will be sitting there punishing yourself couldn't talk properly…* [DDO] *And I used to do what ever the nurses them tell me to do, I do it, I follow what they say. If you don't have that determination you not going to move from where you is then you right back at square one… you have to go on no matter what."*

Vital to controlling and contributing to good health is Doris' belief that you need to be determined to recover and to be able to make a difference to your recovery. It is a modernised, medicalised, individual approach to health, where the responsibility is placed upon the individual.

Recognition of factors that impact on health is one way of controlling and contributing to health, as Margo's extract shows that identification of these factors led to modification in her own lifestyle.

> **Extract 12. Margo:** *"When I had my stroke I wasn't overweight, I didn't have diabetes, I didn't smoke didn't drink. So none of those things contributed to my high blood pressure… I suppose the salt and seasoning I have cut down on that and that's about it really I eat* (.) *more fruits and salads before the stroke no I mean since the stroke I eat more salads, like at work everyday in the week I will have a salad rather than fattening things."*

Controlling what you eat is a positive step towards taking control of your health. It is concerned with discipline and informed choice of how to lead a healthier life and reduce the risk of cardiovascular disease (British Heart Foundation, 1997). Health can be

influenced through making lifestyle choices, a concept often portrayed in the media and held as part of societal beliefs. The onus therefore is on the individual to make these changes.

Margo's belief appears to be that health can be unfair and undeserving. She believes she has done nothing to get stroke, as she was not overweight, smoked or had diabetes. She continues to do the same, with changes in her diet such as eating more fruit and salad. In her eyes it is unfair that she had a stroke, as she never had any precursors or abused her body by unhealthy practices. Margo claims that it can be difficult to achieve a good health status.

> **Extract 13. Margo:** *"I have been working really hard to help my self. I haven't sat about doing nothing. Cause I am not the type of person to sit around and do nothing…* [DDO] *I just think I need to get more fit, you know get better, right now I am just concentrating on getting as well as I could."*

Part of health promotion is concerned with wanting to change your present practice (Corcoran, 2007). Margo's decision to get fit is a way of taking control of her life; although it may be difficult, she acknowledges how this practice contributed to her health. She plays a crucial role in controlling her recovery from stroke, and this is seen through the personal investment in working really hard and not sitting around idly, but being an active participant in her own health. When asked if her health is good, Marie responds:

> **Extract 14. Marie:** *"Well you have to make it up, some people can't make it up at all … wanting to get better."*

Marie believes that some people are able to influence their health, but the effect of stroke may be so severe that they then have no influence over their health. Marie is similar to Margo in believing that the individual plays an important role in recovering, regaining and maintaining health.

Personal control over health can result in positive health practices and illustrates how the individual negotiates health practices (which include discarding, changing or adapting practices). Therefore, health can be controlled through both a psychological and physical approach. One such practice is 'worrying'. Jenny had to learn to relax and stop worrying and, in so doing, she took ownership of her health.

> **Extract 15. Jenny:** *"It makes a big difference because it teaches you to relax more."* **CM:** *"So you think relaxation is a key thing?"* **Jenny:** "Y*eah* (.) *yeah* (.). *I use to always be a worried person worried over everything, but now I try to relax my body, I don't let everything worry me. I try to control myself."*

In the case of Lucy, keeping calm means that her blood pressure is likely to be down (to an acceptable reading), thus maintaining good health. Lucy believes that good health is linked to diet, a view which is enforced by local media, health professionals and family members (Walker, 2001).

> **Extract 16. Lucy:** *"...but if ah is calm yuh know if there is no problem, no trouble, no lickle ting and I'm calm pressure fih down."* ("But if I am calm you know and there is no problem, no trouble, no little things and I am calm then my pressure is down.").

> **Extract 17. CM:** *"What do you understand by the term good health?"* **Lucy:** *"well tuh have ah proper diet, ah proper diet and less maybe try fih be less worried ,yuh know ,but in this country yuh cah stop worrying, every time is ah worry, worry, worry"*. (**CM**: "What do you understand by the term good health?" **Lucy:** "Well to have a proper diet, a proper diet and less maybe try to be less worried you know, but in this country you can't stop worrying every time it is a worry, worry, worry.").

Part of Lucy's identity is linked to her maintenance of good health, through the contribution of the diet she consumes and by reducing her level of worrying, Lucy gives the impression that life in the UK is one where she constantly worries and that where she originates from is a more peaceful and less stressful area/country. There are factors outside her control, such as the current climate of living in the *UK "but in this country yuh cah stop worrying, every time is ah worry , worry, worry"* that she cannot seem to control.

6.2.5 Summary of Sub-theme: Health Can be Controlled and Influenced by the Individual

Contributors to good health and maintenance, such as keeping active, regular physical exercise, healthy eating and reducing worrying, are within the control of these women. These are modifiable factors that the women can influence on their own, thus leading to an ownership of health, involving change and control which in turn shapes who they are. The personal influence on health is derived from the wider context of empowerment, as the women follow the 'rules' to maintain a good health status.

6.2.6 Spirituality: a Way of Maintaining Health

Extract 18. Doris: *"But I thank God for what I can do..."*

Health has been defined and described as a state that is achieved. It fits a social concept and truly becomes part of the individual's character (Corbin, 2003). Spirituality is concerned with belief in a divine force, which to some extent influences the behaviour of human beings (Moss, 2005). The centrality of belief and meaning of health views the body as a gift of God and that the power to heal remains firmly in the hands of God, and the doctor is merely the instrument of God's power (Abrums, 2000).

To some degree, health has been recognised as granted and justly deserved. This concept is closely linked to those who hold a religious belief (Sontag, 1988, 2001), writings on HIV/AIDS (Narayanasamy, 2001) and on nursing and health. Most of the participants interviewed had a firm religious belief; this could be for reasons such as age or a belief based on their cultural heritage, as the women are West Indian migrants to the UK, who came from British colonies where one of the aims of colonisation was conversion to Christianity (Fernandez-Olmos & Paravisini-Gebert, 2003; Stewart, 1999).

Marie holds the belief that health is sacred and given by God, which aligns health to spiritualism. God can grant her good health.

> **Extract 19. Marie:** *"I know there is a God and I pray and things like that and I feel alright to tell you the truth. 'Alright'."* [line 97 p8 is her own term for having good health. The concept of health as divine and granted by God is reinforced by her doctor].

> **Extract 20. Marie:** *"My doctor say you have a stroke a bad stroke and God still spare you life."*

and Doris:

> **Extract 21. Doris:** *"…I think if I had get pain so in life I would not have gone too far yuh know but thank God I am still alive."*

Abrums' (2000) concept of the doctor as God's instrument resounds in this extract. Marie listens to her doctor and accepts what he says that God has spared her life; God is the giver and taker of lives. The concept of God as the one who grants good health is closely linked to the doctor as an earthly God, which Lucy claimed earlier when I discussed being a good doctor. The women view their doctor as the mortal version of the immortal God they believe in. He is the 'lower level' God that helps and guides them in their health and social care needs. Doris believes that God grants health, wealth and strength. Her view is that God is the provider and controller of health and is grateful to God for her health and keeping her alive. He provides all her physical and financial needs; her relationship with God means that she can depend on him as he will not fail her when mortal men may. God is the one who sustains her and because of God Doris' needs are always met.

> **Extract 22. Doris:** *"…I say to them* (her children) *I eh go be no trouble to none of yous, fuh God help me fih I don't have to say lend mih a penny or ah doh have this and I doh have that…"*

> **Extract 23. Doris:** *"So I am happy God is still giving me breath to breathe…"*

God is key to Doris' life. She sees Him as responsible for her life, including her health and her daily needs. Lucy shares similar beliefs to Doris and Jenny (discussed earlier) in respect of spirituality, God and recovery. Evidence of Lucy's spirituality is seen in her belief that God can grant recovery from illness.

> ***Extract 24. Lucy:*** *"...so when people suffer stroke so at least thanks to God they can talk it's the person* […] *you can say thanks God at least they can talk, they can express themselves."*

The ability to verbalise and communicate with your family and friends is important to Lucy's character. In the following extracts, I discuss how she is able to talk with her doctor about her internalised emotions and how communicating through speaking is vital to her (and later on I discuss her need to talk and socialise with friends). Within her system of spiritual beliefs, Lucy acknowledges God as a ruler and supernatural being who can prevent illness. Lucy expresses her belief by saying it is not man but God that keeps her. Her internalised feelings, thoughts and emotions led to a build-up of anger and frustration, leading to high blood pressure. Talking to God and his servant (her doctor) has helped. The fact that God granted her speech, although she had a stroke, means she can express herself and she is grateful. Lucy's devoutness to being a Christian is made below.

> **Extract 25. Lucy: "***I went to the same church for 27 years, like I am an Anglican and d vicar never come and see mih since I get d stroke but I pray for myself I have got my holy bible I got lickle* (little) *books,...* [DDO] *I leave everything in the hands of God and it is God that is keeping me I know he is, my husband* (points to picture) *but as I said and always will say till I die its not the food he is giving me, its not the water he is giving me, its not the best way he cooks for me that is keeping me alive, what's keeping me alive is my faith and the one I cannot see. Because if I wasn't believing in God I wouldn't be here today, I would be six foot deep."*

She acknowledges her husband's physical provisions, but it is God that sustains and keeps her alive. She voices it is her own faith and belief in God that has kept her alive, otherwise she would have been dead and buried. Lucy's deep rooted belief in the existence of a God that looks after and rewards her health is seen during her account of her stroke attack.

> E**xtract 26. Lucy:** *"...the God I cannot see will look after me."*

Her trust in God is reaffirmed in her time of illness. Lucy's belief that God can guide her during periods of acute illness is seen in the above extract, when she calls on God to be her eyes to lead her. This is a type of relationship that is shared by friends, thus showing that the God she serves will look after her in time of need and danger.

> **Extract 27. Lucy:** "... [DDO]. *I tried to come down the step to call the doctor. I said God lead me downstairs with Your eyes so I can see the phone to call the doctor."*

Lucy's belief is that God is fair and when her sister died from a stroke attack she is convinced that it was God taking vengeance for her and, in so doing, her God has looked after her.

> **Extract 28. Lucy:** *"…but that sister that wish me bad about 6 years after she was in the bathroom bathing and when she finished taking a bath she called to her daughter C.. and said her neck, her whole body is hurting her, her legs hurting her take her to the hospital…* [DDO]*, before she reached there she died on the way, my other sister she phoned me and said Gloria* (pseudonym) *had died. You know what I said to her on the phone it's the same stroke she had sent to me God returned it back to her, the same way I had felt the pain the same thing that she had tell me God see her heart. I said I hope she had time before she closed the last eye and said God forgive me for what I have done to my sister."*

Lucy's belief that God was repaying her sister's wrongdoing to her is part of her Christian beliefs and the scriptures from the Bible support her thinking "for it is written, Vengeance is ***mine*****;** I will repay, saith the ***Lord***." (Romans 12:19, *The Holy Bible*). Her belief in God is that he can, and will "forgive us our sins as we forgive those who trespass against us" (Luke 11:2-4, *The Holy Bible*), again based on Biblical readings. Her comment that she hopes her sister asked God for forgiveness reflects her belief that God is a forgiving being.

Lucy relates that illness can be a trial from God; a test of faith to show how much you trust and believe in Him. Like Job in *The Holy Bible*, she views her illness as a test from God.

> **Extract 29. Lucy:** *"Because if I wasn't believing in God I wouldn't be here today, I would be six foot deep."* **CM:** *"So you have been through a long journey."* **Lucy:** *"Oh yes, oh yes, he* (God) *has tried me and bring me back."*

Lucy is concerned about how she is perceived by others for having such a strong belief in God. She is aware that she may be viewed as 'mad' for holding such a firm belief in God.

> **Extract 30. Lucy:** *"I am not mad for believing in God."*

Lucy acknowledges that the existence of a positive spiritual force means that a negative spiritual force is also present and this can influence health and well-being. In the earlier extracts, she informs us of her belief that God can 'try' her through ill-health, but will always be there to guide and protect those who love and worship Him, as well as taking vengeance. In this case, her sister was punished. In the following extracts she relates that health can be attacked by a negative spiritual force, which she has experienced. Lucy is aware that her cultural belief can be viewed as 'stupidness' and 'mad'.

> **Extract 31. Lucy: "***I saw a daddy long leg coming down, coming down, down, and to touch mih…* [DDO] *So when I take the towel for me to hit it, it turned to soot, black soot. I did not see where it go but it was like in a corner then the pain, the pain suddenly by the time I feel the pain I feel my face getting palsy, I said God help me with that pain, suddenly I cannot see … So what my sister wished me that was wot, don't say that I am talking stupidness, because I am an old woman."* **[CM]** "*No, I am not here to judge you on anything."* **Lucy:** *"So what my sister had wished me, she said you say you'll be coming back, you say you'll be coming back as you reach in London you will drop dead….* [DDO] *she said aunt take your dollars you will need it. I said I will not need it cause I am going back home and I have a job there and …she said how will you know you will be able to walk again* (.) *she said how do you know aunt you will be able to walk again and from 1998 three months since I came back from home I never work again. I never work, I never walk."*

She gives further evidence of her belief in a negative and a positive spirituality, showing good triumphs over evil. She believes that her stroke was a result of her sister sending black magic onto her.

> **Extract 32. Lucy:** *"Ok it means something was sent and I suffer seven whole months I never slept, seven months my eyes never closed suffering, I tried sleeping upstairs, downstairs with different pillows but I could not. I am one, I am not educated, but I use to write everything on a calendar. Exactly seven months I don't know what happened or what I did but after I suffered for seven months and I never cried, I never let tears run down from my eyes. I said the God I cannot see will look after me."*

She attributes this negative force (interpreted as 'black magic') as the cause of her stroke attack. The word 'Obeha' in the Caribbean represents one of the negative forms of spirituality and witchcraft that Lucy believed had attacked her in the form of stroke.

> **Extract 33. Lucy: "***I think the stroke was caused through the O I believe that and because it cause through that."*

Lucy's belief in black magic is evidenced by her embodied fear of calling it by its full colloquial name 'Obeha' (see Olmos & Paravisins-Gebert's 2005 work on black spirituality in the Caribbean), so she refers to it by its first initial for fear of the power the practice holds.

6.2.7 Summary of Sub-theme: Spirituality as Part of Health Governance

Earlier, in Chapter 2, I discussed how health has been described as a state that is achieved. I wrote on how it fits into a social concept and, from the interpretative readings in this chapter I will illustrate how its embeddedness becomes part of the individual's character (Corbin, 2003).

Ill-health has become recognised as 'justly deserved' through following the rules of healthy behaviour - in the case of the women in this study, take your medication, exercise, attend treatment centres and healthy eating practices were some of the rules. Ill-health can also be a trial from God, a cultural belief based on Christianity. In the Old Testament of the Bible, Job (a servant of God) experienced a series of ordeals and inflictions - he endured them faithfully to God and was rewarded at the end. A patient with Christian beliefs can look at her illness as a trial from God. She may be more persevering and compliant or, if she views her illness as part of her fate (a fatalistic approach), then there is an acceptance and a notion that nothing my doctor nor I can do will change the state of my health. If the individual or patient holds the attitude that being ill is her own fault, then she will take measures to combat her condition to restore good health. On the other hand, individuals such as Margo

and Marie may take control of their health and see its destiny as in their hands. Self-discipline and good health practices are not linked to spirituality but to behaviour.

6.2.8 Summary of Master Theme: Understanding my Health

Real life context, interactions and beliefs influence the health pathway of an individual through making choices based on practices and beliefs, which at times are rooted in the individual's culture. This theme and component sub-themes illustrate how health is viewed from a personal perspective.

The views of illness and healing stress the importance of the individual and of certain magical and religious rituals. This type of belief and aspect of a religious faith offers clear and important coping mechanisms and strategies. It also implies that illness lies with the individual (i.e., the individual has either committed a sin or is being tested by God). However, with the help of health professionals (instruments of God) and determination, the individual can contribute to their own health through positive health behaviours and practices. From the extracts a pattern emerges, showing how the individual takes into consideration the beliefs and attributes of their illness. They are able to evaluate the risk to their health and the ways in which they can deal with these risks. People do not always act on the objective, but mainly consider their representation on these issues (Sensky, 1997). Therefore, the women may act on what they consider important (represented) rather than what is actually important (objective).

6.2.9 Reflection on Master Theme: Understanding my Health

From the interpretative reading of this theme, I have come to the realisation that the speaker (participant) does not always know all the facts in the same way. This may be as a result of their position, reporting of their experience and the juxtaposition of the different types of knowledge, which in turn produces different epistemological accounts of such an illness and disease. As the women voiced their opinions, it became apparent to me that they

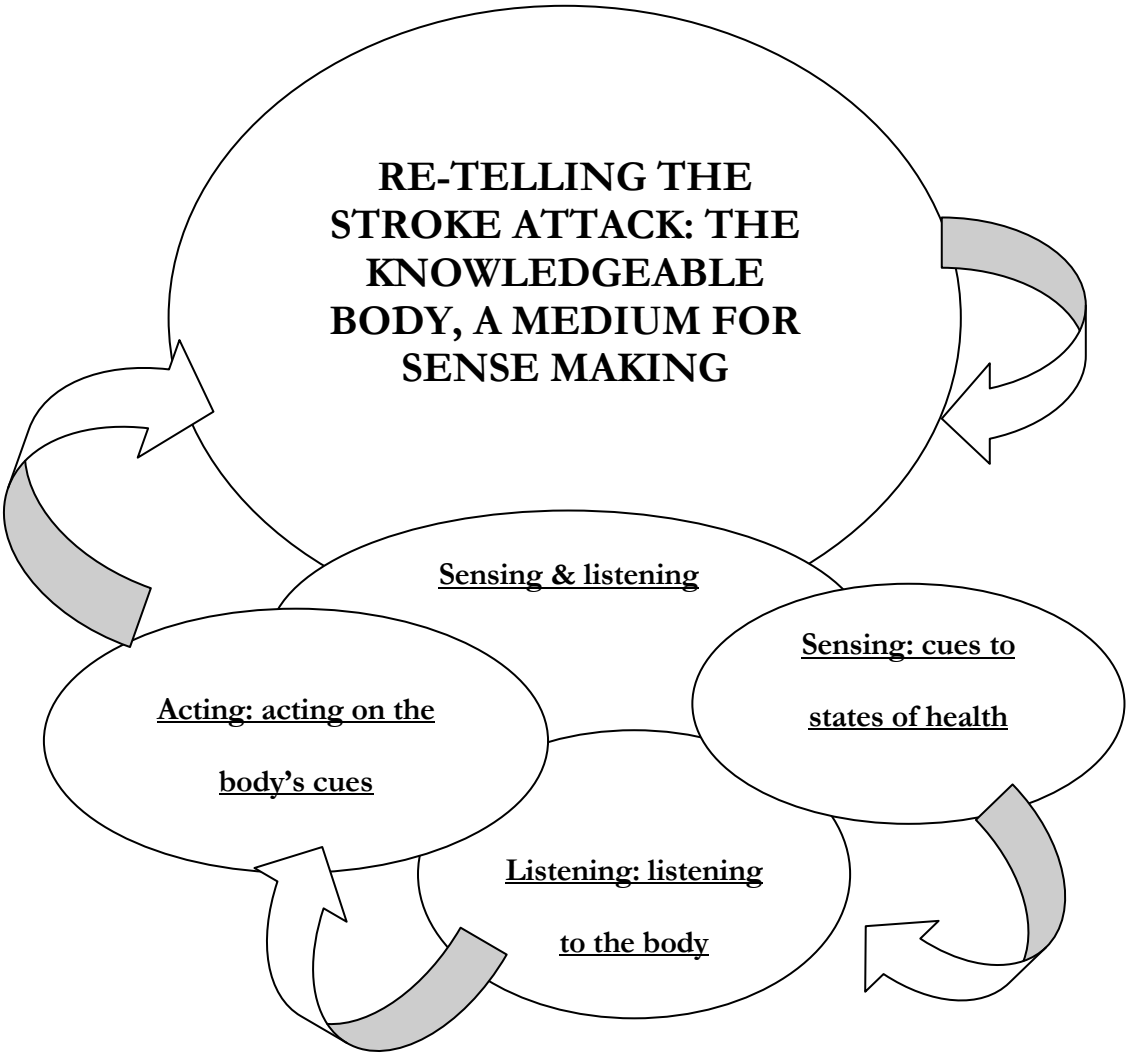
created their own meaning of the illness and that this creation was influenced by the world around them. The next master theme illustrates how the body and person or self used as identity makes meaning and sense of the illness.

6.3 Master Theme 2: Re-telling the Stroke Attack: the Knowledgeable Body, a Medium for Sense Making

6.3.1 Introduction to Master Theme

This master theme narrates the experience of the body as the knowledgeable self and shows how the body is used to navigate the self in response to health and illness (i.e., deciding when the participant is ill and how to respond). In the participants' talk, this is the ability to function in what they relate to as their 'normal' everyday life.

Previously, the body has been used as a compass for diagnosing and treating illnesses and it continues to do so today. The concept of 'health, mind and body' varies across time and place. Galen, an ancient Greek physician, followed the Hippocratic tradition in believing that health or *hygeia* and soundness or *euexia* occurs when there is an equilibrium between the hot, cold, wet and dry components of the body. The four bodily humours were believed to be blood, phlegm, yellow bile and black bile. The belief was that the state of the body could be put out of synchrony if an imbalance of the humours occurred. More contemporary researchers and writers (Helman, 2001; Kelleher & Hillier, 1996; Shilling, 1993; Williams, 2003) have reported on the body as a source of direction for health and health practices. Some have focused their studies on the way different cultural groups interpret illness and how the body is used in tandem to diagnose the illness experienced in order to treat the body and make sense of the situation. Most medical and social anthropologists and health psychologists believe that concepts of health and illness are embodied in everyday talk and in the thoughts of people of all languages and cultures (Marks, Murray, Evans, Willig, Woodall & Sykes, 2005).



Source: Author

Figure 6.3: Re-telling the Stroke Attack: the Knowledgeable Body, a Medium for Sense Making with Sub-themes

The cluster themes for this master theme illustrated in Figure 6.3 are as follows: (1) Sensing: the body's cues to states of health; (2) Listening to the body; and (3) Acting on the body's cues. Collectively, these themes reflect how illness is embodied by these women and becomes part of their everyday lives. It shows how the feelings generated by the body are used to negotiate everyday living.

6.3.2 Sensing: Cues to States of Health

> **Extract 34. Jenny:** *"...if I walk fast I could feel my heart pumping and my breath getting sharp…. you get this blurriness in your eyes and you feel heavy in the head."*

Any theory of meaning that hopes to address the experience of illness should give right of way to the primacy of the body, not only as an object of thought but as a vehicle itself for thinking, feeling and acting (Kirmayer, 1992). Most participants in this study were able to recall their stroke attack. The extracts that follow show how they used their body as the informant to their stroke attack. The following extract illustrates how Margo interprets and senses her body's state of health:

> **Extract 35. Margo:** *"You always know when your blood pressure is high cause you always get really bad headaches, and your shoulders you know they become very stiff and your neck…"*

Through sensing differences, Margo communicates with her body. The physical symptoms she experiences are a sign of her blood pressure getting 'high' or increasing. Jenny's body also provides her with warning signs of her blood pressure increasing.

> **Extract 36. Jenny:** *"When the blood pressure high you get this blurriness in your eyes and you feel heavy in the head"* and in **Line 211** *"…if I walk fast I could feel my heart pumping and my breath getting sharp"* and **Line 221** *"…it is part of the pressure very blurry sometimes you reading something and it is hard."*

The physical sensations experienced through the body are used by the women to monitor their health in relation to their hypertension and stroke. Symptoms such as bad headaches (Margo), blurriness in the eyes and heavy in the head, heart pumping and breath getting sharp (Jenny) are examples of how the women sense their ill-health (and well-being).

Part of the embodied life is becoming an expert in knowing your illness and body. This certainly is the case for Queenie. The limitation of the day as cued by the body

(hypertension and stroke) changes her life on an hourly basis at times; it is also used to indicate her level of dependence on that particular day.

> **Extract 37. Queenie:** *"So I might get up today and say I feeling good so I get myself into the bathroom and do other stuff, comb my hair but then there is another time when I physically can't do it and I need help and support to do that."*

The way in which Queenie experiences bodily sensations with regard to her health sets the scene for how her day will be planned. Based on her 'feeling', she is either able to perform her activities of living (which Phase 1 looked at - problems experienced after a stroke) or decide whether she needs support to perform such activities. Therefore, experiences of life after stroke are not fixed but can be fluid; this fluidity for some is experienced through sensations of ill-health and well-being.

The women use their body to diagnose illness (for example, stress can lead to high blood pressure, which can bring on a stroke attack) (Smeeton, Heuschmann, Rudd, McEvoy, Kitchen, Sarker & Wolfe, 2007). The women are able to determine when their body becomes limited in its ability and is under attack. The following extract from Lucy reflects this.

> **Extract 38. CM:** *"So what makes you think the blood pressure is high?"*
> **Lucy:** "O*h mih head ah feel as fih whole worl on mih head, mih two legs cahynot support de body, the head, de legs mih eyes everything."*

The lived experience of stroke is embodied in the way that Lucy's body speaks to her, indicating when she may need to seek medical attention or, in some cases, practise her own remedies.

In the extract below, Jenny uses her body as a guide to inform her when her blood pressure is high. When the physical symptoms appear, she is able to interpret them as a sign of high blood pressure.

> **Extract 39. Jenny:** *"Because when it* (her blood pressure) *goes up I do not feel normal in my body… when the blood pressure goes up you could feel pumping at the back of your head* (shows back of head lower neck) *and em* (.) *It doesn't feel the same it's like pumping at the back of your head* (.) *weakness in your body and thing…"*

Jenny's feelings are that her body can be 'normal' and 'not normal' by the sensations experienced. Her body guides her; the extract illustrates how the body and the individual are caught up in a fateful embrace. Jenny's talk does not speak of symptoms of illness, but rather feelings and sensations. These are what are used by the lay person to determine the state of their health and also when they need to seek medical attention or advice.

6.3.3 Summary of Sub-theme: Sensing: the Body's Cues to States of Health

Lupton (2004) defines illness as the social lived experience of symptoms and disease, a technical malfunction or deviation from the biological norm. This sub-theme demonstrates how illness (hypertension and stroke) is viewed in a social context through sensations experienced by the body and the person, which leads to the development of meaning making repertoires (discussed later). The women make sense of these experiences through listening to their body. This is mainly based on personal beliefs of their health experiences. They don't often know the medical terminology to describe the symptoms experienced, but they are able to explain them, showing the close relationship they have with their body.

6.3.4 Listening: Listening to the Body

Signals are sent by the body indicating states of health and the ability to perform and engage in daily activities of living such as mobility, cooking, cleaning and maintaining personal hygiene. Based on these signals or cues, the women act accordingly such as resting, relaxing or engaging in activities of daily living. This sub-theme focuses on the re-telling of the stroke attack and how the women listened to their body. This sub-theme looks at the ways in which the participants make the decision on how to respond to the cues from

their body. Those around us, as in the case of Doris, can reinforce determining how to respond to physical signs from the body that are outwardly visible.

> **Extract 40. Doris:** *"And I went by her* (Doris' daughter) *and we had dinner and when I get up to go to the bathroom I noticed my left side was very stiff, I was dragging and she* (daughter) *said mummy stop this rubbish what can happen to you in this short space of time…"*

Sometimes when acute illness occurs, family members and those close to us may find it difficult to comprehend what is going on. In Doris' case, her body was under attack when she was experiencing the first signs and symptoms of a stroke. Her body was beginning to lose some of its functions and her daughter could not understand this. It was up to Doris to listen to her body and respond.

> **Extract 41. Doris:** *"…by the time I get home I call the doctor, and he said I was having a stroke and then he sent me up to the hospital in N****** …"*

In recalling her stroke attack, we can see how Jenny listened to her body through the physical symptoms she experienced.

> **Extract 42. Jenny:** *"So I said all of a sudden I feel my hands, numb me legs feel like heavy so I said that I better go to the hospital, I call for a cab. When I got there I was kinda balancing."*

Jenny listens to her body. She is able to read the signs of numbness in her hands and heavy feelings in her legs as not feeling well and realises the need to act and to go to the hospital. Her body sends the messages through a network of physiological sensations and she listens to these by acting on them as she thinks appropriate.

Doris listens to her body and acts accordingly to the signs of high blood pressure.

> **Extract 43. CM:** *"What are the signs you get when your blood pressure is high?"*. **Doris:** *"My head, I always get this headache, and I put it down to that* (HBP). *So I will either go and lay down. I will go and lay down, draw the curtain and lay down and stay in bed."*

Doris is in tune with her body and when she develops signs of high blood pressure (such as headaches) she heeds the signals and acts in her best interests. She knows that according to the actions she takes after experiencing the bodily sensations she can confirm whether it was her blood pressure being too high or not. This type of practice shows how Doris can impose self-treatment on occasions.

6.3.5 Summary of Sub-theme: Listening: Beliefs for Appraising the Body's Cues

Confirmation of a health status from family members or friends can impact on how an individual perceives themself. Doris' daughter refuses to believe that her mother can become ill in such a short space of time, which in turn can make Doris think she is not truly ill. Therefore, illness representations can be confirmed or rejected by those around us, which can impact on how we behave, such as seeking medical attention or deciding to hold off. The body communicates through feelings and sensations, which are medically labelled symptoms. When these were communicated, the women listened to their body and acted as best they could for their benefit.

6.3.6 Acting: Acting on the Body's Cues

Acting on the cues, the women begin to display a representation of their illness. This can take forms such as being healthy but disabled, or chronically ill but well. For example, the participants may have problems walking and be classed as disabled (e.g. Queenie and Doris) but still view themselves as healthy. In the wider context, a Paralympic athlete equates to disabled and athletic. Athletic has connotations of healthy, fit and competitive that are not always associated with disability (Shilling, 2005). As a person begins to engage with the cues from the body, they begin to paint a picture of themselves within their social surroundings; for these women, first within the home and then in the wider social settings such as community and groups.

The women in this study learned to listen to, sense and act on their body in order to make decisions concerning health and ill-health.

> **Extract 44. Doris:** *"I was having this pain, pain round my waist, but I take it as nothing I went straight back out as I was going by my daughter. I got up and found a belt and put it round my waist. And I went by her and we had dinner and when I get up to go to the bathroom I noticed my left side was very stiff… I just couldn't move my left side properly, anyway I said to her I am going home… By the time I get home I call the doctor, and he said I was having a stroke…"*

Doris ignored her body with the initial signs of pain, then she used her own practice (a belt) to alleviate the pain. This practice could be rooted in past experience or beliefs. With a further sign from her body (the stiffness in her left side), she realised that she needed to call her doctor. Therefore, although the body may have sent signals to Doris regarding illness, she chose how to respond to such signs.

Jenny's body converses with her to indicate when she needs to rest.

> **Extract 45. Jenny**: **"***You have to rest yourself. If you* (.) *overwork yourself like going up and down it pushes your blood pressure up so you've got to rest I doesn't rush me work and finish everything before I rest myself I do something and then I go and rest myself… I lay down and listen to my tape and it help relax my body I do bits by bits."*

In an attempt to listen to her body, Jenny does her work in stages. She staggers her chores in order to avoid physical exertion, which may influence her health negatively by increasing her HBP that can then lead to another stroke. Rest can contribute to health in a positive way and rest takes the form of re-organising her day. A new life that she has to get accustomed to; where she cannot run around as she did previously. A new life where she is more aligned or forced to be in an open dialogue with her body.

6.3.7 Summary of Master Theme: the Knowledgeable Body: the Body as a Medium for Sense Making

The individual uses personal experience and beliefs to make sense of the sensations experienced by the body, so an internal locus of control (Ewles & Simnett, 2004) exists (i.e., I am responsible for my health and therefore I will rest, relax or seek medical attention). Meaning and meaning making in relation to our bodies involves interaction with both internal and external factors, such as personal beliefs and societal influences. The extracts used support the interpretations of beliefs and how they can impact on the way in which the women respond to the conversation with their body.

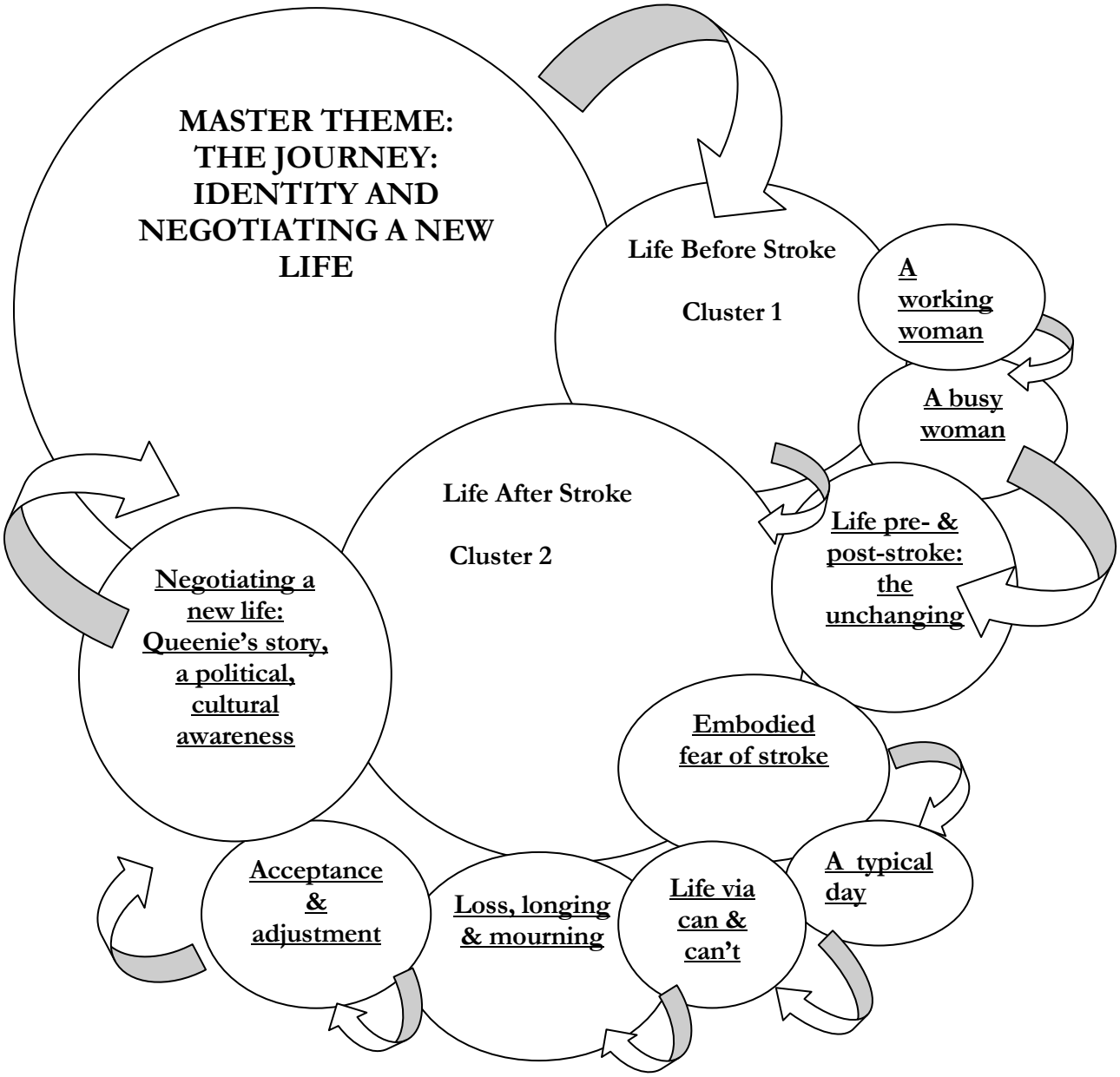
6.3.8 Reflection on Master Theme: the Knowledgeable Body: the Body as a Medium for Sense Making

The body is more than physical matter and goes beyond the organs that constitute it. I realise that the body for the women in this study is a representation of social life that is used to make sense of the world around them. Just as its biological make-up is intricately worked with a nervous system of neurons and cells, its social representation is embedded with personal beliefs informed by cultural practices and social values, which are all acted out and portrayed through the medium of the body.

6.4 Master Theme 3: the Journey: Identity and Negotiating a New Self

This theme looks at the journey of life after stroke. It is concerned with self-positioning in society and alignment to the body and reflected through the experiences of living with stroke. The theme is illustrated in Figure 6.4. It is a journey that considers the loss of the past self prior to stroke (which gets intertwined with youth - i.e., the earlier stages of life) and a journey that reflects on the past and evaluates the present self with regards to the past (healthy, young - i.e., chronological age) self. It captures the journey that invests in the reinvention of the self for the future, which is concerned with managing change and

stability. The cluster theme looks at acceptance of embodying the psychosocial reality of stroke and the re-investment of health by choosing to hold on and value what can stay constant and by choosing to adjust and modify the aspects that have changed. It focuses on the individual's representation in society post-stroke and illuminates the struggle of being labelled by society based on stroke and age affected bodies. It explores how the individual attempts to resist this crippled identity while trying to hold onto a self.



Source: Author

Figure 6.4: The Journey: Identity and Negotiating a New Life with Sub-themes

The following extracts map out the lives of the participants, to illustrate their lives before stroke. They present identities whereby health is intertwined with youth and economic productivity, reflecting carefree independent women.

6.4.1 Cluster Theme 1: Life Before Stroke: a Working Woman

> **Extract 46. Jenny:** *"Well I use to work before you know, I use to work, do night work."*

All of the participants talk of a working life (four of the six women arrived in the UK as adults during the Windrush period). Work was a requisite for their 'new' life in England. To be able to work and therefore be economically viable meant the women needed to have, and be in, good health. The type of work the women engaged in ties in with the work of feminist writers such as Bartley *et al*. (1992), Doyal (2001) and Oakley (1976), based on the gendered labour market, where women did mainly care and service industry types of jobs.

> **Extract 47. Marie:** *"I did catering, I worked in *** Hospital and *** Hospital, I was a hard worker."* **Jenny:** *"I did night work in a canteen."* **Doris:** *"I worked in de sugar factory in Canning Town."*

Queenie, who was born in Jamaica and arrived in London as a teenager, recounts her 'white collar profession'. This shows the position of the women, which reflects a shifting migrant identity as well as a generational difference. Unlike Marie, Jenny and Doris who all had to acculturate to the English society and system, Queenie was brought up in a post-Windrush system, whereby her values and views of women and the type of work they do differ from those who came to England from the Caribbean as adults.

> **Extract 48. Queenie:** *"I always worked in a white collar profession…* [DDO] *my parents gave me a good education and I worked really hard and I thought I'm gonna go and find myself a job in what I was trained to do whatever and I kissed that* (manual job) *goodbye and ever since I have worked in communications. So anything to do with telephones I used to work as a receptionist and stuff like that."*

Queenie lets us know that she was an educated working woman, qualified to do what she considers a respected office job. She boasts that she was good at what she did and that she can do anything to do with telephones, signifying that she worked with telecommunications, part of her life before stroke. Being educated meant that stroke did not take away her knowledge.

The loss of working and inability to be a busy person can lead to social isolation, loss of communication and relationships.

> **Extract 49. Lucy:** *"When you are on your feet people knows you but when you down no-one wants to know. He* (points to husband) *tell me so and so say hello, sometimes it is not shout I want to shout, but say that the person that tells you to say hello they know where I am living, I haven't got a palace I am living in a shack but at the same time you can easily pop in, one minute, two minutes Lucille how are you then a stupid lickle,* (little) *stupid lickle talk you know thing we knew years ago we use to laugh about then we giggle and then you go about yuh business you doh* (don't) *have to come back, yuh can come back every six months, and say Lucille how are you and then go, then all these tings make me feel better right. He* (refers to husband) *always say to me you born alone I say yes we all born alone but we don't all have to live the way we are we need <u>each other</u>."*

Lucy's pre-stroke life was one full of friends and work, which involved socialising and chatting. This feature of her life no longer exists; she acknowledges that she needs other people (i.e. communicating with them) to survive. Stroke has isolated her from her friends, as she cannot go out, but also her friends have isolated her because of her stroke. The lived experience of life after stroke for Lucy involves social isolation, which leads to reduced happiness, when she is able to talk and laugh it makes life 'better' for her.

The ability to work and be an economically producing unit is of great value to the women in this study. Their job defined who they were: a 'hard worker' or a 'white collar professional'. The facility to work meant the women had a busy life before stroke.

6.4.2 Cluster Theme 1: Life Before Stroke: a Busy Woman

> **Extract 50. Jenny:** *"Yeah I don't sit down I have always been a busy woman* (.) *I always finding myself something to do yeah, but I have always been a busy woman. ... ah busy woman."*

Life prior to stroke for this particular group of women was busy, active and independent. For Margo, the hub of activity was based around furthering her education to excel in her career.

> **Extract 51. Margo:** *"Cause I spent six years, doing a part time first degree and then I went and did a three year M.Sc. in planning and property law… as I am not the type of person to sit around and do nothing."*

Prior to her stroke, Margo describes a life full of external engagement achieved through studying and working. After her stroke occurred, she has had to slow down and surrender some of her activities. She relates that she is not used to sitting around and doing nothing, an indication that since stroke she is faced with inactivity. She had always been busy compared to her life after stroke.

Jenny said that "*I am not this person you see sitting in front of you, I used to be a busy active individual prior to stroke*". She is someone who used to be able to race to the bus stop, now she is unable to do this as she needs to give herself time to get there and she is no longer able to race against the clock. She has suffered the loss to mobilise speedily.

> **Extract 52. Jenny:** *"Long ago I use to be on the go every minute… Yes once upon a time I use to give myself if the bus coming in five minutes I use to rush out to the bus stop but now I give myself time to get there... ah take mih time."*

Life before stroke re-told was one occupied by investing in yourself. One such area of investment is keeping busy, which meant that the women were leading a full and active life. The inability to be busy has led to the loss of the previous self.

6.4.3 Summary of Theme: Life Before Stroke

This theme presents the women's voices on work, and how women of a certain class, race, ethnicity and age engaged mainly in service and care work. It illustrates that, prior to stroke, life for the women was concerned with being economically productive and independent. They relied less on family and other networks to get through the day, they were the main carers of their family and now the roles are reversed.

The women tell their story to convince the researcher that although they may be seen as less of whom they were, they are still the same person. Identities can change and new ones form as we adapt to situations and circumstances. However, as the women accept this change from 'busyness', there comes a period of mourning for this loss. This loss is articulated as different levels from a physical (i.e., unable to perform tasks) to a psychological and social loss. Their loss is evident when they talk of how much they miss aspects of their life that they can no longer engage with. The sub-theme begins to set the scene to show how new identities are formed as old ones are lost. However, these new identities are not formed without some resistance, which leads to an internal negotiation of a new self, allowing acceptance and adjustment to occur.

6.4.4 Cluster Theme 2: Life After Stroke

This theme maps the journey of the participants through their experiences of life after stroke. It covers the embodied fear (of stroke recurring) and a typical day in the life of the women living with stroke to the unchanging aspects. It ends with a close-up report of one participant on her social and political views of the lived stroke experience.

6.4.5 Cluster Theme 2: Life After Stroke: Loss, Longing and Mourning of a Previous Life

> **Extract 53. CM:** *"Since you have had the stroke what do you miss most?"* **Doris:** "*Doing things, moving around briskly…"* **Queenie:** *"I miss my job, I miss my job."* **Lucy:** *"I would like to go out."* **Marie:** *"I want to go back as I was before."*

The women voiced a loss of identity, self and a physical body. As identities change and new ones are taken on board, the loss of their previous identity may lead to a period of mourning. Their journey is mapped through the following extracts:

> **Extract 54. Queenie:** *"…as I said after the stroke you lose little bits of yourself."*

Queenie acknowledges that stroke takes away 'bits' of who you are. These 'bits' are interpreted as physical, psychological and social facets that weave the individual's life together.

> **Extract 55. Queenie: "***What's missing is the ability to live a full life again."*

The loss of the ability to be able to live a full life and return to the person she once was is connected to the following extract, where Queenie says that her life was stolen from her at a young age

> **Extract 56. Queenie:** *"…you know I had my stroke relatively young. I became disabled relatively young."*

And in so doing she has lost her physical ability, the ability to do what others (and herself when in good health) take for granted.

> **Extract 57. Queenie: "***A full life is to be able to enjoy and do all the things that I used to be able to do before I became ill… like my husband says if we were to go now on press up I used to beat him every time now to not being able to even think about doing press ups or exercises. It might sound a bit simple but that was what it was like."*

Queenie's reflection on a past self is a loss of the simple things in life, the things that defined who she was, a physically fit woman who was able to work and look after her family.

In struggling to accept the loss incurred by stroke, Margo wants to return to her previous self and life - paid employment.

> **Extract 58. Margo:** *"I went back it was one year, cause I was admitted in April 2000, and I went back to work in October 2001. I begged them to take me back to work… I begged them to take me back."*

Margo's pain can be heard as she tells how she begged her employers to let her return to work. Her begging shows how much it meant for her to re-engage with the labour market. This is interpreted as a need to recover part of her life and lost identity.

Queenie says not working means she is isolated and she has had to adjust from meeting people every day to being on her own.

> **Extract 59. Queenie:** *"I miss my job, I miss my job…* [DDO] *but I would say definitely my ability to work, I always worked I have gone from working and meeting people every day to being isolated."*

Interpreted as 'I am not this person who stays at home or sits indoors all day as I used to work, I was involved in meaningful social activities; stroke is the cause of my isolation'.

Doris feels cheated by her loss of independence and her working self is interpreted in the following extract.

> **Extract 60. Doris:** *"It wasn't time yet for me to really retire from work and I like to go to work."* **CM: "***Do you miss working?"* **Doris:** "*Yes I do miss it."*

It was not yet her time; the illness has stolen her right to work. Stroke has brought a premature ending to her working life; she is forced to explore other avenues. Stroke has been unjust to her; it has taken away something she loved without any warning or replacement.

Margo also feels cheated by stroke. In her case, she was cheated of her promotion.

> **Extract 61. Margo:** *"The good thing is when I was in hospital, the head of planning, came to visit me with another top officer and he said you know something Marge* (Margo) *if you did not have this stroke the team leader where I was he is leaving and he said that we were so impressed with the work that you were doing over the last few years, we were not going to put the job out to advert we were going to give it to you, he said unfortunately you had a stroke, so we can't do that that now."*

Margo does not see the law broken through what is said and done to her, she sees this situation as a commendation. It is an indication of how much she was valued by her bosses and the high esteem she was held in, and this makes her proud of herself and achievements. The cruelty of stroke to steal is seen in the manner her boss informs her of her career progress. Some of the loss from stroke can be more physical and affect the body as in the case of Lucy, who lost a level of bodily control in regards to her bladder.

> **Extract 62. Lucy:** *"I explained to her* (day centre manager) *I cannot come at 8 o'clock in the morning and I said to her that I am embarrassed because many times if I want to urinate by the time I feel it, it doh give me no notice; warning, by the time I feel it already* (gestures to floods of urine passing from body) *I say whether I was ill or not I was never like that so she said oh there is people who is incontinent I said no thanks."*

Health professionals and others may accept the losses incurred by stroke. However, Lucy remains a person with dignity; she is an individual who will not be labelled. She prefers to maintain her dignity and remain within the privacy of her own home, dealing with her incontinence herself. Hence she says 'no thank you' to the day centre manager and she will not allow herself to be seen in a manner that might be unacceptable to others; it is not part of her identity and culture to be seen as incontinent.

Part of West Indian culture in the UK is about being able to go the market and see the food indigenous to the women's homeland. This is a life that involves shopping, socialising, laughing and chatting; a cultural practice that stroke can interrupt.

> **Extract 63. Lucy:** *"Yes I use to go to the market and buy my lickle veg and ting, you know you seeing what you want although I'm in, he goes* (points to husband) *and do the shopping but many times, I would feel like if I goes there and I see these you know, it not the same like, it it's the same ting de potato, de dasheen, the yam and tings, but sometimes yuh eyes jus linger unto something else, and yes I miss it a lot."*

The ability to go out, shop and see the foods she likes and make her choice of vegetables or pieces of yam, feel them and get caught by the other market displays is a painful loss for Lucy, which in her talk is reminiscent of market days.

Life for Lucy is now one of disability. Restriction of mobility makes her feel imprisoned in her own home. Stroke has had two major effects on Lucy; firstly, the inability to do physical tasks; secondly, the illness has a socially disabling impact on Lucy's life and identity. She is unable to participate in that part of West Indian culture which provides her with a link to her community.

> **Extract 64. Lucy:** *"…if I can go out and meet people and see people you know I will become ah have ah laugh; you know coz laughing is good have ah laugh have a chat, but when I am indoors or when I was not going out nowhere, I just feel* (.) *I don't know, I just can't answer all these* (.) *… I use to go out and you know have a walk… It's the same thing I said again if I can go out, I walk around I take a bus I go to the market, you know I look around, I buy this if I feel for it, meet people talk, and then you know I feel relaxed. But when you behind closed doors, it's like a prison."*

This illness has stopped Lucy's 'usual' routine. She can no longer go out and shop and see life as it occurs; stroke has curtailed her social activities and contacts with the outside world. It has stopped her from working (extract 65). The reality of not being able to go out and choose the produce from the market herself, to be able to feel it, stare at it, to make a choice based on what she wants, is a deep loss. The loss of the activities she would have engaged in when she was out shopping is evident in her talk.

> **Extract 65. CM:** *"If you could do something else what would you like to do?* **Lucy:** *I would like to go out… I was working and apart from that I will go out I had friends, I had a friend who had a lickle shop here in the Broadway, I use to go there sit down talk we have laugh and after a time come back and meet other people, you know people I knew, you know we have a laugh a chat in the street and we talk and I go come back home."*

Lucy misses the friends she used to socialise with and the cultural format it takes - meeting in the street or sitting in a shop and chatting and laughing. This type of activity is part of who she was; a social being that worked, laughed, met people, talked and shopped. She was someone who had friends that wanted to laugh and talk with her.

The talk of the women presents an emerging framework for the way in which they manage life after stroke. The next stage in this framework after loss is accepting and adjusting to life after stroke, and is presented in the following sub-theme.

6.4.6 Cluster Theme 2 Life After Stroke: Towards Acceptance and Adjustment of Stroke

> **Extract 66. Marie:** *"My body is not normal, but I don't think I will come back normal… My life has changed… but at the same time its Marie, its me, you understand I don't let it go."*

The extracts below provide evidence of how the women have accepted and adjusted to stroke. It shows that when acceptance and adjustments are made, there is negotiation between the body and self, sometimes leading to the development of a new identity.

> **Extract 67. CM:** "*So how do you manage?"* **Jenny:** "*I just cut down, I use to time gone past I use to rush up to the market, you know carry loads that I was not supposed to. But now if I go out the road I just ah ah select what I carry."*

Jenny's acceptance and adjustment to her stroke-affected body gives rise to a slower woman. She knows she is no longer a woman who can overload herself with shopping, but one who has to prioritise her shopping.

Marie's acceptance of her illness and the impact it has had on changing her identity is linked to my earlier interpretation that the body can be a platform for social representation. Although stroke has given her body a different physical look, her personality and who she is has not changed. The self is the same, it is internally perceived, therefore what happens externally (such as disability) may not always change self-perception. Identity for Marie is concerned with being consistent and an individualised self. Other people may see her physical body and label her as old or disabled, but her perception is that she may be slower but she is still 'Marie'.

> **Extract 68. Marie**: *"No it's me Marie the same person, the Marie who likes to laugh and joke and keep herself busy."*

In accepting and adjusting to stroke, Margo has not stopped being who she is, but has become slower. Again the external (body) may change but the self (internal) remains constant and individualised.

> **Extract 69. Margo:** *"So you know thinking about it, my life has slowed down but it* (stroke) *has not stopped me from doing things."*

Part of the adjustment process entails learning learn how to cope with the effects of stroke and looking at different ways of doing the tasks previously taken for granted (for example, bathing and dressing). Learning to do such things makes Doris feel like a child again, as stroke has reduced her to child-like strategies.

> **Extract 70. Doris:** *"Yes, it's hard getting dressed, but I have to try, I have to try until I find an easy way out…* [DDO] *I know how to get out the bath, I have a chair that put you in the bath, but sometimes you, you want to lie in the bath and when you are in the bath you are like a child you have to roll over and try and press up on one hand, to get up out of the bath. These are some of the little things that you need to do to try and cope. If one thing is too hard you got to try and think what is the easiest way to do it. There is a lot of things that I had to try and do especially like in the kitchen. My daughter didn't allow me in the kitchen you see. But when she come and say she soon come cause she gone to the shops I go in the kitchen and try and I tell you I break up a lot of stuff but at least I was trying and I never let it hold me down yuh know."*

And she also had to learn to drive again.

> **Extract 71. Doris:** *"You must be trying and trying hard, I tried hard everybody used to say send back your car send back your car and I say I ain't sending back the car, de car staying right there, because one day I am going to drive that car and eventually one day my daughter went up de high street and I hop and hop with the two stick and I started the car and reversed it then I say but wait I can't do the three point turn so let me go round so I go round the road and I went down the road and come back in and park the car… I make it happen."*

In accepting her illness and moving forward with her life, she emphasises that she is 'trying' because it is difficult. 'Trying' is Doris' own way of contributing to her recovery, being involved in her care and a way of keeping active. In 'trying' to adapt to a new way of doing things, we are able to see how the individual can contribute to their own recovery.

Queenie's process of adjusting to a new identity began with acknowledging that she was ashamed of whom she had become. As a result of stroke she was in, or had faded into, the background of society.

> **Extract 72. Queenie:** *"They hide away, they hide away. I guess that is what I was saying when I said take back your life cause I was also hiding away, coz number one I was almost skeletal, cause I had lost so much weight I did not want to be seen I did not feel good about myself I did not want people seeing me like that and because of that feeling it hindered my progress because I was not going out there I was spending 99% of my time indoors at home. So I can only come to the conclusion from my own experience they cannot take the shame of it so to speak."*

Queenie hid away from the public because she did not want to be seen as lesser or reduced to a lower level of function. She is now aware that such feelings had only hindered her progress. The shame of stroke is embedded within cultural beliefs and what it is to be a woman.

Life for some of the participants involved worrying, and in acknowledging that worrying is a contributor to hypertension and stroke, they needed to adjust their lives accordingly.

> **Extract 73. Jenny:** *"Well sometime you hear news about* (.) *even a good friend you have you hear something happen to them you relax your body. Yeah sometime you hear some sad news* (.) *and you just take it easy, you don't worry yourself… It makes a big difference because it teaches you to relax more yeah* (.) *yeah* (.) *I use to always be a worried person worried over everything, but now I try to relax my body, I don't let everything worry me. I try to control myself… It make it* (.) *well* (.) *I would say it make me life better because it learn me to relax me body more because I know that if I rush myself things might happen so I don't want nothing to happen so I try to relax more…* [DDO] *If you* (.) *overwork yourself like going up and down it pushes your blood pressure up so you've got to rest."*

Jenny can no longer afford to worry about news of friends. She has learnt how to control her emotions. One step towards this is that she has stopped worrying about news concerning friends. She controls herself and what she worries about. She knows that relaxation is good, while worrying and rushing around is bad for her health. She has learnt to relax her body, although this does not necessarily mean her mind is relaxed.

Queenie's ability to talk of her loss of control is part of accepting her need to depend on other people - the first part of the cycle of life after stroke; accepting loss of control and acceptance of help from others.

> **Extract 74. Queenie:** *"…I have no control, no control* (lowers voice). *You have control over everything when you don't have to rely on people, on their help you know you have that element of control whereas you know I'm gonna do this tomorrow I will get up and do it…* [DDO] *I was dependent on people helping me …uh umm you are dependent on something, that is another thing, that is another element for someone who is quite an independent person to actually suddenly become dependent on <u>something or someone</u>."* **CM:** *"Can you explain the something or someone to me?"* **Queenie:** "*Well the someone is those closest to you in my case it was my husband and family."*

Queenie accepts that she is a woman with no control, which is difficult for a person who has always been independent. Dependency indicates a change in status for Queenie synonymous with disability. As Queenie begins to accept the dependence incurred by stroke, the change in her identity becomes evident.

> **Extract 75. Queenie:** *"Well because of the physical disability, I was not able to clean my own house; I was not able to do the things a normal housewife would do.* (.) *I wasn't able to work that was major, I always worked even though I had my five children I always worked throughout. Uhm being able to*

work gives you that element of independence it also gives you the satisfaction of fulfilling the partnership with your other half so to speak, coz you are working together for a purpose and then you feel you are becoming a bit of a burden, because you are depending on someone else, there were times when I could not get to the toilet on my own, and I was dependent on people helping me to do those things."

The latter part of the extract shows a loss in identity and how she has changed from an independent to dependent woman. It captures the loss of a previous identity; a working woman and housewife. The importance of work is interpreted by her stressing that even though she had five children she still worked. Queenie emphasises the difficulty in maintaining a job and family of such a size - although this has been difficult, it has been rewarding for her considering the severity of her stroke. Raising her family is an achievement.

This extract provides a framework for change. It starts with the idea of the loss of roles (1st stage). In the 2nd stage there is the feeling of burden as dependence sets in; this becomes more apparent in the 3rd and final stage when the implications for (and on) relationships are also apparent, as the individual internalises the feeling of loss and burden and how it affects her relationship with her husband and children/family. She sees herself as unique, she was 'out there', meaning she was in the big pond with the big fishes, and now stroke has reduced her to the small pond with the little fishes, interpreted as a loss of a working woman's identity. She is interpreted as saying 'I am not the woman you see before you, I have not always been ill; I worked in the city'. In her world, to be able to work in the city carries a heavy weight and status. It means you are tough and able bodied, able to survive, which is what she did prior to her stroke.

6.4.7 Cluster Theme 2: Life After Stroke: The Past and Present: Negotiating a New Self

Extract 76. Queenie: *"So you can either sit here and think which one of them is it gonna be or you say you know what I've got what I've got this is what I've got and I am gonna make the most of it and you fight."*

The following extracts illuminate the struggle of surrendering an old identity while having to incorporate aspects of a new one. By taking on new aspects, the women are developing a new identity, such as 'disabled' or 'slower woman'. Part of the negotiation process is interpreted as having the determination to help yourself.

Margo's contribution to a new self is through her own efforts to rehabilitate.

> **Extract 77. Margo: "***I have worked really hard over the last year. I have spent lots and lots of money you know, trying to get private physio, you know to be able to try and walk again, cause I had a stick for three years and then I joined this class in Surrey I used to go there every week, and now its moved to Middlesex I have been going there for a year… But if I take my time I'll be able to do anything you know, most things I use to do before."*

Margo's determination is seen through accessing private physiotherapy classes and even though the location of the classes has moved she continues to attend them. She is proud that she can do most of what she did before. She has used these private classes to help negotiate the post-stroke Margo; not one who is seen as disabled, but a Margo who can be an independent individual and do anything if she takes her time.

Queenie's negotiation of a new identity begins with staking a claim on her previous life. She believes that you should not be a wilting flower, but should try to regain some of your life (for her, it was physical ability). She believes that if you are able to perform, then you can be the person you want to be. In her eyes, dependence does not (or should not) change who you are.

> **Extract 78. Queenie:** *"If there is anything I would like to say to anybody who has just had a stroke is you got to claim your life back cause I know it really difficult especially when you're dependent on other people, but you have to try you never can give up on trying to claim your life back and claiming your life back does not mean that you cannot rely on someone to do something for you."*

For Queenie, "claiming your life back" is an insurance to regain a degree of optimal health, as you are free to rely on others. Reclaiming your life means that you can regain part of your old self. In negotiating a new self, Marie talks of her job.

> **Extract 79. Marie:** *"Yes take the photo and look at it, I make these very big, it is easy and yet not easy to make them. I made one for the manager's office and then I made another one for the office and other one for the front of the office, and then I will start another one to put in the manager's office."*

I interpret Marie as saying, 'I may not be able to work anymore but look at how useful I am. I make art and although it may seem simple it is not, I am able to do intricate detailed and valued work. I do them so well they are on exhibit for all to see'. From building this new identity Marie has also gained a new family, one she can go on holidays with and a family who enquires about her when she does not attend the day centre.

> **Extract 80. Marie:** *"They the managers like them so much* (laughs)*, I enjoy it and they like it, If they don't see me they will phone to ask for me what happens you don't come Marie? They like to see me there so if they don't see me they will like to know why, so when they don't see me they miss me. So next year I am going home to see my brother and thing like that. Two of the managers from the centre are planning to go home with me, they say it's because they like me so much."*

Even after her stroke, this participant is still a valuable person and is worthy of new friendships, which helps in her negotiating a new life for herself, as although she does not work for monetary rewards she has built a network around her.

6.4.8 Cluster Theme 2: Life After Stroke: an Embodied Fear

> **Extract 81. Jenny:** *"It frighten you sometimes because the first feelings you don't want to experience that again, it frighten you because it is frightening you, you go easy, try to relax your body more."*

Margo's experience of stroke has left an embodied fear within her.

> **Extract 82. Margo**: *"I think about the stroke and get worried you know always worried, and frightened it would come back…"*

Stroke has left a mark of fear in both women's lives that can be heard in their voices. It is an element of fear that they do not want to experience such an occurrence again; it is like a

ghost that returns to haunt them. The fear of recurrence is so strong that the women have had to almost tiptoe around their daily activities for fear of another attack. Jenny tells herself to go easy and gets her body to relax for fear of another stroke attack.

6.4.9 Cluster Theme 2: Life After Stroke: a Typical Day

> **Extract 83. Queenie:** *"It features so much in your life, it's the first thing you think of when you get up in the morning."*

This section maps out the routines that make up a day in the life of someone who has suffered stroke. It shows how life is shaped by stroke on a daily basis.

> **Extract 84. Queenie:** *"A typical day I would wake up and like I said first stop is always medication so I would have a cup of tea toast and my medication…* [DDO] *But you know if it is a relatively goodish day once I have taken my meds the medication have lots of different side effects so I would have to really go through and struggle with those side effects. Some days I say I am not just getting out of bed until I feel the side effects have gone off, and then when I feel well enough I will get up and go the bathroom and stuff like that. And then I will uuuhm watch a bit of TV you know the morning programmes… and then later on I will cook some dinner… Most of what I do is like what I do on the computer on the various websites doing research on whatever area I am interested in and that is kinda really my day. So I might get up today and say I feeling good so I get myself into the bathroom and do other stuff, comb my hair but then there is another time when I physically can't do it and I need help and support to do that."*

Queenie's reportage of her day is based on an hourly occurrence of symptoms and the effects of her illness and stroke medication. Her body is dependent on her medication and she has to know how to treat her body. Her blood pressure means that she lives life on an hourly basis. Stroke has affected her life to the extent where she is unable to execute her plans. The severity of the effects of stroke means that some days she needs to have support in order to undertake activities like maintaining personal hygiene.

And for Doris her day is:

> **Extract 85. Doris:** *"A typical day is like I have to get ready to come here* (Day Centre)*, cause when I come here I get a laugh… other than that a typical day is getting ready and get here, when I get here, I don't like to rush, if I come here*

> *and I spend an hour, and then I leave and maybe I go up the high street and I do ah little window shopping and then I go home. I like to walk in and go to Primark, it just attract mih eyes, yuh know me eyes, and then sometimes you see people, who you haven't seen for a long time, you go up on the high street and you bounce them up. Then as you meet up you have a little chat and then you, you, I come home and then back to the TV again, yuh know, if you can do most things you like although in a limited capacity you can live a good life after stroke."*

Doris describes a practice that Lucy longed for (discussed earlier), a practice that most of the participants talk of: going to the high street or to the market. This is a form of socialising - going out to the high street where you may bump into friends and have a chat and a laugh, looking into the shop windows and allowing your eyes to be caught by some of the shop displays. This is part of her typical day when she also attends a day centre. The ability to be able to do this means that she has some control and choice over her life. She is aware of not rushing around, while as a result of being able to do these activities she sees herself as having a good life after stroke.

There are times when the day is determined by the physically embodied and psychological feelings within your body. Stroke can make you depressed - it becomes part of you and you need to learn how to cope with it.

> **Extract 86. Doris:** *"Some days is rough I really feel down, down, down. And when I feel down I just stay indoors and just watch TV, and I will come downstairs make something to eat and go back upstairs, until that feeling pass. I just get depressed sometimes…* [DDO] I *do cry sometimes but not as much as before, but I don't take it and put it on baggage. If I feel like crying, I just cry and when I feel like it I stop."*

Doris has learnt how to live and cope with stroke; she does not take it on as baggage. Her coping mechanism is to cry and let it all out. Stroke can interrupt her whole day if she wakes up feeling depressed. One of the psychological impacts of stroke is that it can cause individuals to isolate themselves from wider society. This is not a result of a physical disability (which can occur), but the direct result stroke can have on the emotional and mental component of a person's life. The way these women cope with the psychological effects determines the outcome of their day and overall recovery.

6.4.10 Cluster Theme 2: Life After Stroke: Can and Can't

> **Extract 87. Queenie:** *"There is a lot less to do, let's put it this way there is a lot less that I am able to do."*

Recovery and life after stroke for this group of women is often predicted on their ability to perform and do everyday tasks. This ability is expressed via the words 'can' and 'can't', able and unable.

> **Extract 88. Lucy:** *"One day I received a letter from my mum and she said to me 'Lucy, can you comb your hair, can you do your housework?' I wrote back to her and I said 'mum this is my handwriting, I can write, I can clean my home, I can comb my hair, I can cook my own food so don't worry'."*

But after her second stroke attack:

> **Extract 89. Lucy:** *"I can't walk properly; I can't do what I use to do before and all these aggravates me; I feel many times I feel frustrated* (.) *the way I use to talk before slower now I can't, many times when I talk dey* (family) *say I am talking too loud and which I don't really, sometimes I don't know that I am talking that loud."*

Her views of good health focus very much on the practicality of being able to speak clearly, to walk and mobilise, the ability to do what she would normally do in her daily routine. Lucy's body has undergone physical changes that have affected her health and body. Therefore her body is similar to a traffic light, it can tell her if she can 'proceed' or not. The inability to perform activities such as walking, and loss of other previous abilities, may further intensify and exacerbate feelings which can impact negatively on her health. The interpretation is that 'my health shapes my social engagement with my family' and part of that engagement is centred on how loud she speaks, as she is not always aware of the loudness of her voice. Lucy's opinions of health are in terms of practicality and the ability to 'be able' to perform. As a result of her stroke she is unable to be as physically active as she would like to be, therefore she views herself as worse off than before her stroke. The extract below reflects how her second stroke increased her inability to meet her own needs.

> **Extract 90. Lucy: "***Well like I said it is a hard ting when you have de stroke coz the tings you use to do before you can't do it, you miss tings like you know I cannot comb my hair, I cannot go in the bath, take a bath."*

The effect of this is that she has become dependent on her daughter to help her with activities to maintain her personal care. This is one of the reasons why, in extract 89, she says all these things aggravate her.

When Margo voices 'can' it is the ability to be able to be independent, such as booking her holidays and travelling independently.

> **Extract 91. Margo:** *"I think 2002/2003 I went to New York and then the following year I went to Trinidad on my own, nobody I just organise it. When people thinking that I can't go out because of the stroke I have been to weddings, I have been out in the night as long as I have got somebody to go out with I'm off."*

Part of being 'able to' and 'can do' is based on resisting the crippled label (identity) imposed by others. Life post-stroke is interpreted as being validated through the ability to perform tasks, albeit simple tasks, such as combing your hair or moving about. If these women can perform such tasks it gives them a sense of achievement, which raises their self-esteem.

6.4.11 Life Pre- and Post-stroke: the Unchanging

> **Extract 92. Queenie:** *"Yes but not only sex, when the stroke hits you, you need to be confident in your relationship, I know for myself I was confident cause my husband has been there for me from day one every step of the way so I was really confident that you know it was a matter of waiting until you know it was possible to do it* (sex). *If they love you enough* (husband/partner) *or are committed enough cause it is a commitment then you get through it."*

Family life and structures were interpreted as being one of the constants within the entire stroke journey; ranging from helping when stroke occurred, to supporting during and after stroke.

> **Extract 93. Queenie:** *"Recovering from the last stroke I had I was down and I was like feeling cut off and really isolated, because there was no one to communicate your feelings to apart from my husband was there but you know after barraging him with everything you want to give him a break but you also wanted to be able just to say how you are feeling. You know I have been married to my husband for thirty one years and most of that time I have had bad health and he stuck with me throughout however I think he knows if the roles were reversed I would do exactly the same for him so its good to have someone who is understanding and like I said before someone who is committed…* [DDO] *He needed to know what he could do or what will be expected of him and how he could best support me or help me."*

During the darkest times of her stroke, Queenie's husband was the only person she could depend on for support. Her husband is committed to her and she knows that she would do the same for him. She felt guilty having to place everything on him; she recognises the pressure and added stress her stroke has placed on her husband as a result of her needs. When stroke occurs it not only affects the women, but there is a network of others who are affected, which starts with the family. In Queenie's case, she felt isolated with no-one to talk to apart from her husband; she believes commitment in a marriage or union can help once the individuals can talk openly. Her family structure is a tower of support to her, as seen in the following extract.

> **Extract 94. Queenie:** *"We* (.) *have* (.) *quite a strong family structure because my husband is such a very strong person and people will say you stuck together* <u>*despite*</u> *and you know the despite is going to be my stroke, yes but the stroke does sometimes put pressure on."*

Queenie knows how difficult her illness has been for her and her family. She is aware of the pressures it has created and placed upon her own family and married life. These feelings are a result of Queenie's own ideas of not being able to fulfil her end of the marriage and partnership due to stroke. Stroke can create and place pressure on a relationship. Roles need to be defined and redefined, and those involved need to know how they can support you, in order for you to continue living your life.

Margo is a mother who has duties and responsibilities towards her daughter.

> **Extract 95. Margo:** *"I can't afford to leave* (go on holidays) *the last three years cause I don't want to leave my daughter… I have a responsibility and duty as a mother to my daughter…* [DDO] *as my daughter is ill and I don't want to leave her, cause she can't go far, she doesn't want any other hospital you know cause she goes to ****** Hospital."*

Even though Margo is still experiencing the effects of stroke, she has to offer support to her sick daughter. She sees this as her motherly responsibility. Her stroke has not stopped her being a mother to her daughter, as she places her daughter's well-being before her own. Although she maintains responsibility, stroke can affect the duty you may have towards other members of your family. For Jenny, the unchanging role of a mother is to care for and to be loved and cared for. This is demonstrated in the following extract.

> **Extract 96. Jenny:** *"Sometimes especially if your family is there you know that they will look after you, but when you go with just friends and if something happen to you there you have to think about them here* (family) *you have to think of yourself as well as them* (family). … *if they* (meaning family) *are alrite them I'm alrite."*

Worrying about your children and their welfare, in Jenny's opinion, is part of being a good mother. Even if something happens to her, they are the first ones she thinks off. Family is core to the lives of these women. The family becomes a central structure around which their lives operate. Sometimes their love, care and regard for their family is so deep that it can overshadow their own health and the socio-political position of their illness. Queenie is one participant who is aware of her socio-political situation, which is presented in the next theme.

6.5 Cluster Theme 2: Life After Stroke: a Politico-cultural Awareness and Stroke: Queenie's Life

> **Extract 97. Queenie:** *"The actual results of the stroke initially uhm was not debilitating in terms of you know I could still move around uhm I think the left side was left very weak and I had a slight twist to the mouth. But it actually led to deeper consequences.*"

Queenie has a socio-political economy that shows an awareness of the healthcare system and how it operates and should operate. Her talk reveals she is politically motivated to help others from her own ethnic background. The analysis and interpretation of the extracts that follow show how the political is shaped by the personal and vice versa.

Although stroke may make you less of the physical person you once were, Queenie has been able to see the positive in her stroke. She displays a form of altruism where she uses her experience to help create a framework to support others.

> **Extract 98. Queenie:** *"...so once I got through the worst part of the illness then it gave me something to do, so I was then able to be in a position where I can offer advice and support to people like myself...* (She acts on this 'position' by) *I got involved with the local government agencies that looked out for people with disabilities because my problem and this is a problem probably many stroke victims do have is that sometimes we are not left with massive physical disabilities like in my case…* [DDO] *yes but there are roots in the local community/borough they provide support for people like myself and I decided that I would have a little go at it on some of the committees and things like that."*

And again:

> **Extract 99. Queenie:** *"It's not like how it used to be you know you heard it from a friend of a friend, you know you can go out there you can get on the web you can ring up your local town hall and you can get some help."*

Queenie is motivated to help others in her position. She formed an organisation offering support to stroke victims. She uses her experiences of life after stroke and shares them with those who need it. This idea directly links to extract 98; forming this organisation gave her a purpose after stroke. It is a way to show her ability to function as an active political person 'despite' (extract 94) stroke. She understands that it can be difficult to find information and support when you need it, as seen in extract 100.

> **Extract 100. Queenie:** *"When I was looking for advice and support I couldn't find it so we created this little framework which is still working… I am part of their committee. Sometimes I help with the community action group where I am*

at the end of the phone for people who wants information on whatever area I can help in and that is normally for a few hours, this is all voluntary."

Limited physical ability does not stop Queenie from viewing herself as valuable and able to contribute to her community concerning her experience of stroke. She believes that although she has residual effects of the stroke, she can still be beneficial to others. Queenie observes how Afro-Caribbean people with stroke are hidden within society. Her political awareness is seen when she uses the term 'BME' (Black and Minority Ethnic) and goes onto explain what BME means. She reiterates her 'education' by using terms that I as an academic and researcher uses, thus she is seen as demonstrating her knowledge.

Extract 101. Queenie: *"...but I still in my mind say to myself because of the high percentage of stroke in African Caribbean communities, BME communities, African Caribbean communities are BME communities primarily. Where are all these people why don't we see them more? Why are they not more visual? I don't know… whether we hide away at home or not?"*

In the dialogue below, Queenie is keen to let us know her opinion on why black women with stroke are hidden in society. She displays an awareness of how stroke can affect Afro-Caribbean women and of their perceptions of themselves.

Extract 102. Queenie: "*We* (black women) *don't want to be seen if we got a limp or what I don't know if that is the same for all women its difficult for me to generalise. This is just what I have actually observed is that when I did make the effort to go to a facility that was set up for people like myself that there weren't many people like myself there. So that led me to believe that either they are embarrassed by the results of their stroke and they don't want to be seen outside or they don't know that that facility exists or they felt like I felt for a little while."* **CM: "***Initially, how did you feel?"* **Queenie: "*E*rr** *umm embarrassed…"*

Queenie is aware that others may be affected by stroke in a similar manner to her. One of the results for her was embarrassment of the physical effects of the stroke attack. She shares her conviction to help others by admonishing and acknowledging.

Extract 103. Queenie: *"So I would like to say to my sisters out there to be a lot more positive in their outlook during such times coz you know I have seen it, you know friend with stroke who now walk with a walking stick. I feel no way about walking with a walking stick if it can get me from here to the gate without someone else helping me, there is no shame in that, there is no embarrassment*

in that… Yeah so I will definitely say to my home girls so to speak, don't hide out there don't feel that because you have had a stroke that it is the end of your life, you know regardless of how severe the stroke might be… If there is anything I would like to say to anybody who has just had a stroke is you got to claim your life back cause I know it really difficult especially when you're dependent on other people…"

The above extract reflects the political closeness Queenie shares with other Afro-Caribbean women, as she refers to them as her 'sisters' and 'home girls'. She is proud to walk with a stick if it means that she does not need to depend on someone else. Stroke can take away your life and she talks of reclaiming the life that can be lost to stroke, a life that she lost. She believes in active participation as part of recovery. This does not only take a physical rehabilitation form, but she believes in psychological reclamation.

Extract 104. Queenie: *"And I think that is what happens to you for me being brought up in the Caribbean to a certain age still having most of the Caribbean teachings, it was imperative that I was a good wife to keep a marriage going and to keep my children focused and do what I can to help them focus and help them to become successful."*

Queenie is no longer able to do what is culturally expected of her, and her dependence on other women to help with her household duties made her feel less of a woman. Culture becomes ingrained in an individual (Jenkins, 1996), and this is what has happened to Queenie. Her Caribbean teachings from childhood followed into her life here in England and she possesses certain concepts in relation to being a woman. Cultural upbringing leads to formulations of womanhood for this participant.

Extract 105. Queenie: *"I would say you know black women* (.) *I feel can become a lot more isolated than the mainstream I think."* **CM**: "Because?" **Queenie: "***Obviously we are a minority community and we are attached to* (.) *how do you put it* (.) t*o be woman in every sense of the word* [when asked in line 39]." **CM:** "*Did you find this when you had your stroke, that such stigmas followed you?"* [Her response in line 40 is] **Queenie: "***Uh am* (.) *yes, yes I did its like when you have a hysterectomy you feel you are no longer a woman, you cannot produce children anymore therefore that takes away from you. And I think that is what happens to you with stroke."*

Queenie emphasises the idea of womanhood and importance of being a black woman, and on how stroke impacts upon this. As a result of Queenie's cultural upbringing, it was

difficult to see herself as a black woman with a disability and it led to her isolation from her community. The severity of the impact of stroke for her is similar to having a hysterectomy, which is interpreted as part of what makes her a woman. Stroke removed this from within her. Also the ability to produce material goods, as she is expected to in her culture (directly related to extract 104), no longer exist and this makes her feel less of a woman.

Her experience of stroke has made her aware of the care needs of stroke victims. She acknowledges that stroke victims need a continuity of care. However, she is keen to point out that this continuity of care is closely aligned to a cultural sensitivity, which should also include gender and sexuality.

> **Extract 106. Queenie:** *"I was really unwell, I contacted disability action they get some help. Ahm however I found that in one week I had had five different people came into my house and I am like* (.) *hold on a minute so I rang up my social worker and said hello look I am a Caribbean woman who was brought up a certain way and I really don't want my body to be seen be five different people in one week it is not acceptable."*

Queenie's cultural upbringing and Caribbean heritage influences and shapes the way she would like her health service to be administered. Dependence on others makes her feel that she is less of a woman, as she cannot function in the way she was taught and brought up to be.

> **Extract 107. Queenie:** *"Whenever you could be seen to be less of a woman and whenever someone has to come in and do all of these things for you, you do feel a bit as if you are not good as the rest."*

When you become dependent after stroke you may begin to compare yourself to others and your feeling of self-worth can be greatly affected. Queenie believed the need to have assistance meant that she was not as good as the rest of her peers. This can be part of the trajectory that led to her initial isolation from the wider society after stroke. Her dependence on others made her feel less in comparison to them.

As discussed earlier, stroke can make you dependent on other people for assistance; the act of dependency can bring about guilt in close relationships such as a marriage or union, as seen in the next extract.

> **Extract 108. Queenie:** *"But I would say in terms of pressure on the relationship it have to be reliant on someone else and feeling that guilt because you putting pressure on this person and then you think is it fair to put pressure on that person. I really did feel guilty with lumbering him* (husband), *which he will have to cope with all of his natural life, it's in for a penny in for a pound."*

Queenie's talk reveals that she has, and needs, a support mechanism/framework to be able to live her life as fully as possible. In her own case, support comes from her family and appropriate local service providers. The recognition for stroke support is interpreted through her isolation and the need to talk to people within and outside of her family network, as she is aware of an imploding situation where she can overload those closest to her as a result of her dependency. As a result of the cultural beliefs she holds (discussed earlier) and lack of information in accessing services or knowing what is available to people with stroke, she was further forced into isolation, as demonstrated in extract 109.

> **Extract 109. Queenie:** *"I was like as you say kinda isolated didn't know how to access services etcetera."*

This isolation caused her to turn to creative writing to help express herself. She needed an outlet for her feelings, in order to accept and adjust to her new life, body and self; saying how she felt helped her in the adjustment process.

> **Extract 110. Queenie:** *"…creative writing course and that was really an important part of my life and I wrote stories and poems."* **CM**: *"Were those stories and poems a reflection of what you were going through?"* **Queenie:** "*Initially yes, it was just to get that thing out about how you were feeling and what not but then ultimately it was eight years I went to that class* (laughs) *it helped me to believe in myself again…"*

And again:

> **Extract 111. Queenie:** *"Ahm but my creative writing gave me quite an outlet, you know it gave me an outlet and I became a part of something because there*

> *was a group it was a group and we all were very close in the end and we all in a group for eight years so you do become close in the end… Some of us have had stories published, I /we used to go to **** Hospital Radio and read our stories to the patients, so you can see the therapy there, it was very, very therapeutic and I still continue to write. One of my granddaughter won young writer of the year award and she said I was inspired by me nanny."*

Writing poems and stories was a way of expressing the feelings Queenie had experienced during and after her stroke. Creative writing became a way to meet other like-minded people and also a form of therapy for her as well as other patients in the hospitals she shared her writings with. Stroke support does not always have to be in the prescribed form of physical rehabilitation - for Queenie, it was about using other social support mechanisms (e.g. the creative writing club). This led her to engage with a wider group of people, where she was able to express herself.

6.5.1 Summary of Master Theme: Life After Stroke

This master theme illustrates the interpreted life after stroke for the women in this study. It shows how the everyday activities (generally taken for granted) such as washing, dressing, cooking and making plans to go out, can become a difficult task due to the effects of stroke. The theme further illuminates how stroke is seen from a political and cultural perspective and how one of the participant's experiences have been interpreted in this light. Life after stroke can be very rewarding if certain steps are taken (for example, rest, support from family and engagement with culturally sensitive support groups).

6.5.2 Reflection on Master Theme: Life After Stroke

Stroke does not only affect a part of the body, it affects the individual's sense of self. These women are not like machines that get broken and then repaired. The lives of these women are complex and intricately woven by embodiment of social, psychological and political factors. Therefore, when stroke strikes it affects all such facets of these women's lives.

The chapter that follows is the final chapter of the thesis, which brings together the discussions from the findings for Phases 1 and 2 of this Ph.D. study.

CHAPTER 7: DISCUSSION, CONCLUSIONS, RECOMMENDATIONS AND REFLEXIVITY

7.1 Introduction

This chapter brings together the findings from the two empirical studies and relates them to the thesis' aims and respective research questions, locating theoretical claims into the relevant literature. While the chief empirical focus of the thesis was to examine manifestations of life after stroke through a mixed methods approach, overall the thesis sought to explore and theorise the theoretical concept of health and the phenomenology of health through the lens of a biopsychosocial approach.

The objectives of Phase 1 were (i) to identify the problems of the physical, psychological and social aspects of daily living that affect the lives of clinic attendees after stroke, and (ii) to evaluate any differences in terms of ethnicity and gender that may impact on these personal matters after stroke. The objectives of Phase 2 were to (i) identify and analyse the subjective and collective meanings of life after stroke among Afro-Caribbean women, and (ii) examine how social practices are represented in everyday living and how these are contained and shaped by the individual's cultural identity, as they engage with life after stroke.

Data collected from a hospital outpatient clinic, together with narratives from inner city Afro-Caribbean women (two of whom were also clinic attendees), were interrogated. The intention was to generate an informative, participant-defined mapping of the lived experience of life after stroke, focussing on contributions from gender and culture. The chapter ends with an overall conclusion to the study, recommendations in light of the findings, and the researcher's final reflections.

7.2 Summary of Findings

It was seen that, across the sample of participants who attended the outpatient clinic, more men (n = 108) than women (n = 77) attended the stroke clinic and that the mean age for the onset of stroke was 68 years $\pm$12.3. Differences with respect to gender group percentages emerged in terms of the profile of difficulties reported with functional and physical, psychological and social domains in life after stroke. Analysis of the stroke patients' data showed that Phase 1 findings, in terms of male gender groups, showed significant differences between Afro-Caribbean and Asian males regarding care support ($p = \cdot 015$), dressing ($p = \cdot 014$), feeding ($p = \cdot 043$), sleep ($p = \cdot 014$), BI ($p = \cdot 013$) and health rating for Afro-Caribbean and Asian males ($p = \cdot 002$). Similar significant ($p = \cdot 005$) differences were established for the BI between the White Caucasian and Asian male groups. In Chapter 4, I concluded that these findings show that of all the male groups, the Asian male patients were found to need more support in order to live with stroke. There was only one significant difference ($p = \cdot 013$) established within the female groups. This was in the choice of bathing, shown between the Afro-Caribbean and Asian women. The percentage of care support that was found between the male and female groups showed that the female groups received more professional care support than the male groups. This was particularly noticeable in the Afro-Caribbean group, suggesting that Afro-Caribbean men receive more non-professional care support (possibly from their own community). The findings from the research interviews of Phase 2 showed how Afro-Caribbean women understand their health in terms of definition and maintenance. They identified the role of the body in the sense-making process, with influences from culture. Another key finding of this study was the journey Afro-Caribbean women underwent after stroke, in terms of their identity and the contribution of culture in negotiating this identity. For example, most interviewees held firm religious beliefs and viewed their health as granted by a spiritual being and justly deserved. These observations highlight the encompassing benefit of adopting a biopsychosocial lens which health practitioners could use to view stroke survivors' health.

In the following sections of this chapter I raise issues for discussion based on the aims of this study. I also discuss and examine the academic position I took when designing and undertaking a mixed methods study.

7.3 Understanding Health Among Stroke Survivors Through a Biopsychosocial Lens

Chapter 2 outlined the transition in our ways of conceiving the nature of 'health', how to define it, how to assess it and how to improve it for clients. I also examined how models of health assist in actualising this view. The view of what 'health' is has evolved to one that is dynamic and dependable on factors such as age, culture and gender. This flexibility allows for situations where an individual may be defined and/or diagnosed as medically ill, yet they may hold their own personal view of health which may be close to or distant from a professional view of ill-health. This personal view becomes the *modus operandi* for the way in which that individual's health is 'acted out' in everyday life. This may also be the case for individuals that survive stroke.

Our understanding of health has evolved over time to incorporate the view that it is not merely the absence of disease, it is also a state of complete physical, social and spiritual well-being (Godlee, 2011). Illustrations of this individualised engagement with health and being/not being healthy are noted by Blaxter (1990) and Hughner and Kleine (2004), who comment that as their participants age they define health in different ways - for example, the ability to function or expect certain illnesses. In the present study, information on age from Phase 1 reported the mean age (at assessment) of male stroke attendees as being 68.7 $\pm$12.5 years (n = 108) and for females 68.2 $\pm$11.7 years (n = 77), signifying the occurrence of stroke with later life. But when asked about health and old age during the interviews, some of the women saw no association between ageing and stroke; however, they did explain that you need to look after yourself as you start getting older.

An important finding is the notion of *caring for the body*, which reflects an acknowledgment that ageing affects the body and one needs to look after it. Furthermore, it conveys the idea that individuals can, to a large extent, recognise themselves as agents with control over their own health. Both of which tie in well with a biopsychosocial perspective of health. In this doctoral study, the narratives of the women interviewed reflect the imperative of *caring for the body* in terms of physical and psychological dimensions. For example, Jenny meditates to 'relax her body' while Marie has to always 'keep busy' (interpreted as being active helps to maintain health).

As stroke survivors age, the effects of stroke contribute to the decline of physical functions (Anderson *et al.,* 2004). This is important, because functional outcome is reported by Wood *et al*. (2010) to impact on social engagement. However, in this current study, ageing was not always viewed as an adjunct to illness. While 48% of stroke clinic attendees reported that they only accepted social contacts but never initiated any, these Afro-Caribbean women from Phase 2 still engaged in social activities. For example, Marie attended day centre classes, Jenny went to church twice a day and Doris attended the day centre then later went window shopping. The implication here is for health providers and professionals in the way in which they view and deliver post-stroke care. Consideration will need to be given on how to help the stroke survivor achieve an aim rather than perform a function (e.g. the aim of getting to church rather than 'can I walk to church?'). Similar to Radomski's (1995) study, there needs to be an understanding of stroke survivors' feelings and ways of engagement, rather than evaluating them based on their physical ability. If this is done, then individuals may perceive their health in a different way, as Radomski claims that the ability to be able to try and function rather than be excluded based on disability is meaningful to the stroke survivor. Caring for the body through such identified actions becomes an imperative for empowering the framing of health.

The younger participants (Margo and Queenie at 47 and 49 years respectively) did not accept their illness as being the end of their day-to-day life, nor did they accept a fatalistic approach to their health as a result of their illness. They viewed it as something that can be

overcome, as they were aware of services and took a positive attitude towards rehabilitation. Nor did they allow themselves to be excluded from work based on functional ability - they essentially had agency over their recovery. The BI median score for the entire clinic attendee population was 15 and for Afro-Caribbean women 17. Section 2.6.2 highlighted that a difference of 4 out of 20 points is likely to represent a real difference. A high BI reflects the ability to function independently in most categories assessed and needing some assistance in some. However, Afro-Caribbean women's talk showed that they were excluded from work based on age and, in some cases, disability. The younger participants developed strategies to continue working - Margo returned to work gradually (part-time), using a tape recorder to help her as stroke had affected her short-term memory, while Queenie began to use the Internet to assist in setting up a self-help group. They adjusted to stroke and created new identities alongside the old self, in order to maintain the roles and facets of their previous life. Here we see that health can be viewed as a means of making a contribution to society a deliberate proactive reintegration as a member of the community.

The older participants accepted that stroke (illness) meant the end of working life for them. Therefore, when health is affected towards the latter end of the ageing continuum, individuals appear more willing to accept it as an indication to end certain activities such as work. In Chapter 2 (see section 2.2) I discussed the work of Blaxter (1990), where her participants reported health as a reserve, simply not being ill, as a life filled with healthy behaviours such as physical fitness, having energy and vitality, social relationships with others and an expression of psychosocial well-being. In my study I found that participants defined their health through their ability to contribute to it; for example, Marie (section 6.2.2) has "to make … up" her health, while the idea of Doris (section 6.2.4) is "Yuh have to just make your mind up and try…". Margo tells us she has a healthier diet of fruit and salads (see section 6.2.2). Such emphasis by the participants in this study shows that health is a status that can be achieved in terms of actions or healthy behaviour. These actions give an insider's view to the personal struggle between managing anxiety and adopting healthy

practices that stroke survivors undergo in order to maintain their health. The emotional resilience demonstrated by this group of women also contributes to framing their health.

On the other side of the coin is the concept that health is a status that is granted by God; one that is justly deserved as an idea that is closely linked to those that hold a religious belief (Narayanasamy, 2001; Sontag, 1988; 2001). In my study, most of the older participants aligned a good health status as being granted by God. The definition and perception of health among stroke survivors was based on the individual's character, with influences from both spiritual and personal beliefs. These melded beliefs make the concept of health dynamics one that may not always fit into the health professional's view, which can sometimes be based on assessments and ability to function in a set way. Worthy of note is that these stroke survivors also used the health services to help advance their health (for example, Margo used private physiotherapy and Marie always listened to her doctors and followed the rules they provided).

Health remains a contentious issue, but from the point of view of the stroke survivors it is defined in terms of comparison to others (i.e. you are healthy if you can talk and walk while others may not), healthy behaviours (i.e. diet and exercise including relaxation), ability to perform (i.e. go to the high street or the market to shop) and social engagement (i.e. going to church or going on holiday). The stroke survivors' perspectives encapsulate a biopsychosocial view of their health. For this group of Afro-Caribbean women, spirituality also guides health and recovery and is seen as granted by God. This concept has implications for healthcare workers, because if the individuals believe that their health is granted by God, they may adopt a fatalistic approach and opportunities for health promotion could be missed or ignored by placing health into the hands of fate. The other side of the coin shows that there exists a 'God vs. full agency' and how this contributes to this group of Afro-Caribbean women's experiences of life after stroke.

7.4 Ethnicity, Culture and its Impact on Stroke Survivors' Views and Engagement With Personal Health

As a result of migration, England has become a settling ground for people from different nationalities. The cultural practices held and maintained by these groups has led to the rise of a multi-ethnic English society (Helman, 2001). The different practices, traditions and beliefs that accompany these groups can impact on both their collective and individual health.

In this study, those who reported higher levels of stroke via clinic attendance were mainly from a White Caucasian ethnic background (52%), compared to Asians (19%), Other (16%) and Afro-Caribbeans (13%). Asians overall reported lower levels of functional ability (median BI 12m 10.5f), while the Afro-Caribbeans' BI was 17f. Ethnic groups can be perceived as homogenous because they belong to the group 'other' (i.e. the non-dominant in any society group they are in). For example, within the group 'Asians' there will be different types (e.g. Southern or Eastern Asians). Similarly, Afro-Caribbeans have their own defining characteristics, whereby Queenie informs us of what it is to be a woman; to her, *"a black woman from the Caribbean"* having to *"be a wife"* and *"keep a family"* are defining characteristics of her ethnic and cultural group. Thus, subjective reporting may not always capture the true abilities of stroke survivors from different cultural backgrounds. For example, in this study the Afro-Caribbean women reported a median score of 2, indicating they needed some assistance with bathing. Yet Doris tells us that she has to be like a baby when getting in and out of the bath, and Lucy has to depend on her daughter to assist her at weekends. In light of Queenie's statement, this higher reporting of functional abilities may be attributed to stoicism, as the women may not have wanted to be seen as less than their former selves. Another contributing factor is that their families were dependent on them, so therefore there was a motive to perform or at least try and perform as they were needed by their families. Although to a greater extent, even though they were crippled by stroke, they continued to perform their daily household tasks

through adjustment to stroke and a differently functioning yet same body; for example, Jenny says “I do some then rest” and “I share up my work”.

Participants reported resting as a mean of controlling their health. This can be linked to the cultural vocabulary used by Afro-Caribbean people when referring to hypertension as ‘pressure’. In order to combat ‘pressure’ they would rest, as was the case of most participants apart from Marie (who had to be busy, which could be her way of fighting against stroke). Using cultural vocabulary is a way of maintaining a cultural ‘internal balance’ or homeostasis. Maintaining this equilibrium can be extended to emotional well-being, as participants spoke of meditating as part of controlling health through rest. Through this manoeuvre, individuals position themselves as normal (e.g., I will rest because it is normal for someone of my age with stroke to do so). By engaging in this act, the individual ensures interpersonal stabilising and cultural homeostasis is maintained. One method is the way in which the individual uses language to hold on to their identity when its fabric has been challenged by stroke. Hall (2003), in her work on culture, symbolism and practice, concluded that language and other innumerable practices (such as greeting someone or how people seek and interpret medical treatment) are practices that create, constitute and maintain a culture.

Just as homeostasis preserves the diversity of biological species, this process of cultural homeostasis through the requirement to manoeuvre oneself into normal conditions (e.g. Marie attending the centre and making handicrafts for sale) for stabilising functions is what preserves cultures. For example, Lucy was unable to maintain her cultural balance by not going to the market and sitting down and chatting with her friends, while Jenny and Doris were able to get to the market signifying their ability to maintain equilibrium. Cultural practices and beliefs based on ethnicity contribute to the way in which individuals perceive, accept and respond to stroke. This thesis suggests that based on their ethnic origin, Afro-Caribbean women hold on to their own beliefs on health which are based on the cultural roles they are brought up to fulfil.

7.5 Culture: Knowledge, Beliefs and Practices in Life After Stroke

Culture and ethnicity are closely linked to each other, yet they are separate. While the former is based on a set of shared beliefs and practices (Helman, 1981, 2001; Kelleher & Hillier, 1996), the latter is not only concerned with observable characteristics but is seen within a complex coalition of the sharing of culture, values, traditions and the perceptions of belonging to every aspect of the lived human experience. Culture is not a single practice (as the narratives of the female participants illustrate), culture is portrayed (influence from cultural heritage is apparent) in the way the women were taught and what practices and beliefs were instilled upon them. Queenie's narrative captures this best *"And I think that is what happens to you for me being brought up in the Caribbean to a certain age still having most of the Caribbean teachings, it was imperative that I was…"*. These experiences may, and can, transfer with the individual and subsequently shape how they think, act, feel and behave.

An individual's views on illness and health are influenced by a cultural lens. The participants' defined factors for stroke centred on heredity; for example, "*mih uncle and brother had it"* (Jenny), *"My mother died from stroke"* (Lucy), "*My whole family have stroke and pressure"* (Doris) and *"some people don't look after themselves*" (Jenny). Participants spoke of how their siblings were affected by stroke and therefore it was not a huge shock to them when they had a stroke. Jenny and Lucy related that as a result of their family stroke history they have always been around it and therefore know of stroke and, in some respects, may have expected it to occur, thus normalising stroke. Acceptance of stroke based on hereditary is misleading to those with a familial history, as there are modifiable risk factors that can reduce the risk of stroke in old age. Education programmes in stroke awareness will need to address such issues which can be seen as myths. Familial history of stroke can sometimes be used to normalise stroke when it occurs.

7.6 Community and Social Settings: Limitations, Possibilities and Injunctions

The community which the individual belongs to has rules and observes practices on how they live and express their identity and who they are in terms of dress, language, food and customary practices. The social settings within which they live and work can provide limitations to these as well as a platform for new possibilities, and sometimes provide injunctions limiting life after stroke. Some communities will support their members in times of need, such as illness.

7.6.1 Interaction with Healthcare Professionals and Healthcare Systems

Section 4.9.1 presented the data for carers by status (i.e. professional or non-professional). Some 30% of the female Afro-Caribbean group received professional support, while only 8% of the men required professional support. This indicates that Afro-Caribbean men received more non-professional care support, whereas non-professional support was not available to Afro-Caribbean females. However, in the qualitative study, all participants had expectations that their family (namely children) would support them after stroke. In contrast, the evidence from Phase 1 showed that the Afro-Caribbean group received more professional care. It is possible that the reciprocity of care hoped for by Afro-Caribbean women was not always returned to them. Healthcare professionals need to recognise that this pattern can emerge in communities where a close cultural bond is shared.

In order to achieve the goal of good and better practice, healthcare systems need constant review and evaluation. In this study, the move from a paper-based patient information system gave rise to an electronic database. This holds essential information that could be shared with different health professionals and can improve the way in which patient subjective self-assessment is undertaken. Understanding the patient's perspective is a valued skill in nursing practice. This skill depends on the ability to listen to the patient and imagine the changes in their life world (Benner & Wrubel, 1989; Walton & Majdar, 1999).

There is a growing body of evidence in the literature that stroke survivors report extensive physical, psychological and social changes (Backe, Larsson, & Fridlund, 1996; Doolittle, 1988, 1992; Folden, 1994; Kirkevold, 2002; Nolan & Nolan, 1998). Essential in patient communication is the ability of nurses and doctors (the first in line of a host of multi-disciplinary team members) to receive (i.e. listen) and give information, which is essential in patient communication. Most of the participants hold the doctor in high regard. A doctor who listens to his patient, as in the case of Lucy,*"...I explain to mih doctor and then he start to give me de tablets although yuh know de same tablets he was giving me before it was not working but when I expressed myself then everything settled ..."* is one who will gain the confidence of his patients. This can lead to a relationship of trust, which may improve health services and the health of the individual. Marie also places trust in her doctor, as she boasted that after the uncertainty of stroke *"I get everything from my doctor"*.

Patient-practitioner interaction is an important determinant of health outcomes, but can often be problematic when practitioners such as nurses and doctors from one culture treat patients of a different culture. Based on my own experience, as evidenced in Chapter 1, health practitioners need to be sensitive to the cultural history and background of their patients and how some of their own cultural experiences may differ from those held by their patients. This understanding can be achieved through teaching and practice that includes a wider multicultural/ethnic context within professional training. For example, a diverse multiethnic area such as Newham can increase staff knowledge through running in-house courses on cultural diversity and ethnic practices, using volunteers representing the different ethnic groups in training and teaching sessions. These volunteers can provide an insight into practices that the practitioner would not necessarily be aware of and might expand their understanding of the issues that their patients are facing.

Engaging with the healthcare service can be difficult for some stroke survivors and impact upon their health. In this study, the map of Newham together with the analysis of bus routes suggests that poor transport may have accounted for clinic non-attendance from

some wards. The Health Development Agency in their document "Making the case: improving health through transport" (2005) indicates that public transport can have a negative impact on the health of older people as a result of times, schedules and routes to hospitals.

7.6.2 Social Roles - Working

Most of the women in Phase 2 occupied two traditional roles (marital and parental), plus a further role as a working woman mainly as a result of their migration to England. Depending on racial and socio-demographic backgrounds (Bhopal, 1997; Nazroo, 1997) the impact of social roles may and can differ. In this study, work provides not only an alternative to welfare, but suggests that Afro-Caribbean women have internalised the societal norm that working people are valued and worthwhile people. Marie's narrative is classic when she tried to returned to work and was not allowed to as a result of her stroke. She then visited her doctor who confirmed that she cannot work but replies that the state will look after her. She goes on to say she is not like other young people who can work but prefer to stay on benefits, as she wants to work.

Margo is of a similar character that embodies work. She returns to work gradually for a few hours a day and uses a tape recorder to document her conversations, as her memory fails her at times. For all the participants, work fulfilled the societal norm of earning. The women were also keen to return to work after stroke, which can be attributed to racial and immigration experiences. For example, those who were part of the Windrush era may have been socialised into the belief that part of being accepted and respected in English society is based on the value of work as a contributing role and civic duty. Therefore, once the women were forced to surrender a working life to stroke they may have encountered personal difficulties, as they may have felt they were no longer valued by the society into which they have tried to merge. When coding for themes associated with work, the concept of work as providing an occupational identity emerged. The drive to work was not fuelled by a desire to earn an income, but as a mode of identification; working woman, hard work

or white collar work all giving rise to an identity influenced by personal and societal values. The interviews showed that the participants' schema allow a value to their lives in that they are able and do go out to work, but when stroke takes away this value the individuals can be left with devalued feelings.

7.6.3 Social Roles - The Family and Worry

The older Afro-Caribbean women talked of their role in the home. They showed great worry and concern for their family, which depicts an interconnection between moral responsibility in health and traditional gender roles. Their responsibility in the domestic and family sphere were fulfilled through having "to make it up" (Marie, section 6.2.4) and "Yuh have to just make your mind up and try" (Doris, section 6.2.4) in the face of illness. The women who had a family spent considerable time worrying about them. Lucy worried for the welfare of her two sons, Jenny worried for her children, while Doris, Margo and Queenie also had children to worry about. All of the women agreed that worries could affect their health significantly in terms of hypertension leading to stroke. Different causes of stroke were discussed. Emotional distress was an influencing factor and 48% of female clinic attendees (Phase 1) reported mild or intermittent depression, which can be considered a sign of emotional distress.

The family is a central agent in caring during times of illness in Afro-Caribbean culture. Chapter 2 reviewed the work of Strudwick and Morris (2010) on the mechanism of support for Afro-Caribbean stroke survivors via the family unit. Most of the women indicated that their family was a significant part of their lives. In Phase 1 (see sections 4.8.1 and 4.9.2), 64% (n = 118) of clinic attendees who had suffered a stroke reported care support from within their home. 85% of female Afro-Caribbean attendees either lived in the same home (55%) as their carer or close by (30%). In Phase 2 it is possible to see culture in action, as when the illness occurred there was a cultural expectation by the women that their families (i.e. their children or husband) would care for them; it is an expected norm that this reciprocity of care occurs in Afro-Caribbean culture. Jenny indicates that her children will

look after her as the reciprocity of care is owed to her. Lucy enjoys the reciprocity of care, as her daughter comes and combs her hair every Saturday. Finch (1989), in her study of women in later life, discusses how children look after their parents in times of illness. Doris experienced such care when she related how her children would come and bathe her in hospital every day. All participants discussed how their children visit them on a regular basis and expressed how they worry for their children and how their children care for them. This indicates the centrality of the family within the Afro-Caribbean community. It also indicates that in time of illness, such as stroke, the family unit comes together to look after their own.

The immigration process entails many changes in the lives of those who migrate; the family-centeredness of immigrant women's well-being is a mediating factor in all aspects of their life after stroke. Family well-being is the focus for these women, as their worth is measured against their family function. The women expressed concern in their ability to perform roles such as mother, spouse, caregiver and employee, as well as caring for themselves. An apparent overarching factor for this group of Afro-Caribbean women is that they emphasised the importance of fulfilling commitments to others rather than to themselves.

7.7 Phenomenologically Grounded Narratives of Life After Stroke

7.7.1 Body - the Body as an Inscription

Given the body's fundamental position in creating one's life world, there is a need to explore Afro-Caribbean women's experiences of their body and life after stroke. The body is physical as it is experienced by others from the outside, and the body is also lived (i.e., the phenomenal body as it is experienced from within - the inside). In Chapter 2, the literature review, I looked at the work of Radomski (1995), Kvigne and Kirkevold (2003) on how the body is framed in the lived stroke experience and how survivors adapt to bodily changes, or as some of their participants described it - bodily strangeness. In this thesis, the

lived experience of the body is viewed in part from the self-reported functional abilities of clinic attendees. Essentially, this is seen in the scores of the BI, where both gender groups reported a median score of 15. This indicates the body as unable to fully function and perform the everyday activities of living. However, as discussed earlier, Afro-Caribbean women had relatively high BI scores (17), indicating a good level of functional abilities.

Participants' descriptions of their lives after stroke wove together the past, the present and the future. Experiences of their current lives were compared and contrasted to experiences with and from their pre-stroke lives. Over time, the women gradually seemed to become familiar with their unfamiliar lives and bodies (i.e. became accustomed to a new life and body after stroke). This is captured in Master Theme 2: the journey; identity and negotiating a new life, and cluster 2: life after stroke.

In order to understand these women's bodily experiences of life after stroke, we need to understand their pre-stroke life. Most participants described themselves as hard working and strong, equating good health with terms such as "*I use to work, do night work"* and *"I worked in **** hospital … I was a hard worker"*, whereby all these were used to describe a pre-stroke body. A body that was woven into the fabric of their lives and they can reminisce about this able body that allowed them to function at a much higher capacity.

In learning to control their health, participants learned to control their body. Here, the body is re-conceived as an integral part of being me and of being-with-life-after-stroke. A major function of controlling the body is maintaining continence. This type of bodily function is captured in the narratives of Lucy, and the semi-structured in-depth interviewing allowed me to probe and examine how continence was affected by stroke. Lucy described her body as an unreliable and betraying body after stroke.

As a result of her continence problems Lucy refuses to go to the day centre. The betrayal is so strong that she used her hands to describe her problems and gestured to indicate the unreliability of her body. The unreliability of the body is also captured by Doris when she

relayed that she broke a lot of crockery when preparing food in the kitchen as a form of adjusting to her bodily capabilities. Marie's body also fails her. She was failed publicly when she tried to walk without her walking sticks and fell in the street. Her pride and non-acceptance of a failing and changed body that has betrayed her stopped her from accepting further assistance from the two women who helped her get up.

In stroke clinic attendees, 57% of the men and 56% of the women (median 2) needed some level of support in mobilising. Out of the ten female Afro-Caribbean attendees, six needed assistance to mobilise and one was wheelchair bound. The narratives of the women interviewed help to better understand how they live with limited mobility. Jenny can no longer run for the bus and Doris has to adopt new positions when getting out of the bath. They both take more time and they do things slowly, as they do not want the stroke "*it frighten you"* (Jenny, Extract 81) to recur. Their bodies have become time-consuming bodies that are no longer young and agile. Margo has to adjust to her body as she needs a walking stick to help her walk and Queenie can no longer challenge her husband to push ups as her body has also betrayed her.

In accepting and renegotiating their bodies, the women thought about and instructed their bodies. For Marie this meant keeping busy, while for Jenny it was the opposite, resting, as she believed that she should rest and not rush around. For Margo it meant private healthcare in the form of physical rehabilitation and an extended body using various aids to help her such as a tape recorder and walking sticks. Doris (Extract 71) had to learn to drive again and learn to *"make it happen"* and Lucy had to learn to control her bodily functions. There needs to be awareness that the medicalisation of the body does not miss the connection between the individual, the phenomenological self and the social world that the individual lives in. In this study, participants were more concerned with the experience of their body in a socialised world. Health practitioners should be able to recognise the body beyond illness and health, and other inscriptions such as a busy, resting and working body existing as everyday bodily inscriptions which give rise to the person's identity.

7.7.2 The Knowledgeable Body

The Afro-Caribbean women interviewed here used their bodies to assess, evaluate and guide their health; they used their bodies as mediums for understanding their health. The sensations experienced through the body helped them to make meaning of their health, which further guided their actions. Kirmayer (1992) acknowledges that the body is a vehicle for thinking, feeling and acting. This was evident in the way all the women in the qualitative phase used their bodies to make sense of what they were experiencing. For these women there was a cycle in the way they used their bodies, from the initial stroke attack to adjusting to and negotiating life after stroke.

The cycle begins with the ability to sense what is happening to the body; for example, Margo had headaches prior to stroke and Doris related experiences of pain in her waist. The second step in the cycle for these women concerned listening to the sensations experienced. Doris ignored what was said to her and used her own treatment. For Jenny, listening means she takes it easy and rests. The final stage of the cycle is about acting on the cues from the body, therefore Margo goes to the doctor to review her headaches and when Doris' personal attempts fail she also goes to the hospital to seek help.

Collectively, the Afro-Caribbean women's talk in this study show that the body is experienced in a social world; therefore illness was experienced socially through the body. Lupton (2003) explains illness as experienced through symptoms - in the qualitative phase participants reported symptoms such as headaches, pain at the back of the neck and waist. In making sense of these sensations, the body becomes knowledgeable and the person uses the body to interpret how far they may proceed before acting, which may involve seeking help or administering their own practices based on personal beliefs. A locus of control exists for this group; Corcoran (2007) and Ewles and Simnett (2004) have discussed how the locus of control is an internal control of health based on beliefs and practices. The women made decisions regarding their health based on the body's interpretation of

sensations and experiences and, in so doing, their individual body is viewed as knowledgeable and a medium for sense making.

7.7.3 Interpersonal Relationships: the Doctor, God and the Family

In this section I will discuss the relationship of the doctor towards the women interviewed, their relationship with and belief in God, and the role of the family in stroke recovery and everyday living. Within the current National Health Service, doctors in general practices are given 10-15 minutes per patient visit (Department of Health, 2003). In previous literature the consultant is seen as king or God (see collected works by Holland, 1999).

The women in this study each reported that they shared a close relationship with their doctor, and their doctor spent time getting to know them and developing a relationship with them. Lucy, for example, saw her doctor as her brother, friend, Godson, husband and earthly God. The description gives an indication of the depth, closeness and regard for the relationship. On the other hand, Margo had no trust in her doctor as he did not listen to her. Health experiences may influence health outcomes if patients share a mutually trusting relationship with their doctor. Lucy believed her doctor when he said that he would look after her at home rather than admit her to hospital. Unknown to her, he has actually broken the rules of the Stroke Care Pathway and National Institute for Health and Clinical Excellence guidelines (2009), but her trust in him does not question his motives as he is, according to Lucy, a *"good doctor"*. Doctors remain in a key position of authority and the way in which they are perceived contributes to the overall engagement stroke survivors have with their services.

A belief in and relationship with God was displayed by the participants. Lucy (Extract 27) called on God at the time of her stroke attack when she asked him to be *"lead me downstairs with Your eyes"*. Marie's belief in God makes her *"feel alright"* and Doris is thankful to God for what she can do. The women use their relationship with God as a coping mechanism as well as a way of adjusting to their illness and a new state of being.

Part of this relationship with God included attention to their lifestyle as Jenny (Extract 45) would listen to her gospel tapes and meditate as she confesses *"it help relax my body"*. Here we begin to see how health is influenced by beliefs and a relationship with a spiritual being.

For these women, a relationship with God is very much part of their culture and everyday life. This should be of no surprise, as they are from British colonies where a major objective of colonisation was conversion to Christianity. The narratives of these Afro-Caribbean women revealed their relationship with God as a source of strength which provided hope and helped in facilitating acceptance of their current health status. The relationship does not extend to the church (except for Lucy and Jenny who say that they attend church). It is a personal relationship that individuals use to comfort and make meaning and understanding of their stroke and, to a wider extent, their health.

The family-centeredness of Afro-Caribbean customs emerged as a dominant backdrop for the narratives on the lived stroke experience. In this study, 71% of clinic attendees indicated care came from within the household (which was taken to mean family). In the female Afro-Caribbean group sample attending the clinic, seven out of ten received non-professional care (interpreted as family). Narratives of the women interviewed do not reflect much support from the family, but support given to the family. As discussed in Chapter 4, Afro-Caribbean women's role salience is potentially pivotal in shaping the lived experience in relation to stroke. The women's relationship with their family was one of love, where the women cared for their family and offered support where they could. Jenny's narrative succinctly captures this *"if they* (meaning family) *are alrite then I'm alrite"* (Extract 96). Integration of the findings from both phases show that although the women received help from their family, they also had a role in supporting the family, an area the Newham Hospital assessment does not cover.

7.8 Individualised Views of Life After Stroke: Loss, Control, and Renegotiation of Health and a New Identity

7.8.1 Physical Loss and Control

In the literature review (Chapter 2) I discussed how individuals make meaning of their experiences of health and illness. Analyses of the clinic attendees' data showed that if physical, social and psychological functioning was diminished (or there was a loss of function), attendees would be more inclined to rate their health as not good. 61% of the attendees rated their health as fair (median 3) and this may be as a result of physical loss. Clinic attendees reported loss of their physical functions in most of the domains they were assessed on (Tables 4.5 to 4.17). All female Afro-Caribbean clinic attendees reported needing assistance in maintaining their daily tasks.

Afro-Caribbean women scored a BI of 15-20, indicating very good physical functioning; however, they still experienced physical loss. The women interviewed in Phase 2 voiced concern regarding loss of function. This concept is closely linked to their personal identity after stroke and is discussed in section 7.8.2 overleaf. As Afro-Caribbean women experienced loss on a physical level, they also developed strategies to control their health. Four of the six interviewees were optimistic that if they worked hard enough they could achieve recovery. Margo attended rehabilitation sessions religiously and in the end she was able to return to work and go on holidays again. Doris' determination to be independent meant she was able to drive her car once again, and Marie's *"wanting to get better"* (Extract 14) meant she undertook voluntary work and made handicrafts for display and purchasing.

In this thesis I have tried to show how stroke attacks the individual in different ways, namely functional and physical, psychologically and socially. Functional and physical attack can often result in physical disability, which can be temporary or permanent. In beginning to accept this loss, the individuals (as seen in this study) develop ways in which

to control their health and ultimately their lives. This group of Afro-Caribbean women (in Phase 2) saw the ability to control aspects of health as lying within the individual, as Doris relates: "*I had the goal and determination to recover… Yuh have to just make your mind up and try and not to make it a hindrance to you"*. Depending on the individual's position in their life continuum when stroke occurs, part of the result is loss of status; for example, from being a working woman to retirement (albeit forced) summarised by Jenny (Extracts 50 and 52) as from *"ah busy woman" to "ah take mih time".*

7.8.2 The Crippled Identity - an Outsider and Insider Gaze

In Chapter 2 I discussed that identities are dependent on variables – the collective and individual (Woodward, 2002). In Chapter 6, via Master Theme 3, I illustrated how identities are given meaning through cultural and socio-political awareness. Social practices, which include engagement with others, are one form of identity, and 44% of the clinic attendees accepted and made social contact post-stroke. Stroke often carries a loss and level of disability. This in turn changes the physical and social identity of the individual (Kvigne & Kirkevold, 2003), leaving the survivor in public as well as private gaze. This insider and outsider gaze is depicted in Queenie's narrative (Extract 93). The effects of stroke can cause the individual to feel embarrassed by their bodily appearance, which may cause the person to hide away from the wider society "*but I still in my mind say to myself because of the high percentage of stroke in African Caribbean communities BME communities... Where are all these people why don't we see them more? Why are they not more visual? I don't know… whether we hide away at home or not?"* As the body becomes crippled, an individual's identity may also disappear and fade into the background.

7.8.3 Spiritual Belief and its Impact on Health

Empirical studies describe the association of health and illness with religiosity and spirituality (Abrums, 2000; Duckro & Magaletta, 1994; Mansfield, Mitchell & King, 2002). Most research conceptualises religion as a multi-dimensional construct in which

religiosity is seen as a function of both religious belief and religious function. Spirituality is seen as distinct; a construct that acknowledges that individuals may have a faith in a divine being or force that provides a personal sense of meaning and life purpose separate from the beliefs and practices of a particular religion (Mansfield *et al.*, 2002; Stewart, 1999; Van Ness, 1996).

Over the past few decades, substantial empirical evidence has emerged that highlights the significance of religiosity and spirituality as a coping resource for individuals faced with stressful situations (Pargament, 1997). Spirituality is significantly associated with positive psychological outcomes; it is tied to decreased emotional distress (Sowell, Seals, Phillips & Julious, 2003) and greater optimism (Biggar, Forehand, Devine, Brody, Armistead, Morse & Simon, 1999). In this study, the findings suggest that religiosity and spirituality occupy a significant role in the lives of Afro-Caribbean women. It provides a context for making meaning (for example, Lucy's explanation for her stroke is based on an evil or dark spirituality). The model of religiosity and spirituality also provides a purpose in the lives of the women, as Jenny keeps busy by going to church twice on a Sunday and meditates, thus signifying that this type of belief may also stimulate psychological and spiritual growth.

Religious and spiritual beliefs can be considered a private concept of health and illness. The women in this study who chose to share this private world showed a value of self-sufficiency through spiritual faith and power. Affiliation to a spiritual or religious organisation may lead to social support, as expressed by Lucy that her vicar should visit her, which in turn would make her feel better. Ironson, Solomon, Balbin, O'Cleirigh, George, Kumar ... and Woods (2002), based on correlational studies, report that both private (i.e. faith in God), and public (e.g. attending religious services) religious practices are equally strong relating to longevity and health outcomes.

The views of illness and healing stress the importance of the individual and of certain religious practices (Baer, Garmezy, McLaughlin & Pokorny, 1987). This type of belief and aspect of a religious faith offers important coping mechanisms, but also implies that the

blame for the illness lies with the individual (i.e. the individual has either committed a sin or is being tested by God). This concept can lead the individual to ignore the wider determinants of health. In this study, the spiritual religious belief is that the body is a gift from God and the power to heal as such remains firmly in the hands of God (as seen in Jenny's and Doris' narratives) and the doctor is merely the instrument of God's powers; as told by Lucy (Extract 3) "*you are my doctor, you are not God… but I am looking at him as my earthly God"*. As seen here, some individuals may use spiritual faith to guide their health outcomes. This belief places the doctor in an earthly God-like position. Therefore, health professionals can use their influence to help direct the health of such individuals.

7.9 Mixed Methods in Stroke Research

When designing this study, I did not conceive a mixed methods (MM) approach at the beginning. However, as discussions with academic supervisors ensued and planning began, the MM approach emerged. Most of the literature on MM (e.g., Bryman 2006; Morse, 2008; 2009; O'Cathain, 2009) give useful suggestions on how an MM study should be carefully designed so as to give credit to both qualitative and quantitative facets of the study. They advise that each method should answer a specific research question. They all give the guidance that this should be done at the outset. I agree with these authors.

However, this study brings to the table the discussion that a single method study can develop into an MM study. I had initially set out to undertake a qualitative study on Afro-Caribbean women's experiences of life after stroke and already had my study design. After many discussions it was considered that it would be useful to see how stroke is reported in a clinically subjected manner and then to further explore a sub-set (Afro-Caribbean women) of this group of clinic attendees to understand the lived (i.e. day-to-day) experiences of living with stroke. Here, theoretical explanatory mapping linked to the participants' accounts (subjective reporting registered with a standardised scoring system) welcomed narrative parallel findings derived from interview data generated by participants in a complementary way. Whilst acknowledging the differences between quantitative and

qualitative paradigms, the MM approach accommodated the use of numeric data to follow a thread. The work of O'Cathain *et al*. (2010) regarding following a thread was used, as the Afro-Caribbean women reported good levels of health via BI scoring. This thread was followed up in the qualitative phase to further understand the backdrop for this reporting, which showed stoicism together with the individual's culture influenced subjective clinical reporting.

This approach coincides with my own ontological and epistemological perspective that reality is something that is unique to each person. By approaching the study of life after stroke from both methodological perspectives, a greater depth of knowledge can be acquired about the stroke experience. Bryman (2006), on integrating qualitative and quantitative methods, concludes that when quantitative and qualitative research are jointly pursued much more complete accounts of social reality can ensue.

7.10 Strengths and Limitations of this Study

7.10.1 Strength(s)

The use of information technology (by way of electronic assessment) can lead to a more comprehensive view of patients' progress and recovery post-stroke. Such information can be used as data to analyse how life after stroke is affected and experienced by stroke survivors. Culture, gender and ethnicity, together with the body and how it is influenced post-stroke, can lead to a better understanding of how life is shaped through meaning making units which can help the health practitioner to provide best care and practice where this particular group is concerned. Using an MM approach has helped me to better understand the way in which patients report their health in clinics, together with narratives of everyday living.

7.10.2 Limitations

The purpose of the study was to identify the functional, psychological and social problems encountered after stroke (a biopsychosocial approach), via examination of self-reported assessments of a group of clinic attendees and narratives of the everyday lives these of Afro-Caribbean women. The aim was to gain a deeper understanding on the extent to which culture, gender and ethnicity influence life after stroke. Only female Afro-Caribbean stroke survivors were recruited for Phase 2. This might be regarded as a limitation, in that it might have been possible to better articulate the experiences of women if they had been compared to the experiences of men. The study did not include those who were dysphasic. This might be considered as another possible limitation, as those whose speech is affected may have shed more light on understanding changed identities post-stroke. A particular limitation for this study was the recruitment of participants into Phase 2. The Afro-Caribbean women who attended the clinic did not wish to share their everyday experiences of living with stroke. I was advised by my supervisory team to recruit from the community. This limits the study, as I would have been able to make a fuller comparison between the self-reported assessments and narratives if all participants were from the Phase 1 dataset.

7.11 Recommendations and Implications for Practice

This study has focussed on life after stroke among Afro-Caribbean women. In identifying patterns of functions reported via the stroke clinic using the BI assessment, Asian men and women indicated higher levels of dependency. In terms of stroke research, the Asian population in the UK is under represented. This study recommends that further work needs to be carried out into how this ethnic group copes with and adjusts to stroke. The findings point out that stroke education should cover all age groups to inform on influencing factors, presentation and possible impact on life. This can be done via outreach work in specialist social groups, such as day centres, as when I encountered problems in recruitment into the qualitative Phase 2 this was where I found participants.

Cultural sensitivity needs to look beyond race and ethnicity, and focus on the systems and values the patient belongs to. In developing a cultural framework which includes in-house courses, discussion forums between patients and health professionals on culture may contribute towards understanding and managing stroke care. Discussions such as these can lead to awareness of the unique spiritual beliefs held by Afro-Caribbean women (i.e. secularised religion, traditional cultural beliefs and indigenous healing) and may assist stroke care nurses in providing competent care, especially as many of these beliefs have implications for and how illness is understood, conceptualised and healed. A major outcome for this could be that health professionals may gain credibility with their patients and thereby increase the likelihood of acceptance or compliance with a treatment plan.

Understanding the roles and definitions of the family, together with the individual's perception of health, is important in nursing and healthcare. An understanding that the bonds of kinship may extend beyond lay understanding and perceptions of family will help the professional to avoid erroneous assumptions about boundaries and support systems. It is important to listen to the patient and understand how they define and view their own health, as this will have implications for how their care is planned and managed. The assessment used in the NUHT patients' general information could be broadened to include spirituality rather than simply ask for the patient's religious denomination. Spirituality should be considered in health, because there is a faith factor involved in a patient's concept of health and illness, and faith can strongly influence health behaviour.

It is important to acknowledge the loss that occurs after a stroke, while at the same time realising the stroke survivor's role in controlling recovery or health decline. Regarding the NUHT clinic, if a health psychologist could be included in the stroke team, this may help to further understand losses associated with stroke. There are different way of researching life after stroke, and MM is a recommended way as the researcher(s) is/are able to view how life is reported from two perspectives which lean into each other. MM, in this case mixing quantitative and qualitative methods, can bring added value to a single method approach.

7.12 Conclusions

Through this study I identified the functional, psychological and social problems encountered after stroke among a group of inner city clinic attendees. I then mapped out how gender, culture, ethnicity and the phenomenologically grounded individual (identity) impacts on and mediates the experience of life after stroke among Afro-Caribbean women living in an inner London borough. Culture, ethnicity, gender and identity have all been seen as factors that influence health in studies on HIV and gay men, and in understanding unprotected sex (Flowers *et al*., 2002); and as also seen in Kelleher and Hillier's (1996) edited work on culture and illness and Higginbottom's (2006) study on Afro-Caribbean women and hypertension.

Accounts by participants of their experience of life after stroke is reflective of and in some ways share commonalities with members of a wider white ethnic majority population (see Benson & Britten [2002] and Kirkevold's [2002] work on women's bodily experience of stroke and Galvin [2005] on identity and disability post-stroke). This is clearly captured in the reporting of stroke via the data collected from the clinic and in the narratives provided by the participants. This thesis demonstrates how a particular group of women report life after stroke via self assessment at a clinic. It shows how, through the lived experience, they attempt to gain control, understanding and make adjustments in order to accept the changes brought about by a stroke; and how their culture and ethnicity influenced the way in which they adapted and adjusted to these changes.

Stress is said to arise from both internal and external factors such as relationship problems, family worries, financial worries, stress of cultural adaptation and the stress of managing daily life after illness (Higginbottom, 2006). Many of the participants in the qualitative Phase 2 accepted stress as a facet of their lives, referring to it as "*you must make it up*" (Extract 14) or "*you have to go on no matter what*" (Extract 11) as being characteristic of their life in England.

Finally gender, culture and ethnicity contribute to the way in which participants in this study live their lives after stroke and influence their identity. The extent to which the findings of this study are generalisable to inner city populations and Afro-Caribbean women and stroke clinic attendees in England is not clear. However, principles from this study may be extracted regarding how this group and other migrant communities/populations (i) report illness and attend clinics, (ii) subjectively assess their functional capabilities, psychological state and social engagements, (iii) make sense of healthcare systems in terms of medical and nursing care based on culture and ethnicity, together with the influence of wider structural issues such as paid employment, health information and assessment recording, and support mechanisms specific to cultural and ethnic groups, and (iv) move towards understanding how illness impacts on identity and performance in everyday life. Collectively, the findings of this study show how individuals use a biopsychosocial approach in appraising their health. It also emphasises the value of qualitative approaches in helping to better understand the quantitative data analysis on the patterns of functional, social and psychological variations in abilities post-stroke.

7.13 Reflexivity: Looking Back

A key methodological learning curve for this thesis' design was at the planning stage, when the researcher needed to ascertain how the components of a sequential design would feed into each other. At this particular stage in the research process, the:

> "integration of mixed methods findings may not always be intended, although that is not to suggest that there may not be some value in exploring connections between the qualitative and quantitative findings even though the research may not have been set up that way" (Bryman, 2007: 9).

A valuable lesson learnt from this process is that bringing quantitative and qualitative findings together has shown that there is greater potential when these are combined. The combination of quantitative and qualitative data in this study has provided greater insight

into the lives of these Afro-Caribbean women after stroke that may otherwise have not been gleaned. The complements of quantitative and qualitative data in this study have, in my opinion, led to a wider understanding of life after stroke for the chosen group, and the ordering of Phase 1 followed by Phase 2 gave me the opportunity to explore further the qualitative findings through the interviews in Phase 2. For example, the score that the individuals gave themselves for bathing and dressing allowed questions to be formulated around how these individuals managed with these activities on a daily basis (following a thread).

In order to fully understand the lived experience of stroke, it was important to explore the participants' experiences and personal circumstances in terms of the cultural context in which they lived. I soon realised people drew on memories to construct stories about themselves that helped them to retain and validate their self-identities within the cultural context that has shaped their lives.

One of the lessons learnt on this Ph.D. journey is that individuals do not recall events as they occur; rather, they selectively recall, telling a story that makes sense to the particular individual. In other words, we create and construct our stories to suit our purpose (i.e. those aspects of the self we wish to expose to the listener), encoding beliefs and views into the stories told. From the beginning of this study I kept a research log book and journal; this enabled me to document important events, feelings and information with participants, health professionals and doctoral supervisors throughout the various stages and progression of the research. The field notes contained in the log book are linked to the narration of the reflections on the process I underwent.

The analysis really began during the collection of the data for the study. I was able to read interviews (Phase 2) and analyse the information entered into the electronic database (Phase 1), then see the patterns emerging, making notes as well as log entries. Reflexivity in the quantitative phase of the study focused on questions such as 'what type of data am I collecting?' and 'How can I analyse and interpret this type of data?'. I considered this the

preliminary analysis stage, whereby this particular type of reflexivity alerted me to the emergent themes that contributed to organising and informing the formal and systematic stages of data analysis.

Reflexivity requires sensitivity to the ways in which the researcher's presence in the research setting has contributed to the data collected. It involves the researcher looking at how their own *priori* assumptions have shaped the data analysis. May (2001) writes on the existence of two distinct forms of reflexivity, endogenous and referential reflexivity. These forms were pertinent to me; when considering the process involved in collecting data, it was endogenous reflexivity that came into play. Endogenous reflexivity refers to:

> "an awareness of the knowledge that is born in and through actions of members of a given community in terms of their contribution to social reality. This includes an understanding not only of 'who' someone is but also 'how' others view them" (May 2001: 7).

Reflection within action is therefore considered endogenous. Within this doctoral study, this type of reflexivity was captured in the field notes I made following the various stages of data collection (i.e. from the design of a database to transferring information into data [Phase 1] and recruitment to data transcription [Phase 2]). Within these notes I documented non-verbal communication (for example, when Lucy used her hands to signify her problems with urinary continence). Included in these notes were also questions to myself, such as "How have I influenced the responses in the interview?" (questioning my professional positioning as a nurse and position as a member of the Caribbean community). The listening to and transcribing of interviews soon after data collection enhanced my field notes as well as data collection methods, as I learnt that I influenced data collection and learnt how to approach participants and position myself so as to develop a rapport that would facilitate data collection.

The notion of reflexivity calls for the researcher to look inwardly at his own assumptions and make these explicit. In this study, this also meant exploration of my own ethnicity, and

reflections on my identity and socialisation. My own Caribbean parents, both whose grandparents (my great grandparents) were originally from India, make me Asian Caribbean, while all participants in Phase 2 were Afro-Caribbean. A major part of my socialisation is that I was brought up in Trinidad within an Asian family whose beliefs and practices were of Asian (or as Trinidadians would say 'Indian') origin. This was not the same for any of the participants for Phase 2, moreover I am from Trinidad. All but one participant was from Trinidad (Margo, of Afro-Caribbean descent). All participants had varying beliefs and practices, yet they held a common bond - all were from a geographical area of the Caribbean, all from a common ancestry, all shared experiences of colonialism.

Colonialism was another issue of identity all participants had experienced, while I only knew of it from an historical perspective. Professional socialisation was another influencing factor in this study worthy of reflection. The interpretation of the quantitative data was based on a biopsychosocial approach, while participants were likely to draw on various explanations rooted in Afro-Caribbean culture for their own explanations of health and illness. I believe that other studies of a similar nature to this doctoral study may not entirely reflect the participants' views if the researcher fails to recognise such influencing factors.

I have learnt that the speaker does not always know all the facts in the same way, due to their position and the juxtaposition of the different types of knowledge which in turn produce different epistemological accounts of illness and disease. However, as the women in this study voiced their accounts, it became apparent to me that they created their own meaning of their illness. It is this creation that has influenced their lived experience of stroke and the world around them. Thus reflecting, there is a public and private way of talking about health - for example, Lucy asked the researcher not to think that she was crazy for thinking a dark spiritual force was responsible for her stroke.

Finally, once I began to analyse the data, I included my own reaction to events. The incorporation of this self-reflective process was essential for me to understand my subjective influence on the interaction and analysis of the content.

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APPENDICES

Appendix 1: Barthel Index of Activities of Daily Living

Barthel Index of Activities of Daily Living

Instructions: Choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following 10 items. Record actual, not potential, functioning. Information can be obtained from the patient's self-report, from a separate party who is familiar with the patient's abilities (such as a relative), or from observation. Refer to the Guidelines section on the following page for detailed information on scoring and interpretation.

The Barthel Index

Bowels
0 = incontinent (or needs to be given enemata)
1 = occasional accident (once/week)
2 = continent
Patient's Score: _____

Bladder
0 = incontinent, or catheterized and unable to manage
1 = occasional accident (max. once per 24 hours)
2 = continent (for over 7 days)
Patient's Score: _____

Grooming
0 = needs help with personal care
1 = independent face/hair/teeth/shaving (implements provided)
Patient's Score: _____

Toilet use
0 = dependent
1 = needs some help, but can do something alone
2 = independent (on and off, dressing, wiping)
Patient's Score: _____

Feeding
0 = unable
1 = needs help cutting, spreading butter, etc.
2 = independent (food provided within reach)
Patient's Score: _____

Transfer
0 = unable – no sitting balance
1 = major help (one or two people, physical), can sit
2 = minor help (verbal or physical)
3 = independent
Patient's Score: _____

Mobility
0 = immobile
1 = wheelchair independent, including corners, etc.
2 = walks with help of one person (verbal or physical)
3 = independent (but may use any aid, e.g., stick)
Patient's Score: _____

Dressing
0 = dependent
1 = needs help, but can do about half unaided
2 = independent (including buttons, zips, laces, etc.)
Patient's Score: _____

Stairs
0 = unable
1 = needs help (verbal, physical, carrying aid)
2 = independent up and down
Patient's Score: _____

Bathing
0 = dependent
1 = independent (or in shower)
Patient's Score: _____

Total Score: _____

(Collin et al., 1988)

Scoring:
Sum the patient's scores for each item. Total possible scores range from 0 – 20, with lower scores indicating increased disability. If used to measure improvement after rehabilitation, changes of more than two points in the total score reflect a probable genuine change, and change on one item from fully dependent to independent is also likely to be reliable.

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Guidelines for the Barthel Index of Activities of Daily Living

General

- The Index should be used as a record of what a patient ***does***, NOT as a record of what a patient ***could do***.
- The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
- The need for supervision renders the patient not independent.
- A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives, and nurses will be the usual source, but direct observation and common sense are also important. However, direct testing is not needed.
- Usually the performance over the preceding 24 – 48 hours is important, but occasionally longer periods will be relevant.
- Unconscious patients should score '0' throughout, even if not yet incontinent.
- Middle categories imply that the patient supplies over 50% of the effort.
- Use of aids to be independent is allowed.

Bowels (preceding week)

- If needs enema from nurse, then 'incontinent.'
- 'Occasional' = once a week.

Bladder (preceding week)

- 'Occasional' = less than once a day.
- A catheterized patient who can completely manage the catheter alone is registered as 'continent.'

Grooming (preceding 24 – 48 hours)

- Refers to personal hygiene: doing teeth, fitting false teeth, doing hair, shaving, washing face. Implements can be provided by helper.

Toilet use

- Should be able to reach toilet/commode, undress sufficiently, clean self, dress, and leave.
- 'With help' = can wipe self and do some other of above.

Feeding

- Able to eat any normal food (not only soft food). Food cooked and served by others, but not cut up.
- 'Help' = food cut up, patient feeds self.

Transfer

- From bed to chair and back.
- 'Dependent' = NO sitting balance (unable to sit); two people to lift.
- 'Major help' = one strong/skilled, or two normal people. Can sit up.
- 'Minor help' = one person easily, OR needs any supervision for safety.

Mobility

- Refers to mobility about house or ward, indoors. May use aid. If in wheelchair, must negotiate corners/doors unaided.
- 'Help' = by one untrained person, including supervision/moral support.

Dressing

- Should be able to select and put on all clothes, which may be adapted.
- 'Half' = help with buttons, zips, etc. (*check!*), but can put on some garments alone.

Stairs

- Must carry any walking aid used to be independent.

Bathing

- Usually the most difficult activity.
- Must get in and out unsupervised, and wash self.
- Independent in shower = 'independent' if unsupervised/unaided.

(Collin et al., 1988)

Appendix 2: University of East London Ethics Committee Approval

Mr Calvin Moorley
School of Health and Biosciences
Stratford

ETH/04/88/0

19 May 2005

Dear Mr Moorley,

Research Ethics Committee: Application for the approval of an experimental programme involving human subjects: Cultural factors, hypertension and their relationship to cerebrovascular disease among Black women in London borough of Newham.

I advise that Members of the Research Ethics Committee have now approved the above application on the terms previously advised to you.

The Research Ethics Committee should be informed of any significant changes in the programme that take place after approval has been given. Examples of such changes include any change to the location, number of participants, scope, methodology or composition of investigative team. These examples are not exclusive and the person responsible for the programme must exercise proper judgement in determining what should be brought to the attention of the Committee.

Appended to this letter is the Interim Report form for which to report the progress of an approved programme involving human participants. I would be grateful if you could return this report to me before the end of your programme and use it to indicate any changes that may occur throughout. In accepting the terms previously advised to you I would be grateful if you could return the declaration form below, duly signed and dated, confirming that you will inform the committee of any changes to your approved programme.

Yours sincerely

Debbie Dada
Direct Line: 0208 223 2976
E-mail: d.dada@uel.ac.uk
Administrative Officer for Research

Research Ethics Committee: ETH/04/88/0

I hereby agree to inform the Research Ethics Committee of any changes to be made to the above approved programme and any adverse incidents that arise during the conduct of the programme.

Signed:..... Date: 21/05/05.....
Please Print Name:

Appendix 3: Barking and Havering Local Research Ethics Committee Approval

Barking and Havering Local Research Ethics Committee
Room 7, 2nd Floor
Becketts House
2/14 Ilford Hill
Ilford
Essex
IG1 2QX

Telephone:
Facsimile:

17 November 2005

Mr Calvin R Moorley
DFocotral Student and Graduate Teaching Assistant
University of East London
Stratford Campus, School of Health & Biosciences
Romford Road
London
E15 4LZ

Dear Mr Moorley

Full title of study: **Cultural factors, hypertension and their relationship to cerebrovascular disease among Black women in the London borough of Newham**

REC reference number: **05/Q0602/62**

The Research Ethics Committee reviewed your response to points raised at the August meeting on the 11 November 2005.

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 favourable opinion applies to the research sites listed on the attached form. [Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed they have no objection.]

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:

Document	*Version*	*Date*
Application		12 July 2005
Investigator CV		
Protocol	1	

Covering Letter		
Letter from Sponsor		08 February 2005
Peer Review	Sharon Cahill	
Compensation Arrangements		11 July 2005
Interview Schedules/Topic Guides	1	12 July 2005
Interview Schedules/Topic Guides	02	12 October 2005
Advertisement	1	12 July 2005
Letter of invitation to participant	1	
Participant Information Sheet	02	12 October 2005
Participant Information Sheet	1	12 July 2005
Participant Consent Form	1	
Participant Consent Form	02	12 October 2005
Response to Request for Further Information		
Supervisors CVs		
project schedule	1	
UEL Ethics Committee approval letter		19 May 2005
Honorary Contract		08 June 2005
letter of confirmation of student status		25 May 2005

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0602/62	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Mrs JR IrwinHunt
Chair

Email: janet.carter@redbridge-pct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
Standard approval conditions [SL-AC1 for CTIMPs, SL-AC2 for other studies]

Site approval form (SF1)

Copy to:

University of East London
Stratfrod Campus, School of Health & Bioscienc
Romford Rd
London
E15 4LZ
[R&D Department for NHS care organisation at lead site]

Barking and Havering Local Research Ethics Committee

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	05/Q0602/62	**Issue number:**	1	**Date of issue:**	17 November 2005
Chief Investigator:	Mr Calvin R Moorley				
Full title of study:	Cultural factors, hypertension and their relationship to cerebrovascular disease among Black women in the London borough of Newham				

This study was given a favourable ethical opinion by Barking and Havering Local Research Ethics Committee on 11 November 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator	*Post*	*Research site*	*Site assessor*	*Date of favourable opinion for this site*	*Notes* [1]
Mr Calvin R Moorley	DFocotral Student and Graduate Teaching Assistant	Dr Shanti Vajayaraghavan Newham University Hospital Nhs Trust Glen Road Plaistow E13 8SL Research & Development,Newham University Hospital Glen Road, Plaistow E13 8SL	Barking and Havering Local Research Ethics Committee	17/11/2005	
Mr Calvin R Moorley	DFocotral Student and	Dr Shanti	East London & The City	17/11/2005	

	Graduate Teaching Assistant	Vajayaraghavan Newham University Hospital Nhs Trust Glen Road Plaistow E13 8SL Research & Development,Newham University Hospital Glen Road, Plaistow E13 8SL	HA Local Research Ethics Committee 3		

Approved by the Chair on behalf of the REC:

..... (Signature of Chair/Administrator)
(delete as applicable)

17/11/05 ..... (Name)

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Appendix 4: Newham Primary Care Trust Clinical Governance Department Approval

Newham NHS
Primary Care Trust

Clinical Governance Department
West Beckton Health Centre
2 Monarch Drive
London
E16 3UB

Tel:0207 445-1114
Fax:0207 445-1117

Sheba.qureshi@newhampct.nhs.uk

Calvin Moorley

08th August 2005

Dear Mr Moorley

Re: **Cultural Factors, Hypertension And Their Relationship To Cerebrovascular Disease Among Black Women In The London Borough Of Newham**

Thank you for returning the Research Registration documentations and your research proposal. The proposed research is currently being reviewed by the Trust. The Trust will not issue R&D approval until the Ethics Committee approval has been forwarded to the Trust. Therefore can you please inform the PCT once you have received ethical approval for your proposed study.

In accordance with Research Governance Framework, you need to be aware of the responsibilities of the research sponsor and responsibilities of the individual researcher (please see attached form). Once the research is completed you will need to forward the final research publication to the PCT.

If you have any quires please do not hesitate to call me at the above number.

Yours Sincerely

Sheba Qureshi
Research and Development Facilitator
Newham PCT

Acting Chair: Marie Gabriel
Executive Committee Co-Chairs: Dr Ashwin Shah, Chris Tate Chief Executive: David Stout

Responsibilities of Individual Researchers

- Conduct the research to the agreed protocol and in accordance with the legal requirements and guidance
- Ensure the honest and respectful treatment of participants , by informing them of the purpose of the study to the guidance required (e.g. on consent and confidentiality), and at all times ensure their safety and well being
- To ensure that the data collected is accurate , relevant and valid
- Protect the integrity and confidentiality of data generated by the researcher
- To manage resources efficiently, such as finance and time
- Report any research related problems, failures, adverse incidents or suspected misconduct to senior body
- Provide accurate, truthful and complete reports and disseminate the outcomes through authorised and agreed channels

Responsibilities of Sponsors

It is the research sponsor's responsibility to ensure that:

- The research proposal respects the dignity, rights, safety and well-being of participants and the relationship with care professionals.
- The research proposal is worthwhile, of high scientific quality and represents good value for money.
- The research proposal has been approved by an appropriate research ethics committee.
- Appropriate arrangements are in place for the registration of trials.
- The principal investigator, and other key researchers, have the necessary expertise and experience and have access to the resources needed to conduct the proposed research successfully.
- The arrangements and resources proposed will allow the collection of high quality, accurate data and the systems and resources being proposed are those required to allow appropriate data analysis and data protection.
- Intellectual property rights and their management are appropriately addressed in research contracts or terms of grant awards.
- Arrangements proposed for the work are consistent with the Department of Health research governance framework.
- Organisations and individuals involved in the research all agree the division of responsibilities between them.
- There is a clear written agreement identifying the organisation responsible for the ongoing management and monitoring of the study, whether this is the sponsor, or another organisation.
- Arrangements are in place for the sponsor and other stakeholder organisations to be alerted if significant developments occur as the study progresses, whether in relation to the safety of individuals or to scientific direction.
- An agreement has been reached about the provision of compensation in the event of non-negligent harm and any organisation, including the sponsor itself, offering such compensation has made the necessary financial arrangements.
- Arrangements are proposed for disseminating the findings.
- All scientific judgements made by the sponsor in relation to responsibilities set out here are based on independent and expert advice.
- Assistance is provided to any enquiry, audit or investigation related to the funded work.

Acting Chair: Marie Gabriel
Executive Committee Co-Chairs: Dr Ashwin Shah, Chris Tate Chief Executive: David Stout

Appendix 5: Newham University Hospital Trust Ethical Approval

Newham University Hospital NHS
NHS Trust

Mr Calvin Moorley
School of Health and Biosciences
Stratford campus
University of East London
Romford road
London E15 4LZ

Research & Development Office,
C/o Academic Centre,
NEWHAM GENERAL HOSPITAL
Glen Road, Plaistow,
E13 8SL.

Tel: 0207 363 8923 / 9266 Direct Line
Fax 020 7363 9463 external (3463 internal)
Email joanne.morris@newhamhealth.nhs.uk
Yvonne.nicholas@newhamhealth.nhs.uk
shanti.vijayaraghavan@newhamhealth.nhs.uk
Dr Shanti Vijayaraghavan, Director of Research & Development (R&D).
Dr Joanne Morris, R&D Manager.
Mrs Yvonne Nicholas, R&D Co-ordinator

2nd March 2006

Dear Calvin

Re: Cultural factors, hypertension and their relationship to cerebrovascular disease among Black women in the London Borough of Newham.

Thank you for providing us with information concerning the above study. This letter is to confirm that the Trust has approved the study and, is providing indemnity to cover the involvement of Newham University Hospital NHS Trust staff and any staff with an honorary contract at Newham University Hospital NHS Trust for purposes of the study. The approval is provided on the understanding that the University of East London has agreed to be the official SPONSOR for the study and has ensured adequate indemnity and monitoring arrangements. In addition, as the Chief Investigator, you must ensure adherence to the ethically approved study protocol and responsibilities outlined in the 'Research Governance Framework for Health and Social Care', 2nd Edition, DH April 2005 available from;
http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopmentAZ/ResearchGovernance/fs/en

Please inform us if your project is amended and you need to re-submit it to the ethics committee **and when the project terminates**. This is necessary to ensure that your approval / indemnity is valid and also helps the office to maintain up to date records. Should any untoward events or incidents occur then it is essential that you immediately contact the Trust Risk Management Team (020 7363 8507 / 8417) and the R & D Office at Newham. We would also ask that you keep us informed of any publications or final reports that are produced as a result of the research.

Please do not hesitate to contact either Dr. Joanne Morris (R&D Manager) on 020 7363 8923 or myself on 020 7363 8001 if you have any further questions.

With best wishes for the study,

Shanti Vijayaraghavan

Dr Shanti Vijayaraghavan,
Director of R&D

Cc Professor David Humber, Academic supervisor UEL, Dr Khaled Darawil, consultant NUHT, Dr Joanne Morris, R&D Manager NUHT;

Requirements outlined in the Research Governance Framework

Requirements for the management of research within Trusts have been outlined by the Department of Health in the publication 'Research Governance Framework for Health and Social Care', 2nd Edition, DH April 2005. This document should be read by all individuals who are involved in NHS research, see http://www.doh.gov.uk/research or the Trust public folders at Newham. Key responsibilities from this document have been summarised for you below,
Please stay in touch with the R&D office at Newham, and in particular let us know when you are completing the study. We wish you all the best in your research. Thank you.

SUMMARY OF RESEARCHERS RESPONSIBILITIES

RESPONSIBILITIES OF THE PRINCIPAL INVESTIGATOR

It is the responsibility of the Principle Investigator to ensure;

- Research is carried out in accordance with the 'Research Governance Framework for Health and Social Care', DOH, March 2001.
- The research receives full ethical approval from the relevant ethics committee/s.
- Ensuring priority is given to the dignity, rights, safety and well-being of participants at all times.
- The research follows the protocol approved by the relevant ethics committee and the research sponsor.
- Any proposed changes or amendments to or deviations from the protocol are submitted for approval to the ethics committee, the research sponsor and any other appropriate body.
- Controlled trials are registered.
- The study complies with all legal and ethical requirements.
- When a study involves participants under the care of a doctor, nurse or social worker for the condition to which the study relates, those care professionals are informed that their patients or users are being invited to participate and agree to retain overall responsibility for their care.
- For helping care professionals to ensure that participants receive appropriate care while involved in research,
- Unless participants or the relevant research ethics committee request otherwise, participants' care professionals are given information specifically relevant to their care which arises in the research.
- Each member of the research team is qualified by education, training and experience to discharge his/her role in the study.
- Students and new researchers have adequate supervision, support and training.
- Proper conduct of the research, which he / she is accountable to his / her employer, and, through them, to the sponsor of the research and to the care organisation(s) within which the research takes place or through which participants, their organs, tissue or data are accessed.
- Reporting of any failures in respect of confidentiality, adverse drug reactions and other events or suspected misconduct through the appropriate systems. 'Appropriate systems' include reporting to Newham Healthcare NHS Trust Risk management system, the R&D office and the care professionals who retain overall responsibility for the quality of patient care.
- Procedures are in place to ensure collection of high quality, accurate data and the integrity and confidentiality of data during processing and storage.
- Arrangements are made for the appropriate archiving of data when the research has finished.
- The findings from the work are opened to critical review through the accepted scientific and professional channels.
- Reports on the progress and outcomes of the work required by the sponsor, funders, or others with a legitimate interest are produced on time and to an acceptable standard.
- Once established, findings from the work are disseminated promptly and fed back as appropriate to participants.
- He / she accepts a key role in detecting and preventing scientific misconduct by adopting the role of guarantor on published outputs.
- Arrangements are in place for the management of financial and other resources provided for the study, including for the management of any intellectual property arising.
- All data and documentation associated with the study are available for audit at the request of the appropriate auditing authority.

- Comply with monitoring of the research as required by Newham Healthcare NHS Trust R&D office, and notify them on completion of the study. Also inform the individual care professionals who retain overall responsibility for the quality of patient care on the progress of the study and on completion.

RESPONSIBILITIES OF OTHER RESEARCHERS

- Bear the day-to-day responsibility for the conduct of research. Responsible for ensuring any research they undertake follows the agreed protocol, helping care professionals to ensure that participants receive appropriate care while involved in research, protecting the integrity and confidentiality of clinical and other records and data generated by the research, and for reporting any failures in these respects, adverse drug reactions and other events or suspected misconduct through the appropriate systems.

Appendix 6: Consent to Participate Form and Information to Participants Letter

UNIVERSITY OF EAST LONDON

Consent to Participate in an Experimental Programme Involving the Use of Human Participants

Title of Study Cultural factors and the lived experience of cerebrovascular disease among Afro Caribbean women in the London borough of Newham

I have read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen to the data once the experimental programme has been completed.

I hereby fully and freely consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

Participant's name (BLOCK CAPITALS): .....

Participant's signature: .....

Investigator's name: .....Calvin R Moorley .....

Investigator's signature: .....

Date: .....20.....

UNIVERSITY OF EAST LONDON
School of Health & Bioscience
Stratford Campus
Romford Road
London
E15 4 LZ

University Research Ethics Committee

If you have any queries regarding the conduct of the programme in which you are being asked to participate please contact the Secretary of the University Research Ethics Committee: Ms S Thorne, Administrative Officer for Research, Graduate School, University of East London, Romford Rd, Stratford, E15 4LZ, (telephone 0208 223 6274 e-mail s.r.c.thorne@uel.ac.uk)

The Principal Investigator

Calvin R Moorley, University of East London, School of Health & Bioscience, Stratford Campus, Romford Road, London E15 4 LZ
Telephone/fax/e-mail Work: 0208 223 4534, Mob 07905 644448, E-mail c.moorley@uel.ac.uk Fax 0208 223 4937

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Project Title

Cultural factors and the lived experience of cerebrovascular disease among Afro Caribbean women in the London borough of Newham

Project Description

The aim of the study is to:

- Investigate cultural and lifestyle factors among Afro Caribbean women age 35+ years that contribute to incidence of cerebrovascular disease.
- Explore the role of cultural phenomenology in shaping subjective perceptions of cerebrovascular disease among Afro Caribbean women in the London borough of Newham.

The study will look at the lived experience of cerebrovascular disease (stroke). The focus is on the cultural meaning and significance attached to the illness and on the perception of one group – Afro Caribbean women age 35+. The study is designed in two phase: **Phase 1** To identify and establish the population for the proposed study, an electronic database using the existing information on patients (approximately 300 records for 2004) and inputting of data from questionnaires gathered in

2005 held in the stroke clinic at Newham University Hospital will be created. Analysis of the database should allow identification of key factors and underlying problems people encounter after a trans-ischaemic attack or stroke and the solutions offered following first contact with their General Practitioner. **Phase 2** will involve semi-structured in-depth interviewing of 15 to 20 patients. The analytic aim is to identify prevalent perceptions and significance that patients assign to the illness, to gain a, richer understanding of the live experience of life after stroke among Afro Caribbean black in the London borough of Newham.

If you a currently a patient, the investigation is in no way intended to form part of your treatment, however benefits form your participation would be valuable as you would have first hand experience of services offered and can recommend how best they can be improved.

Confidentiality of the Data

All information obtained would be transcribed, coded and analysed; all hard copies would be destroyed by shredding. All information would be stored electronically and would remain confidential under the Data Protection Act. At the end of the investigation the study would be written and presented for a PhD award, anonymity and confidentiality of all participants would be maintained throughout the process.

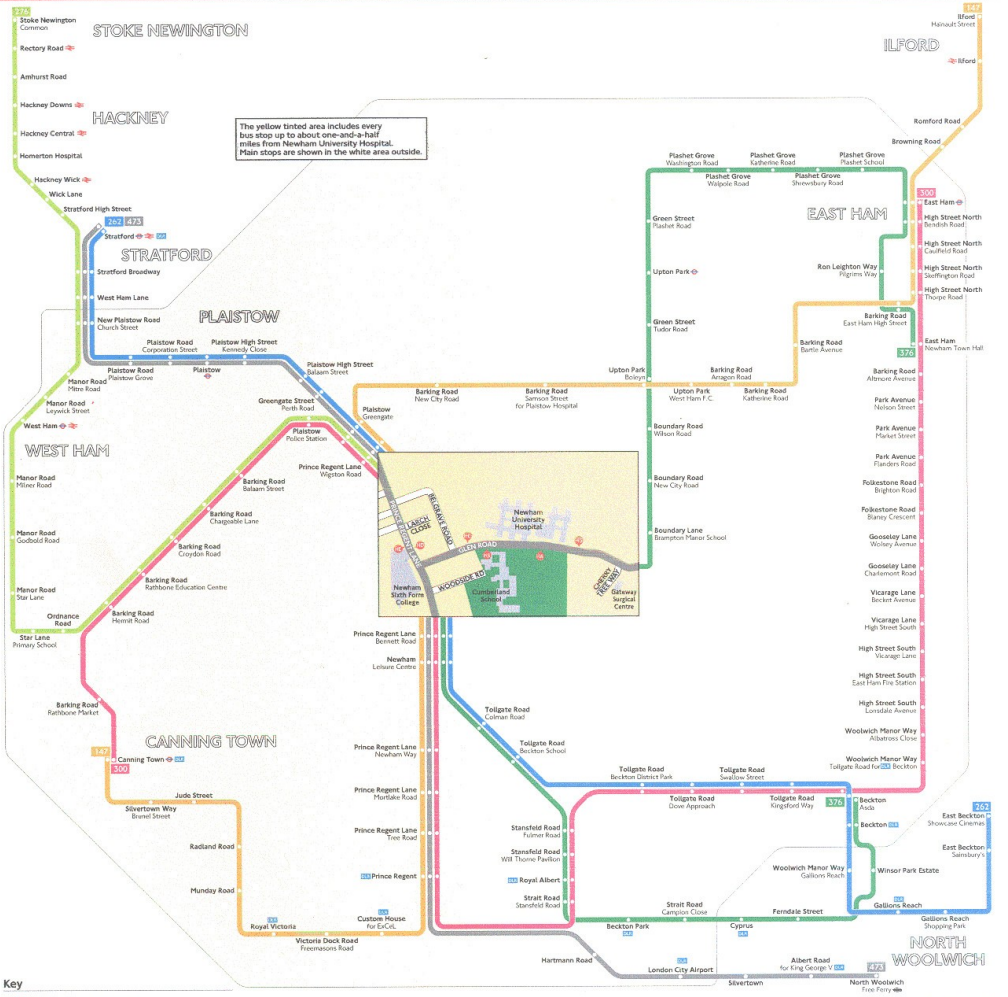
Location

The study would be supervised by the University of East London, Stratford Campus and Newham University Hospital Trust. The study will take place within the London borough of Newham

Remuneration: Nil

Disclaimer

You are not obliged to take part in this study, and are free to withdraw at any time during the tests. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to give a reason.

Appendix 7: Map of Bus Routes to Newham University Hospital Trust

Buses from Newham University Hospital