The meaning and consequences of hypertension for individuals of African Caribbean origin: Perceptions of Primary Health Care Services

Volume 1

An ethnographic study of hypertension in England

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Abstract

This thesis presents a focused ethnographic study of hypertension in people of African Caribbean origin, residing in England. Hypertension remains a major health issue amongst migrant and UK born African Caribbean people. The research investigates the meaning and consequences of hypertension from the participants' perspectives exploring both personal and societal influences on the development and management of hypertension, health beliefs, risk perception and decision-making processes. Perceptions of Primary Health Care (PHC) services are evidenced.

The research draws heavily upon the ethnographic tradition (adjectival), utilising qualitative methods to elicit data from 36 participants. Data were collected using focus group interviews, semi-structured interviews and vignette interviews. The participants were accessed via GP practices and community groups and associations in two English cities. Data was analysed with the aid of Atlas/ti.

The study findings are organised in four themes 1) **Early diagnosis, 2) The meaning of high blood pressure, 3) Consequences and management of high blood pressure, and 4) The participant's experience of PHC.** Almost all participants articulated their hypertension as high blood pressure. High blood pressure and the bio-medically defined condition of hypertension were not viewed synonymously. Stress was regarded as major precursor of high blood pressure, arising from both personal and structural influences, such as migration, cultural adaptation, personal and institutionalised racism, relationship and financial problems. Diagnosis was accompanied by shock and attempts to normalise this experience. Participants' explanatory models of hypertension are presented and considered in the light of existing theoretical frameworks. These explanatory models encompass health beliefs, risk perception and decision-making. Non-concordance and traditional herbal remedies are employed by participants, as strategies of empowerment. A level of satisfaction with existing PHC services was expressed, with a small number of participants using private general practitioners. The implications for PHC services are postulated and the provision of culturally sensitive care.

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Firstly I would to thank the 36 participants of this study and the five members of the consumer research advisory group who generously shared their experiences with me. This study would not have been possible without the financial support provided by the NHS Executive via a National Primary Care Researcher Developer Award. I am grateful for the investment made by the NHS executive and for the implicit belief in the value of this research.

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The study could not have been possible without the support of my family, Simon, Tom, Alice and Hezron. I dedicate this work to my family and parents.

List of tables:

List of figures:

List of Appendices:

Table of contents:

Part One

Part Two

Introduction

This thesis presents an ethnographic study of the meaning and consequences of hypertension for individuals of African Caribbean origin in England and their perceptions of primary health care services (PHC). The study commenced in September 2000 and continued for three years. The study locations were Sheffield and Nottingham. Information from the 2001 census suggests that the African Caribbean population in Nottingham is 3.4% and Sheffield is 1% of the total population (www.neighbourhood.statistics.gov.UK).

The research is grounded in a '*uniquely humanist and interpretative approach*' (Atkinson & Hammersley 1998 p.111): the participant's conceptualisation of hypertension (expressed by participants as high blood pressure) and explanatory models that map out the meaning of high blood pressure for the individuals in this study. Also evidenced are the strategies participants employed for daily management of high blood pressure and their views on both National Health Service (NHS) and private PHC services, accessed in respect of high blood pressure. Significantly, the study conceptualised also forms a pragmatic health services research study (typified by health technology assessment, Murphy *et al.* 1998) that has the potential to impact in a meaningful way on the provision of care for African Caribbean people with hypertension and on the management of hypertension in PHC. The potential impact upon care is achieved via a greater understanding of the participants' beliefs about their condition, insight into factors that enhance or mitigate against the early diagnosis and treatment of hypertension, and perceptions of the prevention, diagnosis and management of hypertension in PHC.

This chapter describes in more detail the focus of the research. The epistemological origins of the research rest on the belief that the meanings and consequences of hypertension are a result of both unique personal factors and structural factors that are the result of the interaction of individuals and communities within a dynamic social world.

The research aims are:

a) To increase understanding of the meaning and consequences of hypertension for individuals of African Caribbean origin.

b) To elicit knowledge and understanding of African Caribbean individuals' decision-making processes, risk perception, and culturally specific health beliefs which mitigate against or enhance the early diagnosis and effective management of hypertension in PHC.
c) To identify and map out African Caribbean individuals' perceptions of prevention, diagnosis and management of hypertension in PHC.

The primary focus of this research

The research conducted was motivated by recognition of the high prevalence of hypertension amongst the African Caribbean community in England (Cappuccio *et al.* 1997, Poulter *et al.* 1997), and the simultaneous recognition of the lack of research evidence in this domain, particularly from a lay perspective. A knowledge of the more general inequalities in health (Karlsen & Nazroo 2002 a & b) that ethnic minority communities experience, inequalities that also extend to the receipt of NHS care (Nazroo 1997, Gerrish 1999, Culley & Dyson 2002), provided further motivation for the study.

My professional background in health visiting and primary care nursing has influenced the orientation of the research towards PHC. Working as a health professional for twenty years in the British National Health Service (NHS) has enabled me to witness many times the potential for 'cultural clash' within a therapeutic encounter. My own ethnic identity as a member of a black and minority ethnic group has further influenced the focus of the research. The topic of hypertension within African Caribbean communities in England is a personal choice but also one of strategic importance to the development of the research evidence base in PHC (Mant 1997). The research was supported financially by a National Primary Care Researcher Developer Award. These awards are expressly designed to further develop the PHC evidence base.

Hypertension within the African Caribbean community is four times more prevalent than in the general population (Capuccio *et al.* 1997, Poulter *et al.* 1997). Current policy agendas are concerned with a reduction in cardiovascular disease (DOH 1999a) and with addressing social exclusion, ameliorating health inequalities, and ensuring that individuals from black and minority ethnic groups receive fair and equitable access, care and treatment (DOH 1999a). These aspects of my professional and personal biography have led to my interest in the topic.

Language used in this research

A glossary is provided in Appendix 1 to clarify for the reader the terminology used in this thesis. It is worthy of note that the terminology used to describe ethnic minority communities in research studies is the subject of ongoing debate (Modood, Berthoud & Nazroo 2002). Current classification systems lack specificity (Gerrish 2000), which could lead to over-generalisation and the stereotyping of the groups in question. The term 'African Caribbean' is adopted to describe participants in this study who have origins in the Caribbean and connections to Africa via historical antecedents. Significantly, communities of Caribbean origin in England often adopt the term African Caribbean to describe community groups and associations. In this sense, the term reflects the group acceptance of the term as existing within a social reality, and such usage demonstrates that the term has meaning and validity for the group (Modood, Berthoud & Nazroo 2002). Adoption of this term does not deny the huge variation in language, culture and traditions within the Caribbean Islands; this is acknowledged. The research also employed the principle of self-assignation of ethnicity (Nazroo 1997) by all participants, notwithstanding the fact that self-assignation alone does not necessarily confer membership of a group (Modood, Berthoud & Nazroo 2002). Rather, membership of the group is both an individual subjective view and subject to conferment by at least some members of that group. However, observers have noted the fluid and situational nature of ethnicity (Jenkins 1997, Atkin *et al.* 2002) depending on the context, time and place.

Philosophy informing the research

The research conducted in this thesis is predicated on the acknowledgement that variations in health and ill-health experiences between and within ethnic groups are not simply determined by culture and ethnicity (Karlsen & Nazroo 2002a & b), but arise from the coalescence of complex factors such as migration, cultural adaptation, racism, reception by the host community, socio-economic influences and prevailing societal ideologies. The limitations of a culturalist approach are succinctly summarised by Karlsen & Nazroo (2002a), quoting the seminal sociological theorist Ahmad (1996 p.190):

> *"stripped of its dynamic social, economic, gender and historical context, culture becomes a rigid and constraining concept which is seen somehow to mechanistically determine peoples' behaviours and actions rather than providing a flexible resource for living".*

The philosophy underpinning the conduct of this research rejects the culturally essentialist viewpoint (Culley 1996, Serrant-Green 2001) that might locate the meaning and consequences of hypertension for individuals as being singly defined by cultural influences. The research seeks to provide a comprehensive and multi-faceted explanation for the experiences of the participants, and one that takes account of and recognises structural factors in addition to personal factors, including factors such as the cultural congruence of services and past incidences of racism.

The experience of chronic illness

Early sociological perspectives on chronic illness arise from Talcott Parson's theory of the sick-role (Lawton 2003), a perspective which focuses on the individual subjective experience of illness within the context of the Western biomedical tradition. In recent decades there has been a rapid growth in knowledge and understanding in relation to the sociology of chronic illness and lay experiences of health and illness. Seminal contributions arise from the work of Bury (1982), who locates chronic illness as a 'biographical disruption', during which individuals are forced to reassess their self-perception, personal biography and life trajectory including personal relationships. Charmaz (1983) provides further insights, postulating the theory of 'loss of self', a notion that arises from the patients' perspective and the context in which they live their lives. Charmaz (1983) advances understanding in relation to the complexity of chronic illness experience and how 'loss of self' can result in negative consequences in the experience of chronic illness. Williams (1984) conceptualised the theory of 'narrative re-construction' to illuminate the ways in which chronically ill people produce stability and coherence from the biographical uncertainty which is a result of their chronic illness. The concepts described form a significant and influential triad of sociological perspectives on chronic illness (Lawton 2003), notwithstanding the North American contributions of Zola (1973), Strauss & Corbin (1988), and Corbin (2003). Recently these seminal theories have been critiqued and further developed by the medical sociology community, e.g., Lawton (2003) and Williams (2000). An example is the publication by Williams (2000) which challenges the original conceptualisation of 'biographical disruption'. Many individuals, especially those in disadvantaged circumstances such as some of the participants in this study, face a life trajectory of 'biographical disruption' as a result of life crises and events. In this sense the advent of chronic illness may not be perceived as disruption but as part of a continuum of biographical reconstruction. Within this continuum chronic illness may be perceived as a minor event compared to other major life events such as bereavement.

Scambler (1998) provides insights on how the experience of chronic illness may result in stigmatisation, often expressed by the individual as shame and embarrassment in relation to how others may perceive their condition. Lawton (2003) suggests that in relation to chronic illness stigmatisation can be both real and anticipated, and the consequences of both may be fear and uncertainty.

Although a myriad of chronic conditions such as rheumatoid arthritis (Bury 1982), thalassaemia major (Atkin & Ahmad 2000a), osteoarthritis (Sanders *et al.*2002), stroke (Pound *et al.*1998), diabetes (Rajaram 1997) and heart problems (Emslie *et al.*2001) are documented, it is worthy of note that few sociological explorations of chronic illness have focused on hypertension, which makes this research timely in an area that to date has been neglected. It is evident in the literature (Gilleard and Higgs 1998, Atkin & Ahmad 2000a, Pound *et al.* 2000, Asbring 2001, Emslie *et al.*2001, Sanders *et al.* 2002) that age and gender factors mediate the experience of chronic illness. These issues will be elaborated on later in the thesis. The issue of ethnicity as a mediating factor in the experience of chronic illness has received far less attention than age and gender, which means that this research makes a further important contribution to the knowledge base in this domain.

Ethnicity and health

People from ethnic minority groups tend on the whole to experience greater ill-health than the general population, and this inequality has been documented in a number of studies over past decades (Marmot *et al.*1984, Donovan 1985, Thorogood 1988, HEA 1994, Smaje 1995). For example, in relation to hypertension, Nazroo (1997) states that Caribbean participants in the Fourth National Survey of Britain's Ethnic Minorities experienced almost 50% higher rates than whites. However, the data did demonstrate a much less marked gender variation for men, while for Caribbean women the rate was almost 80% higher than in the white population. Other measures of morbidity and mortality in this study illustrate similar inequalities for ethnic minority communities in England. The 1999 Health Survey for England (DOH 2000c) further confirms the experience of poor health for ethnic minority populations more accurately by providing evidence of diagnosis, measured hypertension and treatment rates. The study demonstrated an increased prevalence of hypertension for women of Black Caribbean, Indian, and Pakistani origin. Bangladeshi and Irish women exhibited lower rates of hypertension then the general population. In this study Pakistani, Bangladeshi and Chinese men demonstrated lower rates of hypertension then men in the general population. Irish, Bangladeshi and Black Caribbean men were more likely to have received therapy for hypertension than men in the general population.

Nazroo (1997) demonstrated the complexity of the situation, documenting the wide variation in health status between and within various minority ethnic groups. Nazroo (1997 p.2) states:

> *"How patterns of health and health care vary across and within ethnic groups is a reflection of both the social position of these groups and of the individual experiences of people who are members of these groups".*

Thus, it can be observed that the situation is further compounded by the intersection and mediation of social class on the health and illness experience. Cornwell (1984), building on the seminal Black Report (Townsend & Davidson 1982), provided early insights into social class differentials in respect of how health and illness are experienced, though not in minority ethnic communities. Recent work by Karlsen & Nazroo (2002 a & b) and Nazroo (2003) provides us with detailed and in-depth expositions of the relationship between ethnicity, health and social class. Nazroo (1998) suggests that this relationship hinges on three dimensions of the structural context: first, the cumulative influence of disadvantage over a life time; second, the geographical locale of ethnic minority groups in deprived housing tenure and the associated ecological effects; and third, the consequences of living in a racist society.

Karlsen & Nazroo (2002b) analysed cross-sectional data from the Fourth National Survey of Ethnic Minorities, and state that the consequences of both interpersonal racism and the individual's perceptions of the dynamics of racism within wider society have independent negative health consequences. This finding is independent of direct personal racism. In this study those individuals from manual-worker households were 40% more likely than middle-calss households to define their health as poor or fair. This increased dramatically to 150% more likely in households with no member in employment.

Karlsen & Nazroo (2002b p631) conclude that:

> *"...these and earlier findings suggest that racism harms health in terms of actually experienced attacks, perceived discrimination, and the concentration of ethnic minority groups in lower social "indicator used".*

Thus it can be concluded that social class and structural influences coalesce to impact negatively on the health status of ethnic minority populations.

African Caribbean people and hypertension

Throughout the thesis, the term 'high blood pressure' is used when referring to participants' viewpoints and articulations, as this was the participants' preferred term. The term 'hypertension' is used when making reference to the literature or to biomedical perspectives. Hypertension, articulated as high blood pressure by the participants in this study, is a relatively common condition that is often asymptomatic (Benson & Britten 2002). The asymptomatic nature of the condition may result in many individuals living unwittingly with hypertension for a number of years. For African Caribbean people who do experience symptoms presentation for early diagnosis in PHC is influenced by both personal and external factors.

The management and care of African Caribbean people with hypertension is said to be 'problematic' (Morgan 1993). This research illuminates, via an ethnographic approach, the plethora of factors that might contribute to health professionals' conceptualisations of the 'problematic' nature of caring for African Caribbean patients in PHC who experience hypertension. These factors may not be perceived as problematic by the participants themselves, but as resourcefulness and facilitating a degree of control over hypertension. A consideration of the cultural congruence of PHC services and the cultural sensitivity of PHC practitioners is a vital element in understanding the context of care delivery. The danger of conceptualising the challenges of managing the care of hypertensive African Caribbean patients in PHC as 'problematic' is that this experience becomes racialised (Bhopal 1997). I am cognisant of the fact that within this research there exists the potential for racialisation of the research findings (Gerrish 2000). I seek to avoid this by locating the participants' experiences in the context of the broader structural issues mentioned.

Ethnicity and health/social care research

This study reflects a trend towards an increased focus on ethnicity within health and social care practice and research in England (Atkin *et al.* 1989, Atkin & Ahmad 1996, Gerrish *et al.* 1996, Kelleher & Hillier 1996, Modood *et al.* 1997, Nazroo 1997, Higginbottom 2000a & b, Berthoud 2001, Karlsen & Nazroo 2002a & b). This in turn reflects the global trends in movement and relocation of populations, through historical antecedents such as the transatlantic slave trade, European colonialism, civil wars and transgression of human rights and globalisation. All European nation states are characterised by increasingly diverse populations (Dorsett 1998, Bhattacharyya *et al.* 2002). This greater diversity presents challenges for nation states in both policy and practice provision for those who deliver health and social care (Emami *et al.* 2000, Gerrish 2000a). To date, little research in England in health and social care has focused solely on African Caribbean populations (*cf* chapter 4), in comparison to the focus on South Asian populations where a plethora of research evidence exists. The paucity of research conducted with African Caribbeans compared to other populations, e.g., South Asians, may reflect the dominant community perceptions of difference and otherness. For instance, members of African Caribbean communities may be perceived to speak English, and therefore language and communication difficulties may be regarded as less important within health care interactions with African Caribbeans than with those other communities who speak English as a second language. However, it may simply reflect the fact that few of those who construct the research agenda and hold funding budgets are of African Caribbean origin.

Undertaking research in the domain of ethnicity and health can be problematic. There is a growing body of literature that identifies fundamental flaws in relation to researching the health and health-related behaviours of black and minority ethnic groups in the UK. Senior and Bhopal (1994) have identified four fundamental problems, and these have guided my thinking in the literature review and conduct of the research. They focus their comments on ethnicity and epidemiological research, but the issues they highlight have relevance for other areas of health-related research and ethnicity.

First, the ethnicity of the population group studied must be clearly defined, and clearly distinguish ethnicity from nationality and migrant status. Moreover, Bhopal (1997) states that some studies use imaginary ethnic groups such as 'Urdu', based on the language spoken by individuals who may be from several different ethnic groups. Additionally, Senior and Bhopal (1994) claim that the term ethnicity is increasingly used synonymously with 'race'. The term 'race' in relation to scientific research has a very negative history in terms of ethical misconduct and the eugenics movement, mainly arising in the 19th century. The term is still prevalent in some scientific studies today. The latter point is exemplified in the Tuskegee experiment (Bhopal 1998), where black male participants in a research study were deliberately denied treatment for syphilis. It is worthy of note that the 'Helsinki Declaration' (World Medical Assembly 1989), which guides ethical practice in research today in the UK, was the result of unethical research practices in Nazi Germany.

Second, Senior and Bhopal (1994) highlight the heterogeneous nature of the ethnic groups who commonly form study populations in the United Kingdom. For example the term 'Asian' masks a rich diversity and a myriad of languages, traditions, cultures, religions and other factors relevant to health. Additionally, from a global perspective the term may have very different meanings for people in various parts of the world. For example, the term Asian in the USA may refer to people from Vietnam or Korea, while in Australia it may mean communities from Malaysia or Hong Kong. Viewed from this perspective the term becomes meaningless, and certainly does not lead to a deeper understanding of health beliefs and behaviours, or an appreciation of the cultural congruence of health services.

Third, Senior and Bhopal (1994) claim that the lack of clarity regarding the purposes of research of this nature is a major problem. Bhopal (1997) postulates that some research may damage the social standing of minority ethnic groups in the UK, by emphasising the negative aspects of health, over-emphasising these dimensions and deflecting attention from the communities' self-defined health priorities. In other words, researchers must question their own motives in undertaking the research and be clear about the benefits to the community itself. However, researchers cannot be held responsible for the sensationalisation of research findings in terms of negative stereotyping. An awareness of the potential misuse of findings and its wider implications for race relations is essential (Bhopal 1997).

Fourth, Senior and Bhopal (1994) highlight the issue of 'ethnocentricity': that is, the tendency for one's own culture to be given primacy and considered a benchmark against which all other cultures are measured. Ethnocentricism influences the formation of research questions, the operationalisation of research, and the analysis and interpretation of the data. Indeed, it could be argued that the wider research community, including funding bodies, is imbued with an ethnocentric philosophy. The over-arching concern with ethnicity may mean that other confounding variables such as poor socio-economic or educational status may be overlooked. This may result in the findings of a study being wrongly attributed to ethnicity or cultural dimensions, rather than to other determinants such as socio-economic position. My own position as a researcher investigating health beliefs and behaviours and transcultural or multiethnic care is complex. My own values and beliefs are influenced by the experience of bicultural socialisation and parenting in a predominantly monocultural context in terms of professional and secondary socialisation. Whilst an outsider view (dominant culture perspective) of me as a black researcher might presume that I have much in common with potential participants to the study, the participants themselves may perceive me to have little in common with them. Seminal theoretical perspectives on transcultural health care and research (Leininger 1985, 1991) appear to be underpinned by the premise that care givers/researchers are from the dominant cultural groups; whilst in reality this may be untrue. In conducting the literature review and in reporting studies, it is necessary to use terminology which is not necessarily the language I would adopt, but reflects the terminology used by the authors of the studies.

However, current policy frameworks and initiatives do focus on the provision of equitable care for all populations, the amelioration of health inequalities (DOH 1997, 2000a), and reduction in social exclusion (SEU 2000). In this respect the research conducted is timely and pertinent to the health care policy initiatives that, in addition to addressing the issues above, identify a reduction in hypertension and associated cardiovascular disease as a national priority (DOH 1999a).

Ethnic monitoring in PHC

Senior and Bhopal (1994) have suggested that ethnic monitoring in the National Health Service, and a national policy agenda that focuses on addressing inequalities in health, are the main precursors and drivers of growth in the field of ethnicity and health care research. However, it is worthy of note that ethnic monitoring is only mandatory in the acute sector (Chandra 1996). Presently there is no statutory requirement for collection of such data in primary health care settings. Yet most of the contact the general public has with the National Health Service in the UK is in the primary health care setting. The National Survey of NHS Patients (DOH 1999b) revealed that four-fifths of the population surveyed had visited a GP in the previous 12 months. Therefore we currently have a huge deficit in relation to the data available concerning service utilisation in Primary Health Care and the ethnicity of the patient or client. If addressing inequality in Primary Health Care is to be realised in the NHS modernisation programme (D.O.H.1997), it is imperative that in the near future steps are taken to ameliorate this. However, this data collection must be supported by a meaningful classification system for all groups within the UK. Further research is urgently required in this domain.

Methodological framework

Participants' experiences and strategies in relation to hypertension are examined from an ethnographic perspective (Spradley 1979, Hammersley & Atkinson 1995, Fetterman 1998). This methodological approach was selected as it was most appropriate to answer the research questions. Ethnographic research allows phenomena to be explored within the context of the participant's everyday life (Hammersley & Atkinson 1995). The focus of data collection is generally unstructured and achieved via a dialogue and observations between the researcher and participants (Hammersley 1998). Through interpretation and analysis by the ethnographic researcher, the existential and cultural characteristics of groups and phenomena are made explicit and assigned meaning from the perspective of the participants.

The research question in this study is therefore: *What are the meanings and consequences of hypertension for individuals of African Caribbean origin, and how are PHC services perceived?* The research question arises from the increased prevalence of hypertension in African Caribbean communities in England, and recognition of the paucity of evidence on the topic.

This thesis is organised in to two parts. **Part One** presents the literature that provides evidence of the nature and extent of hypertension for African Caribbean people in England, and an account of the methodological approach.

Part Two presents the methods by which this research was carried out, the findings (chapters 7-12), and an integrated discussion and conclusion. Finally, there is a general discussion and reflective comments (chapter 13). Part One and Part Two are contained in volume 1, the Appendices and References are in volume 2.

Chapter 2 explores the historical antecedents that have led to African Caribbean communities residing in England, including the precursors of migration. The concept of hypertension as a clinical condition is examined, and evidence is provided of the prevalence of hypertension in communities of African descent globally, including the variation in prevalence within different population groups in the African diaspora. The chapter goes on to describe theories which have linked the transatlantic slave trade to the contemporary health status of African diasporic communities, and a critical appraisal is made of these theories. It then maps out studies which have expressly focused on hypertension and African Caribbean communities in England, and the current policy agenda in relation to hypertension. Reference is made to the impact of age, gender and social class on the experience of chronic illness, and the current policy agenda. The historical and contemporary perspectives presented in this chapter in relation to hypertension and African Caribbean people are shaped and configured by theoretical and commonplace understandings of 'race' and ethnicity, which are explored in greater detail in the next chapter.

Chapter 3 presents and analyses contemporary understandings of ethnicity, race and culture, in an attempt to contextualise the findings of the study presented later in the thesis. The development of theories of 'race' is critically reviewed. Evolving concepts of old and new forms of racism, including institutional racism, are explored. The chapter traces government responses to migrant communities in England, from post-war economic policy in Britain to the rise of the New Right and Conservatism, Multi-culturalism and Anti-racism. Consideration is given to how ethnicity is described in health-related research and how the concepts evaluated manifest in PHC. This latter point is explored in greater detail in chapter 4.

Chapter 4 examines access to Primary Health Care by ethnic minority communities in England, mapping out the barriers and obstacles experienced. The focus of the chapter is on access to PHC by all ethnic minority groups in England, given the paucity of literature that expressly considers the experience of African Caribbean communities. However, this dimension serves to highlight the similarity and commonality of experience that many individuals from a variety of ethnic minority groups experience in accessing and receiving PHC, notwithstanding the fact that some variation does exist in the use of and access to PHC services between and within ethnic minority communities in England. The critical review of the literature is presented as key themes emerging from the literature. The chapter provides evidence of the context within which African Caribbean people with hypertension experience care. The chapter concludes with an overview of the implications for PHC research and practice.

Chapter 5 outlines the methodological stance adopted and the theoretical concepts underpinning the research. The chapter explores the positivistic and naturalistic traditions. It goes on to describe the history and tradition of ethnography. The chapter defines ethnography, including the ontological and epistemological underpinnings of the stance adopted in this research, and maps out common genres of ethnography used in qualitative research. An exploration of the *focused adjectival ethnographic* approach used in this study is articulated and a comprehensive definition provided. A critique is presented of ethnography and of the limitations of the methodology. The role of the ethnographer is critically evaluated, as are the sampling techniques used and the significance of reflexivity in ethnography.

Chapter 6 explains in detail the methods used in the research. The generation of the study sample, the process of informed consent and the process of data collection are explicated. Theoretical perspectives on the data collection methods of focus groups interviews, semi-structured interviews and vignette interviews are presented, and a critical appraisal is made of these tools, including an evaluation of the usefulness of these data collection tools in this research. Participant biographical details from all three phases of data collection are provided, along with reflective comments on issues such as the participants' use of language. The analytical framework adopted is explored in detail, and the steps and processes used in data analysis fully articulated. A critique is provided of respondent validation and the steps taken to establish a consumer research advisory group. Data in this research were analysed with the aid of Atlas/ti, a qualitative data analysis software package. A critical appraisal and review is made of computer-assisted qualitative data software. Ethical dimensions are considered. The chapter concludes with an in-depth and comprehensive reflexive narrative in relation to the methods used and my role as a researcher, including a critical de-construction of my self-identity and reflections on my own ethnicity, mapping out the influence of this on the research process and the study participants.

Chapter 7 presents empirical data and findings from the focus group interviews conducted. The finding are presented in four themes: 1) early diagnosis; 2) the meaning of high blood pressure; 3) the consequences and management of high blood pressure; and 4) the participants' experience of PHC. The four themes are considered in detail, firstly defining the theme and then exploring the constituent parts of each theme illustrated with verbatim comments from participants.

Chapter 8,9,10 and 11 present data and findings from the semi-structured interviews utilising the focused ethnographic approach. The data and findings from this phase provide a more detailed and in-depth exploration of the phenomena of hypertension as experienced by the African Caribbean participants in this study, thus contributing to the iterative process. The chapter on early diagnosis of high blood pressure embraces such issues as precipitating events, processes and systems that operate to determine participant motivations in respect of early diagnosis in PHC. Significant precipitating events are evidenced, along with diagnosis during routine contact with PHC professionals, symptoms pre-diagnosis, and participants' feelings about the diagnosis of hypertension.

Chapter 9 presents the meaning of high blood pressure, including participants' understanding of the terms 'hypertension' and 'high blood pressure'. Participants elected almost exclusively to describe their condition as 'high blood pressure'. The chapter maps out participants' explanatory models of hypertension in respect of psychological, socio-economic and physiological influences. The impact of wider societal structures, both contemporary and historical, is explored in this chapter.

Chapter 10 evidences the impact of the diagnosis of hypertension on everyday living for the participants, and their responses to managing stress, the perceived precursor of high blood pressure. The strategies participants used to aid daily management of high blood pressure are explored, and the consequences of high blood pressure in the psychological, physiological and socio-economic domains are mapped out.

Chapter 11 explores participants' use of NHS PHC services, including satisfaction and dissatisfaction with these services. Motivations for using private PHC services and the historical experience of participants' use of PHC in the Caribbean are examined, as factors impacting upon contemporary use of PHC in England.

Chapter 12 presents the vignette interview findings. The vignette interviews provided the opportunity for further in-depth exploration of issues identified in the first phase (focus group interviews) and second phase (semi-structured interviews) data collections. The findings are presented in relation to the four themes identified in chapter 7, and provide a thorough and exhaustive exploration of the topics under investigation. The vignettes can be found in Appendix 11.

Chapter 13 presents an integrated discussion of the empirical data and conclusions. Additionally, it provides a general discussion and reflective comments on the work undertaken. The chapter locates the findings within the existing literature on the topic and the broader literature on ethnicity and health, the sociology of chronic illness, and herbalism and non-concordance with hypertension pharmacotherapy. Reference is made to the social class and gender dimensions of hypertension experience, in addition to comparing the findings of this study with the experience of the wider population. The findings are viewed in relation to existing theoretical frameworks such as explanatory models of illness and the internal/external locus of control. A theory is postulated arising from the findings of this research, and the factors influencing hypertension management graphically represented. Policy, practice, education and future research implications are mapped out. Consideration is given to how rigour and robustness were achieved in this research, and to the limitations of the methodological approach in this study. The chapter concludes with a reflective narrative and learning for the conduct of future research.

Chapter 2

African Caribbean Communities and Hypertension

The aim of this chapter is to locate the research undertaken within the broader context of health and health inequalities within the United Kingdom. The condition of hypertension will be defined, along with the associated risk factors. Whilst it is important to explore the biomedical aspects of hypertension, the health experience of African Caribbean communities in the United Kingdom today may be regarded as a consequence of the unique configuration and influence of a given set of historical, social, economic, political and cultural factors. Analysis and deconstruction of these factors are vital in relation to understanding hypertension within the African Caribbean community in the United Kingdom, and global variations in other African communities within the African Diaspora. Therefore, a summary of the ethno-history of this community will be provided exploring the influence of migration, either economic or enforced, on health status.

An important starting point in terms of understanding the health experience of African Caribbean communities in the UK is the consideration of historical factors that may impact upon health status today. Torkington (1995) claims that for African Caribbean communities in Europe today, the historical influence of the transatlantic slave trade, colonialism and imperialism continue to exert influence. This is manifested in the present economic and social experience of African Caribbean communities in the United Kingdom. Leininger (1991 p.48) terms this type of retrospective exploration 'ethno-history' and defines ethno-history as:

> *"Those past facts, events, instances, experiences of individuals, groups, cultures and institutions that are primarily people-centred (ethno) and which describe, explain and interpret human life ways within particular cultural contexts and over short or long period of times".*

Moreover, it is essential that health care professionals develop an understanding of the ethno-history of patients and clients, in order to provide culturally congruent care and to challenge ethnocentrism in health care. Leininger (1991) was in the vanguard of a transcultural nursing care movement which first postulated this concept of ethno-history but other theorists, notably Ramsden (1995) in New Zealand and Papadopoulos *et al.* (1998) in the United Kingdom, have concurred with this viewpoint. Indeed, culturally competent care may only be provided by those who, in order to challenge ethnocentrism in health care, have engaged in a reflective process of acknowledging and understanding their own personal ethno-history.

Economic Migration

The following paragraphs provide a brief exposition of the ethno-history of African Caribbean communities in the UK. Communities of African descent have had a presence in Britain since the Roman era (Fryer 1992, Ramdin 1987, Gilroy 1995). Indeed, in the 18th century, substantial communities existed particularly around port areas such as Liverpool, Bristol and London (Fryer 1992), as a result of the transatlantic slave trade. The work of contemporary artists of the era, such as Hogarth, often included black subjects (Shyllon 1993).

Economic migration largely occurred in the 1950s and 1960s (Ramdin 1987, Fryer 1992, Torkington 1995). This was a direct response to the UK government's request for a mobile workforce in the booming post second-world war years to fill jobs in public services, which the indigenous populations declined. This work was largely unattractive, of menial status and low pay (Higginbottom 2000b). Jobs for the migrant workforce were largely available in public service domains such as transport and the National Health Service (NHS). Larbie *et al.* (1987) recall the then Minister of Health, Enoch Powell actively recruiting African Caribbean nurses and ancillary staff to the National Health Service (NHS). However, the relationships fostered between Britain and former colonies in West Africa and the Caribbean have always been characterised by, and indeed had the expressed purpose of generating, economic interdependence (Fryer 1992, Ramdin 1987) to sustain global markets for UK goods, whether manufactured here or in the former colonies. This contemporary economic and trade arrangement reflects the principles on which the former transatlantic slave trade was established in that trade, whether in human or manufactured goods, was a reciprocal process involving all parties on both sides of the Atlantic.

African Caribbean populations in the UK

Communities of African Caribbean origin, who have migrated to the UK, have ancestry in the Caribbean Islands, including Barbados, Jamaica, Trinidad and Tobago, the Windward Islands, the Leeward Islands, Guadeloupe and the Bahamas, which were former colonial states.

There exists considerable heterogeneity in communities in the UK that might be described broadly as African Caribbean, and therefore a myriad of variables exist that might impact on the health experience, health beliefs and health actions of this community. This diversity is well documented (Alexander 1999, Elam *et al.* 2000) and includes such issues as motivation for migration, language, religion, socio-economic class, level of education, dialect spoken, type of employment, family composition and social networks. Commonality does exist in that a large number of the UK's African Caribbean community live in the major conurbations (Dorsett 1998), although not exclusively so.

Data from the 2001 census suggest that the total minority ethnic population in the UK is 7.9% totalling 4.6 million in number (www.statistics.gov.UK/notices/Cenus.25June03asp). The Black Caribbean population is said to form 12.2% of the minority ethnic population. Aside from this, commentators such as Aspinall (2000), Rankin & Bhopal (1999), Nazroo (1997) and Modood *et al.* (1997) have expressed ongoing concern about the usefulness of the census classification systems. Researchers in the field are developing more sophisticated tools to truly capture an individual's identity: for example, in the United States Hazuda *et al.* (1988) used the approach of self-assignation, in addition to ethnicity and birth of parents and grandparents, in their study of acculturation, obesity and diabetes in Mexican populations. It is however very difficult to know how many people would describe themselves as African Caribbean.

Minority ethnic groups have a younger age profile than the majority white population (www.statistics.gov.UK/notices/Cenus.25June03asp): around 20% of the Black Caribbean population are under 16, while 9% of Black Caribbeans are over 65. The vast majority of this population can broadly be considered to be in the economic phase of their lives, and in considering the age of onset of hypertension, it seems likely that the condition might become more prevalent without the development of preventative interventions.

Hypertension and African Caribbean communities

Hypertension (blood pressure above 140/90 mm hg) is a condition that is said to affect 20% of adults over the age of 40 in the Western World (Morris 1997). In the UK, the DOH (1998) states that high blood pressure is prevalent in 40.8% of men and 32.9% of women. Factors that contribute to the development of hypertension include obesity, smoking, high levels of alcohol consumption, lack of physical activity, socio-economic status and ethnicity (Cooper *et al.* 1997a & b, Cappuccio *et al.* 1998a & b, WHO 2000). Whilst the condition is extremely common, there is evidence to support the view that many of the associated risk factors are modifiable (Cappuccio 1997, Cappuccio *et al.* 1998a & b, Ramsay *et al.* 1999 a & b, WHO 2000). The early detection and treatment of hypertension is hindered by the fact that often the condition can be symptomless (Raleigh 1997, DOH 1999). The prevalence of hypertension is strongly associated with an increased incidence of cardiovascular events and is regarded as a risk factor for stroke (Raleigh 97, Morgan 1995) and coronary heart disease (WHO 2000) with resultant increases in mortality and morbidity. Increased mortality from stroke is a particular problem for African Caribbean communities in Britain (Chaturvedi *et al.* 1993, Cappuccio 1997). Mortality from stroke in African Caribbean people in the UK is three and half times the national average (Raleigh 1997). Additionally, there is an increasing recognition and evidence of the role of hypertension in end stage renal disease (ESRD) in both white (Laville & Gueffier 2000) and minority ethic communities (Kaplan 1994, Raleigh 1997). Both South Asian and African Caribbean populations are said to experience the sequelae of ESRD at three to four times the rate prevalent within the white population in the UK (Raleigh 1997). A similar pattern is observed in African American populations (Suthanthiran *et al.* 2000). Brown (1997) states that in 95% of patients, the cause of hypertension is unknown, and therefore he postulates that contemporary medicine may have limited success in reversing the organ damage in the cardiovascular and renal systems that may be a consequence of hypertension.

Globally, patterns of cardiovascular disease (CVD), including hypertension, among peoples of the African Diaspora present an interesting and complex pattern (Kaplan 1994, Cappuccio 1997, Cooper *et al.* 1997). The British Heart Foundation (1997) has noted that the burden of CVD becomes progressively worse following geographical relocation. Populations in the Caribbean experience greater prevalence than those in West Africa, populations in Europe experience greater prevalence than those in the Caribbean (Cooper *et al.* 1997), and African American populations have the highest levels of hypertension (Kaplan 1994, Ergul 2000, Frazier 2000). It is worthy of note, however, that on the continent of Africa hypertension is more common within urban than rural populations (Cappuccio 1997, Cooper & Rotimi 1997).

The genetic influences that African Caribbean people experience in relation to hypertension are far from clear, as there appears to be conflicting evidence (Chaturvedi *et al.* 1993, Cooper *et al.*1997). However, Cooper *et al.* (1997) state that the relationship between genetic and environmental influences on the development of hypertension in black populations in the USA is not fully resolved.

There is evidence that maps out observed physiological and biochemical differences between black and white populations with hypertension (Larson *et al.* 2000, Frazier 2000). However, the vast majority of these studies are carried out in North America with African American populations (Cooper *et al.* 1999, Diez-Roux *et al* 1999, Pereira *et al.* 2001). This may limit the relevance of these studies for the African Caribbean communities in the UK. Black populations in the USA and the UK experience differing social, economic and cultural influences on health, and thereby on the experience of hypertension. African Caribbean communities in the UK who experience hypertension are largely first generation migrants (Nazroo 1997) or one or two generations removed from the country of origin. In contrast, African American communities have existed in North America for over two hundred years (Harris 1993).

It is known that the experience of hypertension differs between black and white populations; indeed this has been recognised for several decades. The notion of directly comparing black and white populations is contentious (Cooper *et al.* 1997), firstly because of the heterogeneity of black populations (Cooper & Rotimi 1997) and the differing variables that exist in black and white populations, specifically stressors associated with racial discrimination (Cooper *et al.* 1997). The onset of hypertension in communities of African origin is noted to be earlier (Brewster *et al.* 2000, Frazier 2000, Larson *et al.* 2000). In addition to the earlier development of hypertension, the condition/disease is more severe (Larson *et al.* 2000) in black populations. Ergul (2000) states that the pathogenesis of hypertension is different in black and white populations. Blood pressure tends to be higher in black populations, with greater organ damage (Cooper & Rotimi 1997). It has been suggested that individuals of African descent have a genetic propensity to kidney organ damage as a result of hypertension (Raleigh 1997). Moreover, hypertension in black populations is observed to be more resistant to drug therapy (Cooper & Rotimi 1997), although Brewster *et al.* (2000) point out that there is conflicting evidence in relation to this, as some clinical trials have reported the efficacy of antihypertensive therapy and others a lack of efficacy (Rahman 1997). This is further complicated by an observed lack of concordance with antihypertensive pharmacotherapy in some African Caribbean communities in the UK (Morgan 1995).

Black patients are said to 'present with a salt-sensitive hypertension characterized by low renin levels' (Ergul 2000 p.62). Gibbs *et al.* (1999) have observed that many hypertensive studies conducted in the USA and Britain have identified significantly lower renin levels in black populations. Sodium plays an important role in regulating renin in renal physiology.

Historical Antecedents: a theory

A number of theories are postulated in relation to the genetic propensity of black populations to hypertension. Wilson (1986) and Wilson & Grim (1991) have hypothesised the nature and cause of the observed increase in sodium sensitivity that African Caribbean populations in the Caribbean, North America and Europe experience (Ergul 2000). However, within the literature on this topic little reference is made to populations of African descent in Brazil, which is striking as the largest population of African descent that exists globally outside of the continent of Africa is in Brazil (Harris 1993), since the greatest number of enslaved people was transported to Brazil. Theories that relate either to salt supplies in West Africa or the experience of the transatlantic slave trade would need to be tested on the African population in Brazil to be convincing.

Wilson (1986) provides an interesting historical summary of salt supplies in Sub-Saharan and West Africa, although the original historical data sources are not clear. Wilson postulates that salt supplies in West Africa were variable: whilst regions such as Senegal and Gambia had plentiful salt supplies, land-locked regions such as Mali, Burkino Faso and Nigeria experienced greater difficulty in obtaining dietary salt. In the eleventh century salt was traded for gold, 'sometimes pound for pound' (Wilson 1986 p.783). Wilson states that researchers have suggested that biological adaptations to limited dietary salt have contributed to the development of hypertension in populations of the African Diaspora; that is, increased sodium conservation and retention. Wilson (1986) illustrates the differing blood pressures of Senegalese, Gambian and Yoruba (in Nigeria) people. The Senegalese and Gambian populations have lower blood pressure than the Yoruba, emphasising the heterogeneity of the health experience in West African populations and the relationship between salt supplies.

Whilst Wilson presents an interesting polemic, his views do not appear to be substantiated by research evidence. Furthermore if, as Wilson claims, some West African populations were more efficient at sodium conservation because of limited supplies, it is likely that the mortality rates from salt depletive illnesses during the transatlantic slave trade would have been much lower for specific groups of people. These populations would then have been targeted by slavers over three centuries, because the potential of this trait in terms of survival and increased profits would have been observed.

In later writing Wilson and Grim (1991) hypothesise that the 'biohistory' of people of the African Diaspora, embracing both environmental and biological factors, determines the health status of African Caribbean people in the Western hemisphere today. Their theory is based on research and investigation into the historical documents associated with the transatlantic slave trade, and logs kept by plantations owners in the USA regarding the mortality and morbidity of the enslaved African peoples. The transatlantic slave trade existed for at least three centuries (from the sixteenth to the nineteenth); the trade in human cargoes was lucrative and extremely profitable. However, profits depended on minimising losses through death, and a constant supply of new slaves. It is estimated that 12 million people were enslaved (Fryer 1992). Very few individuals captured actually survived the process. Wilson and Grim (1991 p. I-125) state that mortality rate on capture was '12-15%, the death rate from the point of capture to the coast was 10%, and mortality during confinement along the African coast 12%. Of those who disembarked from the ships 10%-30% or more did not survive the first three years of slavery'. These statistics are drawn from the extensive records that are held in various archives and museums in the USA, the UK and the Caribbean.

Wilson & Grimm (1991) postulate that during this period the conditions for the existence of a process of 'natural selection' existed, and therefore inevitable genetic changes in slave populations occurred. Their theory is based on the salt depletion that enslaved populations experienced, both on the West Coast of Africa and during transit to the Americas. At the time (as is still the case today in developing countries), diarrhoea, vomiting and fevers were said to be the major causes of mortality. These conditions are all salt-depletive and conditions in the coastal barracks, and on board the overcrowded ships and plantations, created environments that provided the optimum conditions for salt-depletive illnesses. For example, excessive sweating on enforced marches inland, and seasickness in the holds of ships. It was unlikely that any individual could escape his/her immediate environment and its unsanitary conditions. Wilson and Grim (1991) appear to be presenting a retrospective epidemiological explanation. They state (Wilson & Grimm 1991 p.123) 'normal stools contain only 2.5-5.0 mmol Na+/day, diarrhoeal stools average 100 mmol Na+/l[32] and vomit can contain up to 60 mmol Na/l[21]'. They claim that only those individuals who had a natural propensity to conserve sodium would survive, resulting in individuals surviving with a specific genotype. Furthermore, reproduction rates on plantations were low, and infant mortality 500 per 1000, and therefore only infants with specific traits survived.

Hypertension and the African Diaspora

A great deal of contemporary epidemiological evidence exists in relation to hypertension and associated environmental factors, as exemplified in a study conducted by Cooper & Rotimi. (1997) investigating hypertension in seven populations of West African Origin, and known as the International Collaborative Study of Hypertension in Blacks (ICSHIB). However, epidemiological evidence to date does not explain fully the predilection to hypertension that is the black population's experience. Cooper *et al.*(1997) postulate that psychosocial factors that occur as a result of racial discrimination may contribute. However this is difficult to measure and account for within epidemiological research. Significantly, this dimension limits direct comparison of white and black populations and their experience of hypertension, as the stressor of racial discrimination is not usually present in white populations.

The ICSHIB study is significant in that it was the first study to describe the experience of people of the African Diaspora in a number of locations, namely Nigeria, urban and rural Cameroon communities, Jamaica, St. Lucia, Barbados and the United States, and compare the risk of hypertension. The study maps out associations between obesity, hypertension and sodium intake. This multi-site method facilitates the illumination of the heterogeneity of black populations in their experience of hypertension, whilst enabling commonalties to be established. The investigation employed apparently rigorous methods in relation to inter-rater reliability. A training programme and certification were established for all those measuring blood pressure, and there was co-ordinated calibration of the blood pressure devices across all sites.

The findings of the study demonstrated a 'linear increase in the prevalence of hypertension across populations of the African Diaspora from among the lowest to the highest recorded'; (Cooper *et al* 1997. p. 165) that is, from east to west. This increased prevalence is reflective of the existence of the risk factors seen in the seven populations studied.

Individuals in the Caribbean and United States were found to be consistently more obese than those in Nigeria and Cameroon, with the rural Cameroon population demonstrating the lowest body mass index. Similarly, sodium excretion was found to be lowest in rural Cameroon, intermediate in the Caribbean and highest in the United States. This presumably reflects the hidden sodium content of the refined and processed foods characteristic of the Western diet. The findings demonstrate that environmental influences are the primary determinant of hypertension in peoples of the African Diaspora, although the populations studied share a common genetic ancestry (Harris 1993). The heterogeneity of the experience of hypertension in African Caribbean communities is evidenced. The research conducted by Cooper *et al.* (1997) does appear to support the sodium retention theories of Wilson and Grim (1999), but Chaturvedi *et al.* (1993) dispute this, stating that blood pressure medians in their study were the same in West African and Caribbean-born migrants. However, they do not state whether West African born participants had origins in rural or urban communities, a consideration that could account for increases in blood pressure.

African Caribbean communities in the UK

A number of epidemiological studies have mapped out the increased prevalence of hypertension and its sequelae in African Caribbean communities in the UK (Chaturvedi *et al.*1993, Raleigh 1997, and Cappuccio 1997, 1998). The Wandsworth Heart and Stroke Study (Cappuccio *et al.* 1998a & b), a population-based cross-sectional survey involving 1,500 individuals, established that both systolic and diastolic blood pressure measurements were higher for both men and women of African origin, and that hypertension was more common among people of African descent. However, in terms of explaining the higher blood pressure levels in the population of African origin, the evidence presented in this study is complex: associated hypertensive risk factors such as smoking and excessive alcohol consumption were lower in the sample of African origin. The investigators conclude their findings emphasising important issues for this particular investigation. They emphasis the need to focus on prevention strategies focused on cardiovascular health, in particular the development of culturally congruent primary health care services, as existing strategies focused on the wider population may not be effective (Cappuccio *et al.* 1998).

Morgan (1995) conducted an interesting study that focused on hypertension in African Caribbean communities in the UK from a sociological rather than a biomedical perspective. The study conducted in Lambeth, London, with a matched 'white' population in 15 general practices (60 individuals), demonstrated differences between the two study cohorts. The sample generated may be regarded as lacking in maximum phenomena variation, as all the respondents were contacted via general practices and not all individuals with hypertension may have frequent contact with their GP. Additionally, the African Caribbean respondents were described as a 'working class' and 'first generation migrants', which also limits the variation in the study sample.

Less than half of the African Caribbean respondents were found to take medications as prescribed for hypertension. Furthermore, approximately half of the African Caribbean sample stopped medication completely. The African Caribbean respondents demonstrated a strong belief in the value of traditional herbal remedies for ailments and illness, expressing concern at the possible 'addictive' characteristics of anti-hypertensive therapy. Poor communication between African Caribbean patients and their GPs was identified as further compounding non-adherence to prescribed medication. This lack of communication stemmed partly from a fear of disapproval of 'West Indian' ways. The size of the study limits the generalisability, although important insights are gained. These salient findings indicate that tensions exist between culturally defined health beliefs and contemporary Western medicine. If reductions in the prevalence of hypertension in African Caribbean communities are to be achieved, reducing this dissonance is an imperative, as is an increased understanding and a willingness to view alternative perspectives, together with more open communication by both lay communities and health professionals, in order to create culturally congruent management of hypertension in PHC.

Whilst a high mortality from stroke is established as the pre-eminent health issue for black populations, the evidence is far from clear as African Caribbean communities in the UK, the USA and the Caribbean do not suffer greater levels of coronary heart disease than the wider population (Cappuccio 1997). The higher incidence of hypertension in populations of West African (black) ancestry in urban areas in West Africa, the Caribbean, the USA and the UK, has been the focus of a several research investigations (Kaplan 1994, Cooper *et al.* 1999, Diez-Roux *et al.* 1999, Perieira *et al.* 1999). As yet, a clear epidemiological explanation for the increased prevalence of hypertension and associated mortality in African Caribbean populations remains elusive. It is possible that in future decades a definitive explanation will be provided, as there is ongoing research into the human genetics. Appendix 2 contains a detailed account of the definition, measurement and management of hypertension.

The intersection of social class, gender and age on chronic illness

Chronic illness experience such as hypertension is mediated by social class, gender and age. Hypertension is more common in old age (Dickerson 1995) and evidence from Nazroo (1997) maps out the greater prevalence of hypertension in African Caribbean women than men. The steep social class gradients that are associated with increased morbidity and mortality in the general population have been recognised for several decades (Townsend & Davidson 1982). Although ethnic minority communities experience greater ill health then the general population (Nazroo 1997), this experience is inextricably linked to social class dimensions (Nazroo 1998, Karlsen & Nazroo 2002, Nazroo 2003). Few sociological accounts expressly focus on African Caribbean people with hypertension. However, the sociological literature does advance understanding of how age, gender and social class might mediate the experience of ill health, especially chronic illness.

It seems axiomatic that longevity implies that the individual concerned will have encountered a number of life events or circumstances both positive and negative, so that by old age many individuals will have developed a repertoire of skills and strategies for responding to adversity. A number of studies have demonstrated how age mediates chronic illness (Gilleard and Higgs 1998, Sanders *et al.* 1998), suggesting that older people may be more able to deal with and respond to life events such as the development of a chronic illness, as demonstrated in the study on stroke and older people conducted by Pound *et al.*(1998*)*, who state:

> *'By the time people have survived into their 70s, 80s and 90s, their experiences may have equipped them with considerable skills which enable them to deal with crises and successfully adapt to new situations such as chronic illness'.* (Pound et al. 1998 p.502)

Furthermore, working class older people may be particularly stoical in responding to chronic illness because of the adversity of they have faced in their lives (Pound *et al.*1998, Williams 2000), and because in some senses they expect the onset of chronic illness as a feature of growing older. Recent studies in this domain build on the seminal work of Cornwell (1984), who highlighted the stoicism of many of the working class East Enders who participated in his study. However, Cornwell does remark on the tendency to romanticise working class lives in the East End of London. Chronic illness can occur at any point in the life trajectory. Atkin & Ahmad (2000a) provide evidence of how youth mediates the experience of thalassaemia major in responding to daily living with the condition from a pragmatic and emotional perspective.

Kralik (2002), Asbring (2001), and Emslie *et al.* *(*2001) present sociological accounts of chronic illness that focus on the importance of gender in mediating the experience of chronic illness. Of relevance to the research conducted in this thesis is the study by Emslie *et al.* (2001) examining heart problems and the invisibility of women. They state that coronary heart disease (CHD) is often perceived by health professionals to be a male condition, so that women are less likely to receive an accurate diagnosis of CHD or receive appropriate treatments. The extent to which this perception extends to hypertension is not clear. Thus it can be concluded that African Caribbean people with hypertension experience a number of mediating factors, including age, gender and social class, which impact upon their chronic illness experience.

Meaning and consequences of hypertension

The following paragraphs are meant to provide a brief overview of the possible impact of the diagnosis of hypertension in African Caribbean people. It is not intended to fully explore health beliefs and behaviours associated with hypertension, which will be addressed fully in chapters 7 to 13. Furthermore, it is not intended to pre-empt the findings of the research, but to examine the scope what little is known on the topic.

In the literature concerned with the sociology of chronic illness little attention has been paid to either hypertension or ethnicity as a mediating factor in relation to chronic illness experience. The literature does, however, provide some pertinent insights into the conceptualisations of the meanings and consequences of chronic illness (Pound *et al.*1998, Sanders *et al.*2002). In their study of osteoarthritis in older people Sanders *et al* (2002) use the concept of meaning to signify both significance and consequences, as originally postulated by Bury (1988). In this conceptualisation 'meaning as consequence' refers to the practical considerations that a chronic illness invokes, and the restrictions on social activities and the social disadvantage that might follow. The notion of 'meaning as significance' refers to the symbolic nature of the chronic illness, as perceived both by society at large and by the individual concerned, and which may lead to stigmatization.

The experience of diagnosis of hypertension is very much mediated by the prevailing social, economic and cultural influences in an individual's life (van Wissen 1998). It may be difficult for individual patients to separate out components of their life experience, such as illness or disease, from an overall perspective on their 'quality of life' (van Wissen 1998). Therefore, an affluent employed person with few stressors is likely to respond to the diagnosis of hypertension in a very different way to an individual who may be unemployed and have multiple life stressors, and be living in impoverished circumstances. Indeed 'biographical disruption' (Bury 1982) is said to be less frequently encountered by those in privileged positions (Williams 2000). It is possible that different personality types may respond in different ways, depending on the individual's ability to adapt to changed life circumstances. Furthermore, the level of social support that individuals experience may also be a factor that impacts on perceptions regarding hypertension.

Concepts of health and illness are also culturally defined (Helman 2001). Therefore, as might be expected, the experience of hypertension and interpretations of the meaning and consequences of hypertension are uniquely individual. Van Wissen *et al.*(1998) conducted a qualitative study using interviews with a population in New Zealand to explore the experience of living with high blood pressure. The majority of the participants were of European origin, with only two patients of Maori origin, and this may limit the significance of the findings to an African Caribbean population in the UK. However, some pertinent insights are illuminated. Emergent themes in the findings focused on the participant's reconstruction of a personal outlook on life and the associated health beliefs and behaviours, such as meeting the commitments of daily living outside of the family, recognising symptoms, reactions to diagnosis, modification of lifestyle and medication.

The findings in van Wissen's study highlight the individual's life experience as mediating the experience of high blood pressure. The patient therefore is viewing the diagnosis and experience of hypertension through the lenses of their total life experience, whereas the health professional may view the patient as an individual with a diagnosis of hypertension as that individual presents in surgery or clinic. This compartmentalisation or construction of illness and disease as discrete entity is characteristic of a Western biomedical approach, but does not necessarily reflect lay perspectives that may embrace a more holistic perspective. Furthermore, the social, cultural, and economic context in which a chronic disease such as hypertension is experienced is not static, but changing and dynamic (van Wissen 1998). This study suggests that health professionals in the prescription and monitoring of anti-hypertensive therapies do not take account of this dynamic experience, and therefore patients empower themselves by modifying treatment programmes by non-adherence in order to meet their lifestyles.

An emerging theme in the literature on anti-hypertensive therapy for all population groups is that of concordance or adherence to treatment programmes, and this is reiterated by van Wissen *et al.* (1998), who provide a useful explanation of the concept:

> "*Compliance with treatment is a fundamental prerequisite for therapeutic benefit. Implicit in the compliance concept is the assumption that the circumstances of a person's illness and way of life are compatible with prescribed treatment to the point of therapeutic benefit*". (Van Wissen et al. 1998, p.568)

Van Wissen *et al.* (1998) assert that the 'endpoint of therapy' must be explored fully with patients if therapy is to be successful. Collaboration of this nature is dependent on a high quality interaction between doctor and patient. As outlined earlier, the potential for cultural clash, miscommunication and misunderstanding between doctor and patient is greater if both are not of the same ethnicity. Morgan (1995, 1996) highlighted the issue of communication between doctor and patient as a major determinant in adherence to medication, in what appears to be the only study conducted in the UK exploring the African Caribbean people's experience of hypertension. Van Wissen *et al.* (1998) present the mediating concepts of context and culture on blood pressure experience in a graphic representation as follows:

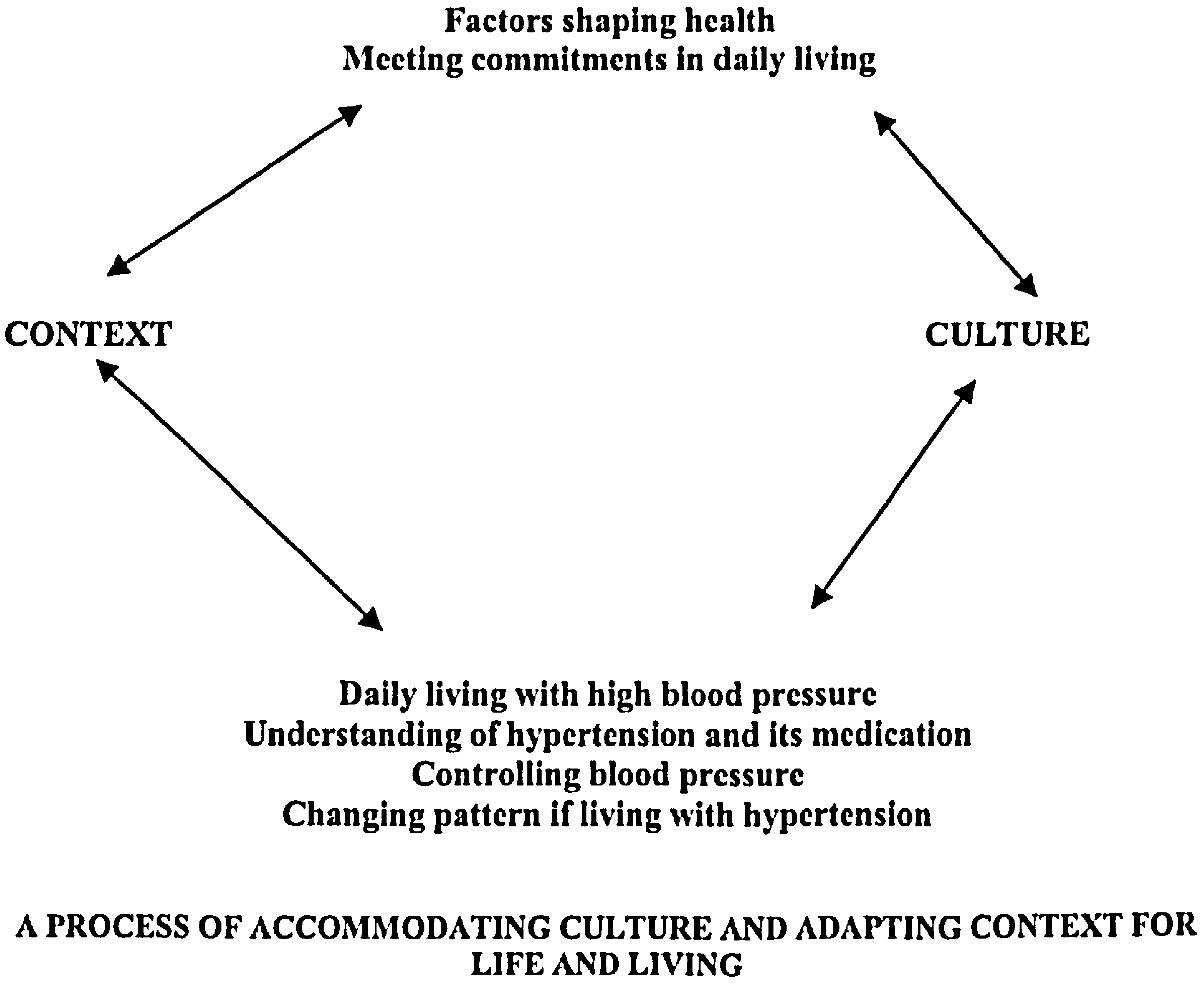


Figure 1: An integrative framework of context and culture to describe the experience of the individual (van Wissen, Litchfield & Maling 1998 p571)

There is little evidence in the UK that specifically focuses on African Caribbean communities and their experiences of hypertension. However, a recent study by Rose *et al.* (2000) mapped out the context for adherence for African Americans with high blood pressure, and provides some useful insights, although if a similar study was to be conducted in the UK with African Caribbean populations the findings might differ. The study established the dynamic and multifaceted experience of adherence depending on life, personal, social and economic circumstances. A major theme to emerge from this study was the patient-provider relationship and the importance of an empathic caring relationship. Mutual goal-setting is dependent on a collaborative relationship; therefore positive perceptions by patients of the caregiver are paramount. Participants in this study were all male (which limits the usefulness of the findings); around 42% reported modifying their medication to meet their lifestyle needs. The cost of anti-hypertensive therapy was reported to be prohibitive for some participants, although this may not be as relevant for the UK. One man reported withholding information about his blood pressure from his employer for fear of retribution. Surprisingly, little reference is made to the side effects of anti-hypertensive therapy, in particular the well-known side effect of impotence, which leads me to question whether respondents were facilitated in sharing more sensitive information.

The most significant study carried out in the UK (as mentioned earlier) examining African Caribbean people's perception and meaning of hypertension was conducted by Morgan (1993) in the early 1980s, with a population of mainly first-generation migrants. Fifteen general practices in the borough of Lambeth participated in the study, with a study sample of 30 individuals. Morgan established that 'cultural clash' and poor communication between GPs and African Caribbean patients might influence concordance with medication.

In summary, it is clear that a plethora of meanings and consequences may exist for hypertensive patients of African Caribbean origin. Effective management and treatment of hypertension in PHC appears to be dependent on the health professional's ability to take account of an individual's unique personal, social, economic and cultural circumstances, acknowledging that these are not static.

Contemporary Policy Agenda

A variety of different social and ethnic groups are disproportionately affected by hypertension (Cappuccio 1996, Poulter *et al.* 1997, Cappuccio *et al.* 1998, DOH 1998). This variation demonstrates inequality in health status, the manifestation of a convergence of differing economic, social, cultural and genetic factors, many of which are outside the control of the individual or community. Early diagnosis and treatment of hypertension is a national priority. Policy documents, such as *Saving Lives: Our Healthier Nation* (DOH 1999a) and the *National Heath Service Framework for CHD* (2000), clearly identify the reduction of cardiovascular disease, including hypertension, as a national imperative.

The early detection and treatment of hypertension is a national priority (DOH 1999a). It is recognised that over 50% of individuals who have hypertension are not successfully treated (DOH 1999). The NHS policy agenda is focused on ameliorating this, and is currently reviewing the approach adopted in PHC to the detection and treatment of high blood pressure.

Summary

This chapter has served to locate the research undertaken within contemporary understandings of the health experience of African Caribbean people who experience hypertension in England. The chapter then explored the factors that have led to African Caribbean people migrating to England, and historical antecedents such as the transatlantic slave trade, and how these factors impact upon the contemporary health status of African Caribbean people. The chapter has analysed in detail both the experience of populations of African origin and hypertension globally, thus importantly providing evidence of the prevalence of hypertension in African Caribbean communities in England. The 1999 Health Survey for England (DOH 2000c) confirms the continuing significance of hypertension for African and African Caribbean communities in, England, although a marked gender differential exists. A higher prevalence of hypertension in women of Black Caribbean, Indian and Pakistani origin was noted. Black Caribbean men in this study were most likely to have received any treatment, which may indicate gender variations in access to PHC. The issue of access to PHC is explored in more detail in chapter 4. A critical analysis is provided of how age, gender and social class mediate the experience of chronic illness. Consideration is given to the meaning and consequences of hypertension and to the myriad of factors that coalesce to shape and determine how hypertension is experienced as a chronic illness.

Morgan (1993) reiterates the findings of an earlier study Cappuccio (1997), in asserting that non-concordance is a major issue for African and African Caribbean communities in the UK. It is anticipated that factors that contribute to either concordance or non-concordance in respect of anti-hypertensive therapy may form an important dimension of the finding of the present study. Furthermore, Cappuccio (1997 p.574) states that 'the quality of hypertension control predicts stroke mortality'. It is clear, then, that effective management of hypertension in PHC, reduction in stroke morbidity, and mortality for African Caribbean communities may to a large extent be dependent on the quality of PHC services in relation to early detection, cultural congruence, disease management and concordance with medication or patient perceived appropriateness of treatment. Notwithstanding all the above issues, the experience of hypertension for African Caribbean communities in England is likely to be mediated by social class, age and gender, as are other chronic illnesses. The analysis undertaken in this chapter is important, insofar as it provides insight into the context in which African Caribbean people experience hypertension in England, as will become apparent in reporting the findings of the study. The historical and contemporary perspectives presented in this chapter, in relation to hypertension and African Caribbean people, are shaped and configured by both theoretical and commonplace understandings of 'race' and ethnicity, which are explored in greater detail in the next chapter.

Chapter 3

Perspectives on 'race' and ethnicity

This chapter explores theoretical perspectives on 'race' and ethnicity in an attempt to establish what is knowledge and what is conjecture or fallacy within this domain. The development of theories of 'race', are examined, and contemporary conceptualisations of ethnicity and social identity. Old and new forms of racism are explored, including institutional racism and how this might be manifested in the PHC setting. Migration in the post-war period in Britain is explicated, with a focus on the political context in which post-war migration developed, exploring the rise of the 'new' right, multi-culturalism and anti-racism. This discourse provides the backdrop and stage on which the participants in this study have lived their lives in the UK and in this sense maps out the broader structural factors that intersect with the participant's life experience.

Complex sociological theories over past decades have attempted to critique, analyse and explain social relations between groups of individuals, the influence of societal structures and the relationship of 'race', ethnicity and culture to wider societal structures (Rex 1986, Phizacklea & Miles 1980, Miles 1982, Solomos 1993). In some instances this has also included revisiting original and seminal perspectives in order to provide new and contemporary insights (Jenkins 1997, Banton 1998, Mac an Ghaill 1999, Nazroo & Karlsen 2001), the significant point being that sociological perspectives offer a perspective, explanation or critique, not necessarily a definitive answer on issues of 'race' and ethnicity.

The following sections map out the historical and emerging theoretical discourses, debates and polemic on 'race' and ethnicity. The aim is to establish the extent to which these broader perspectives intersect and impact upon the health experiences of individuals of African Caribbean origin with hypertension. From this perspective, my concern is pragmatic focused on the lived experience of African Caribbean people with hypertension and a desire for the improvement of Primary Health Care (PHC) services. Furthermore, the intention here is to analyse the relationship between these broader theoretical perspectives and the configuration of PHC services that reflect the health and social policy agenda in the UK; in this sense the policy agenda is a reflection of the underlying values, philosophies and predominant ideologies of the state. The ideology of racism is particularly pervasive to such an extent that the impact of the ideology upon the health experience of African Caribbean populations may result in major physical manifestations or exacerbations of dysfunction and disease processes (Krieger 2000 a & b). This exploration includes consideration of macro-structural processes and micro-processes at the interface between patient and health professional. Typically, debates and discourses (discourse being essentially a speech, conversation, or communication not necessarily associated with arguments or opposing viewpoints and which may be written or oral viewpoint or prescription on a given topic). Mac an Ghaill (1999 p45) provides a more complex definition in relation to sociological discourse:

> *"Discourse refers to specialized and commonsense regulated systems of meaning through which we make sense of the world. These systems of meaning are constructed in and through particular practices which make available social identities or subject positions, and which simultaneously entail relations of power"*

In relation to the health experience of African Caribbean people, discourses enable us to locate this community in terms of social and power-structured relationships with the dominant group. Although, Mac an Ghaill (1999) cautions against an analysis focused on a 'unitary position' as we all hold complex multiple identities and power-structured relationships that are dynamic. An example of this might be feminist discourse and the position occupied by African Caribbean women within this discourse.

Debates concerning 'race', ethnicity, and culture provoke highly charged emotional responses. The concepts and language associated with theoretical perspectives on 'race', ethnicity and culture, especially from a historical perspective can be regarded as contentious and in some cases provocative and pejorative, depending on the context in which the articulations are made. I would therefore direct readers of this section to the glossary of terms used in the research (Appendix 1), to determine my own personal interpretation of concepts and terms used. I have elected to use quotation marks around the term 'race' to signify the contested nature of the concept (Bradby 1995). Much of the debate focuses on distinctions between 'race', racism and racialisation (these concepts are more fully explored in later sections of this chapter) and how manifestations of these concepts impact upon interpretations of African Caribbean patients' experience of health and use of PHC services (Kreiger 2000 a & b). The extent to which the concepts of ethnicity and ethnic identity are capable of measurement and the dynamic nature of both ethnicity and language will also be debated.

The development of theories of 'race': an historical overview

In order to view the research within the broader context of UK society, it is firstly imperative that an historical perspective of how the term and understandings of 'race' have come to be represented in contemporary literature is explored. Additionally, the term 'race' is used in commonplace and everyday lay language and in academic fields of health and related research. The notion that systems of human classification exist infers the existence of biological and genetic determinants in relation to the human condition. An exploration of this nature inevitably demands a critical analysis of how, in the UK, British colonialist and imperialist structures have influenced conceptualisation of the term and the development of knowledge. A critical analysis is required as to how a contested term such as 'race' has manifested a myriad of associated concepts, become integrated into legislative frameworks and taken for granted structures within UK society e.g. race relations, racial prejudice (Banton 1998). A huge semantic challenge would be presented to the English-speaking world if the term were to be replaced (Banton 1998).

The continued focus on 'race' is reflected in the North American literature. Williams (1999) points out that four of the current classifications in the US census appeared in the very first census in 1790. Given the growth in human knowledge in the area of genetic endowment, science and philosophy generally, especially since the inception of the human geno-project, this observation appears astonishing. It is clear then that racial classifications are not informed by scientific evidence, but represent racist ideologies as they exist within societies and are in this sense a social construct (see later sections). The continued emphasis in research of biological differences between populations may in fact serve an important function in the maintenance of racist ideologies within society (Anand 1999).

Conceptualisations of 'race'

Banton (1998) asserts that early use of the term 'race' became commonplace in the 16th and 17th centuries. The meaning of the term 'race' in these early references was apparently connected to the concept of lineage. Many references arise from biblical writings, for example 'the race and stocke of Abraham' (Banton 1998 p.18.). Various religions according to Banton (1998) have supported 'monogenesis. Monogenesis refers to the idea that all human beings were created from Adam and Eve, and that the differences in human beings are superficial.

The emergence of the term 'race' must be viewed within the prevailing economic and social context of the 16th century. Europeans were increasingly engaged in exploration to the continents of Africa, India and the American sub-continent (Fryer 1992). It is likely that many Europeans would have observed for the first time individuals of a different 'phenotype'.

'Phenotype' is the term used to describe genetically endowed physical characteristics, (Fatemilehin 1999). In reviewing historically the emergence of the concept of 'race', Williams (1999) points out that the concept developed prior to the growth of modern science and valid scientific theories concerning genetics.

During the 19th century, evolutionary biologists have postulated that three major *Homo sapien* groups existed: 1) African, 2) Caucasian and 3) Mongoloid (Anand 1999). This viewpoint would appear to imply that these three groups are mutually exclusive and with a distinct genetic makeup. However, it is now recognised (Lewontin 1992, Ahmad 1993) that all human groups have very minute genetic differences, and that most genetic variation occurs between individuals with the same phenotype (Williams 1999, Anand 1999). The concept of 'race' is based on the fundamental premise that in addition to physical characteristics or phenotype, particular types of behaviours can also be ascribed to populations of people. Furthermore, this associated behaviour is deemed to be hierarchical, with some groups of humans displaying behaviours that are perceived as having more merit than others. This perspective emerged in the late 19th century; Smaje (2000) terms this 'scientific racism'. This biologically determinist viewpoint continues to provoke debate and contention (Banton 1998). What is clear is that the concept of 'race' is a social construct that represents a convergence of both biological and social perspectives. The concept enables broad generalisations (usually negative, though not exclusively) to be made about groups of people. Furthermore, various religious, political and self-interest groups have used this concept to further their own ends. The most shocking example in recent times is the doctrine that informed the activities of the Nazis that resulted in the mass genocide of Jewish, Travelling and other groups of people. The transatlantic slave trade was also dependent on this form of human classification and the associated ideology. Historically, the concept of 'race' has therefore enabled groups of people regarded as inferior to be exploited by those who hold power (Williams 1999). New understandings of the concept of 'race' in the 21st century have emerged; as a result of the Nazi atrocities, the scientific community focused attention on the concept of race, deconstructing known and accepted understandings of the concept (Banton 1998, Mac an Ghaill 1999).

Following the genocidal policies of the Nazi regime, in the aftermath of the 2nd World War a number of academics, theorists, and sociologists explored the foundations of the scientific basis of 'race' (Bhopal 1998). This body of work resulted in the 'Declaration of Helsinki' and the debunking of the term 'race'. The rise of the Nazi regime in Europe could only have occurred because of the movement's belief in the concept of 'racial superiority' (Back and Solomos 2000). Although a strong anti-Semitic dimension informed the Nazi regime, genocide of other groups of people also occurred for example, Roma people. The whole existence of the Nazi regime was to bring about 'social engineering' in Europe by eradication of certain groups (Bauman 2000).

What is surprising in the light of scientific knowledge and evidence is the continued primacy of the term in the 21st century. A good example of this is the 2001 census in the UK that adopts the term 'mixed' in the ethnicity section (Aspinall 2000). It is not my intention here to use the terms 'ethnicity' and 'race' interchangeably, but simply to demonstrate how others, in this case the state, have misappropriated and confused terminology.

The domain of collating information on ethnicity is increasingly complex (Nazroo & Karlsen 2001) and it would seem an attempt is being made to facilitate individuals in more accurately describing themselves. However, the term 'mixed' appears to imply that the concept of 'pure' ethnicity exists; this notion appears to have overtones of Nazi philosophy in describing pure races. It is this latter point that illustrates Banton's (1998) claim that the perpetuation of the primacy of the concept of 'race' has and is still maintained via the need for various groups within societies to uphold their own interests. These interests may be political, religious or economic. This continued influence of the concept of 'race' has occurred simultaneously with the growth of science and the philosophy of science that brought about a growth in human understanding and knowledge (Kuhn 1982). Whilst the scientific community has largely rejected the term as having no scientific foundation (Sheldon & Parker 1992), this serves to emphasis the concept as a purely social construct.

'Race' can be viewed as a social construct because of the lack of a scientific biological explanation. The notion of 'race' as a social construct is fully explicated in the seminal text by Banton (1998) in which he presents explanations of the concept of 'race' in four domains:

- ☐ Race as descent
- ☐ Race as a type
- ☐ Race as subspecies
- ☐ Race in current usage

In these four domains he summarises historical perspectives that at that point in history, were accepted explanations for human difference. Some of these perspectives, although without scientific foundation influence accepted understandings of 'race' today. These viewpoints are socially constructed, as all explanations for phenomena that exist within the world are, as a result of their construction by mankind.

Race as descent Banton (1998) states that until the 18th century the dominant viewpoint in Europe was that which had origins in the Old Testament. He states that the Old Testament mapped a number of genealogies by which it appeared possible to establish the relationship of populations around the world. Other explanations for the existence of black people focused on the curse allegedly placed on Noah by the descendents of Ham. The cosmology in both these examples were determined and shaped by the belief that God the creator could punish or reward individuals. In order to avoid directly challenging religious tenets and scriptures, it was argued at the time that Adam was the ancestor of Europeans alone and that the scriptures were incomplete. Christianity in this respect was informed by a belief in monogenesis.

Race as type . Banton (1998) states that this viewpoint can be traced back to Curvier (1769-1832) a French anatomist, who divided human beings into three main groups:

- Caucasian
- Mongoloid
- Ethiopian

He claimed that the three groups of man were different because of biological differences that were little understood at the times. This taxonomy presented was hierarchical, with Caucasian people demonstrating the most desirable characteristics as a result of biology. There is no valid scientific basis for this classification in respect of biology determining the characteristics and culture of mankind; hence it is a social construction. At the time, this explanation was accepted as scientifically based theory. Curvier was extremely influentional, in fact the extent of his influence is seen even today in the continued use of the term Caucasian. A number of others contributed to the belief in a typology of 'race', Charles Hamilton Smith, Robert Knox, James Hunt and Karl Vogt (Banton 1998) these individuals being the main proponents of what we now know to be 'scientific racism'.

Race as a subspecies. Banton's perspective is largely informed by Darwin's work on the origin of the species. He recognised 'geographical races or sub species as local forms completely fixed or isolated' (1998 p57). His evolutionary theories hinged on the notion of superior races and that possible contamination could occur from contact with inferior races. Additionally the superior race could protect themselves from contamination. These ideas form the basis for Social Darwinism and were extremely influential in enabling the Christian population of Britain to have a rationale and justification for colonisation, growth of the Empire and despicable treatment of fellow human beings.

Ethnicity and social identity

Ethnicity as a concept that is different from the concept of 'race' has risen to prominency in health related research, literature, health, and social care service provision (Bradby 1995).

However, it is worthy of note that this increased focus is characterised by a lack of consistency and terminology (Sheldon & Parker 1992). The concept of ethnicity moves beyond perceptions of 'phenotype' into a complex coalition of the sharing of culture, values, traditions and perceptions of belonging that interface with every aspect of the lived human experience (Mac an Ghaill 1999). This is distinct from nationality or old understandings of the concept of 'race' and is not necessarily related to geographical locations or national state boundaries. In considering the health experience of individuals of African Caribbean descent, and the historical antecedents of how black populations come to reside in the Caribbean, communities are perceived to have arrived in the Caribbean as a result of the transatlantic slave trade from Ghana, Nigeria, Benin, Togo, The Gambia or Sierra Leone. It is worthy of note that few of these West African nation states existed in pre-colonial times. The state boundaries are a result of the imposition of artificial state boundaries, defined by colonial masters. The tribes of Africa transcend colonial state boundaries. For example, the Hausa people inhabit Ghana and Nigeria, the Fulani, Ghana, Mali and Burkino Faso. The traditions and ethnic identity of these populations are not defined by nationality. The imposition of boundaries such as those described serves to create further confusion between ethnicity and nationality.

Modood *et al.* (1997) has highlighted the notion of 'fused ethnicities' as a consequence of colonialism, immigration, movement of populations, fusing of cultures. Fusion of this nature is exemplified in the exposure and influence of the 'British' ways of life, and institutions in many countries over several hundred years, especially within the Indian sub-continent. In this sense individuals and communities did not need necessarily migrate to experience this exposure. Additionally, there are those who create new identities and ethnicities for themselves, refusing to accept old orders and understanding. The sociological theoretical debates in this domain focus on the polarity between cultural essentialism, hybridity and diaspora (Coombes & Avtar 2000, Anthias & Yuval-Davis 1992). The difficulty with these terms is the lack of a shared definition (Anthias & Lloyd 2002). For example, the term 'diaspora' has been used by Gilroy (1995) and Hall (2000) with variations in meaning. Similarly the term 'hybridity' is a contested term (Anthias & Lloyd 2002). The similarity between cultural essentialism, hybridity and diaspora is that rather than structural issues being a central concern as in antiracism, they focus on culture and identity. Diaspora is associated with the concept of transnationality (Gilroy 1995) the migration and re-location geographically to countries other than the birth country. Therefore the concept would appear to have not only historical relevance to those populations that have migrated to the UK but also a contemporary relevance in relation to refugees and asylum seekers in the UK and Europe.

The original Greek meaning of diaspora is the spreading of seeds across territories, the implication that these seeds (people) will form new roots in the new environment. In this sense the term 'diaspora' embraces a past history in the sense of where people have come from and the influence of the new location. Whilst the seeds have spread, they can only become mature if the environment is conducive to their development (Anthias & Lloyd 2002). The notion of fixed ethnic boundaries provides a limited understanding here, in terms of scattered or displaced people (either voluntary or enforced). Anthias & Lloyd (2002) claim the notion of diaspora also has considerable influence on those who already occupy the environment and must influence this population in some way. Therefore, the host community is influenced by the migrant communities; good examples of this exist in the UK in terms of the influence various ethnic groups have on diet and other elements of popular culture such as music.

Whilst these considerations may not on a daily basis be pertinent for the individuals or communities themselves, considerable misunderstandings can occur, for those involved in the collection of data in the form of health related statistics for research. Ethnic boundaries are considered to be fluid unlike the immutable boundaries of old understandings of 'race' (Sheldon & Parker 1992, Modood *et al.*1997). However, language is dynamic and Bradby (1995) asserts that the terms 'race' and ethnicity are beginning to be used synonymously because of the difficulties in defining ethnicity and the complexity of the concept. I have certainly observed this in everyday utilisation of the term in health care settings, specifically when health professionals assign an ethnic group to patients and clients without consultation. Furthermore, some individuals use the term 'ethnics' as a pejorative concept.

Other perspectives on ethnicity focus on the concepts of 'primordialism' and 'situation ethnicity'. Cornell and Hartmann (1998) summarise the perspectives of Isaacs (1975) on the topic of primordialism. Primordial attachments stem from 'assumed givens of social existence' (Cornell and Hartmann 1998). This notion gives rise to an understanding of ethnicity as a fixed entity, immutable and essential. These characteristics define the group identity. Isaacs (1975) further explicates the dimensions that define this group identity as the phenotype including size, shape and skin colour, the nomenclature adopted (both personal and family), the group origins, the population, language and religion, the culture and geographical location of the birth place. In Isaac's view, the primacy of these characteristics is immutable and enduring. Whilst it is not possible to deny the immutable nature of many of the concepts that inform Isaac's (1975) view of ethnicity, clearly issues such as phenotype are enduring. The problematic nature of the concept of primordialism is axiomatic.

The most significant challenges to this view are physically embodied in those individuals whose ethnic origin arises from more than one group. In the 21st century, increasing globalisation and travel has resulted in increasing interactions social and sexual relations between various populations, creating many individuals who claim dual, triple or quadruple ethnic origin. What is interesting is the opportunity or desire these individuals may have to publicly and politically assert their membership of certain ethnic groups. In some situations, because of power dimensions, hierarchies and political ideologies that exist in societies, it may not be deemed wise to publicly claim ethnic origin of a particular group if that group is oppressed or discriminated against.

The primordial perspective is limited in advancing understanding of hypertension health beliefs and behaviours of African Caribbean people in this study, as the fundamental concept in primordialism of 'basic group identity', is flawed in the lack of recognition of the dynamic nature of ethnicity.

The notion of situational ethnicity (Jenkins 1997, Mason 2000) hinges on the perceptions, both abstract and material, of the changing parameters and flexible boundaries that characterise ethnic identity. It is worth noting that the concept of ethnicity is common to the human experience, regardless of phenotype or geographical location. Within the Western world, the term is most frequently used in relation to minority communities, who may be less powerful than the dominant group (Banton 1998), although not exclusively. Examples do exist of minority communities holding more power than the majority as in South Africa during the aparthied era and to some extent today. Situational ethnicity reflects the individual's capacity to take on and negotiate multiple identities in a complex social world (Modood *et al.*1997). The individual may therefore move across a variety of boundaries, social, religious and professional (Nazroo & Karlsen 2001). An interesting phenomenon in large conurbations in the UK is that some young white people appear to adopt characteristics of dress, language and behaviours associated with African Caribbean people. An example of this is manifested in African Caribbean hairdressing salons, where white employees appear to have negotiated ethnic boundaries and identities. These young women, I term 'cross-over girls' as they manifest notions of hybridity and negotiated ethnic boundaries.

Ethnicity, is therefore defined by a shared understanding and identity in a specific context or environment (Nazroo 1997, Mac an Ghaill 1999). This internal definition of ethnicity is of course mediated by the external definition of the wider socio-structural processes in terms of health experience. Although we all have the right to self-determination, the external definition is more powerful in determining the health experience and consequentiality is more profound in terms of life experience (Nazroo & Karlsen 2001). The extent to which the concept of 'ethnicity' can be accurately measured is the subject of ongoing discourse and debate, not least in respect of the 2001 census (Aspinall 2001) as discussed earlier. The whole notion of measurement of ethnicity is fraught with difficulties (Nazroo 1997, Aspinall 2000). This to some extent may account for the lack of a strategic nation-wide approach to the collation of ethnicity data in primary health care. The lack of shared understandings of ethnicity and confusion with associated terms such as 'race' and nationality in everyday language, presents huge problems (Back & Solomos 2000). However, if the issue is not addressed in terms of a nation-wide strategic approach, it is unlikely that the policy goals that focus on addressing inequalities in health and addressing issues of social exclusion can be achieved. Furthermore the lack of ethnic data sets, in specific individual general practices that serve population with high ethnic populations, raises serious concerns as to how health needs are assessed at a practice level (Rothera & Pringle 1996) and the extent to which unmet health needs exist in specific practice populations.

Difficulties of measuring ethnicity are not confined to the UK, the US, also face similar and more challenging issues in this domain. Williams (1999) points out that the Census Bureau in the U.S. has routinely changed its racial categories over two centuries, further emphasising the notion of 'race' as a social construct. Complex schemes with seemingly little logic or rationale have evolved in the U.S. e.g. a child with a white father is assigned to the 'race' of the mother, whereas if the father was non-white the child should is assigned the 'race' of the father. However, if one parent is Hawaiian any offspring is be deemed to be Hawaiian (Williams 1999).

The recognition of self-assignation of ethnic identity as an important component in the formation of identity is exemplified in a number of sociological texts (Nazroo 1997, Mac an Ghaill 1999). However self-assignation of ethnicity cannot necessarily influence or change the perception of others. Nazroo & Karlsen (2001) call this the 'internal' and 'external' definition. This is extremely important in consideration of PHC services, as this external definition is likely to have a greater consequence in terms of the service provided and the experience of illness and dysfunction by African Caribbean people (this may be an important phenomena for African Caribbean people in terms of physical manifestations of the external definitions for example in 'white coat' hypertension). This perspective is also shared by Aspinall (1997 p.690) who asserts 'that *self-definition is not as consequential as perception by wider society'*. In other words, whilst self-definition is important in terms of identity, the external definition as imposed by wider societal structures is more profound in determining health experiences and compounding inequalities. Furthermore, Pringle & Rothera (1996) in one of the few studies conducted in Primary Care focused on ethnicity monitoring, provide evidence in their study that individuals self-define in a very different way given free text options then when presented with choices as they appear in the census.

Old and new racisms – cultural stereotyping

The study of 'race', racism and race relations according to Back and Solomos (2000) can be traced to the beginning of the twentieth century in the United States, for example the work of W.E. Du Bois in 1903. However, a greater volume of academic endeavour and scholarship occurred following the social unrest that epitomised the 'Civil Rights Movements' in the United States in the 1960/70's (Kushnick 1998).

The following sections are intended to clarify and explore the term 'racism' as an important component to understanding how racist ideologies might influence the health experience of African Caribbean people within the context of PHC. Furthermore, this exploration is essential to illuminate how racist ideologies might influence strategic policy development, service delivery and care provided in PHC.

Banton (1998) views the transatlantic slave trade as the precursor of racist ideology and racism, although prejudices against black people by white people were evident prior to this abhorrent trade. Banton (1998) identifies two main corollaries to the development of racism. Firstly, the need for ideology to uphold the interests of white populations in pursuit of economic endeavours within capitalism. Secondly, the development of prejudice from white society towards black people as an outcome of status distinctions in white society. Banton (1998), drawing on the seminal text by Fryer (1992) specifically locates English racism as emerging from Barbadian plantations owners who were of the view that "Negroes were beasts and did not possess souls", therefore should not be allowed to be baptised. These attitudes infiltrated English society in the 18th and 19th centuries.

Mason (2000) asserts that the term 'racism' is as contentious as the term 'race' in that the everyday common use of the term is manifold, claiming some theorists use the term to convey ideology, whilst others utilise the term to mean '*attitudes, beliefs, and ideologies and social action and structures*' (Mason 2000 p.9).

In common with others (Bradby 1995, Banton 1998, Back and Solomos 2000) I have argued for a rejection the term 'race'. However, it may be necessary in order to explore the experience of various groups within society to retain the term 'racism'. Bradby (1995) is emphatic in her assertion of the need to retain the concept of racism, specifically in consideration of the health experience of individuals. Bradby postulates that several domains need to be considered; firstly that racism can result in physical injuries. In addition to this is the emotional and psychological manifestation of exposure to racism, which may not be immediately apparent, but may ultimately in terms of psychological and emotional health be far more damaging to the individual or community. Secondly, racist thought and prejudice may be manifested in discrimination. Krieger (2000 p36) states:

> *"Inequality hurts. Discrimination harms health. These seem like straightforward, even self-evident, statements. They are propositions that epidemiologists can test, just like any other proposition about health"*

Institutional Racism

According to Mason (2000), the concept of institutional racism has origins in the United States. During the 1960's, the term emerged in order to draw attention to the wider systematic, structural forms of racism, that were not simply the result of individual actions and prejudice. Manifestations of the concept enable patterns of disadvantage to be clearly identifiable via the negative consequences of a variety of structures and mechanisms that disproportionately affect non-white persons. It is noted by Mason (2000) that there exists a lack of clarity around the term in relation to the intentional dimensions of institutionalised racism.

In the UK recognition of the term and the consequences of institutional racism have been debated more widely as a result of the Macpherson Inquiry into the death as a result of a racially motivated murder of the black teenager Stephen Lawrence. In this report, Macpherson stated that institutional racism is:

> *"The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviours which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people" (Macpherson 1999 para 6:34)*

It is worthy of note that in this definition, intentionality in the concept is avoided by the use of the word 'unwitting', although this does not excuse the institution. Many members of the minority ethnic community in Britain were disappointed by the use of this word. Following, the publication of the report there was an explicit reluctance by the constabulary to accept the findings or acknowledge institutional racism within the police force in the UK (demonstrated in media coverage). A gradual acceptance of the existence of institutionalised racism has occurred; partly via representations of minority ethnic groups, wide media coverage and affirmation of the existence of the concept by the government, forcing many institutions to evaluate their practices and service provision. The NHS in the UK has long been acknowledged as a racist institution (Bowler 1993 a & b, Beishon *et al.* 1995) although little evidence is available from the primary health care setting; further research is required in this domain. Recent policy documents (DOH 1999a) have acknowledged the collective failings of the NHS in responding to the health care needs of minority ethnic populations.

Racialised subjects

Mason (2000 p8) defines racialisation as:

> *"social processes via which social relationships become racialized; that is represented ideologically as entailing race".*

Exploration of the notion 'racialisation' is hindered by the fact the term originates in the concept of 'race'. Therefore in order to fully explore the concept, one must firstly to some extent accept the existence of a contested concept 'race'. Explanations for different health experiences of populations in a racialised view are framed by differences between racial groups (Mac an Ghaill 1999). Whilst the underlying premise is implicitly flawed, the intersection of social class, gender, culture, geography, social inclusion and inequality are ignored or reduced as being secondary determinants of the health experience. In truth, it is likely that material and social disadvantage exert a greater pressure on the health experience of Britain's ethnic minority populations (Nazroo 1997).

Post-war Britain and Immigration

The migration of black populations to Britain is not a result of the altruism of successive British governments; cheap labour was needed. The period following the Second World War in Britain was characterised by a period of economic growth and prosperity (Kushnick 1998, Alibhai-Brown 1999). The labour shortages present in Britain at the time preceded government policy and strategy that focused on facilitating individuals of the British Commonwealth to migrate to Britain as a solution to the labour shortages. The work available was largely unattractive to the indigenous population often being in public services such as transport, the N.H.S. and the textile industry (Kushnick 1998). The low status and low pay associated with this work contributed to prevailing racist views and ideologies in that immigrants were viewed as fit only to do the most menial, and dirtiest of jobs (Kushnick 1998). This era heralded the creation of 'multicultural' Britain as an actuality, in common with other European states, with a colonialist history.

It is worthy of note that a number of trade unions that claimed a socialist heritage were vehemently opposed to mass immigration of this nature, in order to protect, they claimed, the rights of their members (Kushnick 1998). Moreover, African Caribbean and South Asian workers often received differing rates of pay with the tacit agreement of trade unions (Fryer 1992, Ramdin 1987). The 'disposable' and mobile workforce, both past and present, has fulfilled the needs of the capitalist Western States. Globally these mobile workforces are almost exclusively people of 'colour' who make a usually unacknowledged contribution to the prosperity and growth of the nation. Simultaneously the presence of this mobile workforce, is often regarded as problematic and a threat to the stability of the particular society in question. The transatlantic slave trade provided the economic growth required to sustain the rapid period of technological growth and innovation in the industrial revolution in Britain. Similarly the most powerful economic nation in the world, the United States, owes its prosperity to the mass use of 'free' slave labour. The contribution of these migrant communities to economic growth and prosperity in the west is enormous and globally a common thread is that the migrant workforce is exploited and oppressed. Many examples of this type of so-called 'disposable workforce' exist today e.g. migrant Mexican farm workers in the U.S., the recent employment of Philipino nurses in Britain as a short term measure to nursing shortages.

Whilst the British government recognised the need for an immigrant workforce, the context in which this occurred is important when considering the health status of African Caribbean population today, as economic and social status are major determinants of health. Indeed, the economic status of African Caribbean communities in the UK still impacts on the health experience of African Caribbean communities in the 21st century (Torkington 1991, 1995). Immigration and all that followed is of course a 'lived experience' for elders of the African Caribbean today in Britain.

The issue of immigration in post-war Britain was characterised in the political domain by ambiguity and duplicity (Alibhai-Brown 1999). Considerable political opposition and hostile debate surrounded the new immigrant workforce, fuelling nationalism and notions of 'white' supremacy. The debates focused on the potential social unrest, drain on the welfare state and dilution of 'British culture' and the 'British way of life'. The ensuing legislation and strategies for managing ethnic diversity in Britain in this respect are fundamentally informed by dominant racist ideology.

In 1948, the Empire Windrush docked at Tilbury. Four hundred and ninety-two Jamaicans disembarked, achieving historic status as the first post-war immigrants to Britain (Alibhai-Brown 1999). The 1948 British Nationality Act bestowed on subjects of the former British colonies the right to be recognised in statute to reside in Britain. It was therefore the objective of the British government initiative to facilitate immigration to Britain. The following key events have impacted upon the development of 'race' relations in Britain'.

The rise of the New Right and Conservatism

The 1940/1950's in relation to immigration policy, are described as an era of '*laissez faire*' (Kushnick 1998, Carter *et al.* 2000) market forces demanding the movement of populations to form a mobile and disposable workforce. Carter et al (2000) suggest that the end of this era was signified by the introduction of the first Commonwealth Immigrants Bill in 1962. The years preceding this witnessed the demonstration of increasing antagonism towards immigrant community, notably the 1958 Race Riots in Nottingham and North Kensington (Alibhai-Brown

1999). The early 1960's heralded a firm commitment to immigration control by the Conservative party, followed by policies of integration as a result of actual challenges created by immigration and imagined potential problems. Much of the debate focused on threats to the British culture and British way of life, ignoring the lack of homogeneity within these concepts.

A significant event in race relations in Britain was the infamous "Rivers of Blood" speech made by Enoch Powell on 20th April 1968 (Kushnick 1998). Powell warned of the bloodshed and annihilation of the British way of life. The speech was simultaneously applauded by some politicians and the wider populations and disparaged by others. Set within the context of an era of anti-immigration, Powell was not isolated. The preceding 1964 General Election campaigning in the Midlands had shocked immigrant populations when the Conservative campaign included the outrageous and objectionable slogan of *"If you want a nigger for a neighbour, vote Liberal or Labour"*

During the 1960's successive legislative frameworks were introduced to ensure fairer experiences for immigrants; Race Relations Act 1965, Commonwealth Immigrants Act 1968, Race Relations Act 1968 (Alibhai-Brown 1999). However, the Conservative government's pedigree and genealogy in respect of 'race' and immigration was well established by the time of their re-election in 1979. Dominant political ideologies associated with the Conservative party at this time attracted the label of the 'New Right'. The synergistic nature of the New Right's policies and new forms of racism are well documented, notably in tighter controls on immigration and asylum seekers (Alibhai-Brown 1999). The Thatcher years are associated with the growth in cultural racism (Back and Solomos 2000). Cultural racism focuses on the belief in distinct homogeneous and unitary "British Way of Life" and the threats that other ethnic groups posed to this way of life, the emphasis being on language, customs, religion and family. Therefore this way of life would be protected via legislative and policy frameworks, over and above the rights and needs of other groups of people in the United Kingdom with different cultures. It could be argued of course that the New Right's preoccupation with the British way of life is associated with a particular echelon of society and did not for example include the traditions of indigenous white groups such as Travellers or Romany people who hold distinct but entirely British traditions, housing tenure, culture, family and kinship patterns. Furthermore, little regard being afforded to non-white British populations.

Multiculturalism

> *"As the Tebbitt 'cricket test' and the Stephen Lawrence case illustrate, there are those who would retreat from an expansive idea of Britishness into a constricted shell or right-wing English nationalism. My vision of Britain comes not from uniformity but from celebrating diversity, in other words multi-ethnic, multi-national Britain....I understand Britishness as being outward looking open, internationalist with a*

> *commitment to democracy and tolerance*"Gordon Brown, The Guardian, 13th November 1998 (Alibhai-Brown 1999 p.1)

The government has played a role over the past three decades in influencing attitudes towards various ethnic minority communities and the development of integrationist policies (Alibhai-Brown 1999). However, Gerrish et al (1996) state that multiculturalism was developed in response to failed policies of integration through the 1970's/1980's. The premise of multiculturalism is that ethnic diversity should be viewed positively and respect for different ethnic groups encouraged. In terms of policy, celebrations of diversity were often most clearly manifested in the domain of education (Donald & Rattansi 1992). Multiculturalism was much criticised in the 1970/1980's by those engaged in anti-racist struggles (Donald & Rattansi 1992), for the failure to address inequalities, and the wider structural influences of racist ideology. The ongoing commitment by the government to multiculturalism is clearly evidenced in the statement made by Gordon Brown.

Anti-racism

Global migration is now a characteristic of life in the 21st century, either voluntary or enforced. Much of this migration is the result of political, religious or ethnic persecution and cleansing. A unified anti-racist movement does not exist in Britain. Attempts to combat influence of right wing and racist groups and policies have historically in the UK been disparate and characterised by a fragmentary approach. This is in part due to the independence from the state that anti-racist groups in the UK have fostered.

The concepts of anti-racism and multiculturalism as they emerged over recent decades may be viewed as polarised concepts when viewed on a continuum (Gilroy 1995). At the heart of anti-racism in the UK is the concern with structural factors rather then cultural or identity factors. Anti-racism emerged as an alternative to multiculturalism (Gerrish *et al.* 1996). The concern of anti-racism has focused on issues in relation to what we now recognise as institutionalised racism, the inequality of policy directives and direct personal racism. However, in more recent times anti-racism has been discussed within the context of culture (Mac an Ghaill 1999). The radical anti-racist movements of the 1970/80's have were much criticised by the New Right and associations made between anti-racist polices and allegedly ludicrous practices, especially in some of the more left wing London boroughs (Alibhai-Brown 1999). The archetypal narrative relating to this is the spurious claim that school children in some London boroughs were not allowed to recite 'Baa Baa Black Sheep'. Claims of this nature received wide coverage in the tabloid press, all of which helped to contribute to the demise of anti-racism, although the foundation laid by the anti-racist strategies formed an important precursor to the acknowledgement and recognition of institutionalised racism.

Can ethnicity be measured?

The BMJ provide guidelines (McKenzie & Crowcroft 1996) as to how authors in their view should describe their populations, asserting that the terminology adopted should be driven by the hypothesis and variables under investigation. For example, if religion is thought to be an important mediator of suicide levels, reference should be made to practising/non-practising Muslims, Sikhs, Christians etc, which does not necessarily demand reference to ethnic group or origin. McKenzie & Crowcroft (1996) suggest that collection of comprehensive biographical data at the point of data collection e.g. country of birth, country of parent's birth, mother tongue, years in the UK. This approach will be used in this study, although collection of the data need in my view to be carefully balanced with the need to minimise intrusiveness in a relatively new interaction with study participants.

The notion of self-assignation of ethnic groups is becoming widely accepted (Rehman & Walker 1995, Aspinall 1997, 2000) and indeed this is the method by which the 2001 census elicits information. Where populations of individuals have a distinct naming system, researchers have in the past elected to identify those individuals on patient registers or practice profiles, although this approach might be perceived by many as being fundamentally flawed. Selecting potential participants by names associated with ethnicity may have been effective when migrant communities were first generation; in increasingly diverse pluralistic societies, this approach may no longer be useful for sampling in primary care. For example, those of dual ethnic identity may not be identified. Furthermore the heterogeneity of ethnic groups in the UK presents a complex profile. Data from the 1991 census (Fatemilehin 1999) indicate that 26.3% of Black Caribbean men and 14.3% of Black Caribbean women have a white partner; it is likely that this figure has increased over the past decade. Therefore, within African Caribbean communities, ethnic identities and cultural patterns may be less clearly defined; the intersection of social class may be more evident. Those who self-identified themselves as being of mixed descent in the 2001 census (**www.statistics.gov.UK/cci/nugget.asp**) number around 660,000 with the largest group being black Caribbean and white 237,000. This group is largely young with 57.5% being less than sixteen years old. The result is an increasingly complex profile of ethnicity in the UK. Aspinall (2000) asserts the emergence of the new categories in the 2001 census are likely to create new challenges for researchers, as the current and emerging classification systems are widely contested (Aspinall 1997, Bhopal & Donaldson 1998).

A study I previously conducted with African Caribbean young people, facilitated self-assignation of ethnic groups. A number of terms that were not synonymous with state classifications systems were selected by the young people themselves to describe their ethnicity

(Higginbottom 2000a) for example English Jamaican, mixed race Jamaican. This concurs very much with theoretical perspectives pointing out that individuals describe themselves in different ways depending on the context of the question and significantly who is asking the question. Furthermore this self-assignation may change over time, depending on the length of time of migration and the existence of children who may have been born in the host community. How does the young person of dual ethnic identity who looks white, for example describe himself or herself? Additionally, the term 'dual ethnic identity' may be a misnomer, as some individuals may have triple or quadruple ethnic identity, as is the case for some members of my own family who have an African Ghanaian/African Caribbean/English ethnicity. This particular individual has the phenotype of a black person; how can affiliations to white ancestry be claimed within the current political and social context in the UK?

It is important for the researcher to be salient of the fact that perceptions of self-identity including ethnicity can change over time (Rehman & Walker 1995). If individuals were asked ethnicity questions at 5/10/15 year intervals, very different responses might be elicited. Rehman & Walker (1995) concur with McKenzie & Crowcroft (1996), suggesting that a number of criteria might be used to gain a more holistic picture of an individual's identity. For example in addition to the country of birth and self-defined ethnicity, the ethnicity of parents and grandparents could be elicited to provide a more detailed analysis. The sampling frame in this study is that of General Practice profiles/registers. Although many surgeries do not routinely collect data on ethnicity, the majority can identify patients with hypertension. Therefore, those individuals in the practice who are allocated the task of identifying African Caribbean patients mediate the definition of ethnicity in this study. A written criterion is provided (see Appendix 3), but this still does not account for 'gatekeeper effects' that those involved in selection that may consciously or unconsciously use. An attempt to overcome this has been made by arranging to meet with the individual concerned, to discuss the concept of 'African Caribbean' in detail. A recent encounter highlighted this for me. A receptionist of some twenty years in an inner city practice said she had an extensive knowledge of patients in the practice and was very familiar indeed with all the African Caribbean patients in the practice. At the end of the discussions, she asked, "Exactly what country/countries do African Caribbean patients come from?" This has led me to suspect that only those individuals born outside the UK would be included, which might potentially exclude a large number of second generation individuals of African Caribbean origin. Rehman & Walker (1995 p. 494) states, "Even in a relatively large population sample of 5000 respondents, ethnic minorities may number only 300. In an analysis which requires say 12 regions, we would have only 25 ethnic minority respondents in each; further breakdown by a dichotomous variable gives us about 12 in each of those cells." This illustrates the immense difficulty in generating any study sample with black and minority ethnic groups; where ethnic data are limited; the generation of the study sample is even more challenging. Rehman & Walker (1995) suggest a 'snowball sample' where no formal sample exists. This is a strategy I had not intended to use, but difficulties with the generation of the study sample, require I use this approach.

In this particular study, I did at the outset define the study population in writing. This proved to be extremely difficult in the sense that my chosen definition to some extent adopted a reductionist approach in describing people from the Caribbean as 'African Caribbean' as the term is limited in describing the huge diversity and heterogeneity present with this population. Furthermore prior to refinement my initial definition was somewhat imprecise as the original definition also alluded to though do not specify the inclusion of individuals of African descent. I have managed to refine the definition of the study population to a more precise articulation of the characteristics of the study population (see Appendix 3). However, in attempting to engage General Practices in my study, my definition has been challenged by practitioners who have appeared to have both more and less insight into the issues than myself. This has forced to me to clarify my own thinking and articulation of the study population, so in this sense challenges and questions have been fruitful in progressing both my ideas and the research process.

How racisms are manifested in Primary Health Care

All health care systems in the world are shaped and determined by the prevailing economic, political and social context. The UK health care system is not different to others in this respect. The preceding paragraphs have mapped out perspectives on 'race' and ethnicity within the UK context. The NHS is an institution that is subject to all the influences described and explored both as an organisation and as a result of the behaviour of individuals employed within the NHS. It is therefore axiomatic that racism, prejudice and discrimination exist in the NHS as manifest in both institutional and personal racism. The primary health care setting is not exempt from these influences. A good example of the marginalisation of Britain's ethnic minority groups in PHC is the lack of monitoring of ethnicity in PHC and therefore the assessment of specific health needs of practice populations and strategic responses to these needs. In this research study, a number of General Practitioners (GP) with a high number of African Caribbean patients have declined to participate in the study, as is their prerogative. However, this dimension does raise questions as to the value some GP's place on this type of research and ultimately the health needs of African Caribbean patients. Health care professionals are not immune or impervious to the pervasive aspects of institutional racism. The global migration of populations as a result of either voluntary or enforced migration is presenting new challenges for all PHC professionals in meeting the distinct needs of diverse populations, many of whom are psychologically traumatised. This later point is evidenced in this research as PHC staff have emphasised during the conduct of this research the difficulties they face in meeting these needs.

Summary

This chapter has reviewed and presented a critical analysis of historical and contemporary understandings of 'race' and ethnicity in order to contextualise the findings of the study presented later in the chapter. The chapter links to the previous chapter which considered the motivations and precursors to migration that African Caribbean people experience, the prevalence of hypertension in African Caribbean populations and the possible associations between Transatlantic Slave Trade and the contemporary health status of African Caribbean people in England. In this chapter, the concepts of old and new forms of racism including institutional racism are mapped out and critically evaluated, as will be demonstrated in later chapters these issues impact upon the lived experienced of African Caribbean people with hypertension in multiple ways. The analysis undertaken in this chapter is significant in that it provides the opportunity to gain an in-depth understanding of the social, political, cultural and economic aspects of 'race' and ethnicity in contemporary society. In this respect the critical analysis undertaken, provides a theoretical framework in which the experiences of African Caribbean people with hypertension can be located.

This chapter has mapped out the contemporary and historical factors that shape the context of the participants' lives and in this sense impact upon how the health experience of African Caribbean people in the England today. As will become apparent in the findings chapter, the social variation in health status that African Caribbean people experience is not simply a manifestation of cultural difference, but a result of the unique coalescence of factors such as migration, cultural adaptation, structural issues such as prevailing ideologies, the effects of racism and racialisation, the intersection of social class, age, gender and economic issues.

The chapter traces government policy responses to migrant communities in England, from post-war economic policy in Britain to the rise of the New Right and Conservatism, Multiculturalism and Anti-racist providing the opportunity for a critical examination of government responses to the growth of a multi-ethnic, multi-cultural, multi-faith society. An appreciation is therefore gained of the context in which the participants of this study have lived their lives in England. Consideration is also given to how ethnicity is described in health related research. The critical analysis undertaken enables reflection on how societal norms and values concerning 'race' and ethnicity manifest in PHC. This latter point is explored in greater detail in the chapter 4, providing evidence of the influence on care and therapeutic encounters in PHC.

Access to Primary Health Care by ethnic minority communities in England

This chapter explores access to primary health care services by ethnic minority communities in England, mapping out the obstacles and barriers in relation to access. The focus on the broader term of 'ethnic minority' is necessary, as very little contemporary literature exists that focuses expressly on African Caribbean communities and access to PHC. The rationale for this chapter is based on the opinion that it is imperative that the experience of African Caribbean participants with hypertension in this study be viewed within the broader context of provision of PHC services and access to PHC. The objective of the chapter is to establish the extent to which obstacles or barriers prevent access to PHC services in England by ethnic minority communities. It is recognised that this focus is broader than the research question in the overall study. This is based on the recognition of the limited amount of literature on access to PHC that specifically focuses on African Caribbean populations. It was therefore decided to focus on ethnic minority groups in general as many groups experience commonality in relation to shared experience of migration, oppression, racism, communication difficulties and marginalisation in the host community (Nazroo 1997, Alexander 1999). It is acknowledged that any gross similarities shared in accessing PHC by ethnic minority communities in England warrant further detailed investigations specifically for each population, in order to impact on policy development.

Primary health care services

PHC services are the first levels of services available to the general public, usually, although not exclusively, located within general practitioners' surgeries and health centres (some individuals, especially transient communities, may use Accident and Emergency Departments as a form of PHC). More recently, newer forms of PHC have emerged such as Walk-In Clinics, Sexual Health Shops and mobile health buses. A range of practitioners, including doctors, community nurses, midwives and health visitors, may deliver PHC.

Ill-health in ethnic minority communities

Ethnic minority communities in England experience inequalities in relation to morbidity and prevalence of disease and dysfunction (Nazroo 1997, DOH 1999a). The vast majority of first generation individuals of ethnic minority origin are economic migrants. However, nearly 50% of the total minority population are now UK-born and recent years have witnessed an increase in the number of individuals who are refugees or asylum seekers (Alibhai-Brown 1998, Bhattacharyya 2002). The intersection of social class (DOH 1999a, Kushnick 1998) further compounds this experience of poor health. Reflecting on this experience, it might be anticipated that because of the greater ill-health that individuals of ethnic minority origin experience, these populations would be more frequent users of PHC and ultimately, through increased referral rates, have greater use of specialised and secondary care services (although the scope of this chapter does not include the latter two dimensions). The issue of need and utilisation is debated in some of the publications reviewed (Smaje & Le Grand 1997, Goddard & Smith 1998), as is the apparent lack of controlling for socio-economic variables in some of the studies that have focused on ethnicity and access to PHC. The chapter presents a complex scenario with variation both within and between various ethnic minority groups, and variation according to geographical location and disease focus or type of intervention.

Research evidence focused on access to primary health care

A list of the research studies reviewed for this chapter with key themes emerging from each research study can be found in Appendix 4. A major failing of all but two of the studies was the lack of a fully defined and described study population. This is particularly important when investigating ethnic minority communities, as there is wide variation between terminologies adopted to describe ethnic minority communities. Additionally the communities themselves may use very different terminology to researchers. Two studies facilitated the self-assignation of ethnicity; this is an acknowledged gold standard in research involving ethnic minority communities (Nazroo 1997), although additional biographical information is helpful in order to provide a comprehensive approach eg. place of birth, length of migration, religion, language and socio-economic details (Smaje 1995). Some journals, for example BMJ, do give authors explicit guidance in relation to describing ethnic communities (McKenzie & Crowcroft 1996). One study spuriously used the terms 'black' and 'white'; these terms do not necessarily denote ethnicity, or the diverse cultures and traditions minority ethnic communities in England hold. Whilst the terms black and white are crude, they do at some level denote ethnicity. However, the use of these terms raises questions as to how those individuals who hold dual, triple, or quadruple ethnic origin are classified by researchers and authors and the possible failure to recognise cultural diversity within ethnic groups.

Key themes in the literature

The research evidence reviewed on access to PHC by ethnic minority communities can be grouped in to key themes emerging from this evidence.

- *Access to PHC*
- *Language/Communication*
- *Inequalities*
- *Discrimination/Racism*
- *Cultural issues/clash*
- *Practitioner's knowledge*
- *Patient knowledge of services*

Access to PHC

This topic formed a core category as most studies either adopted this concept as a focus of the research question or secondary question (Chaturvedi *et al.* 1997, Smaje 1998, Smaje & Le Grand 1997, Farooqi *et al.* 2000, Free *et al.* 1999, Goddard & Smith 1998, Pui-Ling Li *et al.* 1999). A number of studies investigated access to PHC for ethnic minority communities with a specific disease focus e.g. mental health and alcohol addiction (Commander *et al.* 1997, Commander *et al.* 1999), diabetes (Stewart & Rao 2000) and coronary heart disease (Farooqi *et al.* 1997) see (Appendix 4). Consulting patterns vary according to ethnicity (Carr-Hill *et al.* 1996, DOH 1999a). Adults of South Asian origin e.g. Indian, Pakistani, and Bangladeshi consult more frequently and Chinese patients less than the general population.

Language/Communication

Patients and professionals cited language and communication problems as presenting obstacles in obtaining relevant and appropriate PHC (Carr-Hill 1998, Chaturvedi *et al*.1997, Modood *et al.* 1997, Nazroo 1997, Smaje 1998, Pui-Ling LI *et al.*1999). This seems to indicate the need for a more wide-spread use of interpreters in PHC, or the opportunity for new migrants to acquire English language skills, or the provision of bi-lingual health professionals. Pui-Ling Li *et al.* (1999) in their study highlighted how language difficulties can have serious adverse effects; in one example the Chinese partner of an extremely ill man who was experiencing chest pain was told to come to the surgery the next day to be seen by their GP, which left the patient experiencing great pain overnight and in a potentially fatal situation.

Inequalities

A number of studies included a comparative dimension with the indigenous white population (Commander *et al.* 1997, Commander *et al.* 1999, Smaje 1998, Smaje & Le Grand 1997, Modood *et al.* 1997, Nazroo 1997). This enabled the researchers to establish the existence of inequality in relation to access to PHC by minority ethnic communities. Interestingly, the geographical locale of the ethnic minority community further compounded this inequality in access (Goddard & Smith 1998, Smaje 1998) as in many areas the 'inverse care law' applied. Many ethnic minority groups live in inner city areas that tend to have a lower ratio of GPs per head of population than more affluent areas.

Discrimination/Racism

Discrimination and racism were rarely mentioned overtly, in either the literature reviews or findings of the studies reviewed, with the exception of Cooper *et al.* (1998), Chapple & Gattrell (1998) and (Smaje 1998). This is not to say that this factor did not exist within the PHC context; the reverse may be true (Macpherson of Cluny 1999, Ahmad 1993). What is interesting is that two of the papers (Chapple & Gattrell 1998 and Smaje 1998) that mentioned racism arose from the General Household Survey, which theoretically may be considered to be underpinned by a sociological perspective. This may be significant in the sense that within the discipline of sociology, discourse on race and ethnicity is well developed (Brah & Coombes 2000, Mac an Ghaill 1999, Back & Solomos 2000). It is perhaps true to say that within the domain of PHC and biomedicine in general, the extents to which discrimination and racism exist in service provision have not yet been fully investigated.

Cultural issues/clash & Practitioner's knowledge

It is useful to consider these two themes simultaneously, as the potential for cultural clash in health care interaction is inextricably linked to the knowledge that practitioners have of the communities they serve. One study (Commander *et al.* 1997), reported the issue of cultural clash specifically in relation to mental health and the over-representation of African Caribbean young men in acute mental health institutions, despite the under-utilisation of PHC. Another study (Pui-Ling Li *et al.* 1999) reported this issue as arising from different orientations towards health, illness and medicine. Within the Chinese community, health is an ongoing individual responsibility in terms of maintenance and good health. In contrast, the focus within Western medicine tends to occur on episodic periods of ill health. Similarly, a study focused on South Asian populations (Chaturvedi *et al.* 1998) concluded that cultural clash occurs as origins in socialisation processes. South Asian communities may be orientated and imbued with different models of medicine, as a result of socialisation.

Patient knowledge of services

Patient knowledge of services was reported in two studies (Commander *et al.* 1997), Commander *et al.* 1999) although it is worthy of note that in this particular study, the focus was on specialist services for alcohol addiction, rather than routine PHC services. Patient knowledge was also highlighted by Free *et al.* (2000) to be strongly linked to language barriers and social isolation that the South Vietnamese community experience in London.

Review of Department of Health (DOH) Website and 'Grey' Literature

In order to view the studies on access to PHC by ethnic minority populations, contextually within current policy directives, a review of the DOH website revealed strategic policy directives and documents within the specified time frame (1996 – Jan 2002). (See Appendix 5). The documents and strategies identified are those that expressly focus on ethnic minority health and primary care issues, as opposed to general policy directives. Thirteen policy documents and directives were identified. Additionally, this search uncovered 'grey literature', for example, the 1999 Health Survey for England that focuses on Black Caribbean, Indian, Pakistani, Bangladeshi, Chinese, and Irish communities (both adults and children), this is a comprehensive survey, which includes a chapter on GP consultations. The findings in this study indicate that consultation rates in a two week period were 22% for Bangladeshi men, followed by Indian, Pakistani, and Black Caribbean men (15 – 17%), Irish men (10%) and Chinese men (8%), and compared with the general population (12%). These data were further standardised by age, resulting in South Asian and Black Caribbean men having the highest consultation rates. Similarly consultations rates were highest among Black Caribbean and South Asian women (21% to 24%). Although this report comprehensively maps out consultation rates, it does not provide information about barriers or obstacles experienced in access to services. It is worthy of note, that in relation to high blood pressure that Black Caribbean men were the most likely to receive treatment for their blood pressure. A systematic review of ethnicity and health service access in London was also identified, however in this review PHC is a small component (Atkinson *et al.*2001).

Discussion

Whilst it is evident that the recent past is characterised by a growth in policy documents and directives (Appendix 5), this is not supported by a matched growth in research, particularly in the field of PHC. Whilst the focus of these studies does bear some resemblance to the evidence base in relation to mortality and morbidity that exists in black and minority ethnic communities, the paucity of studies is striking, given the current policy frameworks. The literature review conducted demonstrates that research into access to PHC services is somewhat fragmentary, although it bears some relationship to the current policy agenda and identified need. Studies that do exist are focused on care pathways from primary care through secondary care and specialist services. The domain of PHC in the National Health Service in England is central to health policy and service delivery, therefore access to PHC warrants further focused investigation.

Most, but not all the studies, lack a specific focus on identified communities or ethnic groups, and consist largely of population surveys focused on the total minority population. This approach does not necessarily give in-depth information concerning barriers or obstacles to accessing care. Whilst survey research is valuable, a greater focus on the consumer's perspectives is required particularly for African Caribbean and perhaps a comprehensive review on access to PHC services by all minority populations given the current policy agenda in relation to reduction of social exclusion.

Greater understanding of access, health seeking behaviours and early presentation for diagnosis may only be illuminated with more qualitative studies in the domain. Presently, it would seem that recognition of inequalities is not matched in PHC with a comprehensive evidence base in relation to access and service utilisation. There exists a marked deficit in relation to research in this area. Furthermore, not one single study was identified that focused solely on access to PHC services by African or African Caribbean populations.

The evidence base on access to PHC by ethnic minority populations is far from comprehensive or fully explored (Smaje 1998, Smaje & Le Grand 1997). Studies that are conducted need to take account of need, in relation to utilisation of Primary Health Care services, and the socio-economic variables in analysing findings (Smaje &, Le Grand 1997). A number of studies report conflicting evidence in relation to increased utilisation by ethnic minority communities of GP services (Commander *et al.* 1997, Modood *et al.* 1997, Pui-Ling Li *et al.* 1999). Where the same or decreased use is reported as compared to the white population, account should be taken of need and the greater ill health experienced in ethnic minority communities (Goddard & Smith 1998). Under-utilisation may be an indicator of barriers and inequality e.g. language barriers and the under utilisation of services by Chinese communities (Pui-Ling Li *et al.* 1999, Goddard & Smith 1998). Over utilisation, may demonstrate important positive interventions, and these services may be more user-friendly. Where over-utilisation is reported, this could suggest important opportunities for the identification of effective practice. Some studies report over utilisation of GP services especially by Pakistani and Bangladeshi communities (Modood *et al.* 1997, Nazroo 1997). However, this is not reflected in referral to specialist services and may be an indicator of poor service received (Nazroo 1997). Hence, it can be concluded that establishing and identifying models of good practice may be an important step in developing PHC policy and practice in terms of access to PHC by ethnic minority groups in England.

The Fourth National Survey of Britain's Ethnic Minorities (Nazroo 1997) found that Caribbean people experienced almost 50% higher hypertension rates than whites, however the data did demonstrate a gender variation with a much less marked increase for men, while for Caribbean women the rate was almost 80% higher than in the white population. The 1999 Health Survey for England reports that Caribbean men were reported as being most likely to have received treatment for hypertension indicating that gender differentials in accessing PHC and receiving treatment may exist. Few studies mentioned the social class of the participant, although it is known that most ethnic minority populations who were economic migrants during 1950's and 1960's migrated in order to take up lower paid jobs (Fryer 1992, Ramdin 1997).

What can we learn from this literature?

Lack of referral (to secondary care or specialised services) indicates barriers do exist in care pathways at some level. The nature and form of these barriers require further investigation; this area is sensitive, as it requires a deconstruction of professional practice at an individual practitioner level. Barriers may be related to the cultural congruence of Primary Health Care services. The marginalisation of some ethnic communities, e.g. African Caribbean people, is evidenced in their absence from specific studies; this missing literature highlights to some extent what else needs to be done in terms of improving access to PHC. Most frequently, studies focus on South Asian populations (Chaturvedi *et al.* 1997, Free *et al.* 1999).

Summary

This chapter has critically examined access to PHC by ethnic minority communities in England. The critical appraisal undertaken is significant, as most African Caribbean people with hypertension receive care for their condition in the PHC sector, as will be demonstrated in the findings chapters. In this respect the chapter provides a platform on which to locate the findings of the research undertaken. The chapter builds on the critical appraisals undertaken in chapters 2 and 3, which have more broadly scoped the societal context in which African Caribbean people experience hypertension.

In reviewing the literature on access to PHC by ethnic minority populations, it can be stated that few national studies focused on one ethnic group, and there appears to be a pressing need for more focused studies. A predominance of survey methodology exists; more methodological approaches are needed to investigate this topic more fully. No studies focused exclusively on African Caribbean populations, but such studies are urgently needed, given the greater experience of ill-health and prevalence of chronic diseases such as hypertension. Some studies did highlight gender, age and social class differentials in respect of ethnic minority people accessing PHC. It can be concluded on the basis of the evidence that PHC services need to further develop the provision of culturally congruent services, including the provision of interpreters and practitioners who can provide culturally sensitive care. Over-utilisation or under-utilisation of PHC services may be an indicator of poor interactions and poor service provision.

The focus of the chapter is on access to PHC by all ethnic minority groups in England, given the paucity of literature that expressly considers the experience of African Caribbean communities. However, this dimension serves to highlight the similarity and commonality of experience that many individuals from a variety of ethnic minority groups experience in accessing and receiving PHC, notwithstanding the fact that some variation does exist in use and access to PHC services between and within ethnic minority communities in England.

More audits are needed of the care pathways of ethnic minority patients and their referral to specialist services, clustering on disease foci such as hypertension and diabetes. Patient representatives or advocates may be a useful addition to practice teams, especially in inner cities. The chapter provides evidence of the context of PHC within which African Caribbean people with hypertension experience care and therapeutic encounters, which is important in consideration of the findings of this study.

Chapter 5

Methodology

This chapter explores the history and development of ethnographic research and locates the ethnographic research within the naturalistic (interpretive social science) tradition. An analysis is conducted of two schools of science; positivism and interpretive social science. Selection of the research strategy or methodology in any research study should be determined by the research question (Denzin & Lincoln 1998c). The methodology will exert a powerful influence on the conduct of the research, interpretation of the data and findings. As Denzin & Lincoln (1998p.63) state:

> *"Each qualitative strategy offers a particular and unique perspective that illuminates certain aspects of reality more easily than others and produces a type of results more suited for some applications than others".*

Therefore, a rationale is presented in relation to why the ethnographic approach is most suited to the research questions in this research, following a long and considered period of reflection of a number of qualitative research methodologies. A critique of ethnography is provided and a reflexive account of the process of the research, from the ethnographer's perspective.

What is ethnography?

The term 'ethnography' is derived from the Greek word *ethnikos – ethnos meaning nation* – a picture of people. A dictionary definition provides a straightforward explanation of the term as 'the study of races' (Oxford University Press 1969). Ironically, identification of a fairly superficial definition provides further evidence as to how the contested concept of 'race' (Banton 1998) has become integrated and assimilated to the language of the English-speaking world in a seemingly innocuous context.

There are of course a myriad of more complex and comprehensive definitions of ethnography articulated by social scientists and theorists within the paradigm of qualitative research (van Manen 1995, Fetterman 1998, Hammersley & Atkinson 1995). These will be explored later in more detail. Although there is a lack of consensus as to what exactly constitutes ethnographic research (Atkinson & Hammersley 1998), it is possible to identify key characteristics that all ethnographies share (Atkinson & Hammersley 1998 p.110) in that the ethnography is a mode of social research typified by inductive reasoning and the following concepts:

- Central to the process is the scrutiny of specific social phenomena, as opposed to deductive research that tests out hypotheses
- A propensity to elicit "unstructured" data as opposed to pre-coded data
- The sample size is small and may include just one case
- The product of analysis is narrative description that includes an unequivocal acknowledgement of interpretation of the significance and purpose of human behaviour. There is no quantification of data.

Essentially, ethnographic research is concerned with the study of culture or sub-cultures (Fetterman 1998, Spradley 1979). This includes the overt or explicit dimensions of culture that are known and cognitively salient to members of that culture or subculture and covert or tacit dimensions that may not be articulated by members of the culture or subculture, but nevertheless shared (Fetterman 1998). Therefore the goal is to obtain the most comprehensive and holistic perspective possible (Fetterman 1998). This is dependent on the 'cultural immersion' of the researcher into the culture under investigation; this requires an extensive period of time in the field in a natural setting (Spradley 1979, Fetterman 1998).

In order to explore the ethnographic approach adopted in this research, the following sections will first of all discuss the differences in philosophy and approaches between positivism and naturalism; ethnography is located within the interpretive paradigm (Grbich 1999) that is also referred to as naturalistic inquiry (Lincoln & Guba 1985).

The positivistic and naturalistic traditions

The concepts of positivism (quantitative research) and the naturalistic tradition (qualitative research) form two different paradigms that can be considered oppositional. Denzin & Lincoln (1994) define a paradigm as a group of fundamental beliefs that inform action by the provision of a world-view that will determine how we perceive, interpret and comprehend the world around us. Furthermore, Denzin & Lincoln (1994) state that the concept of a paradigm is underpinned by maxims and precepts that are accepted as truisms, but cannot be proven. Thus, within the world of scientific research different paradigms exist. Within medicine and PHC research and practice, the positivistic paradigm has dominated (Murphy *et al.* 1998). The last two decades has witnessed the emergence of the greater influence of the interpretive paradigm, although this, especially ethnography has been more closely associated with nursing research (Hodgson 2000b, Maggs-Rapport 2001) rather than medical research. As we move into the 21st century, research programmes in PHC increasingly may embrace both paradigms in order to achieve a holistic and complete picture of the phenomena under investigation. Indeed this is desirable (Savage 2000, Murphy *et al.* 1998).

Paradigms attempt to provide explanations for ontological, epistemological and methodological questions. Ontological questions focus on the nature of reality. In this research the ontological question might focus on how the multiple realities are represented for individuals of African Caribbean origin who experience hypertension.

Epistemological questions are concerned with what constitutes knowledge. Major differences between the positivistic and interpretive paradigms exist in relation to what constitutes and forms human knowledge. In positivism the construction of knowledge is informed by laws, statistics and equations. The interpretive tradition is concerned with human experience within the lived social world. For African Caribbean people with hypertension in this study, epistemological questions focus on what constitutes knowledge of high blood pressure in this group and what is the meaning of this knowledge. That is both implicit and explicit knowledge.

Methodological questions focus on the methods and strategies used that shape the forms of inquiry and investigation. Similarly, major differences exist between the positivist and interpretive paradigm in the methods of data collection, principles and axioms that guide the conduct and interpretation of the research. In this research methodological questions focus on what the mechanisms and means are, available for harnessing the knowledge African Caribbean people have of their hypertension and their use of PHC facilities.

Positivism

The philosophical tradition associated with positivism can be traced be to Auguste Comte. The approach may also be termed 'Empirical-Analytical' (Maggs-Rapport 2001). In this tradition only positive facts and that which can be directly observed and measured form the true basis of knowledge and the scientific world. Investigation within the positivist tradition is concerned with the application of laws and testing of hypothesis (Maggs-Rapport 2001). Explanation is provided for phenomena via establishing causal relationships. Criticism of positivism has focused on the paradigm's ability to provide a complete and holistic picture of the phenomena investigated, including the participant's subjective view.

The naturalistic or interpretive tradition

Qualitative research was greatly influenced in its development by the work of sociologists of 'the Chicago School' in the 1920's and 30's (Denzin & Lincoln 1998a). Five distinct phases are identified in the development of qualitative research (Denzin & Lincoln 1998a):

- The traditional 1900-50
- Modernist or Golden era 1950-1970
- Blurred genres 1970-1986
- Crisis of representation 1986-1990
- Post-modern 1990 - present

Interpretism is said to arise from a dissatisfaction of explanations provided by "logical empiricism and instrumental rationality in the 1930's and 1940's (Hodgson 2000a p.2.). It is characterised by an exploration that investigates naturally occurring phenomena within the context of social and ever-changing dynamic social world. Within this tradition is an emphasis on the lived experience of the participants and illumination of the participants' perspective. Therefore contextual information is extremely important and mapping out of the context of inquiry essential in ethnography. The techniques and philosophies that underpin the methodology might broadly be described as social science, embracing disciplines such as nursing, sociology, psychology, anthropology and education (Maggs-Rapport 2001). There is a strong focus on the elicitation of data through observation, interviews, dialogue and documentary evidence (Murphy *et al.* 1998) rather than measurement, quantification and establishing causal relationships or hypothesis testing. There is usually no attempt or indeed desire to make the findings of such studies generalisable to other populations although such research can establish concepts that may have theoretical generalisability (Murphy *et al.* 1998) that is the ability to derive theoretical principles that may have relevance for other populations in other settings.

The Qualitative/Quantitative Debate

Qualitative research (interpretive paradigm) is research that relies on the inductive process; theory or findings are generated and emerge from the data (Miles & Hubermann 1994, Bryman & Burgess 1995). Qualitative research acknowledges the dynamic nature of an ever-changing social world (Denzin & Lincoln 1998a) and furthermore, the influence of the researcher on the research processes, including the responses of participants and interpretation of the data (Atkinson & Hammersley 1998). The purpose is to illuminate the world-view of the participants from their own perspective (Denzin & Lincoln 1998). Conversely, quantitative research relies on the deductive mode of inquiry that seeks to confirm and validate hypotheses. In doing so quantitative research applies the laws of natural science to the human experience (Maggs-Rapport 2001).

Clamp *et al.* (1994) assert that the debates concerning the validity and usefulness of both approaches have origins in the 1960s although many of the debates have far earlier origins in understandings of the growth of human knowledge and science. Silverman (1997), states that the debates of the relative merits of positivism and naturalism continued into the 1970s with arguments often presenting the two paradigms as polar opposites, although Silverman does not subscribe to this viewpoint. Within health related research, the arguments are also inextricably linked to the preference of different professional and discipline groups for either the quantitative or qualitative dimensions of inquiry. Additionally, hierarchies that exist within academia reflect the presence of ideologies within wider society. For example, biomedicine exerts a powerful control not only on illness experience but over other dimensions of everyday life that have become medicalised.

The arguments of previous decades in support of one or the other paradigm of research are further compounded by the gender and class profiles of the different discipline groups in the N.H.S. Hierarchies exist in relation to power and control in the N.H.S. in respect of those who control the research agenda and availability of research funding. It is true to say that during past decades the holders of power were largely white middle class males, who through their professional socialisation had a strong affinity to positivism; this may be one of the reasons why positivism has dominated health related research. In the 21st century, recognition has occurred of the importance of both qualitative and quantitative in pragmatic PHC research has increased. To some extent the change in perception of qualitative research is due to the growth in feminist research literature and discourse (Hill-Collins 1999, hooks 1981, Reinhartz 1992). Feminist researchers have challenged research orthodoxies to such an extent that feminist research is regarded as a methodology in its own right (Reinhartz 1992). The value of qualitative health services research in improving patient care and delivery is now well- established (Savage 2000, Murphy *et al.* 1998).

The origin and history of the ethnographic tradition

Ethnography has strong associations with the discipline of social anthropology. Indeed early ethnographers engaged in the study of 'exotic and strange' peoples often in remote locations (van Manen 1995, Smith 2001) and may have been guilty of objectification of their subjects. The tradition is exemplified in the work of Margaret Mead and others who were closely associated with imperialist and colonialist perspectives (Smith 2001). In this respect, early ethnographers are not well regarded by indigenous peoples of the world (Savage 2000, Smith 2001), as representations of their reality, culture and traditions were most frequently from a eurocentric perspective that located their lived experience as inferior, bizarre and primitive (Smith 2001). Indeed, in recent decades, there has been a fearsome backlash from indigenous people regarding these early studies, most notably from the Maori and Aboriginal populations of

New Zealand and Australia (Ramsden 1995, Smith 2001). Removal and theft by early anthropologists and ethnographers, of art works, religious icons and sacred items has compounded this anger (Smith 2001). Early anthropologists and ethnographers entered their study locations as uninvited 'professional strangers' (Agar 1986).

Whilst ethnographers may have originally studied whole communities or cultures (Fetterman 1998), there is wide agreement that the methodology is eminently suitable for exploring sub-cultures or groups of people within complex, pluralistic societies, as is the case in this research (Spradley 1979, Fetterman 1998, Atkinson & Hammersley 1998).

The inherent power dimensions within the ethnographic tradition most intensely apparent in early ethnographic studies still exist to some extent in contemporary ethnographic research, despite attempts by enlightened researchers to minimise them. This was a salient issue in my thinking during my conduct of the research. To a large extent, I am also an 'uninvited professional stranger' within the African Caribbean community, as no-one in the community asked me to embark on this investigation. However, as a member of a minority ethnic group myself I have endeavoured to ensure that my research is not informed by a eurocentric perspective or colonialist ideals. However, I have to be aware that the secondary socialisation processes I have experienced living in the UK have been very much underpinned by eurocentric perspectives in terms of my education and professional socialisation as a nurse, midwife, health visitor and researcher.

Ethnography in qualitative research

The term 'ethnography' is frequently used interchangeably with the term qualitative research. In part, this may be due to a lack of a shared definition as to what exactly constitutes ethnography (Savage 2000, Hammersley & Atkinson 1995). Savage (2000) states that the term ethnography can apply to both the methodology and the written account of the research undertaken. The following paragraphs map out why an ethnographic approach was selected as the most appropriate methodology to answer the research questions in this study.

Spradley (1980) asserts that "ethnography is the work of describing culture"; this very broad definition is preceded by a longstanding debate of exactly what constitutes ethnography. Hammersley & Atkinson (1995) have called for plasticity in ethnographic research that is fluidity of boundary within the wider paradigm of qualitative research. Muecke (1994) asserts that there is no single form of type of ethnography. Furthermore, Boyle (1994 p.182) suggests "the style and method of ethnography are a function of the ethnographer who brings her or his own scientific traditions, training and socialisation to the research project". Additionally, through discussion with academic and health colleagues, it appears that there are diverse understandings and interpretations of what constitutes ethnography and ethnographic research in practice and different academic disciplines.

It is acknowledged that a classical or pure ethnography demands the inclusion of participant observation as an important method of data collection. However, a number of published studies exist that draw on ethnographic tradition but do not necessarily use participant observation. Hudelson *et al.* (1995) describe their design as 'focused ethnography'; this study uses a number of diverse data collection tools including hypothetical illness scenarios that have some similarity to the structured vignettes used in this study. The focused ethnographic approach has been used specifically to explore symptom recognition, diagnosis, perceptions of illness (Hudelson *et al.* 1995), and all features that appear in this research. (Although, focused ethnography is said to focus on whole communities, rather than subgroups within). Gillibrand & Flynn (2001) term their study 'adjectival ethnography', a term that recognises that the methodology used is not a classic ethnographic study, but primarily uses interviews as data collection.

Streubert & Carpenter (1995) map out six fundamental characteristics of ethnographic research. However three of these could be applied to other qualitative methods

1. Researcher as an instrument
2. Fieldwork
3. The cyclic nature of data collection and analysis
4. The focus on culture
5. Cultural immersion
6. Reflexivity

The six characteristics were very much intended to be part of the research process in this study. This study could be described as a micro or mini ethnography where there is a specific focus on an issue (in this case hypertension and PHC) rather than the total cultural perspective (Streubert & Carpenter 1995). Hammersley & Atkinson (1995), Fetterman (1998) and Savage (2000) have identified the reflexive and contextual elements of ethnography as being pivotal, and the focus on providing understanding of human actions. In addition to recognition that the ethnography is shaped by the nature of the relationship between the researched and the researcher. Ethnographic research is holistic; it may take account of both emic (insider view) and etic (outsider view) perspectives. In this sense, Fetterman (1998) states that ethnography acknowledges the existence of multiple realities.

Genres of ethnography

Four major schools exist within the ethnographic tradition (Muecke 1994) *Classical, systematic, interpretive, critical* each of which represents a specific philosophical view. A number of different forms of ethnography have been described in the literature realist, dramatic, confessional, self and auto-ethnography (van Manen 1995, Savage 2000). It is not possible to explore in depth all the genres in this chapter, however a detailed explanation follows of those that have relevance for this study, and a rationale for the selection of a specific form of ethnography is presented.

Adjectival

Van Maanen (1995 p.10) claims that adjectival ethnography is quite common, especially in the fields of medical ethnography, school ethnography, organisational and family ethnography. Adjectival ethnography differs from the classical genre that uses participant observation as the principal data collection tool, and relies heavily on the ethnographic interview for ethnographic data. An example of a recent adjectival study (Fielding 1993) is the study undertaken by Gillibrand & Flynn (2001) that explored patients' perceptions of the diabetic state, complications and lifestyle. The research questions in the Gillibrand & Flynn (2001) study, very much mirror the research questions in this study as does the focus on a chronic disease state.

A highly regarded ethnography that differs from the classic genre, although not described by the authors as an adjectival study, also relied heavily on ethnographic interviews and documentary analysis; is the study conducted by Strong & Robinson (1990) examining the restructured N.H.S. management culture. The research is termed 'policy ethnography' (Strong & Robinson 1990 p.8). This particular study differs also in the relationship between the researchers and participants. Both researchers had considerable practice and academic knowledge of their domain of inquiry, therefore the distance between the researcher and researched in this ethnography was considerably reduced. It is however worthy of note that the North American tradition of ethnography employs a more rigid definition of ethnography: Morse (1991p.18), in considering an approach that relied heavily on the interview process, states that "*this research could not be considered ethnography*". However Hammersley & Atkinson (1995 p7) in their seminal text state that:

> "*the first requirement of social research according to naturalism then is fidelity to the phenomena under study, not to any particular set of methodological principles, however strongly supported by philosophical arguments*"

Critical ethnography is described as a reconstruction of the original conceptualisations of the methodology into a form that is essentially concerned with empowerment and human emancipation (Manias & Street 2001). The approach focuses on the power dimensions of the research process itself, in addition to the wider structural, socio-political and socio-economic power structures (Hammersley 1998). Manias & Street (2001 p.234), claim that critical ethnography 'provides a useful methodology that facilitates mutual dialogue among participants'. By this, I presume that they refer to all included in the research, including the researchers. However, the power dimensions that exist between the researcher and participants have long been acknowledged, and some doubt is therefore cast on this statement in terms of the level and extent of the reciprocity experienced. Although the approach adopted in this study is not a critical ethnography, it was anticipated that the findings will highlight some of the broader socio-political and socio-economic power structures that impact upon the heath experience of individuals of African Caribbean origin and how these structures impact upon service utilisation.

Strategic ethnographic research

Spradley (1979) identifies 'strategic ethnographic research' as an important form of ethnography. He maps out ten domains of inquiry of which two appear to be synonymous with the stance taken in this research:

- ☐ A health care system that provides adequate care for all members of society
- ☐ Equal rights and opportunities for all classes of citizens, including women, blacks, native Americans, Chicanos, the elderly, children and others.

New and emerging genres of ethnography

A recent article by Johnson *et al.* (2001), 'Arguments for 'British Pluralism' in qualitative health research', argues against the rigid application of methodology and a more flexible approach to the conduct of all forms of qualitative research. The debates presented are interesting, pragmatic and have specific relevance to Health Services Research in the UK and this research.

There are those who argue for the rigid application of methodologies in qualitative research (Maggs-Rapport 2001, Webb 2001) as a means of achieving rigour and robustness in the research process and maintaining the integrity of the methodological approach. In particular, the North American tradition of qualitative research appears to be particularly inflexible (Morse 1991, Leininger 1995). Others, Johnson *et al.* (2001) have argued for a more flexible application of research methodologies and have argued for 'British Pluralism'. This is described as a pragmatic, approach especially in health services research, to bring about tangible findings that can be translated in to concrete benefits and improvements in the care of patients and clients of the British N.H.S. British Pluralism is simultaneously said to maintain rigour via transparency, reflexivity and self-critique by the researcher and others. (Johnson *et al.*2001). This approach however has been termed 'method slurring' (Baker *et al.* 1992) which has a somewhat pejorative tone.

The preceding viewpoints are presented to signify that currently qualitative research in the UK (including ethnography) does not necessarily conform to a classical genre (Johnson *et al.* 2001). Indeed it is likely over the coming decades that new forms or understandings of ethnography will emerge. Wittel (2000) calls for a modernisation of ethnography beyond the recognised boundaries. In particular he calls for a redefinition of the term 'field', suggesting that fieldwork can take place in domains other then geographical locations. Fields might also be viewed as abstract concepts relating to socio-political locations and networks (Wittel 2000). He suggests multi-local or multi-site ethnographies. In an increasingly complex social world, where global migration is a fact of life, ethnographers are no longer necessarily constrained by geographical boundaries, in respect of communities who are diasporic or transnational. Witell's (2000) conceptualisation of modernised ethnographies resonates as a possibility for the future.

Within nursing research, especially in North America, a new genre of ethnography has gained prominency; that of *focused ethnography* (Muecke 1994). Morse (1987) and others make distinctions between focused ethnography and the traditional anthropologic ethnography. Characteristics of focused ethnographies are:

- Conceptual orientation of a single researcher
- The focus on a discrete community or organisation or social phenomena
- Problem focused and context specific
- A limited number of participants
- Participants usually hold specific knowledge
- Episodic participation observation
- Conducted for development in health services

After Muecke 1994

Examples of focused ethnographic studies can be found in the work of Muecke (1994). He goes on further to contrast the anthropologic and health sciences tradition (focused ethnography) in the following table:

Table 1: Contrast between Anthropologic and Health Sciences Ethnography
After Muecke (1994)

Contrast Topic	**Health Sciences** Ethnography	**Anthropologic** Ethnography
Purpose	Improve cultural appropriateness of professional practice	Deepen understanding of a people's social action
Definition of ethnography	As both methods for data collection and as product	As both a conceptual orientation and a production
Primacy of inductive methodology	Variable: inductive methods may be used only after the topic of inquiry has been	Essential, the chief characteristic of of anthropologic ethnography
Conduct of participant observation	At selected events/times only and for a limited period of time	Continuously for a prolonged period usually for at least a year
Language of data collection	The researcher may not know the primary language of the informants; use of language interpreters is common	The researcher uses uses the primary language of the informants; use of interpreters is rare but acceptable in certain situations
Access of informants to the ethnographer	Informants usually live and work separately from the residence and worksite or the ethnographer	Informants have regular immediate access to the ethnographer's life space
The nature of knowing	Contrast and comparison identification of pattern narratives and text	Inference, insight intuition developed as a function of being engaged with the context

Although the research sits very well within the strategic adjectival tradition, it is clear that the ethnography undertaken can also be described as a focused ethnography. Indeed there appears to be a great deal of commonality between Spradley's (1979) conceptualisation of strategic ethnography and the focused ethnographic approach postulated by Muecke (1994) and Morse (1997). However, it is worth noting that a further conceptualisation of focused ethnography exists within the health and social care literature. The focused ethnographic approach developed and advocated by the World Health Organisation is primarily intended to bring about a multi-method rapid appraisal of health problems in developing countries. Hudelson *et al.* (1995) provide a good example of the latter in their study central to which was the acute respiratory infections of children in two rural communities in order to develop relevant health programmes.

My desire to adhere to methodological traditions ensuring rigour and robustness in the research is mediated by the pragmatism that Hammersley & Atkinson (1995) espouse. This is especially important in a research study that is essentially pragmatic health services research that seeks to bring about improvements for patients in primary health care settings.

A critique of ethnography and limitations of the methodology

Much of the criticism of ethnography could be applied to the paradigm of qualitative research in general (Silverman 1997); therefore it may be somewhat spurious to separate out ethnography from other forms of qualitative research in attempting to demonstrate the unique deficits of ethnography. Hammersley & Atkinson (1998) in fact argue that ethnography should not attempt to map out its boundaries in too distinct a fashion, but should be viewed within the broader paradigm of qualitative research within which all the methodologies share characteristics. The fundamental critiques hinge on the perceived polarity between positivism and naturalism as described earlier. Many of the criticisms of ethnography are therefore of an ontological and epistemological nature. In simple terms what constitutes knowledge, what are the forms and representations of knowledge and how might these be captured? Therefore what are the most appropriate tools to elicit realities and representations of knowledge?

Ethnography undoubtedly remains contested (Savage 2000). This is largely because of the ambiguity noted by a number of observers (Atkinson & Hammersley 1998, Savage 2000). It is this very lack of precision and consensus of definition that premises the criticism of ethnography as a scientific endeavour. Therefore, the fluidity of boundaries in ethnographic research (Hammersley & Atkinson 1995) may be regarded as a lack of exactitude and robustness by those who view ethnography from a positivistic perspective that is underpinned by objectivity rather than subjectivity. However, ethnographers (Fetterman 1998, Atkinson & Hammersley 1998) would argue that this approach is holistic and has the ability to capture dimensions of the social world that are covert and tacit that positivistic approaches could not elicit. Within positivism it is only that which is observed via experiment, hypothesis testing and quantified that is valid. Within the social world not all phenomena can be observed in this way.

Reservations have been expressed regarding the credibility and consistency of findings in ethnographic research (Atkinson & Hammersley 1998, Savage 2000). The subjectivity of the approach means that it would be impossible for another researcher to exactly replicate the findings of a previous ethnographic study. This is largely due to the subjective nature of the interpretations made; interpretation being one of the key characteristics of ethnography. The lack of generalisability in ethnographic research has also led to criticisms (Hammersley & Atkinson 1995) regarding the usefulness of the approach and the scientific value of ethnography. Although it is never claimed that ethnographic research will generate findings that are generalisable to other communities or settings, the centrality of culture to ethnographic research makes such a claim absurd.

The rationale for an ethnographic approach in for this research

The research questions in this study are centred on a subculture of an ethnic group: people with hypertension in the African Caribbean community. Spradley (1979 p.iii) states that ethnography is a fundamental tool for understanding 'multicultural' societies of the modern world'. Ethnographic approaches are said to provide a method of accessing health beliefs and behaviours (Savage 2000), as is the case in this research.

The ethnographic approach is therefore eminently suitable to address the research questions in this study, as outlined in the previous sections. A number of other qualitative methodologies were also considered, for example phenomenography (Marton 1994). Phenomenography is closely associated with phenomenology, and may be an extremely useful approach in exploring the meaning of phenomena with individual participants. However, it was concluded that the phenomenographic approach would not enable the vital and pragmatic policy questions around PHC service utilisation to be addressed. In a pragmatic health services research study, it is not possible to apply the principles of a classic grounded theory methodology, as the questions in the research are pre-defined during the process of applying for funding. It may have been possible to utilise a case study approach with a smaller number of participants, but this would present limitations in terms of the development of the theoretical generalisability of the findings.

The term selected to describe this study is *'a focused ethnography which draws on the adjectival tradition'*. This is a synthesis of two approaches described earlier *adjectival ethnography* (Van Maanen 1995, Gillibrand & Flynn 2001) where ethnography primarily relies on interview data and that which Morse (1994) describes as a focused ethnography. The approach adopted also has some affinity with Spradley's (1979 p.15) description of *strategic* *ethnography* in specific domains of applied policy research. It is anticipated that this research will contribute to the development of a specific methodological genre, namely focused adjectival ethnography that will expressly enable the achievement of the goals of pragmatic health services research, underpinned by a rigorous and robust methodology. The approach sits within the British Pluralist tradition of qualitative research (Johnson *et al.* 2001). Synthesis and developments of this nature may strengthen and add further rigour to qualitative methodologies (Johnson *et al.* 2001).

Summary of methodological approach used in this research

- A focused ethnography with draws on the adjectival tradition
- Conceptual orientation of a single researcher
- The focus on a discrete community and social phenomena
- Problem focused and context specific
- A limited number of participants
- Participants hold specific knowledge
- Conducted for development in health services

(adapted from Muecke 1994)

The ethnographer's role

Fetterman (1989), states that the ethnographer is a human instrument. In this respect role of the ethnographer is to eliminate all bias and preconceptions prior to entering the study domain. The extent to which this is truly achievable is open to challenge, as our deeply held, internalised beliefs and values may be impossible to disregard, whether these are subliminal or overt. Fundamental to my role as an ethnographer in this research is my ethnicity, which is different but similar to the participants in this study. I share an understanding and lived experience of what it means to be a member of an ethnic minority group in the 21st century in the UK which to some extent means that I share an emic view of some of the participants' experience. Commonality occurs with the study participants in being a black person, and shared experience of institutionalised and personal racism. However, my cultural background is very different from many participants in the study; as a dual ethnic origin individual with a Ghanaian and English mother, my socialisation and cultural heritage is quite different from many African Caribbean people. This means my role as researcher provides me with a perspective that is etic, as my position within the broader context of society may be very different to the participants. Notions of situational ethnicity (Jenkins 1997) apply not just to participants and the researched but also to researchers. However, others within the academic world may presume and perceive me to have a great deal in common with study participants, as a result of their external definition (Nazroo & Karlsen 2001) of who I am.

This of course does not exempt me from the possibility of an ethnocentric rather than eurocentric perspective of participants, and this possible dimension has remained salient in my cognition during the progression and conduct of the research. Furthermore, participants in the study have often presumed me to be a member the African Caribbean community, which presents ethical considerations as to whether I should share this information if not asked. Frequently, potential participants have made extensive inquires about my personal biography. The latter forming a type of test or examination that I presume I can pass or fail and acts as a 'gate-keeping' process. What is interesting is the extent to which participants might engage in the same investigations if a 'white' researcher conducted this study. Following on from this are questions related to the quality of the data that I elicited and whether the same or differences responses to questions if asked by another person with different characteristics.

The presumption that I am African Caribbean presented further practical problems around language. Many African Caribbean people speak standard English in their everyday lives. Within 'their own' community African Caribbean people may often speak 'patois' and often therefore conduct conversations with me in 'patois'.

Being a 'black' researcher may confer some advantages in terms of participants being more willing to share some dimensions of their experiences with me, but the situation is complex, as relationships are compounded by social class issues, gender and issues of professional socialisation as a nurse, midwife and health visitor.

Early ethnographers were characterised by their difference from the study populations they were investigating. *"Everything is new to a student first entering a different culture"* (Spradley 1979 p.17). Emphasis is placed on gaining entry to the study domain and immersion in the strange and different culture. What is absent from the literature at present is an exploration of the dimensions of ethnographic research when the researcher may be a member of the community or indeed be partially a member of the groups depending on context. What are the rules and principles of ethnographic research when black people conduct research with black people or an HIV positive man with participants who are HIV positive. In these areas, the ethnographic literature is silent. These silences are piercingly loud for those who choose to hear them or are in a position to be sensitive to their sound. There is an assumption within many of the classic texts (Spradley 1979, Hammersley & Atkinson 1995, Fetterman 1998) that the researcher is located socially in a different space to the participants. This of course reflects the power dimensions present within institutions of higher education and hierarchal orders in societies e.g. working class people, black people, people in street gangs do not conduct research.

In many respects my entry into the study domain is eased by my phenotype and the presumptions that participants make about me. However, I am a stranger to the African Caribbean community, as I do not share the history, life-ways, culture and language of the study participants. Furthermore, my previous professional roles have given me some insight and understanding into the physiology and manifestations of hypertension. Some aspects of the ethnography are well known to me, whilst others invisible. My position of ethnographer is less straightforward than if I was a complete stranger to the field. It is the recognition of the influence that the researcher has on the participants and the progression of the research that is essential for reflexivity in ethnography and qualitative research in general.

Reflexivity

Reflexivity is an important dimension of ethnography and qualitative research in general (Hammersley & Atkinson 1995, Denzin & Lincoln 1998). According to Denzin & Lincoln (1998 p278) reflexivity refers to a process by which:

> *"Researchers are obliged to delineate clearly the interactions that have occurred among themselves, their methodologies, and the settings and actors studied"*

Murphy *et al.* (1998p188) state that:

> *"Qualitative research calls for a level of self-conscious reflection upon the ways in which the findings of research are inevitably shaped by the research process itself and analysis which takes such factors into account"*

Reflexivity is therefore focused on making explicit and transparent the effect of the researcher, methodology and tools of data collection on both the process of the research and the research findings. This contrasts with the stance taken in quantitative research where efforts are directed to minimising or eradicating the researcher effect on the research (Murphy *et al.* 1998). Qualitative researchers would question the extent to which the latter is truly achievable, as all research is socially constructed, interpreted and filtered by human beings although adhering to rules and principles, they process and synthesise information in different ways. Furthermore we are imbued with ideologies, values and belief systems that are not necessarily salient in our thinking and may be difficult to deconstruct. Therefore the aim of reflexivity is to acknowledge this influence in a transparent fashion.

According to Denzin and Lincoln, reflexivity is a form of validity termed 'reflexive accounting' in qualitative research. Mays and Popes (2000) are of the view that the reflexivity of the account in qualitative research is one of the major criteria for assessing quality. Therefore it is an essential requirement of all qualitative research.

In respect of the researcher, critical analysis is centred on differences between the researcher and participants, and how this impacts upon progression of the research and interpretation of the findings. In this research some reflexive elements are explored in the preceding section of the Role of the Ethnographer. A reflective diary was constructed and maintained for the whole period of the research, which enabled a critical self-reflection of the research, process and my role within this.

The concept of reflexivity also demands that prior assumptions that the researcher has be made explicit. In this research this dimension is achieved by exploration of my own ethnicity and reflection on my identity and early socialisation. Initially, I perceived myself as a member of the 'black' community to have much in common with participants, but realise now that there are many differences between myself and most of the study participants. For example my primary socialisation was characterised by dual influences both Afrocentric and Eurocentric in the U.K, which is not the same as many of the participants who grew up in the Caribbean. Initially, I had not perceived that it was not possible for me to have a Eurocentric perspective, I have become increasingly aware that via education and professional socialisation, that is largely underpinned by Eurocentrism that I may hold Eurocentric perspectives that may influence the research process. This latter point has been difficult to acknowledge. A further influence on the interpretation of the data is that of professional socialisation that is largely informed by a biomedical perspective; participants are likely to draw a number of different explanations embedded in the African Caribbean culture for their own explanations for health and illness. Murphy *et al.* (1998) highlight the potential of the researcher being blind to data if they fail to - recognise this. Gender and social class exert further influences e.g. a side-effect of hypertensive medication is impotence, some male participants may have been reluctant to share this information with a female researcher.

In summary all these factors merge to form what is described as the "distance" between the researcher and participants (Mays & Pope 2000). However, it may be perceived by funding organisations and others that, those researchers from minority ethnic groups working with minority ethnic study populations are advantaged by their similarity. A shared experience and understanding may exist in respect of commonality of experience, for example personal and institutionalised racism and of a minority ethnic group-membership. Advantage may or may not be bestowed. The situation is complex - to make such an assumption is to racialise this experience both for the researcher and researched, and ignores the heterogeneity in the UK's ethnic minority populations, social class and gender issues. Little had been written on the topic, dissimilarity and similarity could confer both advantages and disadvantages. In this research it is likely for example that some participants have shared with me material they would not share with researchers who are not member of minority ethnic community. On the other hand, social class and gender issues may have restricted access to some domains of enquiry. The situation is complex and is an important area of future research, especially as the ethnic profile of the UK is changing and becoming more complex.

Sampling in qualitative research

The methodology adopted in this research is that of ethnography. In ethnographic research the study sample comprises the community or culture under investigation, whose members demonstrate the specific characteristics required. In this study members of the African Caribbean community who have hypertension in two cities in the United Kingdom form the sampling frame. However, as Murphy *et al.* (1998) state, study samples in qualitative research are not necessarily static, or shaped by the original conceptualisations in the research design, but are recurrent and emergent in nature. Within qualitative research the study sample is identified both at the start of the study and as the emergent research design. It is therefore essential to explore in some detail the principles of sampling in qualitative research, and the systematic approaches to generation of study samples in qualitative research. The following sections will explore the issues described and determine the limitations of the sampling techniques used in qualitative research.

Qualitative research usually employs non-probability sampling techniques (Murphy *et al.* 1998) although not exclusively. This means that it is not usually intended that the findings of a particular study will be generalisable, but that they apply only to the specific population under investigation. The lack of generalisability in qualitative research has led to criticism of the usefulness of qualitative research (Mays & Pope 2000, Giacomini 2001) especially in health services research and health technology assessment (Murphy *et al.* 1998). Furthermore, the lack of transparency in sampling techniques (Coyne 1997) contributes to overall criticisms of qualitative research in relation to the opacity of guiding principles, systematic procedures employed, analytic frameworks used and adherence to methodological frameworks (Mays & Pope 2000).

Coyne (1997) maps out the potential for confusion in the terminology used to describe qualitative research samples. Misuse of concepts and terms may indicate confusion of the theoretical and philosophical underpinnings of methodologies, leading to what has been described earlier as 'method slurring' (Baker *et al.* 1992). Within the qualitative literature (Miles & Hubermann 1994, Coyne 1997, Murphy *et al.* 1998) the most frequently referred to qualitative samples are as follows (It should be noted that this is not an a definitive summary many more exist (see Miles & Hubermann 1994 p. 28):

- Convenience (accidental) samples – participants who are readily available and easy to contact
- Purposive samples – participants who have specific characteristics or features
- Theoretical samples – a component of grounded theory, new or emerging domains to be explored during the process of the research
- Selective sampling- the selection of cases prior to the conduct of research
- Within case sampling – selection of participants within a specific group

Coyne (1997) asserts that the terms purposive and theoretical sampling are frequently used interchangeably and incorrectly. Theoretical sampling is said to be a specific element of the methodology of grounded theory approach (Strauss & Corbin 1998).

Whilst the study sample was broadly defined at the outset of this research (in focusing on African Caribbean with hypertension), the technique of sampling within case (Hammersley & Atkinson 1995 p.45, Miles & Hubermann 1994, Mays & Pope 2000) was also employed in order to ensure that the full range of phenomena are explored. In this case the meaning and consequences of hypertension for a heterogeneous group of African Caribbean people who may use PHC services in a variety of ways. (As discussed, recurrent sampling is emblematic of the emergent nature of qualitative research). Hammersley & Atkinson (1995) focus on three major domains associated with sampling within case – time, people, and context.

People. My intention in this research is to achieve heterogeneity within the sample of African Caribbean people with hypertension. For example, the original research design sought to access participants via General Practice populations. However, not all African Caribbean people with hypertension are frequent users of PHC or may not even be known to their G.P. Therefore, study participants were also sought as the research progressed via community groups and associations. This included groups whose members may be of a younger age group, in order to acquire participants across a wide age range. Specific efforts were also made to contact participants who had not responded to day-time telephone calls, as these participants were likely to be economically active, male and requiring evening appointments for informed consent and data collection.

Time Data collection has taken place over an 18-month period, which provides variation in time and the different influences on participants' experience.

Context The research has taken place in two different geographical locations in a variety of settings, using three different data collection tools.

Achievement of heterogeneity in purposive samples is also termed 'maximum variation sampling' (Patton 1990, Miles & Hubermann 1994) and phenomenal variation (Sandelowski 1998); regardless of the terminology adopted, the goal is to add rigour to possible empirical generalisations that are derived from data arising from the fullest range of participants and settings.

Key Informants

The concept of key informants is an important dimension to most interpretations of ethnographic research (Hammersley & Atkinson 1995, Fetterman 1998, Spradley 1979). Key informants are significant in the generation of study samples (Fetterman 1998) and may act as gatekeepers that enable the ethnographic researcher greater access to the study population. They are also able to reflect upon cultural practices and share this insight with the ethnographer (Roper & Shapira 2000). In this study the key informants have dual function; that of membership of a research consumer advisory group.

Summary

This chapter has served to outline the history and development of ethnographic research and contemporary forms of ethnography, in particular those which are of relevance for health care. A rationale is presented as to why the methodology of ethnography is the most appropriate methodology to answer the research questions postulated. The chapter outlines the methodological stance adopted and theoretical concepts underpinning the research. The chapter explores the positivistic and naturalistic traditions. It goes on to describe the history and tradition of ethnography. Ethnography is defined including the ontological and epistemological underpinnings of the stance adopted in this research and maps out common genres of ethnography used in qualitative research. An exploration of the *focused adjectival ethnographic* approach used in this study is articulated and a comprehensive definition provided.

A critique of ethnography is presented and the limitations of the methodology. In this chapter the role of the ethnographer is critically evaluated the sampling techniques used and the significance of reflexivity in ethnography. The chapter provides evidence of the explicit methodological underpinnings of the research undertaken.

Chapter 6

Methods

This chapter maps out the approach and steps taken in the process of data collection and analysis in this research. The data collection tools are described, and a rationale provided for the selection of the tools. The links between the three data collection tools are described in the process of data collection. The techniques used in the process of analysis are mapped out and the strategies employed to ensure that the data was fully explored. The use of qualitative data analysis software is considered, as are the ethical dimensions of the research. The chapter includes a narrative reflection on the process

Generation of the study sample

The study was conducted in two locations (Sheffield and Nottingham); approval to conduct the study was therefore obtained from the two Local Medical Ethics Committees in the study locations. The process was relatively straightforward with no revisions to the original research protocol.

The qualitative sampling techniques of purposive and snowballing sampling (*cf* chapter 5) are used in the study in order to generate the study sample. Twenty-seven General Practice surgeries in two cities with high populations of African Caribbean patients were contacted by letter, containing a brief explanation of the study. A sample letter was provided for the practices, who them customised the letter to meet their own requirement (Appendix 6). Practices were then contacted via telephone to ascertain their willingness or otherwise to participate in the study. An honorarium of £100.00 was paid to practices that required this. A total of 13 practices in both cities were recruited. Additionally, three practices agreed to participate following initial contact, but later withdrew. One practice stated that it was undergoing a number of major changes and piloting several new initiatives - one participating G.P. retired; one gave no reason.

Thirty-six people of African Caribbean origin participated, all of whom had been diagnosed with hypertension (and were recruited via GP practices, community groups and snowball techniques). A further twelve participants had initially agreed to take part in the study: however four potential participants could not be found at the address given; two potential participants became ill, and two potential participants did not meet the inclusion-exclusion criteria being of West African origin. Four potential participants (in one of the study locations) withdrew following consent and full explanation of the study. None of these four participants provided an explanation as to why, although the partner of one of the four did participate.

The geographical location of the surgeries was generally inner city, although some practices had suburban geographical locations. Each practice was required to identify African Caribbean patients with hypertension in their practice population. This information was retained within the practice and not shared with me in order to maintain patient confidentiality. The letter asked that potential participants contact me directly for more information, using a reply slip and prepaid envelope. This process of identifying African Caribbean patients with hypertension was challenging for all practices, with the exception of one practice that could retrieve this information electronically. All practices could identify hypertensive patients; however, the recording of ethnicity in General Practice was far from systematic (Pringle & Rothera 1996). Therefore, once a list of hypertensive patients had been established, partners and practice nurses were required to identify the ethnicity of the patient in order to send out a prepaid letter to potential participants on my behalf. It was recognised during the process of the research that the utilisation of this approach as the sole generator of the study sample would not necessarily result in the maximum variation of sample required to ensure the topic was fully investigated. There may be many individuals who do not use PHC services, or may be infrequent attendees. It was decided therefore to further expand the study sample to ensure maximum variation by contacting local community groups and associations in the two cities, in order to access a greater variety of participants (see Appendix 7). Variation in participant characteristics was achieved in this study in relation to age, gender, length of diagnosis, economic status and occupation and place of birth e.g. UK and Caribbean participants.

The procedure adopted, requesting that PHC staff identify African Caribbean people in their practice, was potentially fraught with difficulties. Many practices did not routinely profile the ethnicity of their patients. This led to the identification of a number of potential participants who were defined by PHC staff as being of African Caribbean origin who were in fact of African (Nigerian and Ghanaian) origin. A written definition and explanation of the term African Caribbean origin was provided for practices and wherever possible this was also discussed (either by telephone or face to face) with the Practice Manager or Practice Nurse.

Difficulties in observer assignation of ethnicity have been fully explored in earlier sections. However, in this particular study, the study participants were given the opportunity to self-assign ethnicity at the point of informed consent and at data collection. This avoided any potential for wrongly ascribing ethnicity.

Once practices had identified potential participants, the practices distributed on a letter on my behalf explaining the study and signed by the senior GP partner. This included a reply slip. Potential participants contacted me directly using a freepost (no stamp required) envelope. Personal contact was then made by telephone or letter to arrange a mutually convenient time, during which the research was explained in detail and informed consent obtained.

The process of informed consent

'Face to face' contact was established with all participants prior to the data collection in order to obtain the informed consent of the potential participants to participate in the study. Obtaining consent from potential participants required the allocation of at least one hour. Many individuals from the African Caribbean are distrustful of 'official' institutions and some participants enquired as to how the findings of the study would be used in the future. This opportunity for 'face to face' contact facilitated potential participants in 'checking me out', including the opportunity to obtain biographical information from me, and presumably assess my motivations for undertaking the research.

The process of gaining informed consent also became an important dimension of the ethnographic study, as consents were obtained from all but one of the participants in their homes. Many individuals at this time shared with me unsolicited details of their personal lives, relationships and illness experience. This provided me with the opportunity for a form of participant observation and the opportunity to establish rapport in advance of the actual data collection. Individuals may have been less guarded because they were in their own home and the formal process of data collection had not commenced. Establishing rapport is very dependent on communication and the interpersonal skills of the researcher. Engaging participants in general conversations e.g. the weather might, on a superficial analysis, be considered trivial, but conversations of this nature form an important prelude to engagement in the research and help to establish rapport. Potential participants had their own agenda of information they wished to share with me that needed to be addressed before moving on to the topic of the research.

In order to avoid embarrassment and ensure comprehension when individuals had limited literacy levels, the patient information sheet and consent form were verbally communicated to all participants. This was in addition to the provision of written copies. No participant objected to this or said they had previously read the material. It was therefore concluded that this was a worthwhile and useful element of the process of gaining informed consent.

A further sampling technique of *snowballing* (Grbrich 1999, Roper & Shapira 2000) was also used in this study at the point of data collection. Snowball techniques are said to be extremely useful in order to access hard to reach populations (Miles & Hubermann 1994). Therefore, in order to maximise the sampling frame, participants were asked at the time of data collection, focus groups and interviews, to pass on information about the research to individuals they knew with hypertension. Freepost envelopes were supplied in order for potential participants to express interest in becoming involved.

In order to contribute to the maximum phenomena variation of the study sample, local communities groups and associations were contacted by letter (Appendix 8) to establish members' interest in participating in the research. Members of the consumer research advisory group (described later in this chapter) further contributed to the generation of the study sample, by sharing with their social and family networks an introductory letter and free post envelope for interested individuals to respond and register their interest in taking part. In summary, thirty-one participants were recruited via GP practices, and six via community groups and a snowball technique.

The process of data collection and links between the three data collection tools

This research employed three discrete but related phases of data collection. Each data collection stage builds on the previous analysis and findings, enabling a deeper investigation into aspects of the experience of African Caribbean people with hypertension. In ethnographic research this process is known as progressive focusing (Silverman 2000). The methods used are focus group interviews (FGI), semi-structured interviews and vignette interviews.

The FGI established the broader issues of investigation in relation to the research questions. A pilot FGI and one in each of the study locations were conducted, three in total. The findings from the FGI influenced the development of the topic guide for semi-structured interviews that forms the main method of data collection. The final data analysis presented is from the vignette interviews. The vignette interviews are derived from the semi-structured interview data. The vignettes are fictitious; however, the key concepts in the vignettes emerge from the semi-structured interview data and in this sense, they are a conflation of the past-lived experience of several individuals. The vignettes seek to clarify areas of uncertainty in relation to the semi-structured interview findings and provide detailed insights and explanations about these areas (Greenhalgh *et al.* 1998). Themes emerging from each data collection method are analysed and presented (in chapters 7 - 12). Finally, a composite analysis is presented as a coherent narration of the evidence and providing new insights from this research. The three-stage approach used in data collection facilitated an iterative process (Murphy *et al.* 1998) in the conduct of the research, by revisiting themes and phenomena identified in the analysis of the preceding data collection. Furthermore, this approach facilitated data triangulation (Begley 1996) the use of multiple data sources is an important dimension of research that draws upon the ethnographic tradition (Spradley 1979, Fetterman 1998, Hammersley & Atkinson 1995).

Focus Groups

The popularity of focus group interviews (FGI) as a data collection tool has grown in recent years in health related research (Webb & Kevern 2000, Barbour & Kitzinger 1999, Higginbottom 1998). David Morgan (Morgan 2001, personal communication, and FGI workshop) conducted a review of Cinahl in 2000 and identified 433 citations that mentioned FGI and 800 citations via Medline. FGI are compatible with the ethnographic tradition. Hammersley & Atkinson (1995) identify a number of ethnographic studies that have used group interviews e.g. Wood's (1981) study of secondary school children, Pollard's (1985) research with middle school children. Focus groups are also said to be useful in enabling marginalised or vulnerable groups such as minority ethnic communities to have a 'voice', as the vehicle of communication is oral as opposed to written (Kitzinger 1995, Higginbottom 1998). However, the use of FGI is not compatible with all qualitative research methodologies. In particular Webb & Kevern (2000) cautions against the use of FGI in phenomenological research as phenomenology is specifically concerned with the lived experience of an individual, therefore FGI would be an inappropriate data collection tool and a transgression of the underpinning philosophy.

What is a Focus Group Interview?

Krueger (1994 p.6) defines a FGI as:

> *"A carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive and non-threatening environment"*

Krueger's definition appears to allude to the notion that this data collection tool may be useful in enabling the voices of those who are marginalised or oppressed to be heard (Higginbottom 1998). The non-threatening environment to which he refers may be crucial in supporting participants in articulating their views. In this research all the FGI are conducted in local African Caribbean communities, the venue being known to many of the participants. In this respect, the choice of venue is significant in helping to reduce power dimensions between the researcher and research participants.

Strengths and weaknesses of the Focus Group Interview

Kitzinger (1995) asserts that FGI can help to eliminate discrimination against participants who are not literate as reading or written communication is not required as in the case of a questionnaire. The data is derived from the group in their own language and from their conceptualisation of the world. All of these factors are important considerations in this research with the study population of African Caribbean people. Barbour & Kitzinger (1999) are of the view that active engagement by participants is a key characteristic of FGI.

Morgan (1998, 2001) has written extensively on the use of FGI. There are many different approaches and models for using FGI in qualitative research. In this study, the design, conduct and analysis of the FGI is heavily influenced by Morgan's approach. He states that:

> *"Focus groups are a qualitative research tool that relies on group discussions to collect data on a topic determined by the researcher"* (Morgan 2001 no page number given)

According to Morgan (2001), the strength of the FGI is embedded in participant's interactions that enable the revelation of experiences, feelings, and beliefs. The objective is to enable participants to continue a conversation between themselves (as opposed to between the moderator and themselves) that facilitates illumination of consensus or diversity.

Weaknesses include the lack of naturalness that occurs in participant observation and the loss of control that can occur in individual interviews, as participants are in control of the discussion. Morgan (2001) states that the commonly held myth of the over vociferous or vocal participant is rarely encountered, more frequently encountered is the individual who is reluctant to speak.

A number of recent articles have highlighted the limitations of FGI in answering research questions. Cleland & Moffat (2001 p.1121) state that:

> *"focus groups are not the most efficient way of gathering data, when the subject area is complete or participants hold many different and opposing views"*.

Moses *et al.* (2000) point out that in hierarchal communities, such as the rural villages in Uganda where they carried out their FGI; many people are reluctant to challenge the views of elders or more powerful individuals.

How does this critique relate to this study?

The FGI interviews conducted in this research resulted in lively and interactive debates. This debate was conducted in the language of the participants that necessitated the facilitation of the FGI by a co-moderator who was a Patois speaker. However most of the communications in the FGI were in Standard English. Both quiet and vociferous participants were encountered, and the FGI proved to be a successful method of data collection as will be evidenced in later chapters.

The Focus Group Interview Schedule

Whilst the researcher defines the topic area, Morgan (2001) recommends that questions in the topic guide or interview schedule should also facilitate the participants' needs and concerns and may provide important future domains of inquiry. The FGI in this research provides the opportunity for participants to define the major problems concerning hypertension from their own perspective. Morgan (2001) acknowledges that his own approach to the interview schedule or topic guide is heavily influenced by the work of Spradley (1979). He draws on the work of Spradley (1979) largely from his publication "The Ethnographic Interview". Morgan's format for the topic guide is that of a funnel structure moving from broad, less-structured questions (participants' perspectives) to narrow, more structured questions. Morgan (2001) uses Spradley's (1979) concept of the "Grand Tour" questions as icebreakers to the group discussion. This is the approach adopted in this research.

Morgan (2001) identifies a number of moderating styles for FGI.

STYLES OF MODERATING	KEY FACTORS
<u>**Moderator**</u> • Aim to discuss a set of issues • Semi-structured • Questions from researcher • Generates discussion from participants	• Guides a discussion • Middle of the road approach • Concentrates on researchers needs, but some freedom to explore • Active listening
Interviewer • Guided by an agenda • More structured • Focuses participants' viewpoints • Interaction on specific topics • Must stick to topic	• Asks questions receives answers • • More structured
Facilitator • Aim to hear participants viewpoints • Less structured • Works with participants to generate broad ranging discussion • Discussion may focus on unanticipated areas	• Explore themes • Less structured

Table: 2 Moderating Styles (after Morgan 2001)

The moderating style adopted during FGI must be guided by the research topic. In this pragmatic health services research study, the topic area is clearly defined, and outcomes are anticipated by the commissioning body that might directly influence PHC service delivery. It should also provide insights into the meaning and consequences of hypertension for individuals of African Caribbean origin; therefore, the moderator style was selected. This will both facilitate achievement of the research aims and provide the flexibility for participant driven exploration.

Pilot FGI

A pilot FGI was undertaken to ensure that refinements and improvements to the data collection tool could be identified and made prior to the main study (Treece and Treece 1992). In this research the pilot, FGI proved to very useful in identifying some unforeseen problems. The pilot FGI was conducted at a local African Caribbean community centre. A convenience sample of users of the center who were African Caribbean people who had hypertension was established. Although a convenience sample does have limitations in that the range of participants who are African Caribbean people who have hypertension are not represented (Grbich 1999). The advantage of a convenience sample is the rapidity of access to potential participants.

Critical analysis of the pilot FGI data and the moderation of the FGI revealed some deficits in the data collection. The participants of the pilot study were largely older people of African Caribbean origin who spoke Patois as a first language, which resulted in some gaps in the transcript of the pilot FGI. Previous experience of conducting FGI with participants who speak English as a second language (Higginbottom 1998) has revealed that often when participants feel particularly strongly or emotional about their experiences they prefer to use their first language in order to express themselves. A co-moderator was therefore appointed for the FGI in the main study who was a Patois speaker; this is desirable both in terms of the moderation of the groups and the later translation of any of data.

In addition other practical issues were highlighted in relation to the time-consuming nature of collecting biographical details of participants and the provision of refreshments all of which confirmed the need for a co-moderator.

Group composition and size

Some variation exists in the literature in relation to the recommended number of participants in FGI. Macleod Clarke *et al.* (1996) suggest eight participants as the optimum number, Morgan (1998) between four and twelve, whilst Kitzinger (1995) suggest between four and eight. Decisions regarding the number of participants are also grounded in previous experience of conducting FGI in other research projects. Ten individuals were sought in order to build in a contingency for non-attendance, illness etc. Larger groups can also facilitate the elicitation of useful data, however past experience indicates that depth and quality of data is more likely to be achieved with a smaller number of participants.

Homogeneity in the FGI is essential in the sense that participants have shared an understanding of experience of phenomena' (*in this case African Caribbean people with hypertension*). However some heterogeneity is desirable in order to gain the maximum variation study sample described earlier in chapter 5.

A number of major challenges were presented in recruiting to the FGI. During initial contact with participants to share details of the study, participants were provided with a choice of participation in the FGI or interviews. Most participants preferred to be interviewed, which presented some problems for the design of the study that was dependent on the conduct of the FGI to map out the broad areas of investigation. It was originally planned to conduct four FGI; however because of the difficulties of recruitment it was only possible to conduct three FGI. A fourth FGI interview was planned on two separate occasions but the withdrawal of participants due to illness and bereavement meant they had to be cancelled.

Facilitation of Focus Group Interviews

Focus Group 1

The first FGI was conducted at a venue known to all the participants, The Sheffield and District African Caribbean Association's (SADACA) Elderly Persons' Support Centre (EPSU). Previously I had met all the participants in their own homes, when obtaining informed consent. This dimension proved to be extremely useful, as I had already established a rapport with the participants.

I arranged a taxi to collect participants from their homes not only to maximise attendance, but also because I had recruited just 6 participants for the FGI, leaving me no contingency for non-participation or illness. The reason for conducting the FGI without further recruitment was that a number of the participants had been recruited several weeks prior to the date of the FGI. I felt that participants might begin to withdraw or interest may decline if the FGI were to be conducted at a later date and that it was unethical to keep participants waiting.

As discussed the pilot study FGI revealed the need for a co-moderator of Caribbean origin who understood and spoke Patois. The co-moderator used for both FGI was identified via a list of interpreters held by Sheffield Health Authority. A preliminary meeting was held with the co-moderator to introduce the study and establish a shared understanding of the role of the co-moderators. This preliminary discussion was supported by written information and literature regarding co-moderation. Following the FGI the co-moderator interpreted Patois words occasionally used by participants in the FGI e.g. "*boxed his toe,*" meaning he damaged or injured his toe. FGI participants were informed at the start of the interview that the co-moderator was a Patois speaker to ensure that participants were able to express themselves as freely as possible without the constraint of being required to speak Standard English. While the knowledge that the co-moderator was a Patois may have created a degree of reassurance, all the participants largely articulated their view in Standard English.

The venue was a small room in the EPSU centre, with comfortable chairs and the necessary privacy. Light refreshments and fruit were provided for the participants. In order to minimise the loss of data I used two tape-recorders to tape-record the FGI, the fact that all interviews were tape-recorded was discussed with participants when gaining informed consent to participate in the study. This information also appeared on the participant information sheet. Following initial introductions, I obtained biographical details from each participant illustrated in Table 3 following. The FGI lasted approximately 1 hour 45 minutes.

Focus Group 2

This FGI was held in the African Caribbean Association community centre of the second study location, the venue being well known to African Caribbean people in the locality. The venue hosted a library and a number of organised activities. It was centrally located. The building was a converted Victorian school; the rooms were rather large, but well furnished and carpeted. I was accompanied by the co-moderator. The co-moderator was able to assist with housekeeping such as the organisation of the room and refreshments. None of the participants were known to each other, so informal introductions occurred at the commencement of the FGI. One participant was late, due to the late arrival of her taxi. All six participants were transported by taxi to the venue, 5 people participated in the FGI. This was a very interactive and discursive group that lasted 1 hour 45 minutes. The participants appeared reluctant to leave at the end of the discussion. All the participants stated that they enjoyed the discussion group and would welcome further involvement in the study if required. The biographical details of each participant can be found below in Table 4 following. A couple of the individuals in the group were less vociferous than others although good group dynamics were established. Areas of consensus and divergence are identified in the findings chapter 7.

Table: 3 Focus Group 1 Participant biographical details

	Participant (P) 1	P2	P3	P4	P5
Age	77	75	64	60	69
Gender	F	M	M	F	F
Occupation	Housewife	Retired Arc Welder	Retired (due to ill-health) Lorry driver	Retired Nurse	Pensioner
Place of birth	Dominica	Jamaica	Jamaica	Jamaica	Jamaica
Place of birth of parents	Dominica	Jamaica	Jamaica	Jamaica	Jamaica
Place of birth of grandparents	Dominica	Jamaica	Jamaica	Jamaica	Jamaica
Years of residence in UK	44	36	47	38	26
Self-assigned ethnicity	West Indian (British)	Black British	Jamaican	British	West Indian
Religion	Roman Catholic	Anglican	None	Methodist	New Testament Church of God
Other illnesses	Angina	Diabetes	None	None	None
Reasons for migration	To join husband who was residing in the UK	To acquire more stable way of life	Acquire a better way of life	To join husband	In search of work

Table: 4 Focus Group 2 - Biographical Details of Participants

	Participant (P) 1	**P2**	**P3**	**P4**	**P5**
Age	65	70	64	76	70
Gender	F	M	F	F	F
Occupation	Retired	Retired	Retired	Retired	Carer
Place of birth	Jamaica	Jamaica	Jamaica	Jamaica	Jamaica
Parent place of birth	Jamaica	Jamaica	Jamaica	Jamaica	Jamaica
Grandparents place of birth	Jamaica	Jamaica	Jamaica	Jamaica	Jamaica
Years of residence in UK	45	40	41	46	41
Self-assigned	Black British	African Caribbean	Caribbean	Black British	Black West Indian
Religion	Pentecostal	-	Pilgrim Holiness	Baptist	Baptist
Other illnesses	-	Diabetes Cardiac by-pass	Angina	Diabetes	-
Reasons for migration	I like travelling and all my friends leaving for England, also my Dad was here	Sister came, Mother insisted 4 brothers follow her to look after her	To have safe delivery of my first child	Queen came to Jamaica in 1948/1949 Extended an invitation to citizens to come to England	Came with parents

It became clear from the biographical details of the participants in the FGI that older people were more willing to take part in the study. This may be because they have more spare time or are more likely to suffer from hypertension because they are older. In the light of this observation, recruitment for the interview data collection focussed on the need to ensure the engagement in the study of economically active individuals across a wider age range.

Ethnographic Interviews

Cultural analysis is said to be the 'raison d'etre' of ethnographic research (Hodgson 2000a). This analysis is dependent on the data collection tools that characterise ethnographic research; participant observation and interviews (Hammersley & Atkinson 1995, Spradley 1979, Fetterman 1998) eliciting high quality data to enable a deeper understanding of the topic under investigation. As stated earlier in the chapter 5, the research in this thesis draws heavily upon the ethnographic tradition, but is adjectival in approach (van Manen 1995) as there was greater reliance on interviews rather than participant observation as a data collection tool. Fetterman 1998 p.37 states that:

> *"the interview is the ethnographer's most important data gathering technique".*

However, other theorists may argue that a classical ethnography is characterised by participant observation.

Within qualitative research, several types of interview predominate; structured, semi-structured and unstructured interviews (Murphy *et al.* 1998, Fetterman 1998), although Murphy *et al.* point out that it may be a misnomer to call any interview unstructured, as usually researchers conduct an interview with a specified goal or objective. All have associated strengths and weaknesses. In this study semi-structured interviews were selected, a rationale for this selection and critique of the method will follow. However, firstly it is worth considering the perspectives on interviewing within the ethnographic literature. In addition to the commonly used terms of structured, semi-structured and unstructured, ethnographers make the distinction between informal interviews (Fetterman 1989, Roper & Shapira 2000) and formal interviews. Informal interviews are often associated with participant observation in that once a phenomena or event is observed (Roper & Shapira 2000) the ethnographer may immediately following an event ask in an informal or casual manner for further information about the event, similar to conversations within everyday social settings. Formal interviews on the other hand are described as using:

> *"a systematic approach to obtain desired information from participants"* (Roper & Shapira 2000 p.75).

Interview Type	Characteristics
Structured interviews	Administration of a questionnaire Closed questions No opportunity for exploration of responses Deals mainly with the researcher's agenda Attempts to standardise responses
Semi-structured	Loosely defined structure Able to explore responses in more detail Consists of more open-ended questions
Depth interviews	Cannot be called unstructured as research has goals and aims Focus on one or two issues Participant is more able to influence the agenda

Table: 4 Types of qualitative interviews (after Mays & Pope 2000)

It is clear from the above typology that the selection of an interview type must be guided towards the aims, objectives and purpose of the research.

Within ethnographic research Spradley (1979) has given further consideration to the type of question being asked. He suggests commencing with the 'survey or grand tour' question, which he recommends will enable the ethnographer to paint a broad picture of the phenomena. Spradley's (1979) approach to ethnographic research includes a sequenced approach to both research design and questioning using specified steps and a detailed protocol. Mays and Pope (2000 p.14) provide a typology of qualitative interview questions.

Mays and Pope (2000) state that qualitative researchers need to consider how they are perceived by interviewees in relation to personal characteristics, as this can have a profound effect on the interview process. For example, participants knew that I was a health professional. Participants may therefore have been more reluctant to share aspects of their non-concordance; therefore greater probing and explorations may have been required for some participants. Some participants may have held initial reservations, but I felt I was able to establish a good rapport with most participants who freely expressed their views. In any interview interaction, the creation of a confidential and safe environment for the sharing of information is paramount. I believe this was achieved in this study. To some extent this is dependent on the interpersonal and communication skills of the researcher and the ability to establish rapport within a relatively short time frame.

Strengths and weaknesses of qualitative interviews

The qualitative interview offers the potential to obtain a view of the phenomena under investigation from the 'actors' or 'insider' perspective (Kvale 1996) but requires considerable skill on the part on the interviewer (Mays & Pope 2000). Within ethnographic research an important prerequisite appears to be the acknowledgment by the interviewer of personal assumptions and biases regarding the person or people being interviewed. In this study my reflective narrative assisted in making explicit these assumptions, as did a personal reflection on my own ethnicity.

Essentially an interview is a social encounter (Murphy *et al.* 1998), and in this respect, interviewers are likely to respond on an emotional as well as cognitive level to information that is shared. This may be subliminal or salient in the interviewer's thinking; in any event the process of the interview is shaped by the contribution of both the interviewee and interviewer. There does exist however, the possibility that the notion of 'social desirability' may enter the process that is the participant's desire to be viewed positively by the interviewer. Grbich (1999) regards the presentation of self as paramount and cautions interviewers to give consideration to such issues as acceptable (to the study population) forms of dress. For example in this study, as I had grown up in ethnically diverse communities, I was aware that many African Caribbean elders in interview situations would expect the interviewer to be smartly as opposed to casually dressed.

The strength of the qualitative interview is located within the opportunity for the participant to define the phenomena under investigation from their own perspective (Silverman 2000). The depth and semi-structured interview offer the potential to explore and clarify the participant's responses. There are however some practical drawbacks such as the time-consuming nature and subsequent cost of qualitative interviews. Other drawbacks arise from the notion of an interview as a social encounter; it may be that either the interviewee or interviewer, for a variety of reasons does not interact well. The subsequent data analysis of interview data is also extremely time-consuming.

The rationale for selecting semi-structured interviews in this study as opposed to unstructured interviews is informed by the study design and preliminary data collection in the FGI that mapped out the broad areas for further in-depth exploration. Therefore, it was essential to include these topics in the interview topic guide and an unstructured interview may not have facilitated this. In addition, this study was commissioned and supported financially by the NHS Executive via a National Primary Care Award. In this respect, the funding body had certain expectations of the study as a pragmatic health services research to have a direct benefit for patients and primary health care services. Therefore the topic needed to reflect the research aims and questions.

Interviews in this research

The interviews in this research build upon the data elicited in the FGI interviews in providing the opportunity for greater and more in-depth of exploration of the phenomena identified in the first stage of data collection. Each participant was contacted initially by telephone, to arrange an appointment to discuss the study in more detail and obtain informed consent to participation. This proved to be an extremely useful dimension of the research, as it was possible to establish a level of rapport with participants before the actual interview. At this time biographical details were collected (see tables 6 & 7 following).

Interview	Pseudonym	Place of birth	Parents place of birth	Grandparents place of birth	Religion	Self-assigned ethnicity	Language	Family member with hypertension	Other Illnesses
1	Wilton	Jamaica	Jamaica	Jamaica	None	Jamaican	Broken English (participants words)	-	Arthritis
2	Patsy	"		"	Anglican	Jamaican/British	English	-	-
3	Jerome	"	"	"	Church of England (C/E)	Afro-Caribbean	"	-	Cardio-myopathy
4	Darius	"	"	Paternal grandfather of German Jewish origin Grandmother Jamaica	None	Jamaican	"	-	-
5	Petra	"	"	Jamaica	Church of God of Prophecy	Jamaican	"	-	-
6	Edgar	"	"	"	Catholic	Jamaican	"	-	-
7	Jorge	"	"	"	Christian	Jamaican	Patois/English	-	Diabetes
8	Clifford	"	"	"	Baptist	Jamaican	English	-	-
9	Delbert	"	"	"	Baptist	Jamaican	"	-	Diabetes
10	Wesley	"	"	"	Christian	Afro-Caribbean	"	-	
11	Bill	"	"	"	Baptist	Jamaican	English/Patois	Brother/sister	Diabetes bladder problems
12	Lynn	"	"	"	None	Jamaican	English	Mum, husband & sister	
13	Patrice	"	"	"	Baptist	Jamaican	"	Mum, brother & sister	Diabetes Arthritis
14	Barbette	"	"	"	Pentecostal	Jamaican	"	Daughters x 2	Asthma Bronchitis Nervous breakdown
15	Wilbert	"	"	"	Anglican	Jamaican	"	Wife	Bronchitis
16	Carlene	Wolverhampton	"	"	Seventh Day Adventist	Black British	"	Mum, Dad & sister	Internal thrombosis Asthma Varicose veins
17	Loretta	Jamaica	"	"	Methodist	Jamaican	English/Patois	Brothers x 3	Angina
18	Aleeya	Leeds	"	"	C/E	African Caribbean	"	Mum	Anaemia
19	Hyacinth	Jamaica	"	"	Seventh Day Adventist	Black British	English/Patois	-	
20	Carmel	"	"	"	Pentecostal	African Caribbean	English	Daughter	Skin problems & gallstones
21	Carlton	"	"	"	C/E	African Caribbean	Patois	Mum, Granny & two aunts	

Table: 6 Illustrating biographical details of semi-structured interview participants

Interview	Reasons for migration to England	Years of residency in England	Gender	Occupation
1	More work in England post-war and workers wanted from the commonwealth	46	M	Retired steelworker
2	Was younger and wished to travel and explore	44	F	Retired cutlery worker
3	Parents already here, wanted better schooling	47	M	Retired (early ill-health) engineer
4	Everyone came, if you could afford your fare. Jamaica a nice island but only had sun. To find work as a young man, life was very hard in Jamaica	46	M	Retired painter and decorator
5	A better life and brother in England	43	F	Retired catering assistant
6	Traditional, a friend was already here. Worked at St.Andrews University was encouraged by academic staff, Professor and Dr.	41	M	Retired joiner
7	Looking for work, cousin already here	47	M	Retired grinder
8	Travelled to America, Dad was already working on British Rail, came to join him	39	M	Caretaker
9	To find work and earn money	44	M	Retired steelworker
10	With parents	42	M	Part-time student
11	Cousin was here, to better oneself	41	M	Retired early (ill health) building concrete finisher
12	Dad came and returned to Jamaica, Aunty came to England, I wanted to travel	33	F	-
13	First husband encouraged interviewee to come to England	46	F	Retired factory worker
14	Uncle came intended to visit for 5 years. Interviewees husband died in Jamaica	41	F	Retired cook
15	Better life, earn more money	41	M	Driver
16	Not applicable	UK born	F	Community care worker
17	Cousin came to do nursing, brother in Leeds, interviewee hope to do nursing	42	F	Retired shop assistant
18	Not applicable	UK born	F	Midwife
19	Got married	20	F	Residential social worker
20	Fiance sent for her then had 6 children	45	F	Retired hospital domestic
21	Came to join parents aged 8 years	42	M	Youth worker

Table: 7 Reasons for migration, age, gender and occupation

Shortly before the interviews, participants were contacted by telephone to ascertain whether they were still able to participate in the interviews. Each interview was taped-recorded twice to minimise the loss of data. Each interview lasted between 50 minutes and 2 hours. Participants varied in respect of vociferousness, notably some older participants were somewhat tentative in the views they expressed, whereas a number of the younger participants were extremely open and candid.

The interview topic guide in this research was developed from the emergent findings of the focus group interviews, in order to investigate in depth the issues identified. Initially an interview schedule was developed: this proved to be unsatisfactory in that the interview schedule contained questions that limited the exploration of key issues and constrained flexibility. The topic guide proved to be more useful in enabling me as the researcher to check that key points were covered, whilst simultaneously facilitating flexibility to respond to the participant's agenda within the confines of the research.

Vignette Interviews

The vignettes in this study are in part derived from work undertaken by Greenhalgh *et al.* (1998) in developing a qualitative data technique entitled 'structured vignettes'. This data collection method was used by Greenhalgh *et al.* (1998) to explore the experiences of diabetic patients in Tower Hamlets, London. Although, the use of vignettes in qualitative research is well documented, Miles & Hubermann (1994 p81) describe a vignette as:

> *"a focused description of a series of events taken to be representative, typical, or emblematic in the case you are doing. It has a narrative, story like structure that preserves the chronological flow and that normally is limited to a brief span to one or a few key actors, to a bounded space or to all three"*

In this study the vignettes are derived from the first and second stages of data collection (Appendix 11), in that the vignettes are fictitious scenarios that arise from the key constructs in the first and second stage of the data collection. The vignettes were tape-recorded and then played to participants at the start of the interview (a critique follows in chapter 12). Participant biographical details can be found in table 8 following:

Vignette Interview	Pseudonym	Occupation	Age	Place of birth	Parents place of birth	Grandparents place of birth	Religion	Self-assigned ethnicity	Language	Family member with hypertension
1	Richard	Teacher	37	England	Jamaica	Jamaica	none	Afro-Caribbean	English Patois	Mother + brother
2	Marcia	Nurse	52	Guyana	Guyana	Guyana	Seventh Day Adventist	Black	English	-
3	Percy	Retired Arc Welder	75	Jamaica	Jamaica	Jamaica	Anglican	Black British	English	-
4	Rosetta	Retired	67	Jamaica	Jamaica	Jamaica	None	Afro-Caribbean	English Patois	-
5	Reena	Retired Nursing Auxiliary	-	Barbados	Barbados	Barbados	-	-	-	-

Table 8: Vignette Interviews Biographical Details

This approach differs from that taken by Greenhalgh *et al.* (1998). Consultations with Professors Greenhalgh and Helman, revealed that in the original conceptualisation of 'structured vignettes', the intention is to stop the tape at the end of each articulated sentence and then the respondent is asked to state whether they agreed or disagreed with the behaviour or health actions of the person in the scenario. I considered this approach to be fragmentary and also not useful as asking participants to agree or disagree with certain forms of behaviour may be contextually bound or situational or indeed dependent on a myriad of factors. However, the notion of narrative as a vehicle for participants to explore or project their own experiences may be particularly useful, especially when researching the lives of communities who do not share the Western cultural tradition of conveying information via written means, but rely on an oral tradition. Airhihenbuwa (1995) in particular asserts that communities of African descent are strongly orientated to receipt of information in the oral format.

A collective breakdown of all the study participants from all three data collections phases can be found in table 9. This provides the opportunity for reflection on the characteristics of the total sample of participants and the implications this has for the study. It can be observed that the average age of all participants from the three phrases of data collection is 59.37 years and the median age is 59.5 years (37-82 years). In this respect the participants in general can be described as older people, but they may not perceive themselves to be in 'old age'. Only slightly more women than men were recruited to the study, despite the increased prevalence of hypertension in Caribbean women (Nazroo 1997, DOH 2000). Almost all the participants had origins in the Caribbean island of Jamaica with the exception of three participants who had origins in Guyana, Domenica, and Barbados although commonality of experience with other islanders did exist. In this respect in can be concluded that the findings most typically represent the experience of Jamaican people with hypertension. Whilst a number of the participants migrated as young people and children under 10 years Carlene, Hyacinth, Richard, Carlton, Wesley, and Marcia. Only two participants were actually born in the UK. Although,it can established from the biographical charts that many of the remaining participants had resided in England for longer than 40 years.

Table 9: Illustrating characteristics of all study participants

Participant	Age	Sex	Place of birth	Parents place of birth	Grandparents place of birth	Religion	Self-assigned ethnicity
1	82	M	Jamaica	Jamaica	Jamaica	None	Jamaican
2	69	F	"		"	Anglican	Jamaican/British
3	50	M	"	"	"	Church of England (C/E)	Afro-Caribbean
4	70	M	"	"	Paternal grandfather of German Jewish origin Grandmother Jamaica	None	Jamaican
5	70	F	"	"	Jamaica	Church of God of Prophecy	Jamaican
6	75	M	"	"	"	Catholic	Jamaican
7	72	M	"	"	"	Christian	Jamaican
8	62	M	"	"	"	Baptist	Jamaican
9	80	M	"	"	"	Baptist	Jamaican
10	52	M	"	"	"	Christian	Afro-Caribbean
11	60	M	"	"	"	Baptist	Jamaican
12	56	F	"	"	"	None	Jamaican
13	70	F	"	"	"	Baptist	Jamaican
14	78	F	"	"	"	Pentecostal	Jamaican
15	63	M	"	"	"	Anglican	Jamaican
16	39	F	Wolverhampton	"	"	Seventh Day Adventist	Black British
17	73	F	Jamaica	"	"	Methodist	Jamaican
18	38	F	Leeds	"	"	C/E	African Caribbean
19	38	F	Jamaica	"	"	Seventh Day Adventist	Black British
20	72	F	"	"	"	Pentecostal	African Caribbean
21	50	M	"	"	"	C/E	African Caribbean
22	37	M	"	"		-	Afro-Caribbean
23	52	F	Guyana	Guyana	Guyana	Seventh Day Adventist	Black
24	75	M	Jamaica	Jamaica	Jamaica	Anglican	Black British
25	67	F	"	"	"		Afro-Caribbean
26	-	F	Barbados	Barbados	Barbados	-	-
27	77	F	Domenica	Domenica	Domenica	Roman Catholic	West Indian/British
28	75	M	Jamaica	Jamaica	Jamaica	Anglican	Black British
29	64	M	"	"	"	-	Jamaican
30	60	F	"	"	"	Methodist	British
31	69	F	"	"	"	New Testament Church of God	West Indian
32	65	F	"	"	"	Pentecostal	Black British
33	70	M	"	"	"	-	African Caribbean
34	64	F	"	"	"	Pilgrim Holiness	Caribbean
35	76	F	"	"	"	Baptist	Black British
36	70	F	"	"	"	Baptist	Black West Indian

Observations on the participants' use of language

In presenting the data (chapters 7-12) extracts from the FGI and the semi-structured interviews and vignette interviews, it is important to point out the differences in speech patterns between some participants of African Caribbean origin who were Jamaican-born who spoke English and Standard English speakers who were UK-born. These differences may present challenges for the reader in comprehending the meaning of the data extracts. Many older African Caribbean people speak 'Patois'. Jamaican Patois, whilst it is not regarded as a different language as many of the words are derived from English, may present challenges. Difficulties may arise for Standard English speakers as Patois is derived from both West African and European languages. As such, it is characterised by a unique syntax, morphology and grammatical expression (Scott 1998). Furthermore, participants often switched between speaking Standard English and Patois; in some instances this is integrated with an English regional accent e.g. Yorkshire accent. Translation did take place for these instances of dialogue conducted solely in Patois. However, the Standard English often spoken by participants was used with the grammatical expression and syntax of Patois, and is therefore not a simple issue of translation. The syntax of African Caribbean speech may also make the group conversations, in the focus group interviews much harder to transcribe, and creates some comprehension difficulties in making sense of the data extracts for individuals unused to this type of dialogue. It is for this reason that the co-moderator of the FGI was a 'Patois' speaker. The co-moderator assisted with the translation of occasional words used in the FGI and translated one interview.

Paramount in this study was the need to be fully familiar with the spoken audio-taped version of data collection in addition to familiarisation with the written transcripts. The written transcript is a 'flat' or one-dimensional version of an interpersonal communication, lacking in animation and non-verbal communication. Most of the participants in this study did not demonstrate the 'reserve' associated with communication in Northern European countries, but a vivacity of communication enhanced by gesticulation and vocality. The FGI were lively and dynamic discussions. The audio-taped versions of the FGI provide an enhanced understanding of the process of communication by highlighting nuances of speech and vocal inflection. Additionally the field notes made immediately following data collection provide further insights via non-verbal communication and notes on group dynamics that is not possible to convey simply in written data extracts which only provide part of the whole process of communication.

The analytical framework

The framework selected for analysis is Roper & Shapira's (2000) framework for analysis of ethnographic data. Two other approaches were considered and excluded. The Spradley (1979) **Developmental Research Sequence** approach is synonymous with ethnography, and specifically ethnographic interviews, but in addition to analysis extends to the research design with a specific sequence required for different types of ethnographic interview employed during different stages of the research design. Limitations include the time-consuming nature and the focus on ethno-semantics as opposed to a focus on pragmatic research outcomes (Parfitt 1998). The approach is rarely used in the UK because of the complexity of the approach (Parfitt 1998).

Also considered was **Framework** (National Centre for Social Research 2001) although it is currently unavailable as a dedicated software package and has to be used with an Excel spreadsheet. Further limitations include the summarising of verbatim comments that most theorists state are important in ethnographic research (Hammersley & Atkinson 1995, Spradley 1979). The strength of Framework is that it is very suitable to ensure consistency within a team of researchers, (unnecessary in this case) and where rapid results are required. Framework is not located within a specific methodological approach. The underpinning philosophy is focused on the transparency and replicability of the method of analysis. Findings are also deductively and inductively generated. Framework is not compatible with many of the currently available computer assisted qualitative data analysis software (CAQDAS) including Atlas/ti, which is used in the study. A rationale for the selection of Atlas/ti follows.

Roper & Shapira's (2000) framework for analysis of ethnographic data was selected because of:

- ☐ The relevance to ethnographic data
- ☐ The clarity and transparency of the approach
- ☐ The systematic approach to analysis, following clearly defined steps
- ☐ The relevance of the approach to pragmatic HSR
- ☐ The compatibility of the approach with computer assisted qualitative data analysis such as Atlas/ti

This is not to say that the perspectives of other key theorists in the field of ethnography and qualitative research are not drawn upon in the analytical process. Indeed they are utilised to enhance the process of analysis. In any event it is clear that the framework that Roper & Shapira (2000) present has antecedents in the work of key qualitative theorists such as Burgess (1984), Lincoln & Guba (1985) and Miles & Huberman (1994).

Steps in Analysis

The process of qualitative data analysis is characterised by identification and classification of data and progresses to abstract generalisations, explaining patterns of behaviour within the cultural group. The process described below is not linear, but undulating and convoluted. This characterises the iterative process (Silverman 2000) associated with qualitative research as preliminary interpretations are challenged and data is revisited in the light of further data collections and new insights into the data.

Steps in Analysis (after Roper & Shapira 2000)

☐ *Coding for descriptive labels*
☐ *Sorting for patterns*
☐ *Identification of outliers or negative case*
☐ *Generalising: constructs and theories*
☐ *Memoing: reflective remarks*

Analytical induction is the *sine qua non* of ethnographic research. In this research an interesting phenomena was that during the process of gaining informed consent obtained in the participant's home, participants often shared interesting insights regarding their hypertension, although this was unsolicited. Although these conversations do not form part of the formal design of the study, one of the characteristics of ethnographic research is the notion of the informal conversation or interview (Fetterman 1998). This also provided the opportunity to observe the participant in their home environment, in this sense this dimension may be regarded as a form of participant observation. However, as participants did not agree to involvement in a participant observation study, it is not possible for me to use these observations as data. Additionally, important observations of cultural characteristics were made in the participants' home including cultural symbols/icons, socio-economic status, dietary and social habits, relationships with other family members and friends. Atkinson & Hammersley (1998 p.111) state that:

> *"... it has been argued that in a sense all social research is a form of participant observation, because we cannot study the social world without being part of it"*

Preliminary analysis of the data began during the data collection. Reflexive analysis at this time alerts the researcher to emergent themes and informs the formal and systematic process of analysis. Murphy *et al.* (1998 p.188) define reflexivity as:

> *"... we mean sensitivity to the ways in which the researcher's presence in the research setting has contributed to the data collected and their own a priori assumptions have shaped the data analysis"*

Other commentators have noted the existence of different forms of reflexivity; endogenous and referential reflexivity (May 1999). In considering the data collection process it is endogenous reflexivity that is most relevant.

> *"Endogenous reflexivity refers to an awareness of the knowledge that is born in and through the 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 (1999 p.7)*

Endogenous reflexivity is concerned with reflection within actions and in this study; this was captured in the initial field notes following each stage of data collection. These notes extended beyond descriptions of the environment and capturing of non-verbal communications and included preliminary responses by myself to the question, 'What is going on here?' Listening to the audio-tape immediately following data collection enhanced the writing of field notes. The audiotape was then transcribed.

Analysis of qualitative data is dependent on immersion by the researcher in the data collected in order to establish familiarity with the data. This demands frequent reading and systematic review of the transcripts. The initial process commenced with checking the written transcript against the audio-taped version to correct any inaccuracies. It became evident during this process that reviewing written transcripts alone is extremely limited in conveying a comprehensive representation of the communication that occurred during data collection. Listening to audio-taped versions of the data collection created a level of insight into the communication processes that cannot be achieved in a written transcript. As the analysis progressed, it became evident that re-listening to tapes in addition to familiarisation with transcripts was an essential component of the process of analysis. Nuances and inflections of speech cannot be captured in a transcript. Reliance on the transcript alone creates a deficit that may considerably lessen understanding of the meaning of the words and viewpoints articulated.

Coding of data

Once familiarisation with the data had occurred, the data were assigned to the software Atlas/ti in order for the coding process to begin. Codes are defined by Miles & Huberman (1995 p.56) as:

> *"... are tags or labels for assigning meaning to the descriptive of inferential information compiled during a study. Codes usually are attached to 'chunks' of varying size words, phrases, sentences or who paragraphs, connected or unconnected to a specific setting. They can take the form of a straightforward category label or a more complex one (e.g. a metaphor)"*

Codes were assigned to words, sentences or paragraphs, line by line. Each code was defined (using the comment facility of Atlas/ti) and later combined to form abstract categories, themes or domains. Atlas/ti enables the generation of code lists from data sets (12) and across data sets (Appendix 13). It is also possible to generate a list of new codes that occurred 'today' or from a specific data set. This dimension proved to be extremely useful in establishing when analytical saturation of the data had occurred e.g. when no new codes or themes emerged from the data.

With the use of Atlas/ti, the code relationships can also be constructed visually in graphic representations and code hierarchies or typologies can also be illustrated. The coding process resulted in 115 codes (see code list Appendix 13) that would later be reduced as part of the funnelling process, as irrelevant and meaningless codes were discarded.

The coded data were examined in order that phenomena hidden or embedded in the data became more explicit. Consideration was given to the relevance and significance that emergent findings held for the specific research questions and objectives. Roper & Shapira (2000 p.95) identify the following constructs as significant in the coding process:

- ☐ *Setting: the environment or context*
- ☐ *Activities: patterns of behaviour that occur often*
- ☐ *Events: rare and infrequent activities*
- ☐ *Relationships and social structures: kinship, friendship, bonds, enemies, hierarchal*
- ☐ *General perspectives: the group's shared understandings*
- ☐ *Specific perspectives on the research topic/s how people understand the phenomena*
- ☐ *Strategies: ways of achieving goals*
- ☐ *Process: flow of events how things change over time*
- ☐ *Meaning: significance and understanding of behaviour*
- ☐ *Repeated phases: depictions of thought processes*

The use of memos in the process of data analysis

During the coding process, the memo writing function of Atlas/ti was utilised to record reflective comments, initial interpretations, the noting of non-verbal communications and other pertinent comments such as agreement and dissension in the FGI. Memos are not objectively observed or heard, but may lead to theoretical understandings. Roper and Shapira (2000 p.101) state that:

> *"Memos are ideas or insights you have about the data"*

They can be used to challenge the researcher's own analysis of the data. However, it is important during the process of analysis that these memos, along with coding of the data, are revisited by the researcher as tentative findings emerge to ensure that alternative explanations do not exist. In stating this, it is clear that multiple realities and explanations exist in respect of any social phenomena, so it is clear that alternative explanations will exist for any analysed piece of data. However, ethnographic research views the ethnographer as a human instrument; in this sense it is unlikely that any two individuals will make exactly the same interpretation of the same piece of data. The challenge to preliminary coding is important for each study within the context of the research questions posed. (A further check on credibility can be achieved by sharing interpretations with participants and key informants; this is discussed later). Over one hundred memos were written in the process of analysis in this research (see memo list Appendix 15). In this research study, challenges regarding coding and interpretation were systematically recorded at the end of the coding of each transcript (Appendix 16). Codes for each transcript were reviewed and the initial coding challenged in terms of relevance and meaning. It is also important to create a reflective consolidation period during which no coding or analysis is undertaken; the researcher may then return to the coding and analysis after a period of revitalisation that may result in fresh insights. Atlas/ti enables printouts of memo lists for a single data set, theme, category or the whole data set; this facilitates identification of emerging patterns.

Getting closer to the data

The notion of 'closeness' to the data is a theme in theoretical perspectives on qualitative data analysis (Miles & Huberman 1994, Roper & Shapira 2000). All of the following techniques were used in this research. Although the literature is sparse in relation to how pragmatically this might be achieved. An **extreme case** technique was employed (Miles & Huberman 1994) e.g. by posing the question what if the opposite (of what the participant was saying) was true in order to further illuminate and generate meaning from the data. Techniques to increase researcher sensitivity were also employed (Strauss & Corbin 1990) such as identifying and questioning data where the words 'never' or 'always' occurred, considering the context in which the phenomena mentioned always or never occurred might change. In other words what circumstances might change the event described by the participant as axiomatic. Strauss & Corbin (1990) call this technique **waving the red flag**. Preliminary interpretations of the data were also challenged using the **'if then'** technique (Miles & Huberman 1994) asking what would happen if the opposite of the phenomena described in the data occurred. This is described by Strauss & Corbin (1990) as a **flip-flop** technique. Roper & Shapira suggest a further technique of identifying repeated words and phrases. This may provide insight into the participants' world in relation to the most significant issues for them. Roper & Shapira (2000) also state that identification of **'process'** in data analysis as extremely important, where the researcher attempts to establish reason/s for participants' changed or altered viewpoints during the course of the interview. In this research, 'process' emerged as an important domain of focus, as participants frequently changed their viewpoints, especially on what they may have regarded as sensitive areas such as the use of herbal remedies for example. In the early stages of interviewing, participants frequently stated that they did not use herbal remedies, but went on later to refute this. A focus on 'process' certainly brought about a deeper understanding of the data in this research. The changing of participants' viewpoints in this way, may also be relevant to what Helman (2001) has called public and private accounts, as it is clear in some of the interviews that participants shared both public and private accounts especially in relation to explanatory models of health and illness.

Following deconstruction of the whole data set into discrete codes, sorting occurred in order to identify patterns, within case patterns and across case patterns identifying similarities and differences between interviews. Atlas/ti facilitates within case and across the total data set searches and the development of a family of codes that constitute a theme of category. The data in this sense is reconstructed into another macro structure. Graphic representations can be made of the code families and the associations between them using links and symbols (Appendix 14).These form a conceptual map that enables a transparent audit trail in relation to the eventual conclusions reached.

Following this, outliers or negative or non-conforming cases data and findings were identified that did not fit the broader patterns. In the chapters 7 -12 these negative cases are highlighted and confirmed with illustrative codes. Roper & Shapira (2000) recommend the construction of a matrix with demographic details across one axis and broader themes or domains identified for each participant across the adjacent axis. In this way, the researcher can easily identify outliers from the matrix and theme convergence or divergence across data sets. Outliers assist in the development of theory, helping to establish the limits of the researcher's assertions and shed light on emergent areas of consensus. Relationships and associations between the themes are then identified. The final stage is establishing generalising constructs across the data set to enable representiveness or typicality to be established. This dimension is described by Murphy *et al.* (1998) as 'empirical generalisations. Where possible these constructs are presented as taxonomies or classifications or domain maps. The general comments, interpretation and abstraction form a narrative form that leads to theoretical prepositions.

Developing themes in this research

In this research, themes were developed using the Atlas/ti 'family network facility'. A family network is a theme or category. A list of all codes in the data set, identifying in which interview they appear was printed out to establish if patterns existed (Appendix 13). Each code was examined to establish the relationship to other codes. For example is this code associated with, part of, a cause of, a property of, or closely linked or similar code. Where a connection or relationship existed, these codes were grouped together in themes. Following examination of this printed list and manual marking of potential families with highlighter pens across the entire data set, this information was transferred to the software using the family network facility that enables a number of codes to be grouped together in a family or theme (Appendix 17). The family can then be printed out as a list or graphic representation illustrating the code associations (Appendix 18). The codes therefore may be regarded as subcategories of the theme

During this process, outliers or negative codes are identified that do not appear to fit into emergent patterns. Examples of outliers in this study are the codes bereavement, love life, and no worries. The analysis in this study also focuses on absent data that might have been present and absent data that is featured in other research studies and literature. The conclusion of this process is a narrative about each theme, illustrated with verbatim comments.

Commentary on analysis of Focus Group Data

Analysis of FGI data is the subject of contention. Kitzinger (1995) asserts that the group is the unit of analysis; she states in a review of FGI studies that:

> *"I could not find a single one concentrating on the conversation between participants and very few that even included any quotations from more than one participant at a time"* Kitzinger 1995 p.104

Within this view analysis focuses on establishing areas of consensus and dissention between participants.

Morgan (2001) disagrees with Kitzinger in that he states that FGI analysis is not very different from analysing other forms of qualitative data. Whilst he agrees that attention should be paid to consensus and dissension, he does not subscribe to the view that the group is the unit of analysis, but rather that the analysis is focused on the group members having conversations. This study uses Morgan's (2001) approach to facilitation of FGI and Kitzinger's (1995) approach to analysis, identifying areas of consensus and divergent viewpoints. This is because there is general agreement within the qualitative literature (Strauss & Corbin 1990, Roper & Shapira 2000) on the importance of 'process' in qualitative data analysis. Participants' changing of view-points during the data collection can occur more frequently in social settings such as FGI where participants might be exposed to differing perspectives and subsequently change their own view-points. Examples of group consensus and divergence are illustrated in the results chapter 7.

Recently criticisms have also emerged in relation to use of the qualitative data analysis software and FGI data. Concerns have focused on the tendency of qualitative data analysis software such as Atlas/ti to create a one-dimensional or flat representation of the group processes (Catterall & Maclaran 1997). This is significant, as central to the employment of this method of data collection are group dynamics and interactions, in enabling phenomena to be illuminated during social interaction. Catterall & Maclaran (1997) suggest that qualitative data analysis software packages may tend to nullify the researcher's sensitivity to the significant features of group dynamics. Especially, in relation to divergence and consensus within the discussion and instances where participants might change or modify their viewpoints as a result of the discussion. In considering this viewpoint I would, also suggest that traditional manual approaches to the analysis of FGI often neglect the interactive dimensions; very few reported studies provide extracts of group interaction and tend to focus on a single speaker within the FGI. In this research, in order to make transparent the group dynamics and processes in this analysis, areas of group consensus and divergence are identified and a reflective narrative is provided in commenting on the group processes and interactions.

Respondent Validation

Respondent validation or member checking (Mays & Pope 2000, Murphy *et al.* 1998, Hammersley & Atkinson 1995) is suggested by a number of qualitative theorists (Lincoln and Guba 1985, Sandelowski 1986) as an important dimension in relation to establishing and increasing validity in qualitative research. Advocates of the approach have suggested that this is a true measure of the integrity of qualitative research (Lincoln & Guba 1985). The researcher's account and interpretation of findings is compared with participants' views (Mays & Pope 2000). The aim is to establish the extent to which there is affirmation or verification between the members (participants) and the investigators' accounts (Bloor 1983). Possible approaches to respondent validation might include:

- ☐ "Validation of the researcher's analysis by asking those studied to judge the adequacy of the researcher's analysis for themselves" (Murphy *et al.*. 1998 p.179), including the sharing of interim and final research reports.
- ☐ Returning transcripts to participants to confirm the accuracy of the transcript.
- ☐ Partnership and collaborative approaches such as 'Action research'.
- ☐ Establishing lay consumer research advisory groups.

Validation of the researcher's analysis

Whilst some observers have asserted that participant validation is the definitive test of the credibility of a qualitative research (Lincoln & Guba 1985), a consensus on this point does not exist within the literature. Some observers have pointed out the limitations of this approach as a test of validity. Qualitative research is characterised by the emphasis on interpretation of data by the researcher and reconstruction of this data to provide new insights into given phenomena. This activity is subjective, and in the final presentation of the analysis is accompanied by a reflexive account that provides the reader with insights into the researcher's own biases and assumptions. The reflexive account also attempts to map out and highlight researcher influences on the process of the research and interpretation. This is further mediated by the methodological approach adopted or theoretical stance that provides an additional lens via which the researcher views the research. In this respect, interpretations of qualitative data may be uniquely individual, and the individual's own value and belief system mediate the analysis. Bloor (1983), Emerson & Pollner (1998) both state that it is not possible for the investigator and participant to share the same perspectives, which therefore raises doubts about the appropriateness of the respondent validation as validity check. Mays & Pope (2000) locate these differences as arising from the different roles that the participant and researcher occupy in the research process. Mays and Pope (2000) assert it may be more appropriate to regard respondent validation as a method of reducing errors in interpretation, rather than a validity check.

Murphy *et al.* (1998) also point out issues that could be problematic in respondent validation, such as reliance on the fact that participants will read thoroughly the information provided and give examples of studies where this has been problematic (Bloor 1983,1997, Emerson and Pollner 1988). Murphy *et al.* (1998) conclude that respondent validation is not an unproblematic validity check. However, challenges to researchers' findings may produce interesting additional data.

Respondent Validation in Ethnography

The research presented in this thesis draws heavily on the ethnographic tradition; whilst it is acknowledged the study is not ethnography of the classic genre, some core principles of the methodology are observed. The framework adopted for analysis of the data, Roper & Shapira (2000), is explicit in detailing the processes involved in analysis, but does not mention respondent validation or member checking. However, Hammersley & Atkinson (1995) in what is regarded by some as a seminal text on ethnographic research do provide a discourse on the topic. They acknowledge that 'respondent validation', is a notion that has an uncertain and sometimes contested place in ethnographic research" (Hammersley & Atkinson 1995, p. 227). Hammersley & Atkinson (1995 p.230) conclude:

> *"Such feedback, then, can be highly problematic. Whether respondents are enthusiastic, indifferent, or hostile, their reactions cannot be taken as direct validation or refutation of the observer's inferences. Rather, such processes of so called validation' should be treated as yet another valuable source of data and insight."*

In this study I therefore decided to write to all participants to establish their interest in receiving further information regarding the findings of the study. Freepost envelopes were provided for participants' responses; fourteen of the participants replied to say that they would like to receive further information. The objective of this is to establish whether any challenges to interpretations and analysis exist, that may have provided further data, rather than a validity check.

Establishing a consumer advisory group

During this research a consumer advisory group was established to advise on the progression of the research as active partners in the research process. The group consisted of a former chair of a local African Caribbean community association, a person with hypertension, two carers of people with hypertension, and a community member. The group members were recruited via a snowballing technique. The consumer advisory group members' views may be regarded as typical of the community rather than representative.

The emergence of consumer participation in PHC research

The issue of consumer involvement as active partners in the research process has gained prominence over the last decade in health and social care research (NHSE 1999, DOH 1999c). Indeed this is now viewed as a principle tenet of quality within health and social care research (DOH 2001). The drive towards increased consumer participation and involvement is a fundamental precept of the NHS modernisation programme (DOH 1997, 1998, 1999c). This is reflected in the reconfiguration of the NHS in primary care, by the appointment of an increased number of lay representatives on Primary Care NHS Trusts (PCT) as compared to the former Community Trusts and Health Authorities and the appointment of lay Chairpersons to PCT's.

Current knowledge of consumer involvement

The emergence of consumer involvement is not confined to health and social care but is a component of a broader ideological shift in all public and social policies not just nationally but internationally (Beresford & Evans 1999). For example in the United Kingdom, this ideological shift is also reflected in the management structure of educational institutions. These developments are underpinned by a subscription by government to the principles of equity, inclusivity, increased transparency in the research process and the redefinition of ethical principles related to research in health and social care (DOH 2001) in order to bring about more relevant research, increased accountability and ultimately better public policy (Beresford 2000). Simultaneously it is said (Beresford 2000) that the rise of consumerism in the 1980's, diminishing professional power and a less deferential health care consumer (Entwistle *et al.* 1998) have further contributed to the present position.

Ambiguity of terminology

The concept of consumers as 'active partners' in the research process in health care is at embryonic stage of development. The limited literature that is available on the topic is characterised by a lack of shared understanding of the terminology used to describe this experience. A variety of terms are adopted to describe non-health professional involvement e.g. patients (Rhodes *et al.* 2001), users (Jordan *et al.* 1998,Beresford 2000), service users (Rhodes *et al.* 2001), lay perspectives (Entwistle *et al.* 1998), public involvement (DOH 1998). The Department of Health in one document for example uses a multiplicity of terms - patients, public involvement, consumers and users (DOH 1999c). It is clear that all these terms refer to the involvement in research of individuals who are not professional practitioners; in other words people who are not employed by the statutory services as the main protagonists conducting the research in question. It is possible that the terms adopted to describe participation of this nature may refer to patients, carers and members of the wider public. Participants in this research, although experiencing a chronic disease, may not see themselves especially as patients, as the lived experience of hypertension is integrated into everyday life.

The Consumers in NHS Research Support Unit (2000 p1) define the term consumer as:

> "*...patients, carers, long term users of services, organisations representing consumers' interests, members of the public who are the potential participants of health promotion programmes and groups asking for research because they believe they have been exposed to potentially harmful circumstances products or services*"

They go on further to provide a definition of user involvement in their briefing notes for researchers:

> "*... in research we mean an active partnership between consumers and researchers in the research process, rather than the use of consumers as the 'subjects' of research. Many people describe consumer involvement as doing research with consumers rather to, about, or for consumers*"

These definitions have guided the formation and membership of the consumer advisory group in this study.

Differing conceptualisations

Various discipline groups are likely to conceptualise the meaning and experience of consumer participation from different perspectives as a result of professional socialisation processes. For example, it appears, as might be expected, that within the social care literature (Beresford & Evans 1999, Beresford 2000) that 'user' is the predominant term. Within health care domains, this term is colloquially used to refer to a person who misuses substances. However, what is not clear is the extent to which these terms in current use are interchangeable or synonymous. Notwithstanding these criticisms, as consumer participation in research increases greater clarity and definition of the terminology may emerge. More significantly, the principles of non-professional participation may in time become more explicit and refined into a consummate model for the conduct of research.

The process of engagement

Presently the experience of consumer involvement in primary care is not well-charted territory. Whilst the principles are established (NHSE 1999, DOH 1999c), few primary health care researchers have a lived experience of the concept at the time of writing. There is a danger that participation may be viewed as tokenistic (Rhodes *et al.* 2001) especially as the power dimensions between the researcher and researched are widely documented and acknowledged. Research in any field is associated with jargon and specialised technical language, and primary health care and medical research may be guilty of this to a greater extent than other disciplines. Seeking out representatives of marginalized and excluded groups (as in the case in this research) and engaging these individuals in a consumer advisory group is likely to be fraught with difficulties. The issue of power dimensions whilst relevant to all research participants may be particularly important for African Caribbean communities and other minority ethnic communities when every day life is characterised by racism, discrimination and oppression. Some communities are also likely to be experiencing research fatigue; for example personal communication with the Somali Community Development worker in Sheffield, for example has confirmed this and dissatisfaction with 'hit and run' research. Communities that perceive researchers as furthering their own careers without facilitating the realisation of any investments made by research participants are unlikely to volunteer for consumer advisory groups.

As researchers, we are dependent on the integrity and ethical conduct of researchers that have gone before us, as lasting damage can occur if 'ethical footprints' are not left. Likewise our successors are dependent on our integrity and ethical conduct. Tensions are likely to arise as to whether existing networks, community groups and associations should be used or others who may have less experience of committee work. Rhodes *et al.* (2001 p.3) state that they 'sought to combine political expediency with pragmatism'. Therefore individuals were sought from community groups, with the recognition that these individuals were not necessarily representative of the wider community. However, Rhodes *et al.* (2001) comment how this dimension actually aided the cohesion of the advisory groups, and reflected the ability of the members to articulate their views confidently

The value of consumer participation in PHC research

Some observers have noted that there is a moral obligation to include consumers in research (Entwistle *et al.* 1998), as the general public has contributed via National Insurance Contributions to the NHS budget including research funding. In this sense consumers have a right to be included and involved in research. The recognition of differences between lay and professional perspectives on health and illness has long been acknowledged. Entwistle *et al.* (1998 p463) state that "culture and values of those involved can influence the research and the knowledge derived from it". If this is the case, the research conducted by individuals who are distanced from the participants socially, culturally, economically, politically and by ethnicity are unlikely to achieve optimum benefits for patients and clients in PHC services the NHS. Benefits from consumer involvement in research are said to be:

- Identification of the most appropriate and relevant research questions
- Pragmatic and feasible research designs
- Enhanced access to study populations
- Selection of the most appropriate data collection tools
- Valid and meaningful topic guides, interview schedules
- New perspectives on the interpretation of the data
- Formulation of recommendations
- Enhanced research dissemination (NHSE 1999, 1999c,Entwistle *et al.* 1998)

Beresford (2000) states that there is no 'right way' of conducting involvement; in this respect, the process is emergent. However, in this research the development and maintenance of the group is guided by a specific set of principles as follows, which are synthesised from existing literature on the topic and local knowledge of the African Caribbean community in Sheffield and Nottingham.

Clarification of the membership and purpose of the advisory group research study

In order that everyone involved, including consumer advisory group members, supervisors and I, had a shared understanding of the role of the consumer advisory group in this study, the guidelines were established (see Appendix 19).

It was agreed initially that the group would meet three times per year. However, as it became evident that the group needed to meet at critical junctures of the research process. e.g. preliminary interpretations were shared with the advisory group to establish the credibility of the interpretations as recommended by Guba and Lincoln (1989) and a meeting was convened. The group confirmed the credibility of the initial interpretations. The group also commented on the vignette scenarios that I had constructed and took on actors' roles in narrating the vignettes that were then tape-recorded. Three members of the group presented the study with me at a participatory research conference taking on active roles in the presentation to an academic and practitioner audience. This presentation necessitated planning and several rehearsals. During the presentation, the group presented their motivations for participation to the audience and their evaluations of participation, which were very positive. In many respects the group took on the role of 'key informants' as is characteristic of ethnography (Hammersley & Atkinson 1995). The consumer advisory group in this respect was an essential component of the research process; as I am not of Caribbean origin the group facilitated and enhanced my understanding of community norms and values.

Computer assisted qualitative data analysis software (CAQDAS)

The past decade has witnessed a growth in the availability of CAQDAS (Fielding 2001). Some packages are contemporary versions of older software, whilst others are completely new programmes(see table 10). In this research study the data were analysed with the aid of Atlas/ti. CAQDAS cannot analyse data for the researcher as Webb (1998 p.326) states:

> *"The techniques offered by CAQDAS should be used as mechanical tools and not seen as monsters which take over the analysis. The thinking and creative part belongs to the researcher"*

The process of analysis remains completely within the control of the researcher. Several types of CAQDAS exist:

Type	**Characteristic**
Text Retrievers – *The Textcollector, WordCruncher*	Recovers text relevant to themes and categories
Code and Retrieve Packages *HyperQual, The Ethnograph*	Enables coding and attachment to chunks of data and recovery of relevant text
Theory Building Software *NUD*IST version 4, Atlas/ti*	All of the above in addition to theory building

Table: 10 Typology of CAQDAS (after Fielding 2001)

The advantages of using CAQDAS are numerous. CAQDAS provide reliable and systematic storage data and facilitate rapid retrieval of data and systematic within case and across analysis of data. The process of data analysis can be speeded up, although this is not always the case as CAQDAS may encourage obsessive and unnecessarily detailed coding (Webb 1998). Importantly for ethnographic research Fielding 2001 p.453 notes that:

> *"We have noted that ethnography's analytic process is often hidden. CAQDAS offer features to make it transparent"*

Additionally, Atlas/ti the CAQDAS used in this research has additional features such as comments and a memo facility that essentially constitute the preliminary interpretations of data. Atlas/ti has a theory-building component; this is termed a network view. A network view enables the development of a graphic conceptual map, so that memos, codes or segments of data can be used as nodes between which relationships can be demonstrated by the use of symbols. This is important for ethnographic research as the establishment of patterns, analysis within and across cases is fundamental to the methodology (Atkinson & Hammersley 1998). The iterative nature of ethnographic research (Fetterman 1998), demands a transparent audit trail in order to trace the development and origin of ideas, Atlas/ti facilitates this. Silverman (2000) points out that CAQDAS can enable negative or deviant cases to be more easily identified and generally support a more rigorous analysis to support conclusions.

However, a number of commentators have criticised CAQDAS (Webb 1998, Woods & Robert 2000, Silverman 2000). It is possible that a good word processor could take on many of the functions of CAQDAS (Silverman 2000). Most importantly it is possible that CAQDAS may impose limitations on data analysis by constraining the researcher to the format, modus operandi, protocol and configuration of the software. However, it is the responsibility of the researcher to ensure that the process of analysis is researcher driven rather than by CAQDAS. After, all, few of us would be happy to free-wheel down a steep hill in our car and rely upon the car to ensure our safety. CAQDAS are mechanical devices in the same way as cars; therefore the researcher must always be in control of the analytical process. Personal experience of both manual and CAQDAS approaches to qualitative data analysis has led me to conclude that the advantages of CAQDAS outweigh the disadvantages.

The decision regarding the suitability of a specific CAQDAS is difficult in the sense, that in order to make a truly informed decision, the researcher must be trained and fully conversant in a number of programmes. In reality this cannot be achieved, not least because of the financial cost and time investments. Therefore, pragmatic decisions had to be taken regarding the selection of a CAQDAS for this research. Miles & Hubermann (1994 p.316) provide a comprehensive review that helpfully maps out the key characteristics of a number of CAQDAS and most significantly the user-friendliness of each CAQDAS reviewed. Atlas/ti has a number of sophisticated utilities, simultaneously achieving the highest user-friendliness score. Woods & Roberts (2000) state that user-friendliness is possibly the most important criteria for selection and indeed might be the only distinction between currently available CAQDAS. In addition, I had previously received training in the use of Atlas/ti so was well aware of both the parameters and the disadvantages and advantages of using the software in a real life research project. An added bonus is that the developer of the programme Thomas Muhr, is generous in offering email advice should difficulties be encountered. Although within the research community in England NUD*IST and Ethnograph are more commonly employed (Webb 1999).

How the data and results are presented

Chapters 7 -12 following contain verbatim comments and extracts from the data elicited during the conduct of the research. The extracts appear in single line spacing in italics and are presented exactly as the person articulated their viewpoints, however where irrelevant longer passages exist this is denoted by three full stops in the quotations. Explanatory notes in the quotation are in square parenthesis e.g. *[ ]*. The results are presented in themes from each of the three data collections methods, ending with a composite analysis of all three methods. The letter

G is used to signify my speech and participants are referred by a pseudonym in order to maintain anonymity and protect confidentiality. Where a longer passage is presented with dialogue between the participant and myself, both my initial G and the initial of the participant's pseudonym appear.

Ethical dimensions

Local medial ethics approval and informed consent are discussed in earlier sections of the chapter; however there are other ethical considerations in respect of this research.

Confidentiality and anonymity.

No participant in the study was referred to by name. Following the data collection, each participant was allocated a pseudonym. This pseudonym was used at all times to maintain confidentiality. The code cross-reference material was stored in a locked cabinet in a separate location from the data. In the final reporting and public outputs, no participant will be named or identifiable.

Assurances regarding confidentiality and anonymity were provided for participants during the process of informed consent in the participant information sheet and at the start of each data collection. This was especially important during the FGI, when the confidentiality of all information shared within the group was re-iterated. Confidentiality was also discussed and clarified with the consumer advisory group, although none of the members had access to the data produced.

Tensions between the researcher and health professional role

During the process of research I have observed and witnessed several incidences during which the behaviour and actions of the participants was, I considered, detrimental to their health status. For example whilst, obtaining informed consent from a diabetic participant, I noticed the participant was preparing a full English fried breakfast. My role as a researcher meant as a guest in the participant's home, I was not able to comment upon this scene and had to suppress my natural inclination as a health educator. Other instances occurred during the collection of data especially in relation to non-concordance with medication. When participants shared this, at times I felt very uneasy that the participant may be endangering their health but was unable to comment.

Aside from health-related behaviours, participants also shared several events with me in which I considered the behaviour of the health professionals concerned to be contraventions of their professional codes of practice. However, I was not able to comment and to some extent the situation was resolved by the participants themselves as they had, for example, changed their GP. Nevertheless all of these situations created ethical and moral tensions for me in the conduct of research for which I had to find a satisfactory personal resolution in my cognition.

Potential negative stereotyping of the participants

This issue has become salient in my thinking during the process of the research as potentially sensitive data might be produced. It is possible that outputs from the research might be used to negatively stereotype the African Caribbean community especially in relation to areas such as non-concordance. However, I have sought advice on how these dimensions might be articulated in publications from others that have vast experience of research with marginalised communities. For example, in relation to non-concordance, a positive feature of this phenomenon in the research findings is the high level of self-care that exists in this study population. The consumer advisory group is also involved in the development of the dissemination strategy especially within the African Caribbean community in the study locations. As a researcher I wish to continue to develop my research portfolio within the domain of ethnicity and health and social care and therefore it is essential for my own credibility and integrity as a researcher that I leave 'ethical footprints'.

Reflexive dimensions

A major tenet of quantitative research is the need for the research to minimise as much as possible the researcher effects on the research process (Murphy *et al.*1998). Conversely, qualitative researchers endeavour to acknowledge that researchers do influence the research process and strive to make more explicit these effects and influences (Hammersley & Atkinson 1995). As an important principle of qualitative and ethnographic research, it is surprising that so few theoretical texts on qualitative research address this important dimension. For example. Silverman (2000), Miles and Huberman (1994) do not address this in what are highly regarded qualitative research texts. Grbich (1999 p.65) says that:

> *"Reflexivity at the very least involves a process of self-awareness that should clarify how one's beliefs have been socially constructed and how these values are impacting on interaction and interpretation in research settings"*

Within ethnographic research, acceptance of the researcher influence on the process and ultimately the findings is embedded in the acceptance of the notion that the ethnographer is a human research instrument. Thus, Grbich (1999 p.65) goes on to state that:

> *"The process of 'reflexivity is viewed as instrumental in transcending differences of power, culture and class"*

Mapping out the researcher effects and influences on the process of the research and ultimately the research findings can add to the credibility of the research findings (Murphy *et al.* 1998). An important activity at the start of an ethnographic study is to establish the differences in terms of age, gender, social class, professional socialisation, and ethnicity between the researcher and the research participants. This may enable the researcher to establish at a fairly superficial level biases and assumptions that might be held about the study population. However reflexivity is not an object, but a process that must be engaged in throughout the progression of research.

Reflexivity in this study

From the commencement of the study I kept a diary that enabled me to document and record significant events, feelings and interaction with participants during the progression of the research. This diary is distinct from field notes recorded following data collection, although inescapably there is a connection and linkage between the two forms of narration.

The inherent power dimensions within the ethnographic tradition is most intensely apparent in early ethnographic studies and to some extent still exists in contemporary ethnographic research despite attempts by enlighted researchers to minimise these power dimensions. This issue has remained salient in my thinking during conduct of the research. Questions I asked myself include:

☐ What I am taking from the African Caribbean communities in the study locations?
☐ What I am giving the African Caribbean community (if anything)?
☐ How can I be sure my representations and interpretations are true and accurate?
☐ How might the findings of my study be used negatively against the African Caribbean community?
☐ What control if any do I have in this domain?
☐ How does my own ethnicity influence the research participants and me?
☐ How does my personal biography professional background as a health professional and academic influence the research

To a large extent I was also an 'uninvited professional stranger' within the African Caribbean community, as no one in the community asked me to embark on this investigation. However, as a member of a minority ethnic group myself; I have endeavoured to ensure that my research is not informed by a eurocentric perspective or colonialist ideals. I have to be aware, however that the secondary socialisation processes I have experienced living in the UK has very much been underpinned by eurocentric perspectives in terms of my education and professional socialisation as a nurse, midwife, health visitor and researcher. A reflective diary was constructed and maintained for the whole period of the research, which enabled a critical self-reflection of the research process and my role within this. Whilst reflexivity was ongoing throughout the process of the research, it is not possible to give a truly reflexive account until the research study is fully concluded when a retrospective view can be taken.

The concept of reflexivity also demands that assumptions the researcher holds are made explicit. In this research this dimension is achieved by exploration of my own ethnicity and reflection on my identity (Ghanaian father, white English mother) and early socialisation. Initially, I perceived myself as a member of the 'black' community to have much in common with participants, but realise now that there are many differences between most of the study participants and myself. For example, my primary socialisation was characterised by dual influences (both Ghanaian and English) and residence in the UK. This is not the same as many of the participants who grew in the Caribbean. A further influence on the interpretation of the data is that of professional socialisation that is largely informed by a biomedical perspective; participants are likely to draw on a number of different explanations embedded in the African Caribbean culture for their own explanations for health and illness. Murphy *et al.* (1998) highlight the potential of the researcher being blind to data if they fail to recognise this. Gender and social class exert further influences.

In this study most of the participants were of working class origin. Whilst my family has working class origins, by the very definition of my role in the University of Sheffield, it is likely that many of the participants perceived me to be middle class, as denoted by speech, class and general demeanour. Personally, I have reservations about uncritically accepting either the term working class or middle class to describe my position in society. My formative years were spent in a working class inner city location, where many friends and neighbours were of Caribbean origin. Initially I perceived myself to have considerable insight into the Caribbean community in England in terms of my own knowledge of the life-ways and traditions of Caribbean people. I was shocked to discover as the research progressed, that this was not case and that my insight had been very superficial. Similarly, while I had deemed myself able to understand though not speak Jamaican 'Patois', I was surprised to find that I could not understand 'Patois' fully enough for the purposes of a research project despite generally understanding a conversation in 'Patois' in a casual social setting.

It is likely also that gender dimensions exerted a powerful influence. Impotence is a common side effect of anti-hypertensive therapy; however only two of the male participants interviewed in the study shared this side effect with me. This does raise questions as to whether males in a mixed gender FGI would share information of this nature. This has led me to believe that my gender may have inhibited some of the male participants in fully sharing this information with me. Age is also an important consideration when conducting research with African Caribbean populations. Older African Caribbean, similar to older white people in England may consider aspects of their life experience, health and illness as their private business and be quite reluctant to share these, especially with a younger person. At the end of an interview, when I asked if there were any other issues she wished to share, one participant stated she had already told me too much!

My own ethnicity is likely to have influenced the progression of the research in both positive and negative ways. I did explain to participants, for example, that I did not speak or understand Patois, as I was of Ghanaian origin. It is likely that some participants may have shared more with me than with a white researcher, especially in relation to issues of racism and discrimination. It was evident to me that many participants were quite reluctant to share with me details of their use of traditional herbal remedies, for example until I alerted participants to the fact that I was aware of the widespread use of herbal remedies within African Caribbean communities in England. One participant experienced difficulty in believing I was of Ghanaian/English origin as he prided himself in recognising a Jamaican woman, although I explained I did not speak 'Patois' at the start of the interview. Conversing with another black person signified for this individual that the use of 'Patois' was appropriate, regardless of the individuals declared ethnicity.

In summary, all these factors merge to form what is described as the "distance" between the researcher and participants (Mays & Pope 2000). However, it may be perceived by funding organisations and others those researchers from minority ethnic groups working with minority ethnic study populations are advantaged by their similarity. Whilst a shared experience and understanding may occur in respect of commonality in experiences of personal and institutionalised racism and membership of a minority ethnic group, advantage may or may not be bestowed. The situation is complex, to make such an assumption is to racialise this experience both for the researcher and researched, and ignores the heterogeneity in the UK's minority ethnic populations, social class and gender. Little had been written on the topic, dissimilarity and similarity could confer both advantages and disadvantages. In this research it is likely for example that some participants have shared with me material they would not share with researchers who are not members of minority ethnic community. On the other hand, social class and gender issues may have restricted access to some domains of enquiry. This domain of the ethnicity of the researcher and ethnicity of participants are important areas of future research, especially as the ethnic profile of the UK is changing and becoming more complex.

Chapter 7

Findings – Focus Group Interviews

In this chapter, findings are presented from the focus group interviews (FGI) data collection. The FGI represent the preliminary data collection and provided the opportunity for investigation and establishment of the key areas in the semi-structured interviews and vignette interviews. Each data stage in the research builds on the previous analysis and findings enabling, a deeper investigation into aspects of the experience of African Caribbean people with hypertension. Themes emerging from each data collection method are analysed and presented, and finally a composite analysis is presented as a coherent narration of the evidence and providing new insights from this research.

This research investigates 'The meaning and consequences of hypertension for individuals of African Caribbean origin and perceptions of primary health care services'. Hypertension is a medical term, but not one that is commonly used by lay populations. All but one of the participants in this study described their hypertension as high blood pressure. In referring to existing literature and professional perspectives on hypertension, I use the term hypertension. However, when referring to participants' perspectives and worldviews, I use the term high blood pressure, as this is the language of the participants. The term high blood pressure is also used in emergent themes and analytical issues, because participants use this term and they may have differing perceptions or understandings of hypertension. The three-stage approach adopted to data collection facilitates an iterative process (Murphy *et al.* 1998) in the conduct of the research, through the revisiting of themes and phenomena identified in the analysis of the preceding data collection. Furthermore this approach facilitates data triangulation (Denzin & Lincoln 1994, Hammersley & Atkinson 1995).

This section explores four major themes emerging from the analysis of the preliminary data collection of FGI. The purpose of the FGI is to broadly identify areas for more detailed exploration in the semi-structured interviews. According to Morgan (2001) the strength of the FGI is embedded in the participants' interactions that enable the revelation of experiences, feelings, and beliefs. The objective is to enable participants to carry on a conversation between themselves (as opposed to between the moderator/s and themselves), which facilitates illumination of consensus or diversity (Kitzinger 1995).

Recently criticisms have emerged in relation to the use of the qualitative data analysis software and FGI data. Concerns have focused on the tendency of qualitative data analysis software such as Atlas/ti that is used in this research to create a one-dimensional or flat representation of the group processes (Catterall & Maclaran 1997). This is significant as central to the employment of this method of data collection are group dynamics and interactions in enabling phenomena to be illuminated during social interaction. It is suggested by Catterall & Maclaran (1997) that qualitative data analysis software packages may tend to nullify the researcher's sensitivity to the significant features of group dynamics in relation to divergence and consensus within the discussion and instances where participants might change or modify their viewpoints as a result of the discussion. In accepting this viewpoint, I would also suggest that traditional manual approaches to the analysis of FGI often neglect the interactive dimensions; very few reported studies provide extracts of group interaction and tend to focus on a single speaker within the FGI. In order to make transparent the group dynamics and processes in this analysis, areas of group consensus and divergence are identified. Additionally, a reflective narrative is provided in the concluding sections, commenting on the group processes and interactions. In mapping out the findings I would like re-iterate that the findings are presented using the participant's preferred choice of word for 'hypertension', that is 'high blood pressure' and for all other perspectives the term 'hypertension' is used.

Findings

The themes identified are 1) **Early diagnosis**. This theme premises significant events and precursors to participants' presentation for diagnosis in PHC. The theme also includes processes and systems involved pre-diagnosis. 2) **The meaning of high blood pressure**. This theme maps out the impact of high blood pressure on life experiences and opportunities. The impact of wider societal structures; both contemporary and historical are explored. In addition participants' understanding of the cause of hypertension and participants' explanatory models of high blood pressures are evidenced. 3) **Consequences and management of high blood pressure**. This theme includes the impact of the diagnosis of hypertension has on everyday living, and the strategies that participants employ to manage their high blood pressure such as the use of herbal remedies, concordance and non-concordance with medication and finally 4) **The participant's experience of PHC**. This theme explores participants' use of NHS Primary Health care services and private GPs. In addition relationships with both NHS PHC professionals and private GPs are explored. The four themes are considered in detail. Firstly, I define the theme and explore the constituent parts of each theme. Secondly I will map out the multiplicity and range of participants' experience; an exploration is conducted in relation to each theme. Thirdly, absent or missing experiences are further explored, as is taciturnity within the dialogue. Identification of omissions or taciturnity may provide deeper insights into phenomena investigated by enabling clearer elucidation of the evidence that does exist, thereby enabling the researcher to scope and map out the boundaries and depth of such evidence, clarifying what is known and evidenced and what is not known or missing. The themes presented are analysed in this way both in respect of the data available and later in the discussion section in respect of existing literature. A further important dimension is that of reflexivity and the extent to which as a researcher I may have inhibited or facilitated elements of dialogue between participants. This reflexive dimension is explored in the final section.

Early Diagnosis

This theme includes significant events and precursors to presenting for diagnosis in PHC. This includes processes and systems involved pre-diagnosis. The initial diagnosis of hypertension was often accompanied by feelings of shock and disbelief, some participants could relate specific events that they felt had either contributed to or triggered their high blood pressure. Interestingly these events that the participants believed had pre-empted hypertension bear little or no resemblance to bio-medical explanations for hypertension and associated risk factors such as smoking, excessive alcohol consumption, lack of exercise and obesity. This dimension re-iterates the findings of a study conducted by Blumhagen (1980).

Precipitating events

Participants were asked to reflect upon the initial diagnosis of hypertension and identify associated symptoms and events. A degree of consensus occurred in the FGI surrounding the notion that an event or crisis had triggered their hypertension. The following extract provides insight into a specific event that the participant perceived as influencing the development of her hypertension:

> *"So I got the phone call on the Wednesday but I said my brother's got cancer and the doctors said it's bad cancer. I think I took it to heart because the minute I read 'C' I read 'D' you know and it was exactly a week later 'cause I was trying as you were talking, I'd say oh I tried my best to hold on to myself I said please, please don't let anything happen to him 'cause I didn't want...you know blood pressure and stress and I was trying to hold myself you know but I didn't, I didn't hold myself so I went and doctor, he gave me tablets straight away and then I had to go back, was it 3 weeks?"*
> FGI participant

It seems that the participant was overcome by the stress of her brother's diagnosis of cancer. The notion of 'trying to hold on to myself' implies that the individual can actively contain stress and grief and that failure to do so is an individual personal failing. It is evident that the participant locates the illness of her brother as the major precursor to development of her hypertension.

Other participants identified various stressful situations as precursors to the development of hypertension. In the following extract, the participant, an experienced foster carer, describes the difficulties she experienced as a foster carer:

> *"That's my third boy that I've fostered and I was having a problem with the lad and but because I'm a person who sort don't let it rest on my mind, I thought I'm getting away with it you know. I'm not getting any stress from what happening but little did I know although it's not at the back of my mind, I tried to shrug it off, get on with my life. It take effect, you know it's like a hammer it hit you. Although the hammer is off that area that it hit, the wound is still there, that's how I were".*
> FGI participant

> *"I thought I'll stick with this lad although he's you know, police coming to the door and late night knocking down the door and, they're not knocking it down but you know bang louder on black people door than they bang on everybody's else's door and I thought well this is getting from bad to worse so I says right I'll go on the police committee and I went and joined...went on the police committee so I can make official complaint from within. You know because I think this police carrying on bad because they see it's a black person door. You know I feel that it spoils now and the only way to sort of stop them is sort of get in. How to know the workings of the police, how do they deal with black people and that. Although I've got this high blood pressure, I still say I'm going to take on more work which I'm still on the police committee".*
> FGI participant

In the extract above, the circumstances coalesced to create extra stress that the participant believed to be the root cause of her hypertension. The participant clearly did not need the extra work that involvement in the police committee created but this was the only solution and challenge she could make to what she perceived to be racist behaviour. This example demonstrates how wider prevailing ideologies can impact upon the daily experience of an individual of African Caribbean origin living in England and to some extent influence the health and well-being of that individual (Krieger 2000).

The participant's story relates an example of perceived personal and institutional racism and how this individual feels this has affected her health. What is surprising in the FGI data is that this is the only example or reference to both personal and institutional racism and the relationship this might have to both the physical and psychological health of the participants. I expected more accounts and examples of prejudice, discrimination and racism, both within the context of service delivery in PHC and management of hypertension and experiences associated with migration and relocation within a new country and culture. Accounts of early economic migrants from the Caribbean frequently map out the hostile reception that many people experienced within the context of work, occupation and social life. Given these early negative experiences and the racist nature of British society (Macpherson of Cluny 1999), it is surprising that participants did not make connections between these experiences, stress and the arduous nature of many African Caribbean people's lives as economic working class migrants. The two FGI participants in the extracts above appear to locate the development of hypertension, as emerging entirely from external forces or stimuli and make no linkages or connections with what might be regarded as internal and lifestyle factors such diet, smoking, lack of exercise, and obesity. The FGI did not produce any data regarding the familial or hereditary nature of hypertension nor referred to this in the dialogue as a potential explanation for the cause of hypertension.

Another participant was diagnosed with hypertension when receiving investigations in preparation for major surgery:

> *"Well mine started around then (early 1970's) because you see I discovered that I have blockage in my artery so they tested me and they said I needed a by-pass and as it turns out it takes about 3 years before they come to Caribbean to give the operation and during that time they gave me tablets and I was anxious because I had pain and short of breath and eventually I collapsed one day".*
> FGI participant

It is clear from the extract above that this was an extremely significant event in the participant's life trajectory and in common with the first two examples given, a dramatic event. However, for other people, events surrounding diagnosis were not so dramatic, but more insidious in nature:

> *"Well for me I started having pain across here (eye) and it was treated for me for a year, stress whatever till I found it was something else and then I've had tests".*
> FGI participant

Clearly, while events for this individual were less dramatic, she was actually misdiagnosed and potentially the participant could have experienced a far more serious outcome than she did.

What is absent from the data in this domain is any reference to other family members who might also have experienced hypertension. Hypertension is commonly a familial condition and most participants in this study have other family who are hypertensive. It is surprising that other family members did not alert participants to seek out routine screening or medical checks, to establish whether or not they may or may not be hypertensive. Although the pilot FGI data highlighted that there might be a level acceptance and tolerance of 'pressure' (meaning high blood pressure as opposed to hypertension) within the African Caribbean community, as being a normal consequence of growing older. This may be further reinforced by the number of African Caribbean who have hypertension and the frequency that individuals might encounter others with hypertension, resulting in a perception of hypertension as a commonplace or everyday experience.

Presentation for diagnosis in Primary Care

Seeking diagnosis and professional help for some participants was also motivated by an unusual event:

> *"I find driving along the top of Mapperley Plain and I find the road lift like this and I keep, stepping on the brake, braking when there is nothing but the road in front of me. The road it just wasn't flat anymore, it was like that so I stopped the car and go the side of the road and I said 'this is ridiculous'. When I calm down look at the road you know it was till where it was. You know but when I get in the car, start driving along it was like the road and the white line were like this so I went to make an appointment".*
> FGI participant

As far as the participant was concerned, this was the event that motivated her to seek professional help and subsequently be diagnosed as hypertensive. Biomedical explanations for hypertension have little similarity with this participants experience. It is therefore not surprising that participant's explanations for high blood pressure are very different from biomedical explanations.

The participant in the extract above was in a private medical scheme, Lloyds Hospital Plan and was therefore able to see a doctor almost immediately about this event, she choose to use private medicine rather than her NHS GP for her initial consultation during which hypertension was diagnosed:

> *"So I went to make an appointment that same day to the Park Hospital and it takes me two and an half hours to see a doctor at the top because I am a member of Lloyds Hospital Plan, so I can sort of do what I feel like doing and he says your blood pressure up".*
>
> FGI participant

Analysis of the data suggests that the issue of arranging an appointment within two and a half hours of contacting the Park Hospital was an important factor in the participant choosing use private medicine, rather than her NHS GP.

A major change in physical functioning in common with the last extract motivated the participant in the following extract to seek appointment with her GP:

> *"I didn't know I had blood pressure, I just woke up one morning out of my bed and I was going...I've got a sink in my bedroom and I was going to the sink got up of the bed about here and I was to the sink that way and then I saw myself going this way and I went 'oh no' you know and then I put myself back on the bed and they my husband says to me 'what's the matter?' I said I don't know I just felt like I'm going the opposite way to where I wanted to go".*
>
> FGI participant

This incident prompted the participant to seek the advice of her GP. The participant, in contrast to most other participants in this study, sought the help of her GP almost immediately when she experienced signs or symptoms of illness:

> *"If I feel ill I love to go the doctors not that I love to go the doctors but I just love to go and find out what is the matter so I can do something about it. So I says to my friend I'm going to ring the doctor now and tell her and I rang the doctor and she said come in the next day. So when I went... I couldn't see doctor that's Dr. C so I went to a new doctor, Dr. D so I'm still with her now for over a year and the when I went to her and told her what happened to me and How I was feeling, I don't feel quite right, she took my blood pressure and sound me and she says oh you've got...our blood pressure".*
>
> FGI participant

What is interesting about the extract above, is that although the participant is fully aware that she has high blood pressure, she seems reluctant or unable to state this preferring to allude to the notion of hypertension by simply stating 'your blood pressure'. Feelings of shock accompanied the initial diagnosis of hypertension:

> *"I always think I'm a healthy person so I try to*
> *keep that way so when I heard I had blood pressure*
> *I must say that I was shocked and when she gave*
> *me the tablets I says 'well how long have I got*
> *to take these for?' she said 'as long you live'".*
> FGI *participant*

The initial diagnosis of hypertension was for some participants accompanied by a gradual realisation of the seriousness of hypertension:

> *"On the surface you see I thought it was just*
> *one of those things. I mean watch them give me*
> *tablets and let it go away but then he told*
> *me it's for the rest of your life and it's serious".*
> FGI participant

The participant appears to imply he was familiar with hypertension as 'just one of those things', but not fully appreciate of the longevity of the condition. Other participants agreed:

> *I didn't know the full meaning really when they*
> *said high blood pressure, I didn't know the danger*
> *or what could happen to you ...so like a cold*
> *something like that".*
> FGI participant

Other participants disagreed, stating they were aware of the seriousness of hypertension, but did not fully explicate the potential consequences of hypertension:

Participant 1	*"I realise (the seriousness)*
Participant 2	*"I think it serious"*
Participant 3	*"Yes I think"* FGI

Although brief comments were made, clear consensus was evident and signposted an area for deeper investigation in the next stage of data collection, the semi-structured interviews specifically in relation to the extent to which participants understand the seriousness and consequences of their condition. Questions concerning this issue had to be carefully articulated to avoid alarm.

Although a number of participants appeared to experience 'dramatic' events prior to presenting in PHC for diagnosis, this may be a unique feature of these particular participants, as many individuals experience asymptomatic hypertension and therefore may not seek help early in the disease trajectory. The FGI data are limited in the fact that it is not possible to establish how long the individuals were hypertensive prior to experiencing 'dramatic' events. The data also provides some evidence of the tacit knowledge held within the African Caribbean community that 'high blood pressure is just one of those things' so may be regarded as a minor complaint, that does not need the immediate attention of a GP. If the participants did experience early signs and symptoms, what prevented the recognition of these symptoms and help-seeking behaviour? Missing from the data in relation to diagnosis is any reference to the notion of shame or stigma associated with the condition of hypertension. This is surprising as the literature suggests that other chronic conditions e.g. diabetes are stigmatised (Scrambler 1998).

The meaning of high blood pressure

The findings in this theme describe the impact of high blood pressure on life experiences and opportunities. The impact of wider societal structures; both contemporary and historical are explored. In addition participants' understanding of the cause of hypertension and participant's explanatory models of high blood pressures are evidenced.

Explanations for hypertension and lay models of high blood pressure

The data related to explanations for high blood pressure and lay models of high blood pressure are interesting as participants' explanations seem to bear little or no similarity with biomedical explanations for hypertension, often focusing on external triggers or precursors that are perceived as axiomatic causes.

Historical antecedents

The data present perceptions of current hypertensive health status and historical antecedents, specifically the Transatlantic Slave Trade. Whilst it is clearly not possible to establish in the conduct of contemporary studies causal links in terms of illness and dysfunctions with modern-day populations of the African Diaspora, the literature does provide evidence of tentative theories and observations.

The role of diet

The diet given to forebears by 'slave masters' was said by a participant to be fit only for animals and very high in salt content in order to preserve the foodstuffs during the middle passage. In other words, barely fit for human consumption. In the extract below, the participant locates this issue as influencing greatly the genes of African Caribbean people and the propensity towards hypertension:

> *"To me, my contribution people say is when the slavery time when they were going to take in the black people to the West Indies, part of America, all the sort of, give my great grandparents, the salt mackerel and salt fish Yeah it's right I feel that, it's a thing that follows the genes along the line, it's not just happen yesterday unfortunately it's within the genes because he slaves were fed on the things that should have given pigs".*
> FGI Participant

The participant appears to be linking the cause of hypertension with an unhealthy diet that may have acted as a precursor to a form of genetic evolution:

> *"The slave masters bringing us my great grandparents across the water, what they do is catch herring fish, put it in brine and they feed the slaves with that. That were meant to, because it would spoil so they put it in brine to keep it so the slave weren't, they were hungry but it was no good for them"*

> *"Right they didn't want them to die, don't want them to bring them to work, as workhorse so along the line they've fed us, my great grandparents with things like salt or petre. Saltpetre goes into mackerel now, even now in cigarettes there's saltpetre that goes in it and saltpetre's one of the main thing that giving people high blood pressure as well as in the cigarette cause they tell you about cigarettes give you high blood pressure, your blood pressure can get high and that is one of the things that's in cigarette as well so you can see what amount of saltpetre that my fore parents eat which go to the genes of our parents and I think that is where we are suffering with high blood pressure now".*
> FGI participant

The meaning of these statements seems to indicate that the participant is not surprised that African Caribbean populations have hypertension given the experience of previous generations. Statements seem to imply that as this has occurred over generations, it is unlikely to be resolved quickly and easily in the 21st century.

In the participants' view, the lived experience of African Caribbean people with hypertension cannot be isolated either from historical antecedents, both more recent, and the distant past. The social and economic position of African Caribbean people in the study may be causality-related factors in terms of precipitation of hypertension and mediation of the experience of hypertension on a daily basis. Torkington (1991, 1995) agrees with these viewpoints in her writing.

All the statements related to the Transatlantic Slave Trade were made by one participant in one of the FGI. Other participants neither, agreed or disagreed with this participant, but appeared very deferential to this participant's viewpoints. However, some commonality between the FGI participants did existed in identifying diet, specifically the Caribbean diet, as a possible contributory factor in developing high blood pressure. Consensus appeared to be achieved in one of the FGI in relation to the role of a traditional Caribbean diet with the development of hypertension in African Caribbean people in England:

> *"I think its, my idea yes I think black people as far more sensitive. I think we for me at my age when I was in Jamaica we used to use lots of salt, I think that is, that is a lot is lot of sweet, starchy foods".* FGI participant

> *"a lot of black people, take salty food they started...well you know a lot of peas and chicken and fish and yeah, greasy food like that".*
> FGI participant

Whilst participants agreed that some aspects of a traditional Caribbean diet might be unhealthy, other participants disagreed stating that a traditional Caribbean diet was health-enhancing:

> *"Yes I'm afraid to differ here you see because what change what changed, what changes everybody, black people in this country is the custom of eating food because life can get, you remain eating, my mother died when she was 90 years old, my father died when he was nearly 100 and the only thing that affects him, he smoke all his life and until that time you see they never get that kind disease what we are accustomed. When we came to England right, because a dietician, when I was the doctors couple months ago he referred me to a dietician, a lady and she sat down and she gave me a pamphlet and she said what, she was referring to my high blood pressure and that... And she said to me, you know what's wrong with, do you mind the expression 'you people' Caribbean? I didn't object to her saying that because she was directly telling me that the food we eat before was good for our system and she said one of the thing missing in your starch, in your blood, you used to have all the starchy food, the yam and potato and then*

> *suddenly you came here and start to eat fish and chips".*
> FGI participant

However, this viewpoint was countered by another participant who had knowledge of a relative who only ate Caribbean food whilst in England, but went on to develop diabetes:

> *"my Aunty she still here, in her house, there is nothing English in it like food.....when she brought your dinner down it's roast breadfruit, swordfish with tomato and she don't have nothing English in her house.....she's diabetic, she's diabetic".*
> FGI participant

Participants' views were mixed in relation to the health value of a traditional Caribbean diet and how this might influence the development of hypertension. A limitation of the data is that no reference is made to the English diet and how the English diet might influence the development of hypertension. Linked to the diet and a logical progression might be the role of obesity as a risk factor for hypertension, but no mention was made of obesity. This is surprising given the increased prevalence of obesity amongst women of African Caribbean origin (Cappuccio et al. 1998, 2000)

Other perceptions of hypertension

Once diagnosed with hypertension, the extract below reveals how the participant had difficulty viewing herself as the 'type' of person who might be prone to developing high blood pressure:

> *"I didn't realise that I had high blood pressure because I'm a person who always happy as Larry"*
> FGI participant
>
> *"Because if you're a person who hypertensive you tend to be ...you're person who hyper all the time"*
> FGI participant

These extracts are very interesting as this particular participant also gives quite detailed information about the stress she is experiencing in her life, but clearly does not regard herself as 'hyper' or a hypertensive type. Another participant believed that personality type was important factor in being regarded a 'hyper':

> *"Also personality cause other people do have the same thing (stress) and they don't realise but they don't show it, me I got to show and it's so dreadful it's a feeling that, even Dr .J, he told me he said don't worry about it cause it's build in, it built in my personality".*
> FGI participant

The view expressed above does seem somewhat fatalistic, in relation to the acceptance that development of hypertension might be a manifestation of a particular personality type and in this sense immutable.

These statements lead to questions regarding the nature of the term 'hyper' and what this means to the participant. As the answer to this and other associated questions regarding hypertensive types is not apparent in FGI data, the notion of 'a hypertensive type' is explored in more detail in the semi-structured interviews.

Other perceptions focused on the idea that an incident such as a fall might trigger off illnesses such as hypertension and diabetes. As can be seen from the extract below (which is a conversation between several participants) below there was agreement and consensus in the group regarding this notion:

> *"Is a fall a thing can trigger off illness"*
> *"A fall?"*
> *"A fall"*
> *"Yeah"*
> *"Or you know bang yourself, it trigger something else"*
> *"If you fall, I think they said it brings on, it can get you know diabetes from that"*
> *"Yeah and cancer also because you know the story about Bob Marley it's true, your thinking of football. I mean boxed his toe and just that's how he gets cancer"*
> *"Yeah?"*
> *"Yeah, just play football"*
> *"I know they said in, I don't know if this is true, they say that everybody has got a cancer cell"*
> *"That's right"*
> *"And something can trigger it off"*
> *"Also everybody has got a pressure, it's just when it gets high".* Interaction between FGI participants

In many respects that final sentence is correct in a physiological sense, as all humans do have a level of pressure in the circulatory system that allows the blood to circulate in our bodies and defy gravity. However, it is not clear whether the participant's perception of high blood pressure, refers to a medical definition or a lay perspective. What is interesting in the interaction is the taciturnity in relation to personal action and behaviours in relation to the lifestyle. The silence in this domain is a feature of the FGI data, as participants locate the development of hypertension as pre-empted by external events, forces, or stimuli that in a sense, they have little control over. A fall or bang may be considered as a chance accident or fate, over which the participant has no control.

Consequences and management of high blood pressure

This theme explores the impact of the diagnosis of hypertension has on everyday living and experiences such as work, home, leisure, social life and family relationships are explored.

Medication and concordance

Much of the data in the FGI are focused on medication; the different types of medication prescribed, the number of tablets taken and why these medications may or may not be effective. Participants also describe their non-concordance with prescribed medication.

Participants described different motivations for their non-concordance. The participant in the extract below is reluctant to take the prescribed medication as she feels her body will become accustomed to the prescribed medication and render the medication ineffective:

> *"my body's sort of funny, it reject things ever so easily and I thought perhaps that what happened with husband number 1 where I rejected him so early(LAUGHTER). I couldn't be bothered with him you know but anyway they persevered with me until we changed the range of the blood pressure tablets, decided well my doctor look into her hand book and said, she says I've got two left to go in the whole hand book. We don't know if it will suit you but we've got two left to try".*
> FGI participant

The participant in the above extract appears to have tried a number of different anti-hypertensive medical therapies. Somewhat jokingly the participant stated her GP has informed her that she only had two medications left in the 'whole handbook' and furthermore doubts about the suitability of the last two medications are expressed. This seems rather alarming for someone who has a chronic condition such as hypertension that potentially will require lifelong medication. Insight into why the participant does not appear to be distressed by this knowledge can be found in the following extract:

> *"I don't take them because I always a person who keeps saying to myself well I don't want to keep taking them everyday because it going to go against me. You know because it soon don't work for me so I've got Aloe Vera what I have planted at home and I sort of says right I'm going back to root now. And whipping up my Aloe Vera and taking also home-made".*
> FGI participant

The participant does appear to express some concern in the extract above in the sense that she speaks about the tablets 'going against her', in other words not working for her benefit. However she goes on to share that she does not take her medication because she has an alternative, Aloe Vera. Aloe Vera, a plant that commonly grows in Jamaica there are many different types, some of which are houseplants that can be purchased in England. These plants grow outdoors in Jamaica. Many people of African Caribbean origin who acquire this plant often bring back to England plants obtained in Jamaica whilst on holiday. The colloquial name of the plant is 'single or singer bible' which appears to be a according to a participant, a corruption of the Latin term 'semper viva' meaning long life or always long living. The value of this remedy is further validated for the participant when she visited her GP:

> *"I never said to my doctor, well I stop taking the tablets but she says my god your blood pressure is low and you're lower than mine!"*
> FGI participant

The participant had substituted her herbal remedies for the medication prescribed by her GP and this appeared to be lowering her blood pressure. It is therefore not surprising that the participant continued to use herbal remedies for blood pressure control.

Another participant described her non-concordance as emanating from experiencing side-effects from the prescribed medication:

> *"Because my doctor would insist on certain tablets and says this in the one you've got to take and I know full well it give me thrush and I'll say, well I'm not going to argue about it but I'm saying that because I've got something else that I would use herbal that can have the same effect. I'll just let my doctor feel that, yes well I'm taking it but I'm using a herbal thing".*
> FGI participant

The participant in the extract above provides an insight into the level of communication in the GP/patient relationship that appears not to be fully open or honest. The participant's perception that the doctor 'insists' on a course of action appears to suggest a power structured hierarchal relationship with little reciprocity or mutuality in the relationship, especially as the participant is experiencing side-effects from the prescribed medication. There also appears to be a note of conciliation and not wishing to argue or upset her GP. Another participant was surprised to find he was receiving further medication to treat the side-effects of his original treatment:

> *"now I discovered that they are giving me tablets to relieve me from the side-effects of the other tablets. Okay And he confessed you know he told".*
> FGI participant

It is interesting that the participant chose to use the word confess in relation to his GP's communication, as the term usually refers to an acknowledgement of wrong-doing or the committing or an offence or opening up and being honest.

Another participant gave an explanation for non-concordance that lacks a clear motivation for the non-concordance:

> *"Let the doctor see how the get on with these tablets, but what I find, I find that half of the time I never take the tablets".*
> FGI participant

Some diversity therefore exists in the type of non-concordance described in the FGI, ranging from cessation of prescribed medication because of side-effects, to an expressed preference for herbal remedies. In some cases no clear reason was given. One participant expressed a preference for a specific type of prescribed medication, diuretics:

> *"I take the Royal Jelly, Ginseng and I take Aloe Vera, get them all together you know in one blend and I take that but I also take the water tablets but I think because the water tablets help more than the blood pressure will do, tablets will do, that's my feelings anyway".*
> FGI participant

Interestingly the participant makes no reference to whether potential adverse consequences can occur from mixing diuretics and the herbal remedies mentioned.

Participants readily revealed that they did not always take medication, with little probing or further explanation. A consensus existed in the FGI that sometimes one did not take prescribed medication for various reasons for example simply forgetting or going on holiday and feeling more relaxed. None of the participants expressed views that indicated they were strongly concordant with prescribed medication. This domain of non-concordance highlights a significant area for further investigation in the semi-structured interviews in order to uncover deeper understandings of the management of hypertension in PHC for individuals of African Caribbean origin. Important questions raised are, for example, the reasons that participants feel unable to share non-concordance with their GP and the extent to which participants view non-concordant behaviours as 'risky behaviour'. Further exploration is required regarding non-concordance to establish the extent to which non-concordance is an individual behaviour and a manifestation of an individual health beliefs or explanatory models or whether non-concordance are characteristic of people who have migrated from Jamaica.

Herbal remedies

The FGI data evidence that a number of participants use traditional Caribbean herbal remedies and bush teas either complementary to, or as an alternative to, prescribed medication. Furthermore, this method of self-care for some participants is the preferred method of treatment for their high blood pressure:

> *"I take my herbal and I find that it works better than taking these tablets".*
> FGI participants

Although the participant provides no further explanation as to why she believes the herbal remedies are more effective than prescribed medication. The limited value of prescribed medications, are further evidenced by another participant in the following extract:

> *"Nettle and quite a few different things is very good for high blood pressure and it's not tablets from the chemist, it's herb, I'm not saying that they are no good (tablets), they are good but I didn't want to continue on these tablets because sooner or later I know they're going to...they won't work for me if I keep taking them so now as soon as the fresh Nettle coming up in our allotment I'm there picking it instead of cutting Callalou and I steam Nettle, I eat it, it's lovely ".*
> *FGI* participant

The participant is not fully dismissing prescribed medication, but it is clear she has a preference for herbal remedies. Also interesting is the comment of the participant that the herbal remedies she uses are not from a chemist, but a growing plant or bush i.e. natural, from nature. This dimension within the African Caribbean community may be characteristic of the study population when using herbal remedies, as only one or two participants in the entire study sample mentioned purchasing herbal remedies that might be described as a European or Western practice, from a chemist or herbalist such as Holland & Barrett. Consensus and agreement of this was evidenced in the focus group:

> *"A lot of people grow in their house".* FGI participant
> GENERAL AGREEMENT

Some traditional Caribbean herbs are grown inside as they require a tropical climate; often participants grew these in their bathrooms.

Consensus emerged in the FGI regarding the value and efficacy of traditional Caribbean herbal remedies. Occasionally, new knowledge was gained whilst holidaying in Jamaica:

> *"Yes when I was in Jamaica that happened. As I said I took the tablet to take and when I went out I was sweating and somebody, old time lady came to me and said...I said I've got high blood pressure and she said wait on, and me makes her stuff Ginseng root and she wind it up and she give me a bottle full and I tell you I never take any other tablet and I feel, I was sweating most of the time".*
> FGI participant

The participant in this extract makes several references to sweating in Jamaica, but I am not sure of the relevance of this. Usually traditional Caribbean herbal remedies are taken as an infusion of bush tea:

> *"Well only once in the morning, I'm not a tea drinker (English tea) then I tend to have probably ...do something else rather than...I use all sorts, I use Nettle leaves, Rosemary, Dandelion, Cerassee".*
> FGI participant

The exception to this is Aloe Vera from which the inner white resin is used:

> *"What I do is take of the top peel, the top skin of it and the inside of it is a sort of a jelly and I put it in the blender and I blend it and I put some like Ginseng with it".*
> FGI participant

The data in the FGI is limited in the sense that little explanation (with the exception of one extract) is given as to how individual's acquired knowledge of the use of traditional Caribbean remedies. Absent from the dialogue is reference to other family members or key individuals in Jamaica who may have handed down this knowledge via socialisation processes, or indeed whether the participants were recipients of such remedies as children growing up in Jamaica. What is clear is that a tacit knowledge is held by the participants in the FGI. However, this knowledge or its'acquisition is unarticulated. However, one participant stated that she had never heard of traditional Caribbean herbal remedies:

> *"I don't know this is really new to me what everybody is saying very interesting".*
> FGI participant

As only one participant stated that she did not use herbal remedies, this dimension of the study requires further exploration within the semi-structured interviews, in establishing the characteristics of participants who do or do not use traditional herbal remedies and what this might mean for the provision and management of hypertension in PHC for people of African Caribbean origin.

In the FGI the use of herbal remedies was not shared with GP's:

> *"I never said to my Dr. Well I stop taking the tablet".*
> FGI
> participant

The extract above appears to suggest that sharing the use of herbal remedies with GPs may result in negative consequences, although as none of the participants appeared to have shared this information with their GP therefore it is not possible to establish if this would be a consequence. Another participant confirmed this view:

> *"Yes I would (use herbal remedies) but well it's no use ...I couldn't go back to the Dr having said and doing something cause they would have thrown me out"*
> *"Well you see you've got to keep a quiet and it's dangerous you see".*
> FGI participant

The participant in the extract above appears to be suggesting that it would be damaging to his relationship with his GP to share that he was using herbal remedies. Furthermore he suggests that the potential exists for him to be removed from the surgery or his GP's list. Whilst a number of participants shared their use of traditional Caribbean herbal remedies, some participants recognised that perhaps herbal remedies ought to be used with caution in the same way that prescribed medication is used with caution in relation to dosage and potential side-effects:

> *"Yes take one (herbal remedy) for blood pressure and one for cholesterol, you are taking tablets you can overdose, herbs can overdose you have take it wisely".*
> FGI participant

The participant in the extract above appears to be indicating that there are potential dangers associated with using herbal remedies and that care is needed in the consumption. Another interesting dimension to this participant's view-point is the notion of using herbal remedies 'with wisdom'. The participant does not provide an explanation as to how she or others might acquire wisdom on this topic or what wisdom means in the context of herbalism. This participant elaborates on this in the extract below:

> *"You don't keep going (with herbal remedies) you use with discretion everything is in moderation let me tell you*

> *don't, sometime take 5 leaves, should only take maybe two or three or maybe just one leaf".*
> FGI participant

This participant is the only participant in the FGI who expressed a note of caution in the use of traditional Caribbean herbal remedies; it is surprising that none of the other participants referred to this dimension, although they were clearly using herbal remedies.

Consequences of hypertension

Participants discussed areas of their everyday life experience which they had either changed or attempted to maintain as a result of their hypertension. Some of these events were quite dramatic; others less so. The extract below describes a situation when a participant had to curtail a holiday:

> *"This was very worrying, went on holiday to Spain with my friend with her first cousin, and she said to me, following morning she says ooh you frightened me in the middle of the night, you know she was so concerned about me and she say's well when you breathe I didn't think you was going to start again because your breathing stopped. Anyway she says I didn't think you was going to wake up. I break my holiday and come home because this thing really worrying me, I thought supposes I breathe in and I never breathe out, you know and I booked a flight and it wasn't at the time when I should come home so I have to book extra flight and I come home. Went back to the Z Hospital and tell them what my friend said and they says well stay in overnight and we will monitor you sleep and the monitored my sleep and say 'oh your blood pressure's getting worse' and they start me on about 7 different tablets".*
> FGI participant

The extract above demonstrates the negative impact that hypertension can have on commonplace experiences such as going on holiday; this participant's experience was singular within the FGI. Participants were aware of the potential negative health consequences of being hypertensive:

> *"She said because she told you can get stroke and get it, I think it's stroke she said or heart attack? Yeah heart attack".*
> FGI participant

The participant in the extract above is slightly tentative and does not appear to absolutely certain. Another participant agreed that that being hypertensive is accompanied by an element of risk:

> *"...going to have to slow down, if you are over you will have heart attack. I have an hour lay down".*
> FGI participant

Whilst some discussion occurred in the FGI regarding the potential dangerous consequences of hypertension this was between one or two FGI participants. More participants were silent on the issue and did not acknowledge this potential danger.

Little discussion occurred in the FGI regarding what might be described as traditional risk factors associated with hypertension such as diet, smoking, exercise or nutrition with the exception of alcohol. These omissions may be significant in attempting to shed light on how participants perceive their self-defined condition of high blood pressure as opposed to hypertension, a medically defined condition with associated risk factors. What is also absent from the data is any reference to subsequent lifestyle and modification to risk factor activities as a consequence of the diagnosis of hypertension.

Excessive alcohol consumption is a risk factor for hypertension. Discussion occurred in the FGI on alcohol consumption with wide disparity in drinking practices evident among the participants of the FGI. One individual was very adamant that having high blood pressure was not going to change or alter her life-style in relation to alcohol consumption:

> *"No not really because from the day, I know myself I always have a glass of whiskey every night before bed, that's my, I look forward to that and even when I lay in the coffin the bottle over the coffin right, that's mine and I don't drink otherwise, just have one glass of whiskey a night, one drink of whiskey at night with hot water and I always have that and it, even if I have blood pressure - I'm still going to have, I'm still going to have it".*
> FGI participant

It is clear that this participant is only able or willing to make certain lifestyle modifications to assist in the management of her hypertension and in any event, one glass of whiskey, if this constitutes one unit would be described as light to moderate drinking. However her strong views on this topic could be a desire to maintain her lifestyle or a general philosophy of living life to the full:

> *"Well I might as well die merry cause there's no enjoyment, no life you know so I'm not going to cut everything out there is something's what I can do differently moderation".*
> FGI participant

The issue of control and empowerment seems important here, in that the participant needs some control over her life style choices. On the other hand these viewpoints could be related to recognition of the participants own mortality and *why not live life to the full.* It is interesting that the same participant also gives information later regarding that fact that there are only two more tablets in the book to try (because she has experienced side-effects from other anti-hypertensive medication prescribed) and earlier speaks about her reflection on death and dying. The meaning of what is said seems to be related to the notion that I am going to die sooner than most, therefore I am going to enjoy myself as much as possible. Later this participant describes her lack of alcohol consumption outside the home:

> *"You know I can do it differently. I like going to clubs. I'm a club person. Yes I do have a drink when I go to club but I will drink tonic water. I will drink fizz lime and tomato juice. There's lots of things I can choose to drink you know but I'm a happy person. I'm not one for you know".*
> FGI participant

I am not sure why this participant appeared to shift her position, when speaking about alcohol consumption outside the home.

The viewpoints expressed in the extracts above, concerning alcohol consumption were not an area of consensus in the FGI as most of the participants neither agreed or disagreed with the participant or indeed shared information about their own alcohol consumption. In fact most were taciturn about this experience. One participant stated that she had a very small alcohol consumption:

> *" I don't drink so I drop a little rum in my teaspoon".*
> FGI participant

The experience of moderate drinkers does not appear to be present in the FGI data which is surprising, as social life within the African Caribbean community is very important. Following the first wave of migration, many communities established their own social clubs and venues. Therefore it is surprising to me that this experience is absent from the data. No reference is made in the data to the relationship between excessive alcohol consumption and the development of hypertension. It is surprising that participants did not mention this in the dialogue and discussion, although this may be related to that fact that lay interpretations of high blood pressure are not associated with biomedical risk factors.

In describing the consequences of hypertension, participants made little reference as to how their diagnosis might impact upon other family members or their relationships with other family members. Several participants stated that their hypertension did not affect other family members in any way:

> *"Yeah but really I can't see where it affect my family because what'so ever happen I don't allow it to".*
> FGI participant
>
> *No, no if I am ill I don't tell anybody at all. I sort of keep it to myself".*
> FGI participant

I found these viewpoints surprising; in fact, no participant stated that their hypertension impacted on other family members. One participant, however stated that she liked to share with other family members that she felt unwell:

> *"If I've got a headache the whole house know".*
> FGI participant

The data mapping out affects on other family members is somewhat limited from the FGI and therefore this domain provided an important area of further investigation in later data collection. Furthermore, the FGI gave little insight into the psychological consequences of the diagnosis of hypertension in relation to stress, worry or anxiety about the condition.

Consultations in Primary Health Care

This theme explores the participants' perceptions and use of NHS Primary Health care services and private GPs from their own perspective. Relationships with PHC professionals both in NHS and private domains of PHC are determined.

Most participants in the FGI expressed satisfaction with the NHS PHC they received which was usually in the form of GP consultations:

> *"Yeah to me it's a matter of choice, you pick a Dr, that and you say, do want to see them? But as I'm concerned it's a good health service that we are in".*
> FGI participant

Whilst satisfaction with PHC was not universally expressed, the dissatisfaction expressed focused on appointment systems and access to the participant's GP of choice, when there were several partners in a practice:

> *"Sometimes, the doctor that you'd like to see, always either on holiday or is call up and you're feeling really rough today and you can't see the doctor until the next*

> *week and next week you feel, what I am going to the doctor's for you know".*
> FGI participant

As demonstrated in the extract above the participant is not dissatisfied with the actual care provided, but with the processes involved in obtaining an appointment. This viewpoint is further re-iterated in the following extract:

> *"It's always an appointment. I'm not saying it's not good but I'm saying sometimes when you really feel, you think you feel poorly and you want to see the doctor you have to make so likes it's really, really emergency. I've done that a couple of times".*
> FGI participant

Furthermore the participant appears to be stating that he exaggerates the seriousness of his condition in order to obtain an appointment. One participant however, had the opposite experience as her GP operates an 'open house' policy in relation to consultations:

> *"My doctor has an open door during the surgery in the morning, you may not see her but still doctor is there, you can see any one of her doctors".*
> FGI participant

Only one participant in the FGI expressed dissatisfaction with his GP consultations and was quite vociferous in doing so:

> *"Well for six years now I've been angry, the treatment I'm having and as I say if I take the tablets am I right? That's what I'm looking on, is it for the rest of my life you know or am I going to get cured. I've had difficulty walking so I want my car licence back. I've been to him yesterday (GP) for a medical but I feel he's (GP) just laughing".*
> FGI Participant

The participant in the above extract was apparently told he could no longer drive because of his medication and is extremely angry about this. The participant went on further to explain that he was advised by his GP not to reapply for his driving license:

> *"He (GP) said it won't cost you any money to apply for it, it's not worth it because I'll be 65 in April".*
> FGI participant

He believed that ageist mechanisms existed in the treatment and care received in PHC; as he goes on to explain:

> *"Well at my, I believed at, my friend said is there a ceiling on the treatment that you get. The older you get…the less they want to spend on you, I've got evidence".*
> FGI participant

The participant then goes to give further explanation regarding a relative who was registered with the same GP:

> *"My uncle dies in August and he was 76 and he left Dr.X (participant's GP) because he reckoned he was not giving him enough treatment, he left and went to Dr.Y (private GP) and Dr.Y put something in his head saying that the government only pays him keep under 75's".*
> FGI participant

Overall, the participant seemed to be dissatisfied with his GP and care provided, and this was re-iterated by the experience of other family members. Although minor and one more serious concern was expressed in the FGI, participants did not share information as to whether or not they had considered changing their GP or what factors supported their continued registration with the their GP despite a level of dissatisfaction. This domain is further investigated in the semi-structured interviews.

Summary

The FGI interviews provided the mechanisms for a broad scoping of the issues of concern relevant to the research aims and objectives. Four themes emerged from the findings as important areas for further investigation in the main study sample of semi-structured interviews and final data collection method of vignette interviews. The themes identified were **Early diagnosis, the meaning of high blood pressure, consequences and management of high blood pressure and the participant's experience of PHC.** The nature of the FGI, a group discussion means that the themes identified are not investigated in depth; this is the function of the subsequent data collection tools in facilitating a deeper exploration as is characteristic of the focused ethnographic approach.

Chapter 8

Findings – Semi-structured interviews: Early diagnosis

The findings of the first theme (early diagnosis) identified in the data elicited in the semi-structured interviews are presented in this chapter. The themes identified in the analysis of the interview data reflect those in the FGI, to reiterate: 1) **Early diagnosis.** This theme premises significant events and precursors to participants' presentation for diagnosis in PHC. The theme also includes processes and systems involved pre-diagnosis. 2) **The meaning of high blood pressure.** This theme maps out the impact of high blood pressure on life experiences and opportunities. The impacts of wider societal structures both contemporary and historical are explored. In addition, participants' understanding of the cause of hypertension and participant's explanatory models of high blood pressures are evidenced. 3) **Consequences and management of high blood pressure.** This theme includes the impact the diagnosis of hypertension has on everyday living and the strategies that participants employ to manage their high blood pressure such as the use of herbal remedies, concordance and non-concordance and finally 4) **The participant's experience of PHC.** This theme explores participants' use of NHS Primary Health care services and private GP's. In addition, relationships with both NHS PHC professionals and private GP's are explored.

The chapter provides a further exploration of key concepts identified in the FGI by providing the opportunity for individual in-depth exploration. Further evidence is provided in attempting to answer unanswered questions arising from the analysis of the FGI. The semi-structured interviews build and expand on the findings of the FGI by giving greater meaning and insight into the themes, contributing to the process of iteration (Murphy *et al.* 1998) and providing a means of triangulation of the data (Denzin & Lincoln 1998).

Early diagnosis

This theme includes the precipitating events, processes and systems that operate to determine participant motivations in respect of early presentation for diagnosis in PHC. Hypertension is a condition that is frequently symptomless (Morgan 1993). Many individuals may have hypertension but be unaware of this; therefore the condition may progress considerably before a medical diagnosis is made. A number of individuals in the semi-structured interviews expressed shock at the diagnosis and many had a clear recollection of the preceding events although diagnosis may have occurred several decades earlier. Some individuals made links between migration, stress experienced in the host community England, and the subsequent diagnosis of hypertension. In common with the findings of the FGI, participant's explanations in relation to the aetiology and origin of their hypertension did not reflect medical opinion or biomedical understanding of the physiology of hypertension. None of the participants located conventional medical risk factors as the precursors of their hypertension. Participants in the study had been diagnosed with hypertension from 1 year to 24 years.

Significant precipitating events

A number of the participants recalled significant events that they regarded as precipitating their hypertension. For most participants these events focused on personal circumstances and on the events immediately preceding the diagnosis. These accounts are very vivid and perhaps provide a measure of the significance of these events in the participant's lives. Loretta comments:

> *"Well, another thing is, it's like I was under a lot of stress. Erm, and I more think they started through those stress and so on.*
> *But, anyway, the first time I went to the doctor about it was one day. I got up in the morning, and I had this terrible headache. And it was I could hardly lift my head. And I remember, I was on my own in the house, and lying down on the settee, there and we had Insurance man used to come in. The door was sort of left open and he, when he came in, he knew where to find the books and things, but I couldn't even lift my head".*
> Interview 17

The extract above provides evidence of the extent to which the initial symptoms of hypertension immobilised Loretta in her own home, even though she knew a relative stranger was alone downstairs in her home. The incident described occurred twenty-four years ago. I was struck by the Loretta's clear and graphic description as though the event were in the recent past. She goes on further to elaborate:

> *"... And then I started with this heavy nosebleed.*
> *L ...made me seek medical aid and I went to the doctor. And then he said I had, the pressure was so high that he was a bit frightened, in a sense".*
> Interview 17

Interestingly Loretta does not state that she has high blood pressure or hypertension, but states that her 'pressure' was high. The notion of 'pressure' being associated with health and normal was evidenced clearly also in the pilot study FGI, when a participant declined to join the FGI, as he did not have hypertension, but 'pressure'. Other participants have used the word 'pressure'; this is explored in more detail in later in this chapter (*cf* chapter 9). Loretta was sensitive to her GP's anxiety regarding her condition and goes on further to explain:

> *"And he gave me the things to take and he said 'Well, make sure that ... now.' Try to get as much rest and sleep and so on. And then he would check again and if it was like that, or continue like that, then probably he would have to send me to the hospital, because one thing he was, sort of, worried about if I might get a stroke really, because it was so bad".*
> Interview 17

It is clear from the extract above that Loretta was aware of the possibly serious consequences of her condition.

Significant events at work

Jerome described the first signs and symptoms he experienced of hypertension occurring whilst he was at work. Although this event happened twenty years ago, his description was quite vivid:

> *"Erm, well, as a matter of fact I do remember that one, I was at work and we had some visitors around, and I noticed that I wasn't, I kept on being dizzy through the week, but this particular day, we had some visitors around. Well, I'm a bit, you know, nervous when it actually gets to people being interviewed, or even people being shown things, and in our particular department, we had a lot of people coming round, and I think what I must have done is just got really excited, you know, people coming up to us and saying 'Oh, I hope they don't come and see me, 'cause I don't know what I'll be able to say'. Well, anyway, they came past, they didn't say anything, but, by that time I noticed that all my hands just cramped up like that... ...and I got a funny feeling, sensation in the chest... and not being able to breathe, so, one of the chaps came back, and he noticed me, and he says 'It's not like you. What's the matter?' So I says 'I don't really know'. So, after the people went, he says 'I think if I were like you, I'd get down to the medical centre.' So I went down there and told them, checked the blood pressure, and they says 'Your blood pressure's high', you know, and basically that was the end of it. So, they said to, erm, 'when you back home, make an appointment with your doctor'. So I did".*
> Interview 3

Jerome was diagnosed at a relatively young age; 30 years. Interestingly, in his description he states "*that was the end of it*" which in many respects, was a literal statement as shortly following this, the participant was forced to take early retirement from work due to ill-health. Several participants such as Carmel had similar experiences in that their diagnosis of hypertension resulted in early retirement:

> *"And if it wasn't for the illness, you know, because while I was working, I found out that I'm just feeling ill, tired, don't want to get up to go to work, and just feel worn out and like my body's worn down. And, erm, I go to work and erm, I ask for a retirement"...*
>
> *But I had to ask for retirement and I retire I'm 63. And, erm, I still wasn't feeling very well and I had to go to my doctor, because my children says 'Mam, you'd better go to doctor', and when I got to doctor, doctor says 'oh, you have high blood pressure.'".*
> Interview 20

Carmel provides a good insight into how debilitating the condition can be when the individual attempts to maintain a normal working lifestyle. Both Jerome and Carmel were understandably disappointed by their early retirement.

Some participants linked the onset of hypertension to particularly stressful work experiences. There is a long tradition in African Caribbean communities in England in working in public services such as the NHS, Social Services, and other former state-run services such as British Rail. The context of employment in these organisations is characterised by low pay and shortage of staff. The stressful nature of working in such organisations may be compounded by the racist of attitudes of co-workers and line managers (Beishon et al 1995, Kushnick 1998). Hyacinth, a former social worker, remarked:

> *"At the time, I was going through a lot of issues at work and I was [inaudible] lot of issues around race and victimsation I was under extreme stress. So, I went to my doctor and that's when I was diagnosed with high blood pressure".*
> Interview 19

Although Hyacinth did not elaborate on the nature of the racism and victimisation, it is clear that the events had a profound effect on her health and well being, as she was no longer able to continue her employment. Carlton comments on his high blood pressure and employment:

> *"I don't think it was anything in particular,*

> *just knew that I was, erm, feeling so low that I to see the doctor who counselled me for a little while."*
> Interview 21

> *"And the doctor was saying to me 'the job you do is a very stressful one and what's your method of winding down?'*
> *I said I used to, because when I lived on my own, right, because I lived, I go to work and there was no set time. I'd go there and stay".*
> Interview 21

Carlton had worked for many years as an inner city youth worker. The demanding nature of his role meant that work often spilled over into leisure time and time off.

External influences

Two participants made connections between wider socio-economic experiences in the Caribbean and the process of migration as contributing to the development of high blood pressure. Carlton remarks:

> *"All the pressures of lack of opportunities. Take back home, erm, my Grandmother had a lot of children. Right? Possibly very little income coming in to sort everybody out, erm, but what we eat, we have to grow our own. And what we can't grow, we have to find the money to buy. You have to school everybody. You have to clothe everybody, you know. And sometimes, when you think about that, it's a lot of pressure on the family, especially the Mum and Dad. My Grandmother and Grandfather went through these things making ends meet. And then there's all the issues around immigration, you know, to work, to try and make ends meet. My Dad swanning off when I was one year old to slave in America. So, what you're saying, it's actually started, it's starting before people actually migrate, the pressures of life, and then, even then, there's a consequence for the people left behind".*
> Interview 21.

In the extract above, the participant appears to be locating the arduous nature of life in the Caribbean characterised by relative poverty as bearing some relationship to the development of hypertension. Additionally the consequences of migration created additional stress not only for the migrant, but also for those left behind in the birth country that might be caring for children or elderly people. Pressure of life and stress appear to be key components of this individual's explanation. Hyacinth held a similar view in relation to the context of African Caribbean people's lives in England and the stressors experienced that might predispose African Caribbean people to hypertension:

> *"I think it's about what they have to manage and cope with in life. You know, they have to pick themselves up*

> *wherever they're coming from, they have to take on board, foster a new identity. Imagine that you've been picked up from Iceland, and you play somewhere else and then you've got all that to manage here, right? And the environment, the culture, right, because, in a sense, it's asking them to forget their culture and their sense of identity as well, so all that, I'm sure it's added to whatever stress. Of course African-Caribbean people will be, because, you know, their, whatever they have to manage or deal with in life, is a 100 times worse than what any other people have to deal with, because this is not their country. This is a new culture that they have to, in a way, you know, mingle in and get along with. When you go to Rome do as the Romans do. So, can you imagine the big, the big bit of themselves that they're forgetting in order to function in this society?... No wonder why the stress level is that high in this society, or in, you know, in society. That's my opinion. Not a lot of people would agree with me, I think".*
> Interview 19

In the extract above, Hyacinth appears to locate stress as arising from simply living in another culture and not being a member of the dominant group. Additionally she does also appear to allude to the notion of racism, discrimination and oppression especially in the final sentences, although racism and oppression are not expressly mentioned. What is interesting about the comments of Carlton and Hyacinth is that they are both younger people who have worked in public service sectors and in doing so have experienced quite a lot of work-related stress (*cf* later this chapter). They appear to make linkages between personal health and illness with wider societal structures that shape and define individual's lives. Comments of this nature were largely made by younger participants in paid employment.

Significant events during pregnancy

In this study three participants were first diagnosed with hypertension during pregnancy or in the immediate post-partum period. This hypertension continued beyond the post-natal period, as Petra elucidates:

> *"It is a long time, erm, at first when they discovered that I've got it, erm, I wasn't on any medication. At least then there was, I lost the baby in 1969. It still hurt, you know, and that's when they were checking up on things, and then they told me that I got high blood pressure. You see, I wasn't on any medication until I, I can't remember what year I went up here. I was having some pain around here...*
> *...and then they were checking and checking and the doctor discovered I got high blood pressure".*
> *Interviewee 5*

It seems likely that the loss of the baby was a traumatic and significant event in the life of this participant. Further investigations to identify a cause for the death of the baby revealed that the participant had high blood pressure. Carlene remarked that she first recognised symptoms when she was pregnant with her first child:

> *"About, I was carrying my son. 1996. 94.*
> *G So, you've had it for how many years, Carlene?*
> *C 6 years?...*
> *C Well, I was erm, getting my checks, I kept feeling tired, when I was carrying Shian*
> *G So, you was, it was actually when you was pregnant?*
> *C Yes.*
> *G Yes. So, you were getting...?*
> *C Tired and my legs kept swelling up."*
> Interview 16.

The participants who were diagnosed when pregnant did not appear to express the same level of shock or surprise as other participants. This may be due to the recognition and understanding by the women that sometimes during pregnancy women become hypertensive, and that therefore to some extent, the condition is normalised within this context. Perhaps there is also a recognition that during pregnancy hypertension may very well occur. The actual diagnosis of hypertension rather than pregnancy-induced hypertension was confirmed at the six-week post-natal medical check for these participants. Carlene comments:

> *G. And when you went back for the 6 week medical (post-natal check)?*
> *C I still had it.*
> *G So, then, what did they say to you then?*
> *C That I had to go on tablets".*
> Interview 16

Carlene went on to confirm that she was not surprised that she still had high blood pressure due to the fact that she was still experiencing the symptoms of hypertension:

> *G. When you went to the 6 week medical, and it was still up, was you ...surprised?*
> *C Not really.*
> *G You expected it to still be up?*
> *C Yes.*
> *G You did?*
> *C Yes.*
> *G Oh. Why was that?*
> *C It was the tiredness.*
> *G Okay. So you were still having some kinds of symptoms?*
> *C Yes. And my legs, my ankles were still*

> *swelling up".* Interview 16.

The three women participants diagnosed either during or after pregnancy as evidenced appeared to be far more accepting of their diagnosis, than other participants. This may in part be due to the fact that a causal factor could be identified e.g. pregnancy, providing a rationale explanation for the development of hypertension.

Diagnosis during routine contacts with health professionals

A number of participant's did not expressly mention that they had experienced symptoms of hypertension that motivated them to seek help. Often participants were diagnosed as a result of attending the GP surgery for other complaints or conditions. Delbert mentioned that he had received his diagnosis during attendance at a well-man clinic:

> *" And then, when I retired, got a letter*
> *from the nurse, you know, the clinic...*
> *G Right, yes.*
> *D ...and she said I've got to come in for*
> *a, something they do, well-man...*
> *And, of course, when I went, er, she*
> *says my blood pressure was high. So, I mean that*
> *was the first time I did find out.*
> *G Okay. So, you didn't actually seek out*
> *help, yourself?*
> *No, no, no, no, because I didn't feel*
> *ill or anything.*
> *G Didn't feel ill?*
> *No, I didn't".*
> Interview 4.

In many respects the experience of the participant above can be described as an outlier or negative case as this is the only person in the study diagnosed as result of attending preventative services in PHC. Other participants became aware they had high blood during consultations for other things, such as Wesley:

> *W "Was about last year. I went to the doctor.*
> *Because I had a slight numbness on my right*
> *foot.*
> *G What was on your right foot, sorry?*
> *W Erm, it went a bit numb. That's it, yes.*
> *Yes, that was it. So I go to the doctors to*
> *find out what is wrong. And then he gave me*
> *some tablets.*
> *G So, while you was there, did he take your*
> *blood pressure?*
> *W Yes, he did, yes.*
> *G Yes. And, what did he find?*
> *W Er.*
> *G Did he say? What did he say to you?*

> *W He didn't say I had the blood pressure*
> *No. It was a nurse who told me about the Tablets...*
> *G So, he didn't mention to you he thought you had high blood pressure at the time?*
> *W I just can't remember if he did or not. You know".*
> Interview 10.

Interestingly, Wesley appeared to attach far more significance to the numbness in his leg, than to his diagnosis of hypertension. I am not sure the extent to which this might be a form of denial of the condition, or a genuine lack of concern. Another participant had a similar experience. Wilbert remarks:

> *"I told him about the exact thing why I go but he said might as well check your blood pressure...He said I have high blood pressure".*
> Interview *15.*

Commonality exists here with the preceding extract, as both participants were diagnosed during what might be described as routine visits to their GP, yet appeared quite accepting of the diagnosis and did not appear to be as shocked as other participants. Wilbert comments:

> *"Well you don't feel like, say for instance, you're glad about it.*
> *You know but I didn't feel anyway like say I'm worried about it but I know you can get things to help you."* Interview 15

Several participants were diagnosed during care and management of their diabetes. The synergistic relationship between diabetes and hypertension (Raleigh 1997) is well-documented in the literature. Within the African Caribbean community, diabetes is commonly referred to as 'sugar" or 'sugar diabetes', Delbert illustrates:

> *D "I'll soon tell you. Everything happen in the 90's*
> *G In the 90's*
> *D I had sugar diabetes in the 90's, blood pressure in the 90's".* Interview 9

Although, the extract above is quite short, it demonstrates the difficulty participants' experience when asked to describe discrete components of their illness experience. For individuals in this study who experienced diabetes and hypertension, the descriptions of explanations provided often embraced both conditions. Delbert, in common with other participants remarked that he considered his blood pressure to be normal until quite recently. The participant makes a distinction between 'pressure' and high blood pressure:

> *"Well! As a matter of fact I know I have blood pressure*
> *Quite a few years but its only last November that it became high*
> *So when you wrote asking if you could Interviewee me...*
> *I just had ordinary pressure".*
> Interview 9

In fact more participants agreed with this view-point, even though they had been diagnosed with hypertension, once the medication was prescribed and taken, it was perceived by participants that their hypertension was cured, Patsy comments:

> *P "I do my daily work...*
> *as usual, I don't get tired as some*
> *people have high blood pressure and get tired.*
> *Well, I would say my blood pressure is just*
> *normal blood pressure".*
> Interview 2.

Edgar commented how he was diagnosed during an admission for an elective operation for a condition unrelated to hypertension:

> *E It goes from, 'cause I went to the hospital*
> *for this, er, prostate operation and then I lost*
> *a lot of blood and then after they give me, er,*
> *some blood.*
> *Then after that, it (blood pressure) start playing up".*
> Interview 6

This participant's experience of diagnosis is also linked to some interesting perspectives and explanatory models of the causes and meaning of high blood pressure (*cf* chapter 9).

Patsy, in the following extract, could not remember diagnosis or what motivated her to seek help. This provides evidence of a further outlier or non-confirming case. The perspective of the participant in the extract below is in stark contrast to most participants who gave graphic descriptions even 20 years after the event. The participant commented:

> *P "I don't remember now.*
> *P Well, I just, I went to the doctor,*
> *normally and, erm, get a test and then the doctor*
> *find out that I've got blood pressure"...*
> *P No! Can't really remember (EMPHATIC)".*
> Interview 2.

Clifford simply attended his GP surgery to have his passport photograph signed:

> *C "I was lucky if was not for my passport photo; I wouldn't go the doctors it were my lucky day!"*
> Interview 8

Clifford's GP was obviously vigilant in monitoring patients' blood pressure whenever the opportunity arose. The adhoc nature of this event and lack of association with another illness or dysfunction also make this event an outlier in comparison to other experiences of diagnosis.

Two participants appeared to experience communication difficulties or a breakdown in communication with their GP immediately preceding the diagnosis. Both participants expressed a degree of dissatisfaction with the processes leading up to the event. Barbette remarked:

> *"I was eating the Coconut Ice and I suddenly feel, I feel like I was going to die. It was awful! And, by the following morning, I had to call the doctor. And when the doctor come and test me; he said the blood pressure is high. I said 'blood pressure, doctor?!' He said 'didn't you know you had blood pressure?' I said 'no, doctor, you never tell me'. And I told him what he said to me the last time. He said 'I thought I told you had blood pressure from 1982?...*
> *So, that was the only time when he said 'I thought I'd told you.' I said 'no, doctor, you never.' He said 'you got blood pressure from 1982.'".*
> *Interviewee 14*

Barbette was clearly shocked to discover that her GP had diagnosed her hypertension several years earlier but for some reason had omitted to inform the participant. The GP may of course offer a different version of events. Comparisons may be drawn between this example and the experience of sickle cell anaemia, where a pattern of non-disclosure (by medics to those who have the condition) has emerged (Atkin 2002). However, Barbette did acknowledge that she had been prescribed a number of different medications since 1982, but could not exactly state what medication was prescribed. It is difficult to make sense of this situation as the participant had frequent contact with her GP as she also had diabetes. However, it is notable that this elderly lady changed her GP after 32 years (*cf* later this chapter).

Aleeya experienced difficulty in engaging her GP in a dialogue about her signs and symptoms and making a diagnosis, she comments:

> *"And, you know, the doctor kept on saying that*
> *I was too anxious.*
> *And he put the headaches down to anxiety.*
> *And I said to him 'well, no matter how anxious*
> *you are, you can't make your blood pressure*
> *increase so much'...*
> *You know, so he said 'high blood pressure doesn't cause headaches'. I said 'that's the first I've heard that one!'you know. So each time I went to him with the high*

> *blood pressure, he'd just shrug it off, and say 'oh, just calm, down and stop being so anxious'. And then, just by chance, I'd had this high blood pressure for 18 months, and just by chance, I went to see another GP, because there's like four GPs in the practice".*
> Interview 18

It surprising that Aleeya was not taken more seriously as a qualified health professional. She had in fact made several visits to the same GP complaining of symptoms and as a health professional tentatively herself suggested a cause for the symptoms. However, this was disregarded by the GP. This resulted in the potentially dangerous situation of the participant living with the symptoms for a further 18 months before by chance securing an appointment with another GP in the practice who immediately diagnosed her hypertension. Needless to say, the participant did express a degree of anger and dissatisfaction with this level of care, particularly since she was quite certain her blood pressure was elevated, as she was monitoring this at her work place:

> *"...that prompted me to check my blood pressure at work. And I was monitoring it at work as well".*
> Interview 18

The reasons why this young woman's GP refused to take her presentation for diagnosis and treatment seriously are not known. To suggest reasons would be speculation, it is however clearly surprising given her professional background that she was treated in this manner and so little value accorded to her viewpoints and description of signs and symptoms.

Symptoms pre-diagnosis

Nine of the participants in the semi-structured interview cohort did experience symptoms prior to diagnosis that confirm perceived wisdom on the aetiology of the condition (British Hypertensive Society 1997) as this means that the majority of participants did not experience any symptoms prior to diagnosis or experienced symptomless hypertension. By far the most common symptoms amongst the participants in this study were headaches and dizziness. These symptoms in themselves may be regarded as non-specific symptoms as they may indicate a range of conditions and dysfunction as Loretta states:

> *"Well, it was just some niggling headaches and so on and sometimes you get up in the morning, you just don't feel well".*
> Interview 17

Other participants agreed, although sometimes this was accompanied by dizziness:

> *"Yes. Sometimes I was dizzy. And headache as Well."*
> Interview 20

Participants also described other symptoms such as feeling exhausted, not sleeping and generally feeling unwell but being unable to pinpoint why. Carlton describes:

> *"I just, I just felt really crap! Erm,…*
> *G Hmm. What do you mean by 'crap'?*
> *C I just, it wasn't a pain that I could put my finger on*
> *I just know within myself I just wasn't feeling very good.*
> *I was feeling, kind of, low.*
> *Erm, sleeping pattern wasn't very good.*
> *And I was tired all the time".*
> Interview 21

As can be established from the extract above, some of the symptoms experienced by participants feeling generally low and poor sleeping patterns might equally be attributed to stress. Although stress is not regarded as a risk factor for hypertension, it is clear that many of the participants regarded stress as the most important precursor of their diagnosis and features strongly in individual explanatory models of hypertension. (*cf* chapter 9). It also is evident that at the time of diagnosis, the role of stress and anxiety in the causation of hypertension is confirmed and re-iterated by the conversations that at least one GP engaged in with the participants at the time of their diagnosis. Carlton states:

> *"I went to the doctor and she took my pressure and said it was high, put it was down to stress".*
> Interview 21

The participant goes on to re-iterate more clearly that his GP located stress as a pre-emptive in the development of his hypertension, as he remarks:

> *"And the doctor was saying to me 'the job you do is a very stressful one and what's your method of winding down?".*
> Interview 21

Loretta located stress as the precursor of her symptoms of hypertension:

> *"I think the only thing that was on my mind, is that I was not happy. I was under a awful lot of stress. I wasn't happy".* I
> nterview 17

Loretta seemed reluctant to reveal the source of her stress, but later in the interview revealed that she experienced relationship problems. Several participants demonstrated a reluctance to visit their GP once they had recognised symptoms, as Petra and Loretta state:

P "Every now and again, I find a little pain, but, to be truthful, sometime, I think it's what I eat".
Interview 5

L "Apart from just saying, in the morning 'oh, my head is hurting, I have a headache', or so you go to work and you, sort of say to friends 'I'm not with it today. I don't feel well.' I was never in a hurry to rush to the doctor".
Interview 17

Feelings on diagnosis

A number of the younger participants expressed shock and disbelief when they received the diagnosis of hypertension at such a young age. It appears that a common assumption exists within African Caribbean communities that hypertension is a condition that only older people experience part of the aging process. This view could also be reflective of the population at large. When presented with a diagnosis of hypertension, a younger person may need to adjust to self-image and readjust psychologically to changed health status. Hyacinth who was diagnosed in her thirties, states:

"I was thinking 'my age. I'm only 36/7' (years of age), you know 36 and I thought 'blood pressure at this time of life', you know, I thought it was only old people that had blood pressure.
So, then, maybe I was old now. So, yes, I was shocked and, you know, I started to think about, you know, I'm aware that I've gained a lot of weight".
Interview 19

Hyacinth, attempts to seek an explanation for her hypertension, and while she refers to the fact that she has gained weight (obesity being one of the biomedical risk factors for hypertension), she establishes later with greater clarity that stress is the main precursor of her condition. This is an interesting change of position during the course of the interview, as this participant was a well-educated health and social care professional who had a good grasp on the basic physiology of the condition of hypertension.

Carlene expressed shame at being diagnosed with hypertension at such a young age:

"I felt ashamed.
G You felt ashamed?
C I did.
G Yes? Explain that a bit more.
C Well, to me, it's like something's wrong with you. High blood pressure.
And like, my Mum had it, my Dad had it.
I thought 'oh, something older people get it,

> *I'm too young to be getting it".*
> Interview 16

The extract above does provide an insight into the extent to which the condition of hypertension might be perceived to be stigmatising for young people diagnosed with the condition. This stigma may of course create reluctance to seek professional help and early diagnosis in PHC. One younger participant, Carlton, did not express shock or shame as he remarks:

> *C. "Really, not really. I didn't take it for anything. I just think that, erm, like anything else".*
> Interview 21

The viewpoint in the extract above contrasts acutely with the other younger participants in the study and in this respect may be regarded as an outlier or negative case. It is perhaps worth noting that earlier in the interview the participant describes to some extent how he regards hypertension as a 'family thing':

> *C "And, erm, I hadn't really equate to anything else, other than it's a family... Me Mother's got it.*
> *G Your Mum, yes.*
> *C Erm, my Granny had it".*
> Interview 21.

The acknowledgement and acceptance of hypertension as a family issue before diagnosis may have influenced the younger person in the above extract and their acceptance of the condition. However, other younger people (*cf* chapter 12) with an acknowledged strong family history of hypertension experienced feelings of shock at diagnosis at the age of 36. Therefore it is clear that this viewpoint is at odds with other younger people's viewpoints in the study.

The older people in the study, expressed diverse feelings experienced when diagnosed with hypertension. As in the case of the younger participant, some participants such as Petra were quite accepting of the diagnosis and did not express feelings of shock:

> *"I didn't feel any way funny, because I up till now I don't feel any different really, could say well, you know, this is, this is what blood pressure is. I don't know".*
> Interview 5

A number of other participants agreed with the viewpoint above in that the diagnosis did not impact upon them emotionally or psychologically, as exemplified by Darius and Wilbert:

> *D "Well, I didn't really feel anything*
> *about it. I never".*
> Interview 4

> *W "I didn't feel anything really*
> *G Was it a, was it a shock to you?*
> *W Not really, no. No, because I don't know*
> *what it, what it's all about you see, so, it*
> *wasn't really a shock.*
> *G No.*
> *W It's just that I've heard people having,*
> *Having that so".*
> Interview 10

It is worthy of note that all of the participants (except those who were pregnant) who expressed no feelings on diagnosis were male participants. This is not to say that male participants did not express shock or upset on diagnosis; several male participants did.

As stated earlier, the participants who were diagnosed whilst pregnant appeared to normalise their hypertension as part of the experience of being pregnant and this view seemed to extend beyond the pregnancy. Lynn remarked in relation to her feelings on being diagnosed as hypertensive:

> *"Well I thought it was only a thing until*
> *you're pregnant but most people get blood*
> *pressure when they are pregnant so I thought*
> *well it's just through the pregnancy".*
> Interview 12

Other views focused on a lack of understanding of the seriousness of the diagnosis until further explanation of the potential consequences occurred Loretta comments:

> *"Well, I suppose at that time, I know I wasn't*
> *feeling well, but because I wasn't erm,*
> *acquainted with such sort of things, I don't*
> *think I took it too seriously.*
> *G You didn't?*
> *L No. I didn't.*
> *G Yes.*
> *L I think, when I started to take it serious was*
> *when he, sort of, said to me, you know, I could*
> *have a stroke.*
> *G Oh, right.*
> *L And I think that scared me."* Interview 17

Participants also expressed confusion at receiving the diagnosis of hypertension, and questioned as to why they should experience hypertension. Carmel appears to imply that a satisfactory explanation was not received, otherwise the 'why' questions would have been answered:

> *"Oh, I feel terrible. I, you know, I think that was getting me down more because I says 'I do not know why I had high blood pressure.' And when I speak to my friend, you know, they says to me 'it must be kidney or liver problem".*
> Interview 20

The participant in the extract above makes reference to discussing her situation with a friend. This is an outlier, as most of the participants did not discuss the symptoms with anyone other than a partner, sometimes not even their partner. Given the prevalence of hypertension in the African Caribbean community, I had assumed that many people would have friends or relatives who have the condition and therefore would discuss symptoms and the condition in general. This proved not be the case, which has led me to consider that to some extent, the condition may be stigmatised and a sensitive area of discussion for some people (*cf* chapter 9). In common with Carmel, Jerome comments that his primary concern is to understand why he has developed hypertension:

> *"Well, I thought, well, you know, why is this? And general 'why'? You know, he says 'well, we just don't really know, we'll, erm, we've got to do some more research into it...*
> *G Right. Okay. So, did you feel upset about it at the time?*
> *J Very, very.*
> *'Cause it the same old story, you've been healthy and all of a sudden somebody comes along and says your not so healthy now, you know, and you were thinking 'oh'".*
> Interview 3

Both participants in the extracts above demonstrated a level of distress via non-verbal communication, which is difficult to capture in written material.

Presentation in Primary Care

Attempts to enhance or further develop PHC services must be based on empirical studies that map out patients' motivations in respect of presentation in PHC for early diagnosis and treatment. Loretta comments:

> *"Apart from just saying, in the morning 'oh, my head is hurting, I have a headache', or so you go to work and you, sort of say to friends 'I'm not with it today. I don't feel well.' I was never in a hurry to rush to the doctor".*
> Interview 17

The last statement is extremely significant as later in the thesis (*cf* chapter 9), explanations are mapped out as to why African Caribbean people might be reluctant to use PHC services.

Summary

This chapter has presented the findings from the semi-structured interviews that form the second phase of data collection, building on the FGI in providing more detailed and in-depth information. The notion of 'running to the doctor' emerges as a pejorative concept that pervades the thinking of many older African Caribbean people in this study. To some extent, this idea is also held also by younger participants. The data in this theme is limited in some respects. I anticipated that greater reference would be made to family and friends who experienced hypertension and that participants might have approached these individuals to discuss signs and symptoms prior to presentation in PHC. This assumption is based on the prevalence of hypertension in the African Caribbean community in England, and the strong familial patterns that exist. In the semi-structured interview sample, half of the participants had a close family member who also had high blood pressure. Missing experiences from the data are those individuals who sought medical help as soon as the symptoms occurred. Most of the sample received the diagnosis as a result of contact with some form of medical services e.g. pregnancy, another chronic illness, or visiting their GP with another complaint.

A number of the participants appeared to live with the symptoms for several months before seeking medical help. The one individual who did seek immediate medical help was quite seriously ill having collapsed at work and subsequently underwent major heart surgery. On deeper questioning of this individual, it transpired that he had symptoms for several months before the dramatic event at his workplace.

Whilst two younger participants expressed shame or stigma in relation to hypertension, this dimension was not overtly expressed. It is also surprising that none of the participants articulated anger at the diagnosis and incumbent modifications to their lifestyles. Most significantly, only one participant tentatively linked their early experience of hypertension to the risk factors that biomedicine has established as causally related to hypertension. Commonality appeared to exist amongst participants in that many believed stress to be the major cause of their hypertension, although the origin and source of this stress differed.

Chapter 9

The meaning of high blood pressure

This theme is derived from the semi-structured interview data and maps out participants' understanding of high blood pressure and the explanatory models of high blood pressure in respect of psychological, socio-economic and physiological influences. The characteristics of participants' existence are considered in relation to the experience of high blood pressure. The impact of wider societal structures both contemporary and historical antecedents are explored.

Participants' understanding of the terms 'hypertension' and 'high blood pressure'

Almost exclusively, participants referred to their hypertension as high blood pressure. Hypertension is a medical term that is associated with a given set of risk factors, pathology and aetiology (British Heart Foundation 1997, Cappuccio *et al.* 1998, Cappuccio 2000). Most participants were unsure as to whether high blood pressure and hypertension were the same condition. However, this characteristic may be unrelated to the fact that the participants in the study are African Caribbean. Other studies that included dominant white populations in both in the UK (Morgan 1993) and US (Blumhagen 1980) have demonstrated that many individuals frequently do not regard hypertension and high blood pressure as the same condition. Clifford comments:

> *G "Yes. Okay. So, do you think that high blood pressure is the same as 'hypertension'? Have you ever heard of that, 'hypertension'?*
> *C I don't know, what's that then? Is it same or is something, like is different?..*
> *No. I'm not quite sure".*
> Interview 8

In this study both younger and older participants expressed uncertainty as to whether high blood pressure and hypertension were the same condition. Although some participants had heard of hypertension, they perceived high blood pressure and hypertension to be different. Other participants such as Jerome gave longer and more complex explanations for high blood pressure and hypertension. Jerome has had high blood pressure for many years, which led to major life changing surgery and early retirement from his employment. In many respects he was very knowledgeable about his health through frequent contact with medical services and long periods of hospitalisation. However, Jerome concluded that high blood pressure and hypertension were not the same condition, as he explains:

> *G "... Do you think that high blood pressure is the same as hypertension?*
> *J Er, no. I was told hypertension is supposed to be just a newest, erm, situation, erm, being given by a person who's got worries.*
> *G Yes. So you don't think it's the same, then?*
> *J Well, if, in termination of it, it's, 'cause you've got high blood.*
> *G It's entirely your view-point.*
> *J ...yes. It's got; you've got high blood pressure, right, and hypertension. Now, stroke. I was told it's because your blood pressure, this is their terminology. You've got high blood pressure because you worry a lot, so you are hypertension, right. Anything worries you, it's hypertension.*
> *G Right.*
> *J So, hypertension is only because of what you make yourself, and they're literally saying that, you've given yourself blood pressure, because you worry about things, and that is what I was told, and to try that out. When I go to the hospital, even now, my notes state that 'he's hypertensive', right, because 'as soon as he sees a doctor, or anything like that, his blood pressure will, erm, go up".*
> Interview 3.

What is interesting about Jerome's statement is the strong association he believes exists between worry or psychological distress and both high blood pressure and hypertension. Jerome states that high blood pressure is a result of hypertension and alludes to the fact that the extent to which an individual worries is solely under the control of the individual and the individual can '*give themselves hypertension*'. He goes on to describe the labelling on his hospital records and to some extent appears to use the expression *'he's hypertensive'* as a pejorative concept. This theme is continued later in the presentation of findings in relation to data elicited regarding causes of high blood pressure and the notion of hypertensive types.

In summary, a range of responses were elicited regarding the synonymous nature of high blood pressure and hypertension. Participants, who believed that the two conditions were the same, were in the minority; most seemed confused or were very uncertain. I did find this a little surprising given that most participants in the study had been diagnosed with hypertension for several years. Only two people, Aleeya and Carlton, gave a physiological explanation of high blood pressure that would coincide with a biomedical understanding of the condition. The practical significance of this uncertainty and misunderstanding is that PHC professionals may in communication with patients refer to hypertension, when the patient may not be very clear about the meaning of the term or are convinced that they have hypertension.

Although most participants did not have a clear understanding of hypertension as conceptualised by biomedicine, many more viewpoints were offered on the causes of high blood pressure and participants appeared more confident in their responses. Various reasons were given for the cause of high blood pressure.

Participants' explanatory models

Explanations for the cause of high blood pressure form a dimension of participants' explanatory models of hypertension (Kleinman 1980, Bhui & Bhugra 2002). These explanations can be grouped together in over-arching themes that represent common characteristics across the study population. Participants' explanations are presented as arising from the following domains

- ☐ Psychological
- ☐ Socio-economic
- ☐ Physiological
- ☐ Familial

Earlier research by Blumhagen (1980) has conceptualised explanatory models of hypertension as existing only as individual subjective entities. Whilst this might be true, it might also be true to state that common characteristics occur across communities as evidenced in this study. Indeed Western medicine is premised on the notion of common characteristics across communities and populations. The common characteristics in this study arise from stress as being the main precursor of high blood pressure and the mapping out of explanations within the four domains listed above.

The explanations for high blood pressure given by participants in this study provide a snapshot of the individual's perception at a given point in time. It is recognised that explanatory models may be dynamic and change over time depending on such factors as the duration of diagnosis, aetiology of the disease and existence of co-morbidity.

Psychological

Participants' explanations in this domain largely focused on the role of stress in creating or causing high blood pressure. The factors mentioned included a stressful life, worry and anxiety (*cf* this chapter), these were regarded as major precursors of high blood pressure. These factors were emphasised as having a powerful influence of the development of high blood pressure and were afforded primacy in participants' explanations of high blood pressure and lay aetiology of high blood pressure. The explanations presented contrast acutely with biomedical explanations for hypertension that locate risk factors such as obesity, lack of exercise, poor diet and smoking as the main precursors of hypertension.

Explanatory models arising from psychological distress

Commonality existed in participants' location of sources of stress arising from family and personal relationships. Explanations focused on sibling/parent relationships, conjugal relationships and sibling relationships. Jerome shared sensitive information with me as to why he believed his high blood pressure was related to previous and present psychological stress. This explanation in common with other participants was dissonant from biomedical explanations for hypertension as he comments:

> *J "I don't really know. The, well, I know probably psychologically, right, I mean, as I know this is all private*
> *G It's confidential, yes.*
> *J there was, there was problems with my Mother and my Father, right, so…*
> *G Oh, right.*
> *J …that didn't go down very well with a fresh Father, er, she got re-married and she, erm, actually left me over there. That is still the psychology of the problem at the moment between*
> *G Do you still feel upset about that?*
> *J Yes, very upset. It, er really…*
> *G Yes, yes. I can understand that.*
> *J It does screw me up sometimes. Especially when you ask her things and she doesn't want to talk about it. It's none of my business. I'm 50 years old and she doesn't want to talk about it.*
> *G Yes, yes, yes.*
> *J And then she got married to this other chap, and, erm, I brought over, and then he was only a certain discipline from this here step-father, and he had a habit of knocking the hell out of me.*
> *G Oh, really?*
> *J Hmm. Terror. Yes, so. You know, you have little things like that…*
> *G Yes, yes.*
> *J and then, I think we was there for 10 years with him, and then she just left, and, er, that was it.*
> *G Yes.*
> *J And after that, she just flew like a bird, so, whatever she wanted to do, she just went and did whatever she wanted to do. So, I was left at home and, er, I think I was about 16, 17, I left home, and went to live with my girlfriend. Well, the wife, there. So, that was it.*
> *G Yes, yes.*
> *J And she wasn't really bothered. So, if*

> *there's anything, it could be psychological, but he used to knock the hell out of you, or you used to get things like 'you're not my son', right, and you know, and things like that, erm, and this and that. You know, you used to get all things like that slinging at you...*
> *G Yes, yes.*
> *J So, you know, alright, if there was anything, it's probably sub-consciously, but I don't know the father, my first father, that does bug me up to today.*
> Interview 3

It is clear from the extract provided that Jerome was deeply affected by his experiences as a child and young man, and that these experiences still exerted a powerful influence over his present psychological health and well-being and ultimately, he believed his high blood pressure.

A major cause of stress for Aleeya was her relationship with her brother, who had created considerable financial difficulties for her through creation of financial debt as a result of a joint financial venture:

> *"I've got a lot of stress, before I got married, I bought a house with my brother. And we were there for nine years. My brother was supposed to pay me off and take my name off the mortgage and that was all a lot of hassle as well. And then, I went to stay with C, my second daughter, and I got a letter from my brother's house, saying it was three thousand pounds in arrears. And he'd told me he'd been paying the mortgage".*
> Interview 18

For Aleeya the worry of debt and financial arrears was just one of several stressors which she felt had precipitated her high blood pressure. She was also experiencing work stress and had recently divorced her husband. Breakdown of conjugal relationships, divorce and separation was a source of considerable stress for other participants in the study, as Carlton comments:

> *"Yes. And the stress of life. Because at the moment, now, the stress I'm under at the moment, I mean two year ago, my missus walked out on me, right?".*
> Interview 21

Carlton seems to demonstrate a degree of resignation concerning this type of stress, framing the experience with the concept of '*stress of life*' which might be unavoidable. Another participant, Loretta cites past relationship problems as a cause of stress, which she links to her high blood pressure, but refers to this more euphemistically as problems with her 'love life':

> *"...And, erm, probably, you could say,*
> *love life too, wasn't that good".*
> Interview 17

Loretta was reluctant to give further specific details but went on to say how disappointed she was with life in general, as she goes on to state:

> *"...But I must erm, admit that I was under*
> *a lot of stress.*
> *Things didn't work out properly for me.*
> *I was disappointed in many ways, and it, sort*
> *of, got to me, and I think that really helped".*
> Interview 17

A breakdown in the marital relationship created considerable problems for Carmel who was left to raise six children as a single parent which resulted in an arduous life, as she was also employed outside the home during this period:

> *"... erm, because when I did have problems with*
> *me husband having problems with my problems*
> *a lot, I was having it a lot. And he leave*
> *us [participant and six children] from 1973*
> *and I was having a hard time and I could say*
> *well it's blood pressure and all those things.*
> *I could say it caused it".*
> Interview 20

It is clear from the extract above that the participant feels the consequences of the marital breakdown are directly related to her high blood pressure. Overall, most participants identified stress (sometimes expressed as worry) as the main precursor of high blood pressure. The terms 'worry' and 'stress' were used equally by participants in the study the (52 codes related to stress were generated in the analysis and 59 codes associated with worry) (see Appendix 13) Edgar explains after some initial difficulty articulating his viewpoint:

> *G "... Okay. So what do you*
> *think the causes of high blood pressure are?*
> *E Er, it's something...*
> *G Have you any ideas?*
> *E ...something you got, can't really reflect on*
> *what was that.*
> *E You know. You see, what I'm saying is er, I*
> *don't know really.*
> *E But what I think about high blood pressure*
> *is that it's erm,. I don't know if it's*
> *from worry or what. I don't know.*
> *G You think it comes from worry?*
> *E It could. It could".*
>
> Interview 6

Participants shared with me the extent to which they worried about having high blood pressure, so high blood pressure was both perceived as a cause of high blood pressure and a source of worry, as Delbert explains:

> *"Of course it does. If you have any disease you will worry about it. it's a disease you know, it's a very bad disease so you have to worry about it".*
> Interview 9

Other participants shared with me their anxieties about their high blood pressure. Conversely, Aleeya, Clifford and Wilbert said categorically that they did not worry as Aleeya remarks:

> *"No. I don't worry about it at all.*
> *I think if you worry, it will probably make it worse.*
> *Probably increase it more".*
> Interview 18

Aleeya clearly recognises that to worry about her high blood pressure may exacerbate her condition, but what is not clear or explicated is how Aleeya manages to control or alleviate any worries she might have. Carlene re-iterates:

> *G "Do you worry about it?*
> *C No.*
> *G You don't worry about it at all?*
> *C No".*
> Interview 16

In the following extract Wilbert talks about the fact he does not worry, but then goes on to explain that his partner (Lynn) had contradicted this by observing at times that he did worry:

> *"I don't worry about it...*
> *You see and I, I'm not really worried about anything so I don't know really what cause my blood pressure but I'm not that worried person but sometime my Lynn say I worry, I don't know, might be I worry and I don't even know that I'm worrying".*
> Interview 15

The data in this study do not explain or provide insights into why some individuals have a propensity to worry about their health and dysfunction, whilst other individuals appear less disturbed psychologically.

Psychological - occupation and work related stress

Within the domain of psychological stress, work-related stress was identified by a number of participants. A striking feature of the younger participants is that they were all economically active and employed in statutory and public services. This is reflective of the first wave of migrants from the Caribbean who were employed in the public sector. These domains of employment are often charecterised by under-resourcing, poor staffing levels and the demanding nature of the work. In this study participants were employed in the NHS, youth and community care and social work. Carlton comments:

> "... *But I, you know, we get caught up in, I mean the kind of job we [African Caribbean people] do as community workers as well, erm, they're a contributing factor to our condition , because you think about the stress we've had in the community. Er, at the moment I'm chair of XYZ association and I'm working as a youth worker. Just think about the stress that comes with that job. And coupled with all my shit at home, it's a hell of a lot. You know what I mean?".*
> Interview 21

Carlton clearly acknowledges work-related stress and his ethnicity as major factors. He also identifies multiple stressors impacting on his psychological state. His belief in the stressful nature was further re-iterated by his GP:

> *C "And the doctor was saying to me 'the job you do is a very stressful one and what's your method of winding down?".*
> Interview 21

Another participant Aleeya, working in a similar field re-iterated the views of Carlton's views:

> *A "Hmm. I was actually. Yes. I was quite surprised, but then again, I was in a stressful job where we're always understaffed and stuff and you know.*
> *A I was surprised when I first was diagnosed".*
> Interview 18

Carlene, a community care worker also believed that work related stress contributed to the development of her high blood pressure:

> *"I think we lead a more stressful life than others.*
> *To me, we [African Caribbean people] have to work harder.*
> *And when you're running a family and job and all that.*
> *It's, it's stressful.*
> *Because I find that I can work in my group, with my clients and so forth, and I have to work harder than my own staff to get recognised.*
> *Sometimes it's a bit too much for me, but I*

> *have to do it.*
> *G Yes. I understand what you're saying. Yes.*
> *C I find that stressful".*
> Interview 16

What is interesting about the extract above is that Carlene provides some insights into perceptions of institutional racism in her organisation, in that although she is a team leader in a community care setting, she reports she is harder working than the staff she supervises to receive any recognition. Carlene alludes to the fact that she sometimes finds this difficult to cope with, resulting in stress, but that she really does not have any choice other than to work harder than her staff.

Commonality in the theme of work-related stress was further supported by the following comments by a younger participant. She was employed until recently as a social worker, but had left the job, because of racism and victimisation:

> *"Yes, but because of the job, I thought it was, you know, I was putting it down to the job. Over-worked and all that.*
> *Because it was a very highly stressful job as Well…*
> *"So, but nothing was wrong up until 2000, so I'm thinking if I could have gone through bereavement, so much stress, and managed well without a, without having high blood pressure, then and this is really why I'm saying it's purely to the work situation".*
> Interview 18

In summary, most of the participants located stress as the single most important precursor of high blood pressure. Comments on work-related stress were made by younger participants who were economically active. Older participants (over 50 years) who were economically active had little to say about stress within the context of their working lives. In fact, older participants were less likely to make any negative comments, whereas younger participants spoke freely about negative experiences. This may be because the younger participants were second generation migrants who had lived most of their lives in the UK, so possibly felt more confident in articulating unfair treatment at work. A finding of the study is that all the younger participants reported a negative experience of occupational stress, which resulted in cessation of employment for two participants.

Hypertensive types

Several of the participants seemed concerned that there existed a personality type that could be prone to high blood pressure. Data collection on this topic was often initiated by the individual stating they did not think they were the 'type' to have high blood pressure. Carmel explains:

> *"Because I, me, I'm not depressed*
> *And I was thinking that people what depressed get it, blood pressure*
> *G That's what you always thought*
> *C That's what I thought*
> *You know. But I take myself as example. I am*
> *Not depressed. And I still have it!".*
> Interview 20

I have termed the participants' perceived perceptions of individuals who develop high blood pressure as 'hypertensive types'. Comments on hypertensive types were somewhat negatively framed, which may give some indication of the participants' overall perception of high blood pressure. The notion of a hypertensive type appears related to mental or psychological factors e.g. being depressed. Also the idea that 'hyper' or stressed individuals are prone reflects the findings in the FGI data. Other participants felt they were not the type to become hypertensive because they were too young, as Carlton remarks:

> *"...Even though, even though my*
> *parents have had it.*
> *I didn't think it was going to catch me. I*
> *normally equated it, something you get when you get*
> *when you're old".*
> Interview 21

Implicit in this statement is a model of hereditary transfer that locates high blood pressure as commencing in old age.

The comments of younger participants indicate that to some extent having high blood pressure at a relatively young age was stigmatising (*cf* chapter 8).

Socio-economic stressors

Socio-economic stressors emerged as important factors that were perceived by participants to be influential in the development of their high blood pressure. The factors participants identified focused mainly on racism, both personal and institutional, migration, cultural adaptation and financial considerations.

Socio-economic - racism

It is interesting to note, reflecting earlier comments in the previous section on psychological stress, that none of the older participants made any reference to racism during interviews. Although it seems likely that most participants, (many who have lived in the UK for over 40 years), have experienced personal and/or institutional racism at some point during this period, comments in this domain were made exclusively by younger participants. As in the following extract, Hyacinth commented with considerable clarity:

> *"Well, you're talking about racism. We're talking about unfair treatment. We're talking about inequality, you know, you're talking about lack of equal opportunity for black people in this country. Put that all together and top with everything, and just think it's enough to send anybody's blood pressure high. If a black person's trying to go out to, for a managers job then, for example, they have to be 200 times better than, you know, for example, their white counterparts. So, erm, you know, because of this, then I am at a place where I think because through experience as well, my own experience. To say that the pressure of life in general, to sum it up, the of pressure of life, you know, add to, you know, black people and blood pressure".*
> Interview 18

The participant in the extract above re-iterates a theme identified by another participant as being an important influence in the development of high blood pressure in African Caribbean people residing in the UK, that of '*pressure of life*'. Pressure of life appears to have constituent components such as stress, personal and institutional racism, relationships and financial problems. What I find striking is how this notion of pressure of life differs from biomedical explanations for hypertension and how participants make sense of the dissonance in relation to what they believe to be causing their high blood pressure and the biomedical explanations.

Within the context of this study the word pressure is significant in the lives of the participants. Pressure is used colloquially within the African Caribbean community to refer to high blood pressure '*me pressure up*' as Delbert remarks:

> *"I just had ordinary pressure" [blood pressure]...*
> *It is mostly poor people, mostly black people who have this pressure".*
> Interview 9

The term pressure is also used to refer to stress, tensions and obstacles that present in daily life. Carlton and Carlene mentioned the *pressure of life* and *stress of life.* Participants conceptualisation of high blood pressure appear to have some commonality with the participants in Blumhagen's (1980) study of hypertensive patients in North America, in that the condition they describe is not biomedically determined. Blumhagen terms this condition Hyper-Tension which is characterised by lay understandings which largely arise from the individual such as emotional responses to certain stimuli e.g. fear, anxiety, worry, anger and upset.

Another participant made clear linkages between racism experienced at work (although some linkages can be made with the section on psychological stress), and how this might affect health and ultimately high blood pressure. Carlene elucidates:

> *"Like my Mum says 'if you're not recognised, you're not recognised. Just do your job and come home. It's a job at the end of the day.' You know, we try to better ourselves, you want to reach up the scale.*
> *It's a waste of time. 'Cause all it does is damage you health. That's all it's done. 'Cause I've known a lot of black people, who've I've worked with, really, really clever can get high, and you're struggling. And all of it's stress, high blood pressure, it ain't worth it".*
> Interview 16

Carlene goes on to describe the demoralising nature of this experience

> C *"It's like controlling us. 'You're staying there. No matter how good you are, you're good there, you're staying there.' That's how I look at it.*
> G *Hmm.*
> C *You can be better than one person, you can do the job better than one person and you find that person moves up and you, who's really, they've really watched and taken the job off you, is getting up there and you're still stuck in that same situation.*
> G *Hmm.*
> C *And, yet, you've broken your neck to really work hard, to achieve what you want, to get higher.*
> G *Hmm.*
> C *And they're suppressing you down there. And then, when you go home, it's like, you thinking 'why?' That's what I do. That's why I'm getting so stressed. Why? I'm doing everything just like them. How come I can't, how come I'm not recognised? In fact, I'm even doing it better".*
> Interview 16

The extract above powerfully illuminates the experience of institutional racism and how this experience which is stressful in itself might lead to further stress in attempting to de-construct and analyse and make sense of the experience. Carlene's comments also make clear perceived associations between personal and institutional racism and the potential effects on health.

Socio-economic factors – migration

Migration and the resultant life changes characterised the lives of the study participants. Most had migrated during in the late 1950/1960's in response to the British government's invitation to Commonwealth citizens to take up employment in industries and occupations that were no longer attractive to the indigenous population in the booming post-war era. Jerome considered that although migration created stress, to some extent the migrant individual had to take some responsibility for the creation of this stress. However, Jerome's comments are somewhat contradictory as he implies that communities in the Caribbean may have been given a false impression or that unrealistic expectations were created to encourage migration:

> *J. " It's, it's like, I think what they've done, they've actually created their own stress, right. Not through, how can I put it, I may have said that wrong, of not knowing what they were letting themselves in for, right...*
> *G When they came here?*
> *J. Yes. I think they was given false impression that when they came here, that there was going to be, er, pavements were going to be gold and silver, and such like, and they'd be able to get on. Once here, right, they've found out it wasn't so, which is the old saying - the grass is always greener on the other side, and they fell in to the trap, and what's happened with the older generation, you know, they've actually got to this point now, they've got their kids, and they've, they're still split between what they was and what they are. And also, they are having to fit in to a society which is a bit racist, right, which they have to battle through, right, and I think that is also effecting them psychologically as well. And that could be a part of it as stress.*
> Interview 3

Jerome highlights potential tensions that exist for individuals who have migrated, in that once children are born in the host communities, it may be difficult for the individual to return to the birth country. It is acknowledged that many individuals who migrated (Fryer 1992) intended to return to the Caribbean once economic stability was achieved. Jerome further highlights the stress brought about by living in a racist society

Many individuals who migrated to the UK did so with the intention of securing vocational or professional training (Larbie 1987). Many were unable to realise their ambitions because of a variety of reasons. Loretta shared with me her disappointment at not being able to realise her ambitions as was her intention when she left Jamaica:

> *G "What was your disappointment focused on?*
> *L Erm, it's like, things, sort of, what I wanted, I didn't get it.*
> *Because the nursing thing, I wasn't too sure whether I really wanted to do nursing, and I went for an interview, and the result is that I didn't get it. I didn't get it.*
> *And those sort of things, sort of, put you off.*
> *Even when to some extent, I was that disappointed, because it was like I was being forced to do nursing, because at that time, parents had a lot of influence over you.*
> *And they, what they wanted to do, is like, they'll have this or they want you to, in my case, that was what happened, before I left, you know.*
> *So, that was a disappointment and things. And it just, sort of, put me off in many ways". So, I wasn't happy. Life wasn't happy".*
> Interview 17

It seems that Loretta's parents exercised considerable influence over her choice of career, but in spite of the recognition of this fact, Loretta remained extremely disappointed with her failure to realise her ambitions, resulting along with other factors in an unhappy life. When Loretta speaks of the development of her high blood pressure (*cf* chapter 8), she clearly locates the disappointment she experienced as a precursor to her high blood pressure.

Socio-economic -cultural adaptations

Whilst it might be expected that within the study population, the notion of cultural adaptation might be prominent given that most participants were migrants to the UK during the first wave of migration. Most participants did not explicitly locate cultural adaptation (although many alluded to this) and migration as a source of stress with the exception of Hyacinth. Hyacinth migrated much later than most of the participants, in the early 1980s as a young woman. This generational difference and entry into a very different societal context may account for Hyacinth's strong views on the topic and the fact that she was more willing to articulate these views: as Hyacinth comments:

> *H "Well, when I talk about feeling of belonging, I don't know if you remember me talking about black people, what they have to manage and what*

> *they have to deal with, well, black people, I mean a good example I'll give, alright? You talk earlier on about our language, that a lot of people, especially people's who's trying to get on to improve themselves in this society, in this culture, you can't really go into your office and say 'Jesus, Man,me pass out yesterday and me feel so and so in Patois '. Nobody would understand what you was saying, okay? So, then, all of a sudden, you go in and you've got to speak the speak in order for people to understand what you're saying, so can you imagine the amount of pressure that's on, that's, you know, actually placed on you, let alone, carrying out your daily task. If you were to have a Freudian slip and say, you know, "Me na kno what tha mean ya kno" in Patois, some of your white counterparts would be looking at you and thinking what did she say and tha't just one slip you know. In terms of belonging, you know, how it is for the black person then really, so I believe that with a good example you go to Jamaica, and the moment you step off the plane and you go round the market place and you know, you just feel a sense of belonging. You don't have to say anything. You know? It's almost as though you step out of something an armour, and you step in to your culture...All of the added stress have a lot to do with black people and the percentage with blood pressure".*
> Interview 18

Hyacinth's final comment of stepping out of a suit of armour and into her culture when visiting Jamaica on holiday, gives a considerable insight into how she perceives her experience in the host community, as one which demands a barrier or defence for protection.

Socio-economic – financial issues

As might be expected, many of the participants who were economic migrants in the 1950/60's found themselves in demanding occupations that were low-paid by UK standards. This resulted in a degree of financial hardship for some of the participants that they felt had burdened their lives and added to the stressful nature. In Carlton's case, this was compounded by the break-up of his marriage and his subsequent engagement with the Child Support Agency, as Carlton comments:

> *"But if I didn't have a financial problem, all of a sudden I have a financial problem and all these things have, sort of, had their toll. I've got this man knocking down my door wanting his pound of flesh. They bully these people. There was one bloke, I says 'I will have', I says 'how can you have what I don't have?', you know, 'you will pay' yes I will*

> *pay eventually. And sometimes that's how you have to deal with these people and the stress that comes with some of those things, you know. Those bully boys, they come in and I know, and I've tested it, there is a particular company, I don't have any, I've dealt with them now. I've got them out of my space, you know. When, and you go to the doctor after I've had a couple of days with them, and my blood pressure was so high, you know. They have that impact on you. Can you imagine out there, there is all these people, I don't particularly let myself get caught up in, erm, spending frivolously".*
> Interview 20

Carlton clearly identifies the stress of these events as directly influencing his high blood pressure. His comments indicate that he feels he is a victim of circumstance, rather than some one who has spent money unwisely.

However, another participant feels that unrealistic aspirations may be creating unnecessary stress for some community members that may ultimately influence blood pressure, although he is able to resist temptations to overspend:

> *"But, you see, I believe what, what stress out most people, you got say, well, family's alright. You in reasonable health, and this and that, but they thinks too much. They want more than what they can afford to have. They more or less thinking about I should have that house. I should have that car. I should have that this. I should have that that. But when you think about it, you see, well, they, they, they, the means, they can't, they can't, the means can't go up to what they're buying".*
> Interview 8

In Clifford's assessment, cognitive processes affect the psychological state of the individual. In this respect thinking too much can be harmful to well-being. Clifford goes on to expand on this topic, locating credit cards as a major source of stress:

> *"It's like when you start thinking too much what you should have when you can't afford to have it. So, that's what give you problems. credit cards and this and that, they put their selves in extra stress and strain with it".*
> Interview 8

Delbert was also clear that an economic dimension existed in relation to the development of high blood pressure but his statement is not fully supported by a rationale for why this might be:

> *"Well as a matter of fact and according to what is going on in the world, it is the poorest people who always suffer the most. I tell you this, the rich people who die if their money could buy it all of us would be dead and they would be living, but that won't* happen. *It is mostly poor people, mostly black people who have this pressure [high blood pressure]...*
> Interview 9

Physiological explanations

Few of the participants provided a physiological explanation for their high blood pressure. Carlton gave an explanation of the patho-physiological changes during hypertension, which might be regarded as a biomedical explanation, as he comments:

> *"I think the, I think, my understanding of it anyway, is that the blood is pumping around the body and the pressure that's doing it, it's erm, it's higher and it cause the heart to do a lot of more work. So, you're actually putting more strain on the pump. That's generally my understanding of it and erm, what they do is trying to reduce the pressure of the heart doing as much work. The fact is that all the stuff that you pump in through your body and the cholesterol and it'll cause your arteries to block up and you get strokes and all that sort of thing ".*
> Interview 20

Carlton was very much in the minority and his view divergent to other participants. This is interesting in that I would have expected most participants to have been given verbal explanations in relation to their high blood pressure from PHC professionals either at diagnosis or during subsequent management and to have received some supplementary written materials in the form of leaflets. This is not to say that participants were not aware of or understood elements of a biomedical explanation for high blood pressure. Some participants recognised the role of diet, smoking and alcohol as possibly having a negative effect on the blood pressure, but could not necessarily articulate an explanation for this. For example, most participants were aware that a traditional Caribbean diet contained more carbohydrate (rice, sweet potatoes, dumplings) than a typical English diet and possibly more fat. Participants were aware of the constituents of a healthy diet, mentioning an increase in fruit and vegetables and reduction in salts and fats as being beneficial.

Edgar presented a very powerful physiological explanation for his high blood pressure, although this bore little resemblance to biomedical explanations:

> *E "It's just that, what I understand about it (high blood pressure), would think about it, is that erm, as if somebody*
> *have too much blood...*
> *E "I think it's from, because there was*
> *nothing wrong before I had that, erm, operation.*
> *E I've lost that blood and now I've got the*
> *blood transfusion put back, I lost five pints. They*
> *give me back five pints...*
> *...and , erm, three days after, I have, erm,*
> *some complications again, and it all gone, you*
> *know, and then after I get the other set of*
> *blood, then it settles down.*
> *You know, I never loose any more.*
> *And then, from then they started checking*
> *on it to see if it was alright".*
> Interview 6

Edgar's explanatory model is premised on the notion of having too much blood as a result of receiving a blood transfusion following an operation. Furthermore this blood was not his own blood. Once an individual has too much blood, this will rise to the head:

> "...might be having too much blood
> *G Right.*
> *E rising in your head".*
> Interview 6

In Edgar's explanatory model, a resolution to the phenomena of having too much blood is for the blood to be released, thereby creating a lowering of the blood pressure, as he goes on to explain:

> *"...then they say it is very good for people*
> *who have high blood pressure, because it get rid*
> *of something. I don't know...*
> *G Is that, is that something, er, is it like,*
> *erm, Caribbean explanation? Is it something*
> *you've heard in the UK, or something you've*
> *heard back home?*
> *E I've heard it here, really...*
> *E Nostril bleeding..."*
> Interview 6

As can be elicited from the quotations provided by Edgar, this type of physiological explanation for high blood pressure appears to have associations with humoral theories (Helman 2001) and the notion of releasing or purging. This notion is said to be prevalent in Caribbean cultures in the form of purges through the systematic use of laxatives and washouts (Thorogood 1988, Donovan 1986).

Another participant focused strongly on physiological explanations for her high blood pressure. In Carmel's explanatory model, the participant perceived a strong association between the constituent components of her blood, and associations between her liver, kidney and blood pressure:

> *"Oh, I feel terrible. I, you know, I think that was getting me down more because I says 'I do not know why I had high blood pressure.' And when I speak to my friend, you know, they says to me 'it must be kidney or liver problem.'*
> *But, when I go back to the doctors, he says 'well, I take a blood test.' Sometime two bottles. He says 'one for your kidney, one for liver', and its perfectly alright".* Interview 20

Is it possible that by taking blood specimens for liver and kidney function, that Carmel's GP may have reinforced her lay beliefs on the causation of her high blood pressure. Carmel had been reassured by her GP that the cause of high blood pressure was unrelated to her kidneys or liver, as she comments:

> *C "And the doctor they told me that it is blood pressure and from ever since, I'm still carrying it, you know, I'm still going. And then, doctor started to give me, he says 'this is, you know, it's going on too long.' So, he started to give me appointment for every fortnight or things like that to come and check-up, check my blood pressure. And, erm, until early last year, I had these things come out of my body. Because I keep saying to doctor 'why? What's happened?' He says 'well, you don't know', but they keep really and truly, they really checking on my blood to see if it's kidney or liver problem, but they say it is perfectly alright. Even thought the doctor said my liver and kidney's alright".*
> Interview 20

However, Carmel's focus on the problems with her kidney or liver as a possible explanation for her high blood pressure remained a topic of conversation throughout the interview:

> *"It's so big and you don't know, because, I mean the doctor says to you 'these tablets can give you kidney and liver problem.'*
> *G Right. So, is that...?*
> *C And when he say this to me, it's frightening me".*
> Interview 20

> *C "That's why I was saying to the doctor 'I wonder if it is my kidney, or liver...'*

> *C ...'why I'm getting this blood pressure".*
> Interview 20

It seems that Carmel was not really convinced that her high blood pressure was unrelated to her kidneys or liver, as at many points during the interview these major organs are mentioned. It is also interesting that the kidney or liver dysfunction was first suggested by the participant's friend. Carmel seems reluctant to accept biomedical explanations or reassurances about this, her friends' explanations appear to have more meaning and validity for her. It is clear that Carmel was struggling to resolve the dissonance between the two explanations she has been provided with.

Aside from the participants who experienced high blood pressure as a result of pregnancy, the participants did not provide a physiological explanation for their high blood pressure. Several participants also experienced diabetes, although none of these participants articulated a perceived association between diabetes and high blood pressure. These four participants accepted that they had both diabetes and high blood pressure, but did not question the relationship between the two conditions and appeared to be accepting of the existence of co-morbidity in their lives. A notable observation is that participants who had both high blood pressure and diabetes tended to speak about their experience of ill-health in an holistic manner, rather than sharing discrete aspects of their experience of ill-health. Delbert remarks:

> *"The diabetes came first. Do you know how I found out I had diabetes. I was at home one day and Mrs T said to me, that time my wife had already died, she said to me "why are you drinking so much water? "She's always running joke with you and laughing with you, so I just looked at her and she asked when am I going to see the doctor. I told her tomorrow. She said I should take a sample of my urine to the doctor. Just like that. I took a urine sample and the doctor tested it. He asked me when it last tested? I said to him "you have never tested it before. "Oh Delbert", he said "you have a little bit of sugar". But from then till now my diabetes isn't bad because I take tablets. They haven't tested it since November. All they say is that they want to bring down the high blood pressure so that's why they sent me to the hospital. The 18th when I went the doctor doubled the dose of my tablets".*
> Interview 9

At times during the interviews with Delbert, George and Barbette, it was difficult to establish whether the experiences shared related to high blood pressure or diabetes. In a sense asking participants to share aspects of what might be several conditions or dysfunction they experience may be an unrealistic expectation. Barbette explains:

> *"I got some many things wrong with me, that I don't know which is playing up and which not playing up".* Interview 14

It is perhaps only those of us who are socialised through our professional education to view the world through a biomedical lens who would even attempt to elicit such information.

Familial

A small number of participants Hyacinth, Carlene and Carlton were aware of the familial nature of high blood pressure:

> *H "Bearing in mind that we're talking about hereditary as well, because I'm aware that it is hereditary pressure…".*
> Interview 19

> *C "It can stem through families.*
> *G Yes.*
> *C It can follow on. G Yes. Yes. So, there might be some hereditary…*
> *C Yes.*
> *G …aspect to it? So, do you think it can be prevented, Carol, high blood pressure?*
> *C If it's hereditary, I doubt it".*
> Interview 16

> *C And, erm, I hadn't really equate to anything else, other than it's a family*
> *G Is it a, is it in your family? Who? What other family members have high blood pressure?*
> *C Me Mother's got it.*
> *G Your Mum, yes.*
> *C Erm, my Granny had it.*
> *G Yes.*
> *C On my Mother's side most people got".*
> Interview 21

I found the small number of participants mentioning the familial nature of high blood pressure surprising given the prevalence of high blood pressure among African Caribbean people in the UK. The biographical charts indicated that half the participants in the semi-structured interview sample had one or more relatives with high blood pressure.

Perceived resolution of high blood pressure

Some participants held the view that once their high blood pressure had been treated, they would no longer describe themselves as having high blood pressure or being hypertensive, because in a sense their high blood pressure had been resolved. Delbert explains:

> *"So when you wrote asking if you interview me...*
> *G Yeah*
> *D I just had ordinary blood pressure".*
> Interview 10

It seemed important for participants to normalise this experience and in fact this normalising process is part of the construction of explanatory models (Kleinman 1980), regardless of whether they were still on medication and still technically from a bio-medical perspective, regarded as hypertensive. Clifford, Aleeya, Carmel and Carlton and Delbert all mentioned how normal their blood pressure was:

> *C "...and that's what she said. It just a bit above normal*
> *G Yes.*
> *C But, she wouldn't say it was high. She say it's just a bit above normal".*
> Interview 9

> *A "You know, but it's, has been quite normal now, for quite a while".*
> Interview 18

> *C "It had practically gone back to normal and they was just keeping an eye on it. And it was fine. I suppose stressful situations...".*
> Interview 20

> *C "My blood pressure was practically about normal, you know".*
> Interview 21

The need to emphasise normality in terms of high blood pressure does not seem to be a form of denial, but a necessary realignment of perceptions of normality required in order to live with an altered self-perception.

Summary

In this study the explanatory models that informed the health beliefs and thinking of the participants' were not synonymous with biomedical explanations for high blood pressure. The aspects of explanatory models considered in this chapter are the aetiology or cause of the condition, the patho-physiological processes involved (Kleinman 1980, Helman 2001) naming the condition (Lloyd *et al.* 1998). Patterns of distress associated with the condition (Weiss 1997) are considered in addition to the wider structural issues participants believed had contributed.

The dissonance between biomedical understandings and lay explanations in relation to disease and illness causation has long been acknowledged (Helman 2001, Kleinman 1980). Participants perceived their high blood pressure as not arising solely from personal factors as in

Blumhagen's (1980) study but also from external factors such as migration, not belonging, financial problems, racism and discrimination in the work place. This is not to say that factors arising from the individual are not important in the development of high blood pressure. The two dimensions external, and individual, may coalesce to influence the development of high blood pressure. Building on the work of Blumhagen (1980), I term the non-biomedically determined condition the participant's experience HIGH PRESSURE. The term makes reference to both an increase in blood pressure that is a result of both personal and external factors beyond the control of the individual, the main precursor being stress (*cf* chapter 13). The syntax of Jamaican speech means that participants may term the condition PRESSURE HIGH. HIGH PRESSURE/PRESSURE HIGH is a condition defined by the existential characteristics and lay perspectives of the participants in this study.

Chapter 10

Findings - consequences and management of high blood pressure

This chapter explores the impact of the diagnosis of high blood pressure on everyday living for the participants and responses to managing stress, the perceived precursor of high blood pressure. The consequences of high blood pressure for participants in this study are mapped out in the psychological, physiological and socio-economic domains. The chapter explores the strategies that the participants employ to manage their high blood pressure such as the use of herbal remedies, concordance and non-concordance with medication and modifications to their everyday life. Strategies for daily management of high blood pressure focus on concordance and non-concordance and the participants' motivation for their chosen course of action.

Psychological consequences

Although only a few participants worried about having high blood pressure, the stresses of everyday life appeared to be the main psychological dimensions associated with the condition that participants shared with me. Stress and worry were related to financial issues, relationship issues, and the consequences of migration and major life crisis (*cf* chapter 9). Some participants such as Carlene experienced both physical and psychological symptoms as Carlene explains:

> *C "Oh. Certain things. If it's high, I get, it's*
> *like I'm losing breath and I get anxious and I*
> *get very miserable.*
> G Do you?
> *C Yes, I do. I get very miserable.*
> *G Sort of, like, depressed and low?*
> *C Yes. It's funny how it affects me.*
> *G Yes.*
> *C Yes.*
> *G So, you know when it's coming on, then?*
> *C Yes. And, I can feel the headaches coming. I*
> *know, I know I want to get home because I know*
> *it's going to get bad.*
> *And I know [inaudible] kids I've*
> *Got to pick up and I think 'oh, how am I going to*

> *do it?' And then it starts. I think I make it*
> *worse by getting too anxious.*
> *G Yes, 'cause you know it's coming on, yes.*
> *C Yes, and I want to get home'.*
> Interview 16

High blood pressure in this sense can also be a cause of psychological distress. Carlene went on to describe in more detail what she believed to be the main precursors of her high blood pressure:

> *C "You know. When you've got too much on.*
> *You're not able to calm down, just sit down*
> *and relax.*
> *G Yes. What do you mean by too much on? Just*
> *explain a bit what...*
> *C Like me, with my kids and running up and down.*
> *going to work. Coming back. Doing their dinner.*
> *Getting in the bath. Washing them. Getting into*
> *bed.*
> *I haven't got no time to sit down to myself.*
> *So, I get all worked up and start with my*
> *headache and...*
> *G So, you think that's the main*
> *reason for it?*
> *C I think that's mine - too much. Because I find*
> *the days when I'm calmer...*
> *My blood pressure don't go so high".*
> Interview 16

Wilton and Petra felt unable to cope with grandchildren if they felt their blood pressure was elevated needing calm and peace:

> *P "Sometime I try not to stress out myself too much*
> *try to calm down, not stressing, you know sometimes it's*
> *the cause is the grandchildren...I don't want too much of*
> *them around me".*
> Interview 5

Half the participants in the study had a close family member with high blood pressure. Yet I was surprised to discover that the participants did not discuss their condition with other family members or share anxieties about their condition. Participants with familial high blood pressure commonly had two or three relatives with high blood pressure. Some participants sought the support of friends; however, more often, participants preferred to discuss their high blood pressure with their GP. Two participants mentioned drawing support from their faith and the church congregation.

Loretta remarks:

> *L..."the support I got from the church, it was unbelievable".*
> Interview 17

Although stress and worry are located by participants as being the main precursors of high blood pressure, it is not entirely clear from the data where participants draw support from during times of stress. Most participants did not discuss their elevated blood pressure with relatives; it may be however that they shared with me instead their underlying concerns about the precipitating stressful situation.

Socio-economic - the impact of high blood pressure on employment

For some participants their high blood pressure resulted in serious outcomes in terms of their paid employment. Jerome and Lucille both had to retire early from their employment because of difficulties controlling their blood pressure and their poor state of health:

> *L "I just wasn't well. And, erm, I can remember going to work one day, and I was so ill and they had to send me to the restroom and I was in the restroom, actually, all day. And the only reason why they didn't send me home was there was nobody at home*
> *So, they didn't send me home until the evening.*
> *They sent me home in a taxi. And then, the following morning, we went to the doctor.*
> *And I was trying to, you know, that it wasn't as bad as it is, but they took my pressure and it was so bad that he said to me, he just listen to me, he could see that I'm trying to think that I can go back to work, but there was no way I could go back to work*
> *...that week, or anyway. And he gave me two weeks off and I went back and they still keeping me off. I reached the point, once, when they said I would never work again.*
> *G Oh, right.*
> *L That the pressure so bad and it's like it couldn't be controlled or something like that".*
> Interview 17

Jerome was forced to take early retirement at the age of 30 years:

> *"Yes, until they, 'till something happened, and then I went off, and then they found out that the heart is swollen up that much, that it could no longer function. So, the company stepped in and says 'we've got all the records of you, and, erm, you know, you're no skiver, you know what's a name, and the records show that the heart was going down anyway, so, once we've got*

> *all you details, there's no way you could ever work again'.*
> *G "Did they retire you early, then?*
> *J Yes, yes.*
> *G So, how did you feel about that?*
> *J Oh, absolutely smashed. I was, I even asked if I could do 'owt part-time. I even asked if I could do work at home!*
> Interview 3

Jerome's comments provided insights into how desolate he had felt at his premature cessation of work, and the psychological impact of such an event, on a person who already has high blood pressure. High blood pressure for other participants, Carlton, Hyacinth and Aleeya, resulted in extended periods of sick leave from work, whereas Carlene had intermittent periods of sick leave. However, the need to rest presented particular problems for Carlene, as a single mother with young children as she explains:

> *"But, all I've got to do is just rest and lie down. (Inaudible) to be looking after the kids. Cause the women next door, Pat, comes and take them.*
> *G I was going to say, how do you cope with the kids?...*
> *C I can't keep them.*
> *I can't.*
> *G No.*
> *C It's [high blood pressure] too bad.*
> Interview 10

Maintaining employment presented unique problems for Carlene, in that unusually in this study, she is one of two participants with young children and are lone parents. The pressure of getting the children to nursery, and school and herself to her own employment was considerable. In Carlene's view this had a detrimental effect on her high blood pressure. Other participants such as Petra, although of retirement age, wished to carry on working but retired early because of her high blood pressure.

Physiological consequences

Some participants experienced physical symptoms when their blood pressure was elevated whilst others had no physical symptoms. Headaches, dizziness and generally feeling unwell were mentioned as Petra comments:

> *"I know, when the blood pressure high, you feel ill.*
> *Because I usually feel ill.*
> *Sometimes I feel dizzy.*

> *I really feel ill, ill, ill, and I say to*
> *myself 'what's going off in my body?"*
> Interview 5

In relation to understanding the physiological consequences of high blood pressure, some participants were aware of the potential physical consequences of high blood pressure such as experiencing a stroke or heart attack. The remaining participants seemed unsure about the potential physical consequences of high blood pressure. Delbert was very aware of the consequences of high blood pressure; he makes some very interesting comments regarding the prevention of a stroke and heart attack:

> *"High blood pressure is very bad. It can cause things like strokes. It's bad because when it flared up and I went to see the black doctor, I said to her "be careful, don't let me have a stroke. She never told me how high it was...*
> *Yes, it can give you a heart attack can't it? It can give you a heart attack, but I am taking tablets to avoid having a stroke, to avoid my blood pressure going up. My G.P is looking after me".*
> Interview 9

Delbert's comments appear to have association with theoretical perspectives of the locus of control (Rotter 1996, Wallston & Wallston 1978, Wallston *et al.* 1978) as he appears to operate with an external locus that locates the prevention of negative physical consequences entirely with his GP. This is most evident when Delbert states '*be careful, don't let me have a stroke*" and in his concluding comment that his GP is looking after him.

Carlton was aware of potential mortality from high blood pressure, as his sister had died at an early age from high blood pressure:

> *"She was only 42 when she died.*
> *G Oh, really?*
> *C Yes.*
> *G Oh. Was she in Jamaica?*
> *C She was, no, she was here in Britain.*
> *G She was here. Right.*
> *C In Britain. Birmingham.*
> *And the other one died in childbirth.*
> *G Oh, dear. Oh. That's sad.*
> *C From pressure".*
> Interview 21

Anti-hypertensive therapies are known to cause physical effects (Benson & Britten 2002) such as impotence, although only one of the male participants mentioned this, within the context of expressing surprise that his GP had not mentioned this potential side-effect. As a female researcher, it may be that my gender inhibited some male participants in sharing this with me.

Consequences - family members and relationships

As stated earlier in this chapter I was surprised to find that few of the participants discussed high blood pressure with family members. Some insight into the reasons why this lack of openness in family relationships may be gleaned from Loretta comments (following); she speaks of how in the Caribbean one was not allowed to inquire about the personal health of elders, as this was considered to be private. Parallels might be drawn between this experience and the increased privacy around health that existed in past decades in England, to some extent this reserve may still exist in older English people. Loretta remarks:

> *"So, you know, when you're young, before you're, you're not allowed to question parents, like anyway in my country so,I don't know"...*
> *So, erm, I looked back at that many times and*
> *say 'I wonder why?'.*
> *G Yes. Yes. You never asked?*
> *L But, those days, you don't ask much questions*
> *G No. No. of course.*
> *L ...then you don't know...*
> *And, plus, you didn't take those things*
> *seriously.*
> *It's strange when you didn't take those things*
> *seriously. You ask why her face was like that.*
> *The mouth was a little bit twisted, not bad.*
> *A little bit twisted, but you ask 'why?', and*
> *you are told she had a little stroke.*
> *That was it. You don't bother, but as you grow*
> *older, erm, you more think of these things, you*
> *see.*
> *Consider those things, why and so on, but you*
> *never, sort of, question it.*
> Interview 17

Loretta provides a slightly different explanation as to why she chooses not to share her illness with other family, as she does not like relatives 'fussing' over her health:

> *"If there were certain people here, relatives,*
> *friends and all like that, I would say to you,*
> *then, whether it's selfish this or not, it's like*
> *I keep it to myself.*
> *G Oh, right. You prefer not to share it with*
> *them?*
> *L No, because I don't want people to be molly-*
> *codling me, if you want to put it that way.*
> *I don't want too much sympathy.*
> *Just how I am".*
> Interview 17

The data does not provide in-depth insights into the family relationships of participants. Carlene, a younger participant with children, comments on how her condition affects the children:

> *"Yes. It affects the kids.*
> *Hmm.*
> *Affects the kids.*
> *G Do they understand? How do you explain to them?*
> *C Well, I just say 'Mummy's not, Mummy's feeling not very well. Mummy's poorly.' She knows poorly.*
> *Yes, but Joel, the seven year old, he's ever so good.*
> *[inaudible] he knows. He'll keep Jodie, Jodie with him in his bedroom.*
> *Yes.*
> *And he'll make drinks.*
> *He'll make me drinks".*
> Interview 16

The lack of openness which characterised discussion of high blood pressure with family members also extended for some participants to friends. Hyacinth comments:

> *..."I know of one person, friend of the family, but, you know, that have high blood pressure, but it's funny, never really talk about it.*
> *G You don't talk about it? No.*
> *H About the same age as me, I only heard through somebody else*
> *I've only heard from somebody else that she's got it.*
> *And she's got if for a good while.*
> *And she, and the reason why I know, it was when I was prescribed the tablets I was told that she is taking these tablets as well.*
> *But we've never really talked about it".*
> Interview 19

In summary, participants were commonly silent about their high blood pressure, preferring not to share information with relatives and friends. I am not sure the extent to which this feature is a cultural norm or associated with a personality type who may be prone to develop high blood pressure.

Maintaining lifestyle and lifestyle modification – the impact of high blood pressure on everyday life

Individuals who experience high blood pressure are often advised by health professionals to modify lifestyle in order to impact upon the associated risk factors such as reduction in obesity, cessation of smoking, consuming a healthy diet, increasing exercise and reducing alcohol consumption. However it is possible that this type of advice may create some cognitive dissonance for individuals who do not believe their high blood pressure has occurred as a result of biomedically determined risk factors.

Petra, Edgar, Gilbert and Carlene were of the view that they had made no lifestyle modifications as a result of having high blood pressure. Other participants shared a range of experiences. Commonly, participants believed that the type of diet eaten played some part or contributed to the development and maintenance of their high blood pressure, which might in part be related to explanatory models of high blood pressure of the health locus of control (Wallston *et al.*1978). The exact relationship between diet and high blood pressure was not clearly articulated by participants, although several participants were very clear that this was related to the high carbohydrate content of a traditional Caribbean diet. As Carlton remarks a changing lifestyle and environment following migration is pre-emptive in the development of high blood pressure:

> *"Your lifestyle, you leave the Caribbean and you come to Britain and there's a change in your lifestyle and you have to really adapt yourself to that change, you know, come out of one environment, in to another one. You try to continue a lifestyle in a different environment that's not conducive to, you know, I think so anyway. Because we eat, we still eat a lot of the same food, erm, carbohydrates, that sort of stuff...*
> *C Yam,* dumplings, erm, sweet potatoes, cassava. A lot *of starch in those things".*
> Interview 21

Carlton is of the view that a high carbohydrate diet is needed for life in the Caribbean though not necessarily in England. Although commonly participants located a traditional Caribbean diet as being high in carbohydrates, few participants made reference to the fact that a poor English diet high in carbohydrate and fats might also contribute to poor health. Carlton proved to be the exception; he went on to explicate how a change to a more traditional English diet as a result of migration and changing lifestyle might contribute to the development of high blood pressure:

> *"Back home it used to be fresh coconut oil. It used to be no preservatives in it or anything like that. You pick a coconut and you process it and use the oil*

> *from it make a custard from it. And then people come to Britain and they start using things like Lard. For years they're using all them stuff that clog up the arteries, drinking, eating, because you come to Britain and you just delve in to the culture".*
> Interview 21

Other participants mentioned fatty foods, salt and too much meat as components of poor diet and recommended fruit and vegetables as being nutritious and health-enhancing.
Loretta had been overweight when diagnosed with high blood pressure and had successfully reduced her weight, which seems to suggest that she operated with an internal locus of control (Wallston & Wallston 1978):

> *"...and I had it for years after when I cut down.*
> *G Oh. So, when did you cut down?*
> *It was after the blood pressure started troubling me so much. Then I just thought, you know, probably I have on too much weight and so on and I just, I've never been on a diet. I just cut down".*
> Interview 17

Other participants Hyacinth, Carlene, Barbette, Carmel, Lynn, Wilbert and Aleeya were aware of the fact that they were overweight impacted upon their high blood pressure, but agreed reducing weight was a constant struggle. It is worth noting that not all the participants were overweight.

Participants made virtually no comment at all on the role and relationship of physical exercise to high blood pressure, and only Carlton commented on the fact that his high blood pressure prevented participation in exercise. Aleeya had joined a gym in an attempt to loose weight but was forced to stop because of another medical condition.

The most frequent lifestyle modifications mentioned were related to social activities for example participants had stopped taking walks, using the Turkish bath, and attending lunch clubs because of high blood pressure. Smoking was understood by participants to contribute to high blood pressure, however the most commonly mentioned lifestyle modification was alcohol consumption. There seemed to be wide recognition that excessive alcohol could be detrimental to blood pressure as Jorge comments:

> *"And er, well, I used to drink a lot.*
> *G Really? Yes.*
> *J You know.*
> *G What would you call a lot?*
> *J Hmm?*
> *G What would you call a lot? When you say you*

> *used to drink a lot, what's a lot?*
> *J Well, I get up and drink all day.*
> *G In the morning!? In the morning?*
> *J One time, back, I used to wake [states time] to go to the pub.*
> *So, I'd be drinking from [states times] all day.*
> *But, I used to drink Barley wine.*
> *You know?*
> *And er, Special Brew.*
> *So, I go to the doctor & he give me medicine & then tablets.*
> *While I was drinking, while I... taking tablet [inaudible], but erm, I feel better, clear up, start not drink again.*
> *So, It's that Barley wine causing it.*
> *But it make Doctor say stop drinking. I didn't know to do it myself, you know".*
> Interview 7

Jorge seems clear that moderating his alcohol consumption was a direct result of intervention by his GP. Delbert appears to have skilfully managed to make the adjust to his alcohol consumption, but also managed to maintain his main social activity of dominoes and friendships:

> *"...the only thing I have done is to stop drinking. I don't drink, but I don't know if that have anything to do with it. That's the main thing. That's what I've done, cut out drink.*
> *G. Did you use to drink?*
> *D. I drink*
> *G. When you were younger*
> *D. I did drink but I didn't drink like other people. You know, great big pots of beer. I like to visit other places and every year we go around the country playing dominoes*
> *G. So you are in the dominoes club?*
> *D. Yes and when we go out my friends and I will sit down and buy around of drinks. I'll buy them whatever they want, but I only buy myself one whiskey and put a lot of ice water in it and that's all. I don't have another, just the one.*
> *G. You just drink moderately?*
> *Yes. Everywhere I go I tell them I have high blood pressure since last November. Last Christmas all my daughters and grandchildren came for Christmas dinner, and you know I never had a drop to drink. I was too scared".*
> Interview 9

Edgar and Wesley were sure that alcohol consumption was unrelated to high blood pressure, although most information leaflets about high blood pressure state that moderate to excessive drinking of alcohol can affect high blood pressure.

> *E "You know this week, I could be drinking all this week.*

> *I don't mean go out having a drink. I have drinks here. If I feel like having 3 or 4 whiskeys or brandys or...*
> *Whatever, I have a can of beer, or whatever, lager, I have it.*
> *And maybe all this week, I will have it.*
> *And for the next 2 or 3 weeks, I don't have any, you know.*
> *So I don't think, I don't think it much of a problem really.*
> *G No. You don't think it affects your blood pressure?*
> *E No.*
> *I don't think it does".*
> Interview 6

> *W "I wouldn't say drinking. It could be smoking.*
> *It could be to do with smoking.*
> *G Maybe, yes.*
> *W Yes. I wouldn't say drinking.*
> *Because drinking more likely goes to your Liver and places, yes.*
> *So, I wouldn't say drink".*
> Interview 10

Carlton had managed to moderate or cease his alcohol consumption, but his comments appear to be mediated by a note of regret, as he states high blood pressure has changed his life:

> *"Erm, I can't see it, erm, I think the blood pressure's affect my life in that I used to like a drink.*
> *G Oh, right. Yes. Yes*
> *C Very rarely drink.*
> *Because I just get headaches.*
> *No matter how small. I can sometimes have a drink*
> *But if I have, if I drink a bottle of beer, I can guarantee that as the night goes on, I'll be waking up tomorrow with a headache, I get a lot of headaches.*
> *Even when I was diagnosed, I still used to have a drink".*
> Interview 21

Although a clear understanding of the association between excessive alcohol consumption and high blood pressure was articulated by participants, it was accompanied by a limited rationale. In terms of gaining information and knowledge as a resource for living with and managing high blood pressure, most participants mentioned their GP as their first port of call and important source of information. Some participants also mentioned books and leaflets as an information source, and one participant mentioned the Internet.

Commonly participants across the age group in this study had another major illness that impacted considerably on their lives. Conditions mentioned included arthritis, cardio-myopathy, angina, anaemia, diabetes, bladder problems, bronchitis, asthma, gall-stones, skin problems, nervous breakdown, varicose veins and internal thrombosis. Some of the conditions mentioned required treatment in the secondary care sector.

Participant responses to managing stress

A strong focus of participants' explanatory models (*cf* chapter 9) in the semi-structured interview data is the notion of stress and worry. It therefore seems that some participants may have adopted strategies to actively manage stressful situations, however these data were surprisingly absent with the exception of Carlton and Hyacinth. It seems possible that Carlton's GP may have initiated a strategic approach to stress management, as she was concerned that he was worrying about having high blood pressure, as Carlton explains:

> *C "The doctor said to me once, aren't I worried about my blood pressure? And I says 'Well, no.' And, because she thought, maybe, part of the stress is worrying about having blood pressure, but it doesn't. It doesn't affect me in that way".*
> Interview 20

Carlton adopted several approaches to stress management including attendance at a stress management course and the use of relaxation tapes, in addition to taking time off sick from his work role:

> *"And I went on a programme, erm that they were doing at the University about stress management and the surgery actually also provided me with some tapes and stuff like that".*
> Interview 21
>
> *"She said 'I'm signing you off work, I want you to stay out of stressful situations.' So I had a couple, two weeks off work, you know, and ......probably I'll tell you what's been happening - me house burn down!".*
> Interview 21

Hyacinth also used relaxation tapes. Carlton and Edgar share commonality in attempting to take control of the management of stress, by modifying their responses to stressors:

> *E "You know. Little problems that er, you know, that you think about, that this thing and that thing worry about doing this or doing that. And then you just forget the one*

> *thing and then say well, it's better to forget those things. Don't let them worry you, than let them worry you and get to high blood pressure".*
> Interview 6

Carlene and Carmel stated their main strategy was to rest more and not become stressed if their blood pressure was elevated.

Use of herbal remedies

Herbalism, which is the use of herbs and plants as medicinal tonics, infusions and topical applications, is widespread in the Caribbean (Morgan 1993). Traditional herbal remedies of this nature, known as 'bush' are often taken as infusions or 'bush teas' (Scott 1998). The term 'bush' appears to be derived from the fact that most herbs form bushes, having soft leaves on woody stalks and stems. A small number of studies have established the continued use of herbal remedies and bush teas by African Caribbean people living in England (Morgan 1988, Thorogood 1988, Scott 1998). The bush teas are taken for a range of ailments and illnesses including hypertension (Morgan 1988) and diabetes (Scott 1998). The evidence from the studies mentioned appears to support the existence and continued use of traditional Caribbean approaches to healing and the promotion of well-being by African Caribbean populations living in England. In this study, the herbs and bush teas commonly used were Aloe Vera, singer bible, cerasee, rosemary, bread fruit leaves and fever grass (see Appendix 21). Some of the participants shared information with me regarding their use of herbal remedies, only when it became clear to them that I had knowledge of this practice within African Caribbean communities in England.

Some of the participants, Jerome, Petra, Edgar, Lynn, Barbette, Carlene, Loretta, Hyacinth, Carmel and Carlton, used traditional Caribbean herbal remedies, whilst Wilbert, Clifford, Patsy, Darius, Jorge, Wesley, Bill, Patrice, and Aleeya stated that they did not. A lot of data were elicited regarding the use of herbal remedies for general health and well-being which appears in Appendix 22. Presented in the thesis are those accounts that directly relate to high blood pressure.

Specific herbal remedies for high blood pressure

A small number of participants took herbal remedies specifically for high blood pressure. Carmel, for example, took Aloe Vera. Hyacinth, a younger participant used a mixture of garlic, coconut water, lemon and lime. Hyacinth had decided not to take her prescribed medication, preferring to use this herbal remedy, which she believed had lowered her blood pressure. Hyacinth had shared this information with her GP:

> *"Because I really don't believe I taking medicine*
> *I had a chat with my family back home on the telephone and they talk about, you know, coconut water and lime, lemon, lime. Those kind of things.*
> *G Yes. Is that good for high blood pressure?*
> *B Very, very good. Garlic.*
> *And I actually use, a whole month, I use garlic and a lot of garlic and onion for cooking with, erm, use lemon and lime hot in water, when I could get the coconut water, as well, mix with it and it's amazing. I went back the doctor, blood pressure was down. Really, really down. So, I thought it was down about the same point with the tablets as well".*
> Interview 19

Hyacinth clearly had the efficacy of this remedy confirmed by her GP when he told her that her blood pressure was no longer elevated.

Caution with herbal remedies

Carmel was very aware of the dangers of using traditional herbal remedies, in that one might overdose in the same way one might overdose from prescribed medication:

> *" These are very dangerous (points to plant in living room).*
> *G Oh.*
> *C It's good, but you can't drink it too strong.*
> *G What is that?*
> *C The Aloe Vera.*
> *G Oh, yes.*
> C You can drink it, but you can't drink these *things. You know these things, people...*
> *G Well, how do you drink that one, then?*
> *C I, I boil. A little piece.*
> *G Just a piece of the leaf?*
> *C Yes. A little tiny piece, because if you drank it too strong, that's what damage your kidney and your liver".*
> Interview 20

Tacit knowledge of the use of herbalism was said by participants to reside with elders in the family in Jamaica or neighbours. Following migration this source of information may no longer be available. The use of herbal remedies was not universal within this study population. Wilton, Patsy, Darius, Jorge, Clifford, Wesley, Bill, and Aleeya were very clear they did not take herbal remedies.

Obtaining herbal remedies

Exploration with participants as to the acquisition of herbs and traditional herbal remedies provided some interesting insights. Some participants grew their own herbs commonly in the bathroom. Participants in this study most commonly grew Aloe Vera known as Single Bible/Singer Bible as a houseplant (a participant informed me that the term Single Bible is derived from the Latin term Semper Viva meaning long life). This plant was mentioned as a specific remedy for high blood pressure, with the sap rather than the leaves or stem being ingested. Participants frequently said they obtained supplies of herbs when visiting Jamaica on holiday, often obtaining enough supplies to last one or two years, as Carlene comments:

> *"Yes. My Mum's going to Jamaica next month.*
> *And bringing some over for me.*
> *G Yes. So, what will she bring you?*
> *C Like, single bible, and a bush tea that you can drink.*
> *It's bitter, than cerasee.*
> *It's bitter for the blood.*
> *G Yes. But, do you think it enhances your health?*
> *C Yes. Definitely.*
> *G Definitely? Yes. But is the one that she's bringing you, it's not specific for high blood pressure, is it? Or is it?*
> *C Yes.*
> *G It is?*
> *C It helps high blood pressure and sores on my legs and that".*
> Interview 16

Carlton shared with me that often his father returned from holiday with a number of different herbs in a box which were not labelled, creating some confusion as to which remedies were actually taken.

If herbs or bushes could not be obtained on holiday, they could be purchased in some continental or Asian stores (as distinct from an English herbalist). However, participants stated they would not obtain herbs in this way because of the high cost and that they were of low quality being 'old' or not freshly picked. Carlene shared with me that in her location a door-to-door salesman sold herbs and a range of other products for African Caribbean people in the neighbourhood. Some commonly used herbs such as cerasee are available as commercially produced products in herb tea sachets.

Edgar was of the view that both herbal and Western medicines could be used effectively together:

> *"Er, these things [herbal and western medicines] work together, you know.*

> *And er, they have to work together...*
> *G Yes.*
> *E to get things right. So it's not that you are actually draw one section of er...medicine, you know what I'm saying".*
> Interview 6

Concordance and non-concordance

Participants in this study frequently spoke about their medication, in relation to the number of tablets taken, the frequency and medication changes. Most participants were aware of the medication changes experienced and could articulate a rationale for why this change had taken place, often side-effects or simply that the medication was not controlling the blood pressure. It was uncommon for participants to be able to name the medication and the physiological process by which the medication controlled blood pressure. In the daily management of high blood pressure, some participants rationalised their high blood pressure as being normal once medication had been received. One participant Barbette was taking anti-hypertensive therapy for a number of years before she was made aware of this (*cf* chapter 8). Edgar comments frankly on the value of prescribed medication:

> *"So, it's like you'd be taking tablets now, this morning, and you take, you might be on six different tablets. You take all them tablets, all at once. But each one of them tablets are just junk".*
> Interview 6

The issue of concordance with prescribed drug and medication therapy has long been recognised within all populations as an important consideration especially in the long-term management of chronic conditions in PHC such as diabetes, asthma and hypertension (Benson & Britten 2002). This issue may be further complicated for hypertensive patients who are often asymptomatic. In this study some participants experienced no symptoms prior to diagnosis. Therefore it is possible that some individuals may experience difficulties in adjusting to their changed health status and self-image. Less than half of the participants in the semi-structured interviews stated they were concordant with prescribed medication. The remaining participants, Wilton, Patsy, Jerome, Lynn, Barbette and Carmel stated that they took anti-hypertensive therapy as prescribed. Barbette explains:

> *"Whether it tastes good or it tastes bad, whether it's big or it's small, I never get a medication and don't take it".*
> Interview 14

A high level of concordance with prescribed medication may be dependent on the individual holding an implicit belief of Western medicine and biomedical explanations for health and illness. Participants in this study provided a range of explanations (*cf* chapter 9) for their high blood pressure.

Many of the explanations were not synonymous with biomedical explanations. Concordance with prescribed medication did not necessarily mean that the participant was happy with the medication prescribed as Carmel explains:

> *"And, because I know I'm taking tablets, you know, erm, because of my, the tablets what the doctor give me now, it's very, is 100mgs.*
> *I'm so afraid of it, but I still have to take it, so I don't take nothing else.*
> *G No. Yes. So, you don't really like, because you mentioned earlier, you didn't really like taking the tablets.*
> *C Oh, God. I've, oh, God. Every time I take one, I have to hold it up and pray".* Interview 20
>
> *C "I've never liked to take tablets.*
> *I'm afraid of tablets. I'm always afraid of taking tablets, but*
> *G Because, why?*
> *C ...because of this blood pressure now, I have to take it.*
> *G Yes, but why, why are you afraid?...*
> *C It can damage you. I still believe in that. It can damage you inside.*
> *It can damage your kidney, your liver.*
> *I believe in that".*
> Interview 20

Carmel felt very unhappy about taking her prescribed medication because of potential side-effects explained to her by her GP. However, she was resigned to taking tablets to control her high blood pressure. Hyacinth explained that her concordance with prescribed medication was intermittent. Shortly after diagnosis when her blood pressure was very high, she felt compelled to take the mediation because of the potential consequences of high blood pressure, as she explains:

> *"And then I'm aware that I need to do, you know, actually take the course of tablet or prescribed medication that they would prescribe but the thing with blood pressure, I know it leads to stroke so I know it needs to be looked at carefully, but at the same time I'll try.*
> *It would have to be really, really severe for me to, like at the beginning, I know I needed to take those tablets, which I did, for four months.*
> *And it was very helpful".*
> Interview 19

Hyacinth goes on to explain that she is no longer taking anti-hypertensive therapy but is totally reliant on an herbal remedy to control high blood pressure. It is clear that for participants in this study concordance and non-concordance are complex phenomena pre-empted by diverse influences and decision making processes in the management of their everyday lives.

Non-concordance

Participants gave me a range of explanations for their non-concordance with prescribed medication. Some participants expressed anxiety about potential and actual side-effects from the medication. This information was gleaned either from the information leaflet in the medication box, from their GP or as a result of side-effects they had experienced. Hyacinth explains:

> *"...I said to the doctor, because I was having all the side-effects and I'm aware that it could affect your heart as well, and bearing in mind that my Mum died of heart attack, I thought there is no way, I mean heart problem, there's no way I'm going to take some tablets that would actually, you know, put my heart at risk, you see".*
> Interview 19

Hyacinth was also of the view that once a tablet had entered her body she would have no control over which organs the medication might affect, as she comments:

> *"I just don't like it. I feel as though, if there's something wrong, I've got blood pressure, and that tablet could create more problems and just put pressure, because once you put a tablet in your body, that's my thinking anyway, it, you often read this little, you know, leaflet that they put inside and you could affect your kidney and it could affect your heart and I thought then, if I'm only going to have one problem, which is blood pressure, and end up with, with heart problem, or kidney failure or whatever goes it, I'm better off looking at alternative medicine, if it can help".*
> Interview 19

It seems that the drug information leaflet, far from empowering Carmel and Hyacinth with more information, actually fuelled their anxiety and in many senses the information provided was counter-productive to them taking the prescribed medication. Other participants such as Petra, Carlene, Delbert, Carlton, Loretta and Hyacinth had experienced side-effects such as dizziness, headaches, and oedema of the legs and impotence. For some participants, these side-effects precipitated their non-concordance. Carlton remarks:

> *"And I remember when I was on the Tenolol, and I went to Jamaica and I was taking them and after I take my tablets,*

> *I could feel this migraine coming on and it got worse and worse as the went on, you know.*
> *And by not, one day I decided it was the tablets that's causing it. [inaudible]. So, I didn't take them for a couple of days. And the times I didn't take them, I didn't get any headaches".*
> Interview 21

Side-effects from medication impacted upon Hyacinth's everyday life in a profound way:

> *"But, while I was on the tablets, I was aware that I was petrified to go walking in town, shopping because I was feeling so, not right, you know?*
> Interview 19

Not all the participants' experienced side-effects in this study; most commonly participants did not experience side-effects.

Carlene explained how her non-concordance was more closely related to issues of power and control in her life and diverse demands on her time:

> *"Who wants to get up and pop pills all the time. You've got too much things in real life, to think about taking pills.*
> *I don't have time for pills.*
> *G So, you just sometimes were to forget?*
> *C Do you know, I get up in the morning, I don't even think about the pills. What's on your minds, the kids. Getting them off to school, getting one to nursery, getting yourself ready, getting the sandwiches ready and getting to work on time. You don't think about the pills".*
> Interview 16

Within the context of her life, it seems that taking anti-hypertensive therapy was low on Carlene's list of priorities. She was one of two participants who were clear after the initial diagnosis that they had no intention of taking prescribed medication:

> *G "...you didn't like the idea of it?*
> *From the outset.*
> *C I didn't like it, and I put them in a plastic container. Can I find?*
> *G I don't know.*
> *C That's how much I put my mind against it.*
> *G Can't you find it?*
> *C I can't find it.*
> *G The pills still in there?*
> *C the pills are in there.*
> *G Oh, gosh.*
> *C Yes.*
> *G Yes.*
> *C I can't find it.*
> *G So, did you take them at all, Carlene?*

C The first few weeks, I was taking it.
G Right.
C Then one was making me really ill.
G Yes, you said that, yes.
C So, I went up and tells the doctor, she changed it.

G Yes.
C And I says to her 'I ain't taking these.' I just put them in a box and put them away.
G So, you did.
C I put them away and that's it".
Interview 16

Carlene's final comments are articulated in such a way as to indicate the finality of her decision. Carlene's comments seem to indicate that her non-concordance is linked to the notion of empowerment and gaining some control over an event or events over which she would otherwise have little control over. Carlene and Hyacinth had shared their non-concordance with their GP. Hyacinth elucidates:

G "And are you taking the tablets now?
H No.
G You're not taking them?
H No.
G Does he [participant's GP] know you're not taking them?
H Yes.
G He knows?
H I told him.
G And how did he react?
H Well, as I said to you, he gave me a leaflet...
G Yes.
H About blood pressure...
G All the information.
H Information there and I suppose that's what he can do, isn't it, really?
G Yes. Yes. Yes.
H But I know if I need the prescription, it's there, but it's pointless if I'm not using it, isn't it?"
Interview 19

The openness in Carlene and Hyacinth's interactions with their GPs may be reflective of the quality of their relationship. More commonly however in this study, participants stated they had not shared their non-concordance with their GP because of fear of retribution and damage their relationship.

Some participants such as Edgar stated that they had simply run out of tablets and forgotten to obtain a repeat prescription in contrast to Carmel who was very anxious indeed not to run out of tablets:

> *"Well, I got a lot of experience about this blood pressure, because of the tablets I'm taking. The amount of tablets. I have to go back, if I had one strip left, I had to go back to get some more, because doctor says I must not let it run out".*
> Interview 20

Other participants simply forgot to take the medication but remembered the next day:

> *W "Yes, but it's the next day, when I came to take the tablet, that I remembered. I didn't count them. I just remembered that I didn't take one yesterday morning".*
> Interview 10

Sometimes non-concordance was based on the participants' lived experience of the prescribed medication, making no demonstrable impact on their hypertension:

> *C" But, when I was in the doctor, the other day, she said 'are you still taking your tablets?' I said 'yes but I've finished them now' But, I wasn't. My blood pressure gone down. So, I thought 'those tablets was never helping.' So, I told a lie there, I said I was taking, but I wasn't"*
> Interview 16

Commonly, participants did not take tablets whilst on holiday in Jamaica either because they had forgotten medication or because they felt more relaxed and less stressed. One participant modified his anti-hypertensive therapy if he was taking other medication.

In summarising the findings of this theme, a number of key issues emerge. Some participants experienced psychological distress such as worry and mood change as a result of their high blood pressure. Very few of the participants actively managed their stress that was either a precursor of high blood pressure or a result of high blood pressure. Participants also experienced physical symptoms, which to some extent required lifestyle modifications. High blood pressure resulted in some participants retiring from work early and this resulted in both social and economic consequences. Few participants shared their high blood pressure or anxieties concerning this with family members or friends, although participants with children or grandchildren stated that their high blood pressure affected family relationships. Most participants used traditional herbal remedies for health and well-being, with a small number using herbal remedies expressly for high blood pressure. First and second-generation migrants used herbal remedies. Commonly participants were non-concordant with prescribed medication;

a typology of non-concordance exists. Non-concordance is used as an empowering strategy in response to the condition of high blood pressure via which the participants gain a measure of control.

Chapter 11

The participants' experience of Primary Health Care

This chapter explores participants' use of the NHS primary health care services. Reference is made to the use of PHC services in the Caribbean as this may influence participants' contemporary use of PHC in the UK. Factors influencing early presentation for diagnosis in PHC are examined, and perspectives are gained on the quality of the participant/GP relationship, as perceived by the participants. Participants' satisfaction and dissatisfaction of PHC services are also evidenced. It is relatively common in the UK for communities of African Caribbean origin to use private GPs. Motivations for using private GPs are explored, including historical antecedents.

Use of NHS PHC services

Participants in the study presented some evidence to suggest that seeking professional medical attention, at the onset of a dysfunction or disease, may not be a cultural norm for individuals who have migrated to the UK from the Caribbean. This is evidenced in the data, as historical antecedents, prior to migration. In past decades in the Caribbean, the lack of a state-provided formal PHC service meant that through necessity, communities had to develop self-care systems that appear to be deeply embedded in the culture and traditions of the participants. Moreover, medical provision that did exist was only available to the wealthy that could afford such medical care. Loretta comments:

> " *Something can be wrong, could be serious and it take ages for them [African Caribbean people], for it to be diagnosed because they're not running to the doctor...not keen on running to the doctor. That's the sort of way they would feel. Running to the doctor*".
> Interview 17

Loretta appears to view presenting oneself at the GP surgery as soon as symptoms become evident negatively. The notion of *'running to the doctor'* is used by Loretta as a pejorative concept. Hyacinth and Loretta commented on trends they had observed in England and Jamaica in relation to younger African Caribbean people and their readiness to use PHC services. Participants viewed resourcefulness and self-care, as an essential component of life in the Caribbean. This may, mitigate against early presentation for diagnosis in PHC of conditions such as hypertension. Clifford re-iterates this point:

> *C "You only hear about doctors. You never see one, 'cause they, well, it's mostly people living in the country, there are bush things. You know, like, they drink bush tea, they got bush this, bush that".*
> Interview 8

Delbert elucidates further on the scarcity of doctors and PHC in past decades in the Caribbean. Both Clifford and Delbert emphasised how the lack of access to formal PHC services may have contributed to patterns of self-care that existed, and reliance on traditional Caribbean herbal remedies:

> *D..."in those days when we were in the Caribbean, if someone said they had a fever they didn't go to the doctor, they just boil some bitter herbs and drink it. Each year your knowledge increases so we don't know what's out there now..."*
>
> *In those days you couldn't get a doctor because in, those day people knew how to boil bush and that was your medicines. The only time you heard about a doctor was when you heard one was going to operate in Montego Bay and we always call the doctor 'butcher man, 'butcher people'. I have never been to a doctor in Jamaica".*
> Interview 9

Delbert also seems to imply that he did not hold the doctor who was available in Montego Bay in very high esteem.

Relationships with the General Practitioner – satisfaction and dissatisfaction

Participants in this study, largely expressed satisfaction with the PHC services they had received in respect of their high blood pressure, and were very keen to emphasise their positive regard, especially for their GP. In this study all the participants regularly consulted with their GP rather than the practice nurse. This I found quite surprising given the role practice nurses have in chronic disease management in PHC. Carmel, Loretta, Wesley and Delbert, had seen the practice nurse occasionally, for blood pressure monitoring and blood tests. Carlene explains why she values her present GP:

> "*She'll sit down and she'll talk to you. That's why now,*
> *I've started seeing her*
> *Because she's got that nice smile.*
> *C You know, it's genuine and she can spend time talking to use, you know, even your upset she'll go 'well, you need to go Carlene. You need to get it sorted.'*
> *C She's completely different.*
> *G Yes. Is she younger?*
> *C I think she's about in her forties.*
> *G Yes. Well, what's making her different, then?*
> *C I don't know. She got, like, she's got more time for you. Time and patience...I don't know what it is about her, but she looks more genuine. When you go in, she's not quickly taking your notes out. She takes her time. She's like'how's Jodie? [Carlene's daughter] Is she alright? No problems with Jodie?' I says 'no.''It's me, I've come.' She says 'oh.' And then she'll take out your notes and she'll read first, and then she'll say'now.' And she'll sit back. 'Now, what can I do for you now, Carlene?' And then she'll talk. And she'll explain things to you. And then she'll raise her voice a bit, like 'well, you NEED to come and see me more often, Carlene, about your blood pressure, because, do you know the seriousness of it?'*
> *You know, she's different*".
> Interview 15

Carlene appears to focus very much on the non-verbal communication her GP displays during consultation such as her smile, genuineness and the feeling that she has more time for her patients. This theme of non-verbal communication and listening is re-iterated by Carmel:

> "*But I know I can go to my doctor because my doctor K says to me 'any problems, you know, you just come to me.' And she really, she's a very nice doctor.*
> *Anything, she sits down and listens and she'll talk* and *give you her opinion*".
> Interview 20

Having time available for consultations with patients, seemed to be key in relation to participants' expressed satisfaction with their GP. Carlton remarks:

> "*She's a very nice doctor.*
> *Very nice doctor.*

> *Yes. She was very good, actually.*
> *Erm, as a matter of fact, I think I got something like about 50 minutes with her.*
> *G Really?*
> *C Which was quite surprising really.*
> *I've never been into a doctor's surgery and they've taken that much time.*
> *She gave me quite a considerable long time and she spoke to me about a lot of things, you know".*
> Interview 21

Within the GP/patient relationship, the concept of openness emerged as having significance. As the data indicated, for some participants both they and their GP had been lacking in openness on the topic of high blood pressure. Barbette elucidates:

> *"And when the doctor come and test me, he said the blood pressure is high. I said 'blood pressure, doctor?!' He said 'didn't you know you had blood pressure?' I said 'no, doctor, you never tell me.' And I told him what he said to me the last time. He said 'I thought I told you you had blood pressure from 1982?'...And I wasn't told".*
> Interview 14

Barbette was very emphatic that she was not told about her high blood pressure, and discovered this several years later when she became ill. She was taking anti-hypertensive therapies; as she had a number of illnesses, she was unsure of the exact nature of the medication. She had a daily medicine dispenser that she filled with her medication very carefully each Sunday. By the same token, Barbette was very reluctant to be totally honest with her GP, as she remarks:

> *"I didn't tell her. Well, she never ask how I was getting on with it, because I keep getting something for it and it didn't work.*
> *And she never ask me. I believe it's kind of er, a, you know, do I tell the doctors that and say 'well, I told you that it didn't work, but I take some Epsom salt.' I don't think that is the way to go about it, but if she did ask me, I would tell her.*
> *But, she didn't ask.*
> *G So, you've kept it to yourself?*
> *B Yes".*
> Interview 14

Barbette's assertion illustrates very well, how a patient/GP relationship might be based on non-disclosure, and both parties may not be well informed. Wilbert describes aspects of his lifestyle he would not share with his GP, in relation to taking herbal remedies:

> *G "if you was taking herbal remedies like this is it*
> *something you would share with the doctor?*
> *W No, no I never tell him about that.*
> *G No. Do you think it's relevant?*
> *W Is everything you share with yourself*
> *relevant to the doctor? I don't believe it's*
> *relevant no.*
> *G No. Is it, is there a reason why you wouldn't*
> *share it with the?*
> *W No, no, a special reason. I wouldn't just*
> *go down to the doctor and say oh this morning I*
> *had some [inaudible] tea, no. I don't have time for*
> *that".*
> Interview 15

Wilbert's comments highlight the extent to which he is prepared to share aspects of his everyday life with his GP, and resonate with current debates around medicalisation of everyday and social phenomena, such as sexual health. Delbert was simply of the view that he did not wish for full information about his condition from his GP:

> *"She never told me how high it was. The nurse didn't tell me either. My daughters want to know how high it was, but I tell them I didn't ask because all the time she said its high and I don't like to hear that so I didn't bother to ask.*
> *D Yes I never ask that question*
> *G So you don't want to know the level*
> *D Yes I only want to know that it is normal".*
> Interview 9

Delbert clearly did not wish to have any information about his high blood pressure, other than that which affirms that his blood pressure was normal. Conversely, Carlton was upset that his GP had not shared the full facts about the potential side-effects of anti-hypertensive therapies that are known to cause impotence:

> *"Well, yes. It has, the other side-effects,*
> *which I've discussed with the doctor, in terms of*
> *my sex life and things like that, you know...*
> *"They just recognise there are effects but they*
> *never go through in detail what the effects will*
> *be. Sometimes you have to drag it out, because I*
> *brought it [impotence] up, rather than them asking me.*
> *Sometimes people just don't talk about those*

things, do they?
G No. No. No, they don't. No. That is true. Yes.
C And I think sometimes it should be the Dr.
that draws that out. I'm the one that's
introducing it, trying to, sort of, get some
clarity on what's going on".
Interview 21

The main focus of Carlton's comments is concern that he had to introduce the topic during a consultation, whereas he is of the view the GP should initiate conversations of this nature. Surprisingly Carlton was the only male participant to mention impotence as a side effect, which led to specific inquiries about impotence in the final data collection, vignette interviews.

Although commonly, participants expressed satisfaction with their GP and the quality of the relationship that they had been able to establish, some participants were unhappy with the length of time they needed to wait for appointments. Jorge remarks:

"
G [improve PHC] In what way?
J Give you a quicker...
G Quicker appointment. Yes.
J Or sometimes, you need what you go for,
what you want to see them about. You've probably
got worse".
Interview 7

Those participants who expressed dissatisfaction with their GP (Barbette, Carlene, Aleeya and Carlton), had left the particular GP practice and registered with a new GP, or if registered with a multi-partner practice, they had chosen to see another GP. The dissatisfaction expressed ranged from alleged negligence that resulted in a formal complaint to the former Family Practitioner Services to simply not being able to obtain an appointment. Barbette explains the difficulties she had in leaving the GP with whom she had been registered for thirty-two years:

"Because when I was with doctor X... By the
time the appointment come around, you
have to wait two weeks, by the time it come
around you are well again. Then it look like you
are making a fool of yourself.
So, there's no point in you make that
appointment because by the time you get the
chance to see him, you are better.
I've been with him for 32 years and
that was why I change him.
G Dr.X! You've been with him for 32 years?!
B Dr.X. Yes. That was why I change and go
to Greengrass Surgery and if I make an appointment, say
today, Tuesday, the latest I might have to wait

> *is Thursday.*
> *G Right. So, you've changed your doctor there to there.*
> *B... It was hard for me to pull myself away".*
> Interview 14

It is clear that Barbette's longstanding relationship with her former GP created some conflict for her when leaving the practice. On the other hand, Delbert, who also expressed dissatisfaction, remained registered with his GP. Aleeya describes the source of her dissatisfaction:

> *"He was saying that I was too anxious and saying that the blood pressure wasn't causing the headaches.*
> *G Right.*
> *A You know, so he said 'high blood pressure doesn't cause headaches'. I said 'that's the first I've heard that one!', you know. So each time I went to him with the high blood pressure, he'd just shrug it off, and say 'oh, just calm, down and stop being so anxious'. And then, just by chance, I'd had this high blood pressure for 18 months, and just by chance, I went to see another GP, because there's like 4 GPs in the practice."*
> Interview 18

Aleeya was trained a health professional, who had considerable insight into the physiological processes associated with high blood pressure. She also had access to blood pressure monitoring equipment at her work place, and knew her blood pressure was elevated. What is surprising about Aleeya's assertions is that she acquiesced to her GPs viewpoint for 18 months before seeking a second opinion, and this was only by chance.

Carlene had clear and formulated ideas about why she felt that African Caribbean people do not receive an equitable service in PHC, although she was the only participant to articulate this view-point. It may be that my status as a former health visitor (known to participants) may have inhibited some participants in speaking as frankly, or that they were genuinely satisfied with PHC services received:

> *"And, it's like they haven't got time to explain to you.*
> *G In the surgery?*
> *C And I find, when we go in...*
> *G When you say 'we', do you mean black people?*
> *C When black people go in...*
> *I sat down and watched, you don't stay in long with them. You don't stay in long with them.*

> *And I've been, when I went there, erm, two weeks ago, when I went to have my blood pressure taken, this guy was in there and he was in there for ½ an hour, well ¾ of an hour, he was in that room. And everybody kept going 'what the hell, oh I wish he would hurry up.'*
> *And as I went in, it wasn't even five minutes.*
> *It wasn't even five minutes.*
> *G So, why do you think that is, then?*
> *C Because I don't think they have, they've got, they can't understand our problem.*
> *I don't think they understand our problem.*
> *They can't understand to explain to us. I think they believe that we know more in... I think they believe that we know more when we go in, so they don't want to jeopardise themselves by telling us what it is, and they're wrong. If you know what I mean.*
> *G Right. Okay. So, you think that, they think that er, black people have specific knowledge about their health?*
> *C Yes. Because they think that we're witch doctors and all that. We know all them. We know a lot more than what we bargained for. We've just come there, just to, like I say, we just testing them. That's what I feel. Because they never explain the illness. I don't know why. They never explain the illness. Never".*
> Interview 16

Private General Practitioners

It became evident during the course of the interviews that some participants, namely Delbert, Barbette and Carlton, had used private GPs for PHC medical services. This was not confined to first generation migrants; a younger participant born in the UK had in the past used a private GP. Within the study sample this was not a common practice. However, since the phenomena exists and is used in tandem with NHS PHC it is important to consider the motivations, gains and benefits, that participants' feel accessing PHC care in this way provides. However, it is worth noting that all the participants were familiar with the fact that some members of the African Caribbean community in the UK did use private medical services. Morgan (1993) established that populations of Caribbean origin in England used private GPs.

Motivations for use of private GPs

A tradition of using private primary health care and GPs, exists in the Caribbean for those people who could afford to, and lived in close enough proximity (usually towns) to access the services (Morgan 1993). Most people in the study were aware of the existence of private GPs in England through family, friends or relatives who were using the services. It seems that the use of these services also served a social function, as a coach or bus would be hired to take a number of people to different cities in order to use such services.

The study locations are Sheffield and Nottingham, although participants mentioned several cities where they had accessed private medical services e.g. Derby, Birmingham, Leicester. I am uncertain as to what extent this might be a deliberate strategy to avoid recognition by the participants' own NHS GP of this activity, although, some participants had visited private GPs in their place of residence e.g. Sheffield, Nottingham, and Wolverhampton. As Delbert and Barbette comment:

> D *"A different one. Like I've said before we always used one in Birmingham. We would go to a private doctor in Birmingham, or in Derby".*
> Interview 9

> B *"I get lots of invitations from people who are going out to Leicester to private Dr's".*
> Interview 14

The social nature of such occasions is emphasised by the notion of receiving an invitation from a friend as in a party or wedding. Knowledge of the existence of private GPs in other towns also demonstrates the tacit knowledge held within communities and the power of 'word of mouth' as to the best of my knowledge private GPs do not advertise their services.

The use of private medical practitioners also appears to be influenced by the use of private medical care by affluent and wealthy people in England, leading some participants to conclude that private PHC accessed is superior to that which is received in the NHS. Carlton remarks:

> *"I think they think they get what they, if you pay for something you get what you pay for. Erm, sometimes, when I'm in the doctors, they feel that they haven't, there's something about having, when you pay for something, you're getting the best. You know. Because it's free on the National Health Service, you're not getting the best, where as the rich people, they pay for it and they get the best".*
> Interview 21

Carlene and Delbert both believed that the actual treatments or medication received were of a superior quality to medications available on the NHS. Delbert shared his view with me:

> *"But once I knew Dr X [private GP] I've always*
> *use him. Sometimes black people say to me you are*
> *going to Dr X and paying him all that money for*
> *the same tablets you can get from your own doctor.*
> *I say yes but doctor knows more than we do. I'm*
> *surprised to see a man, who used to make fun of me,*
> *going to Dr X now. But when you look after yourself you*
> *don't just sit around and let the pain [inaudible]*
> *when you go to a private doctor you get better stuff.*
> *G. Medication?*
> *Mr D yes, it costs you*
> *It costs you a lot but you are better off for it".*
> Interview 9

The use of private GPs was not confined to first generation migrants born and socialised in the Caribbean; one UK-born participant used private medical care and one participant who migrated as a child. The continuance of traditions such as the use of herbal remedies and private medicine in younger and second-generation migrants illustrates how the process of acculturation can differ between individuals and families. Indeed, there is some evidence to suggest the migrants may become more conservative in terms of preservation of culture and retention of traditions (Schott & Henley 1996). The dynamic nature of culture means that whilst in the birth country, practices and traditions may change. The rationale given for use of private GPs provides interesting insights. Carlene explains very vividly how she feels about visiting a private GP in terms of the respect afforded to her and the time available for discussion. Carlene elucidates:

> *"Because they [private doctors] sit down and they*
> *explain things to you. Whereas these National Health*
> *ones, they haven't got time for you. They come in,*
> *give you a quick examination, there you are. That's*
> *all you get. And so, well, why can't they explain to us.*
> *It's like they think we're illiterate; we won't*
> *understand. 'Oh, don't explain to her. She's illiterate.*
> *Just give her that, she'll take it. That's it".*
> Interview 16

For those participants that used private GPs, the quality of interaction and communication was perceived to be superior to that received in the NHS, and the medication perceived to be of higher quality. Delbert remarks:

> *"Yes, sometimes we even go all the way to Birmingham*
> *to see doctor there [names Dr] Sometimes he*
> *prescribed two or three different tablets and you have to*
> *pay £10 or £12. Once I went and he prescribed me some*
> *tablets and I went to get them at Somewhere Street,*

> *you know in town, I don't know if you remember there was a chemist there. When I went they wouldn't give me the tablet, they think it was too good for black people, so I had to phone the doctor in Birmingham. Well if the doctor prescribes a tablet for you and when you go to the chemist they refuse to give it to you, you have to ring him.*
> *G. Oh, is that the chemist?*
> *D Yes. That's like saying only rich [as opposed to poor/black] people can have it because it costs £10 to £15 you know. I just don't know. Well the fact of the matter is, the private doctor can give you medicine you can't get on the national what your doctor can't give you".*
> Interview 9

The fact that the pharmacist rang to check with the private GP the nature of the medication prescribed, appeared to re-iterate Delbert's belief in the superior nature of the medicaiton.

Some of the insights provided point to past negative experiences of the NHS especially in relation to communication and perceived stereotyping of African Caribbean people. It is therefore not surprising that the ethnicity of the private GP appeared to be a significant factor in accessing a private GP. I do not have an ethnic profile of the private GPs mentioned. However, several were said to be of South Asian origin or black, therefore an additional factor in accessing a private GP may be that the patient can, during the selection process can take into account the ethnicity of the GP. Carlene remarks:

> *"But when I went to a black doctor, in erm, when it's a private doctor, he sat down and was explaining everything".*
> Interview 16

Not all participants in this study expressed enthusiasm about the use of private GPs. Some participants were sceptical about differences in quality of NHS medications and privately prescribed medication. Barbette who had used a private GP later changed her views following a frank discussion with the private GP she consulted:

> *"...I said 'these tablets,' I says 'on the prescription, I've got them already.' He say 'are you sure?' I said yes.' And I took out the bottle. He said 'yes, yes. Of course. These are some new tablets just come down.' He said 'if you got, what's the point?' You can get that free and spend money to buy it. It's the same thing". "You know? And he said to me 'let me explain this to you. A lot of people claim that going to private doctor,*

> *they get better treatment. It isn't better. It's all in the mind..."He said 'I'm telling you this now, as a friend, don't think that the National Health is not doing it's duty, and go and waste money to go to a private doctor, because the same thing the National Health get is the same thing we get. So, it's no different. You get it free from your National Health. And you have to pay me here when you come. So, remember this in future.' And when he told me that, I've never been back to private doctor".*
> Interview 14

The private GP was therefore apparently happy to consult and prescribe, until challenged by the patient regarding her treatments. The comments of Loretta and Wesley cast doubts on the superiority of private medical care:

> *L "No. Because I think, some might be genuine and all right, but I think some of these doctors are only in it for making money".*
> Interview 17

> *W "Costs a lot of money [private GP] and doesn't, we've heard rumours going around that.*
> *G Oh yes. What like, sort of, rumours?*
> *W Just that what they giving you, it doesn't make you Better, but it's just what you believe in.*
> *G Right.*
> *W Yes. Yes, because rumours. Yes*
> *G Yes. So some, you think people in the community use...?*
> *W Yes, but it this way, just being ripped off. Put it that way, yes".*
> Interview 10

Interestingly Delbert, Carlene, Barbette and Carlton, who used private GPs also expressed considerable dissatisfaction with their previous GP services, and gave powerful examples of the level of their dissatisfaction. However, neither Carlene, Barbette and Carlton were still registered with this GP.

New forms of PHC

Participants in this study appeared to have little knowledge of new forms of PHC Direct telephone line or NHS Direct online or Walk in Centers. Carlene was the only participant who had used NHS Direct for a complaint unrelated to her high blood pressure. Wilbert, Lynn and Carlton had heard of NHS Direct and Walk in Centers, but not used these PHC facilities.

Summary

Participants in this study most commonly expressed satisfaction with the PHC services received, which were mainly consultations with general practitioners. Within the consultations time for discussion, active listening by the GP, and positive non-verbal communication were aspects of consultations that were considered to be important and valued by the participants. Openness within consultation was also a key finding, especially in relation to potential side-effects, although not all participants wished for frank discussion about their conditions. Participants also demonstrated a lack of openness during consultations, choosing not to share aspects of their everyday lives.

Some participants used private GPs which may reflect a tradition of paying for medical services in the Caribbean or dissatisfaction with PHC in the UK. Those participants who did use private GPs did so simultaneously with NHS GP consultations. Benefits from the participants' perspectives were said to be a greater explanation of the condition, and superior quality medications, to that available from the NHS. There also existed some scepticism regarding the value of private GPs amongst the participants. Where dissatisfaction had existed with current NHS GP and PHC services, participants appeared to actively manage the situation by changing their GP. Most of the participants were not familiar with new forms of PHC services. The implications of these observations in respect of the research aims are discussed in Chapter 13.

Chapter 12

Findings – Vignette Interviews

This chapter examines the evidence elicited from the five vignette interviews. The vignette findings are organised into four themes; **early diagnosis, the meaning of high blood pressure, consequences and management of high blood pressure and the participant's experience of PHC.**

The vignette interviews provided the opportunity for further in-depth exploration of issues identified in both the preliminary data collection (FGI interviews) and main study sample (semi-structured interviews) and a means of triangulation of the data (Begley 1996) and multiple sources of data collection (Hammersley & Atkinson 1995). The vignettes can be found later in Appendix 11 and are informed and constructed from the findings from the FGI and semi-structured interviews. The vignette interviews (*cf* chapter 6 – methods) facilitated the interviewees in exploring sensitive issues at an early stage in the interview process, and moreover, the participants appeared more relaxed and at ease in doing so. Whereas in the semi-structured interviews, topics such as impotence, non-concordance and use of herbal remedies generally emerged at a latter stage participants were able to discuss these early on in the vignette interview. The acknowledged existence of the phenomena mentioned within the vignette scenarios appeared to permit the vignette participants to share their own personal experiences more openly and with little probing. Two participants; Richard and Marcia commenced, speaking spontaneously, immediately after they had listened to the vignette, with virtually no questioning, commenting on the experience of the individual in the vignette and then projecting and relating their own experience to the individual in the scenario. It was clear the vignettes had resonance for their lives. The credibility of the vignettes was endorsed by participants in their recognition of factors in the vignettes that mirrored the characteristics of their own lives. Furthermore, the vignettes developed were shared with the consumer research advisory group members (who narrated the vignettes so that articulation of the narrative occurred with an authentic Caribbean accent) who confirmed the credibility of the vignettes. The vignette scenarios are focused on distinct phenomena.

- ☐ Vignette 1 – Struggle in the UK , herbal remedies and non-concordance
- ☐ Vignette 2 – Non-concordance, impotence, alcohol, struggle in the UK
- ☐ Vignette 3 – Private GP's

The resulting data from each vignette interview is much more focused in the domains mentioned, although other topics did emerge. This could be regarded as both an advantage and disadvantage of the approach, in that the vignettes frame and to some extent determine the resultant discussion. In this respect the findings presented explore in depth and detail the phenomena emerging from the data, but may not reflect the breadth of experience in the main study sample.

In contrast to the participants of the FGI and semi-structured interview whom were all of Jamaican origin, one participant originated from Barbados and another participant from Guyana. This is a very useful dimension as commonality of experience does exist between the two participants and other participants of Jamaican origin. The first vignette interview participant was a FGI participant. However, this interview revealed very little new data and it was decided to recruit four entirely new participants. These interviews generated much richer data.

Early Diagnosis

In common with participants in the FGI and semi-structured interviews, the diagnosis of high blood pressure for Rosetta was associated with a significant health event at work:

> *"Around about the seventies. But it wasn't until I collapsed at work that I realised that I had high blood pressure".*
> Interview 24

Prior to this, Rosetta had no knowledge or symptoms of high blood pressure. Reena had a similar experience on her way to work although she continued and turned up for work as usual despite feeling unwell:

> *"...so when I did actually fall ill, I was on my way to work and I got a proper angina attack in the middle of the road, would you believe it?*
> *G Oh, dear.*
> *M And I couldn't even move and this was quarter past seven in the morning, in the middle of Greenleaf Road and thankfully, because it was so early...*

> *M Because I just could not move, you know. And, erm, I was on a double shift, I was the only one in charge...*
> *G Where do you work?*
> *M I was in a nursing home.*
> *G Oh, right. Yes.*
> *M Not far from me and, erm, and like a wally, not thinking, you know, thinking there's night staff wanting to go home and I got a right rollicking from my sons, I'm telling you. And three times during that day...*
> *you know, I ended up going to the, erm, to be honest, I didn't even, they kept saying, I had one of the girls take my blood pressure in the evening. This was about half six, because I got another massive attack and I thought...*
> *It was like somebody had taken a bucket of water and thrown it on me.*
> *And, erm, and I still didn't go to the hospital that night. I thought 'oh, no, I just have to get home', and you know.*
> *G So, when did you go to the hospital?*
> *M I went to the doctors the next day. Well, it's because you're in denial.*
> *G Do you think it's anything to do with being a nurse as well? Because if you think...*
> *M Possibly. We're the worst patients, aren't we? And, erm, we're the worst patients. And, actually when my doctor took my blood pressure, I'm telling you, for the first time I've actually seen his mouth drop open and his eyes popped".*
> Interview 23

The extract above demonstrates Marcia's commitment and dedication to her role as a nurse, which unfortunately was quite detrimental to her health. Her concern about relieving the night staff led to her decision to ignore her symptoms, which may have been potentially fatal. Reena, also an auxiliary nurse in a local hospital, had a remarkably similar experience on her journey to work:

> *"I was just, I was standing up and I could just feel myself like I'm going forward, you know.*
> *And I didn't take it for anything.*
> *Because at work, I'd asked them girls to check it. They says it wasn't, it was a bit high, you know, but not too high. At my age, they says, it's, you know, it's [inaudible]. What frightened me that day, I was crossing the road at the bottom, down there, waiting for the bus to pass, and I could find myself like I'm going forward.*
> *And the bus was coming up and I could feel, and so I closed my eyes, you know, but*

> *still I could, I was standing on the pavement,*
> *see the bus coming and I'm standing on the*
> *pavement and I could just feel like I'm going*
> *forward, you know. So, I said to myself.*
> *G Did it scare you? Was you frightened when it,*
> *sort of, happened?*
> *R Yes...*
> *R "So, I says, well, go and get it checked*
> *out properly".*
> Interview 26

These dramatic experiences are clearly frightening for the individuals concerned. Rosetta and Reena had earlier milder warning signs of their elevated blood pressure, which they chose to disregard. On the other hand, Percy was diagnosed when attending surgery for routine monitoring of his diabetes.

The meaning of high blood pressure

Within the vignette interviews, participants' explanatory models and perceived causation of their high blood pressure very much reflected the findings of the main study sample. Stress was the most frequently mentioned precursor arising from work-related stresses, the stress of migration and cultural adaptation. Financial problems were also mentioned, as was the stress of single parenthood.

For the two younger participants, Richard and Marcia, in the vignette interviews work related stress was mentioned as the main precursors of the hypertension. Both Richard and Marcia, similar to other younger economically active participants in the semi-structured interviews; were employed in public and statutory services. Richard taught in a school for children with behaviour problems, immediately after graduation he had worked in a children's home for 4/5 years. He lived 40 miles away from his work base necessitating a daily drive along the M1:

> *"I teach music in Nottingham. And I'm working*
> *with some really difficult kids and I've made the*
> *decision that after this year, that's it. I no*
> *longer want to work with [inaudible children with behaviour*
> *problems] because I feel that they don't, it's nothing wrong*
> *with them, it's me. I'm ready to take on something else,*
> *because health wise, I don't think it's any good for*
> *you at all, you know, you end up shouting all the*
> *time. You're stressed; you're chasing kids all*
> *over the place, you're chasing kids all*
> *over the place and it just adds to the tension*
> *and you just, at the end of the day, you're worn*
> *out. You're so worn out that you can't do*
> *anything else. You can just sit in that, in your*
> *car and drive home".*
> Interview 22

Richard is convinced that his previous and present work roles have created stress that pre-empted his high blood pressure, as he remarks:

> *"I've been reflecting that.*
> *I've been providing a service, since I've left school, that's all I've done, is provide a service for people and I just need to, I want to come out of the, I want to come out of the front line now, erm, because when I was first diagnosed, I was working as a home care assistant and that was, like, looking after the elderly and it's quite demanding and things. You know what I mean? And, er, it was just a routine check because I went, I had some problems with my knees and er, she took, the nurse took my blood pressure and I asked if it was high and she said 'if you was 60 years of age, it would be acceptable'".*
> Interview 22

Richard was previously overweight and was told to lose weight by his GP, as obesity is a risk factor for high blood pressures. Richard successfully reduced his weight by four stones but is still suffering from high blood pressure. His lived experience evidences to him that losing weight as advised by his GP, made little or no impact upon his high blood pressure, as he explains:

> *"Erm, it's your weight, it's your weight, it's your weight, it's your weight', you know, it just did my head in, erm, lost the weight and it's still high!*
> *G Hmm. How did you feel then, when you'd lost the weight and it was still high?*
> *R I mean, I still want to loose some more. I think now it's become an obsession, but I think that doesn't help as well.*
> *G No. But with them saying it was the weight and you lost weight*
> *R And it didn't go down".*
> Interview 22

It is not surprising that Richard found it disappointing that his blood pressure remained elevated when he has so successfully reduced one his risk factors (as defined by biomedicine).

Marcia has worked for many years in the health service. A single parent, Marcia had often worked double shifts in order to give her children a private education; additionally once her family had grown, she became a foster carer and fostered three children. Marcia elucidates:

> *"I think it's [having high blood pressure] that I've had a lot of stress. I mean I've been a single parent for years. You know, bringing up my kids.*
> *G And how many children do you have?*
> *M I've three.*
> *Three boys. And then, also, I took on, erm, three foster children with a lot of problems.*
> *G Oh, my word! So, six children!*
> *M No. Not all at once. I mean the others were [inaudible] and I've always, like, worked and studied. Sometimes I've held down, like, two jobs. I'd do full time nights, come off, work in the day.*
> *G Where do you work?*
> *M I did nursing.*
> *G Oh, right.*
> *M And I'd do, you know, come off and then go on agency nursing, because my kids, because at the time my boys were in private school.*
> *G Oh, were they?*
> *M Yes. They did that from three and half until they reached their teens, and you know, so to keep them in [private school], I had to do it that way and when your young, you're energetic and you know, so, you're burning your candles at every end. Never really took much time in terms of holidays, I mean I'd have holidays with the boys, but it wasn't, it was holidays for them, but not holidays for me, because it's a working holiday, because you're forever caring".*
> Interview 23

I was struck by the arduous nature of Marcia's life and the fact that she could still give to others less fortunate than her own children. It was clear her life had been far from luxurious with little time for rest and relaxation. Reena also mentions stress as being the main precursor of her high blood pressure, arising from life in the UK:

> *"I think it's all this stress. You know, we have so much problems here [in England]. You've got bills to pay. You don't know where the money is coming from. You know, that alone gives you headaches if you think about it. Stress. When you're in the West Indies, you haven't got all that stress".*
> Interview 26

Reena goes on to further explicate other forms of stress in her life, she is quite clear that her high blood pressure started around the time her husband was diagnosed with cancer of the bladder, as she comments:

> *"Well, he had, erm, cancer of the bladder,*
> *so, that was*
> *G Oh, dear. Oh, dear.*
> *R I think that's, erm, he had the round*
> *about the same time that I*
> *Yes. So, I think that's when it [high blood pressure] started".*
> Interview 26

Consequences and management of high blood pressure

Re-iterating the findings of the main study sample, participants in the vignette interviews used strategies to manage their high blood pressure on a daily basis, including use of herbal remedies, non-concordance and rest.

Percy, Richard, Marcia and Rosetta all used traditional herbal remedies. Percy appeared to take cerasee bush tea for general health and well being, whilst Richard expressly used herbal remedies for his blood pressure. Both Marcia and Rosetta had an in-depth knowledge of traditional herbal remedies, and gave detailed information about remedies and their use. The interviews with Marcia and Rosetta were both preceded with Vignette 1 that expressly mentions the use of herbal remedies that may have facilitated a more open dialogue. Marcia provides a rationale for use of herbal remedies by individuals of Caribbean origin:

> *"Yes. Erm, Caribbean people, they're not used to all these pills and what have you. They're*
> *used to natural remedies. I remember as a*
> *child, if anything was wrong, you didn't just run*
> *to the doctor. You know, you tried all the*
> *natural remedies first, and if that didn't work,*
> *that's when you tend to panic and then think, oh,*
> *there's something more serious, you know, because*
> *I can remember my Grandparents, they always knew*
> *what herb, bush or what to, you know, you are to*
> *use, you know. Erm, so you'd do it. Even, take if*
> *you had tonsillitis, you'd never go and get*
> *antibiotics. All they used to do vinegar and*
> *black pepper, scrub your throat, you know, and*
> *get rid of the infection, the pus there and*
> *within a day, you know, you was a lot better, you*
> *know".*
> Interview 23

Interestingly, Marcia, a professional nurse who is of Guyanese origin, uses the same pejorative phrase '*run to the doctor*' as participants of Jamaican origin in the main study sample. Marcia used a variety of herbal remedies. Moreover, it seems that for individuals such as Marcia, the use of herbal remedies signifies a form of self-empowerment, in respect of taking control of one's health and taking matters into one's own hands. Marcia explains:

> *"I'm going to take health in hand myself,*
> *you know, I mean the thing is and substitute*
> *it with natural remedies, because at the end*
> *of the day, it's not curable. It can be controlled,*
> *you know, well, I'm saying it can't be, it's not*
> *curable by conventional medicine, but yet, via herbal.*
> *You know, if you take the right things, then*
> *obviously, you know, you can control it to a*
> *point that."*
> Interview 23

Marcia, Rosetta and Richard all consumed traditional Caribbean herbal remedies specifically to control their blood pressure. In the main study sample, the participants who took herbal remedies tended to do so for general health and well-being those who expressly used herbal remedies for high blood pressure being in the minority. The specific anti-hypertensive remedies mentioned were hawthorn (obtained from English herbalist stores), cho-cho, garlic, singer bible and tuna (a cactus-like plant). Both Marcia and Rosetta had plants growing in their homes. Rosetta had obtained plants whilst on holiday in Jamaica

> *G "Right. Yes. Okay. So, how did you get these plants, then, Rosetta?*
> *R I smuggled them in my case!*
> *G Right.*
> *R Just some little tiny ones".*
> Interview 24

Richard however had obtained little benefit from the hawthorn capsules he had used. Marcia comments on the use of specific herbal remedies for high blood pressure:

> *"...also there's other, erm, stuff you can take like a thing*
> *called Cho-Cho.*
> *G What's that?*
> *M It's a green vegetable.*
> *G Cho-Cho?*
> *M Yes. And a lot of them, they tend to use it in*
> *soup and that. It's a veg, but*
> *G Is that the Chinese vegetable, like the*
> *Chinese Choi-Choi?*
> *M Ah. No. No. No.*
> *G Something different?*
> *M Yes. I've actually got one here, actually and*
> *what it is again, that, if you eat that, that's*

> *meant to bring your blood pressure down.*
> *G Would you show it me, then, this Cho-Cho?*
> *M Yes. Yes.*
> *G Right. Okay. That'll be very interesting to see.*
> *M I'll show you afterwards.*
> *G Yes.*
> *M Right. And, erm, I think that you'll find that in every Caribbean country, erm, you know, you find that they know of some of the things and generally what it is bitter, bitters, any bitters. It could be from the bark of a tree, you know, and I think nationally, I think they know that any bitters is good for lowering blood pressure".*
> Interview 23

Marcia goes on to provide a rationale for why it is essential to take bitters for health, explaining that there are few foodstuffs that have a bitter favour. Marcia's lay knowledge of the use of '*bitters*' is also supported, according to Marcia, via religious edicts in the bible:

> *"Right? But, we're always taught as a child, it was there for a purpose. God knew why he gave the taste for bitter, you know, because bitters is meant for purifying and also you'll see it in the bible, it tells you that bitters*
> *G Really?*
> *M you know, if you take bitter, because it's for cleansing your system."*
> Interview 23

Marcia's comments are interesting. As a trained health professional, I had assumed that Marcia would be very much imbued with a biomedical perspective on health and illness causation and treatments for high blood pressure. This proved not to be the case, as is evidenced in her quotations. However, Marcia's comments may be context-bound, she may in her professional life, provide very different explanations to the questions asked. Alternatively it may be that cognitively individuals synthesize knowledge that arises from the professional (biomedical) medicine and, lay and folk domains of medicine, to form a cosmology arising from multiple domains. Thorogood (1988) established that Caribbean conceptualisations health and illness causation arise from West African sources and medieval theories of humors (*cf* chapter 13).

Richard, Percy, Marcia and Rosetta all stated that they would take herbal remedies as both a complement and alternative to prescribed medication. In consideration of the whole data set in this theme, there appeared to be a synergistic relationship between the use of herbal remedies and non-concordance. Rosetta's comments appear to epitomize this synergy:

> *"And then I started on blood pressure tablets, but my pressure was always up until I went to Jamaica and was introduced to this Tuna [cactus like plant].*
> *G So, your blood pressure was never controlled on the tablets?*
> *R Well, it was just up and down, up and down. You know.*
> *G Yes, right.*
> *R You know, just up and down, but I was really afraid of tablets. I've never wanted to take tablets.*
> *G Why were you afraid of the tablets?*
> *R Well, I had, when I lived in Clifton, I had a friend and she was on the same tablets and I met her in town one summer and she told me that the tablets affected her that much, that she. She was carrying a bag around with her because the tablets damage her insides".* Interview 24

However, Percy stated that he was always concordant with medication and whilst Richard and Marcia shared with me their use of herbal remedies, they did not expressly state that they were non-concordant. Conversely Rosetta shared commonality with participants in the main study in that her non-concordance is associated with vacations in Jamaica:

> *R " When I went to Jamaica and I mislay my prescription. I left my tablets here.*
> *G So, you were on holiday?*
> *R No, I went to my Mother's funeral.*
> *G Oh, dear. I'm sorry about that.*
> *R And, when I got there, I realised my tablets were left here.*
> *G Yes, you came in a rush. Yes.*
> *R So, what I did, I went to see a doctor there, and he gave me a prescription. On my way to get the prescription, I realised that the prescription was left at home.*
> *G Yes.*
> *R So, I saw a friend and I was telling her about my tablets being here, and she says to me, she says 'well, you won't need tablets here'. And she told me about the Tuna and advised me to get my brother to put the Tuna into a glass of water, put it in the fridge and take it and that cut my blood pressure down.*
> *G When was that, when you discovered it?*
> *R It's 1998.*
> Interview 24

This is an interesting experience, as although Rosetta may have an implicit belief in the value of traditional Caribbean herbal remedies via early socialisation processes. The experience does demonstrate the potential Rosetta had for further development and enhancement of traditional beliefs and practices even though the individual may not be resident in the Caribbean. This event provides a good example of the dynamic nature of health beliefs and health actions. Rosetta does appear to use the remedies with some caution, as she explains that if she takes the remedy too often it can result in low blood pressure.

The fear of taking tablets was often mentioned in the semi-structured interviews, and appears to be very much focused on the fact that in addition to having a positive benefit on high blood pressure, anti-hypertensive therapies may also cause side-effects and damage the body in some way. In some respects such fears are grounded as Western medicine can cure very few chronic conditions, and medication may result in iatrogenesis (Illich 1976) for some individuals.

Two participants, Richard and Marcia, mentioned the consequences of high blood pressure and medication on sexuality. Marcia was afraid to have sex for fear of elevating her blood pressure and the possible consequences of this. Richard on the other hand had experienced impotence as a result of the anti-hypertensive therapy prescribed. In common with Carlton in the main study sample, he had initiated a discussion about this with his GP and was angry that this was discussed, as he remarks:

> *"And there's something about impotence as well.*
> *I'm having to go back to the hospital with that as well.*
> *G Really?*
> *R Yes. I am. Yes. It's just...*
> *G So, nobody's said that to you?*
> *R No. They never.*
> *G They never mentioned...?*
> *R They never mentioned it. No doctor's ever mentioned it, actually, until I mentioned it to them, no doctors mentioned it to me.*
> *G So, you initiated the conversation?*
> *R I did. Yes.*
> *G Hmm. And how do you feel about that, then, the fact that they haven't told you any of this?*
> *R Because I think sometimes you take them and sometimes you don't take them because I mean, well what is this really about? I think what's quite frightening is when you read the information on the side-effects. I always do that. That's the first thing I do. I just think to myself 'oh, here we go again!'. But I think they do more damage than they are doing good, I think".*
> Interview 22

In common with participants in the main study sample, the drug information level appears to be provoking anxiety for Richard, rather than being an empowering source of information.

The participants' experience of PHC

The findings in this theme again mirrored the findings of the main study sample, in that all the participants with the exception of Richard expressed satisfaction with their current PHC services, as he remarks:

> *G "Okay. So, would you say you was satisfied, or*
> *R Unsatisfied!*
> *G Yes.*
> *R Unsatisfied, I would say. It's not very good at all.*
> *G So, how could it be improved?*
> *R Erm, just generally asking how you are. What have you been doing? How have you been out the last few weeks? Erm, I suppose what's been happening in your life over the last few months, you know? I think questions like those, you know, generally what's happening. What's happening in your life deeper than that, but if they just paid a bit more interest in you".*
> Interview 22

Richard's comments relate very much to participants' explanatory models in the view that high blood pressure was commonly perceived in this study to be a result of the pressure of life. It would seem logical to ask a patient about aspects of their lives, which they themselves may see as high blood pressure precursors. Richard goes on to elucidate, further identifying environmental rather than personal factors or risk factors as the main precursors of his high blood pressure:

> *"Hmm. I don't know, I just think they need to, er, pay a bit more attention to detail. And recognise, you know, that you're not just a, you're not something that needs patching up, but, you know, there's a lot more, there's a lot more happening. I think it's not just blood pressure. I think it's a lot of other complaints that people have when they go to their GP. Erm, for them to just listen. I think they just need to listen and be aware of this person and what's really happening. But, as I say, for me, it's the environment".*
> Interview 22

Richard's comments suggests that his GP views his condition from a bio-medical perspective in that the body is a machine (Helman 2001) which can be repaired or patched up, whereas what he would really like a more holistic approach which takes account of the existential characteristics of his life.

Reena expressed considerable dissatisfaction with PHC on arrival in the UK during the 1960s and 1970s that had led her to seek out private medical treatment. It may be that historical perspectives such as those provided by Reena may shed light on the propensity of some African Caribbean people to use private GP's. Reena shared with me details of her husband's serious illness (ruptured peptic ulcer) in 1960s when he was prescribed white mixture as a treatment:

> *R"I was ever so cross, you know, I were cross about it because, you know, if you go to doctor and you have indigestion all the time, you think sense would send you for a scan, or anything to see what is really the matter, you know, but...*
> *G So, why don't you think they didn't send people from the Caribbean for investigations? What was the root of the issue?*
> *R I don't know. I wish I knew. I wish I knew. I think they didn't have much interest in coloured people if you ask me.*
> *G Right. Right.*
> *R I think that's my opinion. I don't care what nobody says. I think...*
> *Well, that's it. That's right. Because, you see, when you dealing with these English doctors, they don't have any time for you. That's the way I look at it".*
> Interview 26

Interestingly, Reena, although referring to a past event, talks about this experience in the present tense. The ethnicity of the GP appears to be an important factor for Reena in relation to the quality of care that can be attained; in common with participants in the main study sample, she explains why she chose a private GP:

> *R "But, you see, when you go to a coloured doctor now, they take more time to listen to you. They take more, if they send you for a scans, they send you for x-rays.*
> *G Yes.*
> *R You know, they send you for all different things that. You can't go to the doctor and say 'well, I've got a pain here'. Next month, you go back to tell him the pains not gone. It's*

> *still there. He give you some more tablets. In the meanwhile, why don't he send and send to get you checked out what is causing the pain?".*
> Interview 22

Reena went on to share more details of her early experiences in the UK and private PHC. At the time a 'coloured' private GP was not resident in the area, but used to travel into the area and set up surgery once a month in a private home located in a geographical area which was heavily populated by African Caribbean people. Reena explains:

> *" Well, you see, at that time, there was no coloured doctors, like private doctors, in the area.*
> *G Right. Yes.*
> *R So, he was, he used to come from Birmingham...*
> *R Probably because there was, when I first, there was one used to come from Birmingham.*
> *G That used to come up to Sheffield?*
> *R Yes. It was every first Sunday in every month... [explains geographical location]*
> *R It's up that road, there. He used to come there and there's a house he used to go to, there was a house, because my husband, he used to go up there.*
> *G So, was it somebody's house he used to...?*
> *R Yes. We used to have to go to somebody's' house.*
> *G He used to set up surgery?*
> *R Yes.*
> *G In somebody's house?*
> *R Come from Birmingham.*
> *G The first Sunday in the month. When would that be? What time are we talking about here?*
> *R In the late sixties".*
> Interview 26

I was very surprised by this information as no reference to such mobile PHC services was made in the main study sample. However, it does provide useful contextual information as to how African Caribbean populations have circumvented state-provided PHC services in past decades in order to have their needs met. It is clear if this surgery occurred once per month that Reena was not the sole user of such a PHC service. The level of detail provided about private GP's might be a result of the vignette approach that acknowledged the existence of such practices and facilitated a more in-depth exploration. Rosetta also stated she has used a private GP; unusually she had been recommended to see a private GP by her NHS GP as she comments:

> *"Well, at the time, my GP knew I was going [to see the private GP].*
> *G Oh did he?*
> *R Yes. My GP knew I was going.*
> *G How did he react to that?*
> *R Well, he introduced me to the GP.*
> *G Oh, did he?*
> *R Yes. He told me all about the GP.*
> *G How come? Why did he...?*
> *R That I should try the GP, because I told him that I wasn't satisfied with the tablets I was getting.*
> *G Right.*
> *R You see, so he says, well, I asked him if there was anything that could be done and he suggested this private doctor. So, I went on to see Dr.Z in Smallville.*
> *G And did a lot of Caribbean people see Dr.Z? Was he popular?*
> *R He was quite popular, yes. He was quote a good doctor".*
> Interview 24

Percy stated he would not use a private GP as he was satisfied with his NHS care and Marcia expressed some sceptisim about using a private GP, as she remarks:

> *"Yes. Yes. You know, I feel as very, very sceptical in putting money in their pockets [private GP], if I can go and see you, or the NHS, and then I can come back, say another day, and pay you, and the information that you probably could have given me then and there, I've got to pay you to get that information. And, so, I'm a bit sceptical on it, you know, so, I don't know. But, yet, saying that, I have used a private doctor for my Mum when she cam on holiday, so, I suppose, they do have their uses. But, I don't know. I think it just depends. It just depends".* Interview 23

In this respect, the views of the participants in vignette interviews are similar to the main study collection, in that whilst a small number of participants used private GP's other participants were quite sceptical of their value.

Richard was convinced that in relation to care and management of high blood pressure in PHC, the state agenda was not an altruistic agenda focused on the care and well-being of patients, but rather a more sinister agenda that sought to reduce NHS costs. Richard remarks:

> *" Er, because, it's just this...I mean, I get the impression that the, I mean this is my ideas, that the government people with hypertension, potentially, can put stress on the health service with strokes, heart attacks etc,*

> *and I think this is a big, for me, it feels like a big marketing drive to bring people's blood pressure down. I don't think I know that this is a big drive to put blood pressure down, obviously it's going to take stress off the National Health Service. So, they, GP's have got targets to make. Everyone's got targets to make, but GP's have got targets to meet and that's what they have to do.*
> *G Hmm. So, you're saying that the main objective is not to look after you?*
> *R No. It's to…it's a money saving operation.*
> *G Right. Yes.*
> *R It's a money saving operation, because I feel that they just [inaudible] and they just patch you up and send you away. But mine's not going down. I'm not responding to what they're giving me".*
> Interview 22

In many respects Richard's comments are axiomatic, in the sense that the NHS has finite financial resources, and any savings that can be made by prevention rather than cure of disease and dysfunction are implicit in current NHS strategic policy directives (DOH 1999b).

In summary, the findings of the vignette interviews largely reflect and re-iterate the findings of the main study. In fact the commonality between the data is striking and in this sense triangulates the FGI and semi-structured interview findings. The vignette interviews did facilitate a deeper exploration of key phenomena such as non-concordance, perceptions of PHC, use of herbal remedies that emerged from the semi-structured interviews. The key concepts and phenomena investigated are mapped out in greater depth and detail however, a limitation of the vignette interview approach is the tendency for participants to focus their assertions and discussion on the phenomena in the vignette. The vignette interview data lacks the breadth of the semi-structured interviews, although this may be a desirable characteristic depending on the purpose of the vignette interview.

Chapter 13

Discussion, conclusions and reflections

In this chapter I discuss and synthesise the findings from the three data collection methods utilised, establishing commonality and differences in the data collection tools. The findings are summarised and the extent to which the research questions are answered is established. I reflect upon the validity and credibility of the results and the limitations of the study, and present perspectives arising from the data and offer conclusions. The chapter locates the findings within the existing literature and what is known on the topic, and within the broader literature on ethnicity and health and the sociology of chronic illness. Reference is made to the social class and gender dimensions of hypertension experience, in addition to relating the findings of this study to studies of the wider population. The findings are viewed in relation to existing theoretical frameworks such as explanatory models of illness and the internal/external locus of control. The implications of the findings for service provision, policy, research and the education of PHC professionals are explored.

This study has presented the meaning and consequences of hypertension for people of African Caribbean origin in England, and makes explicit the participants' views on the PHC services they receive for their hypertension. The methodological approach of ethnography (Hammersley & Atkinson 1995) was adopted in this study, and enabled knowledge and understanding of decision-making processes, risk perception, and culturally specific health beliefs to be illuminated by greater insight into the life-ways, cultural dimensions, social mores, norms and values of the participants in relation to hypertension. These viewpoints are mediated and articulated via the researcher, myself as a human instrument. The wider societal influences that shape and define the lives of the participants, such as racism (Mac an Ghaill 1999, McPherson 1999) and socio-economic dimensions (Karlsen & Nazroo 2002a & b), are evidenced. In the literature review this thesis draws heavily on sociological perspectives to aid understanding of both the historical and contemporary position of African Caribbean people in the UK today (Jenkins 1997, Kushnick 1998, Mac an Ghaill 1999, Brah & Coombes 2000, Nazroo 2002a & b). However this is not a sociological thesis, but one that provides a detailed account of a funded pragmatic health services research project.

In reviewing the research aims of this study, it is clear that the data elicited and the findings do provide an increased **understanding of the meaning and consequences of hypertension for individuals of African Caribbean origin** (*cf.* chapters 8 & 9: The meaning of high blood pressure; Consequences and management of high blood pressure). The factors and variables that influence an individual's decision making in relation to hypertension are manifold (*cf.* chapter 8-11: Early diagnosis, Consequences and management and Participants' experience of PHC). Furthermore, this research does **elicit knowledge and understanding of African Caribbean individuals' decision-making processes, risk perception, culturally specific health beliefs which mitigate against or enhance the early diagnosis and effective management of hypertension in PHC** (*cf.* chapters 8 & 9: Early diagnosis, The meaning of high blood pressure) Finally, the findings do provide **insight into African Caribbean individuals' perceptions of the prevention, diagnosis and management of hypertension in PHC** (*cf.* chapter 10 & 11: The consequences and management of high blood pressure, Participants' experience of PHC).

The research questions are answered by the selection of an appropriate methodological approach, that of ethnography (Hammersley & Atkinson 1995). The methodology has facilitated *'a strong emphasis on the nature of a social phenomenon'* (Atkinson & Hammersley 1998 p.110) in this research, namely hypertension as experienced by African Caribbean participants in two locations and the associated experience of PHC. The focus on a small number of cases in detail has further contributed to achievement of the research aims.

The methodology has facilitated the illumination of cultural activity (Spradley 1979) including cultural knowledge, cultural behaviour and cultural artefacts. The methods selected (focus group interviews, semi-structured interviews, and vignette interviews) proved successful in eliciting in-depth and relevant data that provide the answers to the research questions listed above, as set out in the findings chapters, a summary of which follows in this chapter. The findings of the study are presented in narrative form:

> *"...the analysis of data that involved explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations". (Atkinson & Hammersley p.111)*

Ethnicity and health

From the UK evidence it can be concluded that ethnic minority populations experience greater ill health than the wider population (Marmot *et al,* 1984, Ahmad 1993, Smaje 1995, Nazroo 1997). It has also been argued that the quality of health care that ethnic minority populations receive in the NHS is lower then that received by the general population (Bowling 1993a & b, Bhopal 1998, Gerrish 1998, 2000, Free *et al.* 1999). Understandings of the relationship between racism, ethnicity, and health status are embryonic in nature (Karlsen & Nazroo 2002a & b).

However a small number of research studies do produce evidence of the extent to which racism can impact on health status, particularly in relation to hypertension. Krieger & Sidney (1996) and Krieger (1990, 2000 a & b) conducted seminal work in this field in North America, and discovered that those individuals who proactively challenged racism had lower blood pressure than those individuals who suppressed responses to racism. Krieger concluded that suppressed anger resulting from racist incidents created an elevated blood pressure. Participants in this study, in particular younger, economically active participants, expressed anger (*cf.* chapter 9) and explained how this impacted upon their high blood pressure.

Research into suppressed anger in African American populations (McNary 2001) supports Kreiger's findings. As yet, little research has taken place in this domain in England. These North American findings do, however, highlight the importance of positioning the health and illness experience of African Caribbean people in England within the broader structural and ideological influences that shape and define the life experience. We do have evidence to support the claim the ethnic minority populations in England experience greater ill health than the general population (Nazroo 1997). This also applies to hypertension, despite Caribbean women having higher prevalence rates for hypertension than Caribbean men (Nazroo 1997, DOH 2000).

Little is known about the impact of high blood pressure upon the life experiences and opportunities of African Caribbean people in England. In recent years, only one study has been conducted (Morgan 1993) highlighting a lay perspective. However, a large body of literature does exist arising from North America that explores the experience of high blood pressure for African American populations (Kaplan 1994, Ergul 2000, Frazier 2000). However this study mostly explores biomedical or physiological characteristics, and this evidence must be used with caution because of the differing economic, social and political contexts in North America and England. The populations are not the same, although some commonality exists between African American people and African Caribbean people in England (Donald & Rattansi 1992, Gilroy 1995), in terms of personal and institutionalised racism and membership of a minority ethnic group. However, the cultural patterns, traditions, language, kinship and social patterns may be very different. This is not to say that populations that have historical antecedents in West Africa do not share some commonality in culture and traditions (Gilroy 1995).

The paucity of existing literature on the topic of hypertension and African Caribbean communities has shaped and determined this thesis. As very little research evidence exists within the domain, the study was by necessity exploratory in nature.

Hypertension, ethnic minority populations and migration

Hypertension is a major health issue globally for minority individuals, as is evident in consideration of the experience of minority and indigenous populations in both North America (Anand *et al.* 2003, Hajjar *et al.* 2003) and Australasia (Hoy *et al.* 1999, Leonard *et al.* 2002). Other migrant communities, e.g., South Koreans in Western societies, also demonstrate a high prevalence of hypertension, as compared to the host community (Kim *et al.* 2000). In this respect a common thread exists, in the form of hypertension amongst minority communities around the world irrespective of culture and ethnicity. This very fact points to the possible influence of environmental and structural influences.

Earlier studies on hypertension

Morgan (1993) conducted seminal research in England that was focused on hypertension and African Caribbean people. Central to Morgan's study were the beliefs and responses to hypertension by both patients and practitioners. The study included both white and 'Afro-Caribbean patients' of 'working-class origin'. Those participants of 'Afro-Caribbean' origin in the study were first generation migrants (personal communication), whereas the research in this thesis provides an in-depth exploration of the experiences of the African Caribbean participants, some of whom held professional roles and were second-generation migrants. Focusing on a single community or sub-group allows the exploration of traditions, lifeways, social norms, mores and cultural dimensions, all characteristic of an ethnographic approach, to be carried out in more detail, as the focus is on lay rather than professional perspectives.

There may also be other differences between this research and Morgan's (1993) study, and these might be attributed to the ethnicity of the researcher. Differences also exist in the context of care delivery within PHC. Morgan's study was conducted in the late 1980s in a single London borough, prior to the emergence of fund-holding GPs and Primary Health Care Trusts. Additionally, the NHS now has more directives focused on the elimination of inequalities, racism and prejudice in care provision and services (DOH 1997, Alexander 1999, DOH 1999b, DOH 2000a). Morgan's research does not expressly focus on the concept of explanatory models (EM) of health and illness, whereas EMs emerges as a central issue in the findings of this research.

Blumhagen's (1980) study of hypertensive patients in North America is relevant to this research. Blumhagen found that participants attributed their hypertension to individual emotional responses such as fear, anxiety, worry, and anger and upset, and he terms this condition Hyper-Tension. Some commonality exists between the findings of this study and Blumhagen's research, but in this research, participants' explanations for hypertension moved beyond individual factors to include external factors such as migration, cultural adaptation, bereavement, not belonging, and racism and discrimination in the work place. Participants in this research perceived both external and internal influences to coalesce to influence the development of their high blood pressure, the main precursor being stress. In this study 'pressure' had a duality of meaning. Pressure is used by participants to describe blood pressure, e.g., 'me pressure up'. Participants also attributed the development of high blood pressure to the 'pressure of life'. In this study I have termed the condition that participants believe they had PRESSURE HIGH/HIGH PRESSURE, which is distinct from the biomedical condition of hypertension. The following paragraphs summarise the research findings in this study.

Early diagnosis

Evidence from this study suggests that presentation for diagnosis and help seeking are subject to cultural influences (Greenhalgh *et al.*1998, Helman 2001). In this study the experience or lack of experience of formal PHC in the Caribbean exerted a powerful influence on the participants in relation to presenting for early diagnosis of high blood pressure. Helman (2001) describes cultural influences as subliminal assumptions that members of the group share. Ethnicity and culture are not static phenomena but ever-dynamic and changing (Jenkins 1997, Modood *et al.* 1997). When an individual migrates she/he synthesises and integrates aspects of the birth culture, the new culture and other cultures such as professional socialisation and the culture of the socio-economic group, all of which becomes part of a consistently re-constructing cultural and social identity. Synthesis and coalescence of this nature is termed 'hybridity' (Anthias & Yuval Davis 1992, Brah & Coombes 2000, Anthias & Lloyd 2001). Whilst I have suggested that there are cultural influences within this domain, I would not wish this statement to be viewed as a culturally essentialist viewpoint (Culley 2001, Serrant-Green 2001). Health actions are influenced by a myriad of other factors (Becker 1974, Tones 1991) such as education, age, gender, personality, intelligence, physical and emotional state, religion, access to PHC services and location of PHC services, and experience of racism in the NHS (Bowler 1993a & b, Karlsen & Nazroo 2002a & b). A powerful socio-economic dimension may also influence the presentation of African Caribbean people in PHC for early diagnosis of high blood pressure. In the Caribbean in previous decades PHC services did exist for the wealthy and affluent. Economic migrants to England from the Caribbean were largely of working-class origin (Fryer 1992, Kushnick 1998); therefore it is possible that more affluent and wealthy migrants to England who had had previous experience of PHC might have used use formal PHC services in England more readily. The simple lack of familiarity with PHC services, especially during the initial post-migration years, may influence service use greatly. In this study some instances of racism experienced in accessing PHC during the 1960 and 70s are provided (*cf.* chapter 11). Incidents of this nature are likely to be shared within a community and become tacit knowledge.

Lack of formal PHC in the Caribbean required populations to rely on their own skills and resources and the family, especially mothers (Thorogood 1988) and elders, in providing immediate PHC (Helman 2001). These systems of self-care appear to be deeply embedded within the traditions of participants in this research. In this respect resourcefulness of this nature is regarded by the participants as a positive virtue that obviates the need to 'run to the doctor'. In order to utilise fully systems of PHC in England following migration, individuals may need to engage in an active process of deconstruction of traditional values, beliefs and practices. This may or may not be desirable, both for the individuals and for PHC services, as many routine visits to GPs in England have been demonstrated to be for minor ailments (Brogan *et al.* 1998) that could be treated by the individuals themselves (Rogers *et al.*1998). However, in the case of high blood pressure, which is more serious in nature but often symptomless, reluctance to visit a GP may have serious consequences. For the participants in this study all the factors mentioned above coalesce and influence the early diagnosis of hypertension in PHC. In both the FGI and semi-structured interviews participants commonly described significant events that had preceded their diagnosis, e.g., unusual physical events, work-related stress, crisis and stressors. However, a number of participants had been diagnosed during consultations for other conditions, e.g., diabetes or pregnancy.

From the findings in this theme it can therefore be concluded that the participants in this study experienced some reluctance in seeking medical attention immediately symptoms appeared, initially preferring self-care and observation of symptoms. Second, it can be concluded that those participants who received diagnosis during routine medical encounters were more accepting of the diagnosis of hypertension. Third, conclusions can be drawn concerning the initial diagnosis, in that most participants expressed shock at the diagnosis, this being most acutely experienced by younger participants. Fourth, those participants who experienced symptoms commonly reported a major health event before presenting for diagnosis.

The meaning of high blood pressure

The data in this theme maps out the impact of high blood pressure and what it means to have high blood pressure, and explanatory models of high blood pressure are presented. The impact of wider societal structures (both contemporary and historical) is evidenced. In addition participants' understanding of the cause of hypertension and participants' explanatory models of high blood pressure are presented.

In the FGI and semi-structured interviews, participants' EMs bore little resemblance to biomedical explanations for hypertension, and they located stress as the major precursor. Stressors were identified as arising from multiple sources. It can be concluded that participant explanatory models are dissonant from bio-medical explanations of hypertension. Second, stress is perceived as the main precursor of high blood pressure; and third, it can be concluded that hypertension and high blood pressure are perceived by participants as distinct entities and are not perceived as synonymous conditions.

Consequences and management of high blood pressure

The consequences and management of hypertension for participants in this study are broadly categorised into the four domains of psychological, socio-economic, physiological and familial. The evidence maps out the impact of the diagnosis of hypertension on everyday living, and the strategies participants employ to manage their high blood pressure, such as the use of herbal remedies, and concordance and non-concordance with medication.

Participants in both the FGI and semi-structured interviews shared with me their non-concordance and the reasons for this. Some participants expressed a strong belief and preference for what they believed to be natural herbal remedies in preference to prescribed medication. A synergistic relationship did appear to exist between the use of herbal remedies and non-concordance.

What is unique about the African Caribbean participants in this study is not related only to non-concordance as it occurs within the wider population (Britten & Benson 2002), but also to the propensity towards self-care and medication with herbal remedies, complementary to or in place of Western medicines. However, African Caribbean populations in this respect do share similarity with other ethnic minority communities in using folk and lay models of health, e.g., Chinese communities and South Asian communities (Helman 2001). In many situations self-care may be desirable (Rogers *et al.*1998).

Explanations and reasons for non-concordance were diverse, as shown in the typology (later in this chapter). In some senses, non-concordance appeared to give some participants an element of power and control in respect of their high blood pressure, and this appeared fundamental to the daily management of high blood pressure.

The drug information leaflet which accompanies anti-hypertensive medication, far from providing information and allaying anxieties for the participants, was shown in this study to provoke unnecessary stress and worry about potential side effects. It may be more helpful for drug manufacturers to display information in a different way that would enable people who are prescribed the medication to conceptualise the likelihood of experiencing side effects in a more meaningful way, e.g., two people in a million experience this side effect.

Stress the main precursor of high blood pressure

Within the psychological domain, stress was most commonly mentioned in both the FGI and semi-structured and vignette interviews as the major precursor of high blood pressure from the participants' perspective. The causes of stress were identified as the 'pressure of life', work, racism and victimisation, and financial and relationship issues. Few participants appeared to take active steps to manage their stress with stress management courses, e.g., relaxation tapes, although some participants did mention taking rest. Linked to this is the opportunity to share or discuss high blood pressure with another person. Although around half the participants had another family member with high blood pressure, most participants did not discuss their high blood pressure with a family member or friend, which might in itself have provided stress relief.

The socio-economic impacts of having high blood pressure included the loss of paid employment, resulting in early retirement. Single parenthood was also mentioned as creating difficulties within the daily management of high blood pressure.

Therefore, in concluding this theme it can be said that participants exercised power and control in the daily management of their high blood pressure, through the use of herbal remedies and non-concordance. The use of herbal remedies and non-concordance was not restricted to first generation migrants, and a typology of non-concordance existed. Furthermore, participants both modified and maintained their lifestyle in response to high blood pressure. It can be concluded that high blood pressure had both physical and physiological consequences and impacted upon work roles and socio-economic status.

The participants' experience of PHC

The findings in this theme provide evidence of participants' use of NHS PHC services and private GPs. In addition, relationships with both NHS PHC professionals and private GPs are explored.

Individuals who experience chronic illnesses, such as hypertension, diabetes or arthritis, may be non-concordant with medication (Benson & Britten 2002). This is not specific to African Caribbeans, but also a well-documented feature of individuals who are members of the dominant community. A small number of participants consulted with private GPs in order to enhance the management of high blood pressure. The use of private GPs is documented in Morgan's study of both white and black hypertensive patients in the early 1980s, including first generation migrants of Caribbean origin. Some of the findings of this earlier study are supported by this research; however, the research in this thesis focused entirely on African Caribbean people, some of whom are second-generation migrants (*cf.* chapter 6).

Hypertension is often asymptomatic (Raleigh 1997). Individuals may be diagnosed has having hypertension in routine examinations, and be hypertensive for a considerable period prior to their condition being diagnosed. Help-seeking behaviours may be culturally determined; this is demonstrated in the seminal text (Kleinman 1980, Helman 2001). The reasons why African Caribbean people may be reluctant to present for early diagnosis or use a GP are not established in the literature; but they are documented in this research, which enhances understanding of why African Caribbean people may be reluctant to use GPs and present for early diagnosis.

It can be concluded that participants were largely satisfied with PHC services provided. Dissatisfaction resulted in the participant changing their GP. It can be concluded that participants in this study viewed the notion of 'running to doctor' negatively, and this impacts upon the utilisation of PHC services in England. In summary, only a small number of participants, not confined to first generation migrants, used private GPs.

The findings of this study and research on hypertension within the wider population

In an attempt to 'de-bunk' notions of cultural essentialism that are often derived from studies of ethnic minority people in which culture and ethnicity are presented as the over-arching determinants of the health and illness experience, the following paragraphs map out the extent to which the African Caribbean participants in this study shared commonality with the wider population in relation to the experience of hypertension.

The findings of this study may in fact provide evidence of greater commonality with individuals in the wider population who experience hypertension, rather than suggest that this experience is determined by culture or ethnicity. This commonality may be associated with social class dimensions. Although the participants in this study were not exclusively 'working class', the findings do bear some similarity to those of Morgan's study of 'Afro-Caribbean' and 'white' matched working-class respondents (Morgan 1996). Morgan provides a good example of the extent of the similarity between the 'Afro-Caribbean' participants and the 'white' respondents in the study. For example, two-thirds of the respondents (both 'Afro-Caribbean' and 'white') in Morgan's study were diagnosed during routine contact with medical services. Some commonality thus exists with the findings of this study, as a third of the participants in it were either diagnosed when pregnant or during routine contact with PHC services. Another example of similarity in the findings is that half of the white respondents in Morgan's study demonstrated limited understanding of the term hypertension, similar to participants in this study. In relation to the meaning of hypertension, half the white respondents in Morgan's study agreed with participants in this study that tension, stress or worry was a major precursor of the condition, once again emphasising the similarity rather than the difference between individuals of differing ethnic origin. However, a major difference is that in Morgan's study both 'Afro-

Caribbean' and 'white' respondents identified rest and relaxation as an important response to hypertension, whilst in this study this dimension was infrequently mentioned by participants.

A further difference between this study and that of Morgan (1996) is that Morgan's participants were all recruited via GP practices, and in this respect Morgan's work can be regarded as lacking in maximum phenomena variation. Nevertheless, the study makes an important seminal contribution to understandings of how hypertension is experienced by two different ethnic groups.

Explanatory models of health and illness

In summarising the findings of the research it is perhaps useful to consider established theoretical frameworks (table 11) that exist in relation to eliciting explanatory models of health and illness (Bhui & Bhugra 2002) from individuals. The table provides an overview of three approaches to eliciting explanatory models, identifying the key components of each model.

Table: 11 Characteristics of explanatory models and illness perception

Weinmann *et al.* 1996	**Lloyd *et al.* 1998**	**Weiss 1997**
Identity	Naming the condition	Pattern of distress
Causes	What causes it?	Perceived causes
	Is it an illness?	
Consequences		Disease specific queries
Controllability	What do you see about it?	Seeking help and treatment
	What can you do about it?	
	What can your Dr. do about it?	
Time line		General illness beliefs

(After Bhui & Bhugra 2002)

The findings of this study address to a greater or lesser degree all the concepts mentioned in each framework above, as shown in the preceding paragraphs.

Kleinman's (1988) seminal work conceptualised explanatory models (EMs) of illness. An EM is the patient's subjective view of illness, and refers to the patient's unique and individual insight in respect of interpretations and understanding of the illness. Specifically, an EM maps out the following dimensions of illness:

- The aetiology or cause of the condition
- The timing and mode of onset

- ☐ The patho-physiological processes involved
- ☐ The natural history and severity of the illness
- ☐ The appropriate treatment for the condition (Helman 2001)

The findings in this thesis embrace all five dimensions (*cf.* chapters 7-11) of Kleinman's (1980) conceptualisation of EMs, in respect of hypertension and the participant's experience. Kleinman regards EMs as idiosyncratic and multifactoral, arising from a range of personality and socio-economic factors. In this sense EMs are dynamic and contextually bound. Notably, EMs, are regarded as *"not identical to general beliefs about illness that are held by society"* (Helman 2001 p.85). However, Hodgson (2000b) argues that some cultural groups, in interpreting and understanding illness, hold clusters of EMs, although no empirical data is presented to support this assertion. Clustering of EMs did occur in this study (*cf.* chapter 9) as commonality existed between participants. Blumhagen (1980) suggests that only individual EMs are possible. In this respect the findings of this study elaborate and expand understandings of EMs in evidencing clustering.

Both practitioners and patients hold EMs which may not be synonymous with biomedical explanations (Helman 2001). Helman (2001) asserts further that EMs only make sense when examined within the context in which they occurred. For this reason this study has attempted to elicit both personal and structural influences on the hypertensive experience

Perspectives from the sociology of chronic illness

Perspectives from the broader literature on the sociology of chronic illness provide a theoretical lens through which it is pertinent to view the findings of this study (Bury 1982, Charmaz 1983, Williams 1984). It worthy of note that most of this literature arises from studies conducted with the general population in the UK (although not exclusively), and in the case of Charmaz (1983) in North America. From this perspective the following paragraphs enable the experience of the African Caribbean participants in this study to be viewed in relation to the general population, establishing the extent to which commonality in chronic illness experience exists.

The turmoil and upset participants experienced as a result of the development of hypertension is evident in this study in the narrative accounts they provided, and was often described by participants as shock and upset. This feature was especially evident in the narratives of younger participants, such as Hyacinth and Carlene, who had viewed hypertension as a dysfunction of older age. Bury (1982) refers to this turmoil as 'biographical disruption', while Williams (1984) refers to it as 'narrative reconstruction'. Other observers (Rajaram 1997, Willams 2000, Asbring 2001, Karlik 2002) have noted that following this initial phase of turmoil and distress, individuals attempt to normalise or make ordinary their experience. In this respect chronic illness such as hypertension can be viewed as a trajectory that is characterised by a restructuring of the self-identity, including personal relationships with others. The process of normalisation can be viewed as a coping mechanism (Williams 2000). Many individuals in this study, for example, Clifford, Aleeya, Carmel, Carlton and Delbert, exhibited this feature in describing their experience of hypertension (*cf.* chapters 8 and 9). Their attempts to normalise the experience of chronic illness can be regarded as a reconstruction of personal biography and reshaping of self-identity.

The onset of chronic illness can make the prospect of mortality seem more real, and the vulnerability of the human body can become more salient in the cognition of the individual concerned (Bury 1982). Prior to the onset of the chronic illness, individuals may have viewed the vulnerability associated with chronic illness and the prospect of mortality as part of the life trajectory of others. In this study participants often posed the question 'Why me?' Some participants in this study demonstrated 'active denial' (Williams 2000), whereby responses to the illness focused on 'carrying on with life as usual', usually in relation to lifestyle factors such as the consumption of alcohol. As one FGI participant stated, "*Well I might as well die merry*".

The 'biographical disruption' described for participants in this study was accompanied by 'loss of self' (Charmaz 1983), as is clearly demonstrated in this study in the accounts of Jerome, Hyacinth, Carlene and Richard. As a result of their hypertension Jerome and Hyacinth had given up their paid employment, and Carlene and Richard had experienced problems in continuing their work. In a sense this is a form of bereavement, because when diagnosed with chronic illness the individual experiences loss of self-identity, and may not value equally the new identity as an individual with a chronic illness (Lawton 2003).

Age as mediating factor in the experience of chronic illness

A number of sociological accounts of chronic disease have identified the emotional difficulties younger people experience in adjusting to life with a chronic illness. Atkin & Ahmad (2000) studied young people of Pakistani Muslim, Bangladeshi Muslim, Iranian Muslim and Iranian Hindu origin, and in the seminal work of Bury (1982) younger informants had rheumatoid arthritis. In this study, these difficulties are clearly illustrated in the accounts given by the younger participants Hyacinth, Carlton and Carlene (*cf.* chapter 9). Hyacinth and Carlene also expressed shame and stigma in relation to their diagnosis of hypertension, and their accounts of shame make sense in relation to the concept of 'meaning as significance' (Bury 1988), which refers to the symbolic nature of the chronic illness, as perceived by both society at large and the individual concerned, which may lead to stigmatization. However, the perceived stigma of hypertension was not confined to younger participants, and a number of older participants reported that they were reluctant to mention their condition to others, including family members.

At the opposite end of the age spectrum, old age may confer some benefits in relation to responding to chronic illness, given the opportunity older individuals have had to accumulate strategies to cope with the vicissitudes of the life trajectory. In this study the age range in the focus group interviews was 60-76 years (median age 68 years), in the semi-structured interviews 39-82 years (median age 60 years), and in the vignette interviews 37-75 years (median age 51 years). It is therefore pertinent to reflect upon how older age might mediate the experience of chronic illness. Sanders *et al.* (2002), Pound *et al.* *(*1998), and Bury (1982) have all identified the importance of the age of onset of chronic illness in shaping and configuring the individual's response to chronic illness. Being older at the onset of chronic illness may mean that the individual has experienced a number of morbidities prior to the onset of chronic illness (Pound *et al.*1998), and there may also be an expectation that ill-health is a normal dimension of growing older. It is also important to note that ageing and expectations of behaviour during older age may be culturally defined (Sanders 2002).

A strong correlation exists between hypertension and diabetes in African Caribbean populations (Raleigh 1997). This was certainly evident in this study with around one third of the participants experiencing diabetes, and around two-thirds experiencing other co-morbidities. In this respect the findings of this study reiterate the findings of Pound *et al.* (1998), in that some participants regarded the development of hypertension as a normal part of the experience of growing older (*cf.* chapter 7), or 'just one of those things'. Similarly, those participants who were diagnosed during pregnancy or as a result of co-morbidities were more accepting of their hypertension (*cf.* chapter 8).

Social class as mediating factor in chronic illness experience

Cornwell (1984) provides evidence of how social class mediates the experience of chronic illness, and how working-class older people may be particularly stoical in responding to chronic illness because of the adversity of they have faced in their lives. Later studies have confirmed the salience of the personal biography in responding to chronic illness (Pound *et al.* 1998, Sanders *et al.* 2002). Participants in research conducted by Pound *et al.* (1998) and Morgan (1993, 1995, 1996) were described as working-class or as having experienced 'hard-earned lives'. It seems that a personal biography characterised by material and economic disadvantage to some extent prepares the individual for adversity such as chronic illness. As Williams (2000 p. 50) states:

> *"...the biographically disruptive nature of illness is perhaps most keenly felt amongst the privileged rather than disadvantaged segments of society".*

Participants in this study held both manual roles, and professional roles such as teacher, social worker, nurse, and midwife. Interestingly those participants who held professional roles tended to work in the public sector, maintaining the tradition of their parents as first generation migrants working in public services. It is true to say that Carlton, a community activist and youth worker, Hyacinth, a social worker, Richard, a teacher, and Marcia, a nurse, demonstrated in their narrative accounts 'biographical disruption'. This is not to say that other participants did not demonstrate 'biographical disruption'. However, as an addition to the mediating factors evident within the literature (Pound *et al.* 1998, Atkin & Ahmed 2000, Willams 2000, Sanders *et al.* 2002) I would like to suggest that migration and cultural adaptation may be more powerful mediators of the chronic illness experience, in that adjusting to a new culture and host community has a profoundly significant influence on the personal biography of the individual, and is extremely challenging when viewed within a trajectory of life events. The particularly powerful account given by Hyacinth (*cf.* chapter 9) illuminates the enormity of migration and cultural adaptation. For economic migrants such as the individuals in this study, who largely held working-class roles in England, social class dimensions are inextricably linked with migration, cultural adaptation, and the effects of living in a racist environment, and may result in a unique fortitude.

Gender as a mediating factor in chronic illness experience

Studies have highlighted the different responses of men and women in relation to the perceptions and experience of chronic illness (Williams 1999, Lengua & Stormshak 2000). Within the family, mothers are often the main protagonists in care giving in the context of chronic illness (Atkin & Ahmad 2000, 1988) and have a role in health promotion. Examples of this exist in this study in the accounts given by participants of herbal remedies and their ritualistic use in the Caribbean. The responsibility for administration of these remedies rests with the female family members, and usually with the mother in the household.

Caribbean women experience a greater prevalence of hypertension than Caribbean men (Nazroo 1997), and as stated earlier Caribbean men are more likely to have received treatment (DOH 2000c). This does seem to suggest that some gender differentials exist in relation to women receiving diagnosis, care and treatment of their condition and this requires further investigation. It is not clear to what extent hypertension is viewed in the same way as CHD. As Emslie *et al.* (2001) state, CHD is a disease often perceived by health professionals to be a male condition. In this respect women are less likely to receive an accurate diagnosis of CHD or to receive appropriate treatments. The extent to which hypertension is perceived to be a male condition is an important area for future research, and not just for African Caribbean populations, but for all populations.

In the accounts participants in this study gave concerning their care and treatment, the women participants did not express any more difficulties with access and treatment than the male participants. Indeed several women participants were diagnosed during pregnancy, which may reflect the more frequent contact women have with health services. However, a number of the male participants stated that their experience of hypertension presented no difficulties or problems for them. Interestingly, two participants Wilbert and Lynn were husband and wife. Wilbert had stated that he did not experience anxiety or worry, but Lynn gave a very different account of her husband's worry concerning his hypertension.

The diversity of participants' lives is evidenced in the biographical details provided (*cf.* chapter 6). The existence of shared experiences and commonality may be related to social class and economic issues rather than being shaped by cultural issues or ethnicity (Mac an Ghaill 1999, Karlsen & Nazroo 2002a & b). Notwithstanding this, most participants had lived longer in England than in their country of origin. Migration, cultural adaptation, and reception in the host community are all factors which have impacted on the lived experience of hypertension for participants in this study. As examples from the findings of this research illustrate, age, social class and gender can mediate the experience of hypertension.

Internal and external locus of control

Building on the work of Rotter (1966), Wallston & Wallston (1978a) developed the construct of the Health Locus of Control (HLC). The development was initiated by early observations of newly diagnosed diabetics, and patients' active role in their own health care. In this respect the HLC (arising from observations of a chronic disease) is an appropriate construct to frame consideration of the findings of this study. Later a more refined version, the Multidimensional Health Locus of Control Scale (Wallston & Wallston 1978b), was developed.

The purpose of the theory is to explain socio-economic differences in health (Bosma *et al.* 1999), and to measure the extent to which individuals believe their health status is determined by their own behaviour. The questions on the scale are classified as either internally located control (health is within the control of the individual) or externally located control (health is a matter of chance or fate). A number of participants in this study (*cf.* chapter 9) appeared to operate with an internal locus of control, in that they preferred to initiate self-treatment and self-care in order to manage or control their hypertension.

One participant in particular, Delbert, stands out as operating with an external locus of control: he viewed his GP as being wholly responsible for his health, and for the prevention of the complications of hypertension. It can be concluded that the majority of participants in this study operated with an internal locus of control, by the pro-active management of their hypertension.

However, the internal locus of control observed is not synonymous with accepted biomedical conventions, in that an internal locus of control in respect of hypertension might normally be demonstrated via health actions such as taking regular exercise or a low-fat diet. However, in this study the health actions elicited were related to taking non-prescribed herbal remedies or non-concordance.

Non-concordance with prescribed medication

Within the domain of non-concordance, openness in communications between the patient and GP emerged as an important consideration. Some participants did share with their GP their non-concordance and use of herbal remedies, but most did not, and this might have serious consequences for the health of the individual concerned. However, it was clear that reciprocity was not achieved in many GP/patient relationships, as openness was also sometimes lacking on the part of the GP (*cf.* chapter 11).

The explanations participants gave for their non-concordance can be grouped in types of explanation that enable a typology of non-concordance to be constructed. Kluge (2000) states that all typologies are simply a process by which types are grouped together. Kluge's (2000) method of constructing typologies is adopted in the following example. Components of the type have to be heterogeneous at the level of the type, e.g., in these instances the types are all concerned with non-concordance. However, the diversity between the types has to be as great as possible, but whilst the types exist as single entities meaningful relationships between the types must exist (see table 12):

Table: 12 Typology of Non-concordance

Types of non-concordance	Non-concordance
1. Continuous (high)	1a) Medication perceived to be harmful *(Hyacinth,Carmel,Roger,Petra)* 1b) Medication perceived to be ineffective *(FGI participants Roger, Hyacinth, Edgar, Carlton)* 1c) Taking medication not a priority *(Carlene)* 1d) A stronger belief in traditional herbal remedies *(Hyacinth, Carlene)*
2. Episodic (low)	2a) Ran out of tablets *(Delbert)* 2b) Forgot to take tablets *(Wesley)* 2c) On holiday *(Carlton, Carlene)* 2d) Taking other medications *(Carlton)* 2e) Side effects *(Hyacinth, Carlene)*
Non	Concordance

Thus, from the data in this study nine different types (types 1a-2c) of non-concordance can be constructed as illustrated in table 12.

In considering participants' concordance and non-concordance with medication, the data in this study suggests some important future research questions: for example, what are the processes by which participants estimate risk to their health? For example, from the perspective of those participants who had ceased taking medication because of potential rather than actual side effects, what were the decision-making processes that enabled participants to balance this risk against the potential risk of not taking medication. There may also be a synergistic relationship between self-care and use of herbal remedies that would warrant further investigation. Nevertheless, the data that form this theme provide very important insights that provoke further research questions.

Lay, folk and professional sectors of health care

Thorogood (1998) has premised that Jamaican health beliefs and concepts of health and health derive from two cosmologies. First of all, medieval theories of humours, and second, West African conceptualisations of the obstruction of bodily passages. Implicit in the latter view is the need to maintain clear body passages, via purges and laxatives if necessary. Within this world view, the body is linked by one continuous passage from the mouth to the anal orifice, via the uterus and stomach (Helman 2001). This viewpoint certainly appears to have resonance with the viewpoints expressed by Barbette and Loretta in chapter 9, and affinity also exists with Helman's (2001) premise of keeping bodily passages patent , and within individual explanatory models of high blood pressure, such as that provided by Edgar (*cf.* chapter 9).

Kleinman (1980) describes health care systems as forming three domains:

- **Popular sector** is a lay, non-professional sector in which between 70% and 90% of illness episodes are managed. This sector includes perceiving and experiencing symptoms, assignation of labels, health seeking behaviours, authorisation of a specific sick role, self-care and treatment. The family is the main providers of such care.
- **Professional sector** is the organised healing professionals sanctioned by society, usually via legislation, to fulfil this role.
- **Folk sector** is non-professional, non-specialist sector embracing religious and secular healers, such as folk healers, shaman and herbalists.

Observers (Morgan 1993) established that the use of herbal remedies in the Caribbean was informed by West African folk medicine, presumably by way of the tacit cultural knowledge held by those populations transported to the Caribbean by the transatlantic slave trade. However, in this study participants use all three sectors in Kleinman's model both singly and simultaneously.

Herbalism and self-care

The predominance of herbalism in Jamaica as a form of self-care is both a manifestation of lay and folk belief systems (Kleinman 1980, Helman 2001) and a pragmatic response to the limited provision of formal PHC in Jamaica. Observers have established the continued use of herbalism in England (Morgan 1988, Shaw *et al.*1999).

Self-care for many people was the only PHC available, as is clearly manifested in participants' views in this study (*cf.* chapter 8 & 9). In past decades ordinary Jamaican citizens could often not afford the services of a professionally qualified medical practitioner, who was likely to be accessible only by townsfolk. Many of the Jamaican people who migrated to the UK are rural and country folk, and were therefore even less likely either to be able to afford or to subscribe to professional medical services in Jamaica.

It is important to view the use of herbalism within the context of social norms and practices within the Caribbean, both now and in past generations. Research carried out by Thorogood (1988) suggests that women have a prominent role in the creation of herbal remedies and bush teas, and the administration of them to family members. This notion is reiterated in this research, as the use of herbalism and the position herbalism has in the social mores and norms in family life in Jamaica are significant. A number of participants referred to the 'washouts' they received as children growing up in Jamaica, usually administered by mothers, in the form of an infusion usually bitter in taste, therefore known as 'bitters'. This was a regular event and usually occurred over a holiday, such as Christmas or Easter, and in this sense might be regarded as ritualistic cleansing. For many participants, the use of herbalism and self-care may be a powerful dimension of their socialisation process, therefore their belief in the efficacy and value of herbalism remedies may not be readily de-constructed on migration. Indeed for many individuals, the issue may not be salient in their thinking, but an acceptance may exist of the inherent value of herbalism as a 'taken for granted' dimension of life. The self-reliance of rural people in the Caribbean was viewed by participants in this study as a positive attribute.

Use of complementary and alternative therapies in the general population

Herbal remedies have been used globally and in the UK for the treatment of ailments and chronic conditions for many centuries (Little & Parsons 2003), this use is termed phytotherapy. The use of herbal remedies within the general population forms a component of what is known as complementary and alternative therapies or CAMS (Eisenburg 2000). Roach (2000 p.1365) states:

> *"The Royal Pharmaceutical Society predicts that retail sales of herbal and homeopathic preparations and aromatherapy essential oils will total £126m ($176m) by 2002".*

In this respect it can be concluded that some sections of the general population, in common with some of the participants in this study, are strong supporters and users of herbal remedies. The widespread use within the general population of herbal remedies has prompted calls for stricter regulations in relation to such herbal remedies (Roach 2002), and randomised controlled trials to establish the efficacy of herbal remedies (Little & Parsons 2003, Little *et al.* 2003) and to establish the extent to which these remedies create placebo effects. Mason & Tovey (2002 p. 834) articulate the origin of this growth stating that:

> *"People often turn to complementary treatments because of frustration with conventional medicine".*

Frustration of this nature was clearly evidenced in the data elicited from the African Caribbean participants in this study. Participants expressed dissatisfaction with the side effects and perceived efficacy of anti-hypertensive therapies. In this respect strong similarities exist between participants in this study and the general population, so it can be concluded that the use of herbal remedies is not simply a matter of the result of the culture or the ethnicity of the individual. Rather, it may characterise and typify the norms and values of other subgroups within society at large, especially those who experience chronic illness and who perceive prescribed medications as having limited efficacy. As most of the participants in this study had resided in the UK for over thirty years orientation towards the values and norms of the host community is highly likely. However, a major difference did exist: the participants in this study largely grew their own herbal treatments, or obtained dried plants from the Caribbean. This is in contrast to information presented by Roach (2000), which appears to indicate that within the general population herbal remedies are purchased from herbalist stores or pharmacists.

Eisenburg *et al.* (2002 p. 965) state that:

> *"The popularity of complementary and alternative medical (CAM) therapies presents new challenges".*

Whilst it is difficult to argue with the statement above, it is worth noting that most of the participants in this study did not disclose their use of herbal remedies to health care practitioners, so in this respect the challenge to PHC practitioners is veiled and covert.

Within the wider population observers have noted (Litter *et al.* 2003a & b) the increased use of complimentary therapies, especially plant and herbal remedies in the management of chronic disease such as osteoarthritis, rheumatoid arthritis, (Litter *et al.* 2003a & b) dysmenorrhoea (Procter & Murphy 2003) and many other chronic conditions. Clearly individuals, especially those experiencing chronic illnesses, value herbal remedies. The findings of this study demonstrate that more open communication between practitioners and patients concerning the use and role of herbal remedies would enhance therapeutic encounters in PHC.

African Caribbean people and a theory arising from this research

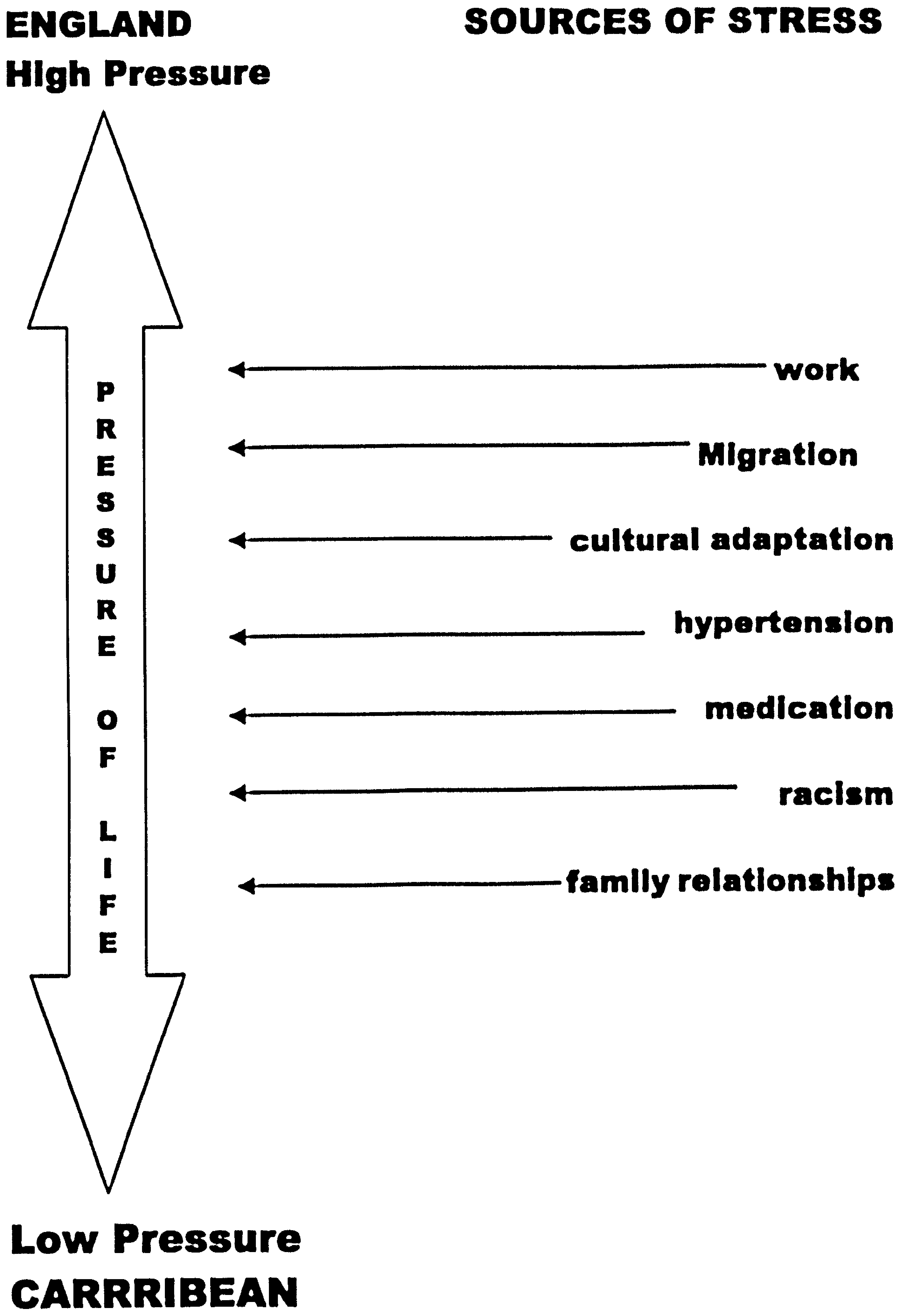
Figure 2 maps out the key factors that participants stated characterised life in Jamaica and life in England, in respect of the stressors said to influence high blood pressure. The factors listed under 'sources of stress' coalesce to create HIGH PRESSURE in England, while the absence of these factors in Jamaica meant, according to participants in this study, a less stressful life, which I have termed LOW PRESSURE. Table 13 presents a comparison of HIGH PRESSURE/PRESSURE, the condition of high blood pressure defined by participants, and the condition of hypertension, as defined by biomedicine. The comparison highlights the differences between professional and lay conceptualisations of the conditions. The differing conceptualisations form the basis of miscommunication and misunderstanding between health professionals and patients during therapeutic encounters in the PHC setting. This may be described as a 'cultural clash' and may ultimately determine the effectiveness of the management and care of African Caribbean patients who experience hypertension.

On the basis of the findings and interpretation of the data, it is possible to propose a theory in relation to the factors influencing the participants' decision-making in this study. Ultimately these decisions influenced the care and management of hypertension in PHC (see fig 2 and table 13 following). No generic claims are made for the theory postulated.

The model presented in figure 3 maps out the antecedent factors that participants in this study described as being precursors to the development of high blood pressure. Some of these factors arise from early socialisation in Jamaica, the experience of migration, cultural adaptation, wider societal influences and the experience of living in England as a migrant. Participants may be reluctant to present for early diagnosis in PHC, as formal PHC services were not part of their lived experience in the Caribbean prior to migration. In order to cope with a lack of PHC services in the Caribbean, individuals and communities were reliant on their own skills and resources to treat illness. To some extent these attitudes appear to be conveyed to second-generation participants born in England.

Often, elders and female heads of the household held tacit knowledge concerning particular remedies or treatments. Knowledge of this type can be regarded as a form of cultural knowledge (Spradley 1979). Knowledge of herbal remedies and plants can be traced to West Africa via the transatlantic slave trade. The cosmology of African Caribbean people in relation to the use of purges and laxatives reflects both the West African origins and appears to have similarity with humoral theories of health and illness in keeping the body passages clear (Thorogood 1988).

Figure 2: Illustrating Pressure of Life



The notion of 'running to the doctor' is viewed negatively. This may have been a necessary philosophy, adopted by individuals in the Caribbean to cope with sickness and illness when formal PHC services were not available. In order to use PHC services effectively following migration, the African Caribbean participants in this study may need to de-construct early socialisation processes in relation to self-care and resourcefulness. However, this may not be desirable, given the existing over-utilisation of GPs services for minor ailments (Brogan *et al.* 1998, Rogers *et al.* 1998). Further, some participants reported past instances when accessing PHC services in the 1960s and 1970s (*cf* chapter 11) which may have created further reluctance to use PHC services and contributed to tacit community perceptions of PHC services.

When a participant receives the diagnosis of hypertension, cognitive dissonance is encountered to some extent, as biomedical conceptualisations of hypertension differ greatly from the participant's own explanatory models of their condition, which they termed high blood pressure. What is not established in the data is how participants make sense of this dissonance. However, it is known that lay explanations (EMs) tend to normalise the experience (Helman 2001). This normalisation was evidenced several times in the findings, in the viewpoint that high blood pressure is not a very serious condition and may be regarded as part of growing older. Before the pilot interview FGI, a participant withdrew stating that he did not need to take part as he had 'blood pressure' as opposed to high blood pressure. Commonly within the African Caribbean community, hypertension is expressed as 'having a little bit of pressure'. This demonstrates the normalising dimension.

Participants wished to take control of the management of their condition because of their history of self-reliance and self-care, even if this control is illusionary. This may be related to participants' 'health locus of control' (Wallston & Wallston 1978). Participants achieved control via the use of herbal remedies, by non-concordance, and by seeking alternative consultations with private GPs. Medication was not viewed by the participants as natural and in some instances was considered health damaging, a view confirmed by the drug information sheet in the medication box.

Whilst satisfaction with PHC services was expressed, dissatisfaction resulted in a change of GP. Both participants and GPs at times seemed economical with the truth. From the participants' perspective this may be another strategy for gaining control.

Table: 13 Comparison of hypertension and high blood pressure

Hypertension	HIGH PRESSURE/PRESSURE HIGH
Diagnosed by a medical practitioner	Defined by lay perspectives
Diagnosed in medical establishment, e.g., GP surgery	Recognised as an aspect of everyday life
Measured by B/P machine	Measured by the existential characteristics of individual lives
Has associated risk factors	Is associated with the pressure of life
Obesity	Migration/cultural adaptation
Smoking	Not belonging
Lack of exercise	Stress – work-related & relationship
Alcohol	Financial stress
Poor diet	Racism
Treatment – medication	Treatment – remove precursors Herbal remedies
Monitored by GP	Monitored by individual according to feelings
Treatment controlled by GP	Treatment controlled by the individual

More general implications of the findings

Coffey *et al.* (1996 p.163) assert that all qualitative data must move beyond narrow confines of the topic under investigation and attempt to establish 'social processes' and 'cultural forms'. The findings of this study are explored in the light of this assertion.

Within the current context of global migration and movement of populations, the findings in this study raise some more general questions, as to how communities moving from less developed countries to developed Western nation states make sense of and utilise systems of primary health care in the host communities. Parallel to this is a consideration of the existing explanations that migrant communities might hold and the systems of self-care that might exist, and how these systems might conflict or support Western paradigms of biomedicine. The phenomena identified in this study are likely to exist in or at least be similar for other migrant communities in the UK. An increased understanding of how migrant communities adjust and understand new systems of health care is likely to bring more efficient use of health services and economic benefits, in addition to impacting upon the health status of the communities involved.

Similarly the lay explanations provided for high blood pressure are likely to exist for other common medical conditions, and to be as divergent from biomedical explanations as has been evidenced in this study. Former colonial states to some extent have experienced racism, both institutional and personal, that is a legacy of such colonial domination of developing countries (Airhihenbuwa 1995, Tuhai-Smith 1999). The wider structural issues are considerable and shape the context of care delivery as experienced by migrant communities (Macpherson 1999, Karlsen & Nazroo 2002a & b). The former supremacy of Western nation states in developing countries might lead one to expect migrant communities to regard Western biomedical approaches as superior to their own systems of health care. This was not the case in the study; quite the reverse is evidenced. This to some extent demonstrates the extent to which systems of PHC may be deeply embedded via socialisation processes. However, it may be that those PHC professionals whose practice is informed by Eurocentric practice (Sutherland 2002) may hold inherent beliefs about the superiority of Western biomedical approaches. Ethnocentrism of this nature (Sutherland 2002) is destined to result in cultural clash, miscommunication and an unsatisfactory encounter for both professional and patient.

The issues of racism, discrimination and prejudice that the participants expressed in this study are unlikely to occur in isolation. It seems probable that other migrant communities have similar experiences that might impact upon health and contribute to illness and dysfunction. Explanations of health and illness causation are not static entities; similarly, use of PHC is subject to a myriad of dynamic influences. All that can be stated with certainty is that these phenomena are in a constant state of flux.

Broader issues are raised regarding the nature of GP/patient encounters and relationships, and the extent to which honest and meaningful communications can be established in the context of PHC delivery. It seems possible that some of the herbal remedies do appear to afford some benefit to the participants. The properties of such remedies need further pharmacological investigation. Global migration is a fact of life in the 21st century (Bhattacharya *et al.*2000) and creates an urgent need for a deeper understanding of the issues outlined above for many populations.

Achieving rigour in qualitative research

Rigour and robustness in qualitative research is to some extent established via a self-conscious and reflective approach, accompanied by an explicit methodological framework. In order to establish the rigour and scientific value of the research in this thesis, the work conducted is now considered in the light of the framework for assessing the quality of qualitative research postulated by Guba and Lincoln (1989): confirmability, dependability, transferability and credibility.

Confirmability

Rigour is achieved in this study via a self-conscious and reflective approach in relation to all aspects of the research. The reflective accounts provided attempt to establish my personal assumptions and biases concerning the study population, and the effects these have had on the engagement of the study population, and the collection and analysis of the data. A reflective diary in the form of a written narrative was maintained throughout the progression of the research. The general methods and procedures are described in detail in the methodological and methods chapters, providing a transparent audit trail.

Dependability

In Guba and Lincoln's model (1981), this dimension is concerned with establishing the consistency and stability of the research and methods. However within a dynamic social world, changes within the research design are inevitable. What is important is that a rationale and account is provided for these changes. For example, in this study it was intended to conduct four FGI in each location. However, during the recruitment phrase, it became evident that many participants were unwilling to participate in an FGI (a more public form of data collection) and preferred individual interviews, therefore only one FGI was conducted in each location. Other factors that demonstrate the dependability of this study (Miles & Hubermann 1994, Begley 1995) are the clearly articulated research questions, and a clear description of my role and status within the process of data collection. Further factors include the adoption of a theoretical methodological approach, ethnography, and the establishment of a supervisory panel of academics with expertise in the field to comment and give guidance on the design and progression of the research.

Transferability

The conclusions drawn in this study apply only to the study population in this research. However, it may be that the participants in this study demonstrate 'typicality' in relation to other participants in similar locations with high blood pressure; in this respect it may be possible to draw empirical generalisations (Murphy *et al.* 1998). Empirical generalisations are reliant on the achievement of maximum phenomena variation within the sampling or within case sampling (Hammersley & Atkinson 1995). The notion of transferability is also dependent on clear descriptions of the characteristics of the population in the study sample. In this study these descriptions are provided in the methods chapter and appendices, and include detailed biographical information. As stated, some diversity is achieved in the study sample. Attempts are made in analysing the data to map out the parameters of the conclusions and claims arising from the analysis. The findings are also congruent with and support some earlier allied studies of African Caribbean populations in England (Morgan 1988, Thorogood 1988, Donovan 1996). Suggestions are made in the discussion as to future research with other migrant populations, in which the findings of this research could be validated further.

Credibility

The focus of concern in this dimension is authenticity and accuracy. It is helpful to consider who/why/when (Crookes & Davies 1998) in relation to the research undertaken. In this research, questions of who/why/what are addressed in the methodology and methods chapters via an accurate and thorough description of the participants and research. The findings are enhanced by triangulation of the data (Miles & Hubermann 1994) and attempts to identify negative evidence and outliers during the process of analysis. The areas of uncertainty for which adequate data was not available are outlined. The findings present a comprehensive and multi-faceted account of the experience of high blood pressure for the African Caribbean people in this study. The credibility of the research conducted is further enhanced by the confirmation of the emergent findings and conclusions by the consumer research advisory group, which found the findings to be credible. Additionally, all study participants were contacted by letter to establish if they required information regarding the findings. Approximately half of the participants replied, and freepost envelopes were provided to enable the participants to comment on the findings, but no comments were received.

Limitations of the research and the methodological approach adopted

An ethnographic qualitative study of this nature relies on a non-probability, purposeful sample in order to generate participants with the correct characteristics, in order to investigate the chosen phenomena. As such the findings are not generalisable to the wider population of African Caribbean people in the UK who experience hypertension. This lack of generalisability may be regarded by some observers as a limitation of the research. However, Murphy *et al.* (1998) have described the type of sampling used in this study as non-probabilistic sampling for generalisation. The intention is to make empirical generalisations for finite populations. (This requires recruitment of individuals who may be regarded as typical and non-typical in relation to the phenomena under investigation). I prefer to term this approach *'non-random sampling for typicality'*, as the findings could be extrapolated to other similar populations in similar circumstances to the original study population. In this study participant-observation during PHC consultations might have facilitated greater understanding and insight into the patient/PHC professional relationship, and illuminated aspects of this relationship, including the quality of communication. In this sense the lack of participant-observation may be regarded as a limitation.

Most, but not all, of the participants were recruited via GP surgeries, so it is likely that some bias exists in the sample, in that not all African Caribbean people with hypertension may be registered with a GP or frequent users of GP services. However the principle of maximum phenomena variation was adopted in this study, so some heterogeneity exists as some participants were also recruited via community groups and a snowball technique.

Initial difficulties were experienced in recruiting both GPs and participants. Tenacity and determination were required to overcome the obstacles and challenges encountered. African Caribbean people are more likely to live in inner city areas (Dorsett 1998). A long established inverse-care law exists in the study locations (Sheffield and Nottingham) in that the inner city locations are served by fewer GP practices. The GP practices that do exist in inner city locations experience considerable pressure in caring for disadvantaged communities, populations who speak English as a second language, and refugee populations. All these factors militate against the involvement of these particular practices in research. Given this, an alternative approach might have been to use existing GP research networks, such as Trent Focus, that validate GP practices as research practices and secure a commitment in principle to involvement in the conduct of research. However, the research practices in the Trent Focus network may not have substantial practice populations of African Caribbean people. The study locations may have influenced recruitment processes, as both Sheffield and Nottingham have ethnic minority populations reflective of the national average, whereas in other conurbations, such as London, Leicester, Birmingham and Manchester, the larger ethnic minority populations might have facilitated access to study participants.

One of the major barriers in accessing participants of African Caribbean origin via GP practices was lack of ethnic profiling in PHC. Only one practice routinely collected data concerning the ethnicity of their study populations, which does lead to questions as to how the health needs of the practice populations can be assessed when fundamental data of this nature are not available.

Another alternative approach in recruiting individuals might have been to work more closely with community groups and associations and the considerable number of 'black' churches in the study locations. The concept of 'user involvement' in research has risen to prominence during the progression of this research (Beresford 2000, Rhodes *et al.* 2001), and networking via community groups and associations may have facilitated greater user involvement, although a consumer research advisory group was established in this research. This approach is just one model of working within a typology of user involvement and participatory research.

It could also be argued, perhaps because of the focus of the study on the lay perspectives, that an exploration of the management and care of African Caribbean people with hypertension from a professional practice perspective might have provided a more holistic account of the phenomena under investigation. Indeed I would regard this as an area for further investigation and future research. However, this is an unapologetic assertion, as the views and perspectives of African Caribbean people in health and health-related research are sadly lacking. Indeed I would advocate a national study investigating the experience of African Caribbean people with hypertension. During the progression of my study, I encountered a number of GPs, especially from the London boroughs, who struggle on a daily basis with the management and care of African Caribbeans who experience hypertension. It is for these reasons I feel that both lay and professional perspectives on the phenomena are required in future research, in order to establish the cultural congruence of services and the cultural sensitivity of caregivers.

Commonality and differences in data collections tools

Commonality does exist between the findings of each data collection tool. The FGI permitted a broad scoping of the key issues of investigation in the main study sample and triangulation of the data (Begley 1996, Murphy *et al.* 1998). A major difference between the FGI and semi-structured interviews was the greater detail and depth of exploration that occurred in the semi-structured interviews, as may be expected. It is my view as evidenced in the data that all three data collection tools were successful in eliciting the information intended. However there are a number of key findings that emerged in the semi-structured interviews that were absent in the FGI data. These include issues such as work place discrimination and racism, the effects of migration and cultural adaptation, single parenthood, managing stress, explanations for non-concordance and many others. This serves to highlight the richness of the data emerging from the semi-structured interview data in comparison to the FGI. This is not to say that the FGI is superficial, but simply that the FGI as a data collection tool constrains the depth of data elicited, because of the number of participants. The vignette interviews have strengths and weaknesses, as previously stated (*cf.* chapter 12). In the FGI nearly all the participants were retired individuals, in the semi-structured around two-thirds were retired and in the vignette interviews half were retired, reflecting progressive attempts to bring maximum phenomena variation in sampling.

The vignette interviews largely reflect and reiterate the findings of the main study. In fact, the commonality between the data is striking and in this sense triangulates the FGI and semi-structured interview findings. The vignette interviews did facilitate a deeper exploration of key phenomena, such as non-concordance, perceptions of PHC, and the use of herbal remedies, that emerged from the semi-structured interviews. The key concepts and phenomena investigated are mapped out in greater depth and detail. However, a limitation of the vignette interview approach is the tendency for participants to focus their assertions and discussion on the phenomena in the vignette. The vignette interview data lacks the breadth of the interviews, although this may be a desirable characteristic, depending on the purpose of the vignette interviews.

Policy and practice implications

On almost all measures of morbidity and mortality including hypertension, the health status of ethnic minority populations is observed to be poorer than the health of the general population (Nazroo 1997). The reasons for this are multi-factorial. Nazroo (1998) suggests that explanations for this rest on three dimensions of the structural context: first, the cumulative influence of disadvantage over a life-time; second, the geographical locale of ethnic minority groups in deprived housing tenure and the associated ecological effects, and third, the consequences of living in racist society. However, as was demonstrated in chapter 4, greater ill health does not necessarily mean more frequent use of PHC services. The reduction of hypertension is a national priority (DOH 1999a), as is addressing inequalities in patterns of disease and ill health in relation to cardio-vascular disease. The PHC evidence base in relation to the management and care of African-Caribbean patients with hypertension is also limited. In this respect the findings of this study provide some important insights, which inform the following recommendations.

Recommendations for strategic policy directives

In relation to strategic policy directives, it seems that more targeted routine screening of presumed well populations is required in order to identify African Caribbean people with hypertension. This recommendation is based on the accounts participants gave, which indicated that many participants had had hypertension for some time prior to diagnosis and that some participants were only diagnosed following a major health event. This recommendation is also based on the finding that the participants in this study in the early stages of illness often preferred self-care and observation to immediately seeking out medical attention. To some extent this is influenced by the limited access to formal PHC that some participants experienced in the Caribbean prior to migration. However, I believe that the propensity towards self-care and resourcefulness evident in this study is a positive feature of the findings, given that studies have established that many minor ailments with which patients present in GP surgeries could be treated by the individuals themselves (Roger *et al.* 1998, Brogan *et al.* 1998).

I suggest that the approach to screening be selective and focused on geographical locations with high ethnic minority populations. There may also be a case for work-place occupational health led screening, as a number of participants mentioned significant events occurring at work prior to diagnosis. Local activities of this nature would be enhanced by national campaigns publicising symptom recognition of hypertension and the prevalence of hypertension in African Caribbean communities. Whilst such messages would emanate from a strategic national approach, the best medium for delivery might be via existing networks such as community groups and associations, black churches and faith groups, local radio programmes whose target audience are black and minority ethnic populations, and employers such as the NHS which have a substantial African Caribbean workforce.

A number of participants mentioned work-place stress as a major precursor of their hypertension. I would recommend that appropriate organisational strategies be in place to provide support for those individuals who experience work-place stress. In this study the economically active participants tended to work in public services, in roles such as teaching, nursing, midwifery, social work, community care and youth work. Employers need to recognise that racism and discrimination can result in work-place stress, as is evidenced in this study, and to that ensure the necessary policies and supports are available.

At Primary Health Care Trust level I would recommend that those responsible for diversity management might work towards a strategic directive that enables PHC professionals to undergo training in the elicitation of patient's explanatory models, as identified earlier in this chapter. Such an approach would benefit all PHC users rather then targeting African Caribbean patients alone, and would prevent stereotyping and stigmatisation.

Recommendations for the education of PHC practitioners

PHC professionals need to appreciate the historical antecedents that have led to ethnic minority individuals living in England. Alongside this is the need to consider and understand how the dynamics of racism and discrimination operate in the wider society, and how this ultimately manifests in the health status and experience of ethnic minority populations. The fundamental starting point seems to be an appreciation and understanding of the factors that Nazroo (1998) identified as key factors in the relationship between ethnicity and health: the cumulative effects of disadvantage, the impact of residence in specific geographical locales, and the impact on health of racism in wider society.

The findings of this study provide a wealth of ethnographic data and an in-depth sociological account of the experience of African Caribbean people with hypertension. For those practitioners who work in conurbations with large populations of African Caribbean people, the findings may be especially helpful in advancing understanding of how a chronic illness such as hypertension is experienced in terms of the patients' personal biography and life trajectory. Insight of this nature is essential to enable PHC professionals to engage with patients in a meaningful way.

Ideally, education and learning on the provision of culturally competent care should appear in core educational curricula, and some attempts have been made, especially in nursing, to achieve this (Culley 1996, Gerrish *et al.* 1996, Price & Cortis 2000, Serrant-Green 2001). Although the theoretical frameworks for such learning and education have been the objects of ongoing debate (Bruni 1988, Gerrish *et al.* 1996, Culley 2001), the underpinning philosophies in various nation states differ. For example, differences exist between the predominant approaches in North America (Leininger 1991, 1999), New Zealand (Ramsden 1995, Grogan 1996) and England (Papadoupolos *et al.* 1998, Serrant-Green 2001).

It is not clear to what extent other PHC professionals have engaged in such learning as a component of core education programmes. The topic of providing care for diverse communities is likely to become increasingly important as global migration increases (Bhattacharyya *et al.* 2002) and responding to diversity in health care will become more challenging.

PHC professionals by very definition have largely completed core educational programmes, but such learning on developing cultural sensitivity could be incorporated into programmes of specialist preparation for primary health care, e.g., GP vocational schemes and specialist community nursing practice programmes. In considering the development of culturally sensitive care, I would suggest that in responding to the needs of hypertensive African Caribbean people in PHC, learning and education might most appropriately be practice-based. In this way practitioners can become more acquainted with the specific needs of their practice populations. For example, discussion with local communities during this research has revealed that most African Caribbean people in Sheffield originate from Jamaica, whereas in Nottingham there exists a substantial Dominican population. Whilst populations might be happy to be broadly defined as African Caribbean, differences in culture and traditions do exist. Jamaican people most often speak English Patois whilst Dominican populations are more likely to speak French Patois. The development of culturally sensitive PHC skills and practice should of course embrace anti-racist and anti-oppressive practice, as this study has clearly demonstrated that racism, both institutional and personal, has a negative effect on the health of the participants. Such insights and knowledge are essential to understand the historical and contemporary factors that might create reluctance to use PHC facilities.

I am not suggesting the culturally essentialist or checklist approach advocated by Leininger (1991, 1995), but an approach to learning that will acknowledge the existence of racism, and gender and social class differences. One approach within a PHC Trust might be to establish mentoring in the provision of culturally sensitive care: a mentor might dedicate time to each practice or PHC service that needed such expertise. In turn, PHC services or practices could establish a cascade system of knowledge dissemination and knowledge showers via appointing their own mentor in culturally sensitive care, to work with other team members.

Recommendations for primary health care professional practice

Most participants in this study expressed satisfaction with PHC services received. However, the findings of this study do indicate that a lack of openness does exist betweens some PHC professionals and African Caribbean people with hypertension. Reflecting on the findings of this study, a key issue appears to be the need for good communication in respect of early diagnosis, ongoing care and chronic disease management, strategies the patients might use to self manage their condition, such as herbal remedies and use of private GPs, and the wider context of the individual's life and how this might impact upon their health status. However, it is worth noting that many of the wider structural issues that the participants identified as either causing or impacting upon their hypertension may be outside the remit of most PHC professionals. However, participants articulated a desire to express these factors, and for these factors to be acknowledged by PHC practitioners during consultations as significant mediators of their experience of hypertension. This can only be achieved where a safe environment for communication is created during the therapeutic encounter.

The diagnosis of a chronic illness is upsetting for many individuals, but in this study the younger economically active participants seemed to experience this more acutely, as the condition of hypertension was frequently perceived to be a condition of old age. This perception may make adjustment to a changed health status more difficult for a younger person with high blood pressure. PHC professionals need to take account of this in their consultations.

I would recommend that in order to engage more closely with all patients, including African Caribbean patients with hypertension, PHC professionals as a fundamental starting point elicit the individual patients' explanatory model of health and illness. This would enable many of key issues identified in the findings chapters to be made explicit and addressed, such as concordance, use of herbal remedies, use of private GPs, satisfaction or otherwise with treatment, and stress or work-related issues. This would facilitate greater understanding by PHC professionals of the patients' orientation to their health and illness experience. The findings of this study indicate that patients' and professionals' perceptions of hypertension and high blood pressure differ greatly. Therefore, the use of guides to elicit patients' explanatory models may be especially helpful.

A number of models exist to guide practitioners in eliciting the EMs of clients and patients (Kleinman 1980, Weinmann *et al.* 1996, Weis 1997, Lloyd *et al.* 1998). I would recommend that key constructs be integrated into the preliminary assessments of African Caribbean people with hypertension in PHC. Kleinman's seminal work focuses on eight questions to uncover a patient's or client's EM, and these might allow cultural adaptation of practice and PHC services, by establishing the ground for negotiation between patient and practitioner. The questions follow:

1. What do you call the problem?
2. What do you think has caused the problem?
3. Why do you think it started when it did?
4. What do you think the sickness does? How does it work?
5. How severe is the sickness? Will it have a short or long course
6. What kind of treatment do you think the patient should receive? What are the most important results you hope to achieve from this treatment?
7. What are the chief problems the sickness has caused?
8. What do you fear about the sickness?

Within the context of contemporary PHC the eight questions listed may be considered over-long, in which case consideration should be given to the shorter models mentioned earlier in this chapter: Weinmann *et al.* (1996), Lloyd *et al.* (1998) and Weiss (1997). The complexity of patients' EMs means that concordance with therapies is unlikely to be achieved unless the PHC professional is aware of the dissonance between practitioner and patient EMs. The patient's subjective experience of hypertension should be sought and elicited, as Barbette shared it with me. "*I didn't tell her. Well, she never ask ...*"

The drug information leaflet which accompanies anti-hypertensive therapies appeared to be a cause of anxiety for some participants in this study. Unnecessary worry and stress concerning potential side effects could be alleviated by more careful explanation by PHC professionals that the listed side effects do not necessarily develop in all individuals. The community pharmacist and practice nurse may be well placed to initiate discussions of this nature. In general more in-depth discussion is required between PHC professionals and patients regarding medication and its potential benefits, as well as the risks of not taking medication as prescribed. In this study male participants stated that impotence, a well-known side effect of anti-hypertensive therapies, had not been discussed with them. These participants felt aggrieved that they had had to initiate a conversation with their GP about impotence, rather than being provided with this information at the time of receiving the prescription.

During consultations it may be useful for PHC to acknowledge that other forms of treatment and care exist which patients may access. In this study around one third of the participants used herbal remedies and a smaller number used private general practitioners, but almost all of these participants declined to share this information with PHC for fear of retribution. Yet information concerning the use of these different forms of care may enable PHC professionals to provide more effective care and treatment plans for patients.

Primary health care services located in areas with high African Caribbean populations would benefit from a greater emphasis on the provision of culturally sensitive care (Culley 2001, Andrews 2002, Camphina-Bacote 2002, Giger 2002, Purnell 2002). An appreciation and understanding of the wider influences on health that African Caribbean populations experience would also have potential benefits in the therapeutic encounter for other minority communities. This appreciation and understanding is most frequently expressed as cultural awareness, cultural knowledge, cultural skill, and cultural sensitivity (Camphina-Bacote 2002). The notion of culturally congruent practice is problematic, in that it is unrealistic to expect practitioners to have an in-depth insight and knowledge of all groups they encounter. It is for this reason that my recommendations for PHC focus on cultural sensitivity (Camphina-Bacote 2002). This might be achieved via the education and training of PHC professionals in developing cultural awareness, cultural knowledge, cultural sensitivity, in order to bring about increased cultural sensitivity in PHC services for all population groups rather than focusing only on African Caribbean populations.

I would suggest that PHC services with substantial populations of African Caribbean people consider undertaking an audit of cultural sensitivity in their practice or service, using a tool such as that developed by Camphina-Bacote (1998): *the Inventory to assess the process of cultural competence among health care professionals* (IAPCC). This is a validated tool that is suitable for use with a multidisciplinary PHC team. The development of culturally sensitive practice in PHC and culturally congruent services does not constitute a product or a single outcome, but is a process subject to ongoing development (Camphina-Bacote 2002). In many respects, the domain of developing culturally sensitive care in PHC for a diverse population is a highly suitable topic for multiprofessional and inter-disciplinary learning, which is very much part of the present government's agenda for the training and education of health care professionals via the modernisation project (DOH 2001). The success of shared and interdisciplinary learning on sensitive or challenging topics is evidenced in the widespread facilitation of ongoing learning in England on topics such as child protection.

Recommendations for future research activities

The current research policy agenda emphasises the role of consumers as active partners in the research process (DOH 1999b, Beresford 2000, Framework for Research Governance in England 2001, Rhodes *et al.* 2001). Expert patients are also emerging as important sources of information, and another approach to PHC-based learning on this topic might be action learning with practitioners, patients and academics, focused on hypertension and African Caribbean communities and creating a reciprocal learning environment.

The learning activities and implications for policy and practice will result in future challenges, by establishing the extent to which activities of this nature can impact upon the PHC of African Caribbean patients with hypertension, and how these outcomes can be measured from both a professional and lay perspective. Future research in this area is recommended, as is research assessing the cultural sensitivity of PHC Services, further testing of the IACPCC in PHC within the UK context, and the application of the approaches which establish patients' explanatory models (Kleinman 1980, Weinmann *et al.* 1996, Weiss 1997, Lloyd *et al.* 1998) in PHC as these arise from mental health care. Urgently needed is a national study of African Caribbean people and their experience of PHC, and cross-cultural comparison with other migrant groups. Further research is required on the extent to which hypertension is perceived as a male condition and why Caribbean men are most likely to have received treatment for their hypertension, given the greater prevalence of hypertension in Caribbean women (Nazroo 1997, DOH 2000). Research is required from the perspective of those participants who had ceased taking medication because of potential rather than actual side effects, in order to establish the decision-making processes that enabled participants to balance this against the potential risk of not taking medication. There may also be a synergistic relationship between non-concordance, self-care and use of herbal remedies which would warrant further investigation. This study focused entirely on patient perspectives, in order to obtain a more comprehensive understanding of the research that is needed into PHC professionals' perspectives.

My final recommendation is that PHC services develop ethnic profiling of their client groups, as is presently required only of acute services (Aspinall 2001). Further research may be needed on the feasibility of this (Pringle & Rothera 1996). I would recommend dissemination of research findings via PHC networks, publications and conferences, to enable practitioners involved in direct care and management of African Caribbean people with hypertension to have access to greater understanding of and insight into the needs and health actions of their clients and patients. The consumer research advisory group had made a number of recommendations for dissemination of the findings within the study population (see appendix 23).

Learning for future research with African Caribbean communities

My development as a researcher commenced early on in the conduct of this research, with a consideration of my own ethnic identity, reflection on the development of my personal values and beliefs, and my own socialisation as a person of dual ethnic origin in England. This initial reflection proved to be crucial in deepening my understanding of how my self-identity is constructed, becoming sensitive to my interaction with the study population and, most significantly, recognising the influence of myself as a human instrument on the research processes (Fetterman 1998). Moreover, recognising the situational nature of my own ethnicity (Jenkins 1997) and the contextually-bound multiple identities that I hold, I was able to establish both the extent of my commonality with the study participants, and in which particular domains my own experience and understandings diverged from those of the participants. Self-awareness and self-knowledge provide the starting point for development of culturally sensitive practice (Andrews 2002, Camphina-Bacote 2002, Giger 2002, Purnell 2002). These reflections led to the recognition that via primary and secondary socialisation processes I had internalised 'eurocentric' perspectives as a person of dual ethnic origin living in England. This was very difficult to acknowledge, especially as the ethnographer's concern is to avoid the imposition of ethnocentric perspectives (Spradley 1979, Hammersley & Atkinson 1995, Fetterman 1998), but it was an essential dimension of the reflexive component of this research.

Although as a black person and member of a minority ethnic group I share commonality with the study participants, I had assumed that I knew much more about the study population that I actually did. My false sense of reality arose from residence in an ethnically mixed geographical location during my early years. I assumed I was familiar with people of African Caribbean origin and the cultures and traditions of African Caribbean people. As the research progressed, I was surprised to discover how little I actually knew about the study population.

Towards the end of the research I became more confident in the knowledge I held about the study population, having by then been immersed in the culture for three years. Recently I have spent time in the Caribbean, and some time in the home of a Caribbean family with exposure to the social norms and traditions of the family. I realise that my knowledge of African Caribbean people, the culture, tradition and life-ways is quite narrowly defined by the phenomena of hypertension and the associated dimensions of PHC. The knowledge I hold is a snapshot of a given phenomena at a particular time and place. The experience is analogous to looking at an interesting and richly decorated room through a keyhole; what I can see through the keyhole is very interesting but, frustratingly, I know that there is much more to see in the room and I cannot see the whole room. I could only see the whole room if I were a person of African Caribbean origin.

My rejection of a culturally essentialist approach to health care and research, as exemplified in the work of Leininger (1985, 1991, 1995), is not simply a result of a critical review and analysis of the literature during the progression of the research. In the spring of 2001 I attended a post-masters programme of Transcultural Nursing Research at the University of Nebraska facilitated by Dr. Leininger. This enabled me to gain first-hand knowledge and understanding from the theorist. My motivation for attending the programme was fuelled by my own cognitive dissonance regarding the recognition of the huge popularity of the Sunrise Model (Leininger 1991) in North America, and the widespread critique of this approach in Europe (Culley 2001) and Australasia (Swenson & Windsor 1995). I concluded that Dr. Leininger had made a seminal and significant contribution to the development of transcultural care, but that the approach has limited relevance for contemporary pluralistic societies, and lacks an appropriate recognition of the wider structural issues which are the subject of ongoing sociological discourse (Mac an Ghaill 1999, Anthias & Lloyd 2001, and Nazroo 2002a & b). My rejection of the culturally essentialist approach is also supported by my own personal biography as a member of a multi-faith, multi-ethnic family. The notion of cultural essentialism bears no resemblance to my lived experience.

Learning for future research work is derived from the reflexive dimensions of the research and the written reflective narrative maintained through out the research. The major challenges in conducting research with African Caribbean communities are in engaging the community and participants (Anderson 1993), gaining the trust of the community (Afshar & Maynard 2000), establishing credibility as a researcher (Higginbottom & Serrant-Green 2003), respecting the cultural norms and values of the group (Lipson 1994) and dealing with disclosures during the research.

Membership of an ethnic minority group does not necessarily confer advantage when conducting research with ethnic minority communities. Differences may exist between the researcher and participants that create 'distance' which somehow needs to bridged, as was the case in this study (Rehman & Walker 1995). In this research this distance was bridged by establishing relationships with potential participants that enabled my personal credibility and integrity to be assessed. (I have no doubt that 'word of mouth' within the community was also important.) Differences between the researcher and participants are likely to arise from socio-economic influences such as education, income, professional socialisation, speech and appearance, even if they share ethnicity. The difficulties of 'black' researchers researching the lives of 'black' communities are recognised (Serrant-Green 2002, Higginbottom & Serrant-Green 2003), although the term 'black' is not especially helpful in aiding understanding of ethnicity and culture. It a truism that debates in this arena are at an embryonic stage.

In this research participants did make assumptions about my identity and ethnicity, although I was careful to provide a brief account of my personal biography when engaging with potential participants. The trust of participants needs to be gained and credibility established with them. In this research, this often happened at the first meeting with potential participants, in the form of a 'checking out' process of questions, and my provision of the correct answers, which at times felt like a cross-examination of my personal motives and integrity.

The fears of potential participants in relation to potential negative stereotyping and racialisation of research findings are well founded (Higginbotom & Serrant-Green 2003). I was surprised to find that although I considered myself able to understand patois within a social context (although I am not a patois speaker), my understanding of it was not sufficient for the purposes of the research project and required the skills of a patois speaking co-moderator and interpreter. I had not considered this dimension at the outset, although it seems obvious now, because my previous research projects within the African Caribbean community had been with younger people. Once engaged, the participants in this study appeared highly interested in the research, as is evidenced in the low withdrawal rate from the study once consent had been obtained. In this respect it is evident that the participants perceived some benefit from the study for other African Caribbean people with hypertension, if not for themselves.

Research fatigue is said to be an issue for some ethnic minority communities (Andersen 1993, Afshar & Maynard 2000). This does not seem to be the case in the African Caribbean community, particularly on this topic where so little research has been conducted. This of course does lead to questions as to why little research has been conducted on what is a major health issue for African Caribbean communities in the UK. In this respect the marginalisation that African Caribbean people experience in the research agenda is reflective of other areas of life.

Research with African Caribbean communities requires sensitivity to the wider structural and societal issues that shape and define the life experience of African Caribbean people in the UK (Fryer 1992, Kushnick 1998, Macpherson 1999). As I have stated, researcher membership of an ethnic minority group does not necessarily confer advantage, but it is clear from the data in this research that some of the participants shared with me specific issues in relation to racism and discrimination that they might not necessarily have articulated to a white researcher. Specific skills are required in researching the lives of African Caribbean communities; respect for cultural norms is paramount. In the case of African Caribbean communities, one example is the manifestation of the tradition of offering food and refreshments as a welcoming gesture and the significance of food as a vehicle for acceptance of a stranger. This means that in the conduct of an FGI the lack of provision of food and refreshments is unthinkable, as it would cause offence.

The notion of culturally congruent research practice has not yet emerged in research language or permeated research-training programmes.