THE SOCIAL CONTEXT OF HEALTH CARE FOR MINORITY ETHNIC GROUPS DIAGNOSED AS HAVING SICKLE CELL CONDITIONS

A thesis presented to the
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of the
University of London
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for the degree of
Doctor of Philosophy

Institute of Education,
University of London,
November, 1993

Abstract

Health care needs are socially defined and care provision is dependent on these definitions. There is generally poor consideration of the needs of people with genetically determined conditions, especially when they are perceived to be rare. In Britain, sickle cell conditions mainly affect people of African and Caribbean ancestry. Sickle cell is considered to be rare by many health professionals despite the fact that 1 in 10 people from these ethnic groups carry the gene, and that each year more than 200 babies are born with serious sickle cell states in London alone.

This study was conducted in two parts. Part 1 examines how much people who with one or more sickle cell genes know about the conditions. It investigates their experiences of and perceived need for health care and their attitudes regarding self-care. The study also examines whether clients have received genetic and other counselling, understood the information provided and whether they were encouraged to use positive health strategies to avoid ill health.

Part 2 examines how the socialisation and education of nurses and health visitors may have affected their knowledge of sickle cell conditions. It assesses their experience of caring for people with the conditions and the contributions they could make to patient/client care. Statutory and voluntary sickle cell counsellors were also interviewed regarding the service they provided, their satisfaction with that service and their perceived needs for improving such services.

The socialisation of individuals is discussed to show how the different racial groups (ie. largely carers versus clients) involved in the study, develop perceptions of each other, and how this could contribute to misconceptions on both sides as well as to the overall health problems of people with sickle cell conditions. Social environments (ie. housing, employment, education, racism and so on) are also discussed.

LIST OF TABLES

I would like to acknowledge the following for their encouragement, patience and advice:

The clients and health carers who took part in this research,
Ann Oakley, my supervisor,
My family,

Thank you all.

INTRODUCTION TO THE RESEARCH

Twenty-nine years ago, I was diagnosed as having sickle cell anaemia (HbSS), after having a series of crises that left me close to death and hospitalised for five months. As I lay unconscious in a South American hospital, I heard the doctor tell my father that I needed an urgent blood transfusion - our blood was compatible. The doctor added that there was every chance that I would not survive the night.

I listened with horror to the pronouncement of my impending death, and quickly made the decision that I had no intention of dying. Five months later, I was given a year to live. Living by instalments became commonplace, until after I reached my 21st birthday, by which time one mischievous doctor, (who used me as a guinea-pig for flummoxing medical students in London's Hospital for Tropical Diseases), proclaimed that I would probably live till I was eighty. Most likely I will prove him wrong too, although I am now more than half-way there. It is possible - I know of one man who, on his sudden death, aged 77 years, was on *post mortem*, found to have suffered his first known sickle cell crisis. He had HbSS. It was at this time, that the use of new sophisticated diagnostic techniques showed that I didn't have HbSS, but rather the 'less serious' SC haemoglobinopathy. My only thought on hearing this, was that it was serious enough the night I nearly died.

Since those days, I had always been curious about my 'illness'. For a long time, I thought it was unique to me,

because I had grown up not knowing anyone else with 'it'. I was curious, because doctors often told me things I could or could not do, and I delighted in doing precisely what I was advised not to, largely ignoring what they suggested I should. Predictions of how long I would live, and other dubious advice served only to make me determined to prove 'them' wrong. However, listening to 'learned' people talk about my dying, having friends and family treat me as though I was no longer valid, (though still loved), affected me more than I realised. This was manifested by my loss of interest in academic work. After all, why bother if you are going to die? It was only after I reached my twenty-ninth birthday, that I returned to my studies.

I coped reasonably well with my 'illness', and have not had a major crisis since I was fifteen. However, most of my coping came from developing an appreciation of what I really could or could not do, quickly learnt from experiences of feeling unwell if I overdid things. I was fortunate in that I had these experiences. Some people are not so lucky, and crises can develop without warning. I was also fortunate in that I was born to a middle-class family, who were able to keep me supplied with the latest American developments in medical care, for haemoglobinopathies.

Eventually I began to meet other people with sickle cell conditions, as I call them, and listened with some horror at the kinds of advice they were given. Professional advice ranged from forbidding aircraft travel and visiting certain tropical countries, through how long an individual might live

to whether an individual could/should have children. All exercise was also forbidden for some people. None of this advice was correct. Travel in pressurised aircraft (and all commercial aircraft are pressurised) is not problematic. Visiting tropical countries where malaria is endemic is possible with adequate supplies of anti-malarial drugs. With regard to the other two pieces of advice mentioned, that depends on the individual, as it does with any individual.

I stress here, that these are the personal experiences of a few people. This kind of advice, often given from childhood indirectly via parents, and later directly as we grow older, can seriously compromise our abilities to cope with the conditions, which can have repercussions for the quality of our future lives. However, given the current state of medical and nursing education about sickle cell conditions, it would not be surprising to learn that these types of unhelpful advice are quite widespread.

This, then is the background which focused my attention on a piece of research which looked at the client's perspective to living with sickle cell conditions in Britain. My focus of health care is for empowerment of individuals with haemoglobinopathies, by the provision of accurate information, health promotion which encourages positive attitudes to life, the protection of self-esteem, and the placing of the possibility of death in perspective. As a result, In 1986, I collected the data for the nursing part of the study. This was followed by client's data collection in 1988-1989.

CHAPTER 1. Health Care and Sickle Cell Conditions

1.0 Introduction

This thesis investigates the knowledge and attitudes of primary health care professionals and users towards sickle cell conditions which affect the health status of certain minority ethnic groups living in the United Kingdom. It draws on theoretical and empirical work in the sociology of health and illness regarding the education and training of nursing professionals, the status and function of health care screening programmes, and the social context within which health services are provided to social minority groups.

Against this background of research and policy debate, the thesis describes an empirical study of nursing professionals which explores their knowledge and experiences of sickle cell conditions, as well as the knowledge and health care experiences of people with the conditions. For the purposes of this work, the expression 'minority ethnic group' will refer specifically to those people for whom sickle cell conditions are a problem. When used generally, the term will refer to people who are 'racially' and culturally distinct from white people of British ancestry. This latter group, will be described as 'white British or white Britons'. This is not intended to ignore those people who are white, but whose ancestors are not British. In the same way, 'sickle cell conditions' and 'sickle cell states' will be used instead of the usual 'sickle cell disease' or 'sickle cell disorders' which many relatively fit participants in this research

objected to. They argued most eloquently as did others in the study that they were not 'diseased' or 'disordered', but rather simply had 'something which made them ill sometimes'. They also argued that other conditions such as cystic fibrosis, thalassaemia and haemophilia did not have 'disease' or 'disorder' attached to them, and some felt stigmatised by these words.

In this thesis, knowledge is defined as having an understanding of nursing or self care which enables the individual to cope with having a sickle cell condition. It includes the recognition of environments which are harmful to the client, the recognition of signs and symptoms of impending and actual crises, described later in this chapter, how sickle cell genes are transmitted and rates of transmission. Finally, basic health promotion strategies to avoid precipitating crises and medical 'facts' about sickle cell conditions are seen as necessary components of knowledge.

The research seeks to provide material which will help nursing and other professionals to understand and care for people with the conditions, so that they may tailor the service they provide to client needs. It also emphasises individuals' needs for information which would help them to avoid illness in themselves or their families wherever possible, and be knowledgeable about family choices and appropriate methods of family planning.

Abnormal haemoglobins, of which sickle cell conditions are an important group, largely affect people whose ancestors

live/lived in areas where malaria is endemic. These people, in countries like Britain, largely constitute minority ethnic groups. For many years, abnormal haemoglobins were (and still are in some quarters), seen by British health professionals as rare illnesses which do not affect significant numbers of people. However, these conditions, discussed elsewhere in this chapter, are very common amongst many minority ethnic groups and therefore are important health concerns to them.

Within recent years, health professionals have come to realise the impact that sickle cell conditions have on the communities they affect, and began screening programmes so that affected families may be identified. Health professionals generally accept that two of the most clearly recognised objectives of screening are:-

a) to assist families to avoid having affected children if they so wish, and

b) to assist families and individuals who are so affected, to explore the best methods of attaining and retaining optimal health.

In Britain, community and hospital based nurses are important members of health care teams providing the health requirements dictated by screening objectives. In the World Health Organisation's declaration at Alma-Ata, primary health care is defined as:

> " Essential Health Care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the

> community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self -determination." (WHO, 1978: 7).

Nursing roles must also be seen within the context of a more recent report which states that 'Health science and technology have come to a point where their contribution to the further improvement of health standards can make a real impact only if the people themselves become full partners in health protection and promotion' (WHO, 1984). The Royal College of Nursing's Standards of Care programme suggests that there should be client participation 'in the assessment of health needs, and in the planning, implementing and evaluation of programmes of health promotion and health care', for both individuals and communities (RCN, 1989: 12). Individuals' integrity in making health decisions and their abilities to perform on their own behalf should take precedence over professional values (Levin, et. al., 1977). The main criteria for measurement of care becomes what the individual sees as relevant, rather than professional evaluations of effectiveness.

In times of serious illness many people with sickle cell conditions are rushed to hospital, some on the point of death, for emergency, life-saving care. Hospital based nurses therefore have a major role to play in returning sick people in hospitals to comparative good health and preparing them for their return to the community. Community based nurses strive to help them to maintain optimal health by promoting positive health strategies.

Only a few health districts in Britain appear to have provided screening and counselling services for people with sickle cell conditions. Identification of affected individuals, families and/or populations and positive counselling strategies, ie. which include the cultural/religious and other needs of individuals and families, are the opposite sides of the screening 'penny'. In other words, there should not be one without the other. Nursing has long recognised the importance of holistic care (Labun, 1988). Cultural and religious tolerance and understanding may encourage clients to express their anxieties and fears, reducing their feelings of isolation, powerlessness, hopelessness, and anger (Soeken and Carson, 1987). This is particularly important for clients who have chronic, disabling conditions. Racism which leads to intolerance, stems indirectly from institutions, but discrimination occurs directly in dealing with people from different cultures and races (Hancock and Sutherland, 1986).

In addition, the provision of clear information about the conditions, their mode and rates of transmission, and ways of avoiding ill-health, are all necessary to help people with the conditions to have effective strategies for improving their health and their chances of having a 'sickle cell illness' free family. These components make up part of the 'scientific and socio-cultural knowledge' which health professionals and people with the conditions need. Individual experiences and perceptions make up the rest of that knowledge.

This study also investigates the knowledge, experiences and perceived needs of people diagnosed as having sickle cell (sc)

genes, ie. people who either have an illness causing condition, or those who have sc trait (carriers for the gene). In addition, the knowledge and experience of hospital nurses and community health visitors regarding sickle cell conditions is examined. Available sickle cell counsellors were also interviewed, so that their perceptions of their work, needs and role as carers could be explored.

This research was designed to test a number of hypotheses. These covered relationships between health services and the health care needs of minority ethnic populations and the experiences, attitudes and behaviour of both health professionals and people with sickling conditions. Specifically, the hypotheses were:

1. That health districts which have large minority ethnic populations provide relatively good screening and counselling services. In other words, they provide screening and counselling services which provide people with relevant information about screening and the conditions (before and after screening as appropriate), health education information and advice, have protocols for treating people who arrive as emergency cases to Casualty Departments, and refer to or inform clients of appropriate community care services including the voluntary sector. These districts are described as having comprehensive packages of care (CPC),
2. By virtue of having comprehensive services, people with sickle cell conditions from these health districts will have greater knowledge than their counterparts in other

districts which do not have comprehensive packages of care (NCPC),

3. People with sickle cell conditions in CPC districts will have ease of access to health care, because of the district's recognised need for the care packages they provide,
4. People with sickle cell conditions will have greater knowledge of them, than those with sickle cell trait because of the former's greater need for knowledge about the way the conditions affect them as individuals. People with sickle cell trait rarely have symptoms of sickle cell conditions,
5. People who have experienced serious illness will have greater knowledge than those who were never ill, as their personal experiences of illness will reinforce what they know about the conditions,
6. People who were diagnosed in childhood will have greater knowledge than those who were diagnosed as adults, as they will have had a longer period of time to learn about and absorb information about the conditions,
7. People who were diagnosed in childhood will be more aware of the strategies they could use to avoid the types of situations which will increase their susceptibility to becoming ill, for example doing physical education outdoors in the cooler months,
8. Perceptions by clients of uncaring attitudes from care staff if present, will be accompanied by perceptions of poor health care as negative attitudes from care givers may lead to negative responses from care recipients. Uncaring attitudes by care staff may be manifested by

unacceptably long delays in carrying out simple requests, such as bringing bedpans to people confined to bed-rest, or the perceived effort not to touch individuals, for example when giving medication, pills are left on the bedside locker, or 'dropped into the hand',

9. People who are unemployed and live in poor housing will have more sickle cell crises, defined in section 1.1.6, than those who are employed and live in better housing. Poverty does not allow people to have as healthy a lifestyle as they could if they were able to afford it. Furthermore, cold, damp housing can increase the individual's capacity for developing respiratory illness. These combined exacerbate the effects of sickle cell conditions,

10. By virtue of their longer period of education, with its wider knowledge base which includes genetic conditions and health education, health visitors will have greater knowledge of sickling conditions than hospital based nursing staff. (Health visitors first go through basic nurse education, then undergo a further 18 months of midwifery training. Most practise nursing care for at least two years before undertaking training as a health visitor),

11. Nurses and health visitors who have cared for people with sickle cell conditions will have greater knowledge of these conditions than those who have had no such experience, as they are expected to be knowledgeable about the care which they provide,

12. Nurses and health visitors in CPC districts will have greater knowledge than their counterparts in other health

districts as having a CPC package includes in-service training about sickle cell conditions for care staff.

1.1 Haemoglobin and sickle cell conditions (states)

Sickle cell conditions/sickle cell states are important health concerns to the groups they affect because they are common, genetic in origin, and therefore hereditary, can be lethal, and may lead to severe complications, such as blindness, deafness, strokes and kidney problems. Carriers for sickle cell genes often are unaware of this because they are generally fit and well, and may not be aware of their carrier status. In order to understand just how important these conditions are, a description is given below, beginning with how normal haemoglobin works, and going on to sickle cell conditions/states.

Haemoglobin (Hb) is the oxygen-carrying pigment of red blood cells which exchanges carbon dioxide picked up in tissue capillaries for oxygen in the lungs. Each red blood cell contains millions of Hb molecules and each molecule has two polypeptide chains (Alpha and Beta chains in adults), made up of various amino acids linked together in different sequences. Haemoglobin is really a mixture of haemoglobins, the predominant form in adults being HbA, which makes up about 90% of the total. A similar component, HbA_2, accounts for about 2.5% and the majority of the balance, sometimes called HbA_3, probably consists mostly of HbA that has become altered as a result of synthesis. Fetal haemoglobin (HbF) is the predominant form during fetal development. At birth, synthesis

of HbF is shut off or at least suppressed to a very low level. By the age of about six months, the level of HbF should be less than 1%, remaining so throughout adulthood. Each polypeptide chain is represented twice in the individual so normal adults are described as having HbAA. Fetuses have HbFF.

1.1.1 Haemoglobinopathies

The abnormal haemoglobins (or haemoglobinopathies) are conveniently classified into two main groups. In the first group, one or more amino acids on the polypeptide chains which make up haemoglobin are altered, giving rise to an abnormal haemoglobin. More than one hundred of these haemoglobins have been described. The commonest, and best known, is that of sickle cell haemoglobin (HbS). Another very common one is known as HbC. Both the S and C mutations occur on the 11th chromosome, each involving a substitution of the sixth amino acid on the Beta chain.

In the second group, there are deficiencies in the formation of normal haemoglobin and these constitute the thalassaemias. One way of differentiating the two types of haemoglobinopathies is to think of the first type having a deficiency in the quality of the haemoglobin, whilst the second type has a deficiency in the quantity of haemoglobin.

1.1.2 Distribution of sickle cell genes

The terms sickle cell conditions and sickle cell states are used to include all haematologic conditions in which sickle

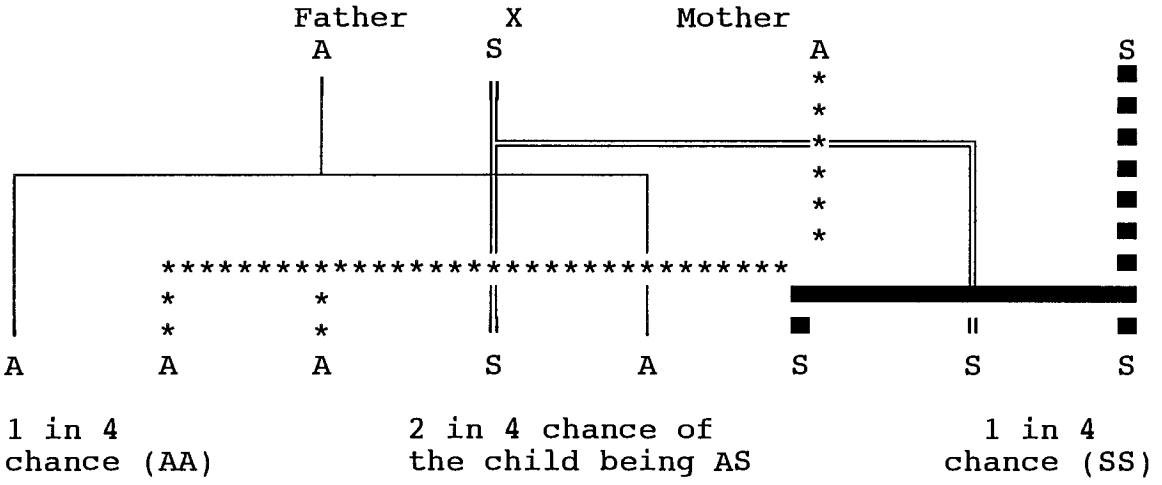
cell haemoglobin (Hb S) is present. This includes sickle beta-thalassaemia, that is, the condition in which sickle cell haemoglobin is partnered by thalassaemia haemoglobin.

Sickle cell (and other abnormal haemoglobin) genes are found in a large geographic area which includes Africa, Asia, the Caribbean, the Mediterranean region, the Middle East and South America. Sickle cell conditions are prevalent in areas where malaria is endemic. Sickle cell, thalassaemia and other abnormal haemoglobin genes are thus most common to descendants of people who originate in these areas. In Britain, this includes black Britons, British Asians, the Chinese, Arabs, white people of Mediterranean extraction and immigrants from those countries where malaria is endemic.

1.1.3 Transmission of sickle cell genes

Sickle cell haemoglobin (and beta-thalassaemia) is transmitted through generations in a regular Mendelian inheritance (Neel, 1949). In order for a child to inherit sickle cell anaemia, (s)he must inherit the sickle cell gene from both parents. These individuals who have two 'doses' of the gene are also described as homozygotes. Carriers for the gene (ie. they each have one 'dose') are said to be heterozygotes. Figure 1.1.3 shows how transmission occurs and the probability of a child inheriting three different haemoglobin combinations. The couple in figure 1.1.3 (both heterozygotes) have a 25% chance of producing a child with normal haemoglobin, a 50 % chance of having a child who is a carrier like either parent and a 25% chance of having a child with sickle cell anaemia (sca).

Figure 1.1.3. Transmission of normal (A) and sickle cell genes (S) from parents who are carriers.



If one parent has trait (ie carrier status), and the other has no sickle cell genes, the couple's children would have a 50% chance of being like either of their parents. If on the other hand, one parent has sickle cell anaemia (ie. Hb SS) and the other has normal haemoglobin, all of the children will be carriers for the sickle cell gene. In terms of inheriting one of the conditions, if both parents are carriers for the sickle gene, each child they produce, has a 25% chance of inheriting sickle cell anaemia; if one parent has sickle cell anaemia and the other carries the sickle gene, each child born to them has a 50% chance of inheriting sickle cell anaemia; if both parents have sickle cell anaemia, all of the children they produce will inherit sickle cell anaemia.

Other abnormal HbS (for example, Hb C and beta-thalassaemia) are transmitted in the same way shown above, and the genes responsible can be substituted for any of the genes in the figure above, to work out transmission rates for any given family.

1.1.4 Sickle cell conditions

Sickle cell anaemia is the most severe of the sickle cell conditions, generally giving rise to severe anaemia. This condition may be lethal. People who are homozygous for abnormal C haemoglobin genes have a mild type of anaemia. Those who are carriers for both the S and C haemoglobins, present with a form of anaemia intermediate between sickle cell anaemia and the mild type, although some or all of the more severe symptoms of sickle cell anaemia can be displayed. Sickle cell beta thalassaemia (sickle B^{thal}) is more complicated. In some types of beta-thalassaemia (B^{thal+}) some normal 'A' haemoglobin is produced. Symptoms for sickle B^{thal+} are similar to sickle cell haemoglobin C in effect. However when the subtype of beta-thalassaemia is one in which no normal haemoglobin is produced (sickle B^{thal-}), the full effects of severe sickle cell anaemia may be seen.

Sickle cell states are manifested in many different ways. Some people may be very ill for long periods of their lives whilst others appear to be relatively symptomless. The severity of symptoms not only varies with the type of sickling condition, but with socio-economic and environmental factors as well (Mann, 1981). People with sickle cell anaemia, for example, are more likely to have severe symptoms, but it is not unknown for people in this group to be comparatively symptom free. On the other hand, while people with intermediate and milder forms generally present a milder clinical course, some can and do have exhibit many of the more severe symptoms.

Symptoms, for those who have them, are also variable in their manifestation. They may range from failure to thrive as an infant, with or without recurrent infections some of which may be quite severe, to crises, that is episodes of intense pain caused by sickled cells agglutinating and obstructing the blood vessels (Serjeant, 1985).

Sickle cell crises, usually in the abdomen, chest, arms or legs, are generally accompanied by a fever and their effects may be severe enough to cause death. Crises occur at variable intervals and factors which precipitate them include hypoxia, dehydration, infection, sudden temperature changes (for example, cold weather affects the number of crises an individual has), trauma, strenuous physical exertion, extreme fatigue and emotional stress (Serjeant, 1985).

In addition people with a sickling condition are more susceptible to infections than their 'normal' brothers and sisters. External and internal inadequacies, for example damp, cold housing or poor diet will increase the risk of infections, which in turn will increase the potential for having crises (Mann, 1981). Other signs and symptoms include anorexia, swollen joints (eg. dactylitis) and jaundice, as well as the usual signs of megaloblastic and iron deficiency anaemias.

Children with sickle cell anaemia can expect to have a delayed puberty, and may be shorter, thinner and weigh less than their unaffected peers (McCormack et al. 1976). They may have a decreased life span during which they will have high

susceptibility to infections such as pneumococcal septicaemia. There is no cure for sickle cell conditions at present and treatment is generally of the symptoms.

Pregnant women with sickle cell conditions have different needs from other pregnant women in order to minimise problems at the birth of the baby (Tuck, 1985; Anderson, 1972; Miller et al, 1981). It is often necessary for these women to be monitored at frequent intervals (in some cases fortnightly), and they may need regular blood transfusions throughout pregnancy (pers. comm. Wonke, 1987).

Complications of sickle cell conditions include retinopathy, (more prevalent amongst those with sickle cell and C haemoglobin), osteoporosis, degeneration of kidney function, cerebrovascular accidents and fibrosis of the spleen (Rabb, 1973; Serjeant, 1974).

The effects of haemoglobinopathies on the individual are similar to those of any other disturbing chronic condition. For example, frequent illnesses/hospitalisation of the child affects his/her performance at school, on a scholastic, social and psychological level. This will obviously have implications for that individual's future chances in terms of self-esteem, employment and general prospects.

The early diagnosis of sickle cell conditions improves the chances for effective management, the individual being more likely to survive with adequate nutrition, prompt treatment of infection (Trowell et al, 1957; Serjeant, pers.comm) and

education for health.

1.1.5 Sickle cell trait

In malarial environments, carriers of sickle cell genes have a selective advantage over those with completely normal or completely abnormal haemoglobins (Alison, 1954; Beutler et al, 1955; Rucknagel & Neel, 1961). This suggests that carriers for the gene have an in-built resistance to malaria. However, malaria can be fatal if it is contracted either by people who have a sickle cell condition or by those who do not have any abnormal haemoglobins. The same protective element appears to be true for other abnormal haemoglobins.

Under normal conditions, carriers of the gene do not generally have symptoms and may never be identified as such, other than by routine blood testing. However, there are certain circumstances in which people with sickle cell trait or a mild form of the conditions are at risk from developing serious illness. These include strenuous exercise combined with high altitude and being anaesthetized for major surgery. Several cases of sudden death occurred in the United States Army and elsewhere, when undiagnosed carriers undertook strenuous exercise in rarefied atmospheres (Ewing, 1974; Jones et al., 1970). In addition, when people with sickle cell genes require major surgery, regardless of whether they have trait or one of the conditions, it is generally necessary for them to receive additional oxygen to avoid the development of crises.

1.1.6 Prevalence

The sickle cell gene is carried by 1 in 10 black people of Caribbean origin (Sutton, 1980). Sickle cell conditions occur in 1:200 people of West Indian origin and 1:100 people of African origin born in Britain (Prashar et al, 1985). This suggests that the 1:10 carrier figure is an underestimate as with these figures and using statistical inference 1:100 black families should be affected. With a transmission rate of 1:4, only 1:400 babies should be born with the conditions. Furthermore, the conditions are not exclusive to black people of Caribbean or African origin (Greenwald & Burrett, 1940; Livingstone, 1967; Serjeant, 1974; Al-Awamy et al, 1984).

There are approximately 6,000 known cases of sickle cell states in Britain (Brozovic, haemoglobinopathy hospital consultant, 1993, pers. comm). This figure is believed to be an underestimate as even if the figure of 1:400 affected births is used, based on population data and the prevalence of the sickle cell gene, it appears that many affected people remain unidentified (Anionwu et al, 1981, DHSS, 1988). Sickle cell conditions are more prevalent among the genetic host (that is, the African and Caribbean) populations, (500:100,000) than is phenylketonuria (10-12:100,000; Lindsay, 1984), hypothyroidism (20:100,000; op cit.), and cystic fibrosis (62-3:100,000; pers.comm. Cystic Fibrosis Society), in the white British population.

In Britain, immigrants from African and Caribbean countries have settled in varying concentrations, mainly in cities

throughout the country (discussed in 2.5.3). Sickle cell conditions are therefore widely distributed throughout England and Wales, though high concentrations are found only in a few areas (Davis et al, 1981).

1.2 Services for sickle cell conditions

A study undertaken by the Runnymede Trust in 1984 identified the services that were provided for sickling conditions within the National Health Service (Prashar et al, 1985). The researchers were particularly interested in screening for sickle cell, provision of leaflets, counselling practices and provision of in-service training.

They found that very few health districts had a policy for caring for those with sickle cell states. The report pointed out that one district, with an minority ethnic population of over thirty per cent, appeared to keep no statistics on clients with sickle cell conditions, had no specialist counsellors, clinics or centres and had to refer clients to another district for specialist care and counselling. Although more districts now provide services for sickle cell conditions, provision is still seen to be inadequate (DHSS, 1993).

The Runnymede Trust report pointed out that the majority of the Regional Health Authorities which took part in the study, said that the questionnaire was 'inappropriate for the region'. In other words, sickle cell conditions were not seen to be a 'problem' for these Authorities, which presumably did

not perceive themselves as having appreciable minority ethnic populations, or alternatively did not recognise the importance of the conditions to these populations.

The report showed that in general, provision of care and information for those with sickle cell conditions is left to individual districts and even hospitals. Prashar and her co-workers (1985) conclude that as a result of this few districts kept any statistics on haemoglobinopathies. They argue that this may have been accompanied by an assumption that sickle cell conditions are not a problem in those districts. This combination could then be seen as an adequate reason for not providing appropriate facilities for the treatment of these conditions.

The Runnymede Trust Report further argues that, despite the growth in numbers of persons now recognised as having sickle cell conditions, general nursing and medical personnel still appear to be giving low priority to the needs of these individuals. Prashar and her co-workers assert that there may be insufficient training given on haemoglobinopathies to either student or qualified medical or nursing personnel. They suggest that this may be due to the lack of agreed policies or guidelines regarding either clinical management or primary care aspects for sickle cell conditions. The points made in the Runnymede Trust report were found to be still largely valid in 1993, and recommendations have been made for improvements to sickle cell services (DHSS, 1993).

1.2.1 Provision of care

Prashar et al (1985) showed that of 76 health districts with an minority ethnic population greater than three per cent, 30 of which have an minority ethnic population of over 10%, only 6 had a comprehensive health care policy for people with sickle cell conditions. They suggest that a comprehensive package of care (CPC) should be organised on two levels: 1. Hospital provision, and 2. The Sickle Cell Centre.

1.2.2 Hospital provision

Hospital provision covers in- and out-patient care. Although the available evidence shows that National Health Service provision for those with sickling is poor, in- and out-patient services are generally provided. Recommendations by the Runnymede Report for in-patient care only address the clinical aspects of the condition. The Report advises of the need for firm guidelines for pain control, rehydration policies and the use of antibiotics. It also states that doctors and nurses must be able to identify quickly the signs and symptoms of sickling crises. However, the nursing contribution that can be made in providing information, counselling, education and support to clients in hospital has been largely ignored in the report.

Furthermore, Prashar et. al. view the out-patient service largely as monitoring the physical growth status of children and the identification of developing complications in both children and adults. Although mention is made in the report of

emotional and educational needs of out-patients, no suggestions have been put forward by the authors, as to who should undertake the task of dealing with these problems seen in out-patients, or how.

1.2.3 The sickle cell centre

The Report's recommendation for the Sickle Cell Centre is that it would 'initiate, organise and co-ordinate' aspects of care which would include the following:

a) Antenatal counselling, prenatal diagnosis, screening of neonates, follow-up of affected babies,
b) Education and counselling of parents,
c) Advising on social, employment and educational matters,
d) Providing an information service for affected individuals and communities, health and other professionals,
e) In-service training for health staff and training of counsellors, and
f) Keeping a sickle cell register, that is a register of all affected individuals and carriers, so that emergency treatments of unconscious people who have travelled to areas where they are not known, can be facilitated.

In order to advise on social, educational and employment matters, the Runnymede report suggests the attachment of social workers to the centres. This seems to imply that each district should have a sickle cell centre which will carry out these tasks. However the report did not discuss how the centres should be set up or by whom, how they would be funded,

or how their effectiveness might be evaluated. The report also did not discuss the potential role of social services for improving health care of people with sickle cell conditions, for example, through housing policy.

1.3 Screening

Haemoglobin variants were maintained by malarial environments as people who were carriers for the genes were offered some degree of protection from the potentially lethal effects of malaria. Over a hundred variants have been identified (Rucknagel & Neel, 1961). In many countries worldwide, malaria was endemic until comparatively recently. It has not been eradicated in many tropical countries. However, colder countries were more fortunate as the cold effectively killed off the malaria vector (ie. the mosquito). Haemoglobinopathies therefore did not become a problem in these countries. That is not to say that they do not exist in some form in these areas, only that they are rare. In some parts of Britain, the incidence of the thalassaemia gene, (unrelated to recent migrations of people with the conditions to this country), is as much as 1:10,000 (The Thalassaemia Society, 1987; Weatherall, pers. comm., 1987). Elsewhere, in other northern climes, sickle cell conditions have been seen to affect white families where investigators have been unable to trace racial admixtures (Schneider et al, 1968; Greenwald and Burrett, 1940). These cases are believed to be extremely rare.

As indicated earlier, sickle cell conditions are more prevalent among the groups of people they affect, than

phenylketonuria and cystic fibrosis are among the general population. Yet, although some of the latter conditions are routinely screened for at birth, there seems to be no general strategy among health districts for sickle cell screening, which is dependent on policy at District Authority level. The theoretical benefits of population screening are:

1. To identify the prevalence of the gene in the population.
2. To educate parents and individuals enabling them to understand and cope with sickle cell conditions in the family.
3. To initiate programmes of preventive and palliative care to individuals and families.
4. To offer an informed choice of termination of pregnancies to families. This ought to be accompanied by appropriate counselling programmes.

Prenatal diagnosis using screening, obstetric and genetic counselling services, combined with well planned strategies to educate the public and health administrators about the conditions and why they should be prevented, help to reduce the incidence of sickle cell states (Weatherall et al, 1984). Haemoglobin electrophoresis which would identify whether individuals have sickle cell conditions or are simply carriers of an abnormal haemoglobin, costs only 15 pence per person (pers.comm. Sickle Cell Society). Babies in utero can be tested by:

1) Chorionic villi sampling at between 10-12 weeks

(Williamson et al, 1981; Weatherall et al, 1985),

2) Amniotic fluid sampling at 16-20 weeks (Kan & Dozy, 1978; Boehm, et al, 1983), and,

3) Fetal blood sampling, also at 16-20 weeks (Kan et al, 1972; Alter, 1981).

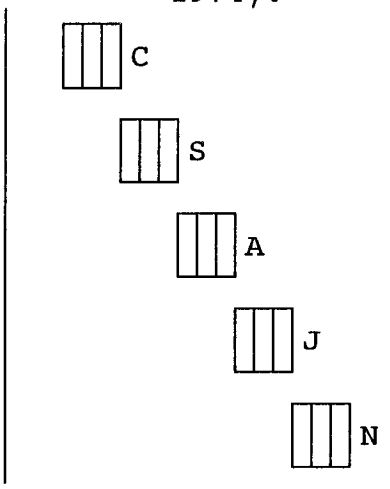
Sickle cell conditions are relatively easy to screen and results are clear and unambiguous (The amino acid substitutions for haemoglobins A, S, C and so on all have different overall electric charges so that they migrate at different rates (see figure 1.3)).

Qualitative tests, such as DNA testing and electrophoresis, produce clear-cut results, unlike quantitative tests like maternal screening alfa-fetoprotein (MSAFP) (Modell and Modell, 1992; Br. Soc. for Haematology, 1988). Studies of laboratory screening techniques, such as cellulose acetate and citrate agar electrophoresis have reported on overall sensitivity of between 93%-100% and a specificity of 95%-100% (Galacteros, et.al., 1980; Gardner and Keitt, 1988; Griffiths et.al., 1988; Githens, et.al., 1990).

1.3.1 Family planning services

After screening, family planning becomes very important for carriers of sickle cell genes. With particular marriages, children can be born with the most severe forms of the conditions. If two carriers for the sickle cell gene have a child, then that child and every subsequent child they produce has a 25% chance of having sickle cell anaemia (Figure 1.1.3).

Figure 1.3. Schematic representation of the relative electrophoretic mobilities of some abnormal haemoglobins (HbS) compared to HB A, on cellulose acetate (adapted from Serjeant, 1974).



To be diagnosed as a carrier for S haemoglobin, an individual has a band at the 'S' position and another at the 'A' position. Similarly to have sickle cell anaemia (ie Hb SS), the individual has bands only at the 'S' position. Hb SC individuals have a band at positions 'S' and 'C'. No abnormal genes are diagnosed when the individual only has bands at position 'A'.

The chances of transmission of sickle cell anaemia become higher if one parent is a carrier and the other has sickle cell anaemia. In this case, there is a 50% chance that each child will have anaemia (Figure 1.4).

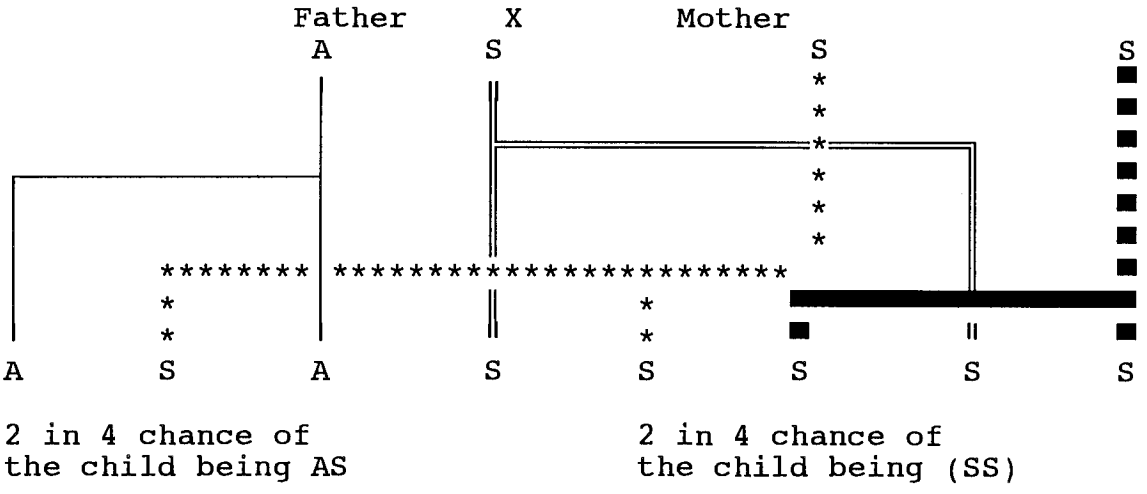


Figure 1.4 Transmission of normal (A) and sickle cell genes (S) if one parent has sca and the other is a carrier.

Therefore, genetic counselling is important not only for those with one of the sickling conditions, but also for those who are carriers for any abnormal haemoglobin, with the chances for passing on the genes and choices for family planning being clearly outlined.

1.4 Primary health care

Health education material (OSCAR and Sickle Cell Society leaflets) suggests that individuals with a sickle cell condition can improve their chances of being comparatively fit and well. In order to do this they need to be sufficiently knowledgeable regarding the effects and implications of having these conditions. Knowledge of sickle cell conditions for health care providers should include an understanding of simple Mendelian genetics, so that the patterns of inheritance could be explained to affected individuals or families. Furthermore, carers should be able to recognise signs and symptoms, understand the pathology of sickle cell crisis and appreciate the effects of crises on the client, so that care is tailored to individual needs.

Knowledge of the conditions also includes knowing what situations could be 'illness-precipitating' and how these can reasonably be minimised. Health promoting activities would help people to avoid environmental conditions and situations which could make them very ill, for example, extreme cold, dehydration, smoky atmospheres, excessive alcohol consumption, strenuous exercise and so on. It may be that these activities could to be a part of the health care package offered to

affected individuals and their families, and provided for under the health visitor's working objectives in the community.

1.5 Summary

Sickle cell conditions are common, important, medical problems in the minority ethnic community of Britain, especially for people of African and Caribbean backgrounds. They are genetically transmitted. Early diagnosis and a healthy lifestyle would contribute to minimising the effects of these conditions. Screening and health care services specifically for these conditions have been developed in an ad hoc and patchy manner, resulting in few facilities for genetic counselling and primary health care in particular.

The next two chapters outline the theoretical and empirical background to the research. Chapter 5 discusses methodological issues and chapters 6 to 13 present the findings of the research. In chapters 14 and 15, the various themes of the thesis are brought together, the conclusions of the research summarized and relevant policy implications outlined.

Chapter 2 - Health and Illness

2.1 Introduction

This chapter sketches the background themes in the literature to the empirical research. It includes sociological theories, and looks at the effects of particular social conditions, such as, unemployment, race and class on health. These factors are important to the study, as they have been implicated as being important to individual well-being. They contribute to the individual's internal and external well being, and this, as was discussed in the previous chapter, and later in this thesis, is important to the health of people with sickle cell conditions.

Health and illness are rather difficult concepts to define. Health as a concept has been given a variety of interpretations. It has been defined by the World Health Organisation (WHO) as a state of complete physical, mental and social well being and not merely the absence of disease or infirmity. However, people of different cultures define health in ways which give explanations of their 'material, social and bodily circumstances' (Stacey, 1988). Health definitions from different cultures concern the psychological and the physical, and include perceptions such as having energy and athleticism, ability to work hard, having a zest for life, not being ill, and being free from emotional and physical stress (Blaxter, 1983a; Cornwell, 1984; D'Houtaud and Field, 1986; Pill and Stott, 1986).

Illness generally refers to what may or may not be the symptoms of disease: pain, discomfort, disability and malaise (WHO, 1978). For lay people, the focus for the concept of illness is subjective. For example, many illness experiences are unaccompanied by obvious signs of disease, while other people may live with disease which has no discernible symptoms such as some types of benign tumours (Field, 1976). People may describe themselves as having illness when they see the doctor, but may have a 'disease' after consultation. Illness is something they have; disease is what their organs have (Cassell, 1976). Individuals have their own perceptions and understanding of the origin of their illness. Their attempts to find meaning regarding their illness and subsequent behaviour, for example what would be the best source of treatment, are shaped by their particular understandings (op.cit.). The same disease and/or symptoms may therefore be interpreted differently by members of different cultures, and their responses to their experiences may also be quite different.

Lay perceptions of the causation of illness include the effects of poverty, poor home and working environments, infection by 'germs' and viruses', genetic predisposition, psychological stresses and strains and 'moral fibre' (Blaxter, 1983a; 1983b; Cornwell, 1984; D'Houtaud and Field, 1986).

Definitions of health and illness vary between cultures, races, periods of time, between individuals and even in the same person at different times (for example, with individuals' socio-economic status, their ability to control their own

lives and those of their families (Stacey, 1988). Generally, prevention of ill health is seen as a matter of individual discipline and control, except in cases of certain types of infection (though while people could not help getting 'germs', they could minimise the risk by cleanliness), chronic or inherited illness (Blaxter, 1983a; Helman, 1981; 1986; D'Houtaud and Field, 1986).

Although people tend to talk about illness and health in ways which parallel that of the biomedical mode, their logical framework is more rooted in socio-economic models (Blaxter, 1983a; Cornwell, 1984). Some ethnic groups, both minority and majority, include symbolic, kinship, witchcraft/magical, and religious models of health and illness (Kleinman, 1986; Herzlich and Pierret, 1986; Lewis, 1986; Young, 1986).

2.2 The sick role

In 1951, Parsons defined health as a 'state of optimum capacity for an individual for the effective performance of the roles and tasks for which he has been socialised'. For Parsons, poor health was a form of deviant behaviour which needed social control, and which allowed individuals to be exempt from their usual obligations.

This Parsonian paradigm did not accommodate chronic illness such as the haemoglobinopathies. It was also shown that variations in the acceptance of Parsons expectations of the sick role, may occur by income, family size, religion, sex and age (Segall, 1976).

2.3 Doctor - patient relationships

In Parsons' paradigm, doctors, who controlled access to the sick role via sickness certification, behaved professionally at all times, using a high degree of technical expertise and knowledge when dealing with health problems. They remained objective and emotionally detached in order to maintain therapeutic leverage. The doctor-patient relationship as one in which both participants worked towards bringing the return of good health (Parsons, 1951). Clients were expected to comply with doctors' orders. This model of the doctor-patient relationship did not account for the possibility of the doctor being the passive member of a relationship, in which the client directed and the doctor co-operated (Friedson, 1970; Gallagher, 1976). This paradigm of the doctor-patient relationship supported the role of science as the dominant contributor to health care, with clients' perceptions of care, largely being ignored by the western medical model.

Stacey (1976) argued that this model bore little relation to social reality, as on consulting the doctor, clients call on the skills of many other people. She suggests that clients can not be wholly objectified, and therefore they are rarely passive recipients of care. Health care should therefore be thought of as a process of interaction between the minds and bodies of clients and carers (Stacey, 1976).

2.3.1 Nurse-patient relationships

There is very little available literature on nurse-patient

relationships. This largely neglected area, is of paramount importance as it is the nurse, who spends more time with the client, often in quite intimate situations. Oakley (1993a) described her own experience as the recipient of nursing care, after poor medical communication of a diagnostic prognosis left her feeling rather distressed. She described how by showing concern for her, and providing her with what information she could, a young nurse was able to provide her with a degree of comfort which contributed to her subsequent recovery. Oakley argued that focusing on the client's physical needs is not sufficient, and that care must involve the whole person.

A good working relationship based on effective communication, is therefore necessary. However, Seers (1989) has shown that nurses are not always appreciative of their clients needs, and often underestimated their requirements for analgesia. Furthermore, Bradley and Edinberg (1986) argue that nurses often label their clients placing them in 'good' and 'bad' categories, depending on whether they are:

> " unhappy with their treatment .. uncooperative .. unappreciative .. stubborn" (Bradley and Edinberg, 1986: 178).

or alternatively,

> " amusing .. optimistic .. cheerful .. grateful" (Bradley and Edinberg, 1986: 178-179).

The authors argue that this type of labelling may become

'self-fulfilling' , as nurses reinforce client behaviours by the responses they give, and can permeate the entire nursing staff in a unit/ward.

2.4 Poverty and health inequalities

It is evident that inequalities in health are correlated with and caused by poverty (Townsend & Davidson, 1986; Whitehead, 1987). These differences are manifest in perinatal, neonatal, infancy, childhood and adult mortality rates for different classes and racial groups, men and women of occupational class V are more likely to die before retirement age than their counterparts in occupational class 1 (Balajaran, 1991, OPCS, 1990; OPCS, 1991; OPCS, 1992). Furthermore, unemployed people in social classes IV and V also have raised mortality and morbidity rates (Moser et al., 1986; (Balajaran, 1991, Balajaran, et.al., 1991, OPCS, 1990; OPCS, 1992). Similar trends are seen with a lowering of income confirming the cycle of deprivation which affects those with small incomes (White, et.al., 1990; OPCS, 1992).

Data collected on chronic health problems have shown that the rate of these types of problems increase fairly consistently with a declining economic status. (OPCS, 1992; Hunt et al. 1985, Bucquet & Curtis, 1986, Blaxter, 1985). However, this is a very complex area as factors relating to poverty, social class, race and mortality are confounded with each other.

2.5 Race and poverty

Poverty is an important social and political problem. It is seen as the inability to provide material needs or comforts, and may be explained predominantly in terms of personal characteristics, or as structural features of industry or the state. It is defined, for the purposes of this work, as relative deprivation. That is to say, individuals, families and groups in the population lack the resources to obtain the types of diet, participate in the activities and have the living conditions and amenities which are encouraged in the societies to which they belong (Townsend, 1979). The experiences of minority ethnic groups have been such that poverty in the United Kingdom has come to be associated in some people's minds with minority status (Townsend, op. cit.). The major areas contributing to relative deprivation are those of employment, housing, education and health.

2.5.1 Race and employment

After the Second World War, Britain solved the problem of a depleted workforce by recruiting labour from dependent colonies. Emotive recruitment drives based on the theme 'Your Mother Country needs You' encouraged many workers in the British West Indies to come to Britain. These workers saw themselves as British, (having been encouraged by the 'mother country' to do so) and, as holders of British passports, having the right to live and work in Britain (Deakin, 1970). They therefore responded to the call, partly to improve their own economic situations, and partly to help the country seen

to be the driving force controlling their countries of birth and their destinies (op. cit.).

Black people settled in the larger British cities, where their labour was in demand (Runnymede, 1982). They were employed largely as unskilled or semi-skilled workers in jobs which were unpopular with the white British population. These jobs tended to be low paid, had difficult working environments and required that people did shift work and worked unsocial hours Runnymede, op.cit.; Unit for Manpower Studies, 1977; Smith, 1976). Black people are found in disproportionate numbers working within manufacturing industries such as car and shipbuilding production and food manufacturing. Within the service sector they are largely over represented in transport, hotels and the National Health Service.

Concentration of black people in the working classes has since been maintained by racial discrimination (Smith, 1977). Even when they have completed higher education, discrimination prevents them from competing equally with similarly qualified whites (Smith, op.cit.; Ballard and Holden, 1975).

The Race Relations Acts of 1968 and 1976 made it illegal for people to be discriminated against in a wide range of situations including employment, housing, education and health care. These Acts culminated in the creation of the Commission for Racial Equality (CRE) which has the power to deal with direct and indirect racial discrimination. The CRE encourages employers to adopt and make a commitment to a publicly stated Code of Practise which advocates equality of opportunities for

all. With the advent of equal opportunity policies being adopted by many employers, many jobs, for example in the administrative and clerical arena which has long been closed to black people (more so women than men) became more accessible. However, with computerisation and the increasing 'electronification' of offices, black people once again appear to be having difficulties retaining these posts, possibly as training programmes are not being made available to them (Bryan et al, 1986).

In addition racism continues to affect the employment prospects of black people. In one study,

> " Out of 317 applications for clerical officer grade jobs between June and November 1976, 110 came from minority candidates and 200 from whites. Yet only 10 of the former were offered jobs, compared with 78 whites. More minority than white candidates rejected for interview possessed the minimum educational qualifications" (Bowere and Franks, 1980: 10).

With the recession and higher unemployment rates, many young people today have never worked. Various Government schemes, such as the Youth Opportunities Programme (YOP) and the Youth Training Scheme (YTS) were created to assist young school-leavers to gain relevant experience which would improve their job prospects. These programmes were seen as being particularly useful to young black school-leavers, as they were more likely than any other of this age group to be unemployed (Runnymede, op. cit.). However, youth training programmes appear to have functioned mainly to create a source of cheap labour. Young black women are disproportionately represented on these courses in the lower categories. Category 'A' training, which provided practical training on employers'

premises, was reserved for unemployed youngsters who had achieved a particular academic standard and tended to exclude black school-leavers who often did not attain this standard (Bryan et. al., 1986).

Today, minorities from the New Commonwealth, particularly those of West Indian and Guyanese origin, continue to be over represented in the manual and working classes. They also experience very high unemployment (Fitzpatrick and Scambler, 1986; Skellington and Morris, 1993). Black people have to make twice as many applications as white peers to obtain work. Many take jobs for which they are overqualified (Runnymede, 1982). Furthermore, people from minority ethnic groups are less likely to be employed than members of the white British population except in cases of severe labour shortage. In times of recession where the policy is generally 'last in first out' they are generally seriously disadvantaged, particularly as it is precisely those industries which are willing to employ them that have large scale redundancies and closures (Runnymede, op. cit.; Bryan et al, 1985).

According to official statistics, there is less unemployment among black women compared with black men. However, biases in the way unemployment statistics are collected means that this may be inaccurate. Black women are discriminated against as women, in addition to the racial aspect, and are generally admitted only to the lowliest and worst paid jobs (Smith, 1977; Bryan et al, 1985).

2.5.2 Race and education

This section looks at educational opportunities for minority ethnic groups in Britain. Poor access to education and subsequent loss of opportunities, combine to prevent many individuals making informed choices about various aspects of their lives. Part of this study, looks at the relationship between education, and the acquisition and comprehension of knowledge related to having sickle cell genes.

On arriving in Britain after the immigration drives of the 1940s, many black people intended to remain here for a specific period, after which they hoped to return to their homelands. As a result, most of the problems their children encountered in schools were tolerated by parents (Bryan et. al., 1985). This was particularly stressful for children of families who decided to remain in this country, as they may have been recently uprooted from their grandparents' homes in their 'home' countries to join their parents and new brothers and sisters in Britain. Often the children could barely remember their parents, if at all. They were then placed within an educational system which was not prepared for them, was racist, had an Anglo-centric base and portrayed white skin colour as superior to black (Dodgson, 1988; Bryan et. al.; 1985; Twitchin, 1988; Runnymede, 1982).

Children became isolated in the classroom, where they were subjected to insensitive questions about their lifestyles from schoolteachers, as well as in the playground where they had to endure verbal and physical abuse. They often spoke a non-

standard form of English and were seen as stupid, withdrawn (yet aggressive and disruptive), uncivilised and unteachable (Coard, 1971). Low expectations from educators resulted in poor performances from students. Eventually many were declared to be educationally subnormal (CRE, 1984). Coard argued that people closely involved in assessment procedures of the child's ability were culturally biased, denigrating, for example, the linguistic skills of the black child as incorrect and inferior, rather than different. Black children were believed by some researchers to have behavioral problems, based on the fact that their homes were overcrowded, had less amenities than would be expected by the white British population and they endured more frequent house moves that the average white family. Furthermore, their problems appeared to have been increased by their mothers being full-time workers who relegated child care largely to baby-minders (Cochrane, 1979; Rutter et. al., 1974; Pollack, 1972). Other studies found that although children of West Indian parents suffered more deprivation, the pattern of behavioral problems were no different to children of British born parents (Earls and Richman, 1980).

The concept of multicultural education did not take shape until the 1970s, when it was seen as being a process for meeting the <u>special</u> (rather than different) needs of children from minority ethnic groups (Twitchin, 1988). In 1985, the Swann Report made it clear that multicultural education would be beneficial to all children, as they would have the opportunity to understand how other cultures live and contribute to the world they live in.

However, there is a suggestion that some schools have a negative effect on the performance of black children (Smith and Tomlinson, 1989). It also appears that teachers are over zealous in punishing black children in school. In a city where only 1 in 14 students were black, nearly 1 in four were formally warned, suspended or expelled (Skellington and Morris, 1993).

2.5.3 Race and housing

When black immigrants arrived in Britain in the 1950s and 1960s, their employment prospects were best in the major cities. Therefore, they settled in the areas where their labour was in demand. At that time, they were not eligible for council housing, as most local councils required residency qualifications (ie. an individual had to live in the borough for a set period of years before s/he became eligible to be housed). In addition, as a result of the Second World War when many homes were bombed, waiting lists for the white British population needing to be rehoused had grown (Dodgson, 1988). Black people had to turn to the private sector, where they were open to exploitation from landlords. At that time there was a 'colour bar', made illegal after the 1968 Race Relations Act (ie. advertisements would prohibit applications from black people). There was also a 'colour tax' (ie black applicants who were successful at finding accommodation had to pay highly inflated rents). Some landlords rejected children, so that if a black woman became pregnant, she could be evicted without further warning (Dodgson, op.cit.).

As a result of this type of discriminatory practice, black people tried to buy their own homes as soon as they possibly could. Some families bought a house together to share. The only homes that were generally made available to black people were those already in a dilapidated state and in parts of the city where there were few amenities and which had become 'run down' (now known as inner city areas). Estate agents wishing to make a quick sale (often of a house with a short lease), took their black clients to these homes which were being vacated by the white Britons and white immigrants (mainly Jewish and Irish) as unfit for human habitation (Dodgson, 1977; Runnymede, 1982). At that stage, most black people intended returning to their countries of birth, and they were therefore prepared to endure whatever they had to as they felt that it would only be in the short-term.

The 1968 Race Relations Act made it illegal to discriminate against black people seeking accommodation. However, it was often difficult to prove that someone had been discriminated against, particularly with the prevailing attitudes of people at the time (including those involved with legal processes). Council housing did eventually become available to black families, but this did not substantially help them with regard to the quality of housing stock offered (Runnymede, 1982). When black families could afford to buy a house of good quality, white vendors refused to sell it to them claiming that they would cause the area to deteriorate (Runnymede, op.cit.).

Thus poor quality housing, poor amenities, overcrowding and

what could become 'undesired sharing' became synonymous with black immigrants. Today, few black families own their own homes. Those who do generally own poorer quality housing than their white counterparts in the appropriate socio-economic group. The low socio-economic status that many black people endure, combined with continuing discriminatory practices, have conspired largely to keep them in the inner cities (CRE, 1989a,b; CRE, 1990a,b).

2.5.4 Race and health inequalities

Racism is a major problem in the National Health Service (NHS). Evidence of discrimination is well documented (Mares et al, 1985; Moore, 1984; Wilson, 1983; Eggleston et. al., 1981). More important however, because of its effects on individuals, is how discrimination is perceived by the people it affects, and whether resulting behaviours can be attributed to cultural values, as well as differences in the socially structured opportunities and circumstances of socially defined groups.

Poverty, stress, racism and cultural differences may have contributed to a number of black immigrants being admitted to psychiatric hospitals. Studies have shown that West Indians in particular, are more likely to be compulsorily detained by police and social workers than through general practitioners (Littlewood and Lipsedge, 1982). They are also more likely to have received invasive treatments, such as electro-convulsive treatment (ECT) and chemotherapy, as they are seen to be unable to 'internalise their feelings'. These relatively dangerous treatments are generally under the control of the

more junior doctors of the psychiatric team (Ineichen, 1986; Knight, 1982; Littlewood and Cross, 1980; Hitch and Clegg, 1980).

Some health authorities have developed equal opportunities policies to make sure that black people do not suffer racism in health care, but have been slow to act on them (Dolan, 1988). Myths and stereotypes about black people and their health care needs and supports, (eg. that they make highly emotional and/or aggressive clients, they are a drain on NHS resources or, conversely, that black communities look after their own) are being challenged, with changes to attitudes and increasing cultural knowledge being urged (Badger, et. al., 1988 Slack, 1980).

The mortality rate for female immigrants is higher than that of white Britons (Marmot et. al., 1983). In addition, there are higher perinatal mortality rates for black women from Africa, the Caribbean and Indian subcontinent than for the white British population. More stillbirths and neonatal deaths also occur in these groups (Whitehead, 1987).

Although information on mortality by racial grouping in Britain is very limited, the Black Report using data from the Registrar General's Decennial Supplement notes that the standardised mortality rates for immigrant men compare favourably with those of the native population in social classes IV and V, but less so in classes I and II. This despite the fact that the immigrants were likely to be younger and fitter than their British counterparts. The Report also

suggests that a downward trend in social mobility as a result of immigration may be responsible for this pattern.

There is a paucity of data on morbidity rates of black people which makes it difficult to compare ill-health amongst this group generally with the ethnic majority population. However, people from these racial backgrounds are believed to have high mortality and morbidity rates for chronic and incapacitating conditions such as, hypertension, strokes, T.B. and diabetes, in addition to the conditions seen to be 'group specific', for example thalassaemia and sickle cell conditions (Whitehead, 1987). Furthermore, it may be that black children have a higher than average morbidity associated with material deprivation (Hood et al. 1970)

The major cause of the observed differences in the mortality rates of social classes and racial groups is generally regarded by medical sociologists as being the differences in the behaviours and beliefs, and living and working conditions of social groups. Occupational class and socio-economic status are important variables in looking at morbidity rates and health inequalities. These are a composite of other related variables such as housing, education, marital status and health behaviours.

Differences in health-related behaviours have been attributed to cultural values. However, it is recognised that these differences may be the product of differences in the socially structured opportunities and circumstances of social class groups (Whitehead, 1987). Health behaviours, when combined

with the results of deprivation in previous generations, reflect the knowledge, attitudes and cultural values of the groups. It is known that many factors have an impact on health. Health promotion programmes can imply that people harm themselves or their children by the excessive consumption of harmful commodities, such as refined foods, tobacco, alcohol, by lack of exercise, or by the under-utilisation of preventive health care, vaccination, ante-natal assessment or contraception. Fuchs (1974) suggests that particular life styles involving the use or lack of use of these commodities and amenities, are known to cut across class. Furthermore, health promotion programmes also imply, that individual or sub-cultural life-styles are rooted in personal characteristics and level of education, through which behaviour is governed, and that educational inputs could provide the means by which changes in personal activities may be brought about.

2.5.5 Women and health inequalities

In industrialised countries, women live longer than men and have a lower mortality rate in all age groups. Despite the fact that they live longer, women are more likely to suffer from both acute and chronic disorder (Graham, 1984). They also use their GPs more than men do (Macfarlane, 1980) although many of them are less likely to have their problems discussed in any great detail by their doctors. They are also less likely to have been visited by their GPs in hospital (Cartwright and O'Brien, 1976).

Housing conditions, dampness, overcrowding and a lack of basic amenities have all been identified as factors which create health problems for women and young, particularly pre-school age, children. In addition, working men in the household may inadvertently take dangerous substances from the workplace to the home. Violence in the home is also a source of physical and emotional damage for women and children, which may be of a deep and lasting kind (Graham op. cit.).

A number of studies have looked at the influence of paid and unpaid work on women's health (Oakley, 1974). Being a 'captive wife or mother' can seriously damage women's health (Stacey, 1985). Stacey quotes Oakley's work in 1980 and 1981 which showed that new mothers who were previously publicly employed had to abandon many activities when the baby arrived. This loss of 'place in the public domain' means that childbirth can also be seen as bereavement. However, the alternative of retaining paid work and combining it with the unpaid posts of wife and mother places another set of strains on womens' mental and physical health.

There are also differences and inequalities in the way women use the National Health Service (NHS). The NHS has not equalised 'women's access to medical care' (Doyal, 1985). Women use the health service to a greater extent than men, for a number of reasons. These include their responsibilities as the guardians of the families' health, reproductive capacity, and their greater longevity. Despite this, there are still marked class differences in use of GP services (Townsend and Davidson, 1986), of in-patient and out-patient hospital

facilities and of preventive services (Doyal, 1985). Furthermore, healthy women are dependent on doctors for information and advice about some forms of contraception which are seen as convenient and easy to use without any loss of sexual spontaneity, such as the pill. This point illustrates the claim made by many feminists that any gains women have made in access to medical care have been accompanied by a growth in the degree of control doctors exert over 'fundamental aspects of their lives' (Leeson and Gray, 1978). Feminist thinkers also see that this control of women's fertility in terms of contraception and abortion is still regarded by many doctors as legitimately theirs. This increased control doctors have over a woman's fertility not only involves the means to protect pregnancy, but also the conditions under which women give birth Doyal, 1985).

2.6 Summary

Many theorists argue that people experiencing ill-health have a duty to recover quickly so that they are able to continue to function fully for the benefit of society. While this may apply to acute illnesses, it is a less appropriate way of viewing the situation of people with chronic conditions. Furthermore, groups of individuals from, for example, different sexes, races and cultures, social classes and so on, have varying perspectives regarding their roles during illness experiences.

Doctors are seen to have a regulatory yet compassionate role in ensuring that ill health does not seriously affect the

smooth running of society, and aim to return the sick to good health as quickly as possible.

However, fundamental inequalities in health care remain. Low income, unhealthy working environments, unemployment, and housing conditions have been shown to be variables which contribute to higher mortality and morbidity rates (Furley, 1990; Wilkinson, 1986; Keithley et al., 1984). Black people in Britain are known to have more difficulty finding work - a the pattern of social and economic disadvantage associated with occupational class and reflected in the working of the labour market (Townsend & Davidson, op. cit.). Racial prejudice and cultural differences mean that good education and decent housing are not easily made available to them. These considerations regarding the wider social context of living and working conditions and provision of health care are an important background for understanding the specific situation of minority ethnic status and sickling conditions.

This literature review in this chapter makes a contribution to the development of the ninth hypothesis, which briefly states that unemployed people who live in poor housing will have more sickle cell crises, than those who are employed and live in better housing. Cold damp housing can increase the individual's capacity for developing respiratory illness. These combined exacerbate the effects of sickle cell conditions. Furthermore, poverty does not allow people to have as healthy a lifestyle as they could if they were able to afford it.

Chapter 3 Provision of health care in Britain

I. The National Health Service

3.0 Introduction

This chapter examines the development of the National Health Service in Britain. The history and sociology of nursing is also examined in terms of nursing's development and stratification of care staff by class, race and gender.

> " Society becomes more wholesome, more serene, and spiritually healthier, if it knows that its citizens have at the back of their consciousness, the knowledge that not only themselves, but all their fellows, have access, when ill to the best medical skills can provide..." Bevan (1946).

Before the creation of the National Health Service, infectious diseases in Britain had already begun to decline. McKeown and Lowe (1974) argued that significant improvements seen in overall health in the nineteenth and early twentieth centuries were due to improvements in living standards, with advances in therapeutic measures playing a much smaller role. Further improvements in sanitation leading to cleaner environmental conditions were initiated by the Public Health Act of 1948.

The first half of the 20th century saw the state increasingly assume responsibility for the provision of health care for individuals. This was partly triggered by the poor physical condition of volunteers for the Boer War (1899-1901). At that time, health care was provided for the rich and the aristocracy in the privacy of their own homes by 'eminent'

doctors (and nurses), who charged for their services. Health care for the poor was provided by voluntary hospitals and workhouse infirmaries (or Poor Law hospitals) which existed during the 19th and early 20th century.

Voluntary hospitals treated the deserving poor, dealt largely with acute health conditions in adults, and attracted the services of trained medics who gave their time and expertise gratis. In return the medical fraternity increased the 'material' available to them for teaching and research and for developing their own expertise (Stacey, 1988; Levitt and Wall, 1992; Abel-Smith, 1964).

Workhouses on the other hand, provided for under the auspices of the Poor Law, treated paupers (the undeserving poor), and accommodated children, the chronic sick, mentally ill people and infectious and other 'unattractive' cases. Workhouses were totally unconnected to medical schools. Conditions in the workhouses were generally appalling and there were few amenities (Abel-Smith, op.cit).

Proponents for social reform had been arguing for collective action in social welfare, opposing the prevailing view (held largely by the Tories) of paternalism, individualism (to be poor was the fault of the individual), laissez faire (stressing the inability of government action to change the position of the poor) and the market economy (the flow of goods and services was left to market forces) (Booth, 1903; Rowntree, 1901). This urge for social reform had been stimulated by a growing working class movement, including the

emergence of Labour Members of Parliament, the development of Trades Unions and the rise of British socialism which called for collective action to overcome the injustices caused by a free market capitalist economy (Titmuss, 1950).

These concerns about health care prompted a number of enquiries dating from 1886 and culminating in the Beveridge Report of 1942 (Stacey, op.cit). This report paved the way for the creation of the NHS which was established on the 5th of July, 1948, to provide health care to citizens paid for through general taxation, but without direct charge at the 'point of entry' into the health care system.

The new NHS made the state responsible for the provision of free health care on the basis of equal access for all citizens. Its intention was to integrate, plan and distribute services effectively, allowing freedom of choice for both individuals and doctors. It was based on the principle of providing universal, comprehensive care for physical and mental health for the population. This would include the prevention, diagnosis and treatment of illness, be easily accessed and would be paid for by the collective efforts of all citizens paying taxes and national insurance payments to the state.

The NHS had three major operational objectives:

1. Adequate and rational public financing of services.
2. Rational control of their distribution.
3. Appropriate planning and co-ordination of workloads and

service delivery based on an effective doctor-patient relationship.

Its aim was therefore to improve services as well as the amount and distribution of services to clients.

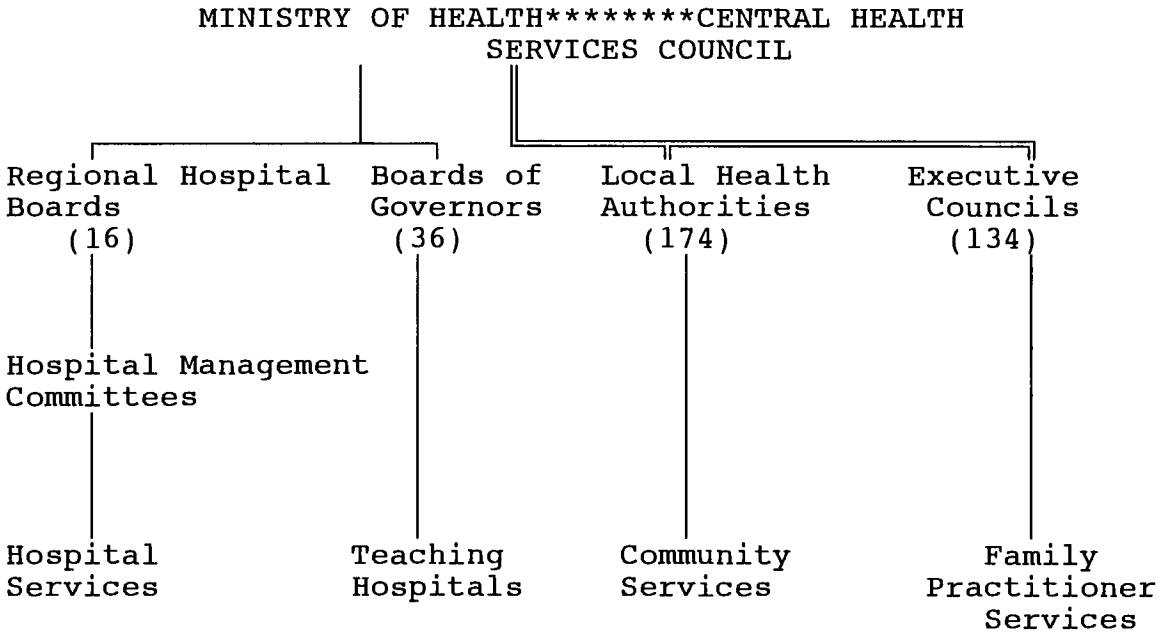
3.1 Structure of the National Health Service

The NHS Act of 1946 established a tripartite structure through which health services would be administered, each part having various responsibilities for different aspects of health care, and reporting directly to the Minister for Health (Figure 3.1). The tripartite structure was designed to run the NHS efficiently, making sure that there was equality of services available everywhere (Allsop, 1986). However, the three parts were operated and funded separately. Therefore there was considerable overlap of services. The dominant focus tended to be on the provision of hospital services, while preventive community medical and nursing services suffered. In addition there was poor liaison between hospitals, community and general practitioner services. This led to unsatisfactory standards of client care and long waiting lists for clients. The tripartite structure remained until 1974, when the NHS was reorganised.

3.1.1 The 1974 reorganisation

With reorganisation, came a new structure for the administration of the NHS. This is shown in figure 3.1.1.

Figure 3.1. The National Health Service 1948 -1974 (adapted from Levitt and Wall 1984).



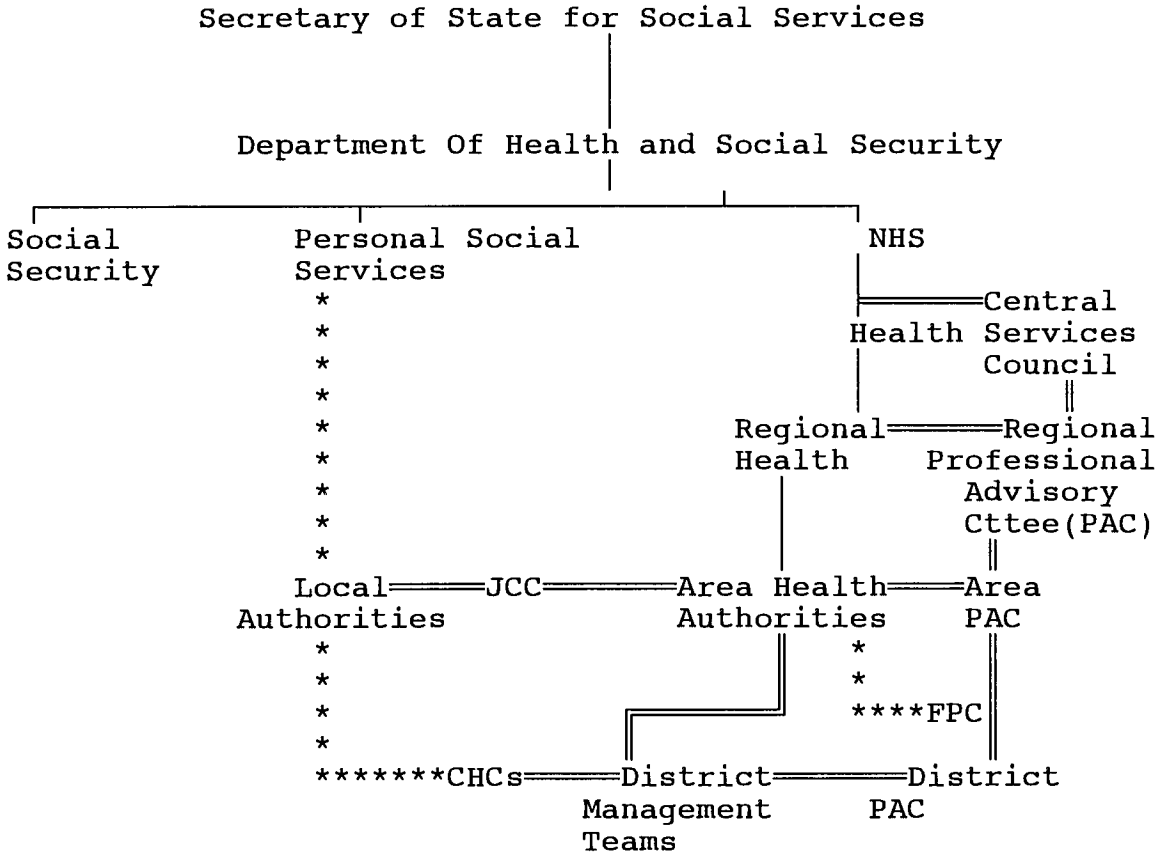
****** = Minister advised by the CHSC
——— = Direct responsibility
═══ = General supervisory powers

Ninety Area Health Authorities (AHAs), with new boundaries matching those of metropolitan districts and the shires, served between 250,000 and 1,000,000 people. They were divided up into Districts which coped with a preferred population size of about 1/4 million. Nineteen of these areas were attached to teaching hospitals (AHA(T)). AHAs were unique in that they were responsible for **both** planning and providing services. They dealt with the provision of hospital and community care, identifying where there were areas of need for services.

The reorganised NHS was seen however, to be too ambitious and ill-conceived (Brown, (1979). It occurred at a time when pay restraints caused the wages of people working in the public sector to fall behind their equivalents working in the private

sector. There was a lowering of morale in the health service and members of the medical profession took industrial action (Abel-Smith, 1978). Furthermore, there were too many administrators, too much indecision, poor management of resources and a complicated system of consultations (DHSS, 1979). More difficulties arose with the Government's decision to phase pay beds out of the NHS.

Figure 3.1.1. The Reorganised National Health Service 1974 - 1982 (adapted from Levitt and Wall, 1992)



JCC = Joint Consultative Committees
FPC = Family Practitioner Committees
——— = Accountability
═══ = Consultation/Advice
******* = Other

As mortality rates fell in the industrialised world, new,

chronic health problems arose. The numbers of people needing medical interventions increased and waiting lists grew. Criticisms about delays in decision making due to elaborate consultation processes, and about the numbers of tiers and administrators were made. The high cost of reorganisation and low staff morale were also highlighted (Brown, 1970).

The distribution of resources was another major problem for the NHS. Although the NHS was created to provide equal entitlement and access to health care, the distribution of health resources from region to region and within regions remained unequal (Scrivens, 1986). In 1975, a working party (The Resource Allocation Working Party (RAWP)) was set up to decide how funds should be allocated to regions, areas and districts in order that equal access to health care was available for people at equal risk. RAWP's recommendations were based on age, sex, standardised mortality rates and different bed use for different groups of people and selected medical conditions. However quality of care was excluded and there are still large regional variations in both costs of treatment and in quality of care (Scrivens, op.cit.).

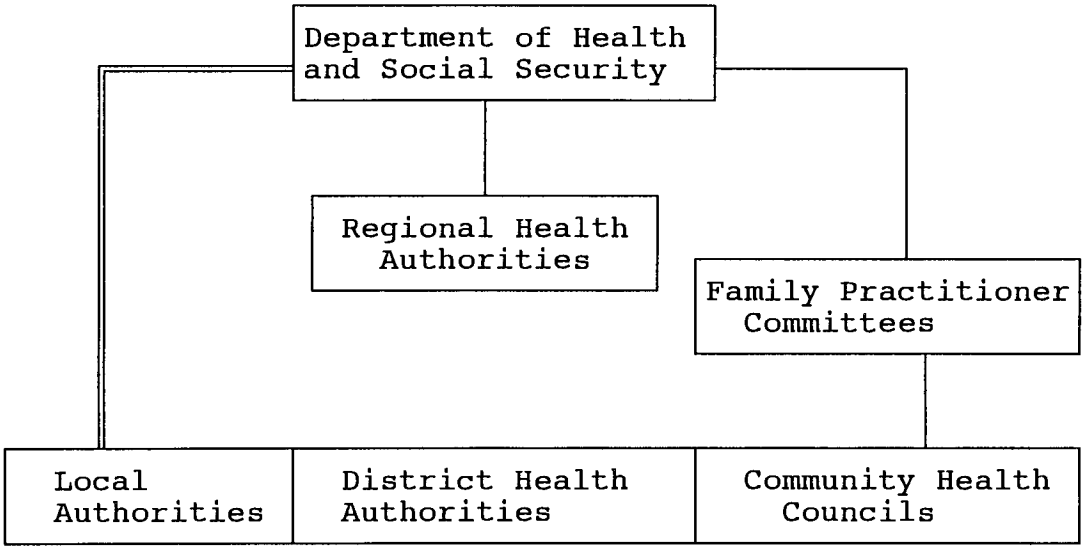
3.1.2 Further restructuring

In 1979, a consultative document 'Patients First' was published by the Government (DHSS, 1979). This incorporated the recommendations of a Royal Commission Report which suggested that Area Health Authorities were too remote from the local community, clients and local service providers (Allsop, 1986). 'Patients First' recommended that the decision

making process should be positioned closer to grassroots level, and that there should be a tighter system of management with a simplified planning structure.

Because of these criticisms, the NHS was reorganised once more in 1982. Figure 3.1.2 shows the new simplified structure.

Figure 3.1.2. The Structure of the National Health Service after 1982



——— = Line of direct managerial responsibility

═══ = Consultative relationships

Unlike the 1974 reorganisation, restructuring in 1982 was seen as a structural simplification and the decentralising of services, possibly losing common boundaries at district health level and diluting technical expertise (Klein, 1983).

The problems of controlling resources led to a new management philosophy with a new enquiry into NHS management (Griffiths,

1983). The Griffiths Report was intended to promote and control change in a positive and centralised manner. Griffiths saw management by consensus as leading to long delays in the management process as the lowest common denominator decisions prevailed. The Report concluded that the NHS needed stronger management and ways of measuring and costing the services it provided. The Report's recommendations left the structure of the health authorities unchanged, but made several changes to methods of managing the Health Service.

From April 1985, a health services supervisory board was responsible for strategic decisions on resources and objectives, while a full time NHS management board implemented the policies decided by the supervisory board. The chairman of the management board was responsible for the NHS at national level, while at region, district and unit (hospital) level management teams were replaced by a single general manager who controlled his or her particular area of service and its resources (Scrivens, 1986).

Reorganisation intended to make the health service more responsive to local needs by bringing decision-making nearer to communities and individuals requiring care, while at the same time the centralisation of services aimed to increase efficiency, lowering the overall costs of the service but without reducing standards of care.

The 1982 reorganisation encouraged 'new blood' managers in the Health Service. This 'new blood' often came from specialisms outside of the health professions, and a handbook of policies

and priorities for health and personal services, 'Care in Action' was issued as a guide and an invitation to view the NHS in a novel way (DHSS, 1981; Davies, 1987). However, 'Care in Action' shifted responsibility of peripheral health and local authorities into the sphere of devising strategies for community care. Informal and voluntary organisations were also called on to provide more complementary services. Despite this shift in policy, the government did not allocate any extra funding for this task. It is therefore highly unlikely that either health authorities or voluntary and informal organisations will be able to provide these services adequately (Allsop, 1986: Webb and Wistow, 1982).

The changes in the NHS over recent years have meant that there is a restriction on its rate of growth; a trend which is still continuing (Radical Statistics Group, 1987). Furthermore, the demand for services is continuing to increase and with the limitations on health service spending this will exacerbate current crises in available resources. Standards of care will inevitably suffer, and those who are unable to pay for their health care will suffer most from increasing waiting lists and poor standards. Many working class people, the unemployed and black people will be susceptible to receiving poor or no care. Women from these groups will be particularly at risk.

During the 1980s, government policies saw major changes in social policy and the social welfare. With the privatisation of pensions (Social Security Act, 1986), central government control of education (Education Reform Act, 1988) and the selling off of council housing stock (Housing Act, 1980),

social policy was transformed. Taxation of individuals was reduced at the expense of collective action in social welfare.

Before long, the public and health professionals began to appreciate the effects of these strategies on the NHS. The political arguments that followed led the Government to produce a White Paper, 'Working for Patients', which was published in 1989 (Department of Health (DOH), 1989). The White Paper advocates a further significant managerial reorganisation, enhanced use of amenity beds within NHS hospitals, a contracting out of care for clients which is controlled by GPs and managers, and the establishment of self-governing hospitals. GP practices would run their own budgets, (in order that money follows the client around), buying NHS and private services for the client.

The government believes that the White Paper is showing the way forward to improved client care, improved choice for the individual, and reduced waiting lists, as clients can be sent to hospitals which can provide immediate treatment for the client's particular ailment. Improved management is also seen to follow from hospitals being forced to compete with each other in order to attract limited resources.

However, the White Paper represents the NHS as being problematic because of its underlying structure, rather than because it is chronically underfunded (Savage and Widgery, 1989). It also further limits NHS funding by introducing tighter cost controls, despite the fact that the Paper itself was supposed represent the response to a cash crisis.

All in all, therefore, the White Paper appears as a threat to the principles and the effectiveness of the NHS, leading to a sharp increase in administrative and medical costs with inadequate government funding (RCN, 1989). Furthermore, as hospitals compete to provide the most cost effective care, there is a danger that **standards** of care in hospitals will suffer. As district health authorities will not necessarily provide certain types of health care (due to buying in care from other hospitals), there will be no guarantee of a comprehensive local service.

The White Paper also outlines a role for local authorities. They will collaborate with nursing and medical staff, and others to assess and plan care needs, and organise the delivery of care within limited resources, despite acknowledging that joint planning in the past has been unsuccessful (DOH, 1989). In order to carry out this new role, local authorities have the status of purchasers and providers of health care, despite the fact that they are have neither the structure nor the resources for this task.

In their response to the White Paper, the RCN argues that it is motivated not by consumers, but by resources. Money was not set aside for community services other than for mental illness, and prevention of ill health is hardly featured (RCN, 1989). The White Paper, therefore, can be seen to represent a threat to continuity of client care from the hospital to community with reduced access to a comprehensive range of primary health care facilities. General Practitioners who are now accountable for the amounts of money their practices use,

may find ways of refusing care to individuals seen to be too expensive (Guardian, 1991; Daily Mirror, 1991).

In 1992, the Department of Health published 'The Health of the Nation' which had the main aim of improving health, and targeted a number of key areas in which progress could be made 'for the year 2000 and beyond' (HMSO, 1992). Health authorities would now be obliged to carry out population needs assessments in order to provide an appropriate service.

The issues raised in this latest Government initiative on health has special relevance for minority ethnic groups, as these groups are very likely to be at risk for many of the key areas targeted.

3.2 Division of health labour in the NHS

The hierarchy of health professionals in the Health Service developed along the lines of class and sex (Stacey, 1988), and later race, with white, middle class males having positions at the top of the pyramid. Black working class women are largely represented at the bottom (Doyal, 1987).

Historically, women have always been health workers. However, their efforts were largely negated from the late fifteenth century, until the middle of the eighteenth century. The scarcity of women in the health sphere appears to have been the result of the professionalisation of medicine. This began in 1512 with Henry VIII's Medical Act, which restricted practitioners to those licensed by the bishops (Leeson and

Gray, 1978). Included in the bishops' criteria for licensing were the attributes of 'moral suitability' and 'religious reliability'. In addition, the Act itself excluded the services of the 'great multitude of ignorant persons ..... common artificers, smiths, weavers and women' (op.cit.).

Leeson and Gray point out that 'the first execution for witchcraft in Britain was in 1479'. Between then and 1735 when the laws were repealed, about 30,000 people, mostly women who were knowledgeable about herbs, health care and midwifery, had died. Leeson and Gray assert that, in addition to the medical men of the day finding death by witchcraft desirable for these women, the church also had its concerns. Church leaders believed that newborn babies were at risk of being offered to the devil by witch-midwives; witchcraft derived from carnal lust, and witches mated with the devil.

Women struggled from about the middle of the nineteenth century onwards to register as doctors on both sides of the Atlantic (Leeson and Gray, 1978). Elizabeth Blackwell and Elizabeth Garrett were the first two women to be included on the Medical register in the late 1850s/early 1860s. Both these women and those that followed them into the medical profession were 'subject to much harassment' by their male colleagues (Leeson and Gray, op. cit.). A bill, passed in 1876, enabled all universities in Britain and Ireland to graduate women, and women slowly began to be admitted to the medical register. During the time of the First World War, there was a significant increase in the number of female medical students, and women doctors were allowed to treat casualties at the

battle front (Elston, 1977). Immediately after the war the numbers of women entering medical school again dropped. Many schools refused to admit them, as they were seen to be a deterrent to the recruitment of male medical students. At this time quotas for women medical students became established, and, although there was a second rise in the number of women medical students during the Second World War, it was not on the scale seen during the earlier war. The quota system was eventually legally abolished with the Sex Discrimination Act of 1975, though more subtle methods for excluding began to be used (op.cit.). Today women remain under-represented in the more prestigious medical specialisms and on the policy-making bodies of the profession.

By Victorian times, particular areas of public work for women had been established. These were the so-called 'semi-professions' of social work, nursing and so on. These 'semi-professions' were seen to be a compromise between the woman's role in the private sphere of the family, and her need to have a 'real social function' (Carpenter, 1977; Garmarnikow, 1978). As they were defined as women's work, they were expected to have a rapid staff turnover which was not necessarily linked to promotion. Any turnover in the professions - men's work - was seen as linked to personal career development.

Carpenter (1977) points out that nursing enabled many women to have some measure of self determination. However, nursing would provide a service for which financial reward would be less important than the element of caring. However, in caring

for and working with strangers, the moral characters of the women would, it was supposed be compromised. They were seen to need protection from the expected but immoral advances that would be made by male doctors and clients. The nursing community was therefore cloistered, and separately controlled by powerful newly created matrons. These women, usually of upper class origin, had influence among their male social peers, and were responsible for all internal management and discipline of non-medical staff in the hospitals, while 'recognising the importance of obedience in clinical matters to the doctors' (Carpenter, 1977). This resulted in the division of labour in hospitals being based on sex differences, and on class differences between women. Later, as immigration from non-industrialised countries became more established, race would become another variable in the division of labour.

Within the health service as in other services, two types of work segregation have been identified. First, men and women employed by hospitals at different levels and ranks, are generally allocated different types of work. Men are often employed as maintenance staff and porters, while more women can be found working as domestics and as catering staff (Doyal, 1985). In addition, women generally occupy places at the lower end of a hierarchical system, for example as nurses and ancillary staff. Women, therefore have less power than men, even among doctors, who are at the top of the hierarchy, male and female doctors generally having different roles and amounts of power. This situation is typical of women's positions in society in general, and in the home in

particular. Second, even when occupied in the same type of work, women are disproportionately found in the lower grades with men most often occupying the higher grades (Stacey, 1985).

3.3 The adequacy of services

A fundamental aim of the creation of the NHS was to provide equality of access to health services to everyone, on the basis of need, thus ending the former restrictions of provision to those who were insured or those who could afford private treatment (Levitt & Wall, 1992).

Although this principle has been modified by the introduction of charges for some services in 1951/2, it has been a significant achievement of the NHS to free people from the fear of not being able to afford hospital treatment.

3.3.1 Access to Health Care

Despite the introduction of free health care, there is much evidence to show that health care services are not equitably distributed in Britain. It is not the poor who make the most use of the health services. The Black Report suggests that access to health care is biased in favour of the non-manual socio-economic groups (Townsend and Davidson, 1986). Bone (1973) found that non-manual workers made more use of family planning services than did manual workers. Cartwright and O'Brien cite a number of other studies which have shown that working classes made less use of post-natal, dental, chiropody

and domiciliary services (1976). In addition, they found that on visiting the doctor, the average consultation time for working class clients was 4.7 minutes compared with 6.2 minutes given to middle class clients. Furthermore, Cartwright and O'Brien revealed that middle class clients discussed more problems with their doctors (4.1 compared to 2.8) than their working class counterparts, though middle class clients were perceived as having less symptoms on average (2.2 as opposed to 3.0). Doctors appeared to be less acquainted with their working class clients than with their middle class clients, though they were more satisfied with working class consultations as these clients were not seen as demanding in terms of asking help in the solution of problems.

Middle class people appear not only to receive better care, but they also make better use of preventive services (Stacey, 1977a). This may in part be due to the fact that they have a greater ability to communicate effectively with doctors who are themselves middle class. In addition, they may be simply better placed than the working classes to avail themselves of health resources.

In terms of access to hospital services, Abel-Smith and Titmuss (1956) examined the class distribution of discharges from hospitals in 1949. They found that despite higher death rates and greater sickness in social classes IV and V, these classes were under-represented in hospitals. They concluded that there were inequalities of access to hospital care. Other studies have shown that, while middle class clients are more likely to be admitted to hospital, they remain as in-patients

for a shorter period of time (Airth & Newell, 1962). Since then, Marsh (1965) has found that social classes IV and particularly social class V are proportionately over-represented. This has been confirmed in other studies (Ashford & Pearson, 1970). This seems to indicate a) that class patterns of hospitalisation have changed since 1949 in such a direction as to allow easier access to care to working class clients, and b) that people from social classes IV an V have more illness which is considered serious enough to warrant hospitalisation.

In addition, several studies suggest that people higher up on the social class scale receive more home visits from the GP, are offered more explanations of their illness and have more referrals to specialist services, than people from the lower classes (Pendleton et. al., 1980; Bucquet et al., 1985; Blaxter 1984).

There are also marked inequalities in the distribution of health services (Cooper & Culyer, 1972; Maynard & Ludbrook, 1980). Ease of access to health care **facilities** have obvious implications for health care utilisation. Tudor-Hart (1971) has argued that an inverse health care law applies in Britain. In other words, the provision of health care is inversely related to the need for it, with poor facilities existing in depressed regions which have high morbidity, and better facilities being found in affluent areas with low morbidity. This argument has been supported by West and Lowe (1976), who found low correlations between the provision of doctors and health visitors and various need indicators including

stillbirths and infant mortality to teenage mothers. In addition, Parkin (1979) argued that distance between the home and general practice increases as the likelihood of consultation diminishes, particularly in the case of elderly or wheelchair-bound people.

Other studies have shown that GPs' surgeries are so located that inner city areas are poorly served. Accessibility to services is greatly extended if people own cars (Knox, 1979; Fox et. al. 1982). Problems getting health care are higher amongst low income groups, elderly people, people with disabilities, adolescents, women with young children and minority ethnic groups (Whitehead, 1987).

The question of mobility becomes important both in terms of lifestyle and access to health care. The centralisation of shopping and recreational facilities, for example, creates accessibility problems for those who lack the means to travel to such locations quickly and efficiently. In the health sector, this trend can be seen in the closure of smaller hospital and community care units, so that resources can be concentrated in larger more central hospitals. The lack of financial resources, transportation, and energy among people who are poor means that these larger hospitals are not easily accessible to them.

Statistics indicate that most black people in Britain are working class (OPCS, 1988). Many of them are either carriers of genes for various sickle cell conditions, or they may have one of the conditions themselves. Programmes largely designed

to meet the health needs of white, Anglo-Saxon, middle class people may not be appropriate for these groups. Furthermore, people with sickle cell conditions have different health needs to other migrants and to white Britons. As black people, they may represent different cultures and will view their health needs from different cultural perspectives.

Inequalities in health care and in access to care, racism, culture and health behaviours are all variables which have an impact on choices available to people who are, or whose families are, at risk from sickling conditions.

3.3.2 Information-giving

Communication is shaped by cultural and socio-economic relationships (Goodenough, 1969). The provision of information about illness and treatments from clinician to client may affect the quality of care in a number of ways. Full, clear information provision would encourage a doctor-patient relationship based on openness, permit the client to contribute more fully to the understanding and treatment of his/her illness and promotion client satisfaction with the therapies received (Mathews, 1982).

As argued above, doctors spend less time with working class than middle class clients, and tend not to appreciate their needs for information (Townsend and Davidson, 1986; Cartwright, 1970). In particular, problems of communication, for example with clients from the Caribbean who speak a non-standard dialect of English may lead to isolation and

depression (Smith, 1976). In addition, even when information is given, dominance tends to be maintained by the use of medical jargon designed to maintain mystification and therefore stratification in the relationship (Waitzkin, 1979).

The problems of communication may persist even when the 'professional' care-giver is from the same 'ethnic' background, as status, based on class and other factors, comes into play, in the same way that it does for the majority ethnic group. In any event, as there are comparatively few doctors, (and GPs in particular), from minority ethnic groups, clients with minority status tend not have access to doctors who are of similar cultural backgrounds to themselves. For example, if a black client has a black doctor, the client may be of Caribbean origin and the doctor, African; an Asian client might be a Bangladeshi Muslim while the doctor might be Sikh Hindu. Despite these problems, doctors and clients who have minority status may be able to communicate reasonably well between cultural groups, especially regarding health conditions which are common to them.

Doctor-client communication difficulties could lead to a belief that care professionals do not understand the needs of clients, other races and cultures, and limit the individual's ability to obtain good quality health care, leaving professionals unable to provide an adequate service. In addition, the centralisation of services, impersonal reception arrangements and insensitive handling, the assumption that clients are malingering, have poor pain tolerance and discrimination towards individuals perceived as being

non-compliant or 'unattractive', adds to difficulties experienced when attempting to obtain health care (Cottle, 1965; Wilson, 1983; Donavan, 1986).

3.4 Health service expenditure

In England, (1981-2) per capita expenditure on health services as a whole ranged from £189.85 in the Oxford region to £251.65 in the North West Thames region; family practitioner services varied from £45.50 in the Trent region to £53.19 in the South Western region (CSO, 1984). There were also variations in health manpower. Variations such as these are to be expected, as different areas have different needs depending on the age of the population and the pattern of illness in the community. In 1976, the Resource Allocation Working Party (RAWP) produced a report (DHSS, 1976) aimed to provide a formula so that health resources could be distributed on the basis of need; the extra resources being used to provide more health facilities improving access to health care for people at equal risk. Calculations for resource expenditure were based on the size of the population being served, weighted by a combination of variables. These included age, sex, marital status, fertility and mortality, as an indicator of morbidity, taking into account the heavier demands made on services by groups such as children, women and elderly people. Adjustments were made for various other factors, such as numbers of long stay psychiatric clients. In this way, it was seen that regions should have a 'target revenue allocation' which would allow for the movement of clients between regions.

RAWP did not affect the overall NHS budget, but provided a means by which resources could be distributed in a more equitable manner. The policy for reallocating resources to impoverished regions began in 1977, but was met with much criticism. It was argued that the working party looked only at the input of resources to the regions, and not at the ways in which those resources would be utilised (Buxton & Klein, 1978). It was suggested that this should be done by adjusting RAWP's formula to take account of changing national priorities. A second criticism made (op.cit.) concerned the use of mortality rates as an index of morbidity. Buxton and Klein argue that these are an inadequate proxy for morbidity and point out that, while standardised mortality rates are associated with morbidity, they are also associated with poor social conditions. In addition, the formula did not include indicators for social deprivation - such variables as income, unemployment levels and housing conditions. Such considerations were deliberately excluded from the working party's indices, as they felt that 'Health Authorities' do not have .... 'an exclusive responsibility in this field'. It was further argued that RAWP did not allow for the availability of services such as primary care and social services which complemented health authority responsibilities. As the unequal distribution of GPs is quite pronounced, so too is the distribution of personal social services (op.cit.).

Another area of debate concerned the impact of RAWP within regions. The greatest problems appear to have been encountered in inner city areas where there are considerable pockets of social deprivation, but the area may be over-provided for in

terms of the RAWP formula because of the existence of expensive teaching hospital services which may not always be appropriate to the needs of the local population. These centres of excellence in health care and internationally renowned research centres were not allowed for in RAWP's calculations.

Despite these criticisms, RAWP's formula has been in use since 1977/78. Maynard and Ludbrook (1980) have suggested that it appears to be working quite smoothly, and deprived regions are receiving more funding at the expense of more affluent regions. However, those regions which received more funding before the implementation of RAWP's recommendations are having to make cuts which in the long term may prove to be detrimental (op.cit). There is also some doubt as to whether regions are allocating resources to districts within their boundaries in the way RAWP intended that they should (Elcock and Haywood, 1980).

It may be that, because RAWP is simply a mechanism for resource allocation, it cannot be a means of bringing about social change. That is, it cannot ensure an improvement of access to services or indeed in client care. There is the added problem identified by Buxton and Klein, that in societies where the supply of medical care is so highly planned and controlled, there are marked inequalities in service provision in relation to need which cannot be easily or quickly changed. Therefore, equality of regional provision according to need is something that will have to be worked at for a very long time if it is to be achieved. Despite these

perceived difficulties, the RAWP approach has been endorsed by both the Black Report and the Royal Commission on the NHS as being perfectly acceptable.

II. Sociology of nursing

The sociology of nursing is important to this work, because it was developed with a singular lack of attention to the needs of people of minority ethnic status. This has major effects on how health care and nursing knowledge developed, and in turn affects the provision of care, based on knowledge, for people with sickle cell conditions. It also impinges on the role and professional development of carers who have minority ethnic status.

3.5 Introduction

Historically, women have always been carers both in the public and domestic spheres (Stacey, 1988). Whether in paid employment or not, women are mainly seen as being responsible for family health. This involves caring for the children, the sick and the aged, ensuring that the home is safe, and taking charge of health education (Voysey, 1975; Graham, 1984).

Women therefore have to adapt their own coping mechanisms for dealing with their own life stresses, in order to achieve the best possible alternatives for the care and education of their families (op.cit.). In order to protect her family's health when resources are scarce, often a woman will absorb any shortages of food and other resources herself (Oren, 1974).

Caring therefore has implications for women's own health which may be particularly harmful, especially when they have chronic health conditions such as one of the sickling conditions.

3.5.1 The nursing profession

The origins of nursing as a 'semi-profession' date back to the spread of hospital nurse training in the 1880s in voluntary and Poor Law hospitals (Abel-Smith, 1975). However, for as long as there have been hospitals, there have been nurses (Woodward, 1978). The emergence of modern nursing was influenced by the work and teachings of women like Elizabeth Fry, Florence Nightingale and Mary Seacole in the nineteenth century (although the important role of the latter, a black woman, is not generally acknowledged), and is linked to the expansion of the hospital system itself.

3.5.2 History of nursing

The need for a large labour force in nursing became intense as the health care sector expanded. Hospitals therefore started to recruit women to nursing. Untrained women, no less than 21 years old and no older than 35 years, able to read and write and to follow the doctors' lectures, and carry out (his) instructions were sought after (Carpenter, 1977; Abel-Smith, op. cit.). Older, more independent women were considered to be less likely to submit to the arduous conditions of work and training, and were seen to be too old to learn the methods of caring for individuals in hospital.

Nurse probationers who had to be obedient, truthful and kind, had to have some work experience, usually linked to household functions, before embarking on nurse training. This allowed young women to get used to the idea of regular duties and hours of work where cleanliness, adeptness and punctuality were the accepted norm (Branca, 1974).

Although women were recruited if they met the above criteria, tasks were divided into those which were essentially menial, to be carried out by working class women, or supervisory. Middle class nurses supervised the 'lower grades of workers' (Abel-Smith, 1975). A hierarchy of authority and duties emerged which has carried over to nursing today.

Qualified and untrained nurses co-existed together with trained nurses working increasingly in administrative positions while untrained nurses did the more mundane jobs. This situation went on until 1939 when the Athlone Interim Report identified frictions between registered and untrained staff (who were, at this point, still outside the control of any regulating body). Registered staff were concerned that untrained staff were a threat to the profession and the public. The Report recommended that untrained nurses be given a recognised status (ie. they would be called 'assistant nurse' or more commonly 'nurse'), and brought under the control of the GNC who would be empowered to set up a roll to which their names would be added to (White, 1985).

The Horder Report (1941) found that, as there was a hierarchy of skills, there should also be a hierarchy of nurses (White,

1985). This Report promoted the training of untrained nurses so that two levels of nurse would be created. This would comprise of the SRNs (RNs today), who had 'advanced' education, (three year training), and who would be less numerous than nurses at the next level - the 'state enrolled assistant nurse' (SEAN - ENs today) who would receive training for a two year period. ENs would carry out routine tasks, leaving RNs free to undertake more of the management duties.

These two levels of nursing were expected to complement each other. First level nurses (the RNs), were seen as competent to assess, plan, implement and review nursing care, coordinating with other members of the nursing team and promoting health (both by teaching and advising), (UKCC, 1985). The second level nurse (the EN), is seen as assisting the first level nurse, accepting delegated tasks and working in a team.

However, although the EN is expected to be subordinate at all times to the RN, job evaluation failed to find any differences in the level and quality of their respective work (DHSS, 1977). Nurse enrolment created a vacuum which was immediately filled by the nursing auxiliary (NAs), an untrained worker. NAs were better paid than enrolled nurse trainees, ie. pupil nurses without any need for training (White, 1985). By the late 1950s, untrained staff made up nearly half of all nurses (including student and pupil nurses), with black nurses being seen largely as 'auxiliary' or 'pupil' nurse material.

Nurse training rules were drafted to define the competencies of first and second level nurses (UKCC, 1983). European

Economic Community directives accept only the three year registration as the appropriate qualification for nursing practise in the U.K. The RCN recommended, therefore, that there should be only one statutory nurse qualification (RCN, 1981; 1983; UKCC, 1982). In 1984, the English National Board recommended that there should be only one grade (ie. level) of nurse. Within this framework, there would also be ' care assistants', under the control of nursing management, but who are not a part of the nursing structure (RCN, 1983).

3.5.3 Nursing care in the home

Community based nurses had their own history, and developed separately to general nursing (Abel-Smith, 1975). In 1863, William Rathbone employed a nurse to visit women in their homes in Liverpool. He insisted that half of the nurses trained in the local hospital were also given experience working in the district (Stocks, 1960). The Queen Victoria Jubilee Institute for Nurses, later renamed the Queen's Institute of District Nursing, had been founded in 1859 to further district nursing and domiciliary work nationally.

The NHS Act (1946) required local health authorities to provide a health visiting service. After 1948, provision of community nursing services became the responsibility of the local health authority under the control of the medical officer of health (White, 1985). In 1958, district nurse and health visitor training became part of the post registration options for further nurse education.

More recently the Cumberlege Report (1986), suggested that as members of the primary health care team, nurses should:

1) provide enough information to clients to enable them to make decisions about their health care on the basis of informed choice, both in terms of prescribed therapies and from a health promotion viewpoint,
2) give community support stimulating people's own ability to improve their quality of life thereby offering them maximum independence and minimising the need for hospital admission,
3) involve partnership with and support for carers,
4) make sure that all disciplines, as well as statutory and voluntary agencies are involved in client care, and
5) Include people in the community as well as health professionals in the planning and evaluation of services provided.

Modern nursing is seen largely as moving towards maximising the client's potential for self-care as people move along an illness-wellness continuum (Orem, 1985). In order to facilitate the acceptance of the client as a member of the primary health team, the nurse has to develop many roles within the nurse-client relationship. These roles include those of information provider, health educator, genetic and psychosocial counsellor, family planner and advocate. With this type of input, care would be sporadic, inefficient and superficial. It is certain that these tasks would need to be

coordinated under the direction of a specialist nurse.

3.6 Nurse education

The official training of nurses in Britain started in 1848, at King's College Hospital, London, then known as St. John's House. However, the course set up by Nightingale in 1860 at St. Thomas's hospital also in London, with funds donated by the public in recognition of her work in the Crimea, was more influential and well known (Woodward, 1978). Training lasted three years, and at this stage involved courses of home management and domestic science, and providing basic care (eg. giving out food and medicines) to people in hospitals. Technical expertise meant little more than taking the client's temperature and pulse correctly, and accurately reporting to the doctor (Garmarnikow, 1978).

Medical lectures were attended by a nurse tutor who would repeat the lecture in non-scientific language, and then give a practical class based on the lecture. This served to help probationers to understand the lecture and to reinforce the differences between medical and nursing expertise. There appears to have been very little true 'nursing content' taught (ie. details of nursing practise) as much of the training was medically oriented (Brockbank, 1970). Training programmes ended with a formal examination which on successful completion saw the 'new' nurse registered with the GNC.

In 1948, the Nurses Act allowed different types of courses for basic nurse training, which allowed collaboration with

institutions of higher education (Owen, 1984). However, the GNC had no powers to control training of further studies which would allow nurses to specialise. This policy doomed nurses to be seen simply as generalist workers. Medicine and surgery became more specialised at this time, and consultants began to demand nurses who were trained to their own particular fields of expertise (Wood, 1947). It was not until 1970, however, that the Department of Health and Social Security (DHSS) agreed to a central system for post-registration specialist training, set up under the auspices of a separate board, the Joint Board for clinical Nursing Studies, rather than the GNC (White, 1985).

The Briggs Report (1972) recommended that all nurses should do the same basic 18 month course, followed by a further 18 months training for nursing registration. Further (post registration) study would lead to higher qualifications in specialist fields, such as midwifery and health visiting. The Report also recommended that nursing, health visiting and midwifery divisions would be controlled by new statutory bodies. The United Kingdom Central Council (UKCC) for Nursing, Midwifery and Health Visiting was set up in 1979 to take over post registration training. It also took control of the statutory bodies in 1983.

As nursing's knowledge-base developed and new specialities emerged, women returning to nursing following a break in practice of several years were advised to take refresher courses (UKCC, 1987). As a result of changes in the requirements of statutory bodies and better programmes of

education for nurse tutors, programmes for student nurses developed enormously (Hooper, 1985). Students were introduced to practical assessments, programmes of concurrent theory and practice and an increase in shared learning between nurses, midwives, health visitors and other health-oriented students.

In 1984, the UKCC established a project to assess the education and training required for the professional practice of all branches of nursing care (UKCC, 1986). The recommendations which followed in the form of Project 2000, as it became known, were designed to enhance the academic credibility of nursing with positive implications for professionalism (Mason, 1991).

Major recommendations of Project 2000 were that student nurses should have student status, receive NHS controlled training grants and be supernumerary to NHS staffing establishments throughout the whole period of preparation. Training which is linked to higher education was implemented, the training of ENs stopped, so that there is now only one level of nurse training available. However, as thousands of ENs exist, this level of nursing has not been abolished and apparently will not be for some time to come (UKCC, 1986). Project 2000 recommended that all ENs underwent conversion courses to become RNs.

3.7 Nurse theory and practice

In the 19th century, nurses simply carried out doctors' instructions. More recently nursing has become more goals and

task oriented and less towards the notion of 'hand-maiden' (at least in principle). Student nurses spend less time on wards during their training, and matrons have been replaced by nurse managers. However, there has been a great deal of frustration and dissatisfaction amongst nurses as nursing theory is not necessarily applied to nursing practise (Fretwell, 1982). This results from a separation between those who teach nurses and those who nurse (Bendall, 1975). Theory and practice diverged, with practical knowledge being seen as being of less value than theoretical instruction (Bendall, op. cit.). The inter-relatedness between nurse teaching, nursing practice and the need for research meant that a growing need for nurses to develop a sound scientific base for practice was recognised (Stevens, 1979; McFarlane, 1976; Aggleton and Chalmers, 1986).

The nursing process, a problem-solving, client-centred approach replaced the task oriented approach to care (Roy, 1976; Orem, 1971; Katz, 1969). This approach involved the use of research to identify areas of good practise, practice being the precursor to theory which is in turn refined by research (Jennings, 1987). Nurse theorists argue that only by developing theories will nurses be able to understand their roles fully. However, because theories are focused on education and professional identities, they are not being used to guide practice and are not offering any real guidance for nursing interventions (Meleis, 1985; Webb, 1984).

Edlund and Hodges (1983) suggest that the role of the nurse is a complex one which encompasses many sub-roles related both directly and indirectly to client care. These sub-roles make

the specialist (and generalist) nurse amongst other things, a practitioner, an educator and a catalyst for change (Fenton, 1985).

Providing physical care is important but is only a part of what nurses do to improve their client's health. Josefson (1988) suggests that the nurse brings to the client 'knowledge of familiarity', that is, they have a shared pool of multi-faceted experiences, which aids their powers of observation, and therefore the care they provide. The problem that nurses have, is that this type of knowledge is not considered to be scientific, as it cannot be 'formalised' (Josefson, op. cit.). However, Oakley (1993a) argues that historical divisions of labour, based on keeping the nurses' role in health care tightly controlled by doctors, have placed constraints on nursing, which limits what they can do for their clients (and themselves as carers). Despite this, clients' satisfaction with nurses rated higher than for doctors, as nurses provided emotional support and information, not granted' by doctors (Oakley, op. cit.). This is not to say that nurses were always sensitive to client needs (Seers, 1989).

A framework for the development of nursing care for anyone with a chronic disorder must be built on the cornerstones of equality of care, community involvement and cooperation between health and social services (ICN, 1973). The International Congress of Nursing report continues,

> " The nurse in providing care promotes an environment in which

> the values, customs and spiritual beliefs of the individual are respected" (ICN, 1973: 3).

The nurse practitioner should therefore provide care bearing in mind the cultural values their clients may have. Like the health visitor, the nurse should make sure that clients in her care understand the information they are given which is relevant to their health status and treatment regimes. In doing so, she must be able to help individuals and their families to develop strategies for overcoming health difficulties, counsel when it is needed and generally educate for health.

The use of these skills is particularly important when considering people with chronic conditions, like sickle cell conditions. When diagnosis is made in childhood, the type of care given throughout the individual's developing years, could very well influence the rest of their lives.

3.8 Socialisation and sexism in nursing

The historical development of the caring professions has meant that gender divisions at this time, that is up till the 1960s, were clearly seen in the health services between doctors (generally male) and nurses (usually female). These roles are stereotypes of the decision-maker (ie. father)/assistant (mother) roles, with curing functions being a part of the doctors' role while nurses were responsible for the caring of clients (Versluysen, 1980; Oakley, 1993a).

During the 1970s, matrons (ie. nurse trained administrators)

were replaced by managers, and nursing skills by management skills. This favoured male nurses, who have made serious inroads into nursing. Although only 10% of all nurses are men, men make up 16% of all registered nurses, 36% of all district level nurses and 27% of all regional level nurses (Elston and Doyal, 1983).

In the same way, nursing reforms have produced class and racial divisions based on first, second, third and other levels of nursing. Ancillary workers, (for example, catering and cleaning staff) are largely women, many representing minority ethnic groups (Doyal et al., 1981; CRE, 1981).

3.9 Black women in the NHS

In the 1950s, the British government, directly or with the aid of subsidies from Caribbean governments, recruited large numbers of workers (Bryan et. al., 1986). These were needed urgently to provide labour in critical areas of the British economy, such as public transport and health.

Many black women joined the NHS with the intention of becoming nurses. They were offered work in areas of nursing which were unpopular with British health carers, for example mental illness, mental subnormality and geriatrics (McNaught, 1988). The women of the Caribbean were offered what looked to be attractive salaries in terms of exchange rates between sterling and Caribbean currencies. Additional incentives included perceived better educational opportunities and the experience of a new way of life (Bryan et. al., 1985).

3.9.1 Racism in nursing

Black workers were largely recruited to work as enrolled or auxiliary nurses. On arrival in Britain, black women accepted for nurse training by the NHS (while still in their own countries), were encouraged to train as enrolled nurses. They made up the largest proportion of enrolled nurses, despite the fact that their own countries did not recognise this type of training. This meant that on completion of their training, they could not return to their countries of origin to work as trained nurses. On realising that they were to receive EN training, some of the more assertive nurse trainees who had successfully passed the GNC's own examination for registered nurse training (done while they were still in the Caribbean), had to 'do battle' to get on the RN course (Bryan, op.cit.). Furthermore, nurses who had completed their EN training successfully found it difficult to transfer to RN courses, as they often received poor references from their senior nurses. Those who succeeded were made to do a further 2 year course, during which time they temporarily lost their EN status and became student nurses (with the attendant student nurses' pay).

With the advent of Project 2000, there was some hope that ENs could get on courses which would train them as RNs without loss of status or pay. However, the effects of Project 2000 appear to be most serious for many nurses as efforts to get on conversion courses fail. It appears that Black ENs (in particular) have found that places are either unavailable or inaccessible (UKCC, 1986). Black nurses continue to have

negative professional experiences in terms of access to training, promotion, recognition and encouragement (Baxter, 1988; CRE, 1987). Furthermore, the introduction of higher academic qualifications for entry into EN and RN training courses prohibits school-leavers who have not been able to accumulate the requisite number of 'O' and 'A' level subjects, from undertaking nurse training.

Black women who succeeded in becoming registered nurses found that on qualifying, prospects for promotion were virtually non-existent (Torkington, 1983; Rooney, 1987; Grimsley and Bhat, 1988). Black nurses have largely remained isolated, and it is only within the last five or six years that the Royal College of Nursing (the main nursing organisation in Britain), has produced a statement of intent for equal opportunities and has begun to be seen as working for all nurses and not just those of the white British population. The effects of the RCN initiatives are yet to be seen. In the meantime, as a result of overt and covert racism, few black youngsters are applying for nurse training (Baxter, op.cit.; Alibhai, 1988). There are fears for the future of black nursing in Britain. Baxter (1987) contends that the number of black and minority ethnic nurses is seriously in decline, and they may disappear from the NHS altogether. Baxter argues that this has been caused by the health service ignoring black nursing contributions over the past forty years, and to the fact that black nurses remain in menial low status jobs missing out on promotion opportunities that have been offered to their white colleagues.

This has been confirmed by the Royal College of Nursing who have attempted to reverse this trend by the temporary appointment of a black Special Advisor to its General Secretary. This advisor had the task of highlighting and facilitating the elimination of many of the problems black nurses face, thereby increasing confidence among members of the present and prospective black nursing community.

3.10 Social services and social work

> " The development of social rights involving equal access to certain public services and benefits, is necessary to complement the civil and political rights that hitherto were considered the hall marks of citizenship" (Weale, 1987: 108).

Health services and health professionals make up one part of what is known as the 'welfare state'. The development of 'free' health services and nursing provision ran parallel to another major aspect of change in the late 19th and early 20th century - that is, the development of social services. Reforms saw the introduction of Acts and Laws to improve the lives of poor people. These included the provision of education, free school meals for poor children, the establishment of minimum wages, pensions, health and unemployment insurance, the introduction of family allowances and the provision of National Assistance (Saville, 1987; Wilson, 1987).

The social policy of the Welfare State espoused the notion of equality and sought to redistribute enough resources to allow poor people to have equal access to health care, education, housing, income maintenance and social security. Social policy was defined as a 'set of structures created by men to shape

the lives of women' as, although it was aimed at both sexes, it operates more in the private than public spheres. The Beveridge Report of 1942, which proposed a system of payments for people who were unable to work as a result of sickness or unemployment, institutionalised a dependent status for women.

Social work has many similarities with nursing. Like nursing, it is a caring profession (Etzioni, 1969; Glastonbury, 1982). Social workers work within a bureaucratic hierarchy in which female social workers have little power and are delegated 'female' tasks such as caring for the family (Glastonbury, op.cit.; Hanmer and Statham, 1988). As there is an element of social policing in the social worker's role, (for example as seen with the ruling on cohabitation), this is at odds with their caring role. Male social workers are concentrated in areas which are seen to be traditionally male (that is, they work largely with criminals) (Hearn, 1982). This parallels the male nurse who works predominantly with people who have psychiatric illness (Carpenter, 1980).

Social worker education and roles developed in a similar manner to nurse education and roles, with increased emphasis on higher education and specialism by type of practise developing (Stevenson, 1981).

3.10.1 Racism and the social services

> " A welfare state .. is .. used .. in an effort to modify market forces .. by ensuring that all citizens without distinction of status or class are offered the best standards available in relation to a certain agreed range of social services" (Briggs, 1961: 22.)

Like the health services, social services developed with little consideration of the needs of minority groups in Britain. Just as in nursing, where black workers were recruited as enrolled or auxiliary nurses, so too social services employed black women largely as care assistants and in other low paid jobs (Torkington, 1983; Carby, 1982).

Black social workers were a most rare commodity until the government attempted to redress this difficulty. The 1966 Local Government Act provided special funding under Section 11, or through Inner City Partnerships and the Urban Aid grants, to improve access for black people into community based caring professions (Rooney, 1987). Rooney argues that the use of special funding served to marginalise black social workers by creating distinct groups within departments, as different criteria, for example living locally and community involvement, rather than formal qualifications, were used to recruit black workers. Black social workers were therefore located at 'lower practice levels'. This in turn created a two-tiered structure of employment (seen also in nursing) which is constructed along racial lines (Dominelli, 1988). Within the hierarchical structure seen in social work, black workers without further opportunities are trapped without the career structure that white social workers have, when white workers are employed in similar ways, they are more easily absorbed into the overall departmental structure. Black people are less likely to be given the opportunity to obtain the credentials which would help them to be similarly incorporated.

3.11 Summary

The NHS and caring services have developed and grown without any noticeable appreciation of the needs of a British multi-cultural population. This is astonishing, for as was described in the previous chapter, the Britain government actively invited people from other countries to live and work here, at about the same time that the NHS was being created.

Since the NHS was created in 1946, a number of measures have been introduced to promote the equal distribution of resources throughout the country, according to regional need. However, despite state financed health services in Britain, health service problems have persisted. Research has shown that there have been continuing inequalities in the distribution of health services and therefore inequalities in access have continued.

Nursing has traditionally focused on management, training, professionalism and primary care issues, without considering the interactions between staff and between staff and clients of different cultures. Nursing professional development which has largely occurred after the migrations of the 1940s, failed to acknowledge the contributions and needs of these minority ethnic groups. This has led to marginalisation of the needs of clients which have not been addressed in nursing (and medical) education. Furthermore, discriminatory practices have channelled and kept black carers who could have been able to provide different perspectives of care, in the least attractive nursing posts and specialisms, with little or no

chance of promotion. This has resulted in young black people showing their distrust of the NHS and nursing profession by their apparent rejection of nursing as a career. It could be argued however, that clients would benefit from having carers of their own ethnic groups available, especially when their illness state is seen as being specific to their particular racial group.

The burden of ill-health is greatest amongst groups living in certain regions and amongst members of particular groups, for example the working class, the unemployed, women and members of minority ethnic groups. Social deprivation is associated with ill-health, and the use and availability of health services appears to be reinforcing inequalities through a lack of adequate services. In addition, health care systems have been shown to be somewhat resistant to change and do not always meet the needs of the populations they serve.

These issues are important for members of the black community, particularly when they have chronic, life-threatening health problems. Poverty, relative deprivation and discrimination all affect mental and physical health. When such considerations are combined with sickle cell conditions which are themselves adversely affected by deprivation and stress, then health care which is freely available becomes most essential.

The development of the welfare services has followed a similar pattern to that of health services. Professionalism of both nursing and social work has occurred in conditions were racism is evident. The experiences of black workers in health care

with regard to their career development are mirrored by those in social services' positions.

Caring, social and welfare services are important to this piece of research, for as we see, these variables have had a major impact on the health and well-being of sample members. Sickle cell conditions predominantly affect people with minority ethnic status. These groups of people are therefore highly likely to suffer inequalities in these important areas. Nurses make up a large portion of the labour workforce of the NHS and are therefore a potential source of power for change. The issue of appropriate and efficient services for those with sickling conditions need to be addressed by those delivering health care - nurses and health visitors.

It is possible that the restructuring of the NHS, and the client-centred approach to nursing care have in recent years, encouraged improvements in care for minority ethnic groups, both in terms of access to care, and in the quality of care provided. Furthermore, districts which have large minority ethnic populations, would have services appropriate to their needs.

This discussion of the development of health care leads directly to the first hypothesis. This briefly states that districts which have comprehensive care services, would provide good screening and counselling services for haemoglobinopathies, provide appropriate information and advice, have protocols for treating emergency and non-emergency cases and refer people to the relevant community

care and voluntary services. The evidence for these districts having a comprehensive package of care, (or not as the case may be), will come from a number of sources as will be seen later in the thesis.

This chapter also contributes to the development of the following hypotheses.
That:

People with sickle cell conditions in CPC districts will have easier access to health care,

By virtue of their longer period of education, health visitors will have greater knowledge of sickling conditions than hospital based nursing staff,

Nurses and health visitors in CPC districts will have greater knowledge than their counterparts in other health districts as having a CPC package includes in-service training about sickle cell conditions.

CHAPTER 4 - Methodological issues in research

4.0 Sickle cell conditions and research

This chapter briefly discusses the debate which surrounds research methods, and outlines the methods used in this study. Research on sickle cell conditions has largely been undertaken by medical professionals, usually using quantitative methods to measure the incidence of the conditions, the effectiveness of chemotherapy on crises, and so on. A few client focused studies looking at the illness experiences of people with sickle cell conditions have been carried out, in the main by specialist sickle cell centres within London where services for black people are generally more available and accessible. This study hopes to use a top-down bottom up approach to assess the knowledge base of nurse carers and their clients. It also hopes to present clients' perceptions of what it is like to have sickle cell genes. The study therefore draws on different methodological approaches in order to achieve this.

4.1 Research methods

Quantitative and qualitative methods make up the dominant research paradigms. Quantitative research is generally seen largely by physical scientists as being the best method for collecting replicable 'hard' data. Such data, it is argued, can be examined by rigorous statistical testing, and predictions made based on the findings (Everitt, and Dunn, 1983). Qualitative methods, on the other hand, are seen as producing 'soft' data, which will not necessarily be

appropriate for statistical analyses and cannot be replicated with any degree of accuracy.

However, qualitative material gives meaning and depth to the 'hard' facts generated by quantitative research. Social scientists believe that social processes cannot be fully explained by the examination of social structures, and that situational and interpersonal factors including symbolic interaction, and individual experience of the everyday world, need to be included as well (Lee and Newby, 1984).

Sociologists identifying with the different research paradigms have employed different methods in sociological research. Today, the arguments are much for 'mixing' methods, as each is seen to have important benefits for the research process (Brannen, 1992).

4.2 Positivism

The aim of positivism is to reduce explanations of all phenomena to the smallest number of principles or laws. Positivists have argued that the logic, methods and procedures of the natural sciences are applicable to social beings, and that with enough time and effort, sociologists should be able to uncover the laws which govern and explain social facts. The basic assumption of this approach is, that even in a rapidly changing environment, there is a definite regularity and order in the natural world (Durkheim, 1974; Weber, 1949). Changes themselves display patterns that can be understood. If it is assumed that behaviour in the social and natural world is

governed by the same principles, then natural science methodology would be appropriate for the study of human society.

Positivists argue that only factors which can be directly observed and objectively measured form reliable data. Thus the feelings and motivations and mental states of individuals which cannot directly be observed are not seen as being acceptable. Positivism depends mainly on challenging predictions set up as hypotheses. When data do not support the theory, positivist researchers must develop their own 'common-sense' explanations. If a prediction fails, then the theory behind it needs to be changed to account for the findings.

Positivism has difficulty establishing convincing scientific explanations for all social phenomena (Walsh, 1972). A famous example is Durkheim's theory of suicide. Durkheim's explanation of suicide rates with states of social integration, ignored the fact that individuals experience events subjectively and give different meanings to those events. The social causes of suicide could not be described without referring to their effects on the psychological condition of individuals, and particularly the differences between male and female thinking (Durkheim, 1952; Douglas, 1971). A further weakness was Durkheim's inability to clarify his notion of the degree of the individual's integration within society (Gibbs and Martin, 1964).

The positivist assumption is that, because there is an underlying cause and effect aspect to social behaviour,

universal laws are discoverable allowing behaviour to be predicted (Walsh, 1972). The application of positivistic methods in medical sociology, showed up major discrepancies in the way health care professionals, and clients perceived health and illness (Friedson, 1970). The lay individual's view of health and illness was seen by health care professionals as being inferior, irrational and therefore less valid than the superior, scientific and therefore rational medical view. Their thinking supported Parson's work on 'the sick role' and the 'doctor-patient relationship' (discussed in chapter 2), but excluded the individual's own perceptions.

Positivistic views have attracted much criticism. Roy Bhaskhar's (1975) explanation is that this is because sociology operates with a realist view of the nature of reality. He argues that it is mistaken to reduce society to groups; the relations within which both individuals and groups stand are primary to sociological analysis. Bhaskhar provides a version of sociological explanation as the movement from people's experiences to the social relations and processes which necessitate them.

A vision of reality based on awareness of the inter-relatedness and inter-dependence of physical, biological, physiological, social and cultural factors, is required for a research approach and the conceptual modes needed to grasp the nature of human phenomena and the universe in which we live (Capra, 1983).

4.3 Qualitative approaches

The interpretive school of sociology prefer to use what are known as qualitative methods, and consists of the phenomenologists, interactionalists and ethnomethodologists (Lee and Newby, 1984). In qualitative research the researcher works inductively. That is, instead of testing theory by deduction, qualitative methods require the researcher to examine the data for patterns and relationships, developing and testing hypotheses to generate theory. Theories already developed may be used to explain the data which are collected in a semi-structured or a totally unstructured way depending on what topics the researcher wishes to cover.

4.3.1 Phenomenology

Phenomenology was proposed as a new research method in 1900, to provide philosophy with 'humanism' as well as rigor (Kockelmans, 1967). The phenomenological perspectives of sociology are seen as offering a radical alternative to positivist methodology. From this perspective, there is a major difference between subject matter of the natural and the social sciences.

Unlike matter, people have consciousness and the individual is more important than the system (Oiler, 1982). Individuals actively create and construct their own social reality and meanings do not have an independent existence which is separate from the social actors'. Instead, meanings are constructed and remodelled by actors in the course of social

interaction (Giddens, 1976). From a phenomenological perspective then, the social world is a world of meaning in which no objective reality lies behind that meaning. Therefore, to treat social reality as anything other than a construction of a meaning is to distort it.

Phenomenology attempts to understand people's experiences, how they make sense of their lives and the worlds in which they live (Douglas, 1971). The means by which people act out their lives and their perceptions of what they do becomes the focus for study, as does they way in which their practices and experiences are maintained, re-affirmed and adapted within their communities (Walsh, 1972). In this way commonalities and uniqueness can be examined to give meaning to social actions (Schutz, 1967).

Phenomenology uses both analytic and concrete inquiry. Analytic inquiry concerns underlying principles, laws and assumptions which give meaning to occurrences, while concrete inquiry is a description of phenomena (Spurling, 1977).

4.3.2 Grounded theory

Grounded theory is rooted in empirical research which fits everyday situations. Like phenomenology, it advocates the gathering of qualitative data, while at the same time formulating hypotheses and concepts in terms of the data being collected (Glaser and Strauss, 1967). The research is directed by the difficulties of the work and by information uncovered. It has been suggested that grounded theorists initially ignore

the literature of theory and fact concerning the area under study, in order that the emerging categories of data will not be contaminated by concepts more suited to other areas (Glaser and Strauss, op. cit.). The suggestion here is that the researcher develops the research question from the data. Emerging concepts are compared with the data set to examine their representativeness, unusual features being examined for relatedness.

4.3.3 Interviews

> " The aim of any research interview is to get truthful information from people on a subject about which they are under no obligation to tell, if they do not wish to" (Stacey, 1985: 72).

There are differing views regarding the use of interviews as a method of collecting data in sociology. Some researchers argue that interviews are interaction situations where problems with validity may occur and are therefore not 'scientific' (Kahn and Cannell, 1957; Moser and Kalton, 1981; Oppenheim, 1982). These researchers who may be of either sex, are often described as having 'masculinist' viewpoints; views which have largely evolved from masculine psychology representing the influences of the dominant social group. 'Masculinist researchers argue that, as the results of an interview will depend in part on the way the participants define the situation and their perceptions of each other, interviewers may communicate their values, attitudes and expectations to the interviewee thereby influencing what is said in the interview (Kahn and Cannell, 1957; Moser and Kalton, 1981; Oppenheim, 1982). This influence is seen as

being particularly more likely in the more informal situation of the **unstructured** interview, that is, one which does not have a formal survey type questionnaire; interviewers could 'lead' respondents to answers which reflect something of what the interviewer expects. Researchers taking the 'masculinist' viewpoint argue that interviewers have to be as non-directive as possible; to refrain from offering opinions and avoid expressions of approval and disapproval, while establishing rapport with their respondents which implies sympathy and understanding; and to guard against communicating their own attitudes and expectations.

The view of 'masculinist' researchers then is that the interview is an information-getting tool which should be designed to minimise any circumstances (including interviewer/interviewee interactions), so that 'bias' may be avoided (Benny and Hughes, 1970). Interviewers should remain detached and in control of the interview at all times.

Oakley (1988) argues that while surveys and questionnaires have an extremely important role, the reality of interviewing includes many issues which affect interviewer-interviewee encounters.

> " 'Proper' interviews in the methodology textbooks owe a great deal more to a masculine social and sociological vantage point than to a feminine one" (Oakley, 1988: 38).

Oakley points out that quality interviews are best achieved if the relationship between interviewer and those interviewed are non-hierarchical and both parties relate to each other and to

the interview. She also emphasised the position of the interviewer who had the initiative taken away from them by interviewees whose hospitality was such as to banish aloofness between them. Furthermore, Oakley asserts that a traditional, 'text-book' interviewing style is problematic for feminist interviewers whose main aim is to validate women's subjective experiences as women and people. She quotes Mamak's comments on interviewing women,

> " I found that my academic training in the methodological views of Western social science and its emphasis on 'scientific objectivity' conflicted with the experiences of my colonial past. The traditional way in which social science research is conducted proved inadequate for an understanding of the reality, needs and desires of the people I was researching." (Oakley, 1988: 55).

Other feminist researchers support these views and argue that 'masculinist' methods assume that individuals share a heterogeneous culture which can be accurately measured (Graham, 1983). Graham argues that women experience the world from a 'complex web of asymmetrical social relationships'. 'Masculinist' methods therefore cannot accurately assess the impact of gender on the means of production and the social relations on which production is embedded (Graham, 1983).

Women interviewing women are able to elicit information mainly for three reasons (Finch, 1984). First, women are used to being asked 'personal' questions, for example through their experiences as mothers by midwives, health visitors and doctors. The woman/woman relationship is therefore conducive to the easy flow of information. Second, women, in the setting of their own home, feel quite comfortable with their guests who also happen to be interviewers. Finally women perceive

that they have similar positions in the structure of society, see themselves as equal and welcome the opportunity to talk to a listener who is seen to be sympathetic.

Although the more formal interview appears to be getting the thumbs down in this discussion, feminists recognise the contribution it can make to research. In structured interviews the wording and order of questions are the same for all respondents, so answers can be easily compared. However, as attitudes and opinions are not discussed, valuable data are lost. Semi-structured interviews offer a reasonable compromise, as they allow the collection of 'quantifiable' data, as well as the stories which people wish to tell.

4.4 The study

The methods used in this study include elements of both survey and qualitative methods. The prevailing feeling, at the time of the study, was that nursing research may not be seen to be valid, to nursing and medical 'experts', if quantitative methods were not used. Structured questionnaires were therefore used to identify what carers and clients knew about sickle cell conditions. Survey methods also obtained demographic and other data, such as hospital admissions and use of other facilities. However, these methods simply do not provide data which gives a good understanding of why people give the responses they do in surveys, and how various experiences and perceptions can affect their knowledge and use of health care facilities. It was therefore necessary to employ methods which would obtain this information, and the

collection of qualitative data was integrated into the study. Semi-structured interviews, which generally lasted about 90 minutes were carried out by the researcher, and encouraged sample members to discuss their experiences, and explore their perceptions of what it is like, in terms of health care and information needs, to have sickle cell gene(s). Much of the interview data produced a view of the ***realities*** of living with sickle cell conditions. In other words, the data provides an insight of how sample members interpret situations which may have an effect on their health and well-being.

Interviews were carried out in the clients' own homes, at times selected by them. This invariably meant that data collection was done in the late evening or at night after young children had been settled in bed. Clients permission was obtained for a tape recorder to be used during the interviews. Tapes were coded to ensure client anonymity, and assurances were made that tapes would be 'wiped' after coded transcripts had been made.

This research is divided into two parts. The first part focuses on clients' perspectives and experiences of health care, and how this affects them. The second examines nurses' and clients' knowledge for sickle cell conditions.

4.4.1 Developing a measure of knowledge for sickle cell conditions.

A search of the available literature showed that there was no measure which could be used for this study to assess what people knew about the established facts concerning sickle cell conditions. It was therefore decided to develop a self-completion measure of knowledge for sample members. The questionnaire for health carers was developed first and was then amended for client usage.

The key activities for the care of those with sickling conditions were identified after a search of the available literature. Specialist health visitors, working with families in which one or more members has a sickle cell condition, and people with the conditions as well as medical experts in this area, were then consulted and agreement obtained that key activities included:

1. Providing factual information about sickle cell conditions, and clearly explaining the mode of transmission of sickle cell genes to offspring.
2. Promoting the use of appropriate and positive health behaviours in order to minimise the effects of the conditions.
3. Encouraging families to discuss their concerns with health carers regarding the conditions.
4. Ensuring that the affected members of the family receive coordinated and continuous care by liaising with community and school nursing personnel.

5. Providing screening for sickling conditions for susceptible populations.
6. Providing genetic and other counselling for affected individuals and families.
7. Recognising the symptoms of sickle cell conditions.
8. Alleviating pain, administering antibiotics and other drugs and maintaining an adequate fluid balance during a crisis.

If these key activities are to be achieved, nurses and health visitors need to be well informed about the conditions. The France-Dawson Knowledge Measure (FDKM) was devised to assess knowledge of five broad categories. These are:

A. Definitions

i) The definitions of certain key words, eg. sickle cell disease, sickle cell anaemia, crisis, and so on.

B. Symptoms

The major symptoms of sickle cell conditions are easily recognised when in combination. Many sickle cell symptoms are common to other haematologic conditions, the exception being the 'crisis'. It is therefore expected that carers should have good knowledge of some of these symptoms.

C. Pathology/epidemiology

Items on the measure identify knowledge about:

i) Which populations are most 'at risk'.

ii) The mode of transmission of sickle cell genes.

iii) The course of sickle cell related illnesses and their treatment.

iv) Environmental conditions which can precipitate crises.

D. Nursing care for people with sickling conditions

People in sickle cell crisis have certain basic requirements of which all carers should be aware. These include the need to be kept warm, pain control, adequate hydration and possibly oxygenation of the client. The nurse takes responsibility for all of these tasks including pain control after appropriate chemotherapy has been prescribed.

E. Health promotion

Items on the measure also elicit responses regarding the following:

i) What advice to give clients with sickle cell conditions about:

   a. How to avoid precipitating crises, eg by keeping warm

   b. The importance of keeping fit and well through exercise, fluid intake, and diet

   c. What to do regarding pain when it begins

   d. Having the family tested for sickle cell haemoglobin

e. How the genes for sickle cell conditions are transmitted

f. The relevance of the sickle gene to family planning

g. Appropriate actions to take when visiting countries where malaria is a problem.

This framework was used to guide the generation of test items. It was decided to construct a multiple choice self-completion measure suitable for administration to groups.

4.4.2 Multiple choice format

A multiple choice format was chosen to test a wide area of general knowledge. Multiple choice questionnaires have the advantage that each respondent's knowledge is evaluated by a uniform measure which does not require as much individual interpretation as would a questionnaire with an open-ended format. A further advantage of using multiple choice measures is that they 'tend to produce a more accurate measure of achievement', that is, the respondents' score is less likely to be inflated by chance events (Shields, 1965). Finally multiple choice tests cut down on the time needed for administration and scoring.

The questions in the measure were based on factual information on sickle cell states which the respondent had to understand in order to judge the selection of appropriate nursing and health promotion strategies. These strategies would normally be used when meeting the needs of people with sickling

conditions and of their families.

a) Description of the measure

On this basis, a self-completion measure was designed consisting of thirty items following a multiple-choice format. These items test knowledge of definitions for specific terms, transmission, pathology, nursing care and strategies for promoting good health. The range of possible scores is 0-30.

Fourteen additional items were included to provide background information including age, qualifications and experience, ethnicity, nursing/health visiting contact with minority ethnic groups and sickling conditions and contact with sickle cell voluntary organisations.

4.4.3 Test-retest reliability

A test-retest reliability study was carried out using two versions of the measure of knowledge. In one version, items were grouped according to content, that is, in a progression of categories from definitions through to health care advice, and arranged in order from fairly basic questions, for example, on how the conditions have arisen, to more complex items requiring respondents to deduce the correct answer. In the second version, the questions were arranged in order from basic to complex regardless of the content. This was done to see whether there would be differences in the scores of respondents filling in the questionnaire, based on the way the questions were presented to them.

a) Sample

A group of nurses (N = 46) attending the Institute of Advanced Nursing Education, based at the Royal College of Nursing undertook to take part in tests to examine the reliability of scores over time. The nurses were students of Nursing Administration and Nurse Education.

The study was explained by the researcher and participants were given code numbers, an assurance of confidentiality was given and no names were taken. Students were asked to see the researcher again after a two-week period. The code numbers were matched with them when they were seen two weeks later. This time interval was selected to reduce the possibility of inflated reliability estimates (Nunally, 1964). The entire test took fifteen minutes to complete.

b) Analysis

Data analysis, including frequency distributions and statistical tests, was done on a hand calculator.

c) Results

Details of these procedures are to be found in Appendix 5. The two versions of the measure were found to be equally reliable (rP=0.78) and there were no differences in mean knowledge scores. This was confirmed by a repeated measure analysis of variance which showed that there were no differences between the two versions of the measure although there were consistent

differences between subjects taking the test.

The scores of a third group of students of occupational health (n = 20) were combined with the first test data obtained, to ascertain whether the test would discriminate between those who had cared for people with sickle cell conditions and those who had not. The measure successfully discriminated between the groups, with those who had nursing experience obtaining higher scores.

The measure also showed lower levels of knowledge for students who were on nursing administration courses compared with those who were on occupational health or nurse education courses. As many of the students of education and occupational health had cared for people with sickling conditions, whilst the students of administration generally had not, this may simply be a reflection of differences in experience of nursing people with sickle cell related illnesses. Students of administration pointed out that most of them had not worked on wards for many years as their tasks mainly involved the administration of nursing services.

c) Effectiveness of the measure

The measure appears to be reasonably reliable and its ability to discriminate between different groups of students suggests that it is also a valid measure of knowledge of sickle cell conditions and their treatment.

e) Items

The items had been rated by health visitor specialists from seven sickle cell centres throughout the country and judged appropriate for testing nursing knowledge about sickle cell conditions and the health care needs of people with these conditions. Item analysis showed that some options were not readily selected and these were amended.

4.4.4 Developing the interview schedule for the 'client sample'

No interview schedules designed specifically to obtain information from black people about their views on pregnancy, childbirth and other issues to do with reproduction were discovered in the literature. In addition no schedules could be located, geared to obtaining information on the experiences of people who have sickle cell genes, including what this means in terms of their health, their lifestyle and their fertility. An interview schedule was therefore developed for use for this study. A review of the literature on reproduction and sickle cell conditions was done, and a small pre-pilot study carried out. A sample of thirty women (out of 40 people invited) with one or more abnormal haemoglobins was seen and issues of ill-health, health care and reproduction discussed with them. Men with abnormal haemoglobins who were invited to take part declined to do so. One reason for this may have been that men who are aware of their diagnosis, as this group undoubtedly were, would have selected partners who were free from sickle cell genes. These men would not necessarily have

any concerns about their partners' reproductive and general health, because neither the women nor any children the partnership produced would have a sickle cell condition; children from such partnerships would at worst, only be carriers of the sickle cell gene.

Sixteen participants were seen in two equal groups, the remainder being seen individually. Both group and individual interviews lasted for approximately one hour. This group had been randomly selected from lists of members on the lists of the Organisation for Sickle Cell Anaemia Research (OSCAR) and were invited to attend a meeting at OSCAR's headquarters. The content of information from these interviews was used to form the basis of the semi-structured interview schedule. This provided background information on age, sex, marital status, Hb type, employment status, education, religion, social class and area of parental origin. The interview schedule which is reprinted in appendix 1 included questions which were intended to give an indication of:

i) illness experiences,
ii) hospital and community care,
iii) health care needs and lifestyle, and
iv) beliefs/opinions about reproduction.

4.5 Some points of interest about the study

The study focused on clients and nurse carers separately. It would have been extremely valuable to observe interactions between the two groups, so that areas of good practice, and

those which could create conflict, could have been identified. More time could have been spent identifying the needs of generalist nurse carers, other than their perceived need for knowledge about the conditions. It would also have been useful to collect information about doctors (ie GPs) who are after all, responsible for and in overall command of primary health care teams caring for individuals. Interactions between clients and their GPs would have given more meaning to community care benefits and difficulties, and interviewing doctors may have highlighted their needs and problem areas. However, this research was funded primarily as an exercise in nursing concerns. Cost, the time needed and the chances of finding people who may have been going through a 'well' phase visiting their doctors for anything other than a routine blood test, meant that this was not feasible. Observations of members of the sample with members of social services would also have thrown light on social problems, eg of housing, employment and so on, but this was equally not feasible, given the problems of cost and timing.

The role of fathers was not much explored in this study. Although ten men were interviewed regarding their attitudes to pregnancy, contraception and abortion issues, the focus was largely on their partners' experiences of reproductive care. Fathers in the sample who were interviewed showed a keen interest in their families' welfare. Further interviewing of their feelings about fatherhood would have been beneficial, but based on the piloting work done for the interview schedule, the schedule was largely geared towards interviewing women. In addition, some men may have been more forthcoming

with a male interviewer, particularly for issues such as the woman's right to terminate a pregnancy.

Finally the researcher is black, female and has a sickle cell condition herself. This was an advantage in understanding what was being discussed. However, it may be seen by 'masculinist' researchers as a disadvantage, for remaining objective and a listener when people were talking about familiar emotions and occurrences was difficult at times.

In recent years much has been written about the importance of the interviewer-interviewee relationship. It has been argued that the research process should be oppressive to neither researcher or the researched (Oakley, 1993b). Furthermore, interviewer-interviewee interactions should take place between members of the same sex, race and class wherever possible as these types of interactions are most likely to produce valuable insights into peoples' lives via the stories they tell (Anderson, 1993; Stanfield, 1993).

At this point, and only for this section, I will address the reader directly, as it is more comfortable to describe my experience of this study in this way. I found it personally very satisfying. If the reactions of most of the people I interviewed were genuine, it appears to have been satisfying for them too. The first reaction from sample members was one of surprise. They were not expecting a black researcher. This was followed by delight by most people, especially when I told them that I too, had a sickle cell condition. They began to see me as a sign of hope and achievement. Hope that I would

make a difference by telling their stories. Achievement because they saw a 'sickler' who 'made it', as they perceived my role as a researcher to be a good thing. A few people were suspicious initially, and wondered if I had come to do 'their job for them' (white people). Although they agreed to take part in the study, and were eventually pleased to be interviewed by a black woman, they indicated that they were not expecting to see any particular improvements in health care, because a black researcher would be powerless in bringing about changes.

Nevertheless, I was always invited in and made to feel welcome, most likely by the offer of a hot drink. After the usual chat about our origins (place of birth and so on), generally initiated by them, I began the process of research. People were asked to fill in the knowledge measure first. They were assured that any questions they could not answer would be discussed with them. The provision of knowledge after the completion of the measure was almost guaranteed to dissolve any concerns people had about my commitment to the ideal of giving their contributions to the sickle cell debate an airing. It also helped to focus many of the questions that would follow, on the conditions themselves, and on what strategies could help with the attaining and maintaining of good health behaviours.

As a nurse researcher, I was bound by how much information I could give to interviewees. For example, I was not allowed to give any information which 'contradicted what they were told by their own doctors'. Fortunately, most 'medical' questions

which could have been problematic for me, required me to have more information than the questioner had. In those cases, I was able to guide the enquirer to a more appropriate source of information, most likely the sickle cell counsellor or the haematologist, after having armed them with the types of questions they needed to ask.

However, three cases posed a problem for me. All of the women were either on the injectable contraceptive Depo Provera, or were considering using it. One of the women was concerned that she was being coerced to take the drug. As it happened, she didn't really need my advice, and talked herself round to making the decision she felt was right for her. The second woman who was considering taking the drug also had some reservations. I helped her to make a decision, by asking her if she was happy with the contraception she was currently using, and suggesting that she should follow her instincts.

The third woman had been using the drug for a year, and had worrying side effects (discussed in chapter 10). She had shown an interest in the study and wished to do some reading of her own. I recommended some reading materials which I knew would help her make her own decisions. I also made sure that she had my telephone number if she needed to contact me again. She did and the content of our conversation is described in chapter 10.

People in the sample made me realise that if nothing else, by providing them with factual information about the conditions, and discussing ways and means of trying to improve their

health, I was making a contribution. It would not be until after the study was over, that I realised that they too had made a contribution to **my** health. I experienced the sudden deafness described by one woman in the study. As a result of her experiences and my subsequent reading on the subject, I was able to persuade my GP to take prompt action, and I am now not as deaf as I could have been. Unfortunately, she appears to have moved away and I was not able to contact her again to thank her.

All of the interactions in the study were comfortable and appeared to be based on feelings of equality, even with male interviewees. However, I did become aware of the benefit of same sex interviewer-interviewee interactions, when one young man initiated a discussion on the woman's right to terminate a pregnancy without her partner's consent. This was triggered by our discussion on abortion, and the case, in the national press, in which another young man had failed to get a judicial ruling preventing his ex-lover from terminating her pregnancy. Although we were able to discuss what happened fairly objectively, I felt that a male researcher would have been more appropriate in this situation, because although I understood what he was saying, my sympathies lay with women.

When the study was completed, I did a number of seminars and workshops to disseminate the results of this work to the people who took part. Since then, I have bumped into a number of them at conferences and study days. When this happens, we always have much to discover about what been happening in each

others' lives and much to learn about coping (or not) with new situations, new problems. Strangely enough, on these occasions I only ever seem to bump into women who took part in the study.

Much of the data in this study comes from clients' stories and as such, this work is giving their perspective, their reality of living with sickle cell. Very few problems emerged with interview data, as so much of it was very similar. People had many concerns about health care provision, and other social variables, such as employment and housing in common. Some of these findings have been seen in other studies (Black et al., 1984)

The study was also not designed to compare sickle cell with other conditions, but rather to look at the experience of sickle cell care where there is perceived to be good health services compared with where there are few services. In this sense, the districts which have poor services are seen as a 'control' group. As a result, many of the analyses will reflect this split. This is not to say that analyses based on other variables, for example sex, age and parenthood, have not been done. Where analyses have been found to be not significant, tables showing them will be placed in the appendix, rather than in the text of the thesis.

CHAPTER 5 - THE STUDY

This chapter describes the design of the pilot and main studies in both client and carer arms of the research.

A. The clients

5.1 The pilot study

5.1.1 Objective

i) To develop and refine the interview schedule and a measure of patient knowledge of sickling conditions, the France-Dawson knowledge measure (FDKM), which was also tested for reliability.

ii) To assess the feasibility of the proposed sampling procedure for the main study.

5.1.2 Method

Clearance for the study was sought from the ethics committees of health districts. The permission and co-operation of consultant haematologists and general practitioners were obtained before letters were sent to individuals to ask for their co-operation with the research. A consent form (Appendix 4) was enclosed with the letter of invitation, along with a stamped addressed envelope. Participants were assured that they could discontinue interviews at any time if they so wished. Complete confidentiality was assured. Interviews were tape recorded and identities protected by the use of code numbers on tapes. Code numbers were also used on interview

schedules. The researcher undertook not to reveal the identities of participants in written or verbal reports.

Having obtained ethical clearance, the pilot study was carried out in two health districts. Both districts, one in London and the other in Avon, had an appreciable minority ethnic population. One district fitted the Runnymede Trust survey criteria (1985) for having a comprehensive package of care (CPC) as was explained in chapter 1. By the same measure, the other district did not meet these criteria (NCPC).

5.1.3 Sample

Ten people aged 16 or over, who have been diagnosed as having a sickling condition or trait, were randomly selected from the lists of each district haematologist.

5.1.4 Instruments

i. The interview schedule was designed to provide information about:

1. Age, sex, marital status.
2. Education, social class, employment status and parental origin.
3. Haemoglobin status.
4. How individuals perceive their health.
5. Extent of any disablement.
6. Access to health care and take up of services.
7. Hospital experience.

8. Perception of their need for services and satisfaction with care.
9. Self-care and management of any crises.
10. Beliefs/opinions about pregnancy, contraception and abortion.
11. Health status of other family members.
12. Social activities and physical pursuits.
13. The social and psychological consequences of sickling conditions for individuals and their families.

ii. The France-Dawson Knowledge Measure of sickle cell conditions (FDKM).

This measure was originally created for carers in this study. The carer study was done first, and this facilitated easier access to client groups in the second stage. For the purposes of this thesis, the majority of the results of the client study will be dealt with first because the work fits more neatly together taken this way. After the study which looked at carers' knowledge was completed, the knowledge measure was adapted and lengthened (from 30 to 40 items) for use with lay people. The additional 10 items were largely concerned with issues for self care. Like the carers' measure, it is a self-completion, multiple choice questionnaire.

5.1.5 Procedure

Letters explaining the purpose of the study and containing a request for co-operation were sent to each person who was

sampled from the haematologist's list. A printed card together with a stamped addressed envelope was enclosed for people to notify the research unit of their decision. Those who agreed to participate were then contacted to arrange an interview in their own home. These interviews, part of which were recorded on tape (with the person's permission), took approximately one and a half hours to complete.

The purpose of the study was also explained and a request for co-operation was made to a convenience sample of people attending hospital haematology clinics who were to complete the FDKM (knowledge measure) during their clinic visit.

5.1.6 Analysis

Responses to the FDKM were coded and analysed on the London University Computer, using the Statistical Package for the Social Sciences version X (SPSS Inc. 1986). The measure was shown to be reliable (Cronbach's alpha = 0.82).

5.1.7 Conclusions

The sampling procedure was found to be feasible and no modifications were necessary. Minor adjustments were made to the interview schedule.

5.2 Main study

5.2.1 Sampling procedure

Using a sampling frame derived from Prasher et al., (1985), requests for co-operation were made to five health districts. These were selected using the following criteria:

1. All the districts have appreciable minority ethnic populations with large numbers of African-Caribbean people.
2. The districts were spread over an area in the Midlands which could be commuted to and from, within a reasonable amount of time. Although there were many other districts which could have been sampled, these tended to be further away from London. These districts which had large minority ethnic populations either tended not to provide good services, or were just beginning to develop services for people with sickle cell conditions. Record-keeping on numbers of people with the conditions, at the time the study took place, were therefore often non-existent. It would have been too expensive and time-consuming to attempt to identify a target population with any degree of accuracy.
3. Three health districts had poor services for people with sickling conditions. One district had comprehensive package of care (CPC) and the fifth district which provided in- and out-patient care referred its clients to the adjoining district,

included in this study, and just described as providing comprehensive services.

4. The districts were among those seen by voluntary organisations as providing minimal services, from which they received regular requests for help from the sickle cell population.

One of the five districts, which had poor services, took almost one year to deliberate giving ethical approval for the study. This district was eliminated from the study and data collection was already complete when Ethics Committee approval was denied. Approval was denied because of the volume of research which was being carried out in the district. Although there have been improvements in sickle cell care in this district, in terms of the provision of information leaflets and a counsellor, at the time of completion of this thesis, services in this district for people with sickle cell conditions are still ad hoc and patchy (pers. comm., the counsellor employed).

5.2.2 People

Four health districts took part in the main study. Sampling using randomly generated numbers which were matched to the numbered client list, was proportionate to the size of the African-Caribbean population in each district. In other words, if a district had a 30% African-Caribbean population, 30% of the people on the list provided were sampled. People in NCPC districts were approached in the same way as was described for the pilot study (section 5.1.5). In the

districts which shared services, the list was held by the sickle cell counsellor. In order to maintain anonymity in these districts, letters explaining the purpose of the study, numbered printed cards, matching client numbers for easy identification, which were to be returned complete with the names and addresses of people who wished to take part in the study and stamped addressed envelopes, were enclosed in a stamped envelope, upon which the counsellor, working with the researcher affixed an address. Counsellor/researcher cooperation was vital for randomness and number matching to be achieved.

Of the 134 people approached, 91 people agreed to take part in the study (67.9%). Fifty-four percent of the sample lived in the district which provided comprehensive services and in the neighbouring district which shared those services. The proportion of people who agreed to take part in the study could have been higher, but a number of people who returned the card expressing a wish to take part in the study, either omitted to supply their names or addresses or both, and a small number of names and addresses were undecipherable. Although it would have been interesting to find out why people who refused to take part did not wish to do so, unfortunately these data were not collected.

A sub-sample consisting of the first thirty people sampled, (ten of whom were male, all of whom were fathers) was selected and their beliefs and attitudes toward fertility and reproduction were discussed with them.

5.2.3 Instruments and procedure

The same instruments and procedures used in the pilot study were used in the main study.

5.2.4 Analysis

Student's T-tests were used to compare levels of knowledge of sample members from participating health districts. Chi-square tests were used to examine variables such as age at diagnosis, length of diagnosis and illness episodes. These analyses were carried out on the Unit microcomputer using SPSS PC+ (SPSS Inc., 1986). Qualitative data were categorised and quantified so that analyses could be done. However, in addition, these data were also treated as case studies in many instances, to illustrate specific concerns.

B. Health Carers

5.3 The pilot study

5.3.1 Objective

i. To assess the feasibility of the proposed sampling procedure for the main study.

5.3.2 Method

Requests for permission to carry out the pilot study were made to two health districts, one within and one outside London.

Both districts were selected because they had appreciable minority ethnic populations. One district had been described as having a comprehensive package of care (CPC) as was discussed earlier, the other was described as having poor services (NCPC).

5.3.3 Sample

It was envisaged that a random sample of 10 hospital nurses and 10 health visitors would take part in the pilot study, with five nurses and five health visitors coming from each district. It was decided to exclude health visitors based in rural areas, as they would be less likely to come into contact with the black populations in whom sickle cell is prevalent.

5.3.4 Procedure

The health districts were asked to supply a current list of all qualified nurses working in general hospitals and health visitors working in city-based clinics. This request was refused and link-workers were chosen who would randomly select staff from nursing lists, arrange the time of interview and provide a room in which the interviews would take place.

The agreed procedure was not followed and nursing staff were asked to volunteer in one district. The full sample of nurses was not achieved. In another district, health visitors were informed about the content of the study and did preparatory reading, even arranging to have medical and other 'experts in sickle cell conditions' to speak at a hastily arranged seminar

day, because they recognised that their knowledge was rather poor. Needless to say, these health visitors had excellent scores on parts of the questionnaire which did not specifically focus on nursing care. This pushed their score up significantly so they were deemed to have 'good knowledge' of the conditions themselves.

5.3.5 Conclusions

This method of sampling was clearly not feasible for use in the main study. It highlighted the need for researchers to have access to staff lists in order to achieve randomness in sampling, more general control over the timing of the study and access to information which is given to members of the sample. The procedural strategy was amended accordingly. Furthermore, the study intended to find out what nursing carers knew about sickle cell conditions **without going to textbooks**. In crisis situations, people with sickle cell conditions may arrive in the casualty department and on wards, at 'death's door'. Carers need to have the knowledge to be able to help these people as much as is possible. In these situations they would not have the time to trawl through libraries for the few available books which would be useful to nursing professionals or organise seminar days to improve their knowledge, before treating the client. In any event, it was the idea that 'someone was coming from the organisation to ask them about sickle cell' which caused them to become so studious on the matter (pers.comm. one of the organisers of the study day). In order to discourage prior preparation about the subject, additional questions on cystic fibrosis were

added to the sickle cell measure, and the Johnson Problem Solving Questionnaire for Juvenile Diabetics was included for administration in the main study. In order to reflect the additional focus on other conditions with a genetic component, and in response to advice from the Scientific Advisory Group, the project was described more generally as a study in genetic disorders.

5.4 The main study

5.4.1 Method

Thirteen health districts were selected because they had large minority ethnic populations and invited to take part in the main study. A number of districts which fitted the 'minority ethnic population criteria' were not invited to take part because of time and financial constraints. Of the thirteen districts, four declined to take part. One explained that district reorganisation meant that they would be unable to participate. Although regional nursing personnel in another district were interested in being involved in the study, district nursing personnel maintained that they did not have the time to take part. The third district declined stating that they had no problems with sickle cell conditions. In a fourth district, only the nurses agreed to take part, health visitors pointing out that pressure of work was too high. Data were subsequently collected from the nurses in this district to test the efficacy of the revised sampling procedure.

Discussions with district nursing staff emphasised the

importance of the researcher being able to sample from nursing lists, while protecting the anonymity of health visitors and ward staff. Lists of staff which only gave the nurses' and health visitors' name and job title were obtained from each district.

5.4.2 Sample

Nine health districts took part in the main study, a response rate of 69.2%. The largest of these districts was described as providing a comprehensive package of care by the Runnymede Trust report (Table 11.1).

A random sample of 10 hospital nurses and 10 health visitors was sought from each district, and letters inviting nurses and health visitors to take part in the study were sent out accordingly.

5.4.3 Instruments.

1. The sickle cell measure of knowledge (FDKM).
2. Johnson's Problem Solving Questionnaire for juvenile diabetics (JPSQ).

5.4.4 Procedure

Hospital nurses and health visitors were randomly selected by the researcher using a table of random numbers. Letters inviting staff to take part in the study were sent out, in batches to a link-person in each district for distribution to

selected nurses and health visitors. The purpose of the study, was explained and confidentiality was assured. A card was enclosed in each letter, together with a stamped addressed envelope. Respondents were asked to complete the card which allowed them to choose between the following responses:

1. I agree to take part in the study
2. I do not wish to take part in the study

Respondents were asked to sign the card and give a telephone number or address where they could be reached. They were also given a direct line telephone number on which they could reverse the charges, should they have any queries about the research. Follow-up letters were sent to non-responders approximately five weeks later. This was done to allow link-persons time to forward letters, particularly to nurses who may have been transferred elsewhere.

The link-worker informed the researcher of dates when an appropriate interview room would be available. Respondents who agreed to take part were then contacted and appointments made for the researcher to visit them. As participants agreed to see the researcher on the days specified, the researcher informed the link-worker that the room would be in use on that day. In some cases, nurses who wished to take part, but could not be at the arranged venue, were seen at home.

5.4.5 Analysis

Student's T-tests and Analyses of Variance were used to

compare levels of knowledge of nurses and health visitors from the participating health districts. Chi-square tests were used to examine variables such as age, length of service and contact with those who have sickling disorders. These analyses were done on London University computer, using the Statistical Package for the Social Sciences version X (SPSS Inc.1986).

CHAPTER 6. The clients' sample - a profile of the sample in districts with and without a comprehensive package of care

6.0 Introduction

Chapters 6 to 10 all deal with results obtained from the client sample. This chapter examines the demographic profiles of sample members from participating districts. The response rates for people who agreed to participate in the research are also discussed.

The lists of clients for two of the districts were held by the same sickle cell counsellor. These were in effect the haematologists' lists as they originated from the haematologists after blood testing. One of the districts fitted the Runnymede survey's criteria (1985) for having a comprehensive package of care (CPC). The other shared its services for the care of people with sickle cell conditions. As care delivery for the conditions were basically the same, the data from these two districts were combined. The other two districts were also combined because neither of them had services which were geared towards the different needs of people with sickle cell conditions. These districts fitted the Runnymede survey's criteria for not having a comprehensive care package (NCPC).

6.0.1 Response rates

The overall response rate for people with sickle cell gene was

67.9%. There were no apparent differences in response rates for the two district sub-samples. The lists for the CPC districts were separated into people with a sickle cell condition (SCC) (this list had a response rate of 83.6%) and those with trait (SCT), which had a poor response with only 17% of those contacted responding. However some people on the SCC list were found to have SCT. This was confirmed by examining the haemoglobinopathy cards they were given after diagnosis. It is logical therefore to include the SCT list with the SCC list for assessing the response rate for the CPC districts (overall response rate 67.1%). The NCPC districts did not have separate lists for people with trait and condition. However it was expected that a number of people with SCT would be included on it. The response rate for these districts was 68.9%.

6.1 Age

The average age of people in the sample overall was 28.6 years, with very little difference between men and women, or between districts (Table 6.1.1)

6.2 Sex

Two thirds of the sample were women, although there are no sex differences in the way sickle cell conditions affect individuals. There was little difference in the distribution of the sexes between the two sets of districts (Table 6.2.1)

Table 6.1.1 Average age of women and men in CPC and NCPC districts

	CPC			NCPC			ALL DISTRICTS		
	n	m	S.D	n	m	S.D	n	m	S.D
Men	14	29.2	8.7	15	28.3	9.7	29	28.7	9.1
Women	34*	27.7	7.3	27	29.6	10.6	61	28.6	8.9
All	48	28.1	7.7	42	29.1	10.2	90	28.6	8.9

* = One woman refused to give her age

Table 6.2.1 Percentage of women and men in CPC and NCPC districts

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
Men	14	(28.6)	15	(35.7)	29	(31.9)
Women	35	(71.4)	27	(64.3)	62	(68.1)
Total	49	(100.0)	42	(100.0)	91	(100.0)

Table 6.3.1 Marital status of men and women from CPC and NCPC districts

	CPC				NCPC			
	S	M	D/S	TOTAL	S	M	D/S	TOTAL
	n	n	n	n	n	n	n	n
MEN	10	3	1	14	10	5	0	15
WOMEN	21	13	1	35	16	9	2	27
Total	31	16	2	49	26	14	2	42

Key: S = Single M = Married/Cohabiting D/S = Divorced /Separated

6.3 Marital status and family size

Similarities were also seen between CPC and NCPC districts for marital status and family size. Few people were separated or divorced (Table 6.3.1). Unmarried men and women accounted for the largest part of the sample, with about a third of the group being either married or in a long term stable relationship (Table 6.3.1).

Families had an average of 1.8 children in the family and there were thirteen single parents.

Table 6.4.1 Ethnicity and Place of Birth

DISTRICTS	CPC			NCPC			ALL
	Local Born	Over Seas Born	Total	Local Born	Over Seas Born	Total	Total
ETH.	n	n	n %	n	n	n %	n %
AC	25	13	38 (77.6)	23	11	34 (81.0)	72 79.1
Afr	1	4	5 (10.2)	0	2	2 (4.8)	7 7.7
Afas	0	0	0 (0.0)	1	0	1 (2.4)	1 1.1
Ca/AC*	4	0	4 (8.2)	2	1	3 (7.1)	7 7.7
Ca/Afr*	1	0	1 (2.0)	0	0	0 (0.0)	1 1.1
Ac/WIAs*	1	0	1 (2.0)	0	1	1 (2.4)	2 2.2
AC/WICa*	0	0	0 (0.0)	0	1	1 (2.4)	1 1.1
Total	32	17	49(100.0)	26	16	42(100.1)-	91 100

ETH = ETHNICITY
AC = African-Caribbean
Afr = African
Afas = African Asian
Ca = Caucasian
WIAs = West Indian Asian
WICa = West Indian Caucasian

* denotes mixed parentage.
- Due to rounding off the percentages in this and subsequent tables do not always total 100%.

Table 6.4.2 Residence (years) in Britain of overseas born people in the sample

	CPC		NCPC		TOTAL	
	n	(%)	n	%	n	%
less than 5 years	1	(2.0)	1	(2.4)	2	(2.2)
5-10 Years	0	(0.0)	1	(2.4)	1	(1.1)
11-15 Years	1	(2.0)	1	(2.4)	2	(2.2)
16-20 Years	6	(12.2)	1	(2.4)	7	(7.7)
21-25 Years	2	(2.0)	4	(9.5)	6	(6.6)
more than 26 years	7	(14.3)	8	(19.0)	15	(16.5)
Local Born	32	(65.3)	26	(61.9)	58	(63.7)
Total	49	(99.9)	42	(100.0)	91	(100.0)

Table 6.5.1 The sample's membership of religious groups

Church	n	(%)
None	37	(40.7)
Church of England	16	(17.6)
Church of God	8	(8.8)
Methodist/Baptist	7	(7.7)
7th Day Adventist	7	(7.7)
Roman Catholic	6	(6.6)
Jehovah's Witness	5	(5.5)
Christian Scientist	3	(3.3)
Rastafarian	1	(1.1)
Muslim	1	(1.1)
Total	91	(100.1)

6.4 Ethnic group status and nationality

The sample was largely African-Caribbean with smaller numbers of Africans and people of 'mixed-race' (Table 6.4.1). Nearly two thirds of the sample were British born. Almost half of the remaining sample had been domiciled in Britain for more than 26 years (Table 6.4.2). No appreciable differences were found between the district sub-samples.

6.5 Religion

Forty-one percent of the sample did not belong to any religious group. Of those who did, the Church of England had the largest following (Table 6.5.1). There were no differences seen between district sub-samples.

6.6 Discussion

The two district sub-samples were very similar with regard to response rate, age, sex, marital status, ethnicity, nationality and length of residence in the United Kingdom.

Poor response rates are sometimes obtained from people who make up minority ethnic groups (Montero; 1977, Cartwright, 1986). However, the response rate for this study appears reasonable. Although the lists for sickle cell conditions from both CPC and NCPC districts included people with sickle cell trait (SCT), it was interesting to note the poor response from people on the SCT list provided by the CPC

districts. This may be an indication that services for sickle cell conditions are geared towards those who need medical and emergency health care; this being more likely for people with the condition as opposed to those with trait.

People tended to belong to the main-stream churches, with seven percent of the sample claiming membership of religious groups which could be described as not being mainstream to British ways of worship (ie. Jehovah's Witness and Rastafarianism). Some of these may have implications for what is seen by 'followers' as acceptable health care. For example, the Jehovah's Witness group rejects abortion and blood transfusions as acceptable therapies. Abortions are seen as abominations, and they believe that blood should be 'used' only in sacrifice to God and that this 'law' cannot be set aside in times of emergency, ie. when transfusion is needed (Watchtower, 1977). Religious considerations in terms of sickle cell treatment could cause problems for this group.

It has been suggested that black women produce large families in order to achieve status in their communities (MacCormack, 1982), to ensure financial and other support from their children in their old age (Shorey-Bryant, 1986) or because they are irresponsible (Ineichen, 1985). The relatively small size of families in this sample does not support these suggestions. Neither does other research (Hood, 1970; Griffiths, 1983). However it is possible that having a heritable condition had a major influence on family

size. It is also possible that economic pressures have a bearing. Indeed families of West Indian and African extraction have shown a tendency to have families of two or three children, reflecting the norm for the majority white population (Hood, 1970; Griffiths, 1983). Family size and reasons given by the sample for limiting it are discussed elsewhere in this thesis.

As expected, the sample was almost entirely African-Caribbean. It was hoped that some of the nine Asian people on sickle cell lists in the NCPC districts would agree to take part in the study. In the event, only one Asian woman participated, despite the fact that sickle cell conditions can be a problem for some Asian groups. This outcome had been predicted by one of the Consultant Haematologists who said that he had great difficulty in trying to convince his Asian clients that sickle cell conditions were not simply a 'black man's disease' but that haemoglobinopathy was also important for some Asian communities. There were no Asians on the CPC districts' list, so no conclusions can be drawn. However, this hints at possible racial prejudices between different minority groups.

It may be that Asian groups in the sample area have not been experiencing ill-health and therefore could see no point in taking part in the study. It is also possible that they may not be well enough informed about sickle cell conditions and their implications. Furthermore, language difficulties and other unidentified reasons may have prevented some Asians from agreeing to take part in the study.

It was also interesting to see the number of people who are of mixed race in the sample. All but one woman had sickle cell trait. It would have been difficult based on this woman's colouring to have identified her as possibly being at risk. This emphasises the importance of screening all babies born in areas where there are large minority ethnic populations, particularly as such a large proportion were British born with children of their own (some of whom were mixed race). This type of screening is already being done in several London health districts.

6.7 Summary

1. It appears that services for people with sickle cell genes focus on the health care needs of people who are ill. This finding seems to confirm the study of nurses' and health visitors' knowledge of sickle cell conditions, (discussed in chapter 12) which showed that hospital nurses were more likely to have cared for someone with a sickle cell condition than were health visitors.

2. The age structure of the sample was such that people may not have completed their families.

3. The small size of the average family observed in this study suggests that black people with sickle cell genes may be limiting their family size. This could be the result of the awareness that they are able to pass the gene on to their children, or simply the effects of

personal choice, harsh economic reality or some other unidentified reason.

4. Asians on haematologists' list did not respond to the invitation to take part in the study. It is possible that they do not believe that sickle cell genes can be 'carried' by them as the conditions are often described collectively as an 'African-Caribbean' disease.

5. Children of mixed race and even of mixed race parentage are currently being born in Britain. It is therefore necessary for screening to include all babies in districts where there are appreciable minority ethnic populations.

6. Religious group membership did not pose any major problems for the sample as a whole, though there was a small minority for whom certain medical treatments such as blood transfusion would be unthinkable.

CHAPTER 7. Qualifications, employment and lifestyle

7.0 Introduction

This chapter describes some of the social conditions under which sample members lived, and how these conditions affected their health and lives generally. Studies have shown that when people are from social class groupings IV and V, and/or were unemployed, they are likely to suffer from poverty and ill-health (Blaxter, 1986; GHS 1984; Whitehead, 1987). People who are out of work have poorer health than those in work, and areas of high unemployment have worse health records than those without (Whitehead, 1987). These were found to be important indicators of health in this sample. Black people in Britain are more likely than the white population to leave school without qualifications (Yult et. al., 1975). Those who migrated from overseas are also seen to be largely poorly educated. They are therefore also seen as being poor employment prospects (Carby, 1982; Brown, 1984; Grimsley and Bhat, 1988).

7.0.1 Age on leaving school

The average age of the sample on leaving school was 16.3 years, ranging from 14 years to 20 years. People from Africa appeared to have stayed in school longer than those who were West Indian or British born (Table 7.0.1). No differences in school leaving age were seen between the two sets of districts.

Table 7.0.1 School leaving age of people who attended British, West Indian & African Schools

Age	British Schools		W. Indian Schools		African Schools		Total	
	n	%	n	%	n	%	n	%
Under 16	7	(11.5)	2	(2.7)	0	(0.0)	9	(9.9)
16+ Years	54	(88.5)	21	(91.3)	7	(100.0)	82	(90.1)
TOTAL	61	(100.0)	23	(100.0)	7	(100.0)	91	(100.0)

7.1 Qualifications

In the study, the highest qualifications attained were recorded, so someone with GCE subjects could also have one or more CSEs, though not necessarily. Approximately one quarter of the sample had no formal qualifications. A further quarter had City and Guilds or certificates for secretarial skills. Sixteen percent had other education qualifications (Table 7.1.1). There were no differences between the two sets of districts.

7.2 Employment status and working conditions

Employed people made up fifty-three percent of the sample. Their jobs ranged from teacher and theologian to cleaners and labourers. Seven people worked on a part time basis. Five of the 91 people had tertiary education. However only two (the teacher and the theologian) had employment which reflected their qualifications. One man who had an engineering degree could only find work as a labourer. Twenty-one percent had clerical and secretarial duties at work. A further 29% did manual work. These figures include those who were part-time workers.

Almost half of the sample were unemployed. Although no data

were collected on how long people had been employed, a few younger sample members volunteered that they had never worked. Once again no differences were seen between district sub-samples. All but five people volunteered that they were actively seeking work. Ten people described financial problems, two of them voicing concern about how they would be perceived as unemployed people. One woman, in describing the financial struggle to care for herself and her child said,

> " Whoever says that the unemployed have it easy don't know what they are talking about. I wish they would exchange their lives with what I have.... they would soon be wanting to change back. We have nothing. It's all I can do to keep me and the baby warm. I live in old clothes, a lot of my chairs and things comes from the skip and I never get out for a treat or anything".

Another described her plight,

> " I wish I had a job because I never have any money ... but they (prospective employers) say I couldn't cope with the things they would give me to do. It looks bad too because I am so young and I don't have a job.... but I don't see any way of getting round it. If I don't tell them that I have sickle cell and something happens, then it will be my fault and I'll lose the job anyway. People must think that I'm lazy or stupid that I can't find a job".

Sample members invariably described situations which led to their unemployment. A theme which was echoed by seven people involved job applications and the interview situation,

> " The worst part about having sickle cell is not being able to hold down a job. I used to put on the application forms (if the information was sought) that I have sickle cell and I noticed I never got interview... so now I don't. Now, sometimes I have an interview and they might ask then, so I have to tell them and I don't get the job. I think that I could be quite a useful worker, as long as people understand what my limitations are".

A further four people described losing their jobs because of the need to take time off work through illness.

" I was in hospital for four weeks and when I came out the doctor kept me off for another five.... when I got back to work, they told me that I didn't work there any more. That was so hard. I had not been working there very long and it was the first time I was sick".

The work environment also played a role in determining people's ability to work. All but two people with a sickle cell condition mentioned the effects of the cold on their health. The third of the group that had trait pointed out that they seemed more bothered by the cold than other relatives.

" I lost my job because they kept putting me to work in the cold storage area (of a supermarket). I explained to the boss that I couldn't work in the cold store area because of the sickle cell but that I could work upstairs in the main shop as a cashier or something. He said that wasn't possible and I had to work in the cold store area. Eventually I became very sick. When I returned to work after some sick leave, I went back to the cold store area. I knew that I was going to have another crisis if I stayed there so I chucked it in. Crises aren't very nice things and although I'd love to hold down a job, I'm not going to risk my life for people who can't be bothered about me."

An employed teacher said,

" It is not a demanding job except in the winter when the cold places additional stresses on my body. But I try to keep myself warm, and fortunately whenever I have been really ill, it's been during the holidays. I seem to cope well until then".

Table 7.1.1 Percent educational qualifications gained by members of the sample

	CPC		NCPC		TOTAL		GB*
	n	%	n	%	n	%	%
No Quals.	12	(24.5)	10	(23.8)	22	(24.2)	(38.0)
CSE	10	(20.4)	6	(14.3)	16	(17.6)	(13.0)
GCE	4	(8.2)	9	(21.4)	13	(14.3)	(25.0)
Higher	-		-		-		(11.0)
City & Guilds/ Secretarial	14	(28.6)	10	(23.8)	24	(26.4)	-
HNC	1	(02.0)	1	(2.4)	2	(2.2)	-
Diploma	5	(10.2)	4	(9.5)	9	(9.9)	-
1st Degree	0	(0.0)	1	(2.4)	1	(1.1)	(10.0)
Higher Degree	3	(6.1)	1	(2.4)	4	(4.4)	-
Total	49	(100.0)	42	(100.0)	91	(100.0)	(100.0)

*National figures adapted from GHS 1987.

Table 7.2.1 Percent Employment status & social class of sample members

	CPC		NCPC		TOTAL		GB*
	n	%	n	%	n	%	%
F/T Empl.	22	(44.9)	19	(45.2)	41	(45.1)	(88.0)
P/T Empl.	4	(8.2)	3	(7.1)	7	(7.7)	-
Unemployed	23	(46.9)	20	(47.6)	43	(47.3)	(9.5)
Inactive	-		-		-		(2.5)
Total	49	(100.0)	42	(100.0)	91	(100.1)	(100.0)

Table 7.2.2 People's satisfaction with their employment

	CPC		NCPC		TOTAL	
PHYSICALLY DEMANDING JOB	n	%	n	%	n	%
Satisfied	8	(16.3)	3	(7.1)	11	(12.1)
Too Demanding	3	(6.1)	2	(4.8)	5	(5.5)
Too Cold	2	(4.1)	1	(2.4)	3	(3.3)
Poor Pay	0	(0.0)	1	(2.2)	1	(1.1)
Sub-Total	13	(26.5)	7	(16.7)	20	(22.0)
JOB NOT DEMANDING						
Satisfied	9	(18.4)	11	(26.2)	20	(22.0)
Too Cold	2	(4.1)	2	(4.8)	4	(4.4)
Racial/Personality Problems/boredom	2	(4.1)	2	(4.8)	4	(4.4)
Sub-Total	13	(26.5)	15	(35.7)	28	(30.8)
UNEMPLOYED	23	(46.9)	20	(47.6)	43	(47.3)
TOTAL	49	(99.9)	42	(100.0)	48	(100.1)

Satisfied vs. not satisfied $X^2_{1df} = 0.01$ NS

Travelling to work in the winter also caused problems.

> " I was always getting sick. It would be fine in the summer when I could cope, but when it is cold, I get sick a lot. The worst time for me was waiting on (for) buses. I get so cold. One time I had to sit on a wall nearby, I felt so sick. People kept staring at me. Anyway the bus came and when I got off it again, I collapsed. A woman called the ambulance. I was off work for a long time that time... five or six weeks. They were really good and kept my job for me. A few weeks later, I was sick again. How can they keep you on when you're always sick. I almost felt sorry for them, but I could understand it. They had to let me go. They even looked sad about it but it doesn't help me .... sometimes I think I'll go mad".

There was no difference in satisfaction with employment between the two districts which provided a CPC and the two which did not (Table 7.2.2). The majority of people who had jobs (52.8%) said that they were satisfied with their jobs (34%). This included five people who said that they were satisfied, because it was 'better than being on the dole'.

Eleven people were generally satisfied with their jobs which they described as demanding because they required some physical input. This input ranged from reaching up to stock shelves to doing building work (Table 7.2.2). A further twenty who were satisfied with their employment did not find the work physically demanding. Of those who were dissatisfied with their work, five said that it was because their work was too demanding while twelve gave other reasons. These reasons included personality problems at work, racism, and boredom (this was the person who had an engineering degree but could only find work as a labourer).

7.3 Housing

Cold, damp housing has been implicated in causing ill-health in families (Townsend & Davidson, 1986; Whitehead, 1987). This can precipitate and/or aggravate the symptoms of sickle cell conditions (Mann, 1981). It is therefore important that homes for affected people should be easy to keep warm. Home ownership and tenancy are shown in table 7.3.1. All of the home-owners said that their homes were warm. Any problems arising (for example those which could lead to cold, damp conditions) tended to be dealt with as soon as they were identified. Accommodation therefore tended to be warmer than those of tenants, in better decorative state and was seen to be more satisfactory. The large majority of the sample lived in some form of rented accommodation (Table 7.3.1).

Homes usually had more than one bedroom, though not all of them were suitable for use.

" We don't sleep in one of the rooms 'cos it's too cold .. it is really cold, and no matter what you put in it (i.e. paraffin or Calor gas heaters). In the winter, like when it is snowing, it is absolutely freezing. Black stuff comes on the walls and ceiling. You wipe it off but it always comes back. We don't sleep in there any more."

This complaint was echoed by three other people, one of whom said,

" The room cannot be lived in. Everything in it gets damp. The walls, your clothes, even the sheets and things, and they start to smell".

Half of the sample felt that their homes were satisfactory and had adequate heating. However one third complained of poor heating. Despite this, 16% of the sample said that although the heating was insufficient, they were satisfied with their homes (Table 7.3.2)

" It's freezing here. It's ever so cold. My heating bills are unbelievable. I came to this house in the summertime. I was here six months and there was damp on the walls".

Another woman explained that she was satisfied with her council house accommodation even though it was not what she hoped for. She said,

" You should have seen the last one I had ... it needed so much doing that nobody lives there now. It is just boarded up. When it rained, water used to pour down the walls. It was years before the council found me this one. It's a bit damp, but not too bad. So, of course I am satisfied with this one".

Twenty four percent of the sample gave other reasons why they were not satisfied with their homes.

Table 7.3.1 Home ownership and tenancy of people in the sample

	n	(%)
Own home	17	(18.7)
Living in Parent's home	10	(11.0)
Rent Private landlord	19	(20.9)
Live with parents/private landlord	7	(7.7)
Rent Council	29	(31.9)
Live with parents/council house	4	(4.4)
Student accommodation	3	(3.3)
Share with friends	2	(2.2)
Total	91	(100.0)

Table 7.3.2 Heating status of and satisfaction with homes

	n	(%)
GOOD HEATING		
Satisfied	46	(50.5)
Not satisfied (decor*)	5	(5.5)
Not satisfied (other)	10	(11.0)
POOR HEATING		
Satisfied	15	(16.5)
Not satisfied (decor*)	5	(5.5)
Not satisfied (Heating)	8	(8.8)
Not satisfied (tower block)	2	(2.2)
Total	91	(100.0)

* Decor = decorative state

These included problems with parents, shabbiness, living in 'bad' neighbourhoods, difficult neighbours, not having enough space and being too far away from offspring (living in different districts). Three people lived in tower blocks. All of them identified problems of mobility. Crises had been precipitated in two cases when elevators did not work and sample members with the conditions had to use the stairs to get to the tenth or twelfth floor. One young woman described climbing the stairs with two or three bags of groceries, a small child and a push-chair, all attempted at the same time, because doing the trip once only was all that she could manage. Any thoughts of attempting two or more trips were banished by the possibility of having the groceries or pushchair stolen while the baby was taken up to the flat.

This effort led her to have a crisis. Another high-rise dweller, a man, who became ill after climbing twelve flights of stairs described being ill when the elevators were not operational.

> " I became ill and had to get the ambulance.. when it got here it took them a long time to get up the stairs. I was in agony all this time. Then when they were taking me down, it was very uncomfortable. I kept thinking I was going to fall off the stretcher. I was strapped in but I still found myself having to hold on. That was very painful. When I was discharged from hospital, they took me back home by ambulance. The lifts were still out. So they took me back up the stairs on the stretcher. When they got there in the end, they looked so bad, I thought I would have to call another ambulance for them".

7.4 Smoking and drinking habits

Poor oxygen supply and dehydration have been implicated as precipitators of sickle cell crises (Serjeant, 1985). It would seem, therefore, that smoking and any situation which would produce a competition for oxygen should be avoided by people with sickle cell conditions. By the same token, dehydration should also be avoided. A common source of dehydration is the use of moderate to large amounts of alcohol. One or two units of alcohol may not cause any problems, but increased ingestion can lead to thirst or severe dehydration depending on the level used.

The sample in both district subgroups was largely non-smoking, and included only 4.4% who were moderate to heavy smokers (Table 7.3.1). Just under half of the sample, 46%, either never used alcohol, or only did so on rare occasions such as Christmas and birthdays (Table 7.4.1). A

further forty-one percent used less than a unit of alcohol a week. People who did not use any alcohol said that they did not do so because of personal tastes, religious or health reasons.

Table 7.4.1 Smoking and Drinking Habits of People in the Sample

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
SMOKING						
Non-Smokers	39	(79.6)	38	(90.5)	77	(84.6)
1-5 Daily	6	(12.2)	1	(2.4)	7	(7.7)
6-10 Daily	2	(4.1)	1	(2.4)	3	(3.3)
11-15 Daily	1	(2.0)	1	(2.4)	2	(2.2)
16-20 Daily	1	(2.0)	1	(2.4)	2	(2.2)
Total	49	(100.0)	42	(100.0)	91	(100.0)
DRINKING						
Non-drinkers	14	(28.6)	13	(31.0)	27	(29.7)
Birthdays/ Xmas only	7	(14.3)	8	(19.0)	15	(16.5)
1-2 Units (Wk)	24	(48.9)	13	(31.0)	37	(40.7)
3-4 Units (Wk)	3	(6.1)	5	(11.9)	8	(8.8)
5+ Units (Wk)	1	(2.0)	3	(7.1)	4	(4.4)
Total	49	(100.0)	42	(100.0)	91	(100.0)

7.5 Social activities and energy levels used

Social activities were divided into four categories. These were: a) going to dances/discos, b) participation in sport, c) jobs about the house, and d) other exercise. Participation in sport included team games like football and netball, and also jogging and swimming. Jobs around the house included tasks such as gardening and general household duties. The 'other exercise' category included working out in a gymnasium, tasks at work, such as lifting and stretching and exercise related to travel, eg. hurrying for a bus and walking to work.

People were asked to rate their perception of how energetically they were able to perform these activities. Responses were recorded on a four point Likert-type scale. These were a) very energetic, b) slightly energetic, c) slightly sedate and d) very sedate.

7.5.1 Dancing

Nearly two thirds of the sample went to dances or discos (Table 7.5.1). Half of them felt that dancing was a very energetic activity (Table 7.5.1).

7.5.2 Sporting activities

About a third said that they took part in sporting activities. Twelve of the twenty-eight people who participated did so either somewhat energetically or somewhat sedately. The remainder rated their sporting performances as very energetic (Table 7.5.1).

TABLE 7.5.1 Activities of and energy used by members of the sample

	CPC		NCPC		ALL	
	n	(%)	n	(%)	n	(%)
DANCING						
Very energetic	14	(28.6)	18	(42.9)	32	(35.2)
Somewhat energetic	11	(22.4)	8	(19.0)	19	(20.9)
Somewhat sedate	8	(16.3)	3	(7.1)	11	(12.1)
Very Sedate	0	(0.0)	1	(2.4)	1	(1.1)
None	16	(32.7)	12	(28.6)	28	(30.8)
Subtotal	49	(100.0)	42	(100.0)	91	(100.1)
SPORT						
Very energetic	6	(12.2)	10	(23.8)	16	(17.6)
Somewhat energetic	6	(12.2)	1	(2.4)	7	(7.7)
Somewhat sedate	4	(8.2)	1	(2.4)	5	(5.5)
None	33	(67.3)	30	(71.4)	63	(69.2)
Sub-total	49	(99.9)	42	(100.0)	91	(100.0)
JOBS ABOUT HOUSE						
Very energetic	9	(18.4)	7	(16.7)	16	(17.6)
Somewhat energetic	9	(18.4)	3	(7.1)	12	(13.2)
Somewhat sedate	3	(6.1)	0	(0.0)	3	(3.3)
Very Sedate	0	(0.0)	1	(2.4)	1	(1.1)
None	28	(57.1)	31	(73.8)	59	(64.8)
Subtotal	49	(100.0)	42	(100.0)	91	(100.0)
OTHER EXERCISE						
Very energetic	16	(32.7)	15	(35.7)	31	(34.1)
Somewhat energetic	17	(34.7)	13	(31.0)	30	(33.0)
Somewhat sedate	10	(20.4)	4	(9.5)	14	(15.4)
Very sedate	2	(4.1)	4	(9.5)	6	(6.6)
None	4	(8.2)	6	(14.3)	10	(11.0)
Sub-total	49	(100.1)	42	(100.0)	91	(100.1)

7.5.3 Jobs about the house

Only 35% of the sample said that they did jobs about the house (Table 7.5.1). Those who didn't tended to live with relatives who excluded them from doing those tasks, or were students in college accommodation. This caused problems for some younger people (3) who complained that they were treated like invalids when they felt quite able to shoulder some of the responsibility.

> " The worst thing about sickle cell is that people won't let you do anything 'cos they think you can't. But if they don't let you try, how can you find out what you can and can't do?"

Half of those who did do jobs about the house said that they

did them very energetically (Table 7.5.1).

7.5.4 Other exercise

Nearly ninety percent of the sample said that they did other exercise. Many of these involved walking to work or hurrying for the bus (36%). Five people said that they regularly worked out in a gymnasium, while the remainder did exercise at home usually accompanied by the television. More than a third rated these activities as very energetic (Table 7.4.1).

7.6 Discussion

The data on educational qualifications contradict the notion that black people are under achievers from an educational point of view; only 24% of the sample left school with no qualifications compared with the national average for the UK of 38%. Those who had no qualifications tended to be women in their forties and fifties, who were educated overseas.

It is possible that having a chronic, debilitating illness encourages individuals to recognise that their future lies with having a good education, which in turn should lead to good employment prospects and improved lifestyles. A life-long interaction with the environmental conditions which precipitate illness episodes may have stimulated this recognition. On the other hand, it may mean that more middle-class people with the conditions receive more information on the conditions at diagnosis, and on the long-

term implications for their health and lifestyles.

Poverty and unemployment have a deleterious effect on health (Fagin & Little, 1984; Marmot et al. 1984; Whitehead, 1987). There was poverty compounded by very high unemployment in this group. Unemployment was 47% compared with a then national average of 10%. Studies have shown that racism relegates black people to the back of the employment and promotion lines (Burney, 1988; Ohri and Faruqi, 1988; CRE, 1990; CRE, 1991). It would therefore have been useful to compare these figures of educational achievement and employment status with records for unaffected black people, in order, particularly to see how much having sickle cell genes affects employment prospects. However, as ethnic monitoring was not a feature of these health districts (and of the country generally), it was impossible to do so.

Having sickle cell related (and other) illness did affect people in employment and lead to unemployment in some cases in the research sample. Cold working environments and heavy physical labour have been implicated as causing problems for employees as they precipitate crises and ill-health. This demonstrates ignorance on the part of employers regarding how environments can affect people with sickle cell conditions. The woman working in the cold storage area who asked for a transfer gives us an example of her employer's racism when he refused her request even though she explained its effects on her health.

People who were long term unemployed or had recently lost

their jobs sometimes blamed themselves 'for not being able to hold down a job', felt stigmatised 'people must think I am stupid or lazy that I can't find a job' and had poor self concepts 'I could understand .. they (can't) keep you on when you are always sick .. sometimes I think I'll go mad'. A few also had accepted defeat in the workplace because even difficult and unpleasant working conditions were acceptable 'because it was better than being on the dole'.

Their concerns about letting the side down seemed to stem from racist stereotypes that black people were lazy, and stupid. Concerns also focused on the employers lack of understanding about sickle cell conditions and how much people with these types of health problems could do in the workplace. The hope that employers could be made to understand the seasonal swings that might be associated with their ability to do certain types of work was universal among the group.

Despite their problems with obtaining and retaining work, there was a strange compassion and understanding of the employers rejection of them as workers, even when they felt that they themselves were being dealt a poor hand. Only a few unemployed people seemed to think that their race contributed to their losing their work. On the other hand, workers felt that despite adequate performances at work, if their employers found out about their health problems, they could easily be used to mask racist reasons for dismissing them. Fear of becoming ill and taking time off might increase opportunities for them to be elbowed out of their

jobs. As a result, despite being advised to take time off work by their doctors, some people insisted in carrying out their duties as normal, hoping that further problems would not develop. These people described themselves as always feeling 'under the weather' and 'not 100%' though they insisted that their health was good enough for work. They therefore placed themselves at greater risk in order to continue to be providers for their families.

It has already been recognised that disclosing one's haemoglobin status, can lead to discrimination regarding employment and life insurance (Headings, 1979). However, unemployed people were able to rationalise the actions of their employers by blaming their illness for what often seemed to them to be unfair actions. This may have been a coping mechanism which they used to boost themselves in a world which was uncertain and unsettling to them. It may also have been the reaction to a situation created by the combination of their poor health, the negative ways in which black people are perceived in society generally, a sense of fair play (misguided or otherwise and a need to be not seen as 'paranoid'. When black people complain of injustices in the workplace, they are often described as paranoid. Once this label has been attached, it seems to act as a spur to white colleagues (who wish to and/or who are not willing to be seen as helping the 'black' in any political way), to behave in such a manner as to further alienate the black worker, often with the result that the black worker resigns (pers. comm. several black workers).

Late in the study the researcher began to identify what could be described as feelings of 'honour' and a close-knit community spirit amongst people in the sample. Unfortunately large scale discussion of ideas of honour and closeness could not be incorporated in the study. This would make an interesting area for study for medical sociologists wanting to examine beliefs about health, illness and coping of black people in Britain, particularly if compared with similar groups in both the countries of origin and with white British people.

By appearing to accept the decision to terminate their work in a magnanimous manner, sample members who lost their jobs through ill-health were able to save some face in front of their ex-employers at least. They were unable to deal with people who only knew of their unemployment, in the same way. To these people, and indeed to the workers, recognising poor health was an admission of defeat which they found difficult to accept. This element of pride and 'honour' appears to similar in context to that seen in DuBoulay's *'Portrait of a Greek mountain village'* where to be less than honourable in one's deeds would bring shame on the individual and on the family (1979).

There were two main areas of difficulty which affected people's ability to obtain and retain work. First, there were those who saw themselves as becoming virtually unemployable. They lived in poor housing (discussed in the next section) had frequent illness episodes and what appeared to be a loss in self confidence and motivation.

They felt distressed that they may be perceived as lazy and worthless. This contributed to them having more illness as they become stressed, are unable to heat their homes adequately and to feed and clothe themselves properly. This in turn made them less likely to obtain employment. Second, people in work, advised to take time off in an attempt to prevent minor illness becoming more serious, often did not for fear of losing their jobs. If they did become ill, they may find themselves in the group just described. Even when they did not become ill enough to take time off work, they never-the-less developed the constant debilitating tiredness that comes with chronic anaemia. This in turn could lead to short tempers, affect the quality and quantity of their work and ultimately to the possibility of termination of their employment. At this point, they would also run the risk of serious illness, and the need to take time off work.

Employed people who went to see their doctors, did not wish to gain access to a sick role, but rather to be **supported medically in such a way that they could continue to work.** When the doctor was consulted in these cases, it was because people had a temporary illness which they hoped to have treated **before** it interacted seriously with their underlying chronic condition, causing them to take time off work. It was not their cultural background which defined how they perceive their illness state, but their fear of unemployment and a culture of poverty. Some sample members did not need access to a 'complete' sick role, but rather wanted recognition that there would be times when their output would be less than usual.

In these cases, doctors become dependent on clients with regard to dispensing sickness certification, thereby allowing them a greater degree of control over whether they would accept sick roles or not. The responsibility for **accepting** sick certification, therefore passed directly to the individual, and acceptance of it created the opportunities for employers to indirectly become the gate-keepers for access to the sick-role, and therefore to become agents for social control.

The education of employers about sickle cell conditions could lead to a reduction of illness events and promote increased employment for these groups. For example, with a little co-operation from employers regarding the deployment of the work-force, employees with these conditions could be allowed to avoid crises precipitating environments, particularly if strenuous exercise is involved. Working in what may be 'marginal' environments are not insoluble problems. For example, if it is absolutely necessary for these people to work in cold areas, they could be provided with adequate clothing and so on. This is done for 'healthy' people in many cases. No one would dream of exploring the reaches of outer or inner space without appropriate precautions being taken. Now that the dangers of Pneumonoconioses are understood, miners, asbestos workers, cotton mill workers and others, are given some degree of protection. It is therefore cruel, unjust and racist to expect black people to work unprotected in environments which could cause them to develop life-threatening health problems.

Problems of travelling to work in the winter could be overcome if people can afford to dress themselves warmly. The teacher in the study explained that stresses made coping difficult especially in the winter, but she coped because she was able to keep herself warm. It was only during holiday periods when she may have relaxed her vigilance that she became ill. This story brings to the forefront the constant awareness of health status, the daily considerations individuals must make to keep themselves well and able to work, and therefore the knowledge of their needs and how to meet them in order to survive well, that is, to have a reasonably healthy existence, is of paramount importance. Tied up with all this and complicating the issue is, the fear of death, shown by the woman in the cold store episode when she quit her job because of the risk to her life.

Unemployed people obviously needed more support that they were getting, to improve their perceptions of themselves and what they could achieve. This combined with employer sensitivity would dramatically improve the chances for this group to find and retain work. However, for this to come about, institutional and individual racism has to be addressed in a manner designed to truly minimise its effects.

Housing

Housing too was a problem for an appreciable number of people in this sample, as it is for black people generally

(Lehmann and Huntsman, 1974). Much of the housing was cold and damp ridden. This is an area of concern generally and studies have shown that racist strategies continue to conspire to keep black people in sub-standard accommodation (CRE, 1989a,b; CRE, 1990a,b; Skellington and Morris, 1993). There were similarities in the employment and housing difficulties of sample members in terms of cold environments and strenuous exercise (for high rise dwellers). For example, only 19% (n=17) of the sample owned their homes, with a further 11% (n=10) living with their parents. The remainder lived largely in rented accommodation and poor heating systems were discussed by a number of people. This is important as cold, damp conditions precipitate infections and ill-health. These health problems can become crises, which may be life-threatening in people with sickle cell conditions. Although the great majority of the sample were working class, with similar working conditions and/or aspirations, differences in the comfort of their homes were seen. Even when the exterior brickwork and the gardens of houses showed signs of neglect, home owners seemed to take a great deal of trouble to ensure that the interiors of their homes were in good condition. People in substandard rented accommodation tended to give up redecorating because the damp came through. The importance of keeping warm and dry, and avoiding environments which could precipitate illness, is always stressed as part of the regime for maintaining good health for people with sickle cell conditions. The effects of other illnesses on sickle cell conditions can be particularly dangerous for the individual.

All of the home-owners were older women who had bought their homes so that their then young children would not have to be brought up in sub-standard rented accommodation. They had obviously recognised the dangers that living in poor housing presented to them and their children, even though they would have had little information of the effects of cold, damp housing on sickle cell conditions. Having weighed up the stresses of a commitment to a mortgage, they felt that the risk was worth taking in order to give their families a better life.

Individuals who lived in high-rise flats found that elevators were often inoperable sometimes for many days or even weeks. The strenuous exercise involved when they had to negotiate many flights of stairs caused them to have a number of serious crises. This had the effect of making them virtual prisoners in their homes as they are unable to go out without risking having a crisis.

Family placement several floors up also causes problems for mothers caring for young families, when one considers the tasks involved in keeping the family fit and well. Visits to primary health care centres, taking children to school, transportation of groceries, other shopping, pushchairs and other paraphernalia of daily living involves the use of endless patience, incredibly good organisation and much assistance from others. The concept of high rise accommodation is therefore sexist. It is also ageist if elderly people who are unable to negotiate several flights of stairs are housed above the first floor. The placement of

black people known to have sickle cell conditions on floors above the first, is racist. As we have seen, this policy causes mobility problems for people who have disabilities, not necessarily visible, as a result of the conditions, and can seriously affect the health of this group of people. The young woman who described her life in high rise accommodation was therefore doubly discriminated against, both as a black woman with a serious health problem and as a mother of young children.

Sample members who needed re-housing found this extremely difficult to achieve. One single man living alone had been waiting for the best part of three years to be rehoused. A few people who were dissatisfied with their homes, indicated that they might be victims of individuals' choices to house them where they were, as did several who were 'satisfied' because their homes could be worse.

In the 1977 consultative document for *Housing Policy*, the government recognised the severe problems black people experienced in obtaining housing (HMSO, 1977). The report suggested that direct involvement of the black population, through self-help means was more likely to be successful than solutions imposed from above. It is obvious from this research, that sample members do not have the resources to help themselves to decent accommodation, possibly because they are being their applications for housing are being considered within a context that does not apply to them. Using a race blind approach to housing allocation creates and sustains the major disparities between minority and

majority ethnic groups in terms of housing outcomes (Skellington and Morris, 1993).

In allocating council housing to people with sickle cell conditions, care needs to be taken to ensure that the accommodation is not likely to create conditions for illness to develop, or exacerbate symptoms already evident. Housing needs to be free of draughts, easy to heat, and if in a high-rise building, no higher than the first floor, and preferably on the ground floor. Housing Departments' medical advisors are responsible for awarding points, on medical grounds, which would help people to be re-housed in suitable council accommodation. Furthermore, environmental health officers advise on repairs to housing stock. It is important, therefore for medical advisors and environmental health officers, to be full aware of the effects of less than optimal housing on sickle cell conditions.

Social habits and social networks

The majority of the sample were non-smokers. This was not surprising, as while smoking is a working class habit, it is not generally seen as a habit of people of African-Caribbean extraction (OPCS, 1992). It was expected that the sample would be largely non-smoking, because of the obvious effects that smoking would have on their health. People with sickle cell conditions generally have problems attracting oxygen, and filling their lungs with smoke can make them physically sick. Non-smoking behaviour therefore would not necessarily reflect health promotion activities designed for the

population at large, but rather more individual experience. All of the smokers in the sample tended to have few problems with their condition and most of them had not thought of the significance of smoking and its effects on sickle cell conditions.

Occasional use of alcohol did not appear to cause problems, and most of the sample took alcohol sparingly or did not drink at all. Those who indulged, generally limited themselves to only one or two drinks, often taken at the weekend and on special occasions. Heavy drinking can lead to dehydration which in turn can precipitate crises. This behaviour may have been evolved as a result of personal experience of the harmful effects of alcohol and sickle cell conditions. Religious beliefs about alcohol usage may also have had some influence.

However, smokers and drinkers in the sample, did not appear to use cigarettes and alcohol as coping mechanisms, as has been seen in other studies (Graham, 1984), possibly because heavy smoking could make them feel ill (oxygen lack) and heavy alcohol use could lead to dehydration.

In terms of diet, whatever their circumstances, women tried to ensure their own and their families health by providing the best they could manage. They believed that red meat was important 'to help the blood' and tried to ensure that some was in the family's meals, together with green vegetables and carbohydrates such as rice. All used vitamins of some sort, most of them the folic acid recommended by their

doctors, though a few admitted to not taking them often 'as they don't seem to do anything'. One woman was so concerned that her and her family's vitamin intake was sufficient, that she went to a 'man who does preparations for health food shops and sportsmen', where she was prescribed a veritable collection of additional vitamin pills. Some of the price tags on the boxes showed that she was paying up to ten times the price she would pay for the same pills at a high street chemist.

These types of cultural behaviours are not therefore contributing to illness episodes seen in these people, as they have developed a culture of healthy living as far as they could. Sample members were only limited by how much they could afford.

Social activities mainly involved going to discos and parties at the weekend with relatives and friends. This seemed to be the highlight of the week as people tended not to see their friends during the week (because of work or other commitments).

A surprisingly high number of people said that they did not do any jobs about the house. On reflection, it may have been that some people did not include cleaning, washing up and other household tasks as 'jobs about the house', but rather interpreted the question to mean redecorating, window cleaning and other such tasks. This possibility did not become clear until quite late in the data collection when one person showed some confusion about the question. Another

person subsequently showed the same confusion. However, a few people did complain that their family was over protective and they were not allowed to do any 'housework'.

A large number of people said that they did other forms of exercise. This largely took the form of aerobics performed with television programmes. People tended to 'keep fit' because they felt that this would improve their chances of getting or keeping their jobs. These activities did not add to people's external social interactions, as they were often conducted in the privacy of their homes, where mothers may be accompanied only by their young children. Only one person regularly took part in sporting events and exercised for fun.

These findings discussed in this chapter have contributed to the ninth hypothesis made in the thesis, namely that unemployed people who live in poor housing will have more sickle cell crises. It is also clear that unsuitable working conditions contribute to ill-health. This obviously has implications for the provision of health and social services (discussed in later chapters), which is tailored to meet individual needs.

7.7 Summary

1. There were differences in age between the African school leavers and people educated in Britain and the West Indies.

2. Less than one quarter of the sample had no formal qualifications.

3. Nearly half of the sample was unemployed.

4. It is possible that poor work conditions led to sickness and loss of employment for 13.2% (n=12) of the sample. This needs further investigation, as this information was reported by respondents.

5. Following the above, it is also possible that some employers are reluctant to employ people who admitted having sickle cell genes.

6. High rise housing for people with sickle cell conditions made them virtual prisoners when elevators did not work. Furthermore, many people lived in housing which could not be adequately and efficiently heated.

7. Most people in the sample lived in rented accommodation, and they could not always be rehoused when things became bad.

8. The sample was largely non-smoking and few admitted to heavy drinking.

9. Dancing was a favoured activity for 69% (n=63) of the sample, but most of the sample did some other form of exercise to keep fit.

CHAPTER 8. Accounts of illness given by sample members

8.0 Introduction

The past and present history of illness among sample members will be explored in this chapter. Sickle cell conditions are variable in the way in which they manifest themselves. This is largely dependent on the type of condition a person may have (Serjeant, 1985). However, large variations may also be seen among people with sickle cell anaemia (the most severe type) (op.cit.).

8.0.1 Type of sickle cell condition

More than half of the sample had some form of sickle cell condition (Table 8.0.1). Six people were not sure whether they had trait or a mild form of the conditions. One person was unaware of having been tested for sickle cell, although he knew that he could be a carrier because his brother was affected by sickle cell. Significant differences were seen between the district sub-samples regarding whether they had one of the conditions or were carriers ($p < 0.05$, Table 8.0.1). The NCPC district had the lower incidence of sickle cell conditions. This is interesting because the frequencies of carriers should be the same. This finding could be the result of good educational programmes which encouraged people to choose partners who are sickle cell free. Unfortunately, this is not the case because the population under study was made up entirely of adults. Services geared towards the needs of people with these conditions were not

available in NCPC districts, let alone 20-40 years ago when most of the sample would have been born. At that time, there would have been a dearth of information about the conditions internationally. A more likely explanation is that there was a serious level of under-diagnosis; mis-diagnosis is highly unlikely as diagnosis is easy and conclusive (pers. comm. several consultant haematologists). Misunderstanding should not have been a major issue either as people were sampled directly from haematologists' lists, ie. were officially diagnosed as having sickle cell genes.

Table 8.0.1 Diagnosis of sickle cell condition and sickle cell trait among sample members.

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
Sickle cell condition	33	(67.3)	18	(42.9)	51	(56.0)
Sickle Cell Trait	12	(24.5)	21	(50.0)	33	(36.3)
Can't Remember	3	(6.1)	3	(7.1)	6	(6.6)
Don't know	1	(2.0)	0	(0.0)	1	(1.1)
TOTAL	49	(99.9)	42	(100.0)	91	(100.0)

$X^2_{2(d.f)} = 6.5$ $p < 0.05$

8.1 Past history

Sickle cell conditions are often repressed in the first three months or so of life when fetal haemoglobin confers some degree of protection from clinical problems (Davies and Hewitt, 1984). It may be that when people are diagnosed at a very young age, they are able to adapt their behaviours allowing them to cope with the conditions. This could have a beneficial effect, leading them to have fewer problems in adult life. This is however not so clear cut, as sickle cell

conditions are very variable not just between individuals, but within the same individual at different times in his/her life (Serjeant, 1985).

8.1.1 Age at first illness

A large proportion of the sample became ill before they were twelve years old (Table 8.1.1). A similarly large group did not have any health problems. Eight percent of the sample had attained adulthood before they had their first sickle cell related illness and were diagnosed as having the conditions.

Differences between the district sub-samples were not significant. A further breakdown of the data between districts with regard to sickle cell status showed that 18 of the 22 people from the NCPC district had a sickle cell condition. This suggests that four people had sickle cell symptoms. Closer examination of the data showed that all of these four people described symptoms such as fleeting pains, limb pains and general tiredness.

Table 8.1.1 Age at which sample members became ill for the first time

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
Under 12 years old	22	(44.9)	15	(35.7)	37	(40.7)
12-17 years old	5	(10.2)	3	(7.1)	8	(8.8)
More than 18 years old	3	(6.1)	4	(9.5)	7	(7.7)
No Illness	19	(38.8)	20	(47.6)	39	(42.9)
Total	49	(100.0)	42	(99.9)	91	(100.1)

$X^2_{2\,(d.f)} = 0.9$ NS

8.1.2 Symptoms

Crises (discussed in the following chapter) were the predominant feature which sample members recalled when they became ill for the first time. These tended to occur in the back, abdomen, limbs and/or joints (Table 8.1.2)

8.1.3 Information given to individuals and their families at diagnosis

Thirty-seven percent of the sample could not recall what information was given to their parents or themselves. A further forty-two percent said that as they did not really have any illness, they were not given any information other than their sickle cell status. These people appear to have been told that although they had a sickle cell condition or trait, it was not causing them problems and therefore there was no need for them to worry. However, they were told that if they began to develop any problems, to report to their doctors. A further seven percent said that they had suffered as a result of having a sickle cell condition but they were told nothing about their illness. Four people (4.4%) were told that they had 'funny blood', were 'very sick' or that they were to have no (more) children. Three percent of the sample said that they were given so much information at their diagnosis, that they could not remember much of what they were told. One other person had been given information at her diagnosis but that had occurred so long ago that she could not remember what she was told. No differences were identified between CPC and NCPC districts. This finding

might reflect a policy in CPC districts of referring people to the sickle cell counsellor for explanations of the conditions and what they might mean, and for general counselling. On the other hand, people in CPC districts may have been given some information at diagnosis which they were too shocked to retain. A diagnosis of sickle cell does hold many fears for people, carrying with it, images of intensely painful crises and premature death. Furthermore, people who were diagnosed as 'carriers' were treated differently to those diagnosed as having a 'condition' in a number of ways, including their needs for information.

Table 8.1.2 Symptoms experienced by sample members when they became ill for the first time

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
Too young/Can't remember	22	(44.9)	15	(35.7)	37	(40.7)
CRISES						
In back/abdomen	3	(6.1)	2	(4.8)	5	(5.5)
In limbs/joints	2	(4.1)	3	(7.1)	5	(5.5)
Pain Everywhere	1	(2.0)	0	(0.0)	1	(1.1)
Fleeting pains/ Tiredness	2	(4.1)	1	(2.4)	3	(3.3)
Other Illness	0	(0.0)	1	(2.4)	1	(1.1)
No illness	19	(38.8)	20	(47.6)	39	(42.9)
TOTAL	49	(100.0)	42	(100.0)	91	(100.1)

8.1.4 Reaction to information given

Many people were unable to remember what their reactions were to the diagnosis. A large proportion (45%) (n=) were too young, and an equally large proportion (43%) (n=) did not have any illness and were told that there was nothing to worry about. The eleven people (12.1% of the sample) who were able to give information on how they felt, described a range of emotions from 'not understanding what the diagnosis meant', through unhappiness, relief (at 'having a name put

to the sickness'), to shock and fear.

8.1.5 Reason for last blood test

Sample members were asked why they were given a blood test largely because many people are often diagnosed by accident. This information emerged during pilot work during discussions and in conversations with a number of counsellors and other specialists in the field. Many people with sickle cell conditions may have 'mild' symptoms which are not necessarily recognised immediately as being related to sickle cell conditions. Others may remain symptomless for long periods. Yet others may never have symptoms, while some may die as the result of their first crisis, which may also have been their first symptom of the condition.

Almost half of the sample said that their last blood test was a routine test to check their haemoglobin (Table 8.1.5). People were tested either three monthly, half-yearly or annually, unless they were recovering from recent illness in which case their blood might be tested fortnightly. Almost a quarter asked their doctors to arrange a sickle cell test after media exposure which highlighted the prevalence of sickle cell genes in black people. A smaller proportion were tested for sickle cell during their pregnancies to establish whether the unborn child could be at risk from the conditions. No district differences were observed.

Table 8.1.5 Reasons given for the last blood test

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
Sickle cell (sc) - routine test	23	(46.9)	19	(45.2)	42	(46.2)
Requested test	10	(20.4)	12	(28.6)	22	(24.2)
Medical	3	(6.1)	5	(11.9)	8	(8.8)
Known sc - ill	2	(4.1)	1	(2.4)	3	(3.3)
Other illness - sc test	2	(4.1)	2	(4.8)	4	(4.4)
Pregnancy - sc test	9	(18.4)	3	(7.1)	12	(13.2)
Total	49	(100.0)	42	(100.0)	91	(100.1)

8.2 Sickle cell conditions in the family

Sample members discussed the incidence of sickle cell genes in their families. They also talked about whether they told relatives, friends and employers about the conditions. There is evidence that people with sickle cell conditions find difficulties retaining employment, obtaining insurance and mortgages, and even convincing friends and relatives that they cannot 'catch' anything horrendous from them (Anionwu and Jibril, 1986, Headings, 1979; OSCAR, SCS, pers. comm.). It has long been recognised within the communities that have sickle cell and other haemoglobinopathies, that they 'run' in families. Marriage and partnership prospects are therefore jeopardised if a diagnosis is known.

More than two-thirds of the sample said that they had their families tested for the sickle cell gene (Table 8.2.1a). A small number of people had only had some of their family tested, as older family members were being left to make their own choices. More than a quarter of the sample said that for various reasons, their families had not been tested.

8.2.1 Incidence of sickle cell conditions in the family

People were not always sure whether relatives had a sickle cell condition or whether they were just carriers for the genes. They simply described them as 'having sickle cell', sometimes exhibiting symptoms and sometimes not. More than half of the sample said that they had relatives with sickle cell (Table 8.2.1b). Almost a third said that as far as they knew, they had no relatives with either a sickle cell condition or carrier status. No district differences were seen.

Table 8.2.1a Percent families tested for sickle cell genes and reasons why some families were not tested

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
Family tested	33	(67.3)	29	(69.0)	62	(68.1)
Only some family members tested	1	(2.0)	2	(4.8)	3	(3.3)
UNTESTED FAMILIES						
No particular reason	9	(18.4)	9	(21.4)	18	(19.8)
No time/ recent diagnosis	5	(10.2)	2	(4.8)	7	(7.7)
No sickness/ no need	1	(2.0)	0	(0.0)	1	(1.1)
Total	49	(99.9)	42	(100.0)	91	(100.0)

Table 8.2.1b Percent incidence of sickle cell conditions in the family

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	%)
No relatives with sc	14	(28.6)	14	(33.3)	28	(30.8)
1 relative with sc	19	(38.8)	15	(35.7)	34	(37.4)
2 relatives with sc	6	(12.2)	3	(7.1)	9	(9.9)
3 or more relatives with sc	3	(6.1)	3	(7.1)	6	(6.6)
Don't know	7	(14.3)	7	(16.7)	14	(15.4)
Total	49	(100.0)	42	(100.0)	91	(100.0)

8.2.2 People told about the diagnosis

Ten sample members had told no-one of their diagnoses (Table 8.2.2). They explained that this was not necessary as they had not been ill. One of these ten added that she had told no-one because it was 'none of their business'. The remaining eighty-one people said that their families knew of the diagnosis. This most likely reflects the hereditary nature of the conditions, with parents being the most likely people to be given the diagnoses of young children. Seventy-nine percent discussed their diagnoses with their friends. Employers tended to be less likely to be told of an employee's diagnosis, but this was not significant.

Table 8.2.2 People who were told about the diagnosis by sample members

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
No-one/not ill	3	(6.1)	7	(16.7)	10	(11.0)
Family only	4	(8.2)	7	(16.7)	11	(12.1)
Family and friends	23	(46.9)	17	(40.5)	40	(44.0)
Family/Friends/ Employers	19	(38.8)	11	(26.2)	30	(33.0)
Total	49	(100.0)	42	(100.1)	91	(100.1)

8.2.3 Families', friends' and employers' reactions on hearing the diagnosis

The descriptions of families', friends' and employers' reactions are summarised in Tables 8.2.3a, 8.2.3b. There were no differences identified between the district sub-samples. Families were significantly more understanding and helpful with friends and employers showing more varied

reactions.

8.3 People's perceptions on how sickle cell conditions affect their health

Approximately half of the sample said that sickle cell conditions had no major effects on their health (Table 8.3.1). Nearly one-third talked about problems of everyday living, for example coping with poor memory and concentration, poor stamina and having to limit their activities so they did not become over-tired. Some discussed aches and pains which could become major crises, while others mentioned complications. These included leg ulcers which affected four people, eye complications (affecting another five people) and kidney problems (one young man was attached to a dialysis machine) (Table 8.3.1).

Table 8.2.3a How the family reacted on hearing of the diagnosis

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
FAMILY REACTIONS						
Helpful/ understanding	36	(73.5)	30	(71.4)	66	(72.5)
Shock/surprise	4	(8.2)	2	(4.8)	6	(6.6)
Curious	1	(2.0)	0	(0.0)	1	(1.1)
Mixed reactions	1	(2.0)	1	(2.4)	2	(2.2)
Don't really understand	1	(2.0)	2	(4.8)	3	(3.3)
Rejection	1	(2.0)	0	(0.0)	1	(1.1)
No reaction	2	(4.1)	0	(0.0)	2	(2.2)
Not applicable	3	(6.1)	7	(16.7)	10	(11.0)
Total	49	(99.9)	42	(100.1)	91	(100.0)

Table 8.2.3b How friends and employers reacted on hearing of the diagnosis

	CPC		NCPC		TOTAL	
FRIENDS' REACTIONS	n	(%)	n	(%)	n	(%)
Helpful/ understanding	18	(36.7)	12	(28.6)	30	(33.0)
Shock/surprise	7	(14.3)	0	(0.0)	7	(7.7)
Curious	11	(22.4)	10	(23.8)	21	(23.1)
Mixed reactions	0	(0.0)	1	(2.4)	1	(1.1)
Don't really understand	3	(6.1)	3	(7.1)	6	(6.6)
Know who friends are	2	(4.1)	0	(0.0)	2	(2.2)
No reaction	1	(2.0)	2	(4.8)	3	(3.3)
Not applicable	7	(14.3)	14	(33.3)	21	(23.1)
Total	49	(99.9)	42	(100.0)	91	(100.1)
EMPLOYERS' REACTIONS						
Helpful/ understanding	3	(6.1)	4	(9.5)	7	(7.7)
Shock/surprise	0	(0.0)	1	(2.4)	1	(1.1)
Curious	1	(2.0)	1	(2.4)	2	(2.2)
Mixed reactions	7	(14.3)	2	(4.8)	9	(9.9)
Don't really understand	3	(6.1)	1	(2.4)	4	(4.4)
No reaction	4	(8.2)	3	(7.1)	7	(7.7)
Not applicable	31	(63.3)	30	(71.4)	61	(67.0)
Total	49	(100.0)	42	(100.0)	91	(100.0)

Table 8.3.1 How sample members perceived the effects on their lives of having sickle cell genes

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
No effects	22	(44.9)	23	(54.8)	45	(49.5)
Complications	4	(8.2)	1	(2.4)	5	(5.5)
Poor memory/ concentration	2	(4.1)	3	(7.1)	5	(5.5)
Leg ulcers	1	(2.0)	3	(7.1)	4	(4.4)
Fleeting aches/ pains	2	(4.1)	1	(2.4)	3	(3.3)
Limited activities	11	(22.4)	9	(21.4)	20	(22.0)
Infection	4	(8.2)	1	(2.4)	5	(5.5)
Complications/ poor stamina	3	(6.1)	0	(0.0)	3	(3.3)
Several of the above	0	(0.0)	1	(2.4)	1	(1.1)
Total	49	(100.0)	42	(100.0)	91	(100.1)

8.4 Discussion

More people with sickle cell trait from NCPC districts were seen in the sample. This is simply a reflection of these districts not keeping separate lists for people with trait from those with the conditions.

The finding that a large proportion of the sample was

diagnosed under the age of twelve years old was expected, as sickle cell conditions are hereditary and can manifest themselves from the point when an infant begins to develop more adult type haemoglobin, ie. from about three to six months old. In these cases, instead of developing normal haemoglobin, they develop the abnormal sickle cell type. People who had no major illness all had either trait or one of the milder types of sickle cell condition. Two of this group did have sickle cell anaemia, but their haemoglobinopathy cards also showed that they had retained some fetal haemoglobin which may have been conferring upon them some of the benefits of normal haemoglobin. Another eight percent of the sample said that they had not become ill until they had reached adulthood. All of this group had some form of sickle cell condition, including three with sickle cell anaemia.

The conditions have been seen to be quite variable in the way they affected individuals. This may in part be a reflection of the different types of condition which are often 'lumped together' as sickle cell disease, and in part, a reflection of different lifestyles and environments.

The dominant feature which emerged when people spoke about illness, was that of the 'crisis'. Very few people attributed other forms of ill-health to their sickle cell. This remains a difficult area for people, and indeed for medicine generally, as sickle cell symptoms are often similar to those of other conditions. For example, joint and other aches and pains could just as easily be attributed to

arthritis and rheumatism as sickle cell conditions and vice versa. Tachycardia and breathlessness on exertion can be passed off by many individuals as 'not being very fit' or 'just getting old', the latter expression being used by five women in their thirties. Generally, only those people whose fleeting aches and pains developed into full-blown crises, or those whose relatives had this experience, identified these and other 'obscure' symptoms such as tiredness and memory loss as being sickle cell related. Further analysis of this group confirms that it is experience of ill-health, rather than other factors, such as education or employment which is related to this level of awareness.

As a result of the large numbers of people who said that they had either had no major illness, or who had been too young to remember being ill for the first time, information on what individuals and their families were told at the time of diagnosis is rather patchy. However, the few people who could remember, indicated that they were given rather vague information. This reflects the findings from other studies in which clients were dissatisfied with the information that they were given at the time of illness (Reynolds, 1978; Hawkins, 1979; Ley, 1982).

A surprisingly large number of people had requested that they be tested for sickle cell conditions. This seems to be a reflection of media exposure about sickle cell conditions. Half of those who requested a test did so because they recalled that one or more of their relatives having unexplained illness (ie the illness was unexplained to them

and may or may not have also been unexplained to their relatives), or they had vague symptoms themselves, which had not been identified as any particular condition. The remaining people were simply curious because they were members of the media's target population, and they did not wish to be unprepared in the event of having one or more children with the conditions.

Only a small number of people did not reveal their diagnoses to their families. This was to be expected, as nearly half the sample were diagnosed before they were eighteen years old. Families were generally seen as being very supportive of affected individuals, but friends and employers had more varied reactions.

What was more interesting was the fact that employers were unlikely to be told of the employee's diagnosis. The problems that the sample experienced in obtaining and retaining employment appears to have contributed in no small measure to this finding (discussed in the previous chapter). The apparent gate-keeping role adopted by employers has obviously not gone unnoticed by members of the sample. The Organisation for Sickle Cell Anaemia Research has also recognised that this is a problem (OSCAR, pers.comm. 1986). Sample members appear to be compensating for this by not disclosing information that they see as being detrimental to their chances of obtaining work.

People who had major problems with sickle cell conditions saw the conditions as affecting their health in various

ways. Many of the problems identified such as poor memory and concentration and tiredness are not measurable, but may be shared by other people with debilitating illness. Other than effects on performance, some of these symptoms may affect an individual's mental state, self-esteem and interactions with others on a day to day basis (Gendron, 1984; Cameron and Gregor, 1987; Long, 1988; Pollack, 1986).

8.5 Summary

1. More than half of the people who took part in the study had some form of sickle cell condition.

2. Severe symptoms were mainly limited to people who had sickle cell conditions, people with trait describing largely minor symptoms.

3. People with a sickle cell condition who were old enough to remember do not recall being given much information about the conditions at diagnosis.

4. Many people who were symptomless at diagnosis were given no information.

5. Employers were not likely to be told that an individual has trait or one of the sickle cell conditions, as people perceived that this compromised their ability to find work.

CHAPTER 9. Sickle Cell Crises

9.0 Introduction

This chapter describes sickle cell crises, sample members' experiences of them, and the health care they received in hospitals and in the community. It also examines how crises are perceived and dealt with at home, information-giving in hospital, and the effects of ill-health on employment.

Sickle cell conditions are chronic illnesses punctuated by episodes of crisis. People who are carriers, that is they have sickle cell trait, do not have sickle cell crises under normal environmental circumstances. The severity of the conditions varies with their type. For example, people with sickle cell anaemia (SS) generally have more severe health problems than those with SC or SF haemoglobin. The term sickle cell crisis refers to any new syndrome which is related to the client having a sickle cell condition and which develops rapidly (Diggs, 1965). They are generally accompanied by acute pain, and the word crisis is used to refer to any pain which is related to having a sickle cell condition. The severity of a painful crisis could vary from a mild transient attack of 5-10 minutes in a joint to severe generalised pains lasting several days or even weeks and requiring hospitalisation (Serjeant, 1985). People having crises are generally febrile, and pain may be in the extremities, back, abdomen and chest. Crises are precipitated by a number of factors such as pregnancy, infection, cold, emotional and physical stress, hypoxia and

dehydration.

9.1 Experience of crises

People in the sample talked about big crises, meaning severe pain episodes for which they needed inpatient hospital care, and small crises which they could cope with at home. Nearly two-thirds of the sample said that they had experienced a crisis (Table 9.1.1). These episodes of pain were seen as normal features of their existence and most were dealt with by individuals themselves. The trend was that people from the districts with a comprehensive package of care (CPC) tended to have more crises than those in districts which were not so described. This was to be expected as there were significantly more people recognised as having sickle cell conditions in the CPC districts (discussed in the previous chapter).

9.1.1 Warnings of impending crises

Half of the sample had warnings that they were becoming ill (Table 9.1.1). The nature of warnings that people had varied somewhat for sample members, some people describing signs that they recognised as a precursor to illness, while others talked about symptoms and other vague feelings. These warnings included feeling the cold and/or being tired to having jaundiced eyes or throbbing pains which developed into the more acute pain of the crisis.

Table 9.1.1 Percentage of people who experienced crises, what warnings they had and what actions they took when they thought that they were about to have a crisis

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
CRISES EXPERIENCE						
No crises	15	(30.6)	21	(50.0)	36	(39.6)
Crises	34	(69.4)	21	(50.0)	55	(60.4)
Sub-total	49	(100.0)	42	(100.0)	91	(100.0)
WARNING SIGNS AND SYMPTOMS						
No warning	7	(14.3)	7	(16.7)	14	(15.4)
Numbness/strange sensations (limbs)	2	(4.1)	2	(4.8)	4	(4.4)
Throbbing pains	15	(30.6)	6	(14.3)	21	(23.1)
Jaundiced eyes	1	(2.0)	3	(7.1)	4	(4.4)
Feel the cold	2	(4.1)	3	(7.1)	5	(5.5)
Extreme fatigue	1	(2.0)	0	(0.0)	1	(1.1)
Several of the above	6	(12.2)	1	(2.4)	7	(7.7)
Vaguely unwell	0	(0.0)	1	(2.4)	1	(1.1)
Not applicable	15	(30.6)	19	(45.2)	34	(37.4)
Sub-total	49	(99.9)	42	(100.0)	91	(100.1)
ACTIONS TAKEN						
Rest/warmth/fluids	4	(8.2)	3	(7.1)	7	(7.7)
Painkillers/fluids	4	(8.2)	5	(11.9)	9	(9.9)
Rest/warmth/fluids painkillers	13	(26.5)	8	(19.0)	21	(23.1)
Rest/warmth/fluids food	2	(4.1)	0	(0.0)	2	(2.2)
Rub with warming liniment	1	(2.0)	0	(0.0)	1	(1.1)
Nothing/doctor if worsens	2	(4.1)	0	(0.0)	2	(2.2)
Nothing/ignore it	1	(2.0)	0	(0.0)	1	(1.1)
Not applicable	22	(44.9)	26	(61.9)	48	(52.8)
Sub-total	49	(100.0)	42	(99.9)	91	(100.1)

$X^2_{1\,(d.f.)} = 3.67$ NS * This just fails to reach significance by 0.17

i. Reactions to warnings

People who had warnings of impending crisis took a number of actions in order to prevent themselves from becoming more seriously ill. A tiny number (3.3% of the sample) said that they did nothing when they felt that they were becoming ill (Table 9.1.1). The majority (43%) kept themselves warm, took extra fluids and rested, and most (25% of the sample) also took some form of painkiller.

9.2 Hospital admissions

Approximately one half of the sample had been admitted to hospital as a result of illness related to having a sickle cell condition (Table 9.2.1). There were no district differences in overall hospitalisation. However, there were significant differences between districts regarding hospitalisation of people in the sample sent to hospital in the year previous to being interviewed (Table 9.2.1). More people from the district with the comprehensive package of care had been admitted to hospital during this time.

9.2.1 Description of the illness causing hospitalisation in the year before interview

People presenting with crises in the chest, abdomen, back and joints made up the bulk of those hospitalised during the year previous to the interview (Table 9.2.1). A smaller number presented with crises in the limbs only. Painful crises were not always localised and three of the twenty-six people who were hospitalised during this period described generalised painful episodes. A further four people had been hospitalised with some 'other' illness such as chest infections and pneumonia which they said later developed into a crisis.

Table 9.2.1 Percentage of the sample's experience of hospitalisation and the symptoms they presented with as a result of admissions during the last year

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
HOSPITALISED						
Never	22	(44.9)	24	(57.1)	46	(50.6)
Once	13	(26.5)	10	(23.8)	23	(25.3)
More than once	14	(28.6)	8	(19.0)	22	(24.2)
Total	49	(100.0)	42	(100.0)	91	(100.1)

Hosp. vs. no hosp. $X^2_{1\ (d.f)} = 1.36$ NS

LAST ADMISSION						
In the last year	20	(40.8)	6	(14.3)	26	(28.6)
1 year plus	7	(14.3)	12	(28.6)	19	(20.9)
Not applicable	22	(44.9)	24	(57.1)	46	(50.6)
Total	49	(100.0)	42	(100.0)	91	(100.1)

$X^2_{2\ (d.f)} = 8.48\ p < 0.02$

SYMPTOMS - THE LAST YEAR'S ADMISSIONS						
Severe pain in						
Chest	4	(8.2)	3	(7.1)	7	(7.7)
Abdomen/back	5	(10.2)	1	(2.4)	6	(6.6)
Limbs/joints	4	(8.2)	2	(4.8)	6	(6.6)
Everywhere	3	(6.1)	0	(0.0)	3	(3.3)
Other	4	(8.2)	0	(0.0)	4	(4.4)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.1)	42	(100.0)	91	(100.0)

Symptoms vs. no symptoms - $X^2_{1\ (d.f)} = 7.8\ p < 0.01$

9.2.2 Activities at time of last illness

Although the onset of crises is often associated with physical exertion, nine of the twenty-six people hospitalised were occupied in sedentary pursuits when they became ill (Table 9.2.2). However, seventeen people (19% of the sample) were either outside on a cold day or were doing a physically exacting task.

i. Actions taken on becoming ill

Actions taken on becoming ill were remarkably similar to the strategies used by people to maintain comparatively good health when they thought that they were about to have a crisis. The majority of people who had been hospitalised

said that they would increase their fluids, use painkillers, keep warm and try to rest (Table 9.2.2). The ambulance was only called when painkillers did not work and pain became too much to bear.

9.2.3 Care while in hospital

Fourteen of the 26 hospitalised people said that they had to wait up to four hours before they were seen by a doctor (Table 9.2.3). Painkillers were generally not prescribed before then. Four percent of the sample said that they had received immediate treatment (ie. within 15 minutes) of complaining to hospital staff of severe pain. These people were in hospital at the time for other illness. A further three percent of the total sample had long delays of more than four hours waiting for medical care (Table 9.2.3).

The complaint that people are kept waiting for unacceptably long periods for emergency pain treatment in casualty is not a new one. A recent study by Black and Laws, (1986) confirms this. Clients often perceived the root of the problem, but could do nothing about it.

> " Basically it is not the nurse's fault. She has to wait for the doctor to prescribe it (usually opiate analgesia)".

However, on the ward, there were times when the nurse was seen to be at fault. At least three people said that although painkillers were prescribed, nurses did not administer it when they should. One woman felt very aggrieved because she felt that her black nurse should have

shown more understanding of her need for analgesia.

> " The nurse was worried that I would get addicted. She could give me the drug but wouldn't. Then when she did, it wasn't the full dose. I could feel the difference. It doesn't work in the same way and doesn't last as long. I was very cross with her 'cos she's black too and I thought 'at least she'll understand', but she thought I'd be an addict".

In this particular case, it appears that the doctor had prescribed an upper limit for extreme pain and a lower limit for maintaining a pain free individual. This nurse is believed to have insisted on giving the lower limit no matter how severe the client's pain.

i. Information given while in hospital

A fifth of the sample (ie 18 of the 26 people hospitalised during the last year) could not recall being given any information regarding their then current bout of ill-health (Table 9.2.3). Eight of the twenty-six people recalled having either their treatment or the cause of their crisis discussed, but not both.

9.2.4 Nursing/medical care at home after discharge from hospital

Twenty out of twenty-six people discharged said that no-one had visited them at home after they were discharged from hospital. (Table 9.2.4). The sickle cell counsellor who worked in the district which had a comprehensive package of care saw three people. All of these three people had been hospitalised more than once in the previous year. Two people

were visited by their GP's after they returned home. Five people who had not been visited at home after discharge said that they would have liked to be seen at home as they felt that they still needed some health care, while three said that visits would be pointless as care staff 'don't do anything' when they arrive.

The six people who were seen at home saw the health care professional an average number of 1.2 times. Visits were done mainly to check on the client's state of health with only one person needing dressings for a leg ulcer.

Three of the six people seen at home were satisfied with their visit(s), the others wanting more information and health care advice regarding their conditions.

Half of the 26 people hospitalised in the previous year said that they needed more information and health education which could be provided if people visited them at home after a crisis. A further seven felt that it was important to be visited at this time, as they may need some help caring for themselves for a few days. The remaining people did not want to be visited, although two people added that others may find this service useful.

Of those who would have liked to be seen, there were ambivalent feelings about the prospect of being visited by care staff. The general concensus was that people would like to know that someone is keeping an eye on their health in the first few days after discharge, but this was tinged with

doubts about the usefulness of the exercise. This ambivalence of feeling seemed to underline a general feeling of no confidence in community care. To quote one individual,

> " I had a nurse come to see me once (for dressings). She did the dressing, asked how I was and left. I suppose that was better than nothing, but it would have been a help if she could tell me about what was causing the ulcer (on the leg which was the reason for the dressing), why I get crises, if there will be a cure for this thing soon and what I can do to make things better".

A woman who had been hospitalised several times during the previous year and had been visited by a sickle cell counsellor pointed out that,

> " It's nice to know that someone will come to check up on you.. if there are any problems, there is someone to help. It's just for a few days until you feel that you can cope again ..."

Another woman said,

> " This woman (the nurse) came a couple of days after I come home from the hospital and she asked me a lot of personal, personal questions .. things like how many men I've been with .. I'm 19 and I only ever had one boyfriend .. we're not planning any kids or anything like that, so what right did she have to ask me these things. The worse thing was I didn't even know her from Adam. She just arrived at my doorstep to plan my family and perhaps my life, for me. I haven't seen her since but if she comes back, I won't be in..."

9.2.5 Time spent ill and off work in the past year

People who had been hospitalised in the past year and could recall how much time they spent being ill, had an average of 2.1 weeks in hospital and a further 2.4 weeks off work (Table 9.2.5).

Table 9.2.2 Activities before becoming ill and actions taken on becoming ill

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
ACTIVITIES BEFORE ILLNESS						
Housework	4	(8.2)	1	(2.4)	5	(5.5)
Running	4	(8.2)	0	(0.0)	4	(4.4)
Outdoors/cold day	5	(10.2)	2	(4.8)	7	(7.7)
Resting/asleep	2	(4.1)	1	(2.4)	3	(3.3)
Watching T.V	4	(8.2)	2	(4.8)	6	(6.6)
Can't remember	1	(2.0)	0	(0.0)	1	(1.1)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.1)	42	(100.1)	91	(100.0)
ACTIONS TAKEN						
Rest/warmth/fluids/ painkillers	17	(34.7)	6	(14.3)	23	(25.3)
Rub	3	(6.1)	0	(0.0)	3	(3.3)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.0)	42	(100.0)	91	(100.0)

Table 9.2.3 Treatment on arrival at hospital and what people were told about what caused the present bout of illness

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
HOSPITAL CARE						
Immediate treatment	4	(8.2)	0	(0.0)	4	(4.4)
Short delay (<15 mins)	3	(6.1)	2	(4.8)	5	(5.5)
Moderate delay	11	(22.4)	3	(7.1)	14	(15.4)
Long delay (>4 hours)	2	(4.1)	1	(2.4)	3	(3.3)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.0)	42	(100.0)	91	(100.0)

Immed/short delay vs. Mod./long delay - $X^2_{1\,(d.f)} = 6.1^{-03}$ NS

WHAT TOLD ABOUT ILLNESS						
Nothing	13	(26.5)	5	(11.9)	18	(19.8)
Treatment explained	3	(6.1)	0	(0.0)	3	(3.3)
Cause discussed	4	(8.2)	1	(2.4)	5	(5.5)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.0)	42	(100.0)	91	(100.0)

Table 9.2.4 Care staff seen in follow-up visits after people were discharged home from hospital

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
No-one seen	14	(28.6)	6	(14.3)	20	(22.0)
GP. visited	2	(4.1)	0	(0.0)	2	(2.2)
District Nurse (for dressings)	1	(2.0)	0	(0.0)	1	(1.1)
Sickle Cell counsellor	3	(6.1)	0	(0.0)	3	(3.3)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.0)	42	(100.0)	91	(1000.0)

Table 9.2.5 Percent time spent in hospital this year and time spent off work.

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
TIME SPENT IN HOSPITAL						
Less than 1 week	8	(16.3)	1	(2.4)	9	(9.9)
1-2 weeks	5	(10.2)	4	(9.5)	9	(9.9)
More than 2 weeks/ up to 4 weeks	2	(4.1)	1	(2.4)	3	(3.3)
More than 4 weeks	1	(2.0)	0	(0.0)	1	(1.1)
Can't Remember	4	(8.2)	0	(0.0)	4	(4.4)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.0)	42	(100.0)	91	(100.0)
TIME OFF WORK						
Less than 1 week	3	(6.1)	0	(0.0)	3	(3.3)
1-2 weeks	3	(6.1)	1	(2.4)	4	(4.4)
More than 2 weeks/ up to 4 weeks	2	(4.1)	3	(7.1)	5	(5.5)
More than 4 weeks	3	(6.1)	0	(0.0)	3	(3.3)
Can't remember	4	(8.2)	0	(0.0)	6	(4.4)
Unemployed	5	(10.2)	2	(4.8)	7	(7.7)
Not applicable	29	(59.2)	36	(85.7)	65	(71.4)
Total	49	(100.0)	42	(100.0)	91	(100.0)

9.3 Home management of crises

Although only twenty-six people had been hospitalised with a sickle cell crisis in the past year, thirty-nine (ie. a third of the sample) had what they described as 'small' crises which they dealt with at home. Of these twenty had been diagnosed for at least fifteen years. This figure includes those people who were eventually hospitalised when other crises became severe. Small crises were described as,

> " pain severe enough to make you feel unwell or concerned, but not strong enough to make you panic".

These minor crises were managed at home, generally without medical intervention.

9.3.1 Frequency of home crises in the past year

Thirty-nine people (forty-three percent of the sample),

described having an average of 4.5 crises which did not require medical intervention during the previous year (Table 9.3.1). Crises occurred largely between midday and midnight (28%), with ten percent of the total sample having crises between midnight and six am. The data contained in Table 9.3.1 suggest that whereas pains in the limbs occur most frequently, clients are more likely to be admitted to hospital for chest, abdomen and back pains. This is to be expected as the latter symptoms are indications of life-threatening crises. No district differences were seen regarding crises which were dealt with by the individual at home.

i. Actions taken to alleviate crisis

As with impending 'big' crises, people coped by adapting their activities. Thirty-two of the thirty-nine people who described having minor crises said that they rested more, kept themselves warm, took painkillers as necessary and increased their fluid intake. Eight people in addition said that they found warm baths, heat pads and massage helpful. Only six people saw or spoke to their GPs requesting prescriptions for painkilling drugs. One person ignored the pain until it went away. No significant differences were observed between the CPC and NCPC districts.

ii. Severity of last crisis

When asked to describe the severity of their last crisis, 18% of the sample said that it was severe compared with 40%

who said that the crisis was moderate to mild (Table 9.3.1). All of the people who said that their last crisis was severe had been admitted to hospital for medical care. There were no district differences.

9.3.2 Emergency help systems outside the health care system

Almost all of the sample (88%) said that they had a close relative whom they could contact for help in case of emergencies (Table 9.3.2). Parents and partners made up the bulk of those who the sample would turn to for help.

Table 9.3.1 Number of crises the sample experienced at home in the past year

	CPC		NCPC		TOTAL	
NO. OF CRISES	n	(%)	n	(%)	n	(%)
1-2	10	(20.4)	5	(11.9)	15	(16.5)
3-4	4	(8.2)	2	(4.8)	6	(6.6)
5+	11	(22.4)	7	(16.7)	18	(19.8)
None	24	(48.9)	28	(66.7)	52	(57.1)
Total	49	(99.9)	42	(100.1)	91	(100.0)
TIME OF LAST HOME CRISIS						
06.01 - 12.00 hrs	4	(8.2)	1	(2.4)	5	(5.5)
12.01 - 18.00 hrs	11	(22.4)	2	(4.8)	13	(14.3)
18.01 - 00.00 hrs	5	(10.2)	7	(16.7)	12	(13.2)
00.01 - 06.00 hrs	5	(10.2)	4	(9.5)	9	(9.9)
Not Applicable	24	(48.9)	28	(66.7)	52	(57.1)
Total	49	(99.9)	42	(100.1)	91	(100.0)
SYMPTOMS						
Pain in the Chest	0	(0.0)	1	(2.4)	1	(1.1)
Abdomen/back	6	(12.2)	2	(4.8)	8	(8.8)
Limbs	14	(28.6)	9	(21.4)	23	(25.3)
Everywhere	5	(10.2)	2	(4.8)	7	(7.7)
Not Applicable	24	(48.9)	28	(66.7)	52	(57.1)
Total	49	(99.9)	42	(100.1)	91	(100.0)
SEVERITY OF THE LAST CRISIS EXPERIENCED						
Severe	12	(24.5)	6	(14.3)	18	(19.8)
Moderate	9	(18.4)	5	(11.9)	14	(15.4)
Mild	11	(22.4)	9	(21.4)	20	(22.0)
Not Applicable	17	(34.7)	22	(52.4)	39	(42.9)
Total	49	(100.0)	42	(100.0)	91	(100.1)

Table 9.3.2 People who sample members would contact for help in case of emergencies

	CPC		NCPC		TOTAL	
	n	(%)	n	(%)	n	(%)
Parents	26	(53.1)	24	(57.1)	50	(54.9)
Sibling	6	(12.2)	2	(4.8)	8	(8.8)
Partner	6	(12.2)	5	(11.9)	11	(12.1)
Children	1	(2.0)	1	(2.4)	2	(2.2)
Other Relative	2	(4.1)	0	(0.0)	2	(2.2)
Parents/partner	2	(4.1)	5	(11.9)	7	(7.7)
Friends/Neighbour	3	(6.1)	3	(7.1)	6	(6.6)
No-one	3	(6.1)	2	(4.8)	5	(5.5)
Total	49	(99.9)	42	(100.0)	91	(100.0)

Siblings, children and other relatives could also be called on for help. Only six percent of the sample said that they were entirely alone. No district differences were seen.

9.4 Discussion

Sickle cell crises, both large and small, featured largely in the lives of some sample members and almost two-thirds of the sample had experienced some form of crisis.

A small number of people described crises which occurred suddenly, giving them no time to appreciate that they were becoming ill. However, the experiences of most sample members indicated that not only were they forewarned that they were about to have a crisis, but that they had enough time to attempt to 'treat' their symptoms so that their health did not deteriorate. If individuals felt cold, tired and in pain, they would warm themselves using heaters, additional clothing and warming drinks, rest (often under bedclothes for warmth) and take painkillers. Sample members appear to have taken these actions as a direct response to what they perceived their needs to be, rather than because

they had been told to do these things. This means that any such actions were likely to be used at the onset of illness, at least initially, rather than prophylactically. People who had been diagnosed for a longer time also tended to dress more warmly than they used to as they associated feeling cold with developing crises. This learned behaviour suggests that people are devising coping strategies in order to deal with the immediate problems of crises.

However, as has been discussed in the previous chapter, there are many variables beyond the sample's control, such as unemployment and inappropriate housing, which can influence the frequency and severity of sickle cell crises.

Over-exertion and cold conditions are well documented as being contributory factors to the occurrence and severity of crises (Serjeant, 1985; Mann, 1981). Sixteen of the twenty-six people who were hospitalised for crises suggested that these two factors were instrumental in their developing them. However crises can, and did occur, when people were at rest and apparently warm, as was the case for nine people. It may be that other factors known to precipitate crises were in operation but these nine people were unable to identify what they were.

The data regarding hospitalisation suggest that people from districts with a comprehensive package of care (CPC) are more likely to have severe crises which require in-patient medical treatment than those in districts where there is no such package (NCPC). However, more people in the CPC

districts were diagnosed as having a sickle cell condition. Only twelve of the twenty people from the CPC district admitted to hospital rated their crisis as severe, that is, pain was in the trunk as opposed to the extremities. It is possible that people in the NCPC districts may have crises at home of an intensity for which people in the CPC districts would attend hospital.

It is probable that people from the CPC district, aware of the importance of aggressive pain therapy, in preventing a developing crisis from becoming more serious, consult their doctors as soon as they felt that their own efforts at containing pain, were ineffective. Furthermore, as people develop confidence in the services provided, they are less concerned that a trip to the hospital would make no real difference to the outcome of their illness compared with their own efforts. People from NCPC districts, equipped with less information about the effects of crises, and unwilling to have to cope with inhospitable casualty departments, delay going to the hospital until doing so becomes more attractive than remaining where they are. These people therefore use the hospital as a last resort when extremely ill, at which time they present themselves for emergency treatment. This appears to be supported in the data, as those people from the NCPC districts who rated their crises as severe were also the ones who were hospitalised. People in NCPC districts who rated their crises as mild included the four people with trait who described having symptoms.

There were a few people in the NCPC districts, with the most

severe form of the conditions who had few if any, major symptoms. There may be a number of reasons for this involving social and genetic components. Dealing with the genetic component first, it is possible that the answer lies in the origins of the ancestors of sample members. Most of the sample was of African-Caribbean extraction. That in itself suggests a melting-pot of many different groups of people come together in the individual. History already tells us that slaves taken to the New World came from many different countries. It is possible therefore that the descendants of these different West Indian groups have differing physical responses to sickle cell conditions. For example, some people may retain higher levels of fetal haemoglobin which will confer some degree of protection against the hazards of having these conditions. However as most people in the NCPC were not provided with cards which gave the amount of fetal haemoglobin they retained, it was not possible to see whether this is an important consideration. The explanation is a possibility, however, as the type of sickle cell condition does not seem to be important here. Although there were differences between the two types of districts in relation to the numbers of people in the sample with sickle cell trait and sickle cell condition, there were no differences in the distribution of the more and less severe forms of sickle cell condition over the two types of districts.

From a social viewpoint, the answer might lie in the relative fitness of individuals. Exercise, diet and type of housing are also important considerations which could

contribute to an individual's poor health (Townsend and Davidson, 1986; Whitehead, 1987). An examination of field notes taken at the time of interview, suggested that people in the NCPC districts lived more often than not in new council estates and none lived in high rise apartments, whereas those in the CPC districts tended to live old, damp ridden housing stock, which could contribute to an increase in the frequency and severity of sickle cell crises. People in CPC districts did not appear to be any poorer than those in NCPC districts. Data on income were not collected, but there were no observed differences in unemployment between the two districts.

It is interesting to note that the crises people tended to deal with themselves tended to be in the limbs. These crises did not readily conjure up a major catastrophe as would chest and abdominal pains for example, and inspired more confidence in people's ability to cope with them. Crises in the chest, abdomen and back, known as 'chest or girdle syndrome' depending on the areas affected, were always taken very seriously by both individual and their doctors, and almost always resulted in hospitalisation. Once again, people appear to have learned from experience which symptoms could be tolerated for long periods without help and which could not. This type of behaviour was often used even when the individual may have been told by her/his doctor to consult him/her as soon as problems occur. As one woman put it,

" It is my problem when the pain starts. I must manage it. If

I cannot manage it, then it is a problem for the doctor".

However, under-medicating an in-patient has the knock-on effect in which that client may spend his or her time looking forward to the administration of the next dose, gradually leading to a state where addiction is possible (Marks and Sachar, 1973). In addition, if the client is not in pain when the drug is given, addiction can occur. The problems of pain control and possible addiction in the case of clients in sickle cell crises have been discussed by Murray and May (1988). They suggested that care staff were 'alarmist' regarding possible addiction to pain-killing drugs. They also found that clients' perceptions of their pain were significantly higher than the pain they (the clients) believed care staff perceived. Seers (1989), in a study which looked at post-operative pain, confirmed that nursing staff rated clients' pain after surgery as less than the clients did.

The study has shown that sample members were poorly informed about the crises for which they were hospitalised. The failure to communicate between doctors and clients has been clearly demonstrated before (Cartwright, 1964; Ley, 1982; Oakley, 1993a). It has also been found that clients undergoing anaesthesia and surgery have benefitted from pre-operative explanations of anaesthesia and pain control (Boore, 1980; Davis, 1984), and threatening medical procedures such as naso-gastric intubation (Padilla et al., 1981), pelvic examination (Fuller et al., 1978) and barium enema (Hartfield et al., 1982). Neglecting to provide

adequate information to people with haemoglobinopathies has also been reflected in other studies (Constantinides, 1987; Darr and Modell, 1988).

Doctors have also been shown to fail to communicate information about clients to nurses (Duff and Hollingshead, 1968). In this study, both doctors and nurses have been seen to fail to communicate with clients in crises. It can be argued that when in severe pain, people are only interested in pain relief. However, as stress is known to have an effect on crises (Serjeant, 1985), providing information at appropriate times should help to relieve anxieties which could be having a knock-on effect on the severity and duration of the crisis.

Sample members who had been hospitalised spent an average of four weeks off work. This created grave problems for some people whose employment was terminated often after one illness episode (discussed in Chapter 7). It also led some people who had less severe illness to continue to work even after being advised by their doctors not to do so.

The data discussed in this chapter makes contributions to my first, third, seventh, eighth and ninth hypotheses. These briefly are:

That health districts which have large minority ethnic populations have a comprehensive package of care (as discussed in earlier chapters). This hypothesis was not proven. Counselling and information giving did not appear to

be a major component of health care. Furthermore, referrals to community care was ad hoc and patchy. There also appeared to be no established protocols, for emergency care, (later implied by interviews with sickle cell counsellors - chapter 13), for the care of people in sickle cell crisis.

People with sickle cell conditions in CPC districts will have ease of access to health care, because of the district's recognised need for the care packages they provide. This hypothesis was proven only in the sense that sample members from CPC districts were more likely to access hospital care than their NCPC counterparts. However, it is debatable whether the quality of care they received was any better than that obtained by NCPC participants.

People who were diagnosed in childhood will be more aware of the strategies they could use to avoid the types of situations which will increase their susceptibility to becoming ill, for example doing physical education outdoors in the cooler months. This hypothesis held true, as people who were diagnosed longer used a number of strategies to avoid small crises becoming more serious.

Perceptions by clients of uncaring attitudes from care staff if present, will be accompanied by perceptions of poor health care. Members of the sample did not see nurse carers as being particularly helpful, especially where pain relief was concerned. Follow-up visits after discharge were also viewed negatively. Although clients had negative perceptions of general nursing (also hinted at in the previous chapter)

and medical care, they were quite optimistic as a whole, about specialist medical care.

People who are unemployed and live in poor housing will have more sickle cell crises, than those who are employed and live in better housing. As there may have been confounding interactions between organisation of care in CPC districts and poor housing, this requires further study.

9.5 Summary

1. Nearly two-thirds of the sample had experienced either a serious or a mild sickle cell crisis at some point in their lives. However, more than half of the sample had never been hospitalised because of their sickle cell.

2. Crises in the chest, back and abdomen generally led people to seek hospital treatment, whereas crises in the limbs were normally dealt with at home.

3. More people from the districts with a comprehensive package of care (CPC) were admitted to hospital in the year before interview, than were admitted from the districts without a CPC. This appears to be because more people from the districts with a comprehensive package of care had more severe conditions. Furthermore, people from CPC districts may be using medical services earlier in the crisis, than people from the other districts. It may also be a reflection of district policy which appears to be concerned with

the provision of emergency care in hospital rather than that of preventive care in the community. It may also reflect social and genetic differences between people living in the two sets of districts.

4. People used a range of strategies for coping with impending and early crises. These included resting, keeping warm, increasing their fluid intake and using prescribed and other analgesia.

5. Cold conditions and tiredness due to over-exertion were implicated as precipitating crises. However, nine out of twenty-six people hospitalised with crises could not identify any causative factor.

6. On arrival at hospital there were unacceptably long delays before painkilling drugs were prescribed.

7. People who were hospitalised were more likely than not to have received no information about their illness.

8. People leaving hospital after crises were generally not seen at home by a health care professional. They were generally ambivalent about how beneficial home visits would be.

9. People who had been hospitalised with crises spent an average of one month on sick leave. Interruption to employment was a considerable problem.

CHAPTER 10. Current Treatment and Health Status

10.0 Introduction

In this chapter, the experiences of sample members, of non-emergency, out-patient care and their use of generalist and specialist medical and nursing services, are examined.

People with sickle cell conditions often have long periods of comparative good health. This is seen in other chronic conditions such as diabetes. While enjoying good health, the health care needs of these groups are generally monitored on an out-patient care basis. This may take the form of regular home visits by a specialist nurse, for example as in some districts for ostomates (Wade, 1990), and young diabetics (Moyer, 1989). Other people with chronic conditions may be seen on a regular basis in out-patients' clinics at the hospital for various health monitoring procedures.

10.1 Out-patient hospital based treatment of sickle cell conditions

Out-patient based care for people with sickle cell conditions may take two forms, sometimes in combination. Active care may occur, as in the case of a particular therapy, or the individual may simply attend out-patient clinic for their haemoglobin levels to be monitored. People with sickle cell anaemia may need regular blood transfusions at periods in their lives when the anaemia is severe. These can and often are done when clients are admitted for the day

or on an overnight basis (pers. comm. Wonke, Consultant Haematologist, 1986).

Sickle cell monitoring is necessary as regular medical tests can identify potential problems which can be prevented from getting worse by early medical treatment (Sickle Cell Society, 1983). The frequency of medical monitoring will depend on the type of sickle cell condition and the clients' medical histories. People who experience medium to large number of illness episodes or with moderate to severe anaemia might be seen fortnightly or even weekly, quarterly or half-yearly by various specialists at out-patients departments. Others with few illness episodes and only slight anaemia might be seen on an annual basis. Depending on the type of condition, this latter group may also be seen annually or indeed more frequently, by other specialist doctors, eg. ophthalmologists and orthopaedic surgeons, as not having crises does not preclude them from having eye, hip and other complications. The early identification and treatment of developing complications is effective in containing the further development of those complications, and may serve as warning signals for starting the monitoring of other organs and systems.

10.1.1 Experience of out-patient medical care

While there were significant differences between districts in the numbers of clients who visited out-patients' clinics, versus those who needed no hospital care, ($p < 0.04$), no district differences were observed between the latter group

and those clients' who needed non-emergency care in terms of sickle cell conditions. This just fails to reach statistical significance, the trend being that districts with a comprehensive package of care (CPC) provided more out-patient medical care than the districts without (NCPC). This is to be expected as more people with sickle cell conditions were in the CPC districts. Two percent of the sample had both sickle cell monitoring and some other form of medical care. More than two-thirds of the sample had regular contact with doctors as out-patients, largely receiving sickle cell related health care, only nine percent requiring other medical care (Table 10.1.1). The remainder of the sample (36%) who did not have sickle cell monitoring were generally carriers, although three people had sickle cell anaemia and another five had other types of sickle cell conditions.

Table 10.1.1 Reasons why people regularly received medical treatment

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
Sickle cell maintenance	26	(53.1)	18	(42.9)	44	(48.4)
Sickle cell related need	3	(6.1)	1	(2.4)	4	(4.4)
Sickle cell and other med. need	1	(2.0)	1	(2.4)	2	(2.2)
Sub-total	30	(61.2)	20	(47.6)	50	(54.9)
Other medical need	6	(12.2)	2	(4.8)	8	(8.8)
No medical treatment	13	(26.5)	20	(47.6)	33	(36.3)
Total	49	(99.9)	42	(100.1)	91	(100.1)

$X^2_{2\,(d.f)} = 5.04$ NS * This just fails to reach significance by 0.95

No medical treatment versus all medical treatment, $X^2 = 4.41$, $p < 0.05$.

No medical treatment vs. sickle cell treatment $X^2 = 3.39$ NS.

10.1.2 Regularity of hospital appointments

People who saw a doctor regularly for the monitoring of their sickle cell condition tended to do so at three monthly or six monthly intervals (Table 10.1.2). A smaller number saw the doctor more often. Eight of the nine people who saw their doctors more often than quarterly had crises recently for which they were hospitalised, and two were regularly receiving blood transfusions. The remaining one person was on home dialysis and was experiencing very poor health. More than half the sample (55%) had been given an appointment to see the doctor in the six months before the interview (Table 10.1.2). No district differences were seen.

a) The last hospital appointment

One in ten of those who were given a hospital appointment failed to keep it (Table 10.1.2). Thirty percent of the sample had seen their doctors within the last two months. One person who said he saw the doctor regularly for sickle cell monitoring had not done so for over a year. He had missed the six monthly appointment and was waiting for the letter calling him to attend the next one. No district differences were seen.

b) Time spent on appointments

People who regularly had appointments with the doctor, for sickle cell care had an average waiting time of 3.4 hours before the were allowed to leave the hospital (Table

10.1.2). No district differences were observed.

The quote below was typical of comments made by several sample members who attended hospital.

> " Sometimes I get an appointment for about 10am, but it's not really an appointment cos you're not seen at that time. The receptionist puts your card in order of when you arrive, and people who got there for nine o'clock say, are all there in front of you. Sometimes at ten o'clock the doctor hasn't started yet. So then you wait .. it could be two hours or more... before the doctor sees you. ... asks how you are ... takes some blood. Then you wait. Sometimes 15-20 minutes later, you see somebody in a white coat (possibly a technician) come and pick up all the bloods which are outside the doctors door.. Then you wait till they come back and all the people in front you in the queue have to get seen first. By the time the doctor gets to you at least another hour is gone .. sometimes an hour an a half. Then he says, your blood's O.K. You can go. That's your whole morning gone. If your appointment is later, say 11.30, half your afternoon is gone as well. I keep going 'cos if I get ill it'll be my fault. But sometimes I get annoyed 'cos when I get there it's 'Hello .. how are you ... I'll just take some blood ... you're alright, you can go'. I wait four-five hours just to see him for two minutes. I don't expect long conversations, but all that time just waiting ... waiting..."

c) Cost of travel

People who saw the doctor at the out-patients clinic were generally unable to quantify how much it cost them to go to the hospital. Eighteen of them had bus season tickets, while 3 used private cars. A further 9 people lived close enough to the hospital to be able to walk. Of the 13 remaining people who used public and other transport, 3 used taxis to attend out-patients clinics. These thirteen people estimated that the cost of travel was an average of £2.25. There were no district differences.

d) Keeping appointments generally

Forty-four of the fifty-three people who regularly were given hospital appointments said that they always kept their appointment (Table 10.1.2). Reasons given by people who did not always attend included forgetting the appointment, feeling too well and being ill at home or as an in-patient. One person showed dissatisfaction with the service when she said that attending clinic had no point (Table 10.1.2).

10.1.3 Use of medical services at hospital

The doctor generally seen was the haematologist, for sickle cell monitoring and care. Other doctors were seen for a variety of medical (and one surgical) reasons which interviewees believed were largely unrelated to their having sickle cell genes. Haematologists had been seen six times on average in the year before interview (10.1.3).

a) Obstetrics, gynaecology and family planning

Twenty-two percent of the sample saw either the midwife, obstetrician or gynaecologist in the year before interview (Table 10.1.4). Significantly more people from CPC districts saw these health professionals than those from NCPC districts ($p < 0.05$). Most of the women who needed this type of care (ie. reproductive care) had sickle cell trait. This result is seen because more women with trait had pregnancies in the past year. This may be a reflection of decisions made by women with sickle cell conditions to limit their

families.

Women who used these services had an average of three visits. There were no district differences. Health professionals were seen in out-patients family planning clinics, except for two cases when the midwife visited the client at home. Consultations were made as a result of pregnancy (13%), family planning care (eg. changes of contraception and the fitting of coils - 36%), reproductive health (eg. infections caused by coils - 3%) and heavy bleeding (1 woman who was on Depo Provera injections). Three out of twenty women who were asked specifically about contraceptive use had been recommended this drug. There were no district differences regarding the reasons why people used professionals for reproductive concerns.

This is the story of a large, very muscular twenty year old woman who had been on Depo Provera for one year. She had regular 'check-ups' of her weight and blood pressure, and had complete confidence in the care she received, despite her worry, confided in the researcher, that she bled continuously and had gained a great deal of weight in the last year. Photographs on the mantlepiece confirmed that she was once a very slight woman.

> " I went to the family planning doctor to go on the Pill because I was beginning to have relationships. The doctor advised me **not to take the pill.** She offered me an injection every three months. She told me that the choice was mine if I went on the injection. She said **that Depo Provera was better than the Pill.** I chose Depo Provera ... I feel that I've been informed because she (the doctor) gave me leaflets for the Pill and underlined the bit that said if you have sickle cell, you shouldn't take it (the appropriate section was underlined in red and highlighted in yellow). **The doctor**

let me know that if anyone with these problems continued to take the pill and then died 'then that would be your risk'. I suppose it's like smoking and running the risk of cancer. Then she let me have a look at some of her stuff (literature) on Depo and **told me it was particularly good for people with sickle cell as they don't have any crises.... in a way you have peace of mind. That was another reason why she said it was so good.** 'You don't have to remember to take your pill every morning'. You just go every three months for your injection. I didn't take Depo immediately. I came home and thought about it. I weighed up the advantages and disadvantages. I didn't jump into it....I haven't had a sickle cell crisis since I was about fourteen (years old).... No I don't have any children, I've never been pregnant..."

The same approach was used on two other women in the sample. One refused to use the drug and the other was still considering using it. The woman who refused the drug said,

" She said that it was my choice to go on the drug, but it was not ... **she spoke to me as if I had no choice.** I was so angry. Anyway I told her if it was my choice I would continue with was I was using 'cos I was having no trouble with it."

None of the pregnant women had been given any general health information regarding their pregnancies by either the midwife or the obstetrician. However, 28 women, not all of whom were pregnant, were given family planning advice. Contraception appeared to be the responsibility of women, while men were not given contraceptive advice other that to not have any children. However, the lone man who had a vasectomy (on his request), did so because he and his partner felt that they had completed their family.

At least one woman showed her suspicions of contraceptive methods.

" I have one child. I won't have any more. I'm getting on a bit now and my son is nineteen. I don't use any contraception. Never have. I was tempted years ago to try one of them things they put inside you, but then my friend who had it started to have all kinds of trouble with it. She didn't bleed regular and had pains and such. Man, she had so much trouble that I look at her and I think to myself, 'Not me. I'm not having that. That thing damage her and I don't want it'. So I chose not to use any of them things. You

> don't really know what they will give you anyway to stop you having children, especially if you're black. I stopped (having children) when I wanted to and I did it healthy so it won't make me sick and maybe make the sickle cell worse and all. I tell you the truth. The best contraception is don't do it. Tell him 'No!'. My partner didn't like that and he left years ago but I had my son and that was all I wanted".

Women also described their need for information and their experiences during their pregnancies. Typical quotes were:

> " I need to know more about becoming pregnant. Everything I should know. Why you have to go into hospital for such long periods (3 women had been admitted to hospital for prolonged rest during their pregnancies). Why the regular check-ups. Why you have to watch your haemoglobin .. they never said how a drop would affect the baby .. about childbirth .. about drugs they were using, like painkillers .."

Inheritance of the genes and the importance of pre-natal screening were questioned after children were born.

> " I wanted to know more about the twins, why one had trait and the other hadn't" ,

and,

> " How can they tell you when you're pregnant that the baby has it, so you should have an abortion, then when you refuse and the baby gets born, they can't tell you exactly what the baby has until it gets its own blood".

Three women who described difficult pregnancy experiences talked about the need for doctors to consider their own familial responsibilities. This could involve the care of other children generally, or older relatives who are unwell. One women who had been hospitalised for several weeks said,

> " I was about two months pregnant .. they took me in to keep an eye on me 'cos my blood pressure went up, and I started to bleed a little. After about two months, I was let out for the weekend .. I didn't go back .. my father was ill and he needed someone .. I began to bleed again .. I was about 4 - 5 months pregnant .. I discharged myself ('cos of my dad) .. I promised I'd be a good girl and go back after a week".

This woman had also been offended by the language used by her doctor who made her promise to be a 'good girl' and return to hospital, but felt powerless to say anything about this for fear it would affect subsequent medical care for herself or her family.

b) Other medical and nursing services used at hospital

Twenty-four percent of the sample consulted generalist medical and surgical personnel for 'other' therapies either solely or in combination with receiving sickle cell care. Other medical conditions which people were being treated for included obvious complications of sickle cell conditions eg. retinopathy (1%), hip complications (2%) and strokes (1%). Some ailments were not recognised by the client to be sickle cell related, but a few may have been, eg. kidney problems (1%) and gall stones (1%). Five women (6% of the sample) had 'blood pressure problems'.

Hospital nurses contributed to care when people were hospitalised during crises, but were usually not seen at out-patients' visits when the receptionist generally took the client's names so that their records are made available for the doctor. The other nurses who were seen at hospital were the midwives, seen by four percent of the sample.

10.2 Sickle cell care and maintenance by general practitioners

The study has found that people with sickle cell conditions tended not to depend on their general practitioners for routine medical care. Only fifteen people in the sample said that they had regular appointments with their GPs for routine sickle cell maintenance and care compared with fifty-eight percent who had regular appointments with the haematologist at the hospital (Table 10.2.1). Visits to the GP were largely for the collection of prescriptions (12%), and for the monitoring of pregnancies (4%).

The cost of attending GPs' surgeries was minimal as most people (12 of the 15 people who had regular appointments to attend GP surgery for sickle cell care) lived within walking distance. Four people said that they did not often attend the GP surgery, three because they had to go to work and one because it was 'pointless' to go. People who did attend, did so on roughly every two months, and waited on average 35 minutes to see the doctor.

Table 10.2.1 Regularity of General Practitioner appointments given to sample members

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
GP. APPOINTMENTS						
Fortnightly	1	(2.0)	1	(2.4)	2	(2.2)
Monthly	5	(10.2)	2	(4.8)	7	(7.7)
Every two months	1	(2.0)	0	(0.0)	1	(1.1)
Quarterly	2	(4.1)	1	(2.4)	3	(3.3)
Bi-annually	0	(0.0)	2	(4.8)	2	(2.2)
Not applicable	40	(81.6)	36	(85.7)	76	(83.5)
Total	49	(99.9)	42	(100.1)	91	(100.0)

Table 10.1.2 Regularity of Hospital Out-Patient appointments given to sample members, the last hospital appointment, reasons why the appointment was not kept and time spent waiting to see the doctor

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
OUT-OUT-PATIENTS						
Fortnightly	4	(8.2)	1	(2.4)	5	(5.5)
Monthly	3	(6.1)	0	(0.0)	3	(3.3)
Every two months	1	(2.0)	0	(0.0)	1	(1.1)
Quarterly	11	(22.4)	5	(11.9)	16	(17.6)
Bi-annually	11	(22.4)	14	(33.3)	25	(27.5)
Annually	3	(6.1)	0	(0.0)	3	(3.3)
Not applicable	16	(32.7)	22	(52.4)	38	(41.8)
Total	49	(99.9)	42	(100.0)	91	(100.1)
LAST HOSPITAL APPOINTMENT						
Within the last fortnight	11	(22.4)	3	(7.1)	14	(15.4)
2-4 weeks ago	3	(6.1)	2	(4.8)	5	(5.5)
5-8 weeks ago	3	(6.1)	5	(11.9)	8	(8.8)
9-12 weeks ago	2	(4.1)	1	(2.4)	3	(3.3)
3+ - 6 months ago	10	(20.4)	8	(19.0)	18	(19.8)
6+ - 12 months ago	3	(6.1)	1	(2.4)	4	(4.4)
Over 1 year ago	1	(2.0)	0	(0.0)	1	(1.1)
Not applicable	16	(32.7)	22	(52.4)	38	(41.8)
Total	49	(99.9)	42	(100.0)	91	(100.1)
KEEPING HOSPITAL APPOINTMENTS						
DID NOT GO						
Forgot appointment	1	(2.0)	1	(2.4)	2	(2.2)
Work/home commitments	2	(4.1)	0	(0.0)	2	(2.2)
Felt too well	1	(2.0)	0	(0.0)	1	(1.1)
No point (useless really)	1	(2.0)	0	(0.0)	1	(1.1)
Ill (home/hospital)	2	(4.1)	1	(2.4)	3	(3.3)
KEPT APPOINTMENT	26	(53.1)	18	(42.9)	44	(48.4)
Not applicable	16	(32.7)	22	(52.4)	38	(41.8)
Total	49	(99.9)	42	(100.0)	91	(100.1)
TIME SPENT WAITING TO SEE THE DOCTOR						
Less than 1 hour	3	(6.1)	4	(9.5)	7	(7.7)
1+ - 2 hours	4	(8.2)	2	(4.8)	6	(6.6)
2+ - 4 hours	20	(40.8)	12	(28.6)	32	(35.2)
More than 4 hours	6	(12.2)	2	(4.8)	8	(8.8)
Not applicable	16	(32.7)	22	(52.4)	38	(41.8)
Total	49	(99.9)	42	(100.0)	91	(100.1)

Table 10.1.3 Doctors seen by the sample for medical treatment in the past year, number of times seen by the doctor and the reasons for seeing the doctor

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
HOSPITAL DOCTORS						
Haematologist	19	(38.8)	20	(47.6)	39	(42.9)
Other Medical	7	(14.3)	3	(7.1)	10	(11.0)
Surgical	1	(2.0)	0	(0.0)	1	(1.1)
Haematologist + other medical	7	(14.3)	3	(7.1)	10	(11.0)
Haematologist + surgical	1	(2.0)	0	(0.0)	1	(1.1)
Not applicable	14	(28.6)	16	(38.1)	30	(33.0)
Total	49	(100.0)	42	(99.9)	91	(100.1)
NO. OF TIMES SEEN BY A DOCTOR IN THE PAST YEAR						
1-5 times	24	(48.9)	19	(45.2)	43	(47.3)
6-10 times	2	(4.1)	4	(9.5)	6	(6.6)
11-15 times	4	(8.2)	2	(4.8)	6	(6.6)
More than 15 times	5	(10.2)	1	(2.4)	6	(6.6)
Not applicable	14	(28.6)	16	(38.1)	30	(33.0)
Total	49	(100.0)	42	(99.9)	91	(100.1)

Table 10.1.4 Health care professionals seen by women with sickle cell conditions and sickle cell trait for obstetric care in the past year, number of times seen by the doctor and the reasons for seeing the doctor

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
REPRODUCTIVE CARE						
Yes/S.C.C	3	(6.1)	1	(2.4)	4	(4.4)
Yes/S.C.T	12	(24.5)	4	(9.5)	16	(17.6)
No/S.C.C	18	(36.7)	13	(31.0)	31	(34.1)
No/S.C.T	16	(32.7)	24	(57.1)	40	(44.0)
Total	49	(100.0)	42	(100.0)	91	(100.1)

$X^2_{3\ (d.f)} = 8.2\ p < 0.05$

S.C.C = Sickle cell condition S.C.T = sickle cell trait

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
CARER SEEN						
Midwife	0	(0.0)	2	(4.8)	2	(2.2)
Obstetrician (Obs.)	4	(8.2)	0	(0.0)	4	(4.4)
Gynaecologist	5	(10.2)	1	(2.4)	6	(6.6)
Midwife + Obs.	6	(12.2)	2	(4.8)	8	(8.8)
Not Applicable	34	(69.4)	37	(88.1)	71	(78.0)
Total	49	(100.0)	42	(100.1)	91	(100.0)
REASONS FOR CARE						
Pregnancy	8	(16.3)	3	(7.1)	11	(12.1)
Family planning advice	5	(10.2)	1	(2.4)	6	(6.6)
Pregnancy and F/P advice	2	(4.1)	1	(2.4)	3	(3.3)
Not Applicable	34	(69.4)	37	(88.1)	71	(78.0)
Total	49	(100.0)	42	(100.0)	91	(100.0)

The following quotes illustrate the clients' perspectives on care given by their general practitioners and may be indicative of their attitudes towards community care generally.

> " I used to go to the GP, but I don't any more. He doesn't know anything really. Whenever I went to see him, he sent me to the hospital. Sometimes, I just felt like I was getting a cold, and knowing that I can sometimes get really sick with it, I used to go to get something to stop it getting worse. But he said to me 'go to the hospital, it could be sickle cell.' If I fall over and hurt myself he says, 'go to the hospital, it could affect your sickle cell'. If I go for the slightest thing, he says, 'go to the hospital'. I can feel when the sickness is sickle cell and when it's not. I can't really explain it. I just feel different I suppose. I just know it's not sickle cell but he won't even look at me. Just says 'go to the hospital".

This problem was echoed by 25% of the sample who felt that their GP didn't know about sickle cell (19%) or did not want to know (5%).

> " My GP knows nothing about sickle cell. When he tells me to go down to out-patients, if I think I can cope then I don't bother. I will only go when I'm desperate and then I go to casualty. They're busy up there (at the hospital), so I don't want to waste their time. I'll see the GP for prescriptions but even then he has to check with my specialist before he will give me one. I'm not even on anything very strong (ie. analgesic)".

and

> " I tried to tell the GP. about sickle cell, but he is not interested. To me he's useless. He just tells me if I'm ill to go to the hospital for treatment. He is not bother about people like me. He won't even touch me if he can help it".

Five people explained that they didn't use their General Practitioner because they had been given information and advice which they had known was incorrect.

> " He told me 'if I have four children, one would get it (ie. sickle cell anaemia). At this stage, he didn't even know if my partner had it or not. As it was, she didn't so all we

could get were children with trait".

This had serious implications which became graphically clear in the words of this woman:

> " I was told to have a termination because the baby would threaten my life and will have the disease. I refused. It was my first baby and I didn't care what it had. I wanted it. Anyway the baby was fine. No sickle cell. I have trait and my husband is completely clear. Of our three children, one, the middle one, has trait. None have been ill. I would have felt such guilt if I had the termination then found out what I know now".

There were however, good reports of GPs from 19% of the sample.

> " He's ever so good. If I'm ill, he'll come out to see me and if I'm really bad, he arranges the ambulance and everything. When I get back from hospital, if he's worried he'll come round to see me. He really is ever so nice".

10.2.2 Other use of GP services

Although the majority of the sample did not use the general practitioner as a source of health care for sickle cell conditions, the GP was often used for other reasons.

The health of the family was the main reason why sample members used GP services (Table 10.2.2). These family needs were usually unrelated to the sick individual (in all cases a child), having sickle cell genes, and more to do with the ailments of childhood. Pregnancy and the collection of prescriptions (including for contraception) were the other main reasons why general practitioners were consulted (Table 10.2.2). These data include the 15 people who regularly had appointments to see the GP.

10.2.3 Medication used

Although a third of the sample said that they did not have regular appointments for sickle cell care (ie. hospital based), only twenty percent of the sample said that they did not use any prescribed medication. This discrepancy was explained by a number of people visiting the general practitioner to get a prescription either on a regular basis or whenever they felt this was necessary. However, generally they did not have any monitoring of their haemoglobin levels.

Prescriptions regularly in use were for vitamins. Folic acid only was used by 43% of the sample with a further 30% using it in conjunction with some other form of regular medication. Antibiotics were prescribed prophylactically for 7% of the sample and 43% had supplies of analgesics.

10.3 Use of community nursing staff

More than half of the people in the district with a comprehensive package of care (CPC) had seen a nurse in the community since being diagnosed as having sickle cell genes, compared with less than one-fifth from the districts without a CPC. This figure was statistically significant ($p < 0.01$) (Table 10.3.1). Nineteen people were visited by the health visitor, for the care of the under fives. There were no cases where these health visitors made any contribution to the mother's sickle cell management. The remaining nurses who were seen were the district nurse (4%) of the sample,

and the sickle cell counsellor (10%) of the sample (Table 10.3.1). Three of the four people who were visited by the district nurse required dressings for leg ulcers which are sickle cell related, one had recent surgery for which dressings were also needed. However, district nurses did not attempt to give sickle cell specific health advice. Thus only ten percent of the sample were seen specifically for their sickle cell condition (Table 10.3.1). These visits established how the client was and provided the means for some health education to be undertaken.

Table 10.2.2 The sample's use of GPs for general services

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
Prescriptions	13	(26.5)	8	(19.0)	21	(23.1)
Family health	21	(42.9)	15	(35.7)	36	(39.6)
Pregnancy only	1	(2.0)	0	(0.0)	1	(1.1)
Pregnancy + family care	1	(2.0)	1	(2.4)	2	(2.2)
Pregnancy, family + prescriptions	3	(6.1)	1	(2.4)	4	(4.4)
Pregnancy + prescriptions	0	(0.0)	2	(4.8)	2	(2.2)
Not Applicable	10	(20.4)	15	(35.7)	25	(27.5)
Total	49	(99.9)	42	(100.0)	91	(100.1)

Table 10.3.1 Contact between nursing staff and sample members and reasons for that contact

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
NURSE SEEN						
Health Visitor (HV)	11	(22.4)	7	(16.7)	18	(19.8)
Sickle Cell Counsellor	8	(16.3)	1	(2.4)	9	(9.9)
District Nurse (DN)	3	(6.1)	0	(0.0)	3	(3.3)
HV + DN	1	(2.0)	0	(0.0)	1	(1.1)
NOT SEEN NURSE	26	(53.1)	34	(81.0)	60	(66.0)
Total	49	(99.9)	42	(100.1)	91	(100.1)
$X^2_{1\,(d.f)} = 7.8\ p < 0.01$						
REASONS FOR SEEING NURSE						
Under fives	11	(22.4)	7	(16.7)	18	(19.8)
Other family care	2	(4.1)	0	(0.0)	2	(2.2)
Health enquiry/ education	5	(10.2)	1	(2.4)	6	(6.6)
Dressings	4	(8.2)	0	(0.0)	4	(4.4)
Not sure	1	(2.0)	0	(0.0)	1	(1.1)
Not applicable	26	(53.1)	34	(81.0)	60	(66.0)
Total	49	(100.0)	42	(100.1)	91	(100.1)

10.3.2 Use of para-medical care

Other health professionals used in the previous year before interview included the ophthalmologist (one person), the dentist (one person), the dietician (one person) and ambulance personnel (19 people). No district differences were seen. This use of paramedical staff is discussed in section 7.6.1c.

10.4 Perceived health status in the previous month

A large majority (74%) of the sample said either that their health in the previous month was either good or very good (Table 10.4.1). Only 9% described their health as poor. Significantly more people from the NCPC districts described their health as good to very good compared with those from districts with a CPC.

Table 10.4.1 The sample's perception of their health in the month before interview

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
Very good	21	(42.9)	26	(61.9)	47	(51.7)
Good	11	(22.4)	9	(21.4)	20	(22.0)
Fair	11	(22.4)	5	(11.9)	16	(17.6)
Poor	6	(12.2)	2	(4.8)	8	(8.8)
Total	49	(99.9)	42	(100.0)	91	(100.1)

$X^2_{1\,(d.f.)} = 3.84$ $p < 0.05$

a) Time off work in the previous month

Twelve of those who were employed needed to take time off work as a result of ill-health. All of these people had

crises which they felt might become worse without rest. They had an average of 1.2 weeks off. There were no district differences.

10.5 Disability

Complications of sickle cell conditions include the destruction of the epiphyses of the long bones, cerebrovascular accidents and kidney complications. People were asked whether they had any disabilities. Eleven percent of the sample said that they had disabilities which were as a direct result of having a sickle cell condition. Of these 3 people (3% of the sample) had hip replacements with 2 more having hip problems, one had major kidney problems and another had a stroke which had left him with mobility problems. Retinopathy was a problem for three percent of the sample. None of these people was totally blind, though some loss of sight had occurred. These people were all registered as disabled. A further six percent of the sample wanted to be registered as disabled partly because they perceived the effects of sickle cell on them as being disabling, and partly because they hoped that it would help them find work (in accordance with the employers' legal requirement to employ some disabled people). Two other people were disabled as the result of accidental injury.

10.6 Discussion

The monitoring of the health of people with sickle cell conditions was done largely in out-patients departments by

haematologists who examined their haemoglobin levels at regular intervals. The rationale behind doing these checks is so that any serious decrease in these levels would alert these professionals to deteriorating health in their clients. At this point, appropriate steps should be taken to arrest developing problems.

Fifty-three members of the sample spent a total 180.2 waiting hours at what was for each of them a single hospital visit, that is, an average of 3.4 hours each. They had an average of six appointments annually with their doctors. These people were therefore waiting to see their doctors for a total of 1081.2 hours annually (or 20.4 hours each on average). Although having to wait for long periods for routine health checks are not exclusive to people with sickle cell conditions, it requires working clients, many of who fear for their jobs, to take the half day or even an entire day off work.

It also created anxieties for clients. First, there was frustration at the amount of wasted time. Second, there was the fear of 'victim-blaming' if the client did not attend clinic, or left before being seen, and illness subsequently occurred. Finally there was a lack of communication which could encourage clients to accept the deprivations of long waiting times without the degree of frustration and fear felt. This lack of communication between doctor and client was largely reflected in comments made by twenty-two other clients.

The drugs used by people for the control of their sickle cell conditions fell into three main groups, most of which were controlled by prescription, charges for which people with sickle cell conditions are not exempt. The first type of drug, a vitamin, was prescribed to all people who regularly saw a doctor. Folic acid which is found in leafy green vegetables, tends to be deficient in people with sickle cell conditions even when they appear to be well fed (Lopez et. al., 1973; Pearson and Cobb, 1964). Many doctors therefore prescribe folic acid routinely for these groups. A third of the sample tended to get three month supplies of folic acid which 10% (of the sample) made last considerably longer (up to a year sometimes). The second type of drug, an analgesic was prescribed for people who regularly experienced pain. Painkillers tended to be of two types. Mild painkillers which could be bought over the counter included aspirin and distalgesic. Stronger analgesics included drugs such as codeine. The final group of drugs was used largely as a prophylactic for preventing infections. A range of antibiotics was used daily as a routine. All except two of the people who had been prescribed antibiotics had been admitted to hospital within the year previous to the interview.

Sample members were generally 'cooperative' with therapeutic regimes, all of them regularly using their antibiotics and analgesics as prescribed. Of the eight people who occasionally forgot to take their antibiotic medication, three said that they made up the amount at the next dose so that their daily dose usually remained the prescribed daily

dose. Painkillers were always prescribed as necessary. However, of the people who were required to use folic acid daily said that they often neglected to take their daily pill, because they did not know what the drug did and could perceive no real benefit to using it.

Consultations with practitioners for reproductive services mainly involved pregnancy and family planning. The management of pregnant women with sickle cell conditions can be complicated, though women can and do have uneventful pregnancies without even the need for transfusions (Davis, 1988). Tuck (1985) points out that there is five percent maternal mortality rate in women with sickle cell anaemia and other sickle cell conditions, but 'undoubtably some of these women will in the event have relatively straight-forward pregnancies'. Babies from women who have sickle cell genes also have a lower birth weight (Hoff et. al., 1983). Pregnant women who are known to have sickle cell conditions are therefore, generally seen by their doctors, as suitable subjects for surveillance over and above which the average woman might expect.

Information given on pre-natal screening was negligible and what little was given was seen to be ambiguous by sample members. Certainly the problem of knowing the diagnosis of the fetus and not that of the newborn should not occur as tests done during pregnancy are conclusive (Weatherall, pers. comm, National Haemoglobinopathy Screening Service, Oxford). Although many haematologists prefer to repeat the test for sickle cell status when affected babies are about

six months old, these tests are largely to confirm how much fetal haemoglobin has persisted within each individual. The higher the proportion of fetal haemoglobin retained, the greater the chances that those babies will have a milder course of the condition. Haematologists are therefore able to be more or less reassuring at that time, than in the antenatal and neonatal periods.

Women in the sample largely highlighted the need for medical intervention during pregnancy, but only if the pregnancy was difficult and 'life-threatening'. However, even in these cases, and despite the risks involved, it was evident that women preferred less intense treatment if there was that option available. The problems of being hospitalised for long periods of time meant that the family at home became elements in a push-pull situation. Women wanted what was best both for the unborn child and for other family members who were in their care.

It is interesting to note the language one of the two women hospitalised for long periods during their pregnancies. She promised her doctor that she would be a 'good girl' and return to the hospital. It is an example of the language used in situations where men have power over women. These paternalistic attitudes help to reinforce the base/super-structure model seen in the doctor-client relationship.

People were concerned about the lack of diagnoses of newborn infants and wondered why they would have to wait 'until the baby had its own blood', when often they may have been

advised to have an abortion because the baby has 'it'. Babies in utero can accurately be tested for sickle cell status, tests being highly sensitive and specific (Boehm et al. 1983; Gardner and Keitt, 1988; Griffiths, et.al., 1988). This has been confirmed by The National Haemoglobinopathy Screening Centre in Oxford, where all sample are sent for testing. It is therefore perplexing that doctors who do not hesitate to advise abortion, delay advising parents of their babies' Hb status. It is possible that these delays place families under undue pressures and generate mistrust of health care professionals, reinforcing any notions they may have of racist treatment.

A Royal College of Physicians Report (RCP) (1989) confirms that little or no information appears to be given for screening and pre-natal diagnosis generally. Furthermore, studies have shown that anxieties are created when pregnant women are exposed to intense medical interventions during pregnancy (Green, 1990). These anxieties must surely be heightened in cases where clear information is not given to women who are aware of the risks of pregnancy to themselves and their babies. Doctors who may be giving information to women may not be giving that information in a way that can be readily digested by individuals. It may also be possible that information is being misunderstood, purely on a linguistic level as could be seen if an English person engages in conversation with an American, Australian and/or South African.

People with sickle cell conditions can become seriously ill

if they develop infections that interact with their conditions. Some types of family planning methods for women who are affected by sickle cell therefore can be fraught with difficulties and require careful medical monitoring for any developing problems. For example, the use of inter-uterine devices can cause pelvic inflammatory disease (Phillips and Rakusen, 1988). This can in turn, cause serious illness in the woman with a sickle cell condition. Oral contraceptives can also be problematic and makers of combination pills indicate that the Pill is contra-indicated for women with sickle cell conditions as it could be injurious to their health. Women who were either using intra-uterine devices or the Pill (both combination and Progesterone only), tended to have their weight and blood pressures checked at every visit to the family planning clinic. Three women however, mentioned another form of contraceptive which they all said came highly recommended by their doctor as being 'perfect for women with sickle cell conditions'. This drug, Depo Provera, was said to be particularly good as it prevents sickle cell crises from developing.

Depo Provera or depo medroxyprogesterone acetate (DMPA) is a synthetic progestogen similar to the hormone progesterone. It can be used as a contraceptive and is given by intramuscular injection (Berer, 1974). The usual single dose of 150 mg. of the drug confers contraceptive protection for at least three months, but other effects can last on average 8 to 10 months (op. cit.). Depo Provera prevents pregnancy by a) suppressing ovulation, b) making the lining of the

womb more likely to reject a fertilised egg, and c) thickening the cervical mucus at the entrance of the womb, so sperm finds it more difficult to enter. DMPA or DP as it is more commonly known, is suspected of increasing the risk to cervical cancer (Powell and Seymour, 1971; Litt, 1975) and endometrial cancer in non-human primates (Family Planning Perspectives, 1979; Weiner, et.al., 1981). It may also cause permanent infertility and damage to the pituitary gland (Upjohn, 1972; Health Research Group, 1976). Women on the drug may suffer from menstrual bleeding and disturbance of the menstrual cycle and have weight changes (weight gains of up to 31.4 kilos have been recorded) (Upjohn, 1972; Leiman, 1972). Other adverse effects of DP may include possible birth defects in children born to women given the drug during pregnancy, effects on breast-feeding infants and effects on female hormones (DP literature sent out with the drug; Berer, 1974). Other side effects include depression, loss of libido, nausea, various aches and pains, amenorrhoea (with prolonged use), asthma, diarrhoea and anaemia (Rakusen, 1981; Berer, 1974).

A Caribbean study on Depo Provera suggested that it might prevent sickle cell crises (de Ceulaer, et.al., 1982). Other studies suggest that effects on menstrual cycle, weight and endometrial cancer are minimal or non-existent (McDaniel and Potts, 1979; Liang, et.al., 1983; Greenspan, et.al., 1980). Berer argues that these studies have received a great deal of publicity to justify the use of DP in third world countries. Indeed the drug is widely used in countries like Mexico, Thailand and Jamaica. Despite the fact that

injectable contraceptives are not licensed for contraceptive use in some countries, such as the USA, studies of the drugs' effects were carried out, on 10,000 predominantly black women, in Atlanta, Georgia (eg. Greenspan et.al. 1980).

Injectable contraceptives have been approved for use by 'most drug safety bodies in Western Europe, including the United Kingdom Committee on the Safety of Medicines' (Bromwich and Parsons, 1990; 65). They are promoted as contraception suitable for women with sickle cell conditions (Bromwich and Parsons, 1990; Hayman, 1993). Furthermore, the Family Planning Association sanction their use, and stress that although some women:

> " may experience acne, greasy hair, dark skin patches, stomach cramps, bloating, headaches, dizzy spells, back pain, depression and mood changes, or loss of sexual interest, ... weight gain, ... a delay in the return of the menstrual cycle, ... this is not harmful to your health" (Hayman, 1993: 43).

Despite these reassurances, there is room for disquiet, and many women have grave fears about the drugs's use, particularly when their experiences mirror those described earlier.

Although all of these women had a sickle cell condition, none of them had children. None had sickle cell crises in the previous nineteen and eleven years respectively (the third woman couldn't remember exactly when she had her last crisis but said that it was a very long time ago). The United Kingdom Committee on Safety of Medicines suggests

that DP should only be used where women have been immunised against rubella and need contraceptive protection for about three months. Its use is also sanctioned where a husband has had a vasectomy and the couple is waiting for his sperm count to reach zero. However, Berer points out that doctors and researchers, both in Britain and overseas use the following descriptions about women for whom they would recommend DP for:

> " **Unmotivated, irresponsible, unreliable, stupid, less competent, incompetent, retarded, promiscuous, of low intelligence, illiterate, problem women."** (Berer, 1974: 10).

Of the three women in this sample, only one had ever been pregnant. She had the pregnancy terminated on the advice of her doctor who considered the pregnancy to be life-threatening. That termination occurred when she was 13 weeks pregnant. Judging from their performances during interviews, these women could not be described by using any of the above words. The use of the drug also could not be justified on the basis that they were having sickle cell crises as they were all in good health.

Rakusen argues that in Britain, it is mainly black and Asian women who are singled out as 'prime targets for DP'. This was confirmed by Brent CHC (1981). Rakusen also points out that DP's manufacturers are known to have paid bribes totalling millions of dollars to hospital employees and

> " employees of foreign governments and to their intermediaries for the purpose of obtaining sales to government agencies". (Rakusen, 1981: 78).

These incentives, combined with the cost effectiveness of the drug makes it popular with population controllers (Rakusen, 1981). Research has also shown that women are not adequately informed about the drug (Savage, 1978). Further research suggests that women are led by doctors to 'choose' the contraceptive by screening the information they give them about the relative advantages and disadvantages of available contraceptives (Trussell et al, 1976; Lane et al, 1976). For this reason, studies involving the use of DP often say that women felt that they 'chose' the drug (Rakusen, 1981). Furthermore, it may be that doctors themselves are poorly informed about this contraceptive, for it has been shown that some doctors are not knowledgeable about at least one other contraceptive drug, the 'morning after pill (Savage, 1990).

There are of course other 'drugless' methods which could be used to control fertility. Barrier methods, such as the use of male and female condoms, spermicides, diaphragms, caps and sponges are used with reasonable success by many couples (Shapiro, 1987; Law, 1986). There has been recent publicity in the national press about the effectiveness of the rhythm method and 'safe periods' for those women who are able to cope with this method. Women can be made aware of their fertile periods, by the use of calender, temperature and cervical mucus methods (Shapiro, 1987). Avoiding unprotected sexual intercourse at these fertile times reduces their chances of conceiving.

These methods are largely not under medical control. It is

possible that there are medical concerns about women who have the potential to produce more that the established optimal 2.4 babies. In the case of women who are able to produce babies who could become expensive to health care, systems, like women who are carriers of potentially debilitating conditions, these concerns may lead to questionable prescriptions of birth control methods.

Men were also advised to avoid having children although there would be no risk to themselves, or to the child if the mother is negative for sickle cell genes. This was not controlled in the same way that women were controlled. The only man who had a vasectomy, had done so because of his wife's ill-health (not sickle cell related), and because he and his wife felt that their family of two sons was complete. However, at least two men did not intend to have children because they were advised not to. This example of male fertility control is either a rare occurrence, or it is perhaps the emergence of a previously unexplored area. It may be that males who are seen to be 'sub-standard' have their fertility controlled in the same way that women experience.

The drive for perfection and genetic uniformity is a dangerous one, as genetic variability is the foundation upon which survival of species depend. All individuals carry in their genetic make-up thousands of recessive genes which can be described as 'deleterious', as if they come together in the right combination, they would cause serious problems and would be lethal in many cases. However, in carrier status,

many of these genes are believed to confer protection in certain environmental circumstances. For example, people who are carriers for abnormal haemoglobins have some protection against malaria. Attempting to eradicate what are seen to be deleterious genes as they become recognised would remove the protective advantages many of these genes confer while in their harmless, carrier state.

The use of words such as 'life-threatening' and 'the baby will not survive' when advising women to abort their pregnancies is inappropriate. This was underlined when one woman in the research sample, advised to abort the pregnancy, refused to do so, had a trouble free pregnancy and produced a healthy baby who did not have sickle cell genes. This woman's husband was perfectly normal. She herself only had trait. These accounts once again raise the frightening spectre of eugenics in the medicalisation of fertility of women known to be carriers of abnormal genes.

This negative medical approach to fertility and its control was recognised by women who often expressed feelings of guilt after having made decisions to terminate their pregnancies. The possibility is that these women could lose confidence in their doctors' advice and refuse to cooperate with regimes which they perceive as being discriminatory. This could lead to doctors refusing to treat people they view as being uncooperative. It may be that some women are already disillusioned with the care provided for them, and do not use health services unless in emergency situations which they cannot deal with themselves.

As a postscript to the idea that doctors might refuse to treat people in a way that is acceptable to them, a young woman who was put on Depo Provera at the age of 19 years old, phoned the researcher in tears a few weeks later. She said that as a result of taking part in this study, she resolved to do a study of her own on sickle cell conditions. In doing so, she found material published on DP which frightened her. She went to see the doctor at the F/P clinic and asked to be taken off the drug. The doctor refused saying that if she (client) did not like the care she was getting, she could find herself another doctor. At this point, the researcher was telephoned. The woman was distraught and asked what she should do. She was advised to do what her doctor suggested. Later the researcher contacted the woman who **had** found a doctor sympathetic to her needs. She would be put on another form of contraceptive when the DP has worked through her system.

Sample members did not see the nurse as having a major role in advising women who have sickle cell conditions about appropriate birth control. Webb (1985), argues that little or no attention has been paid by research, to the relationships between female nurses and women clients. She further argues that nurses have an ambiguous position regarding the care of women with gynaecological concerns, because they (nurses) see themselves as specialist professionals, and particularly as counsellors and supporters of their clients. However, Webb suggests that 'their knowledge base was precarious and their skills acquired in an opportunistic rather than a systematic way'.

It has been shown that West Indian women (a very large percentage of black women in Britain are West Indian or have West Indian parents), have an interest in their reproductive health and monitor the state of their health by noting the time, quantity and quality of menstrual bleeding (McCormack, 1985). Deviations from normal flow would often be attributed to possible complications with various types of contraception and inter-uterine devices in particular. These attitudes, which are not exclusive to West Indian women, were also seen in this study. In this case (as in McCormack's study) services which could provide relatively safe methods of birth control were viewed with suspicion.

Family planning clinics are places where women can learn about gynaecological health, safe birth control methods and other fertility (or infertility) issues. Family planning nurses are currently seeking to be able to prescribe contraceptives without referring clients to doctors (Haslett, 1990). If they are to have this responsibility (and Haslett suggests that family planning nurses have the skills to do so), they have to be able to appreciate the **different** (not special) needs that some black women may have.

The overall feeling generated by the sample was that the GP was 'frightened by sickle cell' conditions because (s)he was not 'an expert' or not interested in the conditions or the people affected by them. This had the effect of relegating the GP to the realms of 'uselessness', with the hospital consultant, 'the specialist' being promoted to the role of

expert. This lack of confidence is understandable if GPs are in fact giving incorrect or incomplete information to their clients. Discussions with three consultant haematologists suggest that many GPs themselves misunderstand the laws of genetic inheritance and often do misinform their clients because of their own lack of knowledge. However, if GPs live and/or work in areas where large sections of the practice's population are at risk for particular conditions, they need to have the knowledge to meet the needs of their clients. When clients are representing different ethnic and cultural backgrounds, understanding and tolerance of these differences are also required. Any misconceptions doctors have of their clients become quickly exposed and may lead to difficulties and client dissatisfaction.

In this research, GPs tended to become tarred (as it were) with the same brush. This resulted in more people rejecting their potential contribution to community based health care, in favour of the hospital based consultant. The focus of care **from the individual's point of view** was subsequently moved away from the concept of community care and this could lead to a further decrease their use of community medical and nursing services.

It is also clear that people with sickle cell conditions are not using community nursing services to any great extent. This may be a direct result of their lack of use of GP services, as GPs are the ones who would normally have the responsibility for co-ordinating client referrals to various specialities. However their lack of use of community

services appears to be as a result of their mistrust of GP services. This provides further confirmation that carers who were viewed as unhelpful, were seen as inadequate in terms of delivering health care.

10.7 Summary

1. Two-thirds of the sample regularly saw a hospital based doctor, usually the haematologist, for the monitoring of their sickle cell conditions.

2. A total of fifty-three people spent a total of over a thousand hours annually waiting to see the doctor.

3. Other than haematologists, female sample members mainly consulted obstetricians and gynaecologists usually for pregnancy and/or family planning care and advice.

4. Three out of twenty women who were asked detailed questions about contraceptive use said that they had been offered Depo Provera injections.

5. Less than one fifth of the sample used general practitioner and/or other community based health services.

6. Eleven percent of the sample had sickle cell related disabilities.

Chapter 11 - The nursing sample

This chapter examines the demographics of the nursing sample, their response rates for participating in the research, and their experiences of caring for people with sickle cell conditions. These experiences are compared with those of caring for people with juvenile diabetes and cystic fibrosis.

11.1 Response rates

Approaches were made to 141 health visitors and 178 hospital ward based registered nurses. The overall response rate was 66% for health visitors and 51% for registered nurses. The response rates for districts ranged from 53% to 93% for health visitors and from 44% to 80% for hospital nurses.

The achieved sample consisted of 90 hospital based nurses and 98 health visitors. A significantly higher response rate ($p < 0.01$), was obtained for health visitors (Table 11.1). Health visitors failed to reach the target number in only one district, with five districts exceeding it. Health visitors were easier to contact than nurses, as they were generally attached to clinics in the community and letters inviting them to take part in the study were more likely to reach them. Furthermore, health visitors may have been more able to manipulate their time than nurses. Only four health visitors were seen at their health clinics. The majority were seen in the interview rooms set aside by the district, as they were able to fit their participation into their

normal working agenda. The additional training that health visitors receive may also have some influence on their willingness to take part in studies of this type.

There were some difficulties in getting a sample of hospital based nurses. Their response rates initially suggested that nurses may be more apathetic than health visitors in taking part in this type of study. However, many nurses said at the time of interview that letters asking them to take part in the study were delayed, mainly because letters which had been delivered to a previous ward had not been forwarded to them. This difficulty appeared to be connected to the fact that many health districts are not able to pin-point at any given time exactly where a nurse might be working. The district in which there was an 80% response rate had a computerised system on which nurses' movements were carefully recorded. As a result nurses received their mail quickly and were able to respond accordingly.

Table 11.1 Percent Response for Health Visitors and Nurses Overall and Within Districts.

TOTAL RESPONSE RATE = 188/322 = 58.4%

DISTRICT	H/V		H/N	
	n	%	n	%
1	11	64.7	11	80.0
2	10	58.8	10	45.0
3	13	80.0	9	52.6
4	10	64.7	10	43.5
5	11	66.7	9	36.0
6	13	92.9	10	50.0
7	11	78.6	10	52.6
8	9	76.9	9	45.0
9	10	52.6	12	66.7
TOTAL	98	69.5	90	50.6

Another problem was that the lists obtained from link-persons which provided very basic information only, for example W/S Jones, Ward 6 or C/N Smith, O.P.D. (W/S referring to ward sister, and C/N to charge nurse). Female nurses promoted from 'staff nurse' the basic title of the qualified nurse, are generally called 'ward sisters'. They may also be called 'charge nurses' in some places (a title invented for use with male nurses). Unfortunately because nurses move from ward to ward, hospital to hospital and district to district, for various reasons, some nurses who had been given the title 'charge nurse' did not readily identify with it and exhausted all possibilities for finding a male 'ward sister' with the same name as themselves. Two or three ward sisters pointed this out during the interview. It remains unknown how many of these letters were returned unopened to the post room.

A third factor which may have affected the nursing response rate was the inability of most nurses to get time off during working hours to attend interviews. Many nurses were seen at their homes, a small number on wards, and when seen in rooms set aside by the district for interviews, they invariably came on their days off or when just off duty. Their participation in the study therefore invariably involved them giving up their off duty time. Nurses are less able to manipulate their working environments to include activities other than those directly related to their ward duties. This restricts their participation in studies of this kind, particularly if there is a shortage of nurses on the ward.

11.2 Sex, Race and Age

Five of the sample were male, all of them were hospital nurses. Nine percent of the sample were not of white British ancestry, and they represented five different ethnic groups. Ten percent of the sample had worked overseas, mainly in the United States and Canada.

The age of the sample as a whole seemed to be fairly well spread out. Approximately one third of the nurses and health visitors were under thirty years old; one third were between thirty and forty years old, and one third were over forty years old. However, on looking at age compared with the status (or job title) of the carer, it becomes clear that health visitors are generally older than nurses as might be expected (Table 11.2).

The breakdown by sex and race appears to reflect the national average of male and minority ethnic staff admitted to the register of nursing.

The age distribution of nurses and health visitors may be reflecting what is seen in nursing and health visiting generally.

It is likely that as nurses get older and more experienced, they may be moving higher up the structure of the career ladder. They may become specialists, administrators, tutors and managers. This could account for the larger numbers of younger nurses in the sample.

11.3 Qualifications of nurses and health visitors

As shown in Table 11.2 the majority of nurses had the basic qualification (RGN) only, whereas the majority of health visitors had additional qualifications Additional qualifications for nurses and health visitors included English National Board certificates (n=20), diploma in nursing (n=7), BSc (Nursing) (n=2), district nurse training (n=3), as well as midwifery qualifications (SCM) (n=55), Children's nursing certificates (RSCN) (n=9), obstetrics certificate (n=9), mental nurse (RMN) (n=3) and mental subnormality training (RMNS) (n=1). In contrast, only forty percent of hospital based nurses had additional qualifications.

Table 11.2 Nurses and health visitors: age, qualifications, length of service and contact with minority ethnic groups.

AGE	H/V n = 98 %	H/N n = 90 %	ALL n = 188 %
Up to 30 years old	13.3	52.2	31.9
31 to 40 years old	38.8	27.8	33.5
41 to 50 years old	31.6	13.3	22.9
Over 50 years old	16.3	6.7	11.7
TOTAL	100.0	100.0	100.0
QUALIFICATIONS			
RGN only	0.0	58.9	28.2
RGN + HV	26.5	0.0	13.8
RGN + RCM/RSCN/OBSTETRICS	0.0	17.8	8.5
RGN + HV + RCM/RSCN/ OBSTETRICS	58.2	0.0	30.3
RGN + OTHERS	0.0	23.3	11.2
RGN + HV + OTHERS	15.3	0.0	8.0
TOTAL	100.0	100.0	100.0
LENGTH OF SERVICE			
Up to 1 year	4.1	7.9	5.9
1-5 years	37.8	41.6	39.4
6-10 years	23.5	27.0	25.0
11-15 years	24.5	9.0	17.0
More than 15 years	10.1	14.5	12.8
TOTAL	100.0	100.0	100.0
CONTACT WITH ETHNIC MINORITY GROUPS			
During the last month	65.3	72.2	69.4
During the last year	22.5	13.3	18.2
Over a year ago	12.2	7.8	10.2
Never	0.0	6.7	2.2
TOTAL	100.0	100.0	100.0

11.4 Experience of nursing members of minority ethnic groups

Almost all of the sample (98%) had cared for someone from a minority ethnic group at some point in their careers. Eighty eight percent of the sample had cared for a member of an minority ethnic group within the last year. All the health visitors and 93% of the hospital based nurses had professional contact with minority ethnic groups and 88% of health visitors and 86% of nurses had contact in the last year (Table 11.2).

11.5 Experience of caring for those with sickle cell conditions

Table 11.3 gives the percentage of health visitors and hospital based RGNs who had experience of caring for juvenile diabetes, sickle cell conditions and cystic fibrosis. Questions were asked about juvenile diabetes and cystic fibrosis, partly so that the study could be described as one in genetic conditions so that nurses gave answers which reflected their general working knowledge of sickle cell conditions in particular. Once that decision was made, nurses' knowledge and experiences of diabetes and cystic fibrosis could be compared with their knowledge and experiences of sickle cell conditions.

The results showed little difference between the proportion of nurses and health visitors who had experience in caring for those with a sickle cell conditions (SCC), juvenile diabetics (JD) or cystic fibrosis (CF). Health visitors were

more likely to have seen someone with cystic fibrosis during the past year than with sickle cell or diabetes. Nurses on the other hand, were equally as likely as health visitors to see a client with CF. Nurses were seen to be significantly more likely than their health visiting colleagues to have cared for someone with a sickle cell condition, or for a young diabetic (Table 11.3).

Table 11.3 The sample's experience in caring for people with juvenile diabetes (JD), sickle cell (SCC) and cystic fibrosis (CF).

STATUS/ HEALTH CONCERN	H/V n = 98 %	H/N n = 90 %	ALL n = 188 %	X^2 (Experience of Condition)	d.f	p
JD						
TOTAL	52.0	73.3	62.3			
LAST YEAR	9.1	22.2	15.5	4.4	1	< 0.03
SCC						
TOTAL	41.8	56.7	48.9			
LAST YEAR	8.2	18.8	13.3	3.6	1	< 0.05
CF						
TOTAL	60.9	53.3	57.2			
LAST YEAR	15.5	13.3	14.4	2.2	1	NS

Table 11.4 Nurses and health visitors who have cared for people from minority ethnic groups and their experience of sickle cell Conditions.

	H/V n = 98	H/N n = 90	ALL n = 188
Nursed someone with SCC	41.8	56.7	48.9
Never nursed anyone with SCC	58.2	39.9	49.0
No Reply	0.0	4.4	2.1
Total	100.0	100.0	100.0

X2 1 d.f = 4.12 p < 0.02

In looking at the experience of caring for people from

minority ethnic groups, it was seen that health visitors were more likely to have seen an individual for reasons other than their having a sickle cell condition. On the other hand, nurses were significantly more likely to be caring for individuals with sickle cell related illnesses than not (Table 11.4).

11.6 Discussion

Based on the experience gained in the pilot study, lists of nurses and health visitors were obtained from participating districts. This method may not useful for recruiting hospital based nurses for a number of reasons. First, nurses are not generally static, that is they do not necessarily work on the same wards all of the time. Hospitals which do not have computerised information concerning the whereabouts of individual staff members therefore take longer to find them in the system.

Second, the nomenclature used to describe staff showed the need for clear, unambiguous, non-sexist working titles to be given to health carers.

Finally, nurses were seen to have to juggle their time to take part in the study (some with some guilt as they pointed out that they 'really ought to be on the ward but they sneaked the time off because of their interest in genetic conditions'.

The majority of health visitors (almost 75%) had qualific-

ations additional to their basic nursing and health visiting certificates. This reinforces the idea of health visiting as a specialism, particularly in the care of the family in the community and of young children as more than half the health visitor sample were also midwives (RCM) or children's nurses (RSCN).

11.7 Summary

1. Nurses found it more difficult than health visitors to find the time to take part in the study.

2. The gender and racial composition of the sample reflected the social composition of nursing generally.

3. Almost all health visitors and nurses had cared for people from African-Caribbean backgrounds.

4. More nurses than health visitors had provided care for people with sickle cell conditions.

CHAPTER 12. Knowledge of sickle cell conditions

12.0 Introduction

This chapter examines the results of the France-Dawson Knowledge measure (FDKM) in terms of a) information seeking behaviour and b) knowledge scores returned by nurses, health visitors and people with sickle cell conditions. The results for nursing carers are discussed before looking at client data.

A. The carers

12.1 Information seeking and sources

With regard to SCC, almost forty percent of the sample said that they had never had any information of any sort about sickling conditions. A greater proportion of health visitors reported that they had information than nurses (Table 12.1).

Schools of nursing appeared to be by far the greatest source of information. Health visitors received more information from a variety of sources about SCC, the main source of information for both nurses and health visitors being the schools of nursing (Table 12.1).

The vast majority of the sample (99%) had not read anything about the conditions in the month before taking part in the study. Ninety-five percent of the sample had never contacted any of the voluntary organisations for information on sickle

cell states.

Table 12.1 Nurses and health visitors responses (%) regarding whether they had had information about SCC or not and the source of their information

	H/V n = 98 %	H/N n = 90 %	Total n = 188 %
No information	28.6	47.8	37.8
Had information	71.4	51.1	61.7
No answer	0.0	1.1	0.5
Total	100.0	100.0	100.0

$X^2_{1\ d.f} = 7.71 \quad p < 0.01$

School of Nursing(S-o-N)	30.6	38.9	34.6
Voluntary Organisations	8.2	0.0	4.3
Health Education Council	11.2	1.1	6.4
Media	2.0	5.6	3.7
Books/Jnls.	7.1	3.3	5.3
Friend/patient	3.1	2.2	2.7
Several sources not including S-o-N	9.2	0.0	4.8
No info.	28.6	48.9	38.2
TOTAL	100.0	100.0	100.0

$X^2_{7\ d.f} = 27.22 \quad p < 0.001$

12.2 Knowledge of sickle cell conditions

The knowledge levels of nurses and health visitors were shown to be low. The overall knowledge score for the sample was 17 out of 30 questions being answered correctly (s.d = 3.67). Scores for hospital nurses ranged from 14.7 to 18.5 compared with those for health visitors, 15.3 to 19.1 (Table 12.2)

12.2.1 Nurses and health visitors compared

There were statistically significant differences in overall

knowledge scores of sickle cell conditions between nursing and health visiting staff (Table 12.2.1). Item analysis showed that nurses were more likely to find questions based on nursing care easier to answer but this was not statistically significant (Table 12.2.2).

However, there were differences seen in specific areas of knowledge between nurses and health visitors. Health visitors had significantly higher scores than nurses in knowledge of disease oriented questions, for example, definitions, signs and symptoms ($p < 0.03$), and pathology ($p < 0.02$). Nurses did slightly better on nursing care ($p < 0.08$). There were no differences demonstrated for nurses' and health visitors' health education knowledge ($p = 0.374$) (Table 12.2.1).

Table 12.2 Mean knowledge scores for nurses and health visitors in each district that took part in the study.

	H/V			H/N			ALL		
District	n	m	S.D	n	m	S.D	n	m	S.D
1	11	18.09	3.96	11	17.91	2.43	22	18.00	3.19
2	10	18.40	3.06	10	18.50	4.06	20	18.45	3.56
3	13	16.92	2.90	9	16.89	5.13	22	16.91	4.01
4	10	17.70	4.52	10	16.60	3.24	20	17.15	3.88
5	11	19.09	2.74	9	17.67	2.69	20	18.45	2.71
6	13	17.85	2.56	10	17.90	2.64	23	17.87	2.61
7	11	15.27	6.21	10	14.70	5.85	21	15.00	6.03
8	9	16.56	2.35	9	17.56	2.65	18	17.06	2.48
9*	10	18.40	2.50	12	16.33	3.37	22	17.27	2.93
ALL	98	17.58	3.64	90	17.10	3.72	188	17.35	3.67

*- This district is described as having a comprehensive package of care.

Table 12.2.1 An analysis of variance showing differences between job title, age and experience of caring for people with SCC.

SOURCE	SUMS OF SQUARES	df	MEAN SQUARES	F	p
Status/ Qualifications	131.26	3	43.74	4.24	<0.01
Age	171.26	2	85.67	8.30	<0.001
Experience of Sickle Cell	84.31	1	84.31	8.17	<0.01
District	95.96	8	1.99	1.15	0.33 NS
Residual	1774.64	72			
Total	2220.16				

12.2.2 District comparisons

No differences in knowledge were seen between districts. This was disappointing as carers in districts with comprehensive care packages should theoretically have had greater knowledge than carers in NCPC districts. In six out of nine districts health visitors had higher scores than hospital nurses (Table 12.2.1).

There is a positive correlation between the size of the minority ethnic population and higher knowledge scores ($r=0.523$) $p < 0.001$. A breakdown of the knowledge scores of nurses and health visitors separately against minority ethnic population size, showed significant positive correlations (H/V $rP = 0.66$; $p < 0.001$: H/N $rP = 0.34$; $p < 0.01$).

12.2.3 Age

With regard to age, younger nurses and health visitors achieved higher mean scores than did older ones. Health

visitors under forty years old had higher scores than the mean score for this group. However, it is nurses under thirty who score higher than the average nursing score. This may be accounted for by the fact that 52% of the health visiting sample was under forty years old whereas 52% of the nursing sample was under thirty years old (Table 12.2.3).

As many nurses under thirty had more experience of caring for people with sickle cell conditions this might account for their better showing in the test. However an analysis of variance using age, experience and job-title showed that there were no interaction effects between these variables (Table 12.2.1).

12.2.4 Qualifications

Health visitors and nurses who had extra qualifications of any type had higher than the mean scores for their group. Those with no post-registration qualification in the case of nurses and no post RGN/HV qualifications scored lower than the average for their respective groups (Table 12.2.4).

12.2.5 Experience of sickle cell conditions compared with no experience

In looking at carer status and experience of caring for those with sickling states, it was seen that nurses and health visitors who had experience (m=18.22) had significantly higher scores than those who had not (m=16.52) (Table 12.2.5).

Table 12.2.2 Analyses of variance showing differences between nurses' and health visitors' knowledge of a) definitions, signs and symptoms; b) pathology; c) nursing care and d) health education

SOURCE	SUMS OF SQUARES	df	MEAN SQUARES	F	p
a) Definitions, signs & symptoms					
Between status	9.91	1	9.91	4.69	<0.03
Within status	393.04	186	2.11		
TOTAL	402.95				
b) Pathology					
Between status	10.74	1	10.74	5.86	<0.01
Within status	340.66	186	1.83		
TOTAL	351.40				
c) Nursing Care					
Between status	4.29	1	4.29	2.97	<0.08 NS
Within status	269.03	186	1.45		
TOTAL	273.32				
d) Health Education					
Between status	0.95	1	0.95	0.80	0.37 NS
Within status	221.96	186	1.19		
TOTAL	222.91				

Table 12.2.3 Distribution of nurses and health visitors across age groups and the scores they obtained.

AGE	H/V			H/N		
	n	m	S.D	n	m	S.D
< 30	13	18.23	2.42	47	18.12	3.15
31-5	19	19.53	3.19	14	16.35	4.05
36-40	19	18.26	3.36	11	16.45	3.36
41-5	16	17.06	2.86	8	16.25	2.38
46-50	15	15.20	3.95	4	15.25	1.50
> 50	16	16.69	4.45	6	14.33	7.37
ALL	98	17.58	3.64	90	17.10	3.71

Table 12.2.4 Additional qualifications of nursing and health visiting staff.

QUALIFICATIONS	H/V			H/N		
	n	m	S.D	n	m	S.D
RGN				53	16.32	3.60
RGN + HV	26	17.04	3.50			
RGN + RCM/RSCN/OBSTET.				16	18.88	3.28
RGN + HV + RCM/RSCN/OBSTETRICS	57	17.67	3.84			
RGN + "OTHER" EG. ENB's				21	17.71	3.89
RGN + HV + "OTHER" EG. ENB's	15	18.20	3.14			
ALL	98	17.58	3.64	90	17.10	3.71

This finding is to be expected, as in providing care for a sick person with an unfamiliar condition, nurses and health visitors may have an incentive for improving their knowledge of the condition.

There were no significant differences between nurses and health visitors who had no experience of looking after people with sickling conditions, but the trend was that health visitors with experience of caring for people with sickling states had higher mean scores than nurses with experience. This neared statistical significance ($p < 0.07$) (Table 12.2.6, appendix). More pronounced differences were seen between health visitors with and without experience ($p < 0.02$), than between nurses with and without experience (NS) (Table 12.2.7, Appendix).

Table 12.2.5 Knowledge scores of nurses and health visitors with experience of sickle cell conditions compared with nurses and health visitors without experience.

	n	m	S.D	t	d.f	p
EXPERIENCE	92	18.22	3.37	3.25	186	0.001
NO "	96	16.52	3.78			

12.3 Discussion

The study found that nurses and health visitors in the sample had a low level of knowledge of sickling conditions, although the two groups of carers answered different parts of the questionnaire more successfully than others.

In districts where there is a policy of care, that is, a 'comprehensive package of care' as described by Prashar and her co-workers in the Runnymede Trust's report (1985), this policy emphasises the need for screening, health education literature, counselling, specialist clinics and in-service training.

However, no differences in knowledge for sickle cell conditions was demonstrated between districts. This is despite that fact that health workers in areas where there are large populations of people from minority ethnic groups have greater experience of caring for those with sickling conditions. Hypothesis 12 was therefore not proven.

Within these districts, health visitors had slightly higher knowledge scores than nurses. It may be possible that health visitors have more access to additional information about sickle cell conditions than nurses.

In addition, nurses and health visitors working in areas where there are large minority ethnic populations are more likely to have had experience in caring for people with sickling conditions. They were also more knowledgeable than carers who had not worked with people who had the conditions, proving the eleventh hypothesis.

There is also the possibility that they may attempt to become more informed about health care needs which may apply to minority ethnic groups. The strong correlation between health visitor knowledge and minority ethnic population size suggests that health visitors are more likely to be able to gain access to sources of information on conditions which affect other racial groups, even though they were less likely than nurses to have cared for people with sickling conditions. This seems to be confirmed by the differences in the patterns of information-seeking displayed by nurses and health visitors in the sample.

Younger care staff were more aware of the problems of sickle cell conditions than older staff. This finding suggested that courses for new care staff included an element of care for sickle cell clients, but highlighted the need for post-basic training for older care staff as part of the on-going process of the development of health carers.

Nurses and health visitors with additional nursing qualifications had higher scores than those without. It may be that either some input on sickle cell states is being made in post-basic courses, or that those care staff with

more qualifications are also more likely to seek information, for example, by reading journals.

There were no relationships between those with additional qualifications and those who had a greater likelihood of caring for people with sickle cell conditions. Indeed, nurses and health visitors in the sample are not equally likely to come into contact with those who have sickling conditions, nurses being significantly more likely to have cared for those with a sickling condition. This finding is interesting, as it seems that people with sickle cell conditions are more likely to be seen by care staff in hospital wards, in other words, when in crisis. The emphasis in the practice of care is not community based. Although health visiting staff had higher knowledge scores than nurses, they appear to have little participation in the care of those with sickle cell related illnesses, (despite the fact that all the health visitors in the sample had cared for someone from a minority ethnic group at some point in their careers).

The schools of nursing were the largest contributors to the education of nurses and health visitors, about sickle cell conditions. However, they reached only one-third of the sample. It is unlikely that the media, books and journals and voluntary and other organisations are the main source of information of sickle cell conditions for nurses and health visitors, as presumably this would be disseminated across all age groups. It may be that younger people and people who choose to do additional courses are more likely to seek

additional information, and may make use of a variety of sources in obtaining that information.

Very few health visitors (8.2%) and no nurses sought information from the voluntary organisations. It may be that insufficient publicity about the voluntary organisations is a contributory factor.

B. The clients

Bearing in mind the low knowledge scores of health carers, it was important to find what information clients had and what their sources were. Once again comparisons are made between districts with a comprehensive package of care (CPC) and those without (NCPC), as clients from districts with a CPC should in theory, have greater access to knowledge about the conditions than clients in NCPC districts.

12.4 Knowledge of who is affected by sickle cell conditions

All but six people said that they knew that sickle cell conditions affected people from African-Caribbean populations (Table 12.4). Seventeen people found out about sickle cell originally because they had relatives or friends with the conditions, or they had seen television programmes about them. No differences were seen between districts with a CPC and those without (NCPC).

Table 12.4 Percentage of people who knew that sickle cell conditions (scc) often occurred amongst African-Caribbean populations and how they found out.

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
DID NOT KNOW	2	(4.1)	4	(9.5)	6	(6.6)
Knew (relative/ friend had scc)	2	(4.1)	4	(9.5)	6	(6.6)
Found out - media	4	(8.2)	7	(16.7)	11	(12.1)
Told by doctor - diagn. childhood	19	(38.8)	17	(40.5)	36	(39.6)
Told by doctor - diagn. teens	22	(44.9)	10	(23.8)	32	(35.2)
Total	49	(100.1)	42	(100.0)	91	(100.1)

$X^2_{4\ (d.f)} = 6.14$ NS

12.5 Sources of information

Once diagnosis of their sickle cell status was confirmed, people in the district sub-samples used a variety of sources to get information about sickle cell conditions (Table 12.5). Significant differences were seen between CPC and NCPC districts. People from CPC districts used more sources to get information about sickle cell conditions, than people in NCPC districts. More than a quarter of people in both sub-samples said that they had not needed to get information regarding sickle cell conditions as they had no problems. These people tended to have sickle cell carrier status. However, they also said that no-one had offered to give them any information either. Only 7 people (six of them in the NCPC districts) said that they did not know where to go for information about sickle cell conditions.

12.5.1 Information about sickle cell conditions

People were asked what information they were given about sickle cell conditions and whether they felt that they

wanted to find out more. Sixty-seven people answered these questions (Table 12.5.1a). This excludes twenty-four people who said that they had not needed any information about the conditions, as they were 'only carriers' and did not have any illness. Thirty people (a third of the sample) who said that they were satisfied that they had been told everything they needed to know indicated that they were informed about family planning, gene transmission and where to get help in emergencies. Nine of these people could not remember what they were told, only that the doctor spent a long time telling it so they believed that their information-giving was thorough. However, forty percent of the sample said that they wanted information on the effects, possible cures, coping with sickle cell conditions and social security benefits they could claim. The four people who mentioned benefits talked about heating needs and one of them also mentioned trying to obtain a telephone for emergencies. No district differences were seen. This need for information about benefits and other material resources is important, as it challenged the assumption often made, that what people need most is health education.

People who said that they had been given enough general information about sickle cell conditions had significantly higher knowledge scores than people who felt that they were given too little or no information ($p < 0.02$) (Table 12.5.1b).

12.5.2 What people were told about transmission of sickle cell genes

No differences were identified between the two district sub-samples in response to a question on information given with regard to the transmission of genes. Nearly a half of the sample (45%) said that they were told nothing of the way sickle cell genes were inherited. A further twenty-five percent indicated that they had been told 'everything' about gene transmission. While thirty-nine of the fifty people who were given information about transmission, believed that they were told everything they needed to know about it, less than a third of them correctly answered the question on transmission rates of the gene correctly on the sickle cell knowledge measure (FDKM).

Information given to sample members ranged from careful partner selection to avoiding having any (more) children (Table 12.5.2a). No differences in what people were told about the transmission of sickle cell genes were seen in the district sub-samples (Table 12.5.2b). However, people in CPC districts received more varied information.

Of the seven people who said that they were told not to have children, six had not yet produced any. They were so advised 'because they (the children) would have the condition'. No other explanations of genetic transmission were recalled by any of this group. These four quotes below are examples of what people felt.

" They tell you not to have more children, but they don't really, really explain why. They just say sickle cell ... Well I've got a friend with sickle cell worse than me and her kids (are) OK".

and

" ... My wife is white ... I really don't understand how the baby could get it".

and

" ... Is nothing to do with sickle cell at all, they just don't want you to have any kids. If I could afford it, I'd have one every five minutes just to show them that it's my body and my child, so I can please myself".

and finally,

" ... Can you imagine it, white man who hardly want to touch me if I'm sick and now he tell me not to have kids and expect me to think he's doing it for my good? .. he's just worried that we'll have all these 'pickney' running round the place".

People who said that they had been given information about the transmission of the gene returned higher scores than those who had not, regardless of whether they received general information or not ($p < 0.0001$) (Table 12.5.2c). There were no significant interactions between information-giving and advice regarding transmission of the genes.

The hospital based doctor was the main source of information regarding the transmission of sickle cell genes, accounting for less than a quarter of the sample. Voluntary organisations accounted for a further eleven percent (Table 12.5.2a).

Table 12.5 Sources of information after being diagnosed as having a Sickle Cell (SC) condition.

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
No information needed	14	(28.6)	10	(23.8)	24	(26.4)
Don't know how to get information	1	(2.0)	6	(14.3)	7	(7.7)
Doctor only	2	(4.1)	7	(16.7)	9	(9.9)
SC Counsellor only	4	(8.2)	0	(0.0)	4	(4.4)
Vol. Organisations (Vol. orgs) only	5	(10.2)	8	(19.0)	13	(14.3)
Nurses only	2	(4.1)	0	(0.0)	2	(2.2)
Books only	0	(0.0)	4	(9.5)	4	(4.4)
Doctor and counsellor	2	(4.1)	2*	(4.8)	4	(4.4)
Doctor, counsellor and Vol. Orgs	4	(8.2)	2*	(4.8)	6	(6.6)
Doctors, nurses and Vol. Orgs.	1	(2.0)	1	(2.4)	2	(2.2)
Doctor and friends	2	(4.1)	0	(0.0)	2	(2.2)
Doctors and books	0	(0.0)	2	(4.8)	2	(2.2)
Counsellor and Vol. Orgs.	11	(22.4)	0	(0.0)	11	(12.1)
Counsellor and books	1	(2.0)	0	(0.0)	1	(1.1)
Total	49	(100.0)	42	(100.1)	91	(100.1)

$X^2_{13\ (d.f)} = 34.1\ p < 0.005$

* = These people travelled to other districts in order to speak to a sickle cell counsellor

Table 12.5.1a People's perception of the amount of information they were given on sickle cell conditions (scc).

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
Enough information	16	(32.7)	14	(33.3)	30	(33.0)
Too little info.	19	(38.7)	18	(42.9)	37	(40.7)
Total	49	(100.1)	42	(100.0)	91	(100.1)

$X^2_{2\ (d.f)} = 2.5$ NS

Not applicable	14	(28.6)	10	(23.8)	24	(26.4)

Table 12.5.1b Analysis of variance showing differences in knowledge scores between people who were given comprehensive information about sickle cell conditions and those who were not.

Source	d.f	Sums of Squares	Mean Squares	F Ratio	F Prob.
Given/not given info.	1	532.97	532.97	10.35	0.002
Residual	89	4581.16	51.47		
Total	90	5114.13			

12.6 Knowledge scores for the sickle cell measure

The knowledge measure included questions on the cause of

sickle cell conditions, their signs and symptoms, people who were most commonly affected by them and how they were transmitted. Questions were also asked about signs of impending illness, appropriate strategies to cope with early signs and symptoms, complications of the conditions, maintaining good health and family planning issues.

The study found that people with sickle cell conditions did not have a general all-round knowledge of the conditions. Item analysis showed that, although people answered more questions on self-care correctly, both generally, and at the onset of illness, questions on the physical and pathological aspects of the conditions proved much more difficult (Tables 12.6, 12.6a, appendix).

12.6.1 District comparisons

There were no differences in knowledge overall between the districts with a comprehensive package of care (CPC) as defined by Prashar et al, (1985), and those without (NCPC) (Table 12.6.1, see appendix).

Table 12.5.2a People's sources of advice regarding the transmission of sickle cell genes.

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
No advice*	19	(38.8)	22	(52.4)	41	(45.1)
ADVICE FROM						
Doctor	10	(20.4)	11	(26.2)	21	(23.1)
SCC	5	(10.2)	3	(7.1)	8	(8.8)
FPD	1	(2.0)	0	(0.0)	1	(1.1)
Vol. Orgs	7	(14.3)	3	(7.1)	10	(11.0)
Doctor and SCC	0	(0.0)	1**	(2.4)	1	(1.1)
Books	7	(14.3)	2	(4.8)	9	(9.9)
Total	49	(100.0)	42	(100.0)	91	(100.1)

$X^2_{6\,(d.f)} = 6.65$ NS

SCC = Sickle Cell Counsellor FPD = Family Planning Doctor

Vol. Orgs. = Voluntary Organisations

* There were no significant differences between 'no advice' vs. 'advice' comparisons
** This person saw a sickle cell counsellor in another district

Table 12.5.2b Information given to people about the transmission of sickle cell genes.

	CPC		NCPC		TOTAL	
	n	%	n	%	n	%
Everything general	17	(34.7)	6	(14.3)	23	(25.3)
Select partner with care	1	(2.0)	1	(2.4)	2	(2.2)
Contraceptive Advice	1	(2.0)	0	(0.0)	1	(1.1)
Select partner/ Contraceptive Advice	1	(2.0)	0	(0.0)	1	(1.1)
Avoid having any/ more children	4	(8.2)	3	(7.1)	7	(7.7)
Transmission of the sc gene	6*	(12.2)	10**	(23.8)	16	(17.6)
No advice	19	(38.8)	22	(52.4)	41	(45.1)
Total	49	(99.9)	42	(100.0)	91	(100.1)

$X^2_{6\,(d.f)} = 8.14$ NS

* Five of these people answered the question on transmission correctly.
** Six of these people answered the question on transmission correctly.

Table 12.5.2c Analyses of variance showing differences in knowledge scores between people who were given advice regarding the transmission of the gene compared with those who were not.

Source	d.f	Sums of Squares	Mean Squares	F Ratio	F Prob.
Advice/ no adv.	1	834.63	834.63	17.36	0.0001
Residual	89	4279.50	48.08		
Total	90	5114.13			

12.6.2 Age and sex differences

No differences were seen in the knowledge scores of men and women in the sample, nor were any differences seen between older and younger people. However, people who were less than seventeen years old when they were diagnosed had more overall knowledge than those who were at least seventeen years old at diagnosis. The latter group had more knowledge than people who did not have any illness. These differences held regardless of whether people had trait or one of the sickle cell conditions. (Table 12.6.2, see appendix).

12.6.3 Number of children and family experience of sickle cell conditions

No differences were seen between parents and childless people. Furthermore, people who recalled having a relative with a sickle cell condition did not have greater knowledge than the group who could not recall any relatives with the condition. (Table 12.6.3, see appendix).

12.6.4 Qualifications and employment

People who left school with C.S.E and G.C.E. qualifications, and those who had other certificates, diplomas and degrees had higher knowledge scores than the people who said that they had no qualifications ($p < 0.004$) (Table 12.6.4). However, there were no differences between those people who were in employment and those who were not.

Table 12.6.4 Analysis of variance of knowledge scores by education

Source	d.f	Sums of Squares	Mean Squares	F Ratio	F Prob.
a) Educational level	1	466.21	466.21	8.93	0.004
Residual	89	4647.93	52.22		
Total	90	5114.13			

12.6.5 Regular hospital appointment and perceived health status in the past month

Although there were no significant differences between sample members who had a regular hospital appointment and those who did not, people who had been admitted to hospital within the year before interview had higher scores ($p < 0.02$) than those who managed to stay out of hospital (Table 12.6.5). There were no significant interactions between these two variables.

No differences were seen in the proportions of people who rated their health in the past month as good to very good and those who said that their health was poor to fair.

12.6.6 Diagnosis, experience of crises and warnings of crises

There were statistically significant differences overall in the knowledge scores of people who had a sickle cell condition compared with those who had trait ($p < 0.01$). There was also a trend for people who had a milder course of illness to have higher knowledge scores than people who had trait. People who were diagnosed in childhood had higher knowledge scores than those diagnosed as adults (Table

12.6.6a). There were no significant interactions between age when diagnosed and type of diagnosis.

Furthermore, people with sickle cell conditions answered correctly more questions on both self-care items and general knowledge questions about sickle cell conditions, than those who were simply carriers, $p < 0.001$ and $p < 0.02$ respectively (Table 12.6.6b).

Table 12.6.5 Analysis of variance of knowledge scores by hospital admissions

Source	d.f	Sums of Squares	Mean Squares	F Ratio	F Prob.
Hospital admissions	1	288.22	288.22	5.31	0.02
residual	89	4825.91	54.22		
Total	90	5114.13			

Table 12.6.6a Analysis of variance of knowledge scores by type and time of diagnoses

Source	d.f	Sums of Squares	Mean Squares	F Ratio	F Prob.
Main effects	2	684.439	342.22	7.04	0.002
Conditn/trait	1	264.085	264.085	5.43	0.003
Erly/late diag	1	204.711	204.711	4.21	0.04
Interaction	1	0.573	0.573	0.01	0.91
Explained	3	685.012	228.337	4.70	0.005
Residual	87	4229.119	48.611		
Total	90	5114.13			

Table 12.6.6b Knowledge scores of people with sickle cell conditions (SCC) and sickle cell trait (SCT) with regard to a) sickle cell self-care items and b) questions about the conditions

	n	m	S.D	S.E	t	d.f	p
a) Care items							
SCC	54	14.12	4.0	0.5	3.73	89	0.001
SCT	37	10.78	4.5	0.7			
b) Other items							
SCC	54	9.41	3.8	0.5	2.32	89	0.02
SCT	37	7.54	3.6	0.6			

Table 12.6.6c Analysis of variance of knowledge scores by experience of crisis

Source	d.f	Sums of Squares	Mean Squares	F Ratio	F Prob.
Had crisis	1	279.83	279.83	5.15	0.03
Residual	89	4834.30	54.32		
Total	90	5114.13			

People who had experienced one or more crises returned higher knowledge scores than people who never had one ($p > 0.03$) (Table 12.6.6c). However there were no differences between those people who regularly had warnings that a crisis was impending and those who were not so forewarned. There were no significant interactions between people who were diagnosed in childhood and those who experienced crises.

12.7 Some comments about living with sickle cell conditions

Jargon used in sickle cell discussions may be causing some difficulty for people trying to interpret what their diagnosis means to them. For example, the use of the word 'trait' meaning that the individual is a carrier of the sickle cell gene may be problematic. Most of the people who had trait (75.2%) said that they had a 'trace of sickle cell'. The assumption was made that people misinterpreted the word 'trait' for 'trace', until a general practitioner giving a talk to an OSCAR seminar group talked about people having a 'trace of sickle cell or mild sickle cell which was nothing to worry about as crises would not occur'.

Sample members understood this to mean that they had a mild sickle cell condition. Although the majority of these people, (60%) of the sample of people who had trait, appreciated that they were very unlikely to develop any serious illness, this caused problems for the rest who had known a relative or friend with sickle cell anaemia. In

these cases, the individual with sickle cell anaemia experienced good health for many years when they suddenly had a major crisis. Until then it had been assumed that these relatives/friends also had a mild sickle cell condition. The sudden serious illness of their relative/ friend made this group concerned that they too would suddenly develop a life-threatening crisis.

> " It was such a big, big shock when my cousin got sick. I always knew he had a trace. Both of us got it. It's supposed to be mild .. and then he nearly went and died. Why this happened I don't know, but it make me worried. I have children .. so I can't get sick like that ... who will look after them if I do..."

and,

> " My friend has sickle cell. They had to take her to hospital one time 'cos she got so sick. She used to have a mild dose of it until it caught up with her. I have a trace of it too, a mild dose. Will I get sick like that too? ..."

The opposite situation occurred when someone with sickle cell who has comparatively good health is told that 'they have nothing to worry about'. It is known that sickle cell conditions can react with specific internal and external environmental conditions to produce ill-health. People who have been largely free from serious illness, could develop crises if they are exposed to these environments. Being told that 'there is nothing to worry about' can encourage people to ignore situations which can be harmful to their health.

> " They said that I have sickle cell anaemia but all of the people I know with sickle cell anaemia are always in and out of hospital, or if not in hospital something is always wrong with them, .. you know,

> flu' and such... But I don't have any of that, so I can't be sickle cell anaemia. I must just have a trace of it like my brother, and he does everything. Anyway I don't have to always wrap myself in cotton wool."

The presentation of some information can also do more harm than good. Certainly the woman who is quoted below became very confused about her parenthood after receiving what appears to have been a rather complex description of the way sickle cell genes are transmitted.

> " My doctor was really very good ... he spent ages explaining about how you can pass on the sickle cell. He drew all these squares and circles and showed me how a boy child can get it and a girl mightn't. He really spent a lot of time .. I remember all the drawings ... For a long time after ... years ... I couldn't trust my parents. I thought they must have adopted me .. I asked them and they denied it ... but I thought I knew, didn't I? I couldn't be theirs because I was the only one that had it. Eventually I accepted that I was theirs, but even now sometimes I wonder."

The implications here are that misunderstandings could lead to mental anguish and a breakdown of health if people relax vigilance where it is needed. People would not be able to make precise decisions about their self-care. They would also not be able to alert their doctors if they are affected by conditions which appear to be unrelated to sickle cell, but which in fact may be a complication of the conditions. In some cases, this will not be a problem as if a black person requires surgery under general anaesthesia, for example, tests will be done by the hospital to see whether the person is sickle positive (that is, they have at least one sickle cell gene) or not. If positive, appropriate adjustments are made to satisfy the client's need for a richer oxygen mixture while they are

anaesthetized. This may not be routinely done for Mediterranean and Asian groups who also ought to be checked for sickle cell genes. They may be occasions when a knowledgeable client may be able to alert clinicians about the development of possible complications.

> " I suddenly went deaf ... oh, it was years ago now .. and I went to the GP. He looked in my ears and said I have earwax. .. Well I clean my ears good so I don't know how he find earwax in them. Anyway he send me away and after a time the hearing come back. Then another time .. maybe a year or two later, the same thing happen again .. whoop, the hearing just gone .. so this time I go to the chemist for eardrops and I give them a week and make sure the ears clean .. but I still can't hear good so I went back to the doctor... by this time I could hear all sorts of noise in my head. Another doctor look in the ears and said some earwax but not enough for any deafness in one ear, and none in the next. And he send me away. I even did ask if it could be to do with the sickle cell and he said no. Anyway, recently I had to go back with my ears .. by this time I changed doctors. I tell this one I can't hear good and I want a hearing aid test. So he fixed it up and I had to go to the hospital. They test me and said I am deaf in both ears because of poor circulation. They said it was the sickle cell causing it and that if I get any more deafness to go straight to them as they could stop it getting permanent. Now why did the GP. not tell me all this first time? I wouldn't be wearing (this) hearing aid now".

Sudden deafness in sickle cell has been documented (Morrison and Booth, 1970; Orchik & Dunn, 1977; Friedman et al, 1980). This situation could have been largely prevented as people with sickle cell who arrive promptly at the hospital with sudden hearing loss could be given treatment to improve the circulation to the ears, thus minimising hearing loss.

The possibility of stigmatisation was also discussed. The two quotes below were taken from the only two people who talked about feelings of stigma.

" When I first heard of sickle cell, I thought it was some new disease that 'white man' bring on us. You know, like they (are) trying to say that AIDS is from black people going with monkeys in Africa. What I'd like to know is if we (are) so terrible and going with monkeys and all, how they (white people) get it (AIDS, that is)? I refuse to believe that this thing (sickle cell) is a black man's disease like the doctors always saying. Anyway for them that has it, they certainly don't believe in doing much."

and,

" Sometimes I ask myself 'Is what we do to make God give us this?' He make them (white men) take away us lands. He make them take away us freedom. And now He give us this (sickle cell). Is what we do?"

People's believed that they learned about sickle cell conditions **solely** by their experiences. This quote is a compilation of similar comments made by virtually all of the people who had experienced sickle cell crises.

" I remember it was near Christmas ... there was a fair up the road. A bunch of us went. It was cold but not too bad. I've felt worse cold. Anyway we was (sic) up on the big wheel and it stopped when we were on the top. I was cold, cold, I thought I would freeze. I realised I could have put on something warmer. Any way to cut a long story short. I had a crisis .. I know it was the cold. Next time I'll dress warmer. I do now anyway 'cos you don't always know when it will turn cold .... It was in the winter. I was waiting for the bus. I got too cold and collapsed.. a lady called the ambulance. So now I dress warmer if I have to go out ... I know it was the flu that started it off ... it went to my chest .. by the time I realised and went to the doctor, it was pneumonia. So now I get the flu, it's to the doctor quick for some medicine. ... I got a crisis because it got too cold, but it's the house, you can't keep it warm, so I go to bed to keep warm or I will get sick ..... I was overdoing it really, wanting to show I could do it. Anyway when the pain start(ed) I couldn't stop it, ... even with the painkillers. It was my own fault. Trying to be what I am not. Anyway I stop now if I start to get tired. And if I get very, very tired, I come home and go to bed. ... I notice that I get tired and cold so I got to bed with a hot drink. The family will then keep me supplied ... I always drink some tea or something. I take a flask to bed with me... I have lots to drink and I'll take a painkiller and go to bed or wrap up warm. It seems to make me feel better."

12.8 Discussion

The majority of the sample was aware that sickle cell conditions affected people of African-Caribbean ancestry. This knowledge stemmed largely from publicity generated by local voluntary groups and the media. Furthermore, people from CPC districts used more sources to obtain information about sickle cell conditions than those from NCPC districts. This is understandable as more people from CPC districts in the sample had a sickle cell condition compared with NCPC districts where more people with trait were represented in the study. In addition, there were more primary sources of information in the CPC districts than in the NCPC ones, namely the sickle cell counsellor and branches of the Organisation for Sickle Cell Anaemia Research (OSCAR). Furthermore, whilst the sickle cell counsellor was seen by only ten percent of the sample, publicity campaigns by OSCAR and other local sources meant that people were made aware of services which were available both locally and nationally.

With regard to the transmission of sickle cell genes, a lack of reasonable information leaves people wondering whether advice is 'for the good of their health' or whether it is racist. The decisions they make will invariably be influenced by their relationship with their doctors. If that relationship is fairly good, they may give the doctor the benefit of the doubt. If it is not, accusations of racist behaviour on the doctor's part will abound. Regardless of which stance the client takes however, (s)he

will invariably not be able to make decisions regarding family planning, which are backed by the knowledge of what is possibly the best scenario for her/him. This could lead to both social, medical and psychological problems in the long run: for example, if people come to believe that they have deprived themselves of having a family for the wrong reasons (in cases where friends 'with worse sickle cell' successfully do so), or if they should decide to have a child with disastrous consequences.

Information may be communicated unhelpfully using medical jargon. It may be therefore, that people simply did not understand information that was given. The example of the woman who doubted her parentage for years is a potent example. The doctor gave her rather detailed information, and by using symbols for showing the supposed sex of the child, had made the discussion too complicated. The sickle cell gene is not sex linked and he would have made more sense to focus solely on the inheritance of the sickle cell gene, omitting the information about whether the baby would be male or female. Although this client was satisfied with the time and information she received, she had years of mental anguish and uncertainties about her parenthood. This fortunately did not do any apparent permanent damage to her relationship with her parents but could have quite easily done so.

Simple explanations coupled sympathetic approaches by carers, would therefore provide people with an understanding of their situations, and allow them to make

truly informed decisions about planning their families.

The difficulties of not understanding how genes are transmitted are also made clear when we consider those people who believed that being a carrier, that is having 'trait' meant that they had a 'trace' or a mild case of sickle cell anaemia. It is therefore important for client friendly advice regarding sickle cell conditions to be given at diagnosis. This must be further reinforced with information provided by sickle cell or genetic counsellors and support groups.

Clear information-giving would also prevent the distressing situation where people feel the burden of stigmatisation.

i. Knowledge and sickle cell conditions

Although overall knowledge could be improved, sample members tended to know the appropriate strategies to use once a crisis had started (much of which followed a medically prescribed regime, ie. they took painkillers (and antibiotics if prescribed), increased their fluid intake and called the doctor if they did not feel better. They tended to rest and keep warm because they felt ill and cold. However, they did not know how the genes were transmitted or what their chances were of passing on the gene to their children with their current partners, which populations were most commonly affected by the conditions, complications and many of the signs and symptoms. It appears that for many, 'self-care behaviours' evolved from

their own experiences rather than were taught by health professionals. This may be suggestive that health education may not be important to people who are often ill. However, because their experiences often brought them into contact with health professionals more frequently than people who had little illness, it may also be that these people 'picked up' more information from carers than they realised. Certainly most doctors will advise any client with a temperature and in pain, to rest, keep warm, take painkillers and drink copiously, consulting them again if things do not improve.

The second hypothesis, that people from CPC districts would have more knowledge that those in NCPC districts was not supported by the findings in this study. There were no knowledge differences overall between the two sets of districts. This was particularly startling as examination of the sample showed that sample members from NCPC districts had more sickle cell trait. It has already been shown that people with sickle cell conditions had more knowledge than those with trait. This seems to confirm the notion expressed earlier in this thesis, that people may be segregated into two groups, that is, those with a condition who are given some information, and those with trait who are not necessarily provided with any information. This may be because some doctors might perceive that there is no need give people information which they may find burdensome, particularly if they (doctors) believe that they (clients) have 'nothing to worry about', in the case of those who have sickle cell trait.

People who had been diagnosed for a long time, regardless of their age, had higher knowledge scores than their counterparts who were more recently diagnosed. This finding supports the sixth hypothesis, and was seen regardless of whether their condition was described as severe or mild. It is possible therefore, that with time individuals acquired knowledge that was relevant to their needs, probably largely by their own experiences of how the conditions affected them in different circumstances.

No differences were seen in the knowledge scores of older and younger people. It would seem logical to assume that older people would have greater knowledge based on their experiences of the conditions. The vast majority who were diagnosed before they were twelve years old could not remember too much of their illness either because they were babies or too ill to remember. Then they mostly did not have serious or even moderate illness episodes after that diagnosis was made. Those who made any comments about this time remembered only that it had been a time of intense worry for the family.

Another possible reason for this lack of difference between older and younger people, is that younger, more recently diagnosed people may have either been better informed than their older counterparts. More information about sickle cell conditions is available now than there was ten or even five years ago. It may also have been that recently diagnosed people remembered more of what they had been told.

There were no differences in knowledge between the sexes, despite the fact that women are generally responsible for health care in the family. There were also no differences seen between parents and childless people, nor were there differences between people who recalled having a relative with a sickle cell condition and the group who could not recall any relatives with the condition.

People who recalled having a family member with the conditions were usually not too closely related to have much 'hands on' contact with them when they were ill. This may have accounted for them having no more knowledge of sickle cell conditions than people who did not appear to have any relatives who were affected.

People with higher varying educational qualifications had higher knowledge scores than those who did not have any qualifications. This was to be expected. However, an interesting finding is that there were no differences with employment as this indicated that unemployment did not necessarily favour unqualified people with less knowledge of the conditions, but rather that a large proportion of those with additional qualifications were unemployed. The reasons for this anomaly are not clear, but may be as a result of people possibly having higher expectations regarding career prospects, or perhaps having a greater awareness of the effects that certain types of jobs may have on their health.

Sample members generally felt that they were not being

given sufficient information about their conditions. People who regularly had check-ups at the hospital did not have more knowledge about the conditions than those people who did not usually see a doctor for these health checks. Long periods spent waiting to see doctors (already discussed) could be used to inform and educate people about these conditions, by using information videos, leaflets and on occasions, a counsellor with whom illness experiences, methods of coping, anxieties, inheritance of the gene and family planning and any other topic of importance could be discussed.

It was interesting to note that people who had been hospitalised in the year before the interview had higher knowledge levels than people who were not admitted. This does seems to suggest that some knowledge is being gleaned with recent or increased hospitalisation. People who had been hospitalised tended to 'pick up points' on questions on signs and symptoms, conditions that can cause crises and some of the 'care' questions. This was quite obviously a reflection of their own illness experiences which were still fresh in their memories, but may also in part, have been a reflection on hospital care. This data confirms the fifth hypothesis.

People who had experienced a crisis regardless of whether that crisis was 'severe' or 'mild' knew more about the conditions than people who never had a crisis. This is understandable as these people were able to call on their own experiences of illness to answer many of the questions

regarding their particular signs and symptoms and the things they did to cope with the crisis.

Although the sample indicated that in general there was not enough information being given to them about sickle cell conditions and the transmission of the genes, those who were given information returned higher knowledge scores. Some doctors argue that they do not wish to give clients information which could lead to anxieties when they (or their children) are unlikely to have serious illness (in some cases of 'mild' sickle cell), or any illness at all (for example, carriers of the genes) (pers. comm. several GPs). While anxiety levels were not measured in this study, it seems quite clear that those who had concerns did **not** have information about the conditions. How this affected sample members was not examined.

12.9 Summary

1. Health visitors used a variety of sources to get information about sickle cell conditions. Nurses, on the other hand, depended almost entirely on schools of nursing for information.

2. Nurses and health visitors have generally low levels of knowledge of sickle cell conditions. Health visitors returned higher knowledge scores. This confirmed hypothesis 10. Health visitors were more knowledgeable about the conditions than about hands-on care strategies.

3. Nurses and health visitors working in areas with large minority ethnic populations were more likely to have had experience in caring for people with sickling conditions, than those from other districts. They were also more knowledgeable than carers who had not worked with people who had the conditions, proving the eleventh hypothesis.

4. No differences in knowledge for sickle cell conditions was demonstrated between districts. Hypothesis 12 was therefore not proven.

5. Nurses did not know enough to recognise many of the symptoms which are indicative of sickle cell conditions.

6. There was a strong correlation between health visitor knowledge and minority ethnic population size.

7. Younger nurses and health visitors who had experiencing caring people with sickle cell conditions had more knowledge than older and inexperienced colleagues.

8. Nurses and health visitors with additional nursing qualifications had higher scores than those without. It may be that either some input on sickle cell states is being made in post-basic courses, or that those care staff with more qualifications are also more likely to seek information, for example, by reading

journals.

9. There were no relationships between those with additional qualifications and those who had a greater likelihood of caring for people with sickle cell conditions.

10. Sample members were aware that sickle cell conditions were a problem for people who were of African and Caribbean descent.

11. People from districts which had a comprehensive package of care (CPC) used more sources to get information than those in districts which did not have this package (NCPC). Despite this, sample members from both sets of districts felt that they were not well enough informed.

12. The doctor tended to be the health professional who gave advice and information about the transmission of sickle cell genes. However, advice was not always specific to gene inheritance and was generally not clear.

13. Professionals often described sickle cell trait as 'a trace of sickle cell'; this caused some confusion for clients.

14. People's knowledge of sickle cell conditions was patchy. Self-care items were more likely to be

correctly answered, but questions about different aspects of sickle cell conditions were problematic.

15. No differences were seen in knowledge overall between CPC and NCPC districts. Hypothesis 2 was therefore not proven.

16. Significant differences in knowledge were seen with educational qualifications, hospitalisation for sickle cell episodes, diagnosis, length of diagnosis and experience of crises.

17. No differences were seen in the knowledge scores of men and women in the sample, nor were any differences seen between older and younger people.

18. People who were less than seventeen years old when they were diagnosed had more overall knowledge than those who were at least seventeen years old at diagnosis. The latter group had more knowledge than people who did not have any illness. These differences held regardless of whether people had trait or one of the sickle cell conditions. This confirmed hypothesis 6.

19. Although there were no significant differences between sample members who had a regular hospital appointment and those who did not, people who had been admitted to hospital within the year before interview had higher scores than those who managed to stay out of hospital.

There were no significant interactions between these two variables. This makes a contribution to proving the fifth hypothesis.

20. People who had experienced one or more crises returned higher knowledge scores than people who never had one. This makes a contribution to proving the fifth hypothesis.

21. Significant differences in knowledge were also seen between people who had been given general information about sickle cell conditions and those who received no information. People who were given advice about the transmission of the genes returned better scores that those who did not receive any advice. This confirms the fourth hypothesis.

CHAPTER 13. Voluntary organisations and community based statutory sickle cell centres

13.0 Introduction

In Britain today, health is being increasingly seen by health services as being, in part, the responsibility of individuals and families, rather than the state. Statutory services therefore expect a larger contribution from the voluntary sector, particularly in relation to the care of dependant groups. In a speech to the Directors of Social Services in 1980, the then Secretary of State for Health, Patrick Jenkins stated that:

> " ...we cannot operate as if the statutory services are central providers with a few volunteers here and there to back them up. Instead we should recognise that the informal sector lies at the centre with statutory services and the voluntary sector providing expertise and support..."

This shift of responsibility from statutory to informal and voluntary sectors was emphasised and reaffirmed by subsequent reports (DHSS, 1981; Webb and Wistow, 1982).

This chapter examines the qualities and scope of voluntary and community statutory provision for people with sickle cell conditions. Interviews were carried out with 1 representative from each of seven branches of the Organisation for Sickle Cell Anaemia Research, a spokesperson from the Sickle Cell Society and 1 Counsellor from each of six Sickle Cell Centres.

13.1 History of the voluntary organisations

The work of voluntary organisations, their professional staff and volunteers make important, but different, contributions, that is, different to health care staff, to the effectiveness of the health service (DHSS, 1974). The efforts of voluntary services in this country have replaced some statutory services, eg. rescuing abandoned/neglected children and meals-on-wheels. Voluntary efforts can complement, enhance and extend statutory contributions, bringing a different dimension of commitment to care:

> " A prime function of voluntary service is to help promote community understanding and acceptance of health care. The practical involvement of the general public as volunteers in the work of the NHS is one of the most effective methods of educating the public and influencing its attitudes ... volunteers .. come into contact with .. professional staff .. at every level..their respective attitudes rub off in both directions" (Royal Commission, 1976: 5).

13.1.1 The Organisation for Sickle Cell Anaemia Research

The Organisation for Sickle Cell Anaemia Research (OSCAR), a registered charity, was founded in London in November, 1975, to raise public awareness about the conditions and 'win over the confidence and support of the black community' (pers. comm. OSCAR, 1987). OSCAR's broad based aims were as follows:

i. To improve public and professional awareness about the conditions

ii. To advise and support affected individuals and their families

iii. To conduct non-medical research

iv. To promote and finance biomedical research

v. To disseminate information about the conditions to the general public

vi. To counsel individuals and families who are positive for sickle cell genes

vii. To help lobby political parties and governments in order to place the issues of sickling conditions on a formal health care agenda

viii. To give limited financial, for example, to provide telephones, assist with heating bills and so on, in cases where seriously ill people with the conditions are unable to get this assistance elsewhere.

ix. To raise funds for the promotion of the above

a) Breaking ground - Setting up a new organisation

" OSCAR came about because of my own experiences..I had a crisis in '64..About three years later I had to go back to the same hospital..pneumonia..a black (ward) sister told me about sickle cell..I felt that if I'm going to have this condition for the rest of my life, I should at least understand it..its effects..how I could live with it..It wasn't until the early '70's when my parents (in America) were able to find some books for me that I started to educate myself..In '74 I met other sicklers..a doctor who was interested in sickle cell introduced me to Professor X..he told me of the problems of highlighting sickle cell to the black community who might not be ready for it..in 1975 OSCAR was officially launched" (OSCAR co-founder, 1987).

The need for organised services for people with sickle cell conditions was recognised by small numbers of black people who were directly or indirectly affected by having a

relative or friend with a sickle cell condition. A small number of medical staff who cared for these people were also supportive of the call for appropriate services to be introduced.

At this time, sickle cell conditions were not even generally recognised by most generalist medical staff, as symptoms were often confused with those of other conditions. For example, a young affected person experiencing severe joint pains and presenting at hospitals and surgeries with pyrexia and swollen joints could very easily be diagnosed as having juvenile arthritis. Likewise, an adult presenting with severe chest pains might be assumed to be having some form of cardiac problem. It was therefore important that health care professionals and the people who were most affected by these conditions were informed of the conditions, their effects and their implications for health practices and health care needs.

i. Racism

In its work to inform the public and health professionals, OSCAR had to overcome several obstacles. These included dealing with racist attitudes from various people, for example a National Front effort to stigmatise sickle cell conditions as something which the dominant population could 'catch' should they have any contact with black people.

> " The National Front was big in 1976. They wrote in their 'Spirit' magazine about sickle cell..they were linking it to leprosy and said that black people were bringing this

terrible disease into this country" (Oscar co-founder, 1987).

The buildings OSCAR headquarters were housed in had bars at the windows and a strengthened outer metal door 'to minimise attacks on the building'.

ii. Ignorance in the black population

However this type of opposition was seen to be less problematic than the thorny issue of educating the black population. Many black people believed that sickling conditions were inventions of a white population to prevent black people from gaining employment, becoming insured and partaking in other social benefits. Others believed that increased racism from the white population would make it virtually impossible for many black people to live harmoniously with their white neighbours.

> " There were a few cynics within the black community who felt that we should keep it under the carpet. Sickle cell was just a concoction the white man was subjecting on a black person..we had to go around to meetings..there weren't any films or slides of what sickle cell was like..Community leaders were against the meetings because the National Front and other right wing groups could play on it..We went ahead anyway because we felt that most people in this country are sensible enough. They were also recognising their own conditions, cystic fibrosis, MS and all that.." (Oscar co-founder, 1987).

The problems of black people not accepting sickle cell conditions were also seen as 'a set back to the movement towards promoting a positive image of black people, movements which started in the United States of America in the sixties and to a lesser extent in Britain in the 1970s' (pers. comm OSCAR, 1987).

iii. Attitudes of health professionals

In these early days, OSCAR's membership was largely made up of volunteers who had no medical, nursing or social work backgrounds. There were therefore some difficulties from a communication point of view with health professionals who used the organisation.

> " Sometimes you are trying to explain something to people (General Practitioners in particular) and you can see that they don't like to be placed in a situation where they don't know anything..there's this barrier which we don't know when it can be broken down, or if it ever will because a lot of GPs felt that they were the doctors and they should know.." (Branch worker, OSCAR, 1987).

There were also problems with black health carers. Doctors were again singled out for these comments:

> " We had not seen many black doctors..those who came did not show any commitment to the care of people with sickle cell..they use the organisation only so far as to further their careers. For example, they would phone up, get some information, then they would probably give a talk somewhere..Rather than getting involved with the organisation, they would just use it" (Another branch worker, OSCAR, 1987)

Some nurses who became OSCAR members were also described as 'manipulating' the organisation for their own 'sort of reason', and as 'trying to hinder the progress of the organisation'.

Raising funds wherever it could, OSCAR developed and their first branch emerged in 1977, also in London. This 'broke away' two years later to become the Sickle Cell Society. Since then, other branches of OSCAR were formed, and at the time of this study in 1987, there were seven branches

(excluding the Sickle Cell Society), in existence.

Today OSCAR claims a membership of approximately 650 clients nationally. This figure appears to refer to London membership alone as the average number of clients on the books of each of the seven London branches was 100 persons. In addition, the Birmingham branch claims to have about five hundred people on their books. Since these interviews, at least three other OSCAR branches, all outside London have been created.

13.1.2 Sickle Cell Society

The Sickle Cell Society's (SCS) stated aims are:

1) To give help and support to families affected by sickle cell disease.
2) To educate the public, professionals and government agencies about the needs of families affected by sickle cell disease.

The SCS, which has approximately 2000 people on their books, some of whom are overseas, is based in London. Since its establishment in 1979 to 1987, the Sickle Cell Society has had self referrals from over 1500 people who wanted to be tested for sickle cell genes. Only 60% of these people were local, some calls coming from other European countries.

Like OSCAR, the SCS had similar problems in setting their

service up. Like OSCAR, it is a registered charity run by committees of volunteers.

13.1.3 The Roles of these Organisations

The voluntary organisations refer clients for screening at specific hospitals, usually based on where the client lives. They also offer some genetic counselling. There is a large health education component to their activities and they produce various leaflets and booklets geared to education at the client level. A major aspect to their work is that of giving general support. This includes financial assistance when there are gaps in DHSS provision, for example with heating and telephone bills, clothing, funerals, furniture, rent arrears and fares to hospitals. Furthermore, they give welfare counselling, advice regarding Health and Social Security tribunals and offer help paying for legal representation when necessary, for example when people with sickle cell disorders who need this type of representation but are unable to pay for a lawyer of their choice. They also visit clients in hospital and at home.

13.1.4 Funding

The voluntary sector relies on the state sector for subsidies in order to provide services and organise themselves (Webb and Wistow, 1982). Both organisations were, and to a great extent still are, funded by their own efforts, raising funds via annual dances, lotteries and so

on. In addition they receive whatever public donations they can attract, as well as a number of small grants for specific purposes from various bodies, such as the local health authority. Inner-city Partnership, Manpower Commission and various other programmes.

OSCAR and the SCS both confirmed that amongst their biggest problems is the need for adequate funds for equipment, administrative staff and possibly permanent premises:

> " We are dealing with a total of five thousand people in Britain who have sickle cell, and when you look at the same figure of 5000 haemophiliacs, we are talking about similar haematologic conditions where there is such discrepancy in the funding of those two conditions. We are talking about haemophiliacs getting 24 to 26 million (pounds) from the DHSS. We are talking about the DHSS giving the Sickle Cell Society and OSCAR twelve and a half thousand each. I mean it begs the question as to why there is such a discrepancy and I will leave it wide open for people to come to their own conclusions" (SCS spokesperson, 1987).

Central government funding to both organisations in 1987 was in the region of £25,000 per annum. This was increased to £30,000 in 1988. While the sum quoted above for government funding haemophiliacs may be inaccurate, the fact remains that this group does attract funding several times greater than sickle cell conditions receive. The comparison of disparate funding between these two conditions does leave many questions. It can be argued that haemophiliacs require frequent blood transfusions to combat the problems of prolonged bleeding. However, many people with sickle cell anaemia also require frequent blood transfusions particularly at times of crisis. Some haematologists give transfusions prophylactically in severe cases, and many pregnant women with sickling conditions are

also regularly transfused. It would seem therefore that differences in frequency of need may be an influencing factor in hospital care. However, this does not significantly affect the needs of these groups in terms of voluntary provision.

Furthermore, as various environmental conditions can precipitate episodes of serious illness in people with sickle cell conditions it would seem to make economic sense for health education and health promotion activities to attract reasonable levels of government funding. Genetic counselling could be undertaken before women became pregnant so that they are able to plan their families from a truly informed vantage point. This is obviously preferable to them being subjected to emotional and physical distress if prenatal screening results in advice to terminate their pregnancies for medical reasons.

Additional funding would allow both voluntary organisations and sickle cell centres to have clerical and administrative back-up, more counsellors (including sickle centre staff who collectively could speak all of the appropriate languages) and more equipment (both for office management and for producing health education materials). This would enable them to provide a coherent service for their clients which is sustaining and reliable. Appropriate funding could also be used to help them move their premises closer to the populations they serve (many of OSCAR's branches and the sickle cell centres were not in central positions).

13.2 Community statutory provision - sickle cell centres

The work of the Sickle Cell Society and OSCAR gained some recognition which resulted in the establishment of a number of sickle cell clinics and centres. At the time of interview, there were seven sickle cell centres in Britain, more than half of which were based in London. The centres were housed in hospitals, health centres and portakabins in the community. They had been set up as a result of public demand which was backed by voluntary organisations together with medical support.

The centres are used for sickle screening of people who request it. They also refer clients to hospitals for screening or treatment, give advice to families about various health and social matters, and they offer ante- and post-natal counselling, genetic counselling and health education services. They give family planning advice and visit clients in hospital and at home.

The centres are the responsibility of sickle cell counsellors all of whom are health visitor qualified, and who received additional training in sickle cell related issues. Only two of these health visitors worked exclusively with people who were diagnosed as having a haemoglobinopathy. As health visitors, the rest are expected to carry other caseloads as well. All of these specialist health visitors liaise with hospitals, do teaching sessions on sickle cell conditions with other nursing and sometimes medical staff, (both hospital and

community based), within and outside of their districts. They also refer people to the Department of Social Security when there is a perceived need for those services.

All of these counsellors were interviewed and they told remarkably similar stories of the problems of running these centres. There were concerns about working without adequate funding, supporting staff, lack of equipment and a lack of decent office space:

> " As you can see I work alone. In fact having two people in here for any length of time could constitute gross indecency. (The office was barely large enough to hold a desk, a filing cabinet, two chairs and a small table.) I only have the table in because sometimes I get a part-time temp to answer the phone when I'm out on visits. That means that when she is unavailable and I'm not here, there is no one to deal with enquiries. I am supposed to visit, teach, carry out my professional duties as well as do all of the admin work and still provide 9 to 5 cover for the telephone. I am also supposed to provide a 'drop-in' service, but I can't be everywhere. Sometimes I get X, (another sickle cell counsellor from another district), to cover for me but it's very difficult as she has an even bigger caseload than I have. As you can see this room is a joke. It's just a broom cupboard really. When I started work here there was nothing in the room. I had to exist by begging, borrowing, stealing, anything! Even letter-headed paper..anything I need I will borrow from the clinic, (another clinic nearby), or scrounge from wherever. The desk, filing cabinet, everything. Even the phone was provided by the mayor when he heard how bad things were. I asked him for an outside line because calls were being sent to the kitchen and to wherever else you could think of. I pinched that table from the clerk's office, and she's insisting that she has it back, but there is no where to put the typewriter. There's no budget at all for this place. Yet the health authority is supposed to fund us, and they are quick to say 'yes, of course we have a sickle cell centre when anybody asks'" (Sickle Cell Counsellor, 1987)

This was an extreme case, but with the exception of two centres which appeared to have less staffing and funding problems, many centres had the problem of not being able to plan any long term strategies for the care of their sickle cell clients. The health visitor quoted above has since been provided with more appropriate accommodation and back-

up facilities.

However the problems of funding, particularly for staff, health education material and equipment, remains problematic for many of the counsellors:

> " We do have a number of staff but all of these posts are funded by short term grants and there is always the worry that they will not be renewed. Some of the grants last for as much as three years, others are only for one year. It's not just the health authority we look to for funds. The Manpower Commission, Inner-City Trust and other organisations will help out, but we can't depend on these forever. What we need in permanent funding and a budget, so we can plan and implement things logically" (Second sickle cell counsellor, 1987)

Often there is just a single counsellor in each centre serving large caseloads of clients:

> " I cannot see people in their own homes, as often I haven't got the time. I invite them to come here which is not ideal, especially in the cases where young couples have new babies with sickle cell" (Third sickle cell counsellor, 1987)

Problems of space, cold offices, crying babies and distraught parents make the centre unsuitable for consultations, but it is often the only way the health visitor counsellor can maximise the numbers of people she sees:

> " I am not meeting the needs of people. I have a large number of West Indians, African, Greeks, Italians, and Asians on my books. I don't speak the different languages. Caring for the thalassaemics is really bad. I don't speak Greek or any of the Asian languages and I don't have a link-worker or anyone with me. I spend so much time trying to get through to people I cannot communicate with that I am failing my own people (the West Indians) because there is not enough time given to them. I think I could teach them in no time because we speak the same language, but it doesn't work that way. I sometimes feel that I am the biggest failure out because I cannot reach (ie communicate with) a lot of people and I'm failing my own" (First sickle cell counsellor, 1987).

At least one sickle cell counsellor resigned from her post in 1986 to return to the West Indies because her support systems were non-existent. She too felt that she was unable to provide the service she knew she could give if it was adequately funded and supported. She left because she believed that she would be able to do a better job elsewhere.

13.2.1 Links with the statutory services

> " The statutory health and personal social services are essential for those who lack other forms of support or whose support is inadequate. Equally important but less recognised, they can help they community to make the fullest use of the whole range of informal and voluntary resources" (DHSS, 1981)

There appeared to be a good relationship between the voluntary organisations and the sickle cell counsellors based in sickle cell centres. Each gave the other whatever support they could within the constraints of their financial and staffing difficulties. This was largely done by meeting each other often, taking part in conferences, study days and so on, and by telephone links as was necessary.

i) Referrals

Referrals between the voluntary organisations and sickle cell counsellors seemed to be automatic. However, voluntary organisations did not get as many referrals from medical and hospital services as they felt they should get:

" There are so many people who eventually find us and say to us that they wished they had heard of us years ago. We advertise whenever we can but with poor funds we cannot really go overboard. So we depend on the doctors and hospitals to let people know that we are here for them to come to if they want" (OSCAR co-founder, 1987)

Sickle cell counsellors felt that their relationships with other health workers were fairly good. Haematologists were generally the most approachable of the doctors they encountered, while general practitioners were generally considered to be the most difficult to communicate with. This meant that sometimes, in some districts, quite serious referral problems could occur:

" It's very hard work to get information out of the hospitals and GPs.. out of the National Health Service. It really is difficult. It's difficult enough if you work within the Service but if you work outside ..." (Fourth sickle cell counsellor, 1987)

and,

" At the moment I rarely see GPs. I need to be able to see them perhaps once a week or once a month so I could say 'hello, how are you? Anyone with sickle cell that you need to refer to me'? But that doesn't happen, not yet. I plan to start visiting their surgeries as soon as I am able to to ask the 'Have you anyone with sickle cell to refer to me'...?" (Fifth sickle cell counsellor, 1987)

In any event referrals, particularly from hospitals, are most likely to be of clients who have had an illness episode. In other words they are more likely to have a sickle cell condition. Carriers for the conditions may be missing out on referrals for genetic counselling and family planning advice even in districts which have sickle cell counselling services.

ii) Social Services

Sickle cell counsellors tended not to see as much of the social worker as they would have liked to:

> " I am not getting much support from them at all. You try to refer somebody and they just sit on it for days or they tell you try the community, or try this or try that. They've never wanted to go and see patients on the ward, so I went to see them a number of times and this seems to be changing now. I am still not satisfied. No I am still not satisfied. There's a lot of room for improvement there. What I would like to see is that patients in hospital are routinely seen by a social worker. Or the social worker would say 'Look I'm here if you need me'. Because sometimes when people are ill, they don't have time to talk about it and they might have a lot of problems that need sorting out..at home or at their work or whatever" (Yet another sickle cell counsellor, 1987)

Voluntary organisations identified another problem with social services liaison:

> " What happens is that we get a lot from social services. They send them to us for financial help of different sorts. We help where we can with heating bills, putting in telephones, buying various appliances and even helping out with funeral costs. But we don't have much money and really it is the social services who should be dealing with those things. We do try and help if they won't, but that's not what our major responsibilities are and I think it's probably racism working against these people. We have to help really. I mean how can you say no when somebody with a family, no job and no money to bury their child or husband or whatever comes to you" (OSCAR spokesperson, 1987)

13.3 Screening

Screening for sickle cell conditions is a priority for both the voluntary organisations and the sickle cell centres:

> " We have been fighting for a national screening policy for newborn infants and it is a particular policy whereby you are not limiting only to sickle or thalassaemia. You are wanting to find other types of abnormal haemoglobins which exist across all ethnic groups, and we have plenty of examples where Caucasians have haemoglobin variants and they have children with a type of haemoglobinopathy, so it

> is cost effective. You are not asking to spend any extra money. It is not seen as anything that is expensive. It has been calculated as costing 15 pence a test and it has been proven that if you do early screening, infant screening and you start people and children with sickle cell on prophylactic medication early enough, the mortality and morbidity rate decreased dramatically. So it is there..the evidence is there. If you are talking about spending money on screening absolutely every child for phenylketonuria, yet the incidence of this really is negligible compared to sickle cell anaemia and you can't incorporate that screening policy (that is, a sickle cell screening policy), I mean .. it's ridiculous" (SCS spokesperson, 1987)

Like the voluntary organisations, sickle cell counsellors argue for universal screening for abnormal haemoglobins because of its relative cheapness and ease.

13.4 The need for recognition and career issues

Both the voluntary organisations and the sickle cell counsellors felt that there was a need for greater recognition of their work. This was seen to be a way of enhancing their chances of attracting more clients, more carers and indeed more funding.

13.4.1 Career Issues

Sickle cell counsellors identified problems in terms of their career structures. They also identified the need for the acknowledgement of their training courses which all sickle cell counsellors have undergone. These were being run by experienced sickle cell counsellors in Brent and Lambeth:

> " I've lost out financially. I now earn less, and in terms of accountability, things are different. Whereas before I was accountable to a health visitor coordinator, now I am accountable to a consultant haematologist and to a locality manager. So I just don't understand..they recognise my

'promotion' as it were in my mileage allowance but not in my salary. I have reached the top of my scale now and will not get any more increments" (A sickle cell counsellor, 1987)

and,

" It could threaten the future of sickle cell counselling in this country. Counsellors have been treated appallingly. Many of us do not have any counselling facilities at all but jolly well should have. I am sad to say that nursing bodies have been very slow to pick this up for us, nurses who are predominantly black, predominantly health visitors" (Another sickle cell counsellor, 1987)

and,

" It needs to be recognised that we are functioning as specialists. We are looking for that to be reflected in terms of our counselling courses being recognised by the DHSS. People are being trained and we need some recognition from the ENB as well. We need that recognition to be reflected in terms of our salary scales..." (A third sickle cell counsellor, 1987)

13.5 Discussion

Voluntary organisations have been recognised as having a major role to play supporting statutory serves. These interviews have shown that there are a good relationships between the voluntary organisations and the sickle cell counsellors. However there are major problems which both of these groups share and which are affecting the efficacy of the service they are trying to provide.

i. Racism

The perceptions of the ethnic majority of sickle cell conditions are probably affected by the now 'historical' position of ethnic health care. During the early 50s and

60s, immigration from black countries accelerated in response to active recruitment drives by the British government to replenish the working class workforce depleted as a result of the war years. The response of the health services was to create the extreme stereotype of the 'coloured immigrant' as someone brought disease into the country, and who once here, created a risk of epidemics because of his origin and living conditions (Deakins, 1970).

Procedures drawn up by Dodge (1969), for 'action to be taken by the Health Department on the arrival of immigrant families', remained largely in use until the 1974 reorganisation of the National Health Service. The result of these procedures appears to be deep rooted racial stereotypes regarding different sections of the minority ethnic population, with West Indians, for whom sickle cell conditions are of concern, being seen as having a 'happy-go-lucky' attitude to life and their health (op.cit.).

Racial discrimination reinforced disadvantages in education, housing and employment, leading to poor housing, low income and hazardous working conditions (Brent Community Health Council, 1981). This in turn has a deleterious effect on health generally (DHSS, 1980) and more specifically on the health of people with sickling conditions.

Despite the passage of time and the contribution made by

members of ethnic minorities to health care in the U.K., many health authorities in areas with significant numbers of minority ethnic residents have not developed adequate strategies for accommodating the needs of these groups (Prashar et al. 1985). This may have resulted from the virtual absence of ethnically sensitive health statistics encouraging beliefs in the rarity of specific medical conditions such as sickle haemoglobinopathies.

ii. Ignorance in the black population

It appears that although a large number of people have heard of sickle cell conditions, there is still a big gap in knowledge about the conditions and their effects. This seems to be a problem even among those people who carry the genes, as this study has shown. The need for information is clearly there as the voluntary organisations will testify judging from the numbers of telephone calls they receive.

iii. Attitudes of health professionals

Despite years of effort by voluntary organisations and sickle cell counsellors, it is evident that there is still much ignorance among health care personnel regarding sickle cell conditions. This may be because this particular type of haemoglobinopathy is described as 'no problem' in many health districts, as it affects ethnic minorities who are small in numbers compared to the ethnic majority. In other words, sickle cell conditions are rare. To the groups affected by them however, they are problematic. The result

of this ignorance combined with institutional and often personal racism may result in some health professionals having a 'bad attitude' towards the care of people with these and other conditions. A Radio London 'phone-in' on minority ethnic health problems showed that many of the calls were concerned with disorders which also affected the majority population, eg. diabetes (Webb, 1979). This indicated that people were even experiencing problems getting attention for complaints which are relatively common.

13.5.1 Funding

A major problem of too little funding and an increasing responsibility of providing a service for the affected population was identified by OSCAR. Having large numbers of volunteer staff who often had jobs and other commitments meant that a comprehensive and cohesive service could not be provided to those who needed it. There was therefore a lack of continuity of care from the point of view of voluntary provision. Volunteers who were unemployed, and who presumably had more time to devote to caring for people with sickling conditions, had their own social supports threatened as social benefits could be cut off for 'those not available for work'. Furthermore, home visits to clients which were seen as an essential part of their work, incurred a level of expense which the organisation was finding difficult to meet. This cost was being passed on to volunteers. In the early days of raising sickle cell awareness in Britain, one of the founders of OSCAR

described how he used his own financial resources in order to give momentum to the movement:

> " The financial burden was on me .. I didn't have my own house and the landlord wouldn't agree to all the people coming to see me .. so I had to have premises .. I did get support from one or two other people, but it was a complete drain on my own salary at the time .."

The Government's reliance on informal carers also has snags for people with sickle cell conditions. Many, if not most, West Indian families can be accurately described as working class. It has been shown that lone parent family groupings are common to families of West Indian origin (Radical Statistics Group, 1986; Haskey, 1991). These heads of family, more often than not women, may have to cope with one or more children with a sickling condition in addition to the problems of bringing up their children. It is highly likely that with all of the other pressures on her time (many hold full time jobs, leaving young children with baby minders, with older ones at school) These women could use the support of voluntary and indeed statutory agencies.

Although the situation may be less severe for two parent families, as these groups have a low earning power combined with high unemployment among black males, many mothers may also be at work all day. These families will also be dependent on available services for the support they need in caring for one or more of its members with a chronic health condition.

13.5.2 Referrals

Both the voluntary organisations wished to see more referrals from medical and hospital services. Moore and Green (1985) have suggested that many professionals felt that they would be compromising client confidentiality and trust if they passed their names on to a voluntary organisation; that non-professionals might do more harm than good, be unreliable and may not be able to sustain their service, and that often they did not have enough information about the service or enough control over its nature to be able to refer clients to the organisation with any confidence.

Professionals do not need to provide lists of names to voluntary organisations. They should inform clients of their existence, however, provide them with appropriate addresses and point out that as they do not have as many details of the service as they would like. It would then be the client's prerogative as to whether they would contact the organisations.

Sickle cell centres are different. They are part of statutory provision and are run by health professionals. These objections should therefore not arise.

13.5.3 Career issues

Health professionals on becoming sickle cell counsellors were seen as working outside of the NHS, though they were

often funded at least in part by health authorities. They were therefore placed outside of the nursing hierarchy for promotion and this has a detrimental effect on their career and salary structures. Their grading effectively stopped and any future pay increases (once they reached the top of their scales) was by way of national annual pay award increases, rather than incremental. This may reinforce the absence of sickle cell counsellors from the dominant population as these posts will not be attractive to them. This will have further implications for the future of sickle cell health care when the present meagre supply of black health visitors and nursing staff runs out.

This chapter was meant to explore the contributions of voluntary and statutory community services for haemoglobinopathies in Britain. Interviews with counsellors, and particularly the counsellor attached to the districts described as having a comprehensive package of care, suggested that at the time of the study, the CPC districts did not have fully comprehensive services. This makes a further contribution to the first hypothesis of this thesis.

13.6 Summary

1. Voluntary organisations for sickle cell conditions have continued to exist, despite the effects of early and possibly on-going racism. This indicates that there is a need for such organisations.

2. Suspicions from within the black community was one of the first obstacles that OSCAR had to overcome.

3. Organisations were (and still are) poorly funded, particularly when compared with organisations set up for people with comparatively more rare ill-health conditions. Funding is insufficient and unstable (that is grants are provided on a short term basis, leading to insecurities regarding the continued existence of jobs and the organisations themselves).

4. Counsellors often had to work in cramped quarters with little or no secretarial or communication backup (that is someone to deal with telephone enquiries and so on. This meant that telephone numbers given for worried members of the 'sickle cell' public were unmanned when the counsellor was not in her office).

5. Despite the limitations imposed by poor working conditions and inadequate and unstable funding, OSCAR and the Sickle Cell Society provide a wide range of services for their clients. These include the promotion of health strategies designed to help people cope with sickle cell, the provision of information about the conditions and how they are transmitted and family planning advice.

6. Other services provided includes referrals to other services, some social assistance in the direst of cases (where statutory social services are unable or

unwilling to assist) and sickle cell screening.

7. Liaison with and educational activities designed for other health care workers is another feature of these organisations.

8. Sickle cell counsellors employed largely by health authorities felt marginalised because they had been removed from the mainstream of health visiting care when they chose to become counsellors. This meant that they had no career structure, with no opportunity for promotion or even advancement along a pay scale.

9. These counsellors tended to have large caseloads, often of a multi-lingual, multi-cultural population.

10. Link-workers and interpreters were not provided.

11. Dissatisfaction with working conditions has lead to at least one trained counsellor resigning to work overseas where her expertise could be more efficiently employed.

CHAPTER 14. The potential for improved health and social services

This chapter looks at the changes which have occurred and are still occurring in the National Health Service, since the bulk of this work was done. It discusses how these changes may have affected health care delivery for people with minority ethnic status, and looks at the contributions the current health care services could make to the care of people with sickle cell conditions.

A. The new National Health Service

The changes in the National Health Service heralded during the 1970s and the 1980s, have continued into the 1990s with a third wave of change (discussed in chapter 3). The first wave (the 1974 reorganisation), established a structure in which it was hoped that managers would provide the appropriate climate for health professionals to deliver positive, efficient and cost effective health care. The second wave of reorganisation came with the Griffiths Report (1983). This Report found that the hoped for general management support was lacking. There was no driving force which sought and accepted direct responsibility for the development and implementation of plans and policies, and for monitoring achievement.

The third wave reforms for NHS restructuring introduced the purchaser/provider split. It also saw the creation of NHS Trusts (which control their own budgets and must compete

for purchaser contracts), and an increase in local autonomy. These trusts have few women, and even less people from minority ethnic backgrounds on Trust boards (Ashburner, 1993). Purchasers, that is, District Health Authorities (DHAs) and GP fundholders (private patients may also purchase services), identify the needs of the population, with the view of improving the health state and lifestyle of that population. The providers, that is, NHS and private sector hospitals, and NHS Trusts, on the other hand, meet those needs which have been purchased.

The NHS is now an internal market, a 'quasi-market' in which customers are represented by agents, but competition is not always among equals (LeGrand, 1990). The internal market reforms became law via the *National Health Service and Community Care Act, 1990*. The impact of these changes, has caused the NHS to become fragmented (Holliday, 1992). It is a business, in which people have become less important than the preservation of business (Thompson, 1993). As a result, employment conditions become less secure for many.

The internal market has also affected the role of management as the business drive predominates. Clinicians, have always had a major influence on the deployment of resources within the NHS. The creation of NHS Trusts has seen them emerge as powerful managers, responsible for a wide range of medical, nursing and supporting resources, purchasers of other services and able to influence policy (Dennis, 1993). However, there have been difficulties

combining managerial responsibilities with maintaining a clinical practise. This has resulted in discontinuity between higher management and service deliverers (Thompson, 1993).

With the introduction of GP fundholding in community care, GPs have entered the wider management arena. Fundholding practices control their own budget, shopping around to buy in health care for its clients. They are the GP equivalent of NHS Trusts. Non-fundholding practices has care bought in on its behalf by a DHA.

However, GPs and clinical managers are being made accountable for the money they spend and whether they are giving 'value for money'. This appears to have the effect of shifting the burden of rationing NHS resources from the Government to the medical profession (Willis, 1993). One effect of purchasers focusing on cost efficiency, would be to shift resources away from the acute setting to the community, as seen in the rationalisation of hospital services in London (Tomlinson, 1992).

The reforms may affect hospital services in one of two ways (Holliday, 1992). First, there could be increased hospital specialisation, for example in high-tech treatment areas, so that they develop a 'competitive edge'. Alternatively, they could become 'low-tech, low-cost hospitals offering cheap, routine treatments' (Holliday, op. cit.). If this does occur, there could be a return to the days when poor people (deserving or otherwise), receive health care in

'workhouses', whereas the rich (deserving or otherwise), have access to the best care available.

Certainly this does not bode well for people from minority ethnic groups, and for people with chronic diseases. In 1988, a National Association of Health Authorities (NAHA) Report argued that there was a lack of planning on the part of health authorities to integrate provision 'for the needs of black and minority ethnic groups' into training, planning and delivery of service. This problem has not been addressed by the new NHS changes. Indeed with the current emphasis on self care, it would seem logical for people with sickling conditions to be educated towards achieving and maintaining the best possible health that they can. This would have the benefit of helping people to help themselves to be fitter, while maintaining their ability to lead as full a life as possible, and with the full knowledge that in case of unforeseen emergencies, a knowledgeable health care team will be able to help them.

However targets for health promotion, published in the *Health of the Nation* in 1992, does not include the specific needs of minority ethnic groups (Ahmed, 1991). The *Health of the Nation's* emphasis on primary care provision, combined with Cumberlege's emphasis on community care, may serve to exacerbate the neglect of clients from minority ethnic groups in the community, (also found in other studies, see Evers, et.al., 1989, Atkin et al, 1988; Black and Laws, 1986; Balajaran, et.al., 1989). This plus an attitude on the part of the individual that the hospital is

best, seen in this study, could have disastrous consequences possibly resulting in loss of life if people wait until they become gravely ill before seeking emergency care at hospitals.

Effective health promotion interventions could drastically reduce hospitalisation and expensive in-patient therapy. Prashar et al (1985) calculate that in 1984, the cost of in-patient therapy for people with sickle cell conditions to Brent Health Authority was approximately £150,000, compared with an approximation of £10,000 spent on out-patient care. However, it should be recognised that while improved care and education may cause a reduction in hospitalisation, some people may require frequent in-patient care. These people should continue to be supported and encouraged in order to minimise the problems of a lowering of self-esteem and confidence.

Keeping clients out of hospital has several benefits as:

a) They are kept in familiar surroundings, thus reducing the stress of having to be in hospital,
b) Complications may come with long periods of being in hospital, for example poor venous access and infection (Rozzell et al., 1983), and
c) Clients come to realise that they have some control over the conditions and the way their lives are affected by them.

Whitehead (1989) suggests that although nurses can achieve

impressive results in promoting health, 'progress is very slow and health education is still seen by some as some kind of optional extra'. the government see health promotion as a low status, low priority activity (Whitehead, 1989). Only a thousandth of the budget given to the National Health Service was allocated to national health promotion bodies, with cash advances from the Department of Health to the Health Education Authority for 1992/93 being £30.9M compared with £29M in 1991/92. Social and environmental influences such as the effects of unemployment and housing, on health have been largely neglected. However, it has been shown that health promotion interventions could empower individuals from minority ethnic groups to make their own decisions about health (Parsons and Day, 1992).

However, the NHS reforms appear to be undermining community-based sickle cell and counselling services (Potrykus, 1993). With the separation of hospitals and community trusts, haematology departments took over the management of haemoglobinopathy counselling in some areas. Some counsellors have lost out on clinical grading (discussed on p.319), and at least one black head of a haemoglobinopathy centre has left because of 'unusual restrictions' placed on her. She has since been replaced by a white director in a service where all of the work is done by care staff from minority ethnic backgrounds (Potrykus, op.cit.). Furthermore, it is feared that money has been diverted from counselling and information provision into medical research (Potrykus, op.cit.).

The Community Care reforms (1990) made Local Authority social services departments responsible for providing community services, a task undertaken in collaboration with medical, nursing and other interests (Davis, 1993). Social services departments also assess individuals' needs, designing care arrangements and ensuring their delivery within the available resources. Although NHS service delivery has not been transferred to Local Authority control, it must be planned jointly with social services.

Primary health care services are the most cost-effective way of improving the health status of populations and caring for those who are ill within limited resources (RCN, 1987). Primary services should help people to make informed decisions regarding health care, promote good health, provide community support which increases the individual's quality of life while offering maximum independence and involve all disciplines and statutory and voluntary agencies (Cumberlege, 1986).

B. Nurse professionals

> " The profession of nursing has a commitment to promote optimal standards of health, combat disease and disability and alleviate suffering. The primary responsibility of nurses is to protect and enhance the wellbeing and dignity of each individual person in their care. Nurses should recognise and accept responsibility for the total effects of nursing care on individuals. This responsibility is in no way affected by the type of origin of the person's need or illness or by his age, sex, mental status, social class, ethnic origins, nationality or personal beliefs" (RCN Code of Conduct).

The traditional socialisation and education of nurses has resulted in nursing 'expertise' being divided up in terms

of class and race. As a consequence, institutionalised racism with nursing care was allowed to flourish, both in terms of service delivery and employment. Black people receive fewer health services and health needs are either not being addressed, or are being addressed in racist ways (Torkington, 1991).

Clinical grading, in 1988, attempted to evaluate the jobs of all nurses. Grading definitions such as 'continuing responsibility', 'without supervision' and 'regularly in charge' became the basis of dispute with management and unions having different interpretations of the phrases (Potrykus, 1992a). The group of carers most affected by down-grading, were the second level nurses. Analysis of appeals against the grading received showed that 70% of those appealing had minority ethnic status. The nature of regrading meant that there was ample opportunity for local managers to treat staff unfavourably on racial grounds (CRE quoted by Potrykus, 1992a).

With regrading came concerns about the mixture of nursing skills available to the community (skills-mix), and a number of reviews were carried out an attempt to match community nursing resources to health care needs. Skill-mix review may be defined as the setting out of a list of activities in a given area, agreeing who is suitable to do these activities, then examining what happens in practise (Carlilse, 1991). However, Cowley argues that this is a definition of 'grade-mix' (Cowley, 1993). She suggests that 'skill-mix' allows a clear and necessary link to be made

between needs, skills and outcomes, three criteria which are essential in determining appropriate staff numbers.

Skill-mix has caused some consternation among community based health carers, as it is seen as being an attempt to cut costs, by encouraging general practitioners and others to employ lower grades of care staff (at less cost), to undertake what are often described as 'basic' nursing tasks (Potrykus, 1992b; Sylvester, 1992; Cowley, 1993; Shaw and Shaw, 1993). In addition, studies appear to indicate that a) general practitioners want G grade nurses, as they have the skills to be effective quickly without bothering the doctor, and b) that there were significant differences in the quality of care given by different grades of staff, higher grades providing better quality (Young, 1993). Once again, skills-mix exercises have been seen to de-skill community carers from minority ethnic groups (Howes, 1992).

Nurse education

Cultural aspects of care have not been a part of medical and nursing education (Mares et al., 1985; Poulton et al., 1986). National centralisation of sickle cell programmes within nursing syllabuses would facilitate the standardisation of educational material in basic training courses. Educational material could be developed and tested by 'sickle cell experts in the field', and based on identified client need. Generalist and specialist nursing and health visiting staff could then be offered in-service training, study days being allocated as part of their

normal nursing routine. Nurses and health visitors who wish to 'specialise' would attend ENB haemoglobinopathy courses. It is important that ENB courses are run in all districts which have an appreciably large ethnic community.

It would seem logical to have in-service training courses on abnormal haemoglobins, for all health care staff. This would make sure that older nurses returning to work after a long break, and other nursing and health visiting personnel are kept informed of the trends in nursing care for these client groups. The school of nursing was seen in this study to be the main source of knowledge of sickle cell conditions for nurses and health visitors. This role needs to extended to reach more health care staff. Existing courses should be improved so that nursing professionals have a clearer idea of all major aspects of caring for someone with a sickling condition. Districts and regions can make sure that the services provided for this group are evident and appropriate.

Schools of nursing could provide a resource for all nursing (including health visiting) groups. Additional input could be provided by in-service training and should include the participation of hospital staff who would receive the study days as part of their normal nursing routine. Nurses may be unable to get time off to attend these training sessions and they miss out on vital information.

Input to the in-service training courses should include elements of transcultural nursing, as it is essential to be

aware of all the unique variables which need to be taken into account in order to provide acceptable and effective nursing care to clients of all ethnic groups (Leininger, 1978). Schools of nursing should therefore plan and stipulate the means by which a multicultural approach to nursing education is to be effected. Byerly (1977) has suggested that the recognition of the importance of cultural aspects of health care, implied from general statements about human nature, rights and quality of life can easily be lost in the process of curriculum development if not specifically emphasised in the philosophy and objectives.

Care should be taken so that ethnocentric viewpoints and attitudes do not make contributions to the curriculum superficial. Models for developing cultural diversity in nursing curriculums are available (Spector, 1977; Roper, 1976) but these will not be discussed here.

Teachers from ethnic minorities involved with the preparation of the curriculum could contribute to discussions helping to create a bank of culturally sensitive concepts and theories to be examined. These could include, for example, beliefs and attitudes towards the 'rites of passage' which every culture has. Under this broad heading would come concepts such as birth, marriage, contraception, health and illness, death, as well as, decision making, diet, religious beliefs, roles, hygiene, privacy, communication patterns and interpersonal and group relationships.

The majority of nurses and all of the health visitors in the sample, had provided health care for people from minority ethnic groups. This suggests that nurses and health visitors are probably the best positioned health workers to provide information and health advice for these clients. However, the relationship between these carers and their clients would be compromised if carers appear unknowledgeable about their health needs and how they could be met.

Some clients may not be fluent English speakers, for example some Africans, Asians, Italians and Greeks, so it is important that interpreters, or carers who are able to communicate easily with them are involved in care provision, and provide optimal care.

Nursing professionals can redress their contribution to inequalities if health care for minority ethnic groups, by re-examining nursing care policies and guidelines. Senior nurse managers have a largely political role to play in the development of nursing care policies for this group.

In caring for any group which may have difficulties in being able to have access to the type and quality of care that is needed, professional nurses have a mediating role, interceding on their client's behalf, when care is either inappropriate or inadequate. This would involve the coordination of health and social services, informing the client of the roles and relationships between various health care providers and clarification of information

given by others (Nelson, 1988). Nurse-managers would therefore have to have a clear commitment to high quality care in order to enable clients to see nurses as being caring supportive individuals who are able to get things done.

A major aspect of the nursing's role would be to assess the efficacy of care regimes, bringing about changes whenever necessary. This may require nurses and their professional and trade union organisations, to bring about changes which could mobilise social, economic and political resources particularly as there is a massive component of self-care in cases of chronic conditions.

Racial discrimination

Historically, white people have been seen to be the 'norm' from which black people differ (Satow and Homans, 1982). Institutional racism is rooted in the belief that people who are not white are in some way culturally disadvantaged, deprived or under-privileged and that as a result they are inferior to white people. These attitudes prevent some health carers from developing positive encounters and relationships with black clients (Hankins-McNary, 1970).

People who are ill do not lose their ability to perceive negative attitudes towards them and this could add to the general discomfort they are already feeling. Moreover, clients could perceive these attitudes as racist, (whether they are or not), and lead to a lack of cooperation on

their parts, with their therapists. Care staff would have to learn to identify any preconceived ideas or attitudes they may have which could present obstacles to client care, and if necessary with the help of training, prove that idea or attitude unfounded.

It may be necessary for some clients to be cared for whenever possible, and in particular in the community by professional carers from the same racial/cultural background. This would require the involvement of more care staff from 'minority ethnic groups' in the planning and delivering health care.

Some carers have argued that they treat everyone the same, taking a colour blind approach when dealing with black clients (Larbie, 1989; King's Fund, 1989). This approach is a prerequisite for disaster as even people who are seen as 'problem-free' and 'desirable' have to be treated as individuals. It is unlikely that a middle-class woman aged 88, who has fallen and broken both legs will be treated in exactly the same way as a middle-class woman aged 22, who has the same injuries through a skiing accident.

Carers would normally be expected to explore various routes in providing for these two women. Therefore, they should not appear to be reluctant to do so for people from other races and cultures. Until we can find other more acceptable words for this perceived reluctance to achieve the same goals of returning clients who are not white to the best possible health, words like 'racism' and 'racial

discrimination' will continue to be used. Until carers show willing regarding these goals, words like these will be the only ones needed.

Baxter (1989) argues that the professional-client relationship is an unequal one with health visitors, for example expecting,

> " to gain access to homes and be familiar with personal details about the client. On the other hand, the client is expected not to be too familiar with the personal life of the health visitor but to show deference in regarding her as an expert" (p70).

It is important therefore that health professionals visiting people in their homes remember that they are often **uninvited, sometimes unwanted guests.** It is up to them to lead the way in making these visits pleasant and helpful to clients, if clients wish them to be there. Without this effort, the carer could quite easily continue to be rejected by clients.

Nurse professionals could use the opportunity offered by a changing health service, to convince clients of their own professionalism, by providing a service which promotes holistic health and increases the individual's self-confidence and self-esteem.

C. Social services people with sickle cell conditions

Psychological, social and environmental variables interact with chronic states such as sickle cell conditions to exacerbate symptoms. Therefore, providing optimal care for

the individual requires that carers from different disciplines are involved. When health is made worse by social conditions, there should be cooperation between health and social service workers. It has been shown that this is not always the case and that health visitors and social services workers do not always have good working relationships, often work in isolation from each other and are not cognisant of each other's roles and training (Corney, 1980). The sickle cell client is therefore dependent on the health visitor to carry out many of the 'social' type tasks that are needed. However, as many black people are not referred to community nursing studies, this must mean that many people could be trying to cope with caring for themselves without adequate knowledge of what help they can receive and where to apply for it.

As with most families, women tend to care for family members who are ill. When that member of the family is chronically ill, women often remain at home to care for them. These women are largely unpaid carers (Doyal, 1985). This study has shown that many were also unemployed. Their need for social work inputs which are sensitive to their needs, is therefore quite clear.

Financial benefits and material resources

Voluntary organisations have been seen to be providing people with sickle cell conditions with many of the benefits they are entitled to, but are unable to get from Social Services. It may be that many people in the sample

were already in receipt of supplementary or unemployment benefit. However, it is not known if those in poorly paid jobs were receiving income support, or indeed whether they were aware of its existence, as the existence of other sources of financial assistance such as family credit and community charge benefits.

The Social Fund also exists to assist people with exceptional expense, such as cold weather payments (adequate heating in the winter being of utmost importance to the sickle cell family; community care grants and funeral payments. People who are likely to have crises may need a telephone link-line so that help can be summoned in an emergency.

Housing is especially important as it should be damp free, draught free and easy to heat. Some sample members lived in homes that were clearly unsuitable and unhealthy places to live in. Rehousing people with sickle cell conditions could be achievable with appropriate certification form the GP. It could also be made available with the recommendation of social workers, when an individual lives in what is clearly unhealthy housing. Other related benefits such as home helps, maternity allowances, invalidity allowances and so on could be provided according to need.

CHAPTER 15 - Summary and Recommendations

15.1 Summary

This thesis makes a contribution to the body of knowledge of research in that it takes a top-down, bottom-up approach to sickle cell care. The research has discussed carers' knowledge and experiences of caring for people with sickle cell conditions, and makes recommendations for improvements in nursing care in both hospital and community settings, as well as for nursing education. The thesis has also focused on clients' knowledge of the conditions, and their perceptions and experiences of life with sickle cell. Health care needs, such as care during crises, information needs and health advice are discussed in some detail. The contributions of specialist sickle cell counsellors, their working conditions and career prospects have also been discussed, as has the role of sickle cell voluntary organisations. Social aspects, such as unemployment and housing have also been covered.

This chapter brings together the summaries of the literature review and evidence discovered in the research.

The literature review showed that sickle cell conditions (a group of haemoglobinopathies), are common, important, medical genetic problems in the minority ethnic community of Britain, especially for people of African and Caribbean backgrounds. Early diagnosis and a healthy lifestyle would contribute to minimising the effects of these conditions.

Screening and health care services specifically for these conditions have been developed in an ad hoc and patchy manner, resulting in few facilities for genetic counselling and primary health care in particular.

Many theorists argue that people experiencing ill-health have a duty to recover quickly so that they are able to continue to function fully for the benefit of society. While this may apply to acute illnesses, it is a less appropriate way of viewing the situation of people with chronic conditions like the haemoglobinopathies. Furthermore, groups of individuals from, for example, different sexes, races and cultures, social classes and so on, have varying perspectives regarding their roles during illness experiences.

Doctors are seen to have a regulatory yet compassionate role in ensuring that ill health does not seriously affect the smooth running of society, and aim to return the sick to good health as quickly as possible. However, fundamental inequalities in health care remain. Low income, unhealthy working environments, unemployment, and housing conditions are variables which contribute to higher mortality and morbidity rates. Black people in Britain are known to have more difficulty finding work - a the pattern of social and economic disadvantage associated with occupational class and reflected in the working of the labour market. Racial prejudice and cultural differences mean that good education and decent housing are not easily made available to them. These considerations regarding the wider social context of

living and working conditions and provision of health care are an important background for understanding the specific situation of minority ethnic status and sickling conditions.

This part of the literature review generated a number of hypotheses for testing in this study. Namely, unemployed people who live in poor housing will have more sickle cell crises, than those who are employed and live in better housing. Cold damp housing can increase the individual's capacity for developing illness.

The NHS has developed without any noticeable appreciation of the needs of a British multi-cultural population. Furthermore, medical and nursing professional development has failed to acknowledge the contributions and needs of these minority ethnic groups. This has led to marginalisation of needs of clients; needs which have also not been addressed in nursing (and medical) education. Carers from minority ethnic groups who could have been able to provide different perspectives of care, are concentrated in low-prestige, low paid work.

Since the NHS was created in 1946, a number of measures have been introduced to promote the equal distribution of resources throughout the country, according to regional need. However, despite state financed health services in Britain, health service problems have persisted. Research has shown that there have been continuing inequalities in the distribution of health services and therefore

inequalities in access have continued.

Nursing has traditionally focused on management, training, professionalism and primary care issues, without considering the interactions between staff and between staff and clients of different cultures. As a result, the needs of minority ethnic groups, both as carers and as clients, have been largely ignored.

Caring, social and welfare services are important to this piece of research, for as we see, these variables have had a major impact on the health and well-being of sample members.

Nurses make up a large portion of the labour workforce of the NHS and are therefore a potential source of power for change. The issue of appropriate and efficient services for those with sickling conditions need to be addressed by those delivering health care.

It is possible that the restructuring of the NHS, and the client-centred approach to nursing care have in recent years, encouraged improvements in care for minority ethnic groups, both in terms of access to care, and in the quality of care provided. Furthermore, districts which have large minority ethnic populations, would have services appropriate to their needs.

This has led directly to the development of hypotheses on knowledge for sickle cell conditions, both for carers and

clients:

- that these districts would provide good screening and counselling services for haemoglobinopathies, provide appropriate information and advice, have protocols for treating emergency and non-emergency cases and refer people to the relevant community care and voluntary services.
- People with sickle cell conditions in CPC districts will have easier access to health care,
- By virtue of their longer period of education, health visitors will have greater knowledge of sickling conditions than hospital based nursing staff,
- Nurses and health visitors who have cared for people with sickle cell conditions will have greater knowledge of these conditions than those who have had no such experience, and
- Nurses and health visitors in CPC districts will have greater knowledge than their counterparts in other health districts as having a CPC package includes in-service training about sickle cell conditions.

The summaries below are from the 'data' chapters.

It appears that services for people with sickle cell genes focus on the health care needs of people who are ill. This finding seems to confirm the study of nurses' and health visitors' knowledge of sickle cell conditions, which showed that hospital nurses were more likely to have cared for someone with a sickle cell condition than were health

visitors.

The age structure of the sample was such that people may not have completed their families.

The small size of the average family observed in this study suggests that black people with sickle cell genes may be limiting their family size. This could be the result of the awareness that they are able to pass the gene on to their children, or simply the effects of personal choice, harsh economic reality or some other unidentified reason.

Asians on haematologists' list did not respond to the invitation to take part in the study. It is possible that they do not believe that sickle cell genes can be 'carried' by them as the conditions are often described collectively as an 'African-Caribbean' disease.

Children of mixed race and even of mixed race parentage are currently being born in Britain. It is therefore necessary for screening to include all babies in districts where there are appreciable minority ethnic populations.

Religious group membership did not pose any major problems for the sample as a whole, though there was a small minority for whom certain medical treatments such as blood transfusion would be unthinkable.

There were differences in age between African school leavers and people educated in Britain and the West Indies.

Less than one quarter of the sample had no formal qualifications.

Nearly half of the sample was unemployed.

It is possible that poor work conditions led to sickness and loss of employment for 13.2% (n=12) of the sample. This needs further investigation, as this information was reported by respondents.

Following the above, it is also possible that some employers are reluctant to employ people who admitted having sickle cell genes.

High rise housing for people with sickle cell conditions made them virtual prisoners when elevators did not work. Furthermore, many people lived in housing which could not be adequately and efficiently heated. This caused sickle cell related illness to occur.

Most people in the sample lived in rented accommodation, and they could not always be rehoused when things became bad.

The sample was largely non-smoking and few admitted to heavy drinking.

Dancing was a favoured activity for 69% (n=63) of the sample, but most of the sample did some other form of exercise to keep fit.

Unemployed people who live in poor housing will have more sickle cell crises. It is also clear that unsuitable working conditions contributed to ill-health.

More than half of the people who took part in the study had some form of sickle cell condition.

Severe symptoms were mainly limited to people who had sickle cell conditions, people with trait describing largely minor symptoms.

People with a sickle cell condition who were old enough to remember do not recall being given much information about the conditions at diagnosis.

Many people who were symptomless at diagnosis were given no information.

Employers were not likely to be told that an individual has trait or one of the sickle cell conditions, as people perceived that this compromised their ability to find work.

This data made contributions to a number of hypotheses. These briefly were:

- That health districts which have large minority ethnic populations have a comprehensive package of care. This hypothesis was not proven. Counselling and information giving did not appear to be a major component of health care. Furthermore, referrals to community care

was ad hoc and patchy. There also appeared to be not established protocols for the care of people in sickle cell crisis.

- People with sickle cell conditions in CPC districts will have ease of access to health care, because of the district's recognised need for the care packages they provide. This hypothesis was proven only in the sense that sample members from CPC districts were more likely to access hospital care than their NCPC counterparts. However, it is debatable whether the quality of care they received was any better than that obtained by NCPC participants.

- People who were diagnosed in childhood will be more aware of the strategies they could use to avoid the types of situations which will increase their susceptibility to becoming ill, for example doing physical education outdoors in the cooler months. This hypothesis held true, as people who were diagnosed longer used a number of strategies to avoid small crises becoming more serious.

- Perceptions of uncaring staff will be accompanied by perceptions of poor health.

Nearly two-thirds of the sample had experienced either a serious or a mild sickle cell crisis at some point in their lives. However, more than half of the sample had never been hospitalised because of their sickle cell.

Crises in the chest, back and abdomen generally led people to seek hospital treatment, whereas crises in the limbs were normally dealt with at home.

More people from the districts with a comprehensive package of care (CPC) were admitted to hospital in the year before interview, than were admitted from the districts without a CPC. This appears to be because more people from the districts with a comprehensive package of care had more severe conditions. Furthermore, people from CPC districts may be using medical services earlier in the crisis, than people from the other districts. It may also be a reflection of district policy which appears to be concerned with the provision of emergency care in hospital rather than that of preventive care in the community. It may also reflect social and genetic differences between people living in the two sets of districts.

People used a range of strategies for coping with impending and early crises. These included resting, keeping warm, increasing their fluid intake and using prescribed and other analgesia.

Cold conditions and tiredness due to over-exertion were implicated as precipitating crises. However, nine out of twenty-six people hospitalised with crises could not identify any causative factor.

On arrival at hospital there were unacceptably long delays before painkilling drugs were prescribed.

People who were hospitalised were more likely than not to have received no information about their illness.

People leaving hospital after crises were generally not seen at home by a health care professional. They were generally ambivalent about how beneficial home visits would be.

People who had been hospitalised with crises spent an average of one month on sick leave. Interruption to employment was a considerable problem.

Data discussed made a contribution to the eight hypothesis, that is,

- perceptions by clients of uncaring attitudes from care staff if present, will be accompanied by perceptions of poor health care as negative attitudes from care givers may lead to negative responses from care recipients. In this study, although clients had negative perceptions of general nursing and medical care, they were generally quite optimistic as a whole, about specialist medical care.

Two-thirds of the sample regularly saw a hospital based doctor, usually the haematologist, for the monitoring of their sickle cell conditions.

A total of fifty-three people spent a total of over a

thousand hours annually waiting to see the doctor.

Other than haematologists, female sample members mainly consulted obstetricians and gynaecologists usually for pregnancy and/or family planning care and advice.

Three out of twenty women who were asked detailed questions about contraceptive use said that they had been offered Depo Provera injections.

Less than one fifth of the sample used general practitioner and/or other community based health services.

Eleven percent of the sample had sickle cell related disabilities.

Nurses found it more difficult than health visitors to find the time to take part in the study.

The gender and racial composition of the sample reflected the social composition of nursing generally.

Almost all health visitors and nurses had cared for people from African-Caribbean backgrounds.

More nurses than health visitors had provided care for people with sickle cell conditions.

Health visitors used a variety of sources to get information about sickle cell conditions. Nurses, on the

other hand, depended almost entirely on schools of nursing for information.

Nurses and health visitors have generally low levels of knowledge of sickle cell conditions.

- Health visitors were more knowledgeable than nurses about the conditions. Their knowledge was focused more on medical considerations than about hands-on care strategies.

Nurses did not know enough to recognise many of the symptoms which are indicative of sickle cell conditions.

Younger nurses and health visitors who had experiencing caring people with sickle cell conditions had more knowledge than older and inexperienced colleagues.

Sample members were aware that sickle cell conditions were a problem for people who were of African and Caribbean descent.

People from districts which had a comprehensive package of care (CPC) used more sources to get information than those in districts which did not have this package (NCPC). Despite this, sample members from both sets of districts felt that they were not well enough informed.

The doctor tended to be the health professional who gave advice and information about the transmission of sickle

cell genes. However, advice was not always specific to gene inheritance and was generally not clear.

Professionals often described sickle cell trait as 'a trace of sickle cell'; this caused some confusion for clients.

People's knowledge of sickle cell conditions was patchy. Self-care items were more likely to be correctly answered, but questions about different aspects of sickle cell conditions were problematic.

- No differences were seen in knowledge overall between CPC and NCPC districts.

- Significant differences in knowledge were seen with educational qualifications, hospitalisation for sickle cell episodes, diagnosis, length of diagnosis and experience of crises.

Significant differences in knowledge were also seen between people who had been given general information about sickle cell conditions and those who received no information. People who were given advice about the transmission of the genes returned better scores that those who did not receive any advice.

Voluntary organisations for sickle cell conditions have continued to exist, despite the effects of early and possibly on-going racism. This indicates that there is a need for such organisations.

Suspicions from within the black community was one of the first obstacles that OSCAR had to overcome.

Organisations were (and still are) poorly funded, particularly when compared with organisations set up for people with comparatively more rare ill-health conditions. Funding is insufficient and unstable (that is grants are provided on a short term basis, leading to insecurities regarding the continued existence of jobs and the organisations themselves).

Counsellors often had to work in cramped quarters with little or no secretarial or communication backup (that is someone to deal with telephone enquiries and so on. This meant that telephone numbers given for worried members of the 'sickle cell' public were unmanned when the counsellor was not in her office).

Despite the limitations imposed by poor working conditions and inadequate and unstable funding, OSCAR and the Sickle Cell Society provide a wide range of services for their clients. These include the promotion of health strategies designed to help people cope with sickle cell, the provision of information about the conditions and how they are transmitted and family planning advice.

Other services provided includes referrals to other services, some social assistance in the direst of cases (where statutory social services are unable or unwilling to assist) and sickle cell screening.

Liaison with and educational activities designed for other health care workers is another feature of these organisations.

Sickle cell counsellors employed largely by health authorities felt marginalised because they had been removed from the mainstream of health visiting care when they chose to become counsellors. This meant that they had no career structure, with no opportunity for promotion or even advancement along a pay scale.

These counsellors tended to have large caseloads, often of a multi-lingual, multi-cultural population.

Link-workers and interpreters were not provided.

Dissatisfaction with working conditions has lead to at least one trained counsellor resigning to work overseas where her expertise could be more efficiently employed.

Conclusion

In order for the NHS to provide equitable care for all ethnic groups, the individual must not be allowed to become lost in the intricacies of big business. The current changes currently being made to the NHS appears to be excluding the needs of minority ethnic group client and carers. Health managers therefore need to recognise that there is a need for health professionals from minority ethnic groups to contribute to health policy, nursing and

medical education and all other departments which impinge on health care provision and service delivery.

Furthermore, sickle cell care remains ad hoc and patchy. This service needs to be evaluated and improved where improvements are needed. This would entail, ensuring that sickle cell counsellors have adequate resources (human and financial) to meet the needs of their client group. It is possible that a lack of support will see a 'skills-drain' of experienced counsellors, out of the country. As the numbers of black youngsters applying to become nurse carers have decreased over the years, this will be a serious loss to the provision of sickle cell care.

Institutional racism causes problems for people from minority ethnic groups and research is needed to investigate its impact on the ways in which this can affect health.

In this research, sample members have described how their lives and health have been affected by the society in which they live. Collective protests and representations to governments by all concerned people could lead to action for equality of opportunities, helping people from all backgrounds to recognise the value of minority ethnic groups, and improving the social conditions under which they live.

Episodes of ill-health were influenced by inequalities in the ease of access to decent housing, employment and other

this area. It seems to be strange that access to employment which will in some, albeit small way, help to decrease the burden on taxpayers and improve the economy, is denied. Access to decent housing, which would improve both physical and mental health status and turn out fitter members for the workforce, is denied. Information on keeping well, is denied. Information on particular reproductive issues, which will allow women to have fulfilment producing the healthy babies they want, who would (taking the most cynical view) become workers for the economy, is also denied. What is not denied is expensive medical therapy which may be seen to be a drain on the communal purse.

Recommendations

In caring for those with sickle cell conditions and other abnormal haemoglobins, health care personnel ought to have a clearly defined health care policy whereby they may optimise client care.

Nursing and health visiting staff are particularly well placed to ensure that many objectives are met, by promoting good health practices appropriate to the needs and accepted by the cultures of the groups concerned. They can also undertake and reinforce general and genetic counselling, and encourage positive coping strategies, in addition to having a strategy for care when crises occur.

The following recommendations are made:

1. All student doctors and nurses should undergo basic training in genetics if they don't already do so. This courses should include teaching on sickle cell conditions.

2. Education for health carers should include cultural components which would allow cross cultural tolerance and relationships to develop smoothly.

3. In-Service training courses dealing with sickle cell conditions should be made available to all care staff, particularly in areas where there are appreciable minority ethnic populations. These courses should also include communication skills.

4. Regions which do not have a policy for providing training, planning and delivery of care which is sensitive to the needs of people from minority ethnic groups should formulate appropriate policies, implement and monitor them to ensure that they are working as they should.

5. Hospitals employing nurses who have had a career break of perhaps three years or more should have refresher courses available if they wish nursing knowledge to be current with the everyday trends. In addition all nurses who have basic qualifications only should be encouraged to attend these refresher courses every three to five years.

Since this work has been completed, the Royal College of Medicine has announced that curricula changes were to be made to medical training. Nursing and health visiting curricula are also being amended in an on-going process.

There is no easily found information on the current state of in-service training. However, a Report from the Standing Medical Advisory Committee on Haemoglobinopathies, released in 1994, has recommendations for the development of appropriate care policies for these conditions. The Royal College of Nursing, recommends that carers returning to nursing should take refresher courses.

6. The care provided by nursing and health visiting staff should be sensitive to the cultural and religious needs of individuals.

7. If programmes of health care are to be effective, client oriented and culturally appropriate, nurses and health visitors should plan, implement, assess, and monitor the care they provide.

8. In order to be effective, health carers ought to have a blueprint for action geared towards improving the services they provide.

9. Specialist clinics and counsellors (including nurses providing hospital care) should play a major part in the management, prevention of critical episodes and promotion of good health for clients with these

conditions.

Although nurses plan, implement, assess and monitor the care they provide, research is needed to assess whether nursing care is sensitive to the needs of individuals from minority ethnic groups. The SMAC Report makes recommendations which could become a blueprint for care. Specialist sickle cell counsellors in some areas appear to be becoming marginalised by the changes in the NHS. This area would benefit from further investigation.

10. Genetic counselling should be provided for both carriers of, and individuals with sickle cell conditions, in order to help them make informed choices about planning and rearing their families.

11. Genetic counselling of adult clients and parents of sick children should at least be initiated at the hospital and reinforced both in the community and when people are preparing to start families.

12. Clients should be encouraged to speak of concerns and to explore their feelings about their diagnosis and proposed treatment regimes.

While it is difficult to know what counselling is available at the hospital, since this study was completed, sickle cell counsellors have more than doubled in number.

13. Information-giving while in hospital should include

details about the current crises; this should include exploring with the client possible reasons why the crisis occurred, and their treatment programmes and any attendant consequences.

14. Clients should also be provided with information which would help them to cope with caring for themselves, or their children, after discharge. This will require that doctors and nurses communicate with each other and with their clients. It is also important that care staff know how much clients have understood the information given to them.

15. Information given to clients about the transmission of genes to their children, and about contraception, should be clear and accurate so that truly informed choices can be made about family planning strategies.

16. General information given to clients, should be clear and concise so that people have a clear understanding of what they are being told.

17. All information given should be reinforced at subsequent consultations, until both doctor and client are satisfied that only new information needs to be imparted.

Further research, possibly with participant observation, is required to investigate the area of information giving.

18. Educational material made available to pregnant women should reflect their needs and should be largely practical. People wish to know what they should be doing to keep themselves well, both in order to prepare for pregnancy and childbirth, and during pregnancy.

19. It is particularly important that women are given clear information on the way the genes are transmitted, preferably before pregnancy occurs.

20. Written and verbal information and educational aids about screening and pre-natal diagnosis would be useful aids when women reach child-bearing age.

21. When women are advised to terminate pregnancies, it is vital that they are fully informed about all other choices that are available to them. Any woman agreeing to termination should be referred to a counsellor for bereavement counselling.

Health promotion in pregnancy for women with sickle cell is a much neglected area. Some local sickle cell centres produce their own educational material, but there is no national drive on this. The Health Education Authority obviously have a role to play here, and recent discussions with the Director has suggested that the Authority has an interest in this area.

22. Well defined objectives for the care of those in the

community should be developed, priority being given to the health information and health promotion needs of people with sickle cell conditions, both in terms of the way individuals are affected and what they can do to help themselves.

23. Visits at the home by health and other carers, should be acceptable to the client. Carers will only break down cultural barriers between them and their clients if they can convince them that they are interested in a working partnership, in which both parties have equality and dignity accorded to them.

24. Specialist nurses should undertake the teaching of positive health strategies and encourage these by the distribution of health promotion material. There should be emphasis on direct participation of the client in health promotion and the use of a problem solving approach to care.

The SMAC Report focuses largely on hospital care. It is possible that it can be used to produce community guidelines. Some health promotional activities are being done by specialist counsellors.

25. Sickle cell conditions should be discussed in more public arenas in a sensitive and wide ranging manner. This and other educational programmes about black people generally can help to dispel some of the racist attitudes many people have to endure from the general

public.

26. In order to keep more 'high-risk' populations informed, sickle cell conditions and their problems should be highlighted by the use of posters, articles, seminars, etc. in places and publications frequently used by them, for example in their churches, gymnasia, newspapers and at other social events.

27. Care staff, nursing and medical, should be able to communicate clearly with clients, either directly or indirectly, (as in cases where interpreters are used), and be able to assess their abilities for self-care and self-reliance.

28. With some organisation, time spent waiting to see the doctor could be spent on information-giving and health promotion. Specialist sickle cell clinics or a room set aside would be useful for educational and self-help activities.

29. If the main reason for visiting out-patients clinics is simply for the monitoring of blood, as the majority of those who had regular appointments seemed to be indicating, sickle cell clinics could easily be accommodated in the community as indeed happens in some districts. Comparatively 'well', unemployed people using this service could be encouraged to take some of responsibilities for bringing a 'self-help' focus to information- and experience-sharing with

others.

30. Doctors should not simply tell clients with sickle cell conditions, who may be living in an environment conducive to good health, not to worry until 'something happens'. While reassurance is necessary, it would also be to the client's benefit to understand how sickle cell conditions could react in various environmental conditions.

Since the completion of this research, there have been a number of conferences, programmes in the world of dance and theatre, and media exposure about the conditions. Attempts have been made to match the ethnic backgrounds of sickle cell counsellors with their clients. However, there are still too many African-Caribbean counsellors with large caseloads of Asian and Mediterranean born people. Several self-help groups are now in existence, a number of these in the districts which took part in this research. These have however, been initiated by clients themselves, rather than health carers.

31. People diagnosed as having sickle cell genes, should be referred to the nearest local sickle cell counsellor if one is available, for counselling. This should be in the form of a fixed appointment, rather than people being given a slip of paper, or literature with an address on it, and expected to make first contact themselves.

32. Health authorities should be aware of he existence of sickle cell voluntary organisations, or at least of the voluntary organisations directory, and make this sort of information available to their staff.

33. People diagnosed as being positive for the sickle cell gene should be given information which allows them the opportunity to contact one of the voluntary organisations if they so wish.

34. Funding for professional community services and for voluntary back-up should be placed high on the agenda of the Minister for Health. Poor service provision now may prove to be uneconomic in the long term.

In some districts, clients are being referred to sickle cell counsellors. However, it is not known to what extent voluntary organisations are being involved, or whether more emphasis has been placed in attracting the attention of carriers to these organisations. Towards the end of the study, a number of splinter sickle cell organisations came into being. This has the effect of depressing the already low sums of money being awarded to sickle cell voluntary organisations, by the government. Within recent months however, these groups have come together to thrash out their differences and work together in a cohesive way.

35. In evaluating the care they provide for minority ethnic groups, nurses are well placed to collect and analyze information which could provide goals for

nursing care plans, and highlight the clients' health care needs generally. Research could also be used to assess the efficacy of the care provided to this group as a whole.

36. There appear to be gaps in the service provision for people with sickle cell conditions in many health districts in Britain. Nursing research findings could be used to improve nursing knowledge of the conditions, thereby facilitating the protection and the promotion of the interests of clients and their families.

37. Nurses at ward and district levels could use research to make contributions to regional and district policy making for the care of people from minority ethnic groups.

38. Research should be undertaken to ascertain how perceived racism from health professionals affect family esteem and family fertility.

As yet, there has been no research commissioned to investigate these areas.

39. The important issue of 'Whose benefit is screening for?' should be considered and discussed with relevant medical and nursing staff as well as with 'at risk' groups, so that planning for comprehensive and effective health strategies may be undertaken.

40. Families who have not been screened for sickle cell conditions could be encouraged to do so by media exposure targeting these groups.

41. Visits to the clinic by affected people could also be used as a means of targeting families who have not yet been tested.

42. More babies are likely to be born in the coming years, with sickle cell trait. These babies may not be noticeably black, and indeed their parents may not be. All babies born in communities with appreciably large minority ethnic populations, should be routinely screened for haemoglobinopathies.

There is a role here for the Health Education Authority.

43. The problems of working environments, continuing education and career structures for sickle cell counsellors should be addressed and rectified if community sickle cell services are to be optimised.

44. An effective preventive programme of health care, will need to involve doctors, nurses, midwives, social workers, teachers, and organisers of voluntary services and their workers.

45. Social services could help to reduce the effects of variables, such as poor housing, unemployment, and financial hardship, which contribute to the occurrence

of crises and ill-health. Telephones can alert medical help early in the onset of serious episodes and can lead to a reduction of time spent in hospital as early treatment reduces the chances of prolonged illness. Helping people to bury their dead when they cannot afford to do so themselves is clearly a community responsibility.

46. People who have received a doctor's note explaining that they have a life threatening condition, should be speedily rehoused. Any delays deemed as being unacceptably long, should be investigated as should any death which occurs while the victim is waiting to be rehoused.

Sickle cell counsellors appear to be becoming more marginalised in some areas. It appears that their status and position has been eroded by clinical grading and skills-mix programmes.

47. Employers should be educated about the conditions and encouraged to ensure that working environments do not contribute to ill-health for people with sickle cell conditions.

48. Workers who are given their cards because they have been made ill by their working conditions should be able to claim for unfair dismissal.

This is an area where health promoters have a role to play.

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APPENDIX 1 - INTERVIEW SCHEDULE

DAPHNE HEALD RESEARCH UNIT

SICKLE CELL CONDITIONS CLIENT BACKGROUND QUESTIONNAIRE

STRICTLY CONFIDENTIAL DATE: / /

TIME STARTED _____

This interview is being done to get an understanding of how you view sickle cell the conditions, which affect many families. The information you share will be used to help to find ways of improving health care for families in which one (or more) member(s) has a sickle cell disorder. What you say is therefore very important and I will leave my tape recorder running so that I do not miss any of this interview. Everything discussed today will be treated in complete confidence, your name will not be included on any documents and the tape will be destroyed when the project is finished. Please ask about any questions that are not clear to you. Thank you.

1. Did you know that sickle cell conditions are common amongst black families?

___(1) No ___(2) Yes **If yes, GO TO b**

a) Have you ever heard of sickle cell conditions?

___(1) No ___(2) Yes **If no, GO TO 2**

b) how did you come to hear of sickle cell conditions?

2. I know that you have had a blood test within the last five years or so,

a) Do you know what the test was for?

___(1) No **GO TO b**

___(2) Yes What was the test for?

b) Do you know what was found?

___(1) No **GO TO 3**

___(1) Sickle cell anaemia
___(2) Sickle cell trait
___(3) SC disorder
___(4) SBeta-thalassaemia
___(5) Other
___(6) Other
___(7) Other
___(8) Don't know

3. Are you currently being treated by a doctor?

___(1) No **If no, or not SCC, GO TO 14**

___(2) Yes Do you mind telling me what you are being treated for?

4. Are you regularly seen by a hospital doctor?

___(1) No **GO TO 9**

___(2) Yes

5. How often?

___(1) Every 2 weeks
___(2) Monthly
___(3) Every three months
___(4) Every 6 months
___(5) Once a year
___(6) Other (what?)

6. When was your last hospital appointment?

a. Did you keep it?

___(1) No Why not?

___(2) Yes

7. If you went straight to the clinic and back again, how long does it take you from leaving home to go to the hospital to returning home (on average)?

___(1) Less than 30 minutes
___(2) 31 mins. to 1 hr.
___(3) More than 1 hr.
___(4) More than 2 hrs
___(5) More than 3 hrs (how long?)

8. Are you always able to keep hospital appointments?

___(1) No Why?

___(2) Yes

9. Are you regularly seen by a GP?

___(1) No **GO TO 14**

___(2) Yes

10. How often?

___(1) Every 2 weeks
___(2) Monthly
___(3) Every three months
___(4) Every 6 months
___(5) Once a year
___(6) Other (what?)

11. When was your last GP appointment?

a. Did you keep it?

___(1) No Why not?

___(2) Yes

12. If you went straight to the GP's and back again, how long does it take you from leaving home to go to the doctor's to returning home (on average)?

___(1) Less than 30 minutes
___(2) 31 mins. to 1 hr.
___(3) More than 1 hr.
___(4) More than 2 hrs
___(5) More than 3 hrs (how long?)

13. Are you always able to keep GP appointments?

___(1) No Why?

___(2) Yes

In the last year, have you used any of these services?

Facility	No. of times	Reason
Health visitor home visit at hospital		
GP home visit at hospital		
Ambulance Physio. Psychologist		
Hospital Dr. in casualty in OPD in ward		
Midwife Obstetrician Gynaecologist		
Others (who) _____ _____		

GO TO 30 IF DIAGNOSIS UNKNOWN

15. What do you do if you need information or help regarding sickle cell?

___(1) Have not needed any **GO TO 17**
___(2) Nothing **WHY?**
___(3) Sickle Cell Society
Which branch?
___(4) OSCAR
Which branch?
___(5) Thalassaemia Society
Which branch?
___(6) Religious leader
___(7) Went to library
___(8) Asked nurse **WHO?**
___(10) Asked doctor **WHO?**
___(11) Asked friends/relatives
___(12) Talked to others **WHO?**
___(13) Have not known what to do
___(14) Other **WHAT?**

16. Did you find out all that you wanted to?

___(1) No Discuss.

___(2) Yes

17. Have you told anyone that you have sickle cell gene(s)?

___(1) No	Why?	___(5) Other relatives
___(2) Yes	Close family	___(6) Other friends
___(3) Yes	Close friends	___(7) Other 1
___(4) Yes	Employers	___(8) Other 2

How did each react?

Close family
Close friends
Employers
Other relatives
Others

18. Tell me about the beginning of your illness:

a) How old were you?
b) What were your symptoms?
c) Who first made the diagnosis of sickle cell?
d) What were you told about sickle cell?
e) How did you feel about the diagnosis?

19. Have you ever had a crisis?

___(1) No — Do you think sickle cell affects your health?

How? **GO TO 23**

___(2) Yes

20. Do you generally know when you are about to have a crisis?

___(1) No **GO TO 22**

___(2) Yes **How do you know?**

21. What is the first thing that you do when you think that you are going to have a crisis?

22. Other than the crisis, do you think that sickle cell affects your health?

How?

IF ADMISSIONS FOR CRISES ALREADY MENTIONED, GO TO 24
IF CRISES, BUT NO ADMISSIONS, GO TO 27

23. Have you ever been admitted to hospital because of sickle cell?

___(1) No **GO TO 28**
___(2) Yes

24. Have you been admitted to hospital in the last 12 months?

___(1) No **GO TO 26**
___(2) Yes

25. Please tell me about your admissions to hospital in the last 12 months, INCLUDING ROUTINE TRANSFUSIONS?

Date of hospitalisation (Month and year) [Most recent first]	Length of Stay	Time off sick	Reason for admission
A			
B			
C			
D			
E			

26. Thinking about your last stay in hospital, how did your illness start?

PROMPTS

a) Was it sudden or did it start slowly?

b) What time of day was it when you became ill?

c) What were your symptoms?

d) What were you doing when the symptoms started?

e) What did you do?

f) What happened when you got to the hospital?

g) Before you left hospital, did anyone discuss your illness with you?

Who?

What were you told?

h) Did anyone, eg. a nurse, come to see you at home after you left hospital?

IF NO, GO TO j

Who?		How often?	
Who?		How often?	
Who?		How often?	
Who?		How often?	

i) Did you feel that you needed any more visits?

Why/why not?

j) Do you think that home visits are/would be helpful?

27. Have you had any crises during the past twelve months when you did not go to the hospital?

___(1) No **GO TO d**
___(2) Yes How many have you had?

PROMPTS a) Tell me about the most recent one you had.

b) What action did you take?

c) Do you ever

i. Phone the community nurse?

___(1) No ___(2) Yes

ii. Phone the hospital nurse?

___(1) No ___(2) Yes

iii. Phone the sickle cell counsellor?

___(1) No ___(2) Yes

iv. Phone the GP?

___(1) No ___(2) Yes

v. Other What?

d) Thinking about your last crisis, would you say that it was:

i) Severe
ii) Moderate
iii) Mild

28. Are you on any tablets from the doctor?

___(1) No **GO TO 29**

___(2) Yes

a) What tablets are you on? (May I see the bottles?)

	Name	Dose	Times daily	Times taken
i)				
ii)				
iii)				
iv)				
v)				
vi)				

b) Do you ever forget to take your tablets?

___(1) No

___(2) Yes When? DISCUSS

29. Are you registered disabled as a result of having sickle cell?

___(1) No

___(2) Yes What is your disablement?

___(3) Tried to Why?

30. Do you smoke?

___(1) No

___(2) Yes How many cigarettes/cigars do you smoke a day?

31. When did you last have an alcoholic drink?

___(1) Drinker How much did you have?

___(2) Non-drinker Is there any special reason why you do not drink? What?

32. If you take part in any of these activities, how energetic would you say you did them?

	Very Energetic	Somewhat Energetic	N/A	Somewhat Sedate	Very Sedate
Dancing What type?					
Sport? What					
Work out What?					
Gardening					
Jobs in the house What?					
Other What?					
Other What?					
Other What?					
Other What?					

33. Are you

___(1) Single ___(4) Divorced

___(2) Married/living together ___(5) Widowed

___(3) Separated

34. Have you any children? How many?

35. Has your family been tested for sickle cell?

___(1) No Is there any reason why they have not been tested?

___(2) Yes

36. Do you know if anyone else in the family has sickle cell?

___(1) No

___(2) Yes

a) Could you tell me about them please?

First Name	Age	Trait/ Condit.	HEALTH STATUS				Days off work last month
			V. Good (1)	Good (2)	Fair (3)	Poor (4)	
A (Self)							
B							Rel.ship
C							
D							
E							
F							

37. Have you received any information/advice about the chances of sickle cell being passed on to your children?

___(1) No

___(2) Yes What? Who gave you this?

___(1) G.P.

___(2) Health Visitor

___(3) Hospital (nurse)

___(4) Hospital doctor

___(5) Sickle Cell Society

___(6) OSCAR

___(7) Counsellor

___(8) Other (who?)

___(9) Don't know

As most of the people I will be talking to may either have young families, or may be preparing to have families, I have included a section which deals with beliefs about issues concerning pregnancy and childbirth.

38. Some of the questions will be for people who have sex. Does this apply to you?

___(1) No

___(2) Yes

IF NO CHILDREN MENTIONED EARLIER,

39. Have you ever been pregnant?

___(1) No

___(2) Yes

PREGNANCY

40. Some people choose whether to have children or not.

a) Did you make a conscious decision (not) to have children?

___(1) No

___(2) Yes If yes, what were your reasons?

CHILD/CHILDREN	CHILDLESS
___(1) No	___(1) No
___(2) Did not choose	___(2) Did not choose
___(3) Sickle cell related	___(3) Sickle cell related
___(4) Other health related	___(4) Other health related
___(5) Non health related	___(5) Non health related
___(6) Other	___(6) Once had child(ren) - (probe)
___(7) Other	___(7) Other
___(8) Don't know	___(8) Don't know
___(9) Not applicable	___(9) Not applicable

b) Have you any concerns about rearing a family? What?

___(1) None	___(5) Other (what?)
___(2) Sickle cell related	___(6) Other (what?)
___(3) Other health related	___(7) Other (what?)
___(4) Cost	___(8) Don't know?)
	___(9) Not applicable

41. What have you been told about pregnancy?

a) Were you given any advice regarding sickle cell and having children **before** your(partner's) last pregnancy?

b) What were you told? Did you find out everything you wanted to?

c) What did you think you needed to know?

d) Were you given any advice regarding sickle cell and having children **during** your (partner's) last pregnancy?

e) What were you told? Did you find out everything you wanted to?

f) What did you think you needed to know?

IF NO CHILDREN, GO TO 43

42. Has anyone ever discussed childbirth with you?

Who?	What did they say?
___(1) GP	
___(2) Health Visitor	
___(3) Hospital (nurse)	
___(4) Hospital doctor	
___(5) Midwife	
___(6) Other (who?)	
___(7) No-one	

CONTRACEPTION

43. What is your opinion on family planning?

a) Do you approve of family planning?

b) Do you see any advantages of family planning? What?

c) Do you see any disadvantages of family planning? What?

44. Have you ever been given any advice about contraception?

___(1) No

___(2) Yes what?

a) Did you find out all you wanted to? If no, why not?

IF NOT SEXUALLY ACTIVE, GO TO 45

b) Do you use contraception?

___(1) No Is there any particular reason why you do not use any form of contraception? What

___(2) Yes

c) What type of contraception do you use?

d) Are you satisfied using this method? Why/why not?

ABORTION

45. Have you ever lost a baby before it's birth?

___(1) No **GO TO m**

___(2) Yes

PROMPTS a) What happened? Did it happen naturally or was it planned?

___(1) Naturally Were you given any information about what happened? What?

___(2) Planned **GO TO c**

b) As far as you know, was this because of sickle cell?

c) Were you given any information before the termination? What?

d) Who gave you this information?

e) Did you find out all that you wanted to know?

IF SICKLE CELL RELATED OR FETAL ABNORMALITY,

f) How many weeks were you /was your partner at the time of diagnosis?

g) How many weeks were you /was your partner at the time of termination?

h) Did a nurse/doctor come to see you/your partner after the termination?

i) Were you/was your partner told anything after the termination? What?

j) Did you find out all you wanted to?

k) Did you discuss losing the baby with anyone? If no, why not?

l) How do you feel about any possible future pregnancies?

m) Do you think that abortion should be easily available?

___(1) No Why not?

___(2) Yes Why?

n) Are there any (other) circumstances when you think abortion is appropriate?

46. When were you born? ___/___/___

47. Were you born in (district)?

___(1) No Where? _____

___(2) Yes

48. If overseas, how long have you lived in this country?

_____months/years

49. To what ethnic group do your parents belong?

MOTHER	FATHER
___(1) African Caribbean	___(1) African Caribbean
___(2) African	___(2) African
___(3) African Asian	___(3) African Asian
___(4) Caribbean Asian	___(4) Caribbean Asian
___(5) Caucasian	___(5) Caucasian
___(6) Other (What?)	___(6) Other (What?)

50. Is there anyone, other than care staff, who you can call on in an emergency? Who?

___(1) Close relative	___(5) Other friend
___(2) Close friend	___(6) Other 1
___(3) Neighbour	___(7) Other 2
___(4) Other relative	___(8) No-one

51. Do you mind telling me if you belong to a religious group?

___(1) No Which?

___(2) Yes **GO TO 52**

___(1) Baptist	___(6) Rastafari
___(2) Methodist	___(7) Hindu
___(3) Church of England	___(8) Roman Catholic
___(4) Jehovah's Witness_	___(9) Other
___(5) Christian Scientist	___(0) None

52. Are you employed now? ___(1) No **GO TO 53**

___(2) Yes

a) If yes, what do you do? _____

b) Do you work ___(1) Full-time ___(2) Part-time

c) Is your work physically demanding?

___(1) No

___(2) Yes DISCUSS

d) Are you happy with your job?

___(1) No Why not?

___(2) Yes

e) Has there been any problem with your taking time off work because of ill-health?

___(1) No

___(2) Yes DISCUSS

53. How old were you when you left school?

a) Do you have any qualifications? What?

___(1) CSE
___(2) GCE
___(3) City and Guilds
___(4) Diploma (what)
___(6) Degree (1st)
___(7) Degree (higher - what?)
___(8) Professional (what?)
___(9) None

54. Do

___(1) Own your home
___(2) Rent from a private landlord
___(3) Rent from the council
___(4) Share accommodation rented by someone else

a) How many rooms do you use exclusively?

b) Does that include

(circle each) IF SHARED, WITH HOW MANY?
bathroom?
toilet?
kitchen?

c) Is the heating adequate in the winter?

d) Are you satisfied with your accommodation? Why/why not?

55. How has your general health been in the last 3 months?

___(1) Very good
___(2) Good
___(3) Fair
___(4) Poor

56. Is there anything else you would like to add regarding yourself or other family members?

___(1) No

___(2) Yes What?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Interview time (minutes) _____

APPENDIX 2 - FDKM1

ROYAL COLLEGE OF NURSING OF THE UNITED KINGDOM

FDKM1 STRICTLY CONFIDENTIAL

DATE / /

This questionnaire is to help us find out what nurses know about genetic disorders. Please try to answer all of the questions. You are not going to be marked individually, so do not worry if you are unsure of the answers. From the questions below, select the option which best completes the answer for each statement by placing a / beside the number. CHOOSE ONE ANSWER ONLY. If you change your mind, you can cross out the tick and mark your new choice. Please fill in the time started/finished at the beginning and end of this questionnaire. Thank you.

Time started :

1. The term sickle cell disease is used to describe

——(1) Sickle B-thalassaemia
——(2) Haemoglobin SC disease
——(3) Sickle cell anaemia
——(4) All sickle cell disorders

2. Sickle cell disease is caused by

——(1) Viral infection
——(2) Familial inheritance
——(3) Malarial parasites
——(4) Bacterial invasion

3. The sickle cell gene is found

——(1) Only in Afro-Caribbean people
——(2) Only in Afro-Asian populations
——(3) In many racial groups
——(4) In no Caucasian groups

4. If someone has sickle cell anaemia, it means that (s)he has

——(1) AS haemoglobin
——(2) SS haemoglobin
——(3) SC haemoglobin
——(4) SF haemoglobin

5. If both parents have sickle cell trait and they have four children

——(1) One child will have sickle cell anaemia
——(2) Two children will have sickle cell anaemia
——(3) Each child has a 25% chance of having sickle cell anaemia
——(4) Each child has a 50% chance of having sickle cell anaemia

6. Sickle cell trait can change to

——(1) Sickle cell anaemia
——(2) Sickle B-thalassaemia
——(3) Haemoglobin SC disease
——(4) None of the above

7. Sickle cell genotypes, ie. SS, SC, AS, SB^{thal} etc. can be identified on blood testing by

——(1) Haemoglobin electrophoresis
——(2) The sickling test
——(3) A solubility test
——(4) A haemoglobin count

8. Common signs and symptoms for sickle cell disease may include

——(1) Severe pain
——(2) Enlarged abdomen
——(3) Blurred vision
——(4) All of the answers above

9. A common occurrence in sickle cell disease is

——(1) Thrombocytic episodes
——(2) Intramuscular haematomas
——(3) Abnormal leucocytes
——(4) Severe pruritus

10. Sickle cell crises are caused by

——(1) Muscular myopathy
——(2) Idiopathic atrophy
——(3) Vascular thrombi
——(4) Cerebral aplasia

11. Sickle cell crises may occur when

——(1) Fluid intake is insufficient
——(2) There is hypoxia
——(3) The body cools rapidly
——(4) Any of the above answers apply

12. During painful crisis, patients at home should preferably have

——(1) No analgesia
——(2) Oral analgesia
——(3) Intravenous analgesia
——(4) Intramuscular analgesia

13. Dactylitis in children with sickle cell disease is caused by

——(1) Genetic malformation of the fingers
——(2) Localised blockage in the fingers and toes
——(3) Pressure of unsuitable shoes on the toes
——(4) constant injury to the fingers and toes

14. Children with sickle cell disease often have

——(1) Splenomegaly
——(2) Acromegaly
——(3) Haematomyelitis
——(4) Syringomyelitis

15. During crisis, the adult patient's fluid intake should be

——(1) Up to 1L of fluid daily
——(2) 1-2L of fluid daily
——(3) 3-5L of fluid daily
——(4) 5+L of fluid daily

16. Priapism in sickle cell disease can be seen in

——(1) All males
——(2) All females
——(3) Only sexually mature/maturing males
——(4) Only sexually mature/maturing females

17. Sickle cell disease

——(1) Has no effect on intelligence
——(2) Is generally found in slow learners
——(3) Is associated with moderate mental impairment
——(4) Produces severe mental retardation

18. Sickle cell complications

——(1) Can occur at any time after the first 3-6 months of life
——(2) Do not occur in the first year of life
——(3) Only occur during puberty
——(4) Only occur during adulthood

19. In sickle cell disease, there is likely to be a reduction in

——(1) Erythrocytes
——(2) Leucocytes
——(3) Haemoglobin
——(4) Neutrophils

20. Immediately after surgery, the patient with sickle cell disease should routinely have

——(1) A blood test
——(2) A bone marrow biopsy
——(3) An intra-arterial transfusion
——(4) An intravenous infusion

21. For patients with sickle cell disease who need blood, exchange transfusions are preferable to a straight transfusion to prevent

——(1) Bilirubin accumulation in the blood
——(2) Iron overload
——(3) Kernicterus
——(4) ABO incompatibility

22. In general, people with sickle cell disease may need dietary supplements of

——(1) Iron
——(2) Folic acid
——(3) Vitamin B12
——(4) Vitamin B6

23. People with cell disease should eat

——(1) A high protein diet
——(2) A low fat diet
——(3) Whatever they like
——(4) A balanced diet

24. Patients at home with a mild cold or fever should

——(1) Have fluids deprived for 8-12 hours
——(2) Keep to their usual fluid intake
——(3) Decrease their fluid intake
——(4) Increase their fluid intake

25. People with sickle cell disease should be advised to

——(1) Avoid all exercise
——(2) Exercise occasionally
——(3) Have regular, moderate exercise
——(4) Have regular, strenuous exercise

26. People with sickle cell disease should be taught to check

——(1) The pulse for missed beats
——(2) The urine for acetone
——(3) The gums for inflammation
——(4) The sclera for jaundice

27. People with sickle cell disease should be taught how to

——(1) Monitor their blood for sickling status
——(2) Check their pulse for bradycardia
——(3) Take their temperature for signs of fever
——(4) Test their urine for hyperglycaemia

28. Parents of young children with sickle cell disease should be taught how to examine their abdomens to detect changes in the size of

——(1) The kidney
——(2) The spleen
——(3) The gall bladder
——(4) The pancreas

29. When someone is diagnosed as having sickle cell disease, (s)he should be advised to

——(1) Have their close friends tested for sickle cell
——(2) Have their family tested for sickle cell
——(3) Tell their employers about the diagnosis
——(4) Tell their family and friends about the diagnosis

30. People with sickle cell disease who are travelling to malarial areas

——(1) Are naturally protected from getting malaria
——(2) Must regularly take anti-malarial agents
——(3) Should have a blood transfusion prior to departure
——(4) Should be advised to cancel the trip

31. The child with cystic fibrosis will

——(1) Grow out of it
——(2) Not grow out of it
——(3) Develop cancer
——(4) Develop asthma

32. Cystic fibrosis is <u>most</u> common in

——(1) Chinese populations
——(2) Asian populations
——(3) White populations
——(4) Black populations

33. Which of the following should alert the nurse/health visitor to the possibility of cystic fibrosis

——(1) Strong, musty-smelling urine
——(2) Hair loss and alopecia
——(3) Bulky offensive stools
——(4) Spasticity of muscle

34. A major effect of cystic fibrosis

——(1) Exocrine glands
——(2) Endocrine glands
——(3) Parathyroid glands
——(4) Suprarenal glands

35. The diagnostic test for cystic fibrosis is

——(1) Glucose tolerance test
——(2) Creatinine clearance test
——(3) Guthrie test
——(4) Sweat test

36. Generally, the diet for someone with cystic fibrosis should be

——(1) Low in fat
——(2) Low in carbohydrate
——(3) Rich in calcium
——(4) Rich in iron

37. Cystic fibrosis patients need physiotherapy to help them to

——(1) Walk without aids
——(2) Improve muscle tone
——(3) Reduce constipation
——(4) Cough up plugs of urine

38. Children with cystic fibrosis should be taught diaphragmatic breathing to

——(1) Allow the airways and muscles to relax
——(2) Determine whether the child is wheezing
——(3) Prevent anxiety and apprehension
——(4) Decrease developing dyspnoea

39. Cystic fibrosis on its own

——(1) Has no effect on intelligence
——(2) Is often found in slow learners
——(3) Is associated with moderate mental impairment
——(4) Produces severe mental retardation

40. A low fat diet helps to minimise

——(1) Nausea
——(2) Anorexia
——(3) Steatorrhoea
——(4) Diarrhoea

41. Techniques which must be taught to parents of children with cystic fibrosis include

——(1) Postural drainage
——(2) Vibration
——(3) Percussion
——(4) 1, 2, and 3 above

42. When a child is diagnosed as having cystic fibrosis, his/her parents should be advised that although the disorder is rare

——(1) They should have no more children
——(2) No other children will be affected
——(3) Each child has a 1 in 4 chance of having CF
——(4) Each child has a 1 in 20 chance of having CF

43. Postural drainage at home in the "well" child should ideally be carried out

——(1) 2-3 times daily for up to 30 minutes each time
——(2) 2-3 times daily for up to 10 minutes each time
——(3) Once daily for up to 30 minutes each time
——(4) Once daily for up to 10 minutes each time

Time finished :

INTERVIEW SCHEDULE

DATE ___/___/___

These questions are simply to help us get a general background of your nursing experience with specific groups. Your replies are strictly confidential.

1. Sex: ___(1) Female ___(2) Male

2. How old are you?

___(1) Up to 30 years old
___(2) 31-35 years old
___(3) 36-40 years old
___(4) 41-45 years old
___(5) 46-50 years old
___(6) Over 50 years old

3. Ethnic group:

___(1) Afro-Caribbean
___(2) African
___(3) African Asian
___ (4) Caribbean Asian
___(5) Asian
___(6) Caucasian (white)
___(7) Chinese
___(8) Other (what?)

4. In what year did you qualify as RGN? Year_____

a) What other nursing qualifications have you got?

_____

5. Have you ever worked as a health professional anywhere other than the British Isles?

——— (1) No ——— (2) Yes

IF NO, GO TO QUESTION 6.

IF YES,

WHERE?	HOW LONG FOR?

6. How long have you worked in this (current) district?

——— (yrs) ——— (mths)

7. Have you nursed/visited anyone from an ethnic minority group? (Select one only please)

___(1) In the last month
___(2) In the last 3 months
___(3) In the last six months
___(4) In the last year
___(5) Over a year ago
___(6) Never

8. Have you, as far as you know, ever nursed/visited anyone diagnosed as having juvenile diabetes?

___(1) In the last month
___(2) In the last 3 months
___(3) In the last six months
___(4) In the last year
___(5) Over a year ago
___(6) Never

9. Before I wrote to you, have you ever had any information on juvenile diabetes?

___(1) No ___(2) Yes

IF NO, GO TO QUESTION 15.

10. Where did you get your information from?

___(1) School of Nursing
___(2) BDA
___(3) Health Education Council
___(4) Other (what?)

11. Have you read anything on juvenile diabetes in the last four weeks?

___(1) No ___(2) Yes

If yes, what?

12. Have you ever contacted any charitable organisations for information about juvenile diabetes?

___(1) No ___(2) Yes

IF NO, GO TO QUESTION 15.

If yes, which?

13. How often do you contact this source of information?

___(1) Very often
___(2) Often
___(3) Sometimes
___(4) Rarely

14. Who do you speak to in these organisations?

___(1) Health Visitor
___(2) Social worker
___(3) Parent of child with juvenile diabetes
___(4) Health Education Officer
___(5) Other (who?) _____
___(6) Don't know

15. Have you, as far as you know, ever nursed/visited anyone diagnosed as having sickle cell?

___(1) In the last month
___(2) In the last 3 months
___(3) In the last six months
___(4) In the last year
___(5) Over a year ago
___(6) Never

16. Before I wrote to you, have you ever had any information on sickle cell?

___(1) No ___(2) Yes

IF NO, GO TO QUESTION 22.

17. Where did you get your information from?

___(1) School of Nursing
___(2) Sickle Cell Society
___(3) OSCAR
___(4) Health Education Council
___(5) Sickle cell clinic
___(6) Other (what?)

18. Have you read anything on sickle cell in the last four weeks?

___(1) No ___(2) Yes

If yes, what?

19. Have you ever contacted any charitable organisations for information about sickle cell?

___(1) No ___(2) Yes

IF NO, GO TO QUESTION 22.

If yes, which?

20. How often do you contact this source of information?

___(1) Very often
___(2) Often
___(3) Sometimes
___(4) Rarely

21. Who do you speak to in these organisations?

___(1) Health Visitor
___(2) Social worker
___(3) Parent of child with sickle cell
___(4) Health Education Officer
___(5) Other (who?) _____
___(6) Don't know

22. Have you, as far as you know, ever nursed/visited anyone diagnosed as having cystic fibrosis?

___(1) In the last month
___(2) In the last 3 months
___(3) In the last six months
___(4) In the last year
___(5) Over a year ago
___(6) Never

23. Before I wrote to you, have you ever had any information on cystic fibrosis?

___(1) No ___(2) Yes

IF NO, END.

24. Where did you get your information from?

___(1) School of Nursing
___(2) Cystic Fibrosis Society
___(3) Health Education Council
___(4) Other (what?)

25. Have you read anything on cystic fibrosis in the last four weeks?

___(1) No ___(2) Yes

If yes, what?

26. Have you ever contacted any charitable organisations for information about cystic fibrosis?

___(1) No ___(2) Yes

IF NO, GO TO END.

If yes, which?

27. How often do you contact this source of information?

___(1) Very often
___(2) Often
___(3) Sometimes
___(4) Rarely

28. Who do you speak to in these organisations?

___(1) Health Visitor
___(2) Social worker
___(3) Parent of child with cystic fibrosis
___(4) Health Education Officer
___(5) Other (who?) _____
___(6) Don't know

THANK YOU VERY MUCH FOR YOUR HELP. I APPRECIATE IT.

APPENDIX 3 - FDKM2

ROYAL COLLEGE OF NURSING OF THE UNITED KINGDOM

FDKM2 S T R I C T L Y CONFIDENTIAL

DATE / /

This questionnaire is to help us find out what people with sickle cell know about the conditions. Please try to answer all of the questions. You are not going to be marked individually, so do not worry if you are unsure of the answers. From the questions below, select one option which best completes the answer for each statement by placing a / beside the number, for example, if you think that people with sickle cell should have a high protein diet, place your tick beside number 1. CHOOSE ONE ANSWER ONLY. If you change your mind, you can cross out the tick and mark your new choice. Thank you.

1. People with cell disease should have

——(1) A high protein diet
——(2) A balanced diet
——(3) A low fat diet
——(4) Whatever they like

2. When at home with a mild cold or fever, it is advisable for someone with sickle cell to have should

——(1) Have fluids deprived for 8-12 hours
——(2) As much fluid as usual
——(3) More fluid than usual
——(4) Less fluid than usual

3. People with sickle cell should be advised to

——(1) Avoid all exercise
——(2) Exercise occasionally
——(3) Have regular, moderate exercise
——(4) Have regular, strenuous exercise

4. If someone has sickle cell medical help becomes necessary

——(1) At the first sign of pain
——(2) As soon as painkillers are taken
——(3) An hour after painkillers are taken
——(4) Only if painkillers have not worked

5. People with sickle cell may need to see the doctor if they have an infection because it

——(1) Will increase the risk of a crisis
——(2) Will lower the body temperature
——(3) Can cause the blood pressure to fall
——(4) Can spread to other family members

6. People with sickle cell may sometimes lose the sense of

——(1) Smell
——(2) Touch
——(3) Taste
——(4) Hearing

7. People with sickle cell conditions need to know how to check their

——(1) Pulse for missed beats
——(2) Urine for sugar
——(3) Mouth for ulcers
——(4) Eyes for jaundice

8. People with sickle cell disease should learn how to

——(1) Test their blood
——(2) Check their pulse
——(3) Take their temperature
——(4) Measure their blood pressure

9. Parents of young children with sickle cell disease should learn how to examine their tummies to detect changes in the size of

——(1) The kidney
——(2) The spleen
——(3) The pancreas
——(4) The gall bladder

10. When someone is told that (s)he has sickle cell, the most important thing to do is

——(1) Have his/her close friends tested for sickle cell
——(2) Have his/her family tested for sickle cell
——(3) Tell his/her employers about the diagnosis
——(4) Tell his/her family and friends about the diagnosis

11. People with sickle cell who are travelling to malarial areas

——(1) Are naturally protected from getting malaria
——(2) Must regularly take anti-malarial agents
——(3) Should have a blood transfusion before they leave
——(4) Should be advised to cancel the trip

12. The combination of smoking and having a sickling condition is not a good one, because the effects of smoking will

——(1) Decrease blood oxygen
——(2) Decrease fluid retention
——(3) Increase internal bleeding
——(4) Increase the blood pressure

13. People with sickle cell genes who have to travel by plane for long periods of time, should not drink alcoholic drinks because they are more likely to become

——(1) Drunk
——(2) Dehydrated
——(3) Bad tempered
——(4) Physically sick

14. Women with sickle cell conditions who are pregnant may need blood transfusions to prevent

——(1) Complications at childbirth
——(2) general discomfort in pregnancy
——(3) Baby from getting sickle cell trait
——(4) Baby from getting sickle cell anaemia

15. Pregnant women with sickle cell conditions are routinely seen throughout pregnancy by their doctor at least every

——(1) 2-3 weeks
——(2) 4-6 weeks
——(3) 8-10 weeks
——(4) 12 weeks or so

16. Women, with sickle cell conditions, of childbearing age

——(1) Can use some contraceptive pills
——(2) Can only use IUDs (eg. the coil)
——(3) Should avoid sex if they don't want a baby
——(4) Should depend on their partners to use the sheath

17. People with sickle cell may be routinely prescribed

——(1) Antihistamines (to prevent allergies)
——(2) Anticoagulants (to prevent blood clotting)
——(3) Anticonvulsants (to prevent convulsions)
——(4) Antibiotics (to prevent infections)

18. If someone with sickle cell has bleeding in the eye, (s)he should remain calm, in order to decrease

——(1) Abrasions in the eye
——(2) Cataracts in the eye
——(3) Pressure in the eye
——(4) Drainage in the eye

19. In terms of giving blood, people with sickle cell trait

——(1) Can become blood donors
——(2) Do not have enough to give
——(3) Will have crises if they give any
——(4) Could spread the gene to those getting the blood

20. People need to know whether they have sickle cell trait, because it has implications for

——(1) Participating in work activities
——(2) Enjoying a full social lifestyle
——(3) Using family planning strategies
——(4) Obtaining house and life insurance

21. It is important for people with sickle cell to avoid

——(1) Spicy foods
——(2) Disco dancing
——(3) Stressful events
——(4) Sporting activities

22. Sickle cell is caused by a form of

——(1) Virus
——(2) Gene
——(3) Germ
——(4) Cancer

23. Sickle cell is found

——(1) Only in Afro-Asian populations
——(2) Only in Afro-Caribbean people
——(3) In many racial groups
——(4) In no white groups

24. If someone has two sickle cell haemoglobins, (s)he has

——(1) SF disorder
——(2) Sickle cell anaemia
——(3) Sickle cell trait
——(4) Sickle beta thalassaemia

25. If both parents have sickle cell trait and they have children, each child has a

——(1) 100% chance of having sickle cell anaemia
——(2) 75% chance of having sickle cell anaemia
——(3) 50% chance of having sickle cell anaemia
——(4) 25% chance of having sickle cell anaemia

26. The term sickle cell disease is used to describe

——(1) Sickle cell beta thalassaemia
——(2) SF disorder
——(3) Sickle cell anaemia
——(4) All sickle cell disorders

27. Sickle cell trait can change to

——(1) SC disorder
——(2) Sickle cell anaemia
——(3) Sickle beta-thalassaemia
——(4) None of the above

28. Sickle cell can be detected

——(1) In the unborn baby
——(2) At birth
——(3) At six months old
——(4) All of the above answers

29. Symptoms for sickle cell include

——(1) Severe pain
——(2) Racing heartbeat
——(3) Feeling like vomiting
——(4) All of the above answers

30. A possible symptom for sickle cell is

——(1) Blurred vision
——(2) Noisy wheezing
——(3) Frequent coughing
——(4) Severe itching

31. Sickle cell crises are caused by

——(1) Low body weight
——(2) High blood sugar
——(3) Blocked blood vessels
——(4) Poor muscular development

32. Sickle cell crises may occur when

——(1) Fluid intake is insufficient
——(2) Oxygen supply is not good
——(3) The body cools rapidly
——(4) Any of the above answers

33. During painful, minor crisis, the **best** action for **people at home** to take is to

——(1) Avoid painkillers bought over the counter
——(2) Take prescribed painkilling tablets
——(3) Go to the hospital for pain treatment
——(4) See the GP for a painkilling injection

34. Swollen fingers and toes in children with sickle cell are caused by

——(1) Being born that way
——(2) Crises in the fingers and toes
——(3) Pressure of tight shoes and gloves
——(4) Constant injury to the fingers and toes

35. It is most important for young children with sickle cell to be

——(1) Immunised against ordinary childhood diseases
——(2) Protected from playing with other children
——(3) Encouraged to take extra iron tablets
——(4) Given more vitamin D

36. During crisis, adults should drink

——(1) Less than 1 litre of fluid daily
——(2) 1-2 litre of fluid daily
——(3) 3-5 litre of fluid daily
——(4) More than 5 litre of fluid daily

37. Sickling in the penis for **several hours** may lead to

——(1) Incontinence
——(2) Infertility
——(3) Impotence
——(4) Infection

38. Sickle cell conditions

——(1) Has no effect on intelligence
——(2) Is generally found in slow learners
——(3) Is associated with moderate mental impairment
——(4) Produces severe mental retardation

39. Sickle cell complications

——(1) Can occur at any time after the first 3-6 months of life
——(2) Do not occur in the first year of life
——(3) Only occur among teenagers
——(4) Only occur during adulthood

40. People with sickle cell often need extra

——(1) Iron
——(2) Folic acid
———(3) Vitamin B12
——(4) Vitamin D

THANK YOU VERY MUCH FOR YOUR HELP. I APPRECIATE IT.

APPENDIX 4 - LETTERS

Dear

AN INVESTIGATION OF SICKLE CELL CONDITIONS

I am writing to ask for your help and co-operation in the above study which is being carried out with the full knowledge and support of the Consultant Haematologist and the District Health Authority. Your own doctor has also been informed.

The main purpose of this study is to find out what people know about sickle cell conditions, the kinds of problems faced by sickle cell sufferers, and the use they make of the NHS and voluntary services. This information will be extremely useful when planning services in the future.

Your name has been randomly selected from the list of people who have seen the haematologist. This does not necessarily imply that you have the sickle cell gene.

I would be grateful if you would agree to an interview which will take approximately 1-2 hours to complete.

I enclose a stamped addressed envelope for your reply and would be grateful if you would let me know as soon as possible, using the enclosed form, whether you are able to participate. If you agree to participate, you will not be identified in any way, and what we discuss will not be revealed to anyone.

On receiving the returned form, my secretary can then arrange interviews at mutually convenient times, at your home. If you have any queries, I will be pleased to answer them. I can be reached on 01-629-0663 (reverse charges). I look forward to hearing from you soon, as I have a sickle cell condition myself, and will be most interested in what you have to say.

Yours sincerely,

M. France-Dawson, MSc, BSc (Hons), RGN, RMN
Research Officer
Daphne Heald Research Unit

PLEASE TICK THE APPROPRIATE BOX AND RETURN THIS FORM IN THE PRE-PAID ENVELOPE SUPPLIED. THANK YOU.

I agree to participate in the study

I do not wish to participate in the study

.....

.....

.....

I understand that all information will be treated as confidential and that my identity will not be revealed. I also understand that I will be free to withdraw my consent and to discontinue my participation at any time.

NAME ..... DATE.....

SIGNATURE .....

TEL. NO. (work) ..... EXT ..... HOME .....

Please give times when it is best for me to phone you

.....
...

.....
...

Dear

AN INVESTIGATION OF SICKLE CELL CONDITIONS

I would like to thank you for taking part in this study. Your participation is greatly appreciated.

At the end of the study, in Spring 1990, I will arrange a seminar with the local hospital, and I will write to inform you of when this will take place.

Best wishes for the future,

Yours sincerely,

M. France-Dawson, MSc, BSc (Hons), RGN, RMN
Research Officer
Daphne Heald Research Unit

APPENDIX 5

Table 4.1 The means and standard deviations using the two versions of the measure.

KNOWLEDGE SCORES

Test version	n	m	S.D.	p
A	23	18.48	3.1	NS
B	23	18.60	3.4	
TOTAL	46	18.54	3.2	

r_p=0.78

Table 4.2 A one-way repeated measure analysis of variance showing differences between subjects across tests, and comparing the two tests.

ANALYSIS OF VARIANCE USING VERSIONS A AND B OF THE MEASURE

SOURCE	SUMS OF SQUARES	df	MEAN SQUARES	F	p
Tests	4.79	1	4.79	3.07	NS
Subjects	888.08	45	19.74	12.65	<0.01
Tests X Subjects	70.21	45	1.56		NS
Within	958.29	90			
TOTAL	963.08				

Table 4.3 Differences in mean knowledge scores of those who had cared for people with sickle cell and those who had not.

KNOWLEDGE SCORES

Experience	n	m	S.D.	t	p
Nursed sickle cell patients	44	19.55	3.0	3.06	< 0.01
No experience of sickle cell	22	16.68	3.0		
Total	66	18.59	3.3		

Table 4.4 Differences in mean knowledge scores of students on education courses and those studying administration.

KNOWLEDGE SCORES

Student Type	n	m	S.D.	t	p
Students of education	29	19.90	2.45	4.82	< 0.01
Students of administration	17	16.24	3.03		
Total	46	18.54	3.20		

Table 4.5 Differences in mean knowledge scores of nursing students in occupational health and those studying administration.

KNOWLEDGE SCORES

Student Type	n	m	S.D.	t	p
Students of occupational health	20	18.70	3.5	2.27	< 0.05
Students of administration	17	16.24	3.03		
Total	37	17.57	3.48		

Table 12.2.6 Knowledge scores of health visitors with experience of sickle cell compared with nurses with similar experience.

	n	m	S.D	t	p	
HV	41	18.53	3.45	1.84	0.07	NS
HN	51	17.65	3.22			

Table 12.2.7 Knowledge scores of nurses and health visitors with and without experience of caring for people with a sickling condition

	H/V				H/N			
	n	m	S.D	p	n	m	S.D	p
no experience	57	16.61	3.5	< 0.002	39	16.38	4.2	NS
experience	41	18.93	3.5		51	17.65	3.2	

Table 12.6 Knowledge scores of people in CPC and NCPC districts with regard to a) sickle cell care items and b) questions about the conditions.

	n	m	S.D	S.E	t	d.f	p
a) Care items							
CPC	49	12.76	4.5	0.6	0.03	89	0.97
NCPC	42	12.79	4.5	0.7			
b) Other items							
CPC	49	8.53	3.7	0.5	0.31	89	0.76
NCPC	42	8.79	4.1	0.6			

Table 12.6a Knowledge scores of people with sickle cell conditions (SCC) and sickle cell trait (SCT) with regard to a) sickle cell care items and b) questions about the conditions.

	n	m	S.D	S.E	t	d.f	p
a) Care items							
SCC	54	14.12	4.0	0.5	3.73	89	0.001
SCT	37	10.78	4.5	0.7			
b) Other items							
SCC	54	9.41	3.8	0.5	2.32	89	0.02
SCTC	37	7.54	3.6	0.6			

Table 12.6.1 Knowledge scores of people diagnosed as having one or more sickle cell genes in districts with and without a comprehensive package of care (CPC).

Districts	n	m	S.D	S.E	t	d.f	p
CPC	49	22.29	7.2	1.03	0.2	89	0.86
NCPC	42	22.57	7.9	1.23			

Table 12.6.2 Knowledge scores of a) older and younger sample members, and b) men and women in the sample.

	n	m	S.D	S.E	t	d.f	p
a) Age							
Below 30 yrs old	63	23.11	6.9	0.88	1.0	89	0.32
30+ years old	28	21.41	8.3	11.6			
b) Sex							
Female	62	22.10	8.1	1.03	0.6	89	0.56
Male	29	23.10	6.1	1.14			

Table 12.6.3 Knowledge scores of people with children compared with those who were childless.

	n	m	S.D	S.E	t	d.f	p
Parents	44	23.48	7.6	1.1	1.3	89	0.20
No children	47	21.43	7.5	1.1			