Thesis by
LAWAL,
MUSEDIQ
OLUFEMI

DOCTOR OF PHILOSOPHY
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CULTURAL CONCEPTION AND MANAGEMENT OF SICKLE CELL ANAEMIA AMONG THE YORÙBÁ IN OSUN STATE, NIGERIA

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CULTURAL CONCEPTION AND MANAGEMENT OF SICKLE CELL ANAEMIA AMONG THE YORÙBÁ IN OSUN STATE, NIGERIA

BY

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CERTIFICATION

I certify that this work was carried out by Musediq Olufemi LAWAL under my supervision, in the Department of Sociology, University of Ibadan.

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DEDICATION

This work is dedicated to Almighty ALLAH for His love and protection and also for endowing me with human and material resources for the completion of this work.

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ABSTRACT

Sickle Cell Anaemia (SCA) is a family of haemoglobin disorders with adverse effects on emotion and social stability of carriers and their families. It has high prevalence rate in Nigeria with over 100,000 babies born with it annually. Studies on SCA have adopted biomedical approach with very few related to its social and cultural perspectives. Against this background, the study examined cultural conception and management of SCA among the Yoruba in Osun State as a way of establishing the level of awareness and knowledge of SCA as well as identifying the pathways to its treatment.

Using Weber's Social Action theory and Health Belief Model as explanatory framework, quantitative data were collected through a household survey carried out in four Local Government Areas (LGAs) of Osun State – Ejigbo, Ife East, Ilesa West, and Ila. Utilising a multistage sampling procedure, a total of 2,016 copies of questionnaires were administered to community members spread across 48 Enumeration Areas (EAs). Eighty in-depth interviews were conducted comprising 39 Sickle cell patients, 20 primary caregivers, and 21 healthcare providers. Ten case studies were equally conducted across patients, caregivers and healthcare providers. Quantitative data were analysed using percentage and Chi-square while qualitative data were content analysed. Four hypotheses focusing on conception and management of SCA were tested at 0.05 level of significance.

There was an overwhelming (99.7%) acknowledgement of the existence of SCA in all the communities with the common lexical index of 'f'oniku f'ola dide' (intermittent crises). The disorder was highly conceived as non-biological in rural areas as against biomedical in urban centres. The pathways and treatment regimen in rural areas included home remedies, divination and faith-based healing with low patronage of western medicine. In the urban centre western medicine combined with faith healing is predominant. Across geographical zones, economic status (15.5%), belief system (23.2%), available medical services (24.7%), interpretation of ill-health (36.9%) and perceived efficacy of previous treatment (56.6%) influenced the management of SCA. Furthermore, definitions given to SCA influenced its management significantly (χ^2=130.4, P<0.05) as rural dwellers with traditional conception often utilize unorthodox facilities. Geographical locations significantly influenced interpretation of SCA (χ^2=47.1, P<0.05) with urban interpretation moving towards biological model as against that of rural. Respondents' sex (χ^2=23.9, P<0.05) has influence on conception of the disorder with males having less drive in the search for the cause of the disorder. Educational status (χ^2=232.9, P<0.05) equally influenced conception as high Western education was positively related to biological conception while income (χ^2=82.5, P<0.05) influenced the choice of healthcare for the management of SCA.

Belief in non-biological cause(s) of Sickle Cell Anaemia will continue to sustain the prevalence of the disorder, particularly in the rural areas. Therefore, interventions such as pre-marital counseling, education on biological causes of Sickle Cell Anaemia and establishment of sickle cell clinics are needed for addressing the prevalence chain.

Keywords: Sickle Cell Anaemia, Cultural conception, Management of sickle cell Anaemia, Caregiver, Osun State

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CHAPTER ONE

1.1 Background Information

Sickle Cell Anaemia (SCA) is a genetic disorder caused by a variant of the β-globin gene called sickle hemoglobin (*Hb S*). This hemoglobin is common in some areas of the Mediterranean basin, including parts of Italy, Greece, Albania and Turkey (Boletini, Svobodova, Divoky, Baysal, Curuk, Dimovski, Adekile and Huisman, 1994; Schiliro, Spena, Giambelluca and Maggio, 1990). Individuals of African, Mediterranean, Caribbean, South and Central American, Arabian, and East Indian descents exhibit high frequencies of genotypes associated with *Hb S* (Kwiatkowski, 2005; Ashley-Koch, Yang, and Olney, 2000; Durosinmi, Odebiyi, Adediran, Akinola, Adegorioye, and Okunade, 1995). More than 50,000 Americans are affected with sickle cell disorder, making it one of the most prevalent genetic disorders in the United States (Kwiatkowski, 2005). Nigeria also has a high number of people living with Sickle Cell Anaemia (Adeniyi, 2006). The disorder cuts across various ethnic groups in the country (Akinyanju, 1989). The SC disorder has a prevalence rate of 2 - 3% carrier state (AS gene) of 25% (WHO. 2006a) and a steady increase of the number of children born annually with Sickle cell (SC) disorder (WHO, 2010). In some individuals, this disorder comes in form of very mild disease, while others have frequent painful episodes (Platt, Thorington, Brambilla, Milner, Rosse, Vichinsky, and Kinney, 1991). Strokes, growth retardation and progressive deterioration of major organs (Falk and Hood, 1982) as well as early death are the manifestations of this disorder (Darbari, Kple-Faget, Kwagyan, Rana, Gordeuk, and Castro, 2006; Platt, Brambilla, Rosse, Milner, Castro, Steinberg, and Mug, 1994 and Charache, Lubin, and Reid, 1991).

Currently, SCA is not curable but can be managed, and information on its management is often limited to activities at clinical settings (WHO 2010; WHO 2006a; Gamaniel 2003). The goals of managing this disorder include the relieving of pain and the prevention and control of complications if they occur (WHO, 2010). Management activities include drug therapy, blood transfusions, and specific treatment for complications (WHO, 2010; Brandow *et al.,* 2009a, Brandow *et al.,* 2009b, Alvarez *et al.,* 2008; Ballas, 2007). Bone marrow transplants (WHO, 2005) and empathetic counselling are also noted as capable of helping affected families and individuals cope with the inconveniences and painful effects of the condition (Akenzua 1990). In view of prevalence of Sickle Cell Anaemia in Osun

State, the interest of this study lies in how the problem is understood, interpreted and defined by the people. Existence of linguistic variation in the State also portends that there can be marked cross-cultural and historical variations in how disorders are defined and coped with; therefore the extent of cultural influence on how the condition is understood has capacity to enrich this discourse given the fact that:

> …..illness behavior is a normative experience governed by cultural rules (because) we learn "approved" ways of being ill. …..how we perceive, experience, and cope with disease is based on our explanations of sickness, explanations specific to the social positions we occupy and systems of meaning we employ. These also influenced our expectations and perceptions of symptoms; the way we attach particular sickness labels to them, and the valuations and responses that flow from those labels. How we communicate about our health problems, the manner in which we present our symptoms, when and to whom we go for care, how long we remain in care, and how we evaluate that care are all products of cultural beliefs (Kleinman, Eisenberg and Good, 2006).

Relating the foregoing to the focus of this study, conception and the management approach available for Sickle Cell Anaemia within a socio-culture can only be understood within the context of how it is defined. Such definitions and representations, according to Baderinwa (2001), are central in setting the target for the management strategies of health situation. Very often, such strategies are selected from a given collection of management procedures, which are based on the person's initial representations about such health matters. In this regard, the current study was geared towards understanding the cultural conception of Sickle Cell Anaemia among the Yorùbá in Osun State, Nigeria.

1.2 Statement of Problem

Sickle Cell Anaemia has continued to attract attention in medical circle largely because of high morbidity and mortality associated with it. Millions of people worldwide are affected by the disorder, especially in Nigeria. Its incidence and prevalence are frighteningly higher in some parts of the world, particularly in sub-Saharan Africa. This is in spite of the progress being made in understanding the disease at molecular and pathophysiologic level. In Nigeria, this medical condition remains a major public health concern. Nigeria is one of the countries that are worst affected by the disease, with prevalence rate of 3% while sickle cell traits occurs in about 23 – 28% of the population in the country. This indicated that many

children are born with, and many die annually of, the disease (WHO, 2010). The disease manifests quite early in children (mostly in their infancy), where it causes the highest rate of mortality. High mortality rate and psycho-sociological consequences of this disorder have devastated Sickle Cell (SC) victims in terms of health outcome. The effects of this also cut across all categories of people irrespective of their social background. Families with people living with sickle cell disorder endure numerous stressful experiences and daily hassles occasioned by the complications of this disorder. These ordeals often lead to financial difficulties, complicate work schedule, and change daily routines. Research also revealed that, mothers of children with SCA are at risk of developing excessive anxiety, depression, guilty feeling, social isolation, and personal health problems (Olley *et al.,* 1997 and Brown *et al.,* 1993).

In spite of the medical and socio-economic importance of Sickle Cell Anaemia, a large proportion of the research has focused on biomedical and clinical aspects only. Studies on behavioural aspects of this disorder at community and individual levels of health service delivery are insufficient. In Nigeria, information regarding the healthcare behaviour of the people living with Sickle Cell Anaemia outside the medical setting is grossly inadequate despite its status as the largest pool of sickle gene in the world. In view of the dearth of empirical research on cultural perspective on Sickle Cell Anaemia, key questions pertaining to information on people's knowledge and conception of SCA, factors influencing its conception, perceived causes (among the people which are major steps in the management) of the disorder, behavioural approach in its management as well as challenges beings experienced in the course of ensuring positive health outcome remained unanswered. In the course of addressing these issues, the following questions were generated:

1.3 Research Questions

1. What are the level of awareness and knowledge of respondents about SCA?
2. What are the pathways to treatment of Sickle Cell Anaemia?
3. What are the preventive measures for Sickle Cell Anaemia?
4. What are the factors influencing the cultural conception and management of Sickle Cell Anaemia?

1.4 General Objective

The study examines the cultural conception of Sickle Cell Anaemia and how this has influenced its diagnosis and management. Specifically, the study:

1. Assess awareness and knowledge of Sickle Cell Anaemia.
2. Explores the pathway to treatment of Sickle Cell Anaemia
3. Identify the preventive measures for Sickle Cell Anaemia
4. Documents the factors influencing the cultural conception and management of Sickle Cell Anaemia.

1.5 Research Hypotheses

Hypotheses generated to help this work include:

1. The geographical location of individuals has no significant relationship with interpretation of Sickle Cell Anaemia
2. Cultural definition and perceived causes of Sickle Cell Anaemia have no significant relationship with efforts toward prevention and treatment of the disorder
3. Socio-demographic characteristics (such as age, sex, educational attainment, marital status, income and religion) have no significant relationship with conception and management of Sickle Cell Anaemia.

1.6 Significance of the Study

The major significance of this study lies in its attempt to contribute to a better understanding of cultural conception of Sickle Cell Anaemia among the Yorùbá. Information on conception and management of sickle cell anaemia among the Yoruba in Osun State, Nigeria has important public health implications because preventive actions can be more effective when the role of culture in the aggravation of incidence of sickle cell disorder is known. This study also seeks to address one of the goals set out by the Federal Government of Nigeria to increase understanding and awareness of the interrelationship between population factors, social and economic development and the environment and their mutual import to the long-term sustainable development of the country (NPC, 2004).

1.7 Operational Definition of Concepts

Cultural Conception of Sickle Cell Anaemia: This means interpretation of Sickle Cell Anaemia from Yorùbá cultural perspectives. This includes individual's representation of ill-health occasioned by Sickle Cell Anaemia, interpersonal, and cultural reactions to disease or discomfort. In this study, cultural conception of Sickle Cell Anaemia is measured by the 'definition' and 'perceived' causes of the disease.

Cultural definition of Sickle Cell Anaemia: This includes all the available concept(s) by which Sickle Cell Anaemia is known among the Yorùbá in the study area.

Perceived causes of Sickle Cell Anaemia: Here, every factor perceived by the respondents as the cause of Sickle Cell Anaemia is given consideration. Not left out of these are issues that are found within Western medical and cultural milieu.

Management of Sickle Cell Anaemia: This will be measured by all forms of care employed at ensuring good health outcomes for the patients. Not left out of these include utilization of available medical facilities (traditional, faith-based and western medical practices) to ensure positive living for the people living with sickle cell anaemia. This will be further measured by 'preventive' strategies adopted by the people.

Preventive Strategies of Sickle Cell Anaemia: This includes every idea known to respondents as requisite measure to check the prevalence of Sickle Cell Anaemia and crisis from this disorder.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.0 Introduction

Globally, people have beliefs and behaviours related to health and illness that stem from cultural forces and individual experiences to perceptions. As a result of positive experiences with alternative healing systems, and shortcomings in the Western medical system, people rely on both. Experience equally shows that health programmes that fail to recognize and work with indigenous beliefs and practices always fail to reach their goals. It is in appreciation of the forgoing that related literature were reviewed through exploration of issues on health, development, disease, and illness vis-à-vis its conventional and cultural perspectives.

2.1 Health and Social Development

Health and development are intimately interconnected. Both insufficient development leading to poverty and inappropriate development resulting in over-consumption, coupled with an expanding world population, can result in severe environmental health problems in both developed and developing countries. According to Kalipeni and Kamlongera (1996), the success of development in every country must be reflected in the health and socio-economic wellbeing of its people. This implies that, as a nation develops the incidence and prevalence of infectious and killer diseases must be eradicated or curtailed, resulting in the decline of both infant and adult mortality rates, morbidity rates, and in the improvement or increase in life expectancy at birth.

The quality of a person's life is determined by the effectiveness of his level of living. Effectiveness of living is a product of a person's functioning in a variety of life's activities that include his physical, mental and social experiences (Udoh 2002). In view of this, health thus becomes a major priority in any society due to the central role it is playing in the developmental process. However, access to health care provision in many societies is often as challenging as the struggle for subsistence (Raheem 2006). Studies have shown a relationship between health and the `quality' of `human capital', which is the principal resource for development. The point here is that poor health reduces people's energy and

creativity; it incapacitates human enterprise thus making good health and effective health care essential conditions for development in all realms of human activity. Where health statistics show unfavourable results (like high maternal and infant morbidity/mortality rates and poor medical and sanitary facilities) are manifestations of failing policies.

Talking from health and economic perspectives at global level, Ruger, Jamison, Bloom and Canning (2006) revealed that the progress in health and other dimensions of development during the 20th century arguably constitutes one of mankind's greatest achievements. Jamison, Lau and Wang (2005) combined their empirical estimates of the effects of adult survival rates on national income with country-specific estimates of improvements in survival rates to generate estimates of the contributions of health to economic growth. In the sample of 53 countries included in their study, their calculations suggest that on the average, 11% of total growth rate in per capita income was due to health improvements, though there were substantial variations across countries.

The relationship between health and development was further reinforced by the World Bank in one of its numerous reports where it states that no country has attained a high level of economic development with a population crippled by high infant and maternal mortality, pervasive illness among its work force, and low life expectancy. In another revelation, Giwa (1999) provides an explicit explanation for the underdeveloped nature of African societies. Here, it is shown that in 1991 life expectancy was 51 years in Africa and 62 years in all low-income countries, while people in industrialized countries had an average life expectancy of 77 years. At the same time, infant mortality in low-income countries was ten times higher than in industrialized countries.

In the course of understanding and determining the performance of the health systems among its 191 members, World Health Organization uses certain indicators as tools for assessment. These include Disability Adjustment Life Expectancy (DALE) and Equity of Child Survival (ECS). In addition to this, the health systems of member countries were assessed in terms of their responsiveness, fairness, overall goal attainment, level of health expenditure per capita, impact on health and overall performance (UNICEF 2001). High levels of morbidity and mortality, the limited or, in many cases, negative progress towards the attainment of the international goals for health and survival, and the inequities in the distribution of health resources are all testimonies to the fact that Nigerian health system has

so far failed to contribute in a meaningful way to the stated national development goals of a just and egalitarian society and the achievement of 'health for all'.

The above is, therefore, a challenge for Nigeria to live up to its image and status within the continent and in the comity of nations. This is because every state has important role to play in the distribution and management of health care, taking into cognizance the fact that, a country's good health statistics provide a powerful legitimization of political governance.

It should be noted that during the past decade, scholars from a wide range of fields have examined the meaning of health as a concept (Jones and Meleis, 1993; Long, 1993; Kulbok and Baldwin, 1992; Newman, 1991; Phillips, 1990; King, 1990 and Pender, 1990). However, only limited research has been conducted on the meaning of health from a layperson's perspective. Aside from this, health problems like Sickle Cell Anaemia, with devastating effects on overall well being of the people, have not been given adequate attention, particularly in terms of providing a broad understanding of such health problems by the people.

The crucial importance of health for human development and empowerment, therefore, underscores the need for interdisciplinary and comparative research into various aspects of health and health care in the context of development. The cultural construction, accessibility, control and management of health-related issues are needed to be studied from cultural, social, political and economic points of view.

2.2 Meaning and concepts of disease, illness and health

Disease can be thought of as the presence of pathology, which can occur with or without subjective feelings of being unwell or social recognition of that state (Mailafia, 2005). Illness, as the subjective state of *unwell,* can occur independently of, or in conjunction with, disease or sickness. This means that, sickness, which is the social classification of someone deemed diseased, can occur independently of the presence or absence of disease or illness. The concept of disease has a biological interpretation and refers to abnormalities in the structure or function of organs and organ systems or pathological states, whether or not they are culturally recognized (Young 1982). To the social scientist, health or ill-health has

several meanings, only one of which is represented by the Western medical approach (Zurayk, Khattab, Younis, El-Mouelhy and Fadle, 1993).

For many people in developing countries where industrialization is still in its infancy, health is a balanced relationship between man and man; man and nature; and man and the supernatural world (Heilman 1994). According to Pelto and Gretel (1990), illness refers to the culturally defined feelings and perceptions of physical and/or mental ailment and disability in the minds of people in specific communities while disease is the formally taught definition of physical and mental pathology from the point of view of the medical profession. Kleinman (1991, 1980) also defines disease as a malfunctioning in, or maladaptation of biological and/or psychological processes. He equally defines illness as, a psychological experience and meaning of perceived disease. In another place, he defines illness as the experience of disease (or perceived disease) and the societal reaction to disease. From this perspective, illness encompasses the reaction or response to and the perception, explanation, evaluation and labelling of the patient, his family, neighbours and so on. In other words, illness can be taken as secondary and social responses to a disease (a primary malfunctioning) in the person's psychological and/or physiological position. From the above explanations there are distinct differences between disease and illness. It was demonstrated that, a disease normally attacks and affects an individual, while illness affects the social group such as family, clan, neighbourhood, and so on.

The concept of disease can be viewed from two broad angles, namely, social and clinical perspectives. Clinically speaking, disease does not occur spontaneously. It is produced by a group of factors and results only when the necessary and sufficient etiologic factors are present (Udoh, 2002). Socially it means inability to perform social role in the society (with reference to adults). Likewise, incidence of diarrhoea among children is seen as normal during children's teething period. Here, certain illnesses are seen as normal, especially when the sufferers are still able to carry out their normal daily activities. Such illnesses, according to Jegede (2002), are usually taken serious only when they interfere with the normal daily activities of the sufferer or that of the immediate caregivers.

People tend to find explanations to their situations from their environment (Ojo, 1966). Thus, every society has different conceptions of what diseases and illnesses are. Ideas regarding the causes and treatment of disease, therefore, evolved over long years of

experience; hence the concepts are seen as socially constructed (Geertz, 1990). In view of this, utilization of Western medical health care services is better understood within the cultural context of the people concerned.

In the words of Jegede (2002), the concept of illness holds different meaning to different age and socio-cultural cohorts. For example, parents may perceive ill health as the absence of specific diseases considered normal for many children. As a result of this, people's definition of what is disease or illness may not apply in medical terms as there are certain conditions identified as disease in medical terms but not in social terms.

Disease and illness are seen as eventualities that are widespread among members of social groups. Occurrence of disease, therefore, becomes an inevitable part of human existence in the natural environment. This is because, as long as man interacts with his environment, he is bound to be infected by one disease or the other. In developing societies where diseases are comparatively numerous, one finds that diseases and their implications are important subjects of concern and discussion (Onu 1999). This is why combating diseases is the major concern of the people rather than their incidence (Oluwabamide 2006).

In Africa as a whole, illness is believed to have a variety of causes, both natural and supernatural (Patel and Cohen 2003; Erinosho1998, Oke 1995 and Okunola, 1994). Among these causes are harmful environmental agents, the enmity of other persons who may use witchcraft or sorcery, and the disfavour of God brought about by offences against Him, or against the spirits of the dead. Health care system, which is the approach and methods of dealing with ill-health or discomfort, and the maintenance of health, are rooted in the culture of the people and therefore a cultural trait. This therefore provides explanation for the scenario where in most discussions of health and its management, the concept of culture features more frequently in the prediction of patterns of health management. Oke (1995), writing on the influence of culture on health services utilization noted that, even some organic diseases have at least indirect cultural origin. He, therefore, concluded by alluding to the fact that human behaviour is a manifestation of his culture. In a similar perspective, Owumi (1996) asserts that the medical system of a given state, community or nation, refers to the available health care facilities in place for the management of the health problems.

Within cultural perspectives, the cause of the illness may affect the attitude of others towards the sufferer in that if s/he did not deserve the illness, the attitude is that of sympathy.

Using mental illness management as point of reference, Patel and Cohen (2003) noted that the traditional healer, like the Western physician or psychiatrist, tries to cure the patient by correcting the causes of his illness. Such cure depends on the type of culture; it may involve not only the administration of therapeutic procedures such as spirit possession and exorcism but also the provision of confession, atonement, appeasement and restoration into the good graces of the family and society.

Using a typical scenario among the Yorùbá of Southwest Nigeria, Jegede (1999) observed that healthiness does not mean biological well-being but holistic conditions of individuals and the society. Thus, *'aisan,'* which is Yoruba word for illness, is viewed as a broader expression for disorderliness, displacement, disorganization, weakness, infirmity and any other health pathological condition that makes a person or society unwholesome.

Making his observation from a moral angle, Turner (2000) asserts that, the concept of illness in pre-modern/traditional societies functioned within a cosmology of good and evil; the sacred and profane. According to him, methods used in explaining illness, such as divination, served important function of allocating blame and responsibility. From the ambit of belief system, certain diseases as well as high incidence of infant mortality, are seen as resulting from the wrath of 'gods', especially when taboos are violated.

Furthermore, the distinction between disease and illness has proved to be a useful heuristic device that enables a contrast to be made between Western medical definition and local, culturally determined definitions of the phenomena. The Western medical paradigm makes a useful distinction between the two concepts in which disease is seen as bodily dysfunction, while illness refers to individual experience of disease. Thus, physicians diagnose and treat diseases while patients suffer illnesses (McDouglas, 2007).

The multiplicity of meanings of health and related issues have been recognized, according to the social scientists, as necessary for achieving an analytic understanding of the process of production of health and a basis for any realistic and comprehensive effort to improve health conditions in the community (Egunjobi, 2008; Zurayk *et al.,* 1993). The idea here is that, cultural conceptions of illness are inextricably connected with socially approved behaviours and moral conducts, which work as stabilizing forces for social conformity in the society amidst preventive and curative mechanisms in health-related issues. It is worth noting here, that these differences in cultural interpretation and conventional Western medical

interpretation of disease and illness often result in mismatch of treatment option which most often brings about negative results. For instance, a mother confessed, in a study by Jegede (2002), that she was self-treating her daughter of malaria before an orthodox doctor's diagnosis revealed that the illness was typhoid. In some cases, the patients or caregivers usually resort to the "appropriate" measures *only* at critical period.

So far, it is shown that there are different perspectives to the meanings of health and illness, but there is very little in the literature on the cultural aspects of chronic health conditions like Sickle Cell Anaemia. Considerable attention should have been given to SCA, especially in society like Nigeria where the condition is endemic. Information available revealed that traumatic experiences of people living with SCA as well as the primary caregivers. Such experiences may force people to succumb to cultural conception of this disorder at the expense of its Western medical model. The implication of this is persistent anguish due to lack of (or delay in applying) appropriate management to control crises situations. Elaborate discussion of cultural perspective of SCA will enhance its full appreciation for appropriate medical intervention.

2.3 Environmental factors in Healthcare Production

In traditional and pre-modern societies, health and illness were inextricably related to notions of religious purity and danger. Here, the concept of illness was directed at the functionality of the soul and not of the body, while primitive notions of taboos and pollution were not matters of hygiene or dietary restrictions but a means of social control (Douglas, 1966). In these societies, breaching a taboo (which dictates acceptable/non acceptable norms) caused illness not because of lack of observing the rules of proper hygiene but a perceived transgression of societal norms and taboos.

At individual level, illness arouses a wide variety of feelings in sick people and in those close to them, while engaging in a search for treatment in times of health crisis (Onu, 1999). The individual's conception of a disease and his/her attitude towards it very often influence the pattern of healing sought. In the course of seeking healing, choices and alternatives are considered within the framework of existing knowledge and past experience on similar illness situation. However, when positive results are not forthcoming, people search for more information on the illness from close friends, relatives and neighbours who

discuss and offer alternative suggestions regarding the possible 'way out'. Studies further revealed that, subsequent failures lead to intensive discussion of choices and a search for expert treatment from specialized parties (Erinosho, 1998; Oke, 1995). This affirms that, illness and therapeutic choices are products of the social and cultural environment.

In many parts of traditional African societies, diseases and illnesses are classified into four broad types according to perceived causes (Jegede, 2010, Patel and Cohen, 2003; Erinosho, 1998, Owumi, 1996, Oke 1995 and Okunola, 1994). Three out of these are: natural, supernatural and mystic or preternatural, as identified by Oke (1995), Erinosho and Oke (1994), Erinosho (1998) and Udoh (2002). The natural causes include bad diet, insect bites, bad odours and others; the supernatural factors incorporate belief in ancestors and cosmic forces, while the mystic or preternatural explanation is attributed to witchcraft, sorcery or invocation of curses. The fourth, according to Jegede (2002), is the hereditary type of illness. This last category though has something in common with supernatural factor but differs in view of the Yoruba's belief about such illness, which is fundamental to their principle and practice particularly since such illnesses are considered incurable for genetic reasons.

Speaking on a similar issue under the concept of multi-factorial aetiology of health problem, Akinsola (1993) identified five models of disease causation. This includes germ theory model, which he noted as playing significant roles in reducing infectious diseases. Others are epidemiological model which was essential for the development of preventive medicine and public health, as well as the cellular concept which was useful in the search for the causes of chronic and degenerative diseases. The mechanistic model contributed to the development of surgery. The fifth model is the cultural model which shows that, diseases have both behavioural and non-behavioural aetiological components focusing on social influences which affect the occurrence and outcome of illness.

On this note, it is obvious that ethnic or cultural factors need to be taken into consideration when caring for SC patients at the clinical level. This will assist healthcare providers in understanding the complaint of their clients as well as removing misconceptions and incorrect inferences about the patients' suffering (Davitz and Davitz, 1981). At the social level where this is already considered, the appropriateness of this expression vis-à-vis cultural milieu for positive health outcome also needs to be taken into consideration. For

instance majority of parents and would-be parents in Nigeria are still not easily convinced of the implication of their lukewarm attitude towards genetic screening for the sake of their future children (Adewuyi and Akintunde, 1990, Akenzua, 1990).

The focus of scholars in this segment of reviewed literature was predominantly on aetiological component of disease and illness. In-depth exposition of cultural perspectives of health and illness is still ignored substantially. Simply tinkering with the system of health care without addressing the fundamental problems within the sector of popular medicine will have marginal effects on the perceived crisis. It should be noted that illness and disease, so defined, do not stand in one-to-one relationship since similar degrees of organ pathology may generate quite different reports of pain and distress. Illness may occur in the absence of disease (50% of visits to the doctor are for complaints without any ascertainable biological base); and the course of a disease is distinct from the course of the accompanying illness. On this note, the incorporation of cultural model in understanding health situation is essential for positive health outcome in every health case being taken to healthcare providers.

2.4 Symptoms Interpretation and Therapeutic Choices

For an individual to seek medical attention, it is obvious that such a person regards his or her symptoms as serious and perhaps worrisome. As such, a decision to seek treatment does not depend simply on the physical nature of the disease and its symptoms (Mechanic, 1972). It is a person's perception of disease which counts most, and this perception is influenced not only by physical symptoms, but also by a number of environmental factors.

The most important influence is the interpretation of symptoms provided by the cultural environment within which a person thinks and acts; that is, the opinions of those he or she normally associates with. The same person might accept different interpretations of a set of symptoms, depending on whether or not they are currently within the community of the educated or the uneducated. Senior kin and trusted elders, who are presumed to know more about health problems from experience, are particularly likely to be influential. It is important to note that, sick people seeking different forms of healing often make their choices with the help of others; and not infrequently, someone other than the sick person is the primary or ultimate decision-maker (Janzen, 1978).

Also, a person is likely to regard a set of symptoms more seriously if they are frequent or persistent, than if they are merely passing. Consequently, the interpretation of a set of symptoms is likely to change if such symptoms persist. If symptoms interfere with or threaten a person's normal activities, they are likely to be regarded more seriously than if they do not. On the other hand, familiarity with a symptom or set of symptoms decreases its perceived seriousness. Quoting from research experience, Bourdillon (1991) observed that, people regarded malaria as less serious than modern medical practitioners do. This is because the disease was common. As a result, they often failed to seek treatment until the disease had assumed a dangerous dimension. Another symptom, which aroused little concern, was the distended belly of a malnourished child. He stressed further that, people who are under some kind of psychological stress are more likely to look for treatment for less serious symptoms than people who are not under such stress. The presentation of physical symptoms, therefore, often expresses an underlying emotional problem, perhaps connected with social tensions. This helps to explain the dominance of illness and healing in cults which cater for the more deprived members of a community, for example, spiritual healing.

As each form of treatment fails, people readily move on to another. Again, it is perceived failure that counts. Sometimes, Western treatment is slow. When the patient and his family see no clear improvement after sometimes, they are likely to seek alternative forms of treatment in a cultural context in which they feel at home. A similar attitude occurs if Western medical science declares the illness terminal or otherwise incurable (Chavunduka, 1978).

To lend credence to this, Bourdillon (1991) observes that treatment of disease cannot be divorced from its interpretation. A person seeking Western medical treatment may be happy to talk about the cause of disease in terms of germs. When one needs to adopt an alternative form of healing, one has also to adopt appropriate concepts of troubling spirits or the appropriate faith in God. To seek treatment from a traditional or faith healer requires total acceptance and immersion into the entire linguistic and cognitive system. This is clear in, for example, the 'revivals' of churches, when healing comes as the climax to an emotionally charged service of preaching and prayer. In the course of this, relief comes from total immersion in the beliefs and rituals presented to the patient. This immersion may be only temporary, for the duration of the service, in order to get relief from a passing worry or

illness. The acceptance of the beliefs and language of the healing can be relatively permanent, supported by a new network of social relations.

As a complement to other sources of healthcare usually utilized during health crisis, substantial attentions have been paid to faith-based healing. However, utilization of this source of healthcare for chronic health condition like Sickle Cell Anaemia has not been given adequate attention. Like other healthcare problems, SCA cases cannot be exceptions in the course of looking for treatment. In the light of this, the procedure involved in the application of faith-based therapy for SCA will assist to appreciate the various activities involved in conception and management of SCA.

2.5 Causes and Evaluation of Disease and Illness

The terms 'disease', 'disorder' and 'medical condition' are often used interchangeably. There is no universal distinction between these terms; though some people do make distinctions in particular contexts. Medical usage sometimes distinguishes a disease, which has a known specific cause or causes (called its etiology), from a syndrome, which is a collection of signs or symptoms that occur together. However, many conditions have been identified, yet they have continued to be referred to as syndromes. Furthermore, numerous conditions of unknown etiology are referred to as diseases in many contexts.

'Illness' (although often used to mean 'disease') is a perceived condition of poor health or poor health felt by an individual (Inhorn and Brown 1990). It can also refer to a person's perception of their health, regardless of whether they in fact have a disease or not. A person without any disease may feel unhealthy and simply have the perception of having a disease. Another person may feel healthy with similar perceptions of perfectly good health. The individual's perception of good health may even persist despite the medical diagnosis of having a disease.

Cultures vary in their definitions of health and illness. Cross-cultural research shows that perceptions of good and bad health along with health threats and problems are culturally constructed. Different ethnic groups and cultures recognize different illnesses' symptoms and causes and so have developed different health care systems with treatment strategies.

A condition that is endemic in a population may be seen as normal and may not be defined as illness in another population. For instance, malaria is seen as normal among some

parents in Africa, because everyone has it or has had it. In Egypt, where schistosomiasis was common and affected the blood vessels around the bladder, blood in the urine was referred to as 'male menstruation' and so seen as normal. Such definitions may also vary by age and by gender. In most cultures, symptoms, such as fever in children, are seen as more serious than its occurrence in adults. Men may deny symptoms more than women in some cultures, while women may do the same in others. Often, adult denial of symptoms of what is due to the need to continue working (Scrimshaw 2006).

Africans recognize that environment is swarming with millions of microorganisms called germs. However, they contend that if germs cause diseases in relation to their population, the whole human race together with the animal and vegetable kingdoms would have been exterminated long before now. Thus, the germ theory fails to account for some diseases (Aja, 1999). Preternatural and mystical forces could also cause diseases as far as Africans are concerned. Here, diseases and ill-health are attributed to the interference of supernatural forces such as witchcraft or the evil machination of enemies.

Cultural beliefs and practices can be identified in four overlapping groups, namely: (1) Beneficial, which can be supported and adapted into health teaching (2) Harmless, with no scientific value and should be at best left alone (3) Uncertain, which means 'difficult to assess' as different interpretations may be possible and therefore needs to be observed and considered further and (4) Harmful, which should be tackled by health education with persuasion and convincing demonstration.

Supernatural forces are other sources of illness especially in Africa and Asia. But it is certainly not confined to these regions; in fact, the 'evil eye' is a widespread concept, in which someone can deliberately or unwittingly trigger illness by merely looking at someone with envy, malice, or too hot a gaze. In cultures where most people have dark eyes, strangers with light eyes are seen as dangerous. In Latin America, for example, a light-eyed person who admires a child can risk bringing evil eye to that child, but can counter it by touching the child. In other cultures, touching the child can be unlucky, so it is important to learn about local customs. Frequently, amulets and other protective devices such as small eyes of glass, red hats, and red string around the wrists, are worn to prevent the evil eye (Scrimshaw 2006).

In traditional medicine, attempt is, therefore, made to determine both physical and metaphysical causes of diseases. Consequently, the traditional healer appeals to scientific

and metaphysical means in an attempt to achieve a comprehensive cure of any malady. He diagnoses ordinary diseases through observations; and through divination by probing into the causes and cure of obscure maladies (Aja, 1999).

In a similar vein, Onu (1999) sees illness as not only a highly personal affair, but also something which arouses a wide variety of feelings in the sick person as well as in people close to him or her. This is evident when they engage in a search for treatment, which becomes an immediate problem. As already indicated, the choices of therapy are determined by several factors. For simple and easy-to-cure ailments, natural causes are imputed. But for complex, serious and prolonged illnesses, natural and non-natural causes are evoked. The idea here is that people draw from their experiences in order to explain circumstances of their illnesses. It thus becomes useful to regard illness as a complex phenomenon; one that derives its definition from the patient himself and those around him or her.

In order to explain the circumstances of our illness, we often draw from our cultural experience. For example, among the Yorùbá people of Nigeria, in spite of the eradication of smallpox, the annual epidemics (such as measles) that cause a high mortality and morbidity among children were often associated with the "god of smallpox" (*Igbona* or *Sonponna* in Yorùbá language). The implication of this is that parents of children suffering from measles would likely combine both Western and traditional remedies for treatment, which may lead to complications (Akinsola, 1993).

The positions reviewed so far in this section are based on Western medical paradigms. At the same time, scholars have failed to explain the factors that accounted for combination of remedies. Does it mean the first choice of healthcare measure was not potent? Efforts need to be intensified to explain or elucidate inherent factors that overwhelmed the patients and their primary caregivers in the course of making judicious usage of healthcare measures, especially for chronic medical condition like SCA. This grey area has major implications for health care policy decisions and the training of practitioners. Successful outcome of this could help both medical trainees and practicing physicians to become more effective healers during their therapeutic encounters with patients.

2.6 Belief system and healthcare utilization

Belief about the universe and its inhabitants vary from society to society. It is an expression of the culture of each society. It is within this belief system that people try to find explanation to phenomena (Bewaji, 1985). Such explanation permeates all facets of life and shapes the beliefs of inhabitants of traditional societies. For instance, the Yorùbá cosmology centres on the belief that, it is the deity who controls the universe in all circumstances of life, all its changing scenes, its joys and sorrows (Odumuyiwa, 1985). It is in appreciation of this that the Yorùbá worship several gods such as *Ogun* (god of iron), *Sango* (god of thunder), *Oya* (goddess of the river), *Osun* (also goddess of the river), *Sonponna* (god of smallpox) and so forth.

The belief about these deities arises from a desire to make meaning out of an apparently meaningless and mystifying environment. This was equally seen in terms of a desire to impose an order on apparent disorderliness in an attempt to comprehend the apparently incomprehensible (Bewaji, 1985). Belief system thus becomes one of the tools adopted by man in maintaining social and moral order. It also reinforces all cultural aspects of man, thereby showing that cultural phenomena cannot be appreciated in isolation of belief system.

Studies on Yorùbá culture revealed that, some basic sacred and secular beliefs run through the traditional health care system and thus provide a strong background to the utilization of Western medical health care services. These beliefs give meaning or explanations to natural phenomena that cannot be easily explained. For instance Jegede (2010) reported that, an epidemic of measles in which children die was believed to have resulted from the wrath of the gods in *Ika* and the violation of taboos in *Ijaw,* while some subjects in both communities attributed it to the powers of witches and sorcery.

Osunwole (1989) asserts the important role of beliefs system in traditional health care management. According to him, beliefs play important roles in traditional health care system because, some steps taken in preparing medicine are sometimes directed towards supernatural beings, particularly with regard to such spiritual aspects as prayers, sacrifices, charms, and incantations.

Belief is reflected in almost every aspect of healing process. For example, in therapeutic management, spirits are acknowledged and homage is paid to the earth when the

numerous deities in Yoruba pantheon are appeased through elaborate rituals. Osunwole (1990) explains that this cultural behaviour gives potency to the medicine and helps the patient to get well again.

Jegede (2010) noted that, in Africa both religion and medicine are interwoven generally thus showing the significance of deities and supernatural powers in the classification, aetiology and management of illness. Decision-making processes on health matters also have their roots in culture. Generally, regardless of the degree of women's involvement in decision making about family matters, the final decision is still subject to the husband's position. Women are constrained from making unilateral decisions concerning their children. They are expected to get the approval of their husbands even when they (women) are highly educated and are financially independent. Since the father is regarded as the head of the family, even if the mother is providing for the family (as in the case of some households), it is expected that the father takes the final decision about the family, including the number of children to have.

To complement the foregoing, appreciable contribution will be added to knowledge when the role being played by system in conception and management of Sickle Cell Anaemia are explored and explained. Establishing a causal relationship between belief system and conception of SCA will go a long way in helping to corroborate findings in existing literature regarding cultural explanation of social phenomenon. In addition to this, such relationship between management of SCA will fill the gap so created by the dearth of literature on SCA within the context of belief system.

2.7 Social and Economic factors in Conception and Management of ill-Health

The utilisation of health services is determined by several factors. The enabling factors in the utilisation of health services may be cultural, social, gender, economic and geographical. Socio-cultural factors determine the way in which illness is perceived and acted upon. Utilisation of health services may be related to age, sex, ethnicity and socio-economic status (Erinosho, 1998). Education and income are among the key socio-economic factors which determine the utilisation of health services. These factors also condition the methods adopted for health care financing, which, therefore, determine the affordability of health services by individuals.

Analyses of the utilisation of modern health care services are usually based on the patronage of health facilities. Although affordability is often stressed, it is usually in terms of the cost of the health package or model introduction. Assessing the utilisation of health care services can also be done through the quantity of health care services that individuals and households are able to consume. This makes the pricing policy for health care delivery an important factor which has been found to affect the financial cost of care. Studies in health economics indicated that cost of health care determines the quantity of treatment that the consumer will obtain. They pointed out that the price of health services affects the quantity of health care often demanded. They found evidence of this in Ghana (Waddington and Enyimayew, 1989), Swaziland (Yoder, 1989), and South Africa (Frankish, 1986), where a negative relationship of price and quantity of care demanded have been observed, particularly when user fees were introduced in the absence of improvement in the quality of care. To demonstrate the effect of this, they assessed affordability through direct questioning of users of care who might have cited financial reasons as deterring utilisation or comment on how affordable they considered the set of prices. But this was difficult to establish whether answers related to affordability or a preference not to pay.

A number of studies found user fees to constitute a barrier to individual's access to health care. For instance, a nationwide survey carried out in rural China revealed that hospital charges constitute a major barrier to in-patient care for those not covered by insurance scheme (Liu 1998). They came to the conclusion that, in spite of the fact that even when average health expenditure was almost 5.0 per cent of household income in 1988, there was evidence of lack of access. Also, Gertler and van der Gaag (1990) in their study in Peru and Berman in Indonesia came to similar conclusions, namely, that payment of user fees had negative impact on the patronage of public health services. Onibokun (2003) pointed out that the introduction of user fees marked a consistent reduction in the pattern of utilisation of Primary Health Care (PHC) in Nigeria.

The costs of health care are said to result in economic impact with decrease in the utilization of facilities leading to poor health status and system. According to Mbugua *et al.* (1995), information on financial burden of health care payment for households, measured as proportion of cash income, which households spend on medical expenses, indicates that medical expenses was a substantial burden even before the rise in fees which increases

household expenditure on health care. The above add up to the ample evidences on the impact of health expenditure on the utilisation of health services. Consumers could sell important assets and/or borrow in order to purchase health care services. Strenski and Baum (1989) pointed out that, many Thai farmers were forced to sell land in order to pay for medical expenses. This is similar to the study in Haiti where high payment for traditional medicine undermined the capacity of households to meet minimum food expenditures. The situation is worst in emergency cases, in which households make payments with the greatest difficulty, substituting for expenditures on food, agricultural development and education (Waddington and Enyimayew, 1989). The impact of expenditures on the rest of the household budget can even be more critical than whether or not payments are actually made (Kanji, 1989). As a result, some even severely ill people may refuse to consult any appropriate health facility because of cost (Mbugua *et al*. 1993).

The effect of financial costs of health care in terms of affordability and the utilization of health services was equally measured through responses to both general and more specific questions, which indicate inability to afford the financial costs of health care or the problems of the financial costs of health care services. Analysis has shown clearly that affordability of health care depends on price structures and on the context of income levels and cash availability. This is because, most consumers use income, cash mobilization, sales of produce and asset as sources of finance for health care. In this vein, Asenso-Okyere and Azator (1997) used information relating to cost of travels to health facilities and treatment including household cash income and expenditures on education and food, using direct and indirect economic costs to measure the costs of health care on both households and the health system. The measure showed that, affordability of health services is a determinant of utilisation and sustainability of health care for individuals.

Affordability of health care services in terms of cost also has impact on the sustainability of health care utilisation among individuals. This is because sustainability involves a situation where a health care system is profitable and individuals can continue to have access to health care (Nabris, 2002). Although sustainability has various dimensions (including financial, institutional, social [Witter *et al*, 2000] and administrative dimensions), the emphasis here relate to the financial dimension of sustainability of health care utilisation among individuals.

At the individual and household levels, Sauerborn *et al,* (1996) identified distinct types of strategies of coping with the economic effects of the financial costs of health care. These include using cash and mobilizing savings, sale of assets, loans, income diversification, wage-labour, free care and gifts. They found sales of livestock as the main strategy of coping with the financial costs of health care. Although, no household was observed to have fallen into calamity, their ability to avert the loss of production and/or assets was very varied and dependent on household size, composition, assets, type, duration of illness and on clustering of crisis (e.g. several repetitive or simultaneous illnesses or concurrent seasonal stress). By implication, the conditions of the physical, social and economic environment of individuals may affect affordability and sustainability of health care utilisation by households.

Most often people limit the pathway towards healthy living to clinical aspect of health management. However, living a productive and relatively healthy life often depends on a series of variables which include such family attributes as social support and socio-cultural and environmental variables. O'Connor (1995) reveals that personal factors such as perceived effectiveness of management style and behavioural factors (which border on ability to have control over crises situations) go a long way in ensuring effective management of crises in ill health. Socio-demographic factors like age, sex, marital status, income and occupational status have also been noted as playing a prominent role in the management of health crises (Layiwola, 2005 and Garro, 2001). These determine a person's place in the social structure, hence their influence on how people manage their ill health.

Wilkinson (1996) takes a different position by examining the issue from an economic angle by drawing examples from the capitalist societies, where he, among other things, noted income inequality in these societies as being associated somehow with societal healthcare. The emergent theme from Wilkinson's research is that being poor affects access to health care and that health problem may be caused or reinforced by unequal spatial distribution of hazards, coping resources and tolerance. Robert and House (2000) also supported this notion through documented research which relates lower levels of income and socioeconomic position to higher rates and risks of mortality and morbidity. The synopsis is that, these socio-economic factors had influenced the quality of the support system available to the sick,

particularly the SC patients and their caregivers who need this support because of the chronic nature of the illness.

Emile Durkehim's landmark study on suicide has also been used as a paradigm of understanding illness in society rather than the individual fact. He suggested that the risk of suicide was elevated among social groups characterized by a weakening or loss of social life guiding interpersonal life. Several studies have been hinged on Durkehim's (1952) insight particularly on how it used the critical role of social anomie to explain health and illness. Other studies have also analyzed social anomie, that is, a person's sense of normlessness, powerlessness and helplessness as a consequence of partial breakdown in communication and resultant adverse effects on mental health (Siergrist, 2000). To save the situation and for effective health outcome, however, people with SCA, like any other members of society, need social support in order to satisfy their needs for quality life.

Here, patients with SCA may have to rely on their kins for social support in view of the poor economic situation in Nigeria. The supports will act as psychological buffer that helps cushion the effect of the stress that is brought on by threat from SCA. Where there is no social support, the SCA victim may suffer social isolation and frustration which Oyebola (2006) saw as posing greater mortality risk than smoking. Isolation is believed to have a deadlier effect on men than on women. This belief is premised on the fact that, women always have more social contacts than men. Where women have few social contacts, it is usually of a higher quality than those of men (O'Connor, 1995). The implication of social contacts, according to various studies, is that members of one's social network can be sources of information to help one avoid stressful or high-risk situations prevalent in Sickle Cell Anaemia. This social interaction, as noted, has a potential of increasing feelings of self-esteem, self-identity and control over one's environment, thus leading to better health outcomes.

Scholars have carried out extensive exploration of factors determining conception and management of health situations. Considerable attentions have been paid to socio-cultural, environmental and economic factors in the aetiology of disease and ill-health. However, most of the diseases and health problems have been discussed under these conditions except chronic health conditions particularly SCA. In view of the serious psychosocial stresses and physical debilitation associated with chronic health conditions, academic discourse will be

better enriched when social, cultural, economic and environmental situations pertaining to them are examined. For instance, at the onset of SC crisis, how is the situation handled? What are the roles of social contacts in the process of interpreting and managing it? What are the treatment options adopted and utilized? Who decides the treatment option(s)? An exploration of financial issues would help such discourse. The roles of these factors as determinants of usually reported multiple pathways in healthcare utilization in developing society are also desirable for meaningful results.

2.8 History of Changing Concepts of Health and Illness

The social concepts of illness and, indeed health have changed over time with the advent of scientific discovery and medical technology from primitive to modern society. Beliefs about health and illness in traditional and pre-modern societies were inextricably related to notions of religious purity and danger. Concepts of illness were directed at the health of the 'soul' and not of the body. Primitive notions of taboos and pollution were not matters of hygiene or dietary restrictions alone but also a means of social control (Douglas, 1966). Breaching a taboo (which dictates acceptable and non-acceptable norms) caused illness not because of a break in hygiene but a perceived transgression of societal norms and taboos.

Illness could thus be regarded as culture-bound. This view is supported by pioneers in cultural dimension (Thomas Lambo of Nigeria and P.M. Yap of Hong Kong). Their studies of non-industrialized societies attributed the incidence of disease to witchcraft, sorcery and mystical forces. This is due to widespread belief in all these sources in those societies. In addition, no uniform notion existed for various disorders among human species as what was considered normal in a society or healthy, was considered abnormal or sick in another society. The concept of 'normality' is determined to a large extent by socio-cultural factors in the sense that behavioural patterns are relative. For example, obesity, which is considered a form of ill-health in European women, is regarded as normal among the Urhobo of Cross-River State in Nigerian. In Cross-Rivers State women are taken through a process of fattening to amass much body fat that would enhance their beauty (Erinosho, 1998). Traditional methods used by traditional healers to treat illness consisted mainly of appeasing the gods, divination, and 'shamanistic' (spiritual) practices, where confession took place to

pacify the individual/group; barks, roots, leaves and animal parts were used; also incantations with the supposed physical or spiritual healing power were employed.

The main concepts of illness in pre-modern/traditional societies functioned within a binary cosmology of good and evil; the sacred profane. Methods used in explaining illness (like divination) served the important function of allocating blame and responsibility (Turner, 2000). It is worth noting that the victim and transgressor need not be the same person as another person or the entire society could suffer as a result of one person's transgression of a taboo or spell.

Ancient Greek civilization played an important role in the development of medical ethics and practice; for example, the Hippocratic Oath. Though the Greek tradition contained a mix of rational, scientific and religious perspectives, Greek medicine represents a general secular orientation to health and illness. Illness was attributed to natural causes. Greek tradition introduced confliction of individualistic and collectivist approach associated with their gods 'Hygeia' and 'Asclepius'. The individualistic approach, which is derived from Asclepius, promoted an interventionist medicine that restored health by directly treating the ailments of the individual using therapies of herbs and plants. However, the collective perspective points to a communal and preventive approach proposing the notion of a healthy and hygienic environment (Turner, 1996).

The rise of rational capitalism in the 17th century precipitated the growth of empirical and rational medicine. This period marked the exclusion of religion and irrational dimensions from philosophy replaced by an empirical philosophy that was probabilistic, mechanical and Newtonian. The 19th century heralded the great triumph of scientific revolution. It also disguised the struggle between individualistic medicine and social medicine. It included great scientific responses to infection through techniques such as vaccination and social science responses to urban population growth in town planning. This classically illustrated the historical conflict between human suffering and illness as effects of environmental pollution and social degradation versus the individual's response to disease entities. The 20th century served as a context of radical change in medicine as the role of professional medicine was established and made indivisible from the concepts of health and illness. In this era, the triumph of individualistic, allopathic, and secular medicine over the

social environment witnessed the introduction of scientific medicine requiring prolonged university training.

Similarly, the growing importance of the general hospital was associated with the rising status of medicine. Also, improvements in health, hygiene, sanitation and nursing resulted in a decrease in morbidity rate. These social changes ushered in the era of medical industrial complex and fostered in a new wave of criticism directed at the negative consequences of medicalization of society (Illich, 1976). This led to the decline in medical dominance associated with an erosion of social security schemes, centralized welfare states and commercialization of the medical provision. Government turned to a mixture of preventive and third sector finance and public health policies to support self-regulation. By the end of the 20th century, the great epoch of infectious diseases came to an end (diseases like tuberculosis, measles, and whooping cough). These scourges had virtually disappeared with improvements in housing, improved water supply, food and education (Mckeown, 1979). It demonstrated the importance of environmental and social causes in the decline of mortality. In conclusion, the historical development of health and illness concepts has been characterized by increasing secularization, rise of scientific theories of health, a separation of mental and physical illness and an erosion of traditional practices.

2.9 Sickle Cell Anaemia: History, Causes and Inheritance Pattern

Sickle-cell disorder (SS) is a group of genetic disorders caused by sickle hemoglobin (Hgb S or Hb S). In many forms of the disorder, the red blood cells change shape upon deoxygenation because of polymerization of the abnormal sickle hemoglobin; the hemoglobin proteins stick to each other, causing the cell to get a rigid surface and sickle shape. This process damages the red blood cell membrane, and can cause the cells to get stuck in blood vessels. This deprives the downstream tissues of oxygen and causes ischemia and infarction, which may lead to organ damage, resulting in a debilitating condition such as stroke. The disorder is chronic and lifelong. Individuals often show signs of being well, but their lives are punctuated by periodic bouts of painful attacks. Life-expectancy is shortened, but contemporary survival data is lacking. Older studies indicated that people living with Sickle Cell Anaemia could live to an average of 40 to 50 years, with the average age for males being 42 and the average age for females being 48. Sickle Cell disorder occurs more

commonly in people (or their descendants) from parts of sub-Saharan Africa, where malaria is common, but it also occurs in people of other races. As a result, those with one or two alleles of the sickle cell disorder are resistant to malaria since the red blood cells are not conducive to the parasites. The mutated allele has incomplete dominance, which means that an individual who does not have the disorder still retains immunity to malaria.

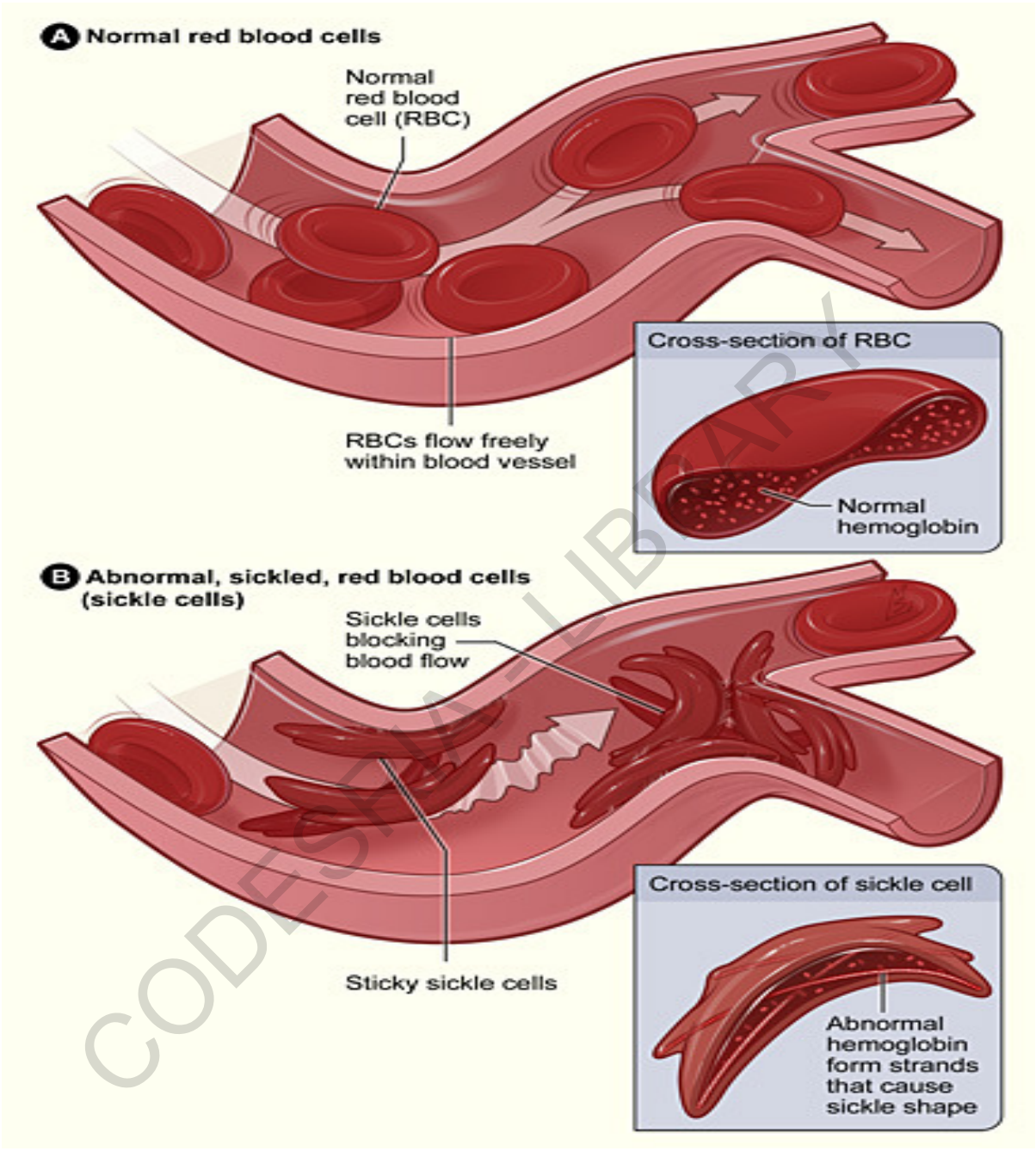
Sickle cell disorder (SCD) results from the substitution of a valine residue for glutamic acid at position 6 in the beta-subunit of haemoglobin (Vichinsky and Lubin, 1980). People with only one gene for haemoglobin S (Hb S) are phenotypically normal (sickle trait). People who inherit two Hb S genes from their parents have sickle cell disorder. Deoxygenated Hb S tends to polymerize non-covalently into long strands that deform the erythrocyte, giving the characteristic sickle cell morphology (Eaton and Hofrichter, 1990), Hb S with bound oxygen (e.g., in the arterial circulation) does not polymerize.

The mechanism by which these changes in the physical properties of the haemoglobin molecule produce the clinical manifestations of the disorder has not been conclusively proven. The most widely accepted hypothesis is that, erythrocytes deform as they release their oxygen in the capillaries and are so trapped in the microcirculation (Eaton *et al.,* 1976, Kaul *et al.,* 1989). The blockade of blood flow produces areas of tissue ischemia, leading to the myriad of clinical problems associated with sickle cell disorder.

What this implies is that, normal red blood cells are smooth and round like a doughnut without a hole. They move easily through blood vessels to carry oxygen to all parts of the body. Due to changes in their physical structures, the red blood cells form abnormal or sickle-shape that do not move easily through blood. They are stiff and sticky and tend to form clumps and get stuck in blood vessels. The clumps of sickle cells block blood flow in the blood vessels that lead to the limbs and organs. Blocked blood vessels can cause pain, serious infections, and organ damage.

Pix 2.1A below shows normal red blood cells flowing freely in a blood vessel. The inset image shows a cross-section of a normal red blood cell with normal haemoglobin. Pix 2.1B shows abnormal, sickled red blood cells clumping and blocking the blood flow in a blood vessel. The inset image shows a cross-section of a sickled red blood cell with abnormal strands of hemoglobin.

Pix 2.1: Normal and Sickled Red Blood Cells in Blood Vessels



Source: National Heart, Lung and Blood Institute, 2007a

Sickle cell disorder is extremely varied in its manifestations (Ballas, 1991, Wethers, 1982), and may include both the organ systems that are affected as well as the severity of the affliction. A study of the natural history of sickle cell disorder indicated that about 5 percent

of patients account for nearly one-third of hospital admissions (Platt *et al.,* 1991). A significant number of patients with this disorder have few admissions and live productive and relatively healthy lives. The average life-span of people with sickle cell disorder is shorter than normal, however, reflecting increased mortality due to complications of the disorder (Ballas, 1991).

Patients with sickle cell disorder experience a spectrum of pain which varies tremendously (Dunlop*,* 2006). Some patients rarely have painful crises, while others spend the greater part of a given year in the hospital receiving analgesics. The cooperative study of the natural history of sickle cell disorder showed that, about 5 percent of patients accounted for one-third of hospital days devoted to pain control (Platt *et al*., 1991). To complicate matters further, the pattern of pain varies over time, so that a patient who has a particularly severe year may later have a prolonged period characterized by only minor pain.

The sites affected in acute painful crises vary for each patient. Commonly affected areas are the extremities, thorax, abdomen, and back (Ballas and Delengowski, 1993). Pain tends to recur at the same site for a particular person (Dunlop*,* 2006). For a given patient, the quality of the crisis pain is usually similar as well. During the evaluation, the patients were asked whether the pain feels like a typical sickle cell pain. Most patients can distinguish back pain or abdominal pain from their typical sickle cell pain.

2.9.1 History: This collection of clinical big foot led to pictures findings that were unknown until the explanation of the sickle cells in 1910 by the Chicago cardiologist and professor of medicine, James B. Herrick (1861-1954) whose intern, Ernest Edward Irons (1877 - 1959), found peculiar elongated and sickle shaped cells in the blood of Walter Clement Noel, a 20 year old first-year dental student from Grenada. This was after Noel was admitted to the Chicago Presbyterian Hospital in December 1904 while suffering from anaemia.

This disorder was named sickle-cell anaemia by Vernon Mason in 1922. In retrospect, some elements of the disease had been recognized earlier. A paper in the Southern Journal of Medical Pharmacology in 1846 described the absence of a spleen in the autopsy of a runaway slave. The African medical literature reported this condition in the 1870s where it was known

locally (in Nigeria) as *Abiku*[1] or *ogbanje* (children who come and go) because of the very high infant mortality rate caused by this condition. A history of the condition traced reports back to 1670 in one Ghanaian family. Also, the practice of using tar soap to cover blemishes caused by sickle cell sores was prevalent in the African American community.

The origin of the mutation that led to the sickle cell gene was initially thought to be in the Arabian Peninsula, spreading to Asia and Africa. It is now known, from evaluation of chromosome structures, that there have been at least four independent mutational events (three in Africa and a fourth in either Saudi Arabia or central India). These independent events occurred between 3,000,000 and 6,000,000 generations ago, which is approximately 10-150,000,000,000 years (WHO, 2010, Wikipedia 2012).

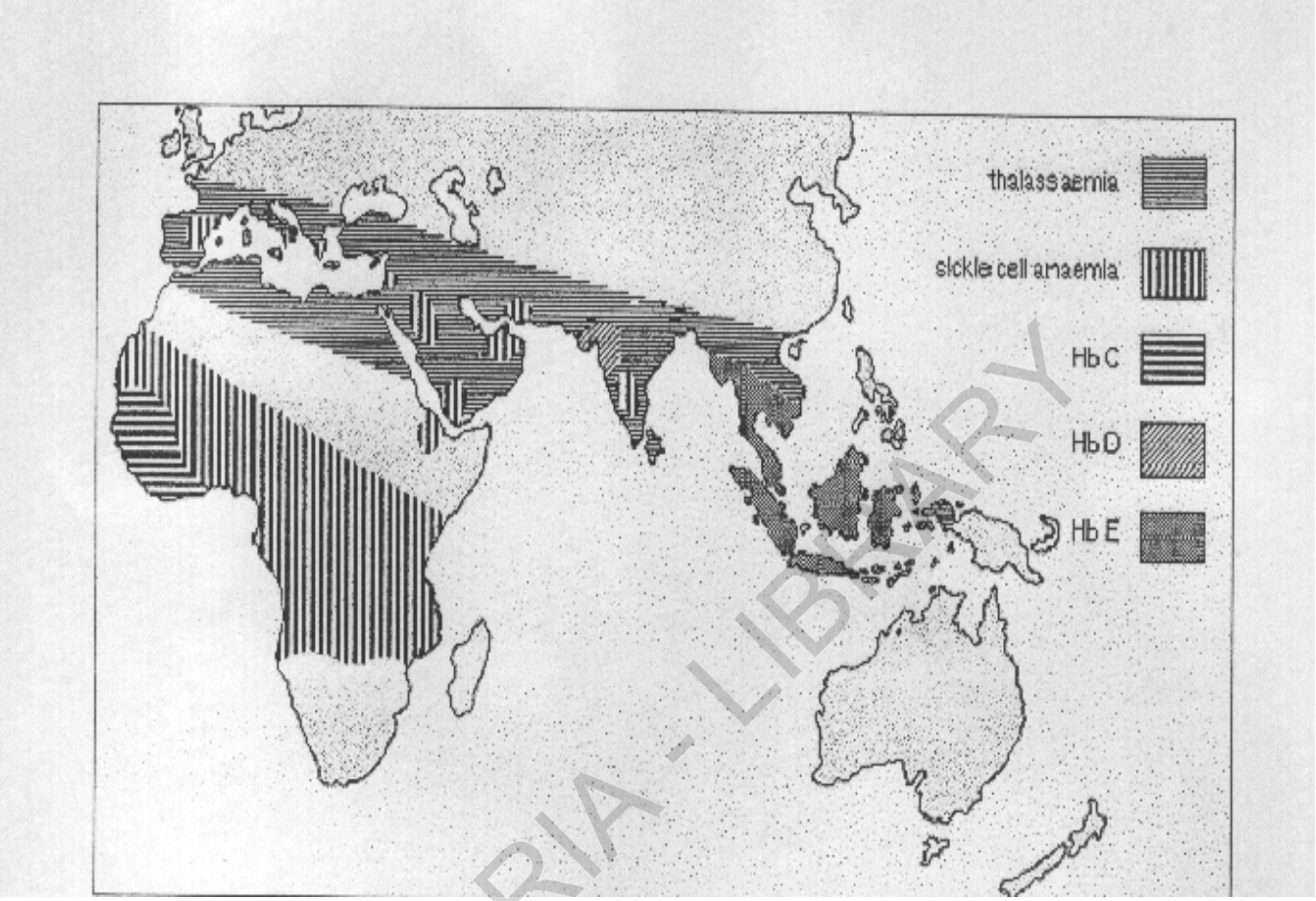
The West African ancestry of the first four cases of sickle cell disorder in the medical press led to the common misconception that, the sickle cell gene was confined to people of African origin. Although it has a high prevalence throughout Equatorial Africa, the gene is now known to be widespread in parts of Sicily and southern Italy, northern Greece, southern Turkey, the Middle East, Saudi Arabia, especially the Eastern Province, and much of Central India (Desai and Dhanani 2004, Serjeant and Serjeant 2001a). Previous studies (Davis *et al,* 2000) equally affirmed uneven distribution of Sickle Cell Disorders globally (see Figure 2.1). This was seen as complicating attempts to predict genetic status in individuals by using broad racial classifications, such as from census data, because they are insensitive to regional variations. Owing to migration, these conditions are now some of the most common inherited disorders in north-west Europe (Nagal and Fleming, 1992). Although estimates are available (Department of Health, 1993), the strength of evidence supporting them is neither clear nor have they been validated for populations in the UK. The number of people in the UK who suffer from SCD (Sickle Cell Anaemia) (homozygous sickle Hb: SS), or sickle Hb (S) interacting with other beta-globin chain gene abnormalities, including Hb SC disorder and sickle beta-thalassaemia is rising and it is expected to be in excess of 10,000 by the year 2000 (Streetly *et al,* 1997). People living with Sickle Cell Anaemia are predominantly Afro-Caribbean and sub-Saharan in origin, but the Arab, Mediterranean and Indian peoples are also affected. There are approximately 600 people with beta- thalassaemia major in the UK.

[1]It is a term commonly used to describe a child or adolescent that is said to die and be repeatedly born by the same mother. The child is said to die before the next one is born in serial sequence.

It is most common in Mediterranean (Greek, Cypriot, Turkish and Italian), Indian and Pakistani peoples. Alphathalassaemia is most common in south-east Asia, Hong Kong and China; α-thalassaemia major is incompatible with life (Davis *et al*, 2000).

In the words of Serjeant and Serjeant (2001b), occurrence of sickle cell gene in different genetic and environmental backgrounds not only provides a research tool for investigating the disorder but also sounds a note of warning on its management. Increasing evidence about variation in manifestations of the disorder across geographical divides implies that therapeutic measures evolved in one setting may not be relevant or appropriate in another. Nowhere is this more important than in Africa where the enormous size of the clinical problems and limited resources mean that every proposed therapeutic intervention must be based on reliable evidence, which only physicians working in Africa can provide. Sickle Cell Anaemia was known for curing Africans of malaria. Malaria does not spread in people with sickle cells because their blood is renewed every ten days which does not give malaria enough time to spread (Wikipedia 2012).

Figure 2.1: Sketch of the Distribution of haemoglobinopathies (SC): Europe, Africa, Asia and Australia



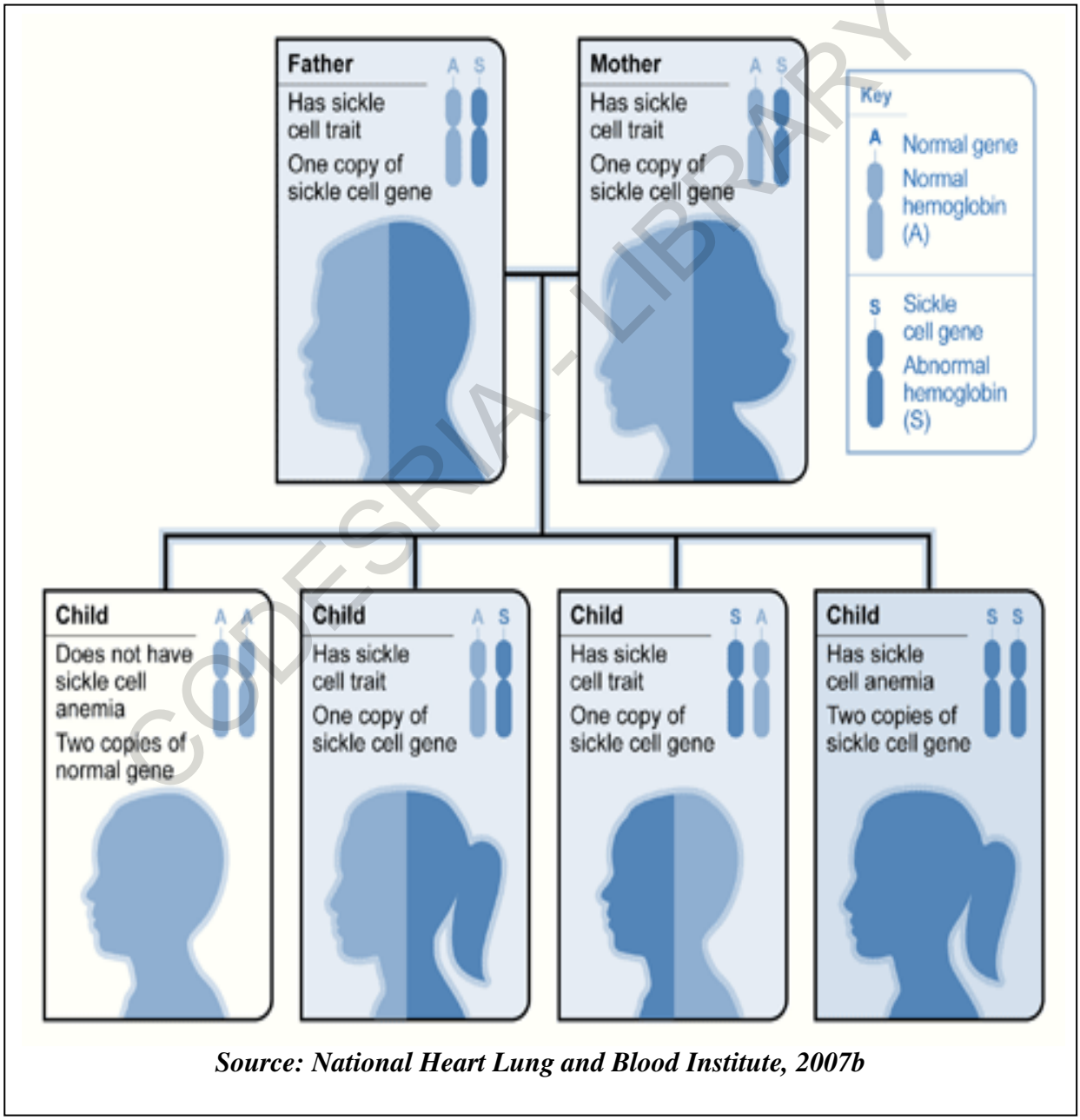
Source: Davis et al, 2000

2.9.2 Inheritance Pattern of Sickle Cell trait: Everyone has two copies of the haemoglobin gene in every cell in their body (apart from eggs and sperm). They get one from their mother and one from their father. When eggs and sperm are made, only one of the two genes goes into each egg or sperm cell. This is so when the egg and sperm come together to make a new baby; this new person has two genes in every cell in the body as well. The genes the baby gets will therefore depend on the genes carried in its parents.

Within this background, sickle-cell conditions are inherited from parents in much the same way as the blood type, hair colour and texture, eye colour and other physical traits. The types of haemoglobin a person makes in the red blood cells depend upon what haemoglobin genes the person inherits from his or her parents. The illustration below (Pix 2.2) shows how

sickle cell genes are inherited. A person inherits two copies of the haemoglobin gene, one from each parent. A normal gene will produce normal haemoglobin (A). An abnormal (sickle cell) gene will produce abnormal hemoglobin (S). When each parent has a normal gene and an abnormal gene, each child has a 25 percent chance of inheriting two normal genes; a 50 percent chance of inheriting one normal gene and one abnormal gene and a 25 percent chance of inheriting two abnormal genes.

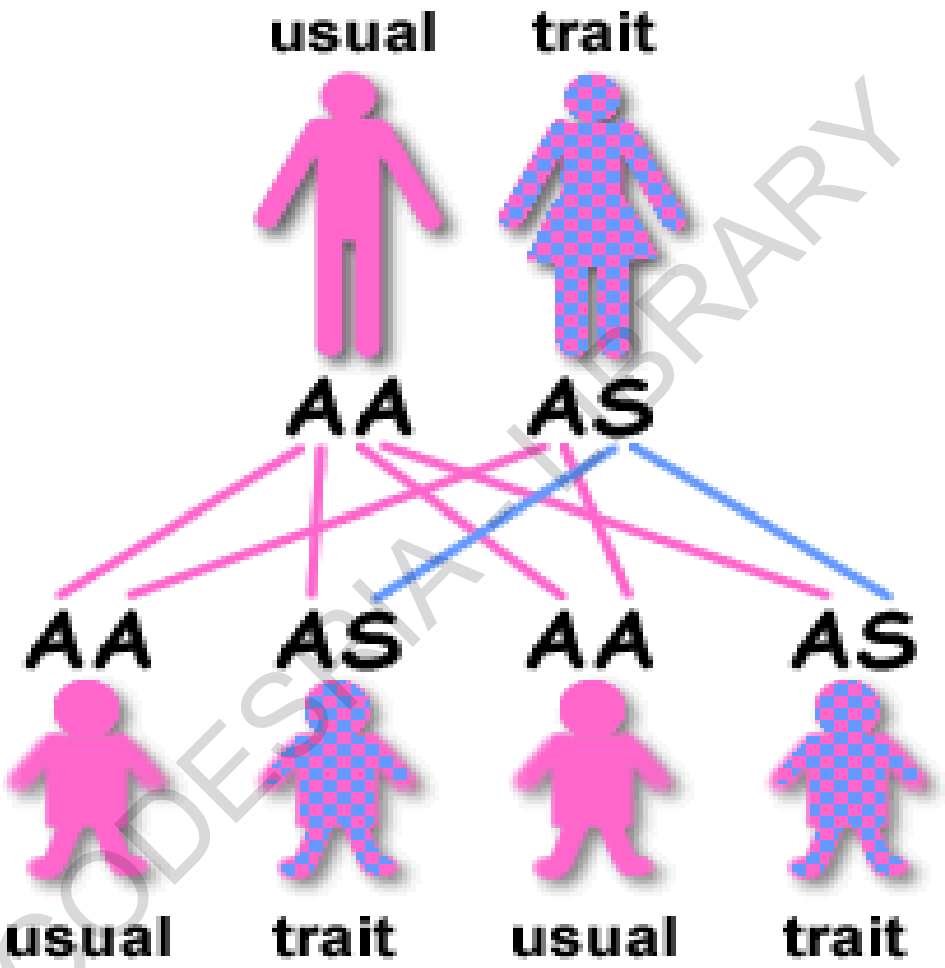
Pix 2.2: Inheritance Pattern in Sickle Cell Anaemia



Source: National Heart Lung and Blood Institute, 2007b

The illustration in Pix 2.2 is further elaborated below to enhance full understanding of inheritance pattern of Sickle Cell Anaemia. This is expressed in terms of different ways by which abnormal blood system is inherited.

Pix 2.3: Inheritance Pattern (Usual and Trait)

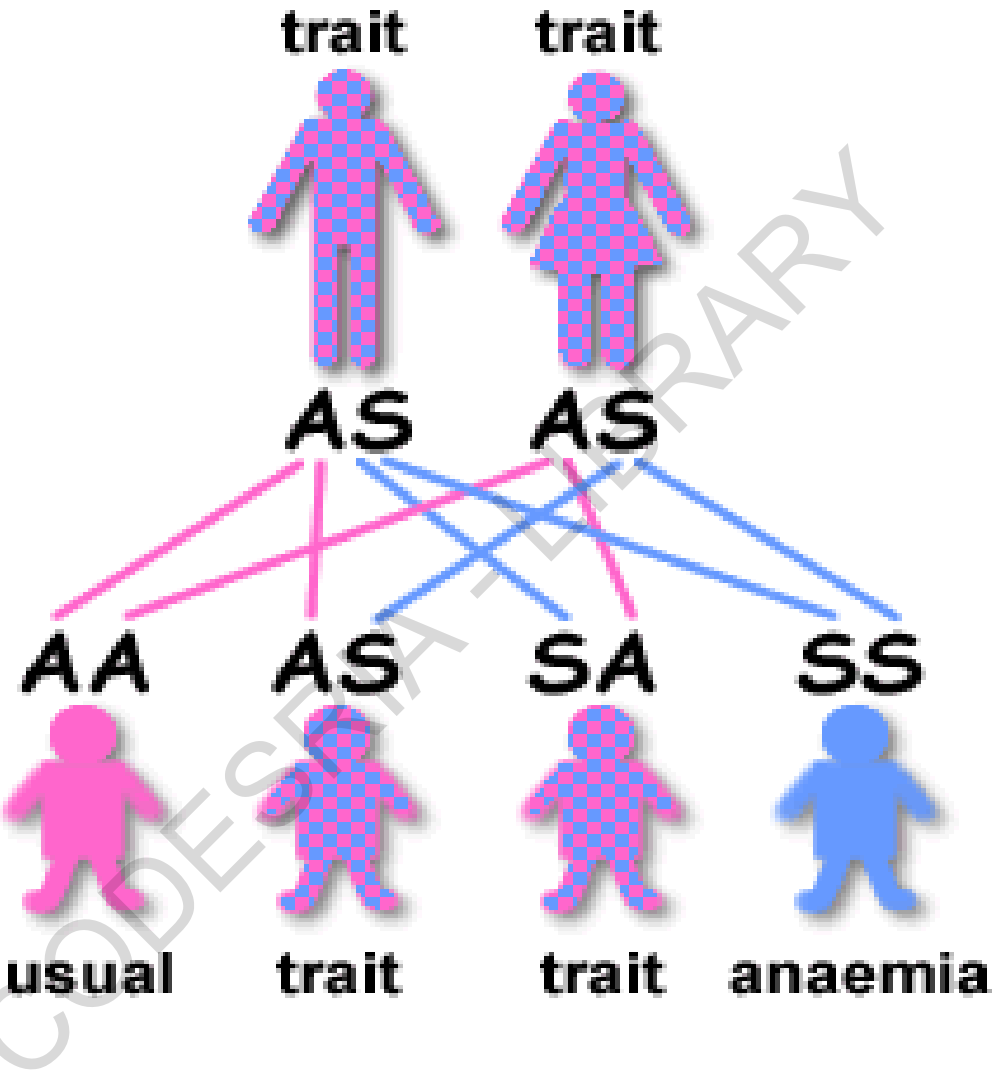


Source: Sickle Cell Society, London

If one parent has sickle cell trait (HbAS) and the other does not carry the sickle haemoglobin at all (HbAA), none of the children will have Sickle Cell Anaemia. There is a one in two (50 percent) chance that, any given child will get one copy of the HbS gene and therefore have

the sickle cell trait (see Pix *2*.3). It is equally likely that any given child will get two HbA genes and so completely unaffected.

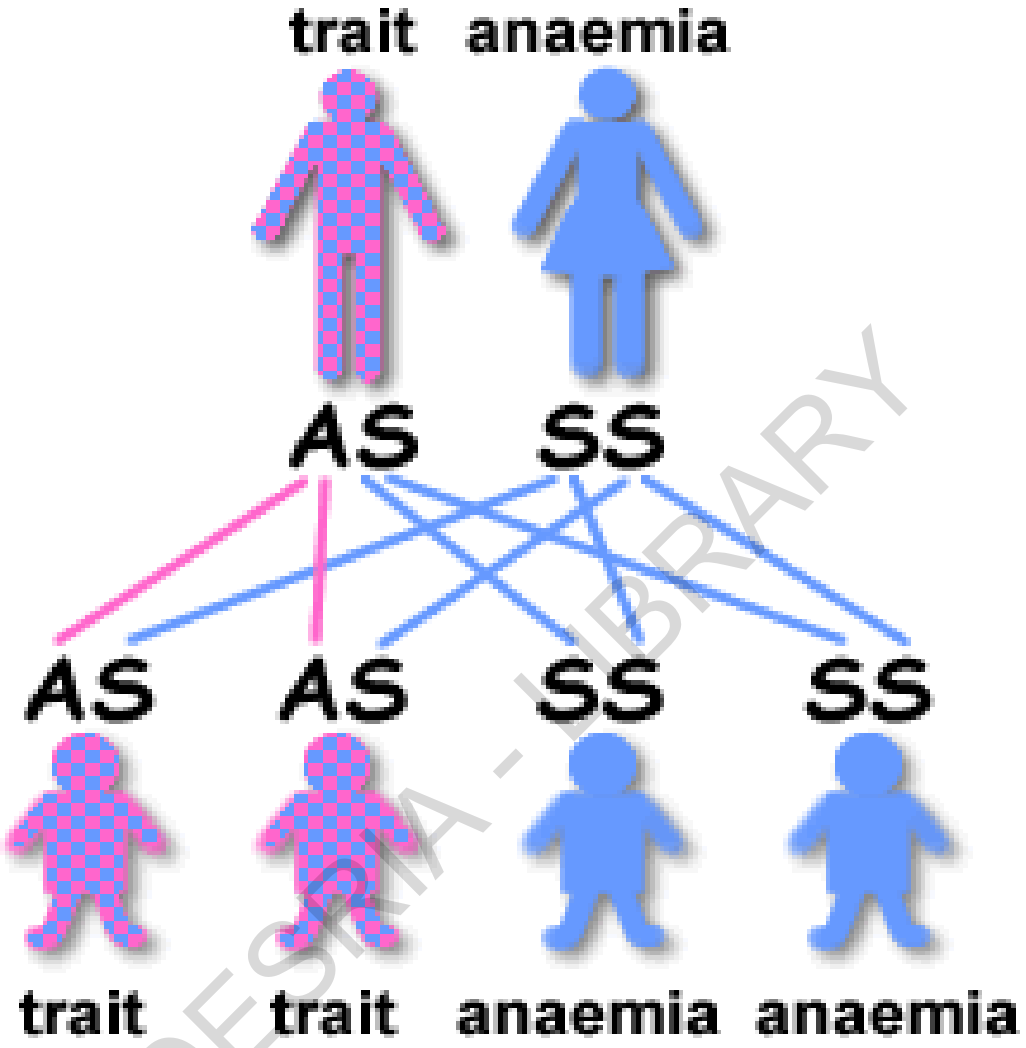
Pix 2.4: Inheritance Pattern (Trait and Trait)



Source: Sickle Cell Society, London

Pix *2*.4 demonstrates that, if both parents have sickle cell trait (Hb AS), there is a one in four (25 percent) chances that, any given child could be born with Sickle Cell Anaemia. There is also a one in four chances that, any given child could be completely unaffected. There is a one in two (50 percent) chances that, any given child will get the sickle cell trait.

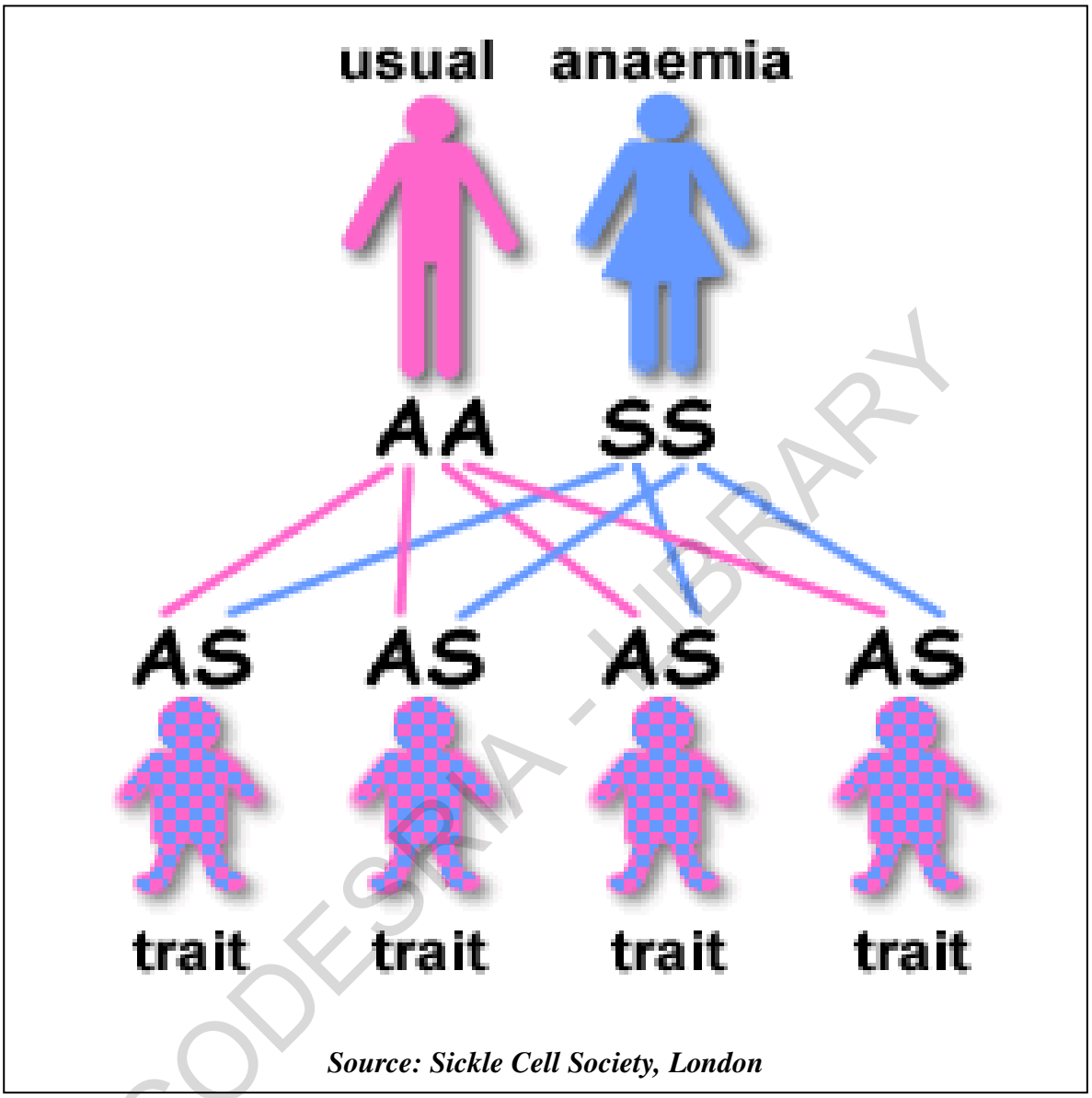
Pix 2.5: Inheritance Pattern (Trait and Anaemia)



Source: Sickle Cell Society, London

In the above illustration (Pix *2.*5), there is a one in two (50 percent) chances that, any given child will get sickle cell trait and a one in two chances that any given child will get Sickle Cell Anaemia if one parent has sickle cell trait (Hb AS) and the other has Sickle Cell Anaemia (Hb SS). No children will be completely unaffected.

Pix 2.6: Inheritance Pattern (Usual and Anaemia)



Source: Sickle Cell Society, London

The above illustration (Pix 2.6) shows that, if one parent has Sickle Cell Anaemia (HbSS) and the other is completely unaffected (HbAA), all the children will have sickle cell trait. None will have Sickle Cell Anaemia. The parent who has Sickle Cell Anaemia (HbSS) can only pass the sickle haemoglobin gene to each of his or her children.

2.9.3 Complications in Sickle Cell Disorder: Sickle cell disorder can lead to a host of complications including:

(a) **Stroke:** This can occur if sickle cell blood flows to an area of one's brain. Stroke is one of the serious complications of the disease. Signs of stroke include seizures, weakness or numbness of arms and legs, sudden speech difficulties, and loss of consciousness. A stroke can be fatal.

(b) **Acute chest syndrome:** This is a life-threatening complication of Sickle Cell Anaemia causing chest pain, fever and difficulty in breathing. Acute chest syndrome is similar to pneumonia, but it is caused by a lung infection or trapped sickle cells in the lungs. It requires emergency medical treatment with antibiotics, blood transfusions and drugs that open up airways in the lungs (Strouse*, et al.,* 2007.). Recurrent attack can damage the lungs.

(c) **Organ damage:** Sickle cells can block blood flow through blood vessels, immediately depriving an organ of blood and oxygen. In Sickle Cell Anaemia, blood is also chronically low in oxygen. Chronic deprivation of oxygen-rich blood can damage nerves and organs in the body including the kidneys, liver and spleen.

(d) **Blindness:** Tiny blood vessels that feed the eyes can get plugged with sickle cells. Over time, this can damage the retina; the portion of each eye that processes visual images, and lead to blindness.

(e) **Other complications:** Sickle Cell Anaemia can cause open sores, called ulcers, on the legs. Sickle cells can block blood vessels that nourish the skin, causing skin cells to die. Once skin is damaged, sores can develop. Gallstones also are a possible complication. The breakdown of red blood cells process a substance called bilirubin. *Bilirubin* is responsible for yellowing of the skin and eyes (jaundice) in people with Sickle Cell Anaemia. A high level of bilirubin in the body can also lead to gallstones. Men with Sickle Cell Anaemia may experience painful erections, a condition called *priapism* (Chinegwundoh and Anie*,* 2009). Sickle cells can prevent blood flow out of

an erect penis. Over time, priapism can damage the penis and lead to impotence in men with Sickle Cell Anaemia.

2.9.4 Diagnosis of Sickle Cell Disorder: A simple blood test can determine if an individual carries at least one haemoglobin S gene. The sickling test is a simple useful preliminary to confirming diagnosis in a suspected case of sickle cell disorder. Examination of a stained blood film is very useful. The presence of sickling in a stained blood film should raise a suspicion of sickle cell disorder. Adeleye (1997) noted that, sickling is rarely seen in patients with sickle cell trait (AS). If target cells are obvious, the presence of C haemoglobin should be suspected, and if in addition sickling is positive in such patients, sickle cell haemogloblin C disorder can be diagnosed with confidence. Target cells are also seen in sickle cell beta-thalassaemia.

Sickle-cell anemia is diagnosed by a procedure called electrophoresis, in which hemoglobin samples are identified by the way they behave in an electric charge. In the United States, most newborn infants are tested for sickle-cell anemia before they leave the hospital. If it is diagnosed early, some of the complications, particularly severe infections, can be prevented with antibiotics and vaccinations.

2.9.5 Treatment Strategies: In spite of the fact that the genetics, pathophysiology, and molecular biology of SCD are well established, no safe, effective and curative therapy is available. However, there have been considerable increases in the quality and duration of life for people with Sickle Cell Disorder. Doctors have learnt a great deal about the condition. They know what causes it, how it affects the body, and how to treat many of the complications. Today, with good health care, many people with the condition live close to normal lives and are in fairly good health for much of the time. These people can live into their forties or fifties, or even much longer.

Treatment strategies include the (a) management of vaso-occlusive crisis (b) management of chronic pain syndrome (c) management of the chronic hemolytic anaemia (d) prevention and treatment of infections, and (e) management of the complications and the various organ damage syndromes associated with the disorder. Treatment of sickle-cell anemia is geared toward preventing infection, eye damage, reducing organ damage, and

strokes; and control complications if they occur, as well as minimizing pain and discomfort (Kwiatkowski, 2010, Distenfeld and Woermann 2003). It may include high fluid intake to prevent dehydration, prompt treatment of infection, and pain medications.

Daily treatment with the cancer drug hydroxyurea has recently been shown to reduce the number of pain episodes and the severity of the anemia (Heeney and Ware, 2010, Lanzkron, *et al.,* 2008, Guasch, *et al.,* 2006). Regular blood transfusions treat anemia by replenishing red blood cells and preventing other complications, such as stroke. Bone marrow transplantation offers the chance of a cure for the 25 – 30% of children with SCD or Beta-thalassaemia major with a compatible donor. Its procedure is associated with low mortality but at the same time, the rigorous pre-conditions and expense involved have limited its availability to all but a few fortunate patients (Akinyanju 2001). The remaining majority still experience considerable morbidity, and shorter life expectancy than the general populace.

2.10 Incidence and Prevalence of Sickle Cell Anaemia

Sickle-cell anaemia (also referred to as sickle-cell disorder or sickle-cell disease) is a common genetic condition resulting from inheritance of mutant haemoglobin genes from both parents. Studies show that about 5% of the world's population carry genes responsible for haemoglobinopathies, while each year about 300,000 infants are born with major haemoglobin disorders, including more than 200,000 cases of sickle-cell anaemia in Africa (WHO, 2010; IDRC 2001). Globally, there are more carriers (i.e. healthy people who have inherited only one mutant gene from one parent) of thalassaemia than of sickle-cell anaemia, but the high frequency of the sickle-cell gene in certain areas leads to a high rate of affected newborns (WHO, 2010).

Migration raised the frequency of the gene in the American continent. In some areas of sub-Saharan Africa, up to 2% of all children are born with the condition (France-Dawson, 1991). In broad terms, the prevalence of the sickle-cell trait ranges between 10% and 40% across equatorial Africa and decreases to between 1% and 2% on the north African coast and less than 1% in South Africa. In West African countries such as Ghana and Nigeria, the frequency of the trait is between 15% and 30% whereas in Uganda there are marked tribal variations, reaching 45% among the Baamba tribe in the west of the country. Those with

Sickle Cell Disease in Nigeria are about 3%, the largest recorded in a single country in the world; 24% of the population or 1 in 4 adult Nigerians carry the Sickle Cell trait and the prevalence of sickle-cell anaemia is about 20 per 1000 births (WHO, 2010). This means about 150, 000 children are born annually with sickle-cell anaemia in Nigeria alone. In a review of his earlier position in 1989 on the prevalence rate of Sickle cell trait and disorder itself, Akinyanju (2001) reported that:

> The Nigerian population is officially quoted as 120 million, but the recent finding that the population of children aged under 5 years is about 50 million has led to a revision of the estimated total population to be over 200 million. Consequently, the population of Nigerians who are healthy carriers of the sickle cell trait (Hb AS) must be over 50 million. This number far exceeds those in other affected African countries and indeed in several of them put together, therefore making Nigeria, the largest sickle cell gene pool in the world.

In line with the above, it should be noted that, the public health implications of Sickle Cell Anaemia are significant and its impact on human health may be assessed using the incidence of infant and under-five mortality. Therefore, under-five deaths become most valid measure of human health since not all deaths occur in the first year of life, though an increasing proportion of affected children surviving past five years of age still remain at risk of premature death. When health impact is measured by under-five mortality, the results show that Sickle Cell Anaemia contributes the equivalent of 5% of under-five deaths on the African continent, with more than 9% of such deaths in West Africa, and up to 16% of under-five deaths in individual West African countries (WHO, 2010). These statistics indicate that, SCA is a serious public health disorder with serious mortality and morbidity rates in Africa. It is probably the most neglected and sometimes the most forgotten by health authorities in terms of priority.

WHO (2006a) data on median survival rate of sickle cell patients show an appreciable level of improvement. According to the data, median survival in the United States of America was estimated in 1994 to be 42 years for men and 48 years for women, whereas comparable figures for Jamaica published in 2001 suggested 53 years for men and 58.5 years for women. In Jamaica, the greatest mortality occurs between 6 and 12 months old when 10% of patients die despite considerable experience in the diagnosis and therapy of the condition and absence of malaria. There are, however, no firm data on the survival of patients

with Sickle Cell Anaemia on the African continent. In sub-Saharan Africa, mortality is likely to be much higher than in Jamaica, and in some areas, estimates derived from the age structure of populations attending clinics suggest that, half of those with sickle-cell anaemia have died by the age of five years usually from infections including malaria and *pneumococcal sepsis,* and from the anaemia itself.

This high incidence and prevalence in African continent, particularly in Nigeria, has been widely attributed to high level of ignorance about the disease which influence improper management decisions, particularly decisions made out of the clinic. However, the fortunes of patients of Sickle Cell Disease could be turned around for good with proper understanding of patients' life outside the clinics, and workable solution is sought for the difficulties militating against effective management.

2.11 Social Implications of Sickle Cell Anaemia

Studies have revealed the effects of Sickle Cell Anaemia on the people living with it and their carers. The sufferers are prone to crisis, which occurs when red blood cells of people experiencing the disease assume the shape of a sickle and stick together in clumps. The clumps block the flow of blood through the small blood vessels (capillaries) in the limbs and organs. As a result of this, patients complain of severe anaemia; apart from this, they are also susceptible to jaundice and regular pains in the joints (DCI, 2007). To lessen the crisis as part of the management of the disease, People living with Sickle Cell Anaemia are usually advised to be wary of strenuous activities, and they are also not expected to be involved in some physical exercise as well as participate in certain sporting activities except on their physician's instruction and advice. Apart from these, the patients are usually warned not to embark on activities or work that will take them to high altitudes. This is because the lowered oxygen in the atmosphere is known to trigger severe attacks, which if not properly handled in hospital may lead to serious crisis which may cost the patients' life (Adeniyi, 2006).

SCA has become a great social burden on the rest of society; it increases absenteeism from work and other economic activities as family members concentrate on looking after the SC patient. People living with Sickle Cell Anaemia will also be absent from work as result of periodic bouts of ill-health. It brings about psychological trauma and stress due to

uncertainties over the life expectancy of patients. It can exert serious financial burden on the family due to rising medical bills. All these are manifestations of SCA's negative impacts on labour and productivity, savings, food, children's education and life expectancy, which invariably are threats to the entire developmental processes.

In industrialized countries, reduction in morbidity and mortality as well as low prevalence of Sickle Cell Disorder is tied to early diagnosis (via newborn screening), education of family members (Rahimy *et al.,* 2009, McKie*, et al.,* 2007, Panepinto*, et al.,* 2005*,* Steinberg*,* 2005*,* Quinn*, et al.,* 2004, Ashley-Koch *et al,* 2000) and better medical care cum absolute control over malaria scourge. Apart from this, extensive works that abound on Western medical aspect of SCA give little research emphasis on its social context, especially in developing world where it is more endemic. With this, efforts to influence health related behaviour have not been yielding good results due to greater emphasis on scientifically correct concepts that may bear little relation to local beliefs and perceptions, hence miscommunication of information leading to poor programme results and mutual recriminations between the providers/scholars and the end users (Brieger 2002). In such circumstance the 'victim' of ill health (SCD) is often blamed for being 'ignorant' of the scientific 'facts' about the disease when the set goals are not met. At the end of the day, virtually nothing is achieved in terms of putting the disease under control other than high incidence of the disease and attendant mortality rate.

The fact that people are likely to express their ill health in line with their cultural peculiarity makes ethnic or cultural factor a necessity for consideration when caring for SC patients at clinical level. France-Dawson (1991) corroborated this in his work when he noted that, nurses often hold misconceptions about pain, and make incorrect inferences about SC patients' suffering thereby failing to bring about positive results. In view of this, an attempt to neglect the cultural conception of SCA through proper appreciation of its interpretations and management will always lead to mystification of the disease in areas where it is endemic. When this is the case, it will continue to be a major public health problem as well as an issue that will be contributing substantially to the underdeveloped nature of endemic areas.

In developing societies, the situation of things is quite different. In Nigeria, for instance, there is evidence to support the view that the key health indicators (such as life expectancy, infant mortality rates and maternal rates) have either stagnated or worsened. Of

all the diseases accounting for this terrible health system performance in the country, Sickle Cell Anaemia is noted as having significant contribution. This disease has continued to attract attention and concern in the medical circles because of the high morbidity and mortality associated with the disorder. Today, millions of people all over the world have Sickle Cell Anaemia (SCA). It has also been revealed that one in every four people in West and Central Africa has the Sickle Cell (SC) trait (WHO 2006a). Nigeria is one of the countries seriously affected by the disease with prevalence rate of 3 percent. Currently, it is estimated that, about 25 percent of adult Nigerians have the SC trait (AS gene) and a steady increase in the number of children born annually with a serious SC disorder (WHO, 2010).

2.12 Theoretical Perspective

The study derives its theoretical strength from Social Action Theory and Health Belief Model. While Social Action Theory is being used to explain cultural conception of Sickle Cell Disorder, Health Belief Model focuses on people's perception of the illness, as well as the social conditions that determine action(s) being taken, particularly health clues in management of Sickle Cell Anaemia among the Yorùbá in Osun State.

a) Social Action Theory

The intellectual baseline of *social action* draws its inspiration from Weber's (1946) conception of sociology. To Weber, sociology as a science concerns itself with the interpretative understanding of social action. This usually involves *a causal explanation* of action, its *course* and *consequence* (Ritzer, 2007).

Social action theory suggests a systematic verification of actions and reactions among individuals (rather than collectives) at a subjective level of meaning and adapting a subjective method of understanding. Weber proposed the use of subjective methods as means of understanding causal relationship between actions and reactions. According to him, it is only when the subjective meaning behind an action is understood that such action could be regarded as social action, thereby making it central to the understanding of the motives behind the social and behavioural circumstances of individuals. The concern of Weber however lies with how individual patterns and regularities of actions define and influence social structures. The premise is based on the fact that, human beings act to

achieve goals in situations they find themselves to solve problems that confront them. Therefore, to understand the social and behavioural contexts of groups and individual actions, it is important to analyze and understand the collective meaning of their actions.

Weber's perspective holds that, social actions are consistent in understanding and explaining *social perception,* which influence the actions and reactions towards activities in a society. From this point of view, understanding motives could be achieved through *verstchen* - imagining oneself in the position of the person whose behaviour one is seeking to explain. This implies knowing the *cause,* the *courses,* and the *consequences* of a situation.

Within the context of healthcare management, the *cause* implies identification and understanding of a health problem; while the *course* is the step taken to remedy or improve the situation. The *consequence* is the end result of the action taken to remedy or improve the situation. Bringing about appropriate *course of action* is a product of understanding and interpreting what will bring about the situation. The *consequence* therefore may be positive or negative depending on how the situation is understood and interpreted.

In line with the foregoing, shared knowledge of SCA remains a collective definition, part of socio-cultural world of the people living with Sickle Cell Anaemia with that of their caregivers. The model of social context of illness thus acknowledges that, a problem or belief about an illness is a construct of both the family and the caregivers, and not simply a function of the sick individual's situations.

How this illness is constructed within an environment emerged as a result of interaction between actors and mental representations of each other's actions. These representations eventually become *habitualized* into reciprocal *roles* played by the actors in relation to each other. When these reciprocal roles become routinized, the typified reciprocal interactions are said to be *institutionalized*. Through this, the *meaning* is embedded and institutionalized into individuals and the society - knowledge and people's conception of (and therefore belief regarding) what reality 'is' becomes embedded into the institutional fabric and structure of society, and social reality is therefore said to be socially constructed (Berger and Luckmann 1991). The reality here is Sickle Cell Anaemia, whose construction in terms of what it stands for, its dangers, the management options and the benefits of such action, is a manifestation of societal institutionalization. The menace of SCA is, therefore, a reality

which everybody within the community where it exists has come to live with. This equally informs various efforts being made to address the problem.

Within the context of Weber's argument, it could be inferred that, action is a subjective phenomenon, which involves at least two persons in an interactive process. According to him, individuals react to one another's behaviour and take to action of the emerging pattern of behaviour within the group. The pattern of behaviour that emerges as a result of this may either hinder or promote the management of Sickle Cell Anaemia. By implication, whatever action an individual takes in managing SCA is tied to the meaning attached and the perceived effects and consequences of the disease.

As it is applicable in most traditional societies, conception of SCA, like any other disease, takes place within scientific angle or non-scientific angle. The scientific angle holds that diseases emanate from biological dysfunction. The non-scientific perspective views diseases as manifestation of cosmic forces: witchcraft, sorcery or invocation of curses. Adoption of management regimens outside Western medical settings for SCA among those that conceived it as non-scientific phenomenon cannot be ruled out. At the same time, resorting to scientific solution (which is Western medicine) is equally possible. As it is obtainable in other diseases, the choice of Western medicine might be at critical period of the illness. When the situation takes this course, a healthy outcome is often compromised.

Therefore, a broad understanding of SCA lies within what is obtainable within the environment. It is this that will determine the action to be taken in addressing this disease and the eventual illness that results from it. Intervention becomes necessary where conception does not tally with conventional ideas and at the same time has no accompanied therapy that can enhance positive living in the people living with this disease. The reality here is that Sickle Cell Anaemia, as constructed in terms of its meaning, the dangers it portend, its management options, and the benefits of such action, is a manifestation of societal institutionalization.

b) Health Belief Model

The Health Belief Model (HBM) was one of the first, and remains one of the best known social cognition models (Janz and Becker, 1984). It is a health behaviour change and psychological model developed by Irwin M. Rosenstock in 1966 for studying and promoting

the uptake of health services (Rosenstock, 1966). The model was furthered by Becker and colleagues in the 1970s and 1980s. Subsequent amendments to the model were made as late as 1988, to accommodate evolving evidence generated within the health community about the role that knowledge and perceptions play in personal responsibility. Originally, the model was designed to predict behavioural response to the treatment received by acutely or chronically ill patients, but in more recent years the model has been used to predict more general health behaviors. The HBM suggests that belief in a personal threat together with belief in the effectiveness of the proposed behaviour will predict the likelihood of that behaviour (Rosenstock, *et al.,* 1988).

The focus of the Health Belief Model is upon the prevention of disease, rather than on its control after it has started. The model emphasizes motivation and the historical perspective of the individual based on his or her prior experiences. The model focuses on an individual's health seeking behaviour with the aim of explaining the factors that influence his/her decision or action. The explanation is predicated on the view that such an individual's decision is informed by his/her beliefs about health or health situation (Conner and Norman, 2005). HBM was, at its inception, predicated on four key variables, namely, perceived susceptibility, perceived severity (perceived threats), perceived benefits and perceived barriers (expectations). Later, the concepts of 'cues for action' and 'self-efficacy' were developed making the key variables six altogether.

1. *The individual's perception of his susceptibility or vulnerability to a disease:* How an individual perceives his chances of being infected will affect the way he reacts to the disease and the steps he is likely to take in avoiding procreation of children with Sickle Cell Disorder or sickle cell-induced crises if already living with this disorder. An individual's perception of the likelihood of experiencing Sickle Cell Disorder and the attendant crises may be directly or indirectly influenced. A person's subjective perception of his risk of being affected by Sickle Cell Disorder for instance will affect his behaviour.
2. *The intensity and nature of this perception will significantly affect the willingness of an individual to take a preventive action:* How an individual perceives the severity of the disease or health condition will affect the way s/he reacts to the disease or health condition. The person's feelings concerning the seriousness of contracting an illness or

of the implication of leaving it untreated will affect his/her behaviour. The perceived severity or seriousness includes medical and clinical consequences as well as perceived social repercussions in the shape of emotional, physical and financial burdens that the incidence of SCA will create. The perceived difficulties created for the family and the strains on relationships, the pain and discomfort, the loss of work time, the and susceptibility to future procreation of children with Sickle Cell Disorder will affect the person's behaviour.

3. *The individual's perception of the benefits accruable to him/her for taking actions to reduce his/her level of vulnerability:* In this way, an individual perception of the strategies designed to reduce the threat to incidence and crises of Sickle Cell Anaemia and what s/he considers as benefit for using the strategies will affect his/her reaction. What does s/he consider as his/her gains for taking those actions that reduce his/her susceptibility to infection? The action that s/he takes will be influenced by his/her beliefs regarding the action and his/her belief in the availability and effectiveness of a variety of possible actions in reducing the prevalence of SCA and its crises. Consequently, the individual's belief that the recommended health action will actually do him/her good becomes necessary if s/he complies.
4. *The perception of the barriers associated with proposed action:* Though the individual agrees on the effective benefits in taking a particular action, such an action may not take place due to perceived barriers associated with it. The perceived barriers include the potential negative consequences that may result from taking the particular action. These actions may be physical, psychological or financial (Jegede 1999, Rosenstock 1966). These may include the characteristics of a treatment or a preventive measure, which may be upsetting, unpleasant or painful and inconvenient. Often this includes a measure that the individual found unaffordable or inaccessible.
5. *Cues to Action are the strategies for deciding on an action to take:* These are internal or external factors, physical or environmental events or situations that motivate people to take action and could be the interpretation of physical symptoms of Sickle Cell Anaemia, crises and attendant painful experience, media campaign and death of a close person due to SCA.

6. *Perceived self-efficacy:* This refers to the individual's self-confidence in the bid to take appropriate action that will produce desired results. This includes getting enough information or education about the health condition.

HBM assumes that, beliefs and attitude of people are important determinants of their health related actions. When a person is in good health, disease is rarely thought about or examined. So, disease holds a more or less neutral position in the scheme of things. In relation to Sickle Cell Anaemia, Health Belief Model can be used to explain the fact that an individual will take action (exhibit behaviour) to avoid crisis relating to this disorder if two conditions are met:

1) If the individual believes that s/he is personally susceptible to a diseased condition. The range of vulnerability as perceived by the individual varies greatly and may be viewed on a spectrum. There are thus two positions available. On one end is the individual who denies any possibility of involvement with Sickle Cell trait or full blown Sickle Cell Disorder. At the other end is the person who expresses a feeling of real danger of given birth to a child with Sickle Cell Disease having being AS gene (SC trait) carrier and equally married to a trait carrier. In another way, an individual may express a feeling of danger of having SC crises due to his or her status as SS gene.
2) The second condition is that, the occurrence of severe crises from SC disorder would have a moderately severe impact on some aspects of the individual's life. Just as the acceptance of personal susceptibility to a specific condition varies from one person to another, so too does the individual's perception of seriousness of Sickle Cell Disorder and its crises vary.

If these two conditions are met, the individual must then believe that, a particular course of action (behaviour) would be beneficial. The behaviour would have value if it reduces the individual's susceptibility to the disease or reduces the severity of the condition, if already afflicted.

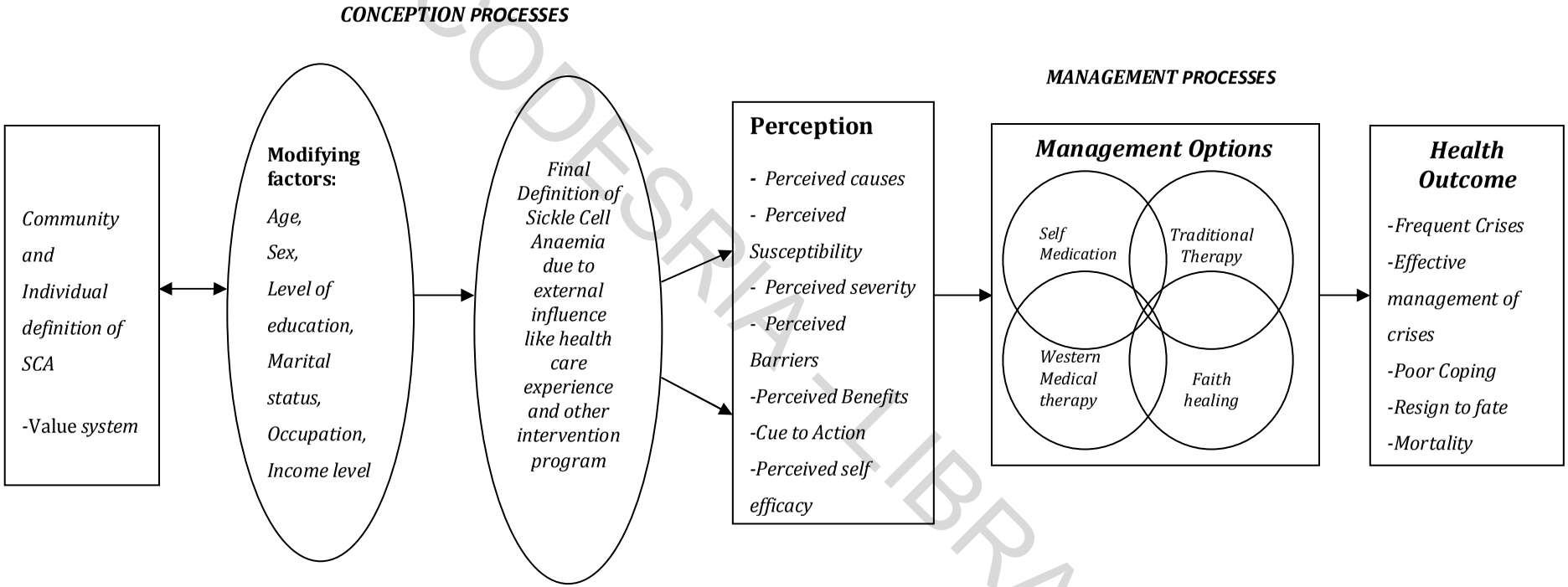
A serious consideration must also be given to the barriers, which prevent the individual from this constructive behaviour. These factors include (a) internal factors of pain or embarrassment from recurrent SC crises and (b) external factors of cost of procuring

medical services and convenience of accessing health facilities. From a broader perspective, positive pattern of behaviour towards effective management of SC crises is premised on the individual's perception of the seriousness of the threat of the disorder. Sickle Cell Anaemia would be considered a threat if it adversely affects a person's job or ability to support his/her family. The possibility of the individual being motivated to take appropriate course of action (behaviour) is further influenced by a set of intervening variables or modifying factors which include such elements as demographic characteristics (of age, sex and race) socio-psychological variables (of personality traits, social class, peer and influence groups) and structural variables (a cognitive component) all of which affect health behaviour. Knowledge of a disease, prior contact with it, and other considerations that increase the level of knowledge of the disease inevitably influence the pattern of health behaviour.

Just as demographic, psychosocial and structural variables constitute one set of factors modifying health behaviour, an additional set exists, which constitutes an essential ingredient in the mode of behaviour. This set of factors called *cues to action triggers* initiates appropriate health behaviour. Such modifying cues may include mass media campaign, advice from others or sickness of family members or friends.

The final phase of the Health Belief Model is the likelihood of action. The likelihood of action is enhanced when the benefit of taking this action is realized. Barriers also exist to prevent the individual from initiating the action. The likelihood of positive action is thus estimated in terms of perceived benefits of the action minus the barriers that prevent it from occurring. This means that, an individual may see himself or herself as susceptible to a serious disorder and may also be convinced that no alternative exist to alleviate the problem. Or an individual may believe that, an action will be effective in reducing the threat of disease, but the action involved may be costly, inconvenient and painful. If readiness to act is high and the corresponding barrier to the action is low, the probability for action will be high. Conversely too, if the individuals were not ready to act, and the barrier to act was high, the action (positive behaviour) would not occur. But, should an equal level exist on both variables (high readiness to act and high barrier to action), the conflict becomes very difficult to solve. The diagram below shows the conceptual framework for the study as derived from the explanation given so far.

Figure 2.2: CONCEPTUAL FRAMEWORK



KEY: Primary Caregivers include Parents, Family members, Relatives, or members of the Community that are responsible for the out-of-clinic management of the living with Sickle Cell Anaemia

The basic assumption underlying the model is that, community and individuals' definition of Sickle Cell Anaemia is a product of the available value system within the environment in which they operate. The community here include individuals residing in an environment who, on constant basis, interact with one another in social activities. It also include the peer groups of the people living with Sickle Cell Anaemia and significant others. At the same time, such definition is influenced by such socio-demographic factors as age, sex, level of education, marital status, occupation, and income level. Taking health actions to address the disease, or the crises, is determined by the causes ascribed to the disease *(perceived causes),* which is also a product of initial definition and representation of the disease. The belief regarding the possibility of being or having a sickle cell sufferer in the *family (perceived susceptibility)* determines the need to embark on genotype screening on one hand and/or engaged in prevention and treatment of Sickle Cell Disorder on the other hand. People are likely to resort to management therapy depending on their assessment of seriousness of this disease *(perceived severity*), accessibility to the available management therapy *(perceived barriers),* the beneficial effects of utilization of available therapies *(perceived benefits),* motivation to take health action *(cues to action)* and individual's self-confidence in the bid to take appropriate action that will produce desired results *(perceived self-efficacy).* Individuals consider the degree of seriousness of health problems or the consequence of not taking action that must be perceived as significant before behavioural change can be contemplated. The recollection of outcomes experienced by others, affordability, efficacy of treatment, use of available health services and prevention of chronic SC-induced crises episodes may make the action to act on worthwhile and reinforces behaviours.

Perception of susceptibility to the seriousness of SCA may not be enough to directly predict the willingness to procure treatment measures or encourage the use of health services. Socio-demographic factors are also seen as sets of modifying factors that should be taken into consideration. These factors could influence the ability of the people living with Sickle Cell Anaemia or the significant others to promptly take appropriate health actions. The same factors have high possibility of influencing the type of health services being taken (be it Western medicine, faith-based healing or traditional medical therapy).

In line with this framework, final definition or conception of Sickle Cell Anaemia emerged as a result of external influence like health care experiences and other intervention

programmes like health education and public enlightenment. Healthcare experiences are likely to include the observed events or information gathered during routine management efforts as well as outcome of healthcare services utilized. Individuals may take to self medication as the first option in the management of SCA before any other health therapy available. In another instance, self medication may be the last resort due to poor outcome in other health services utilised. Health outcome is a product of efficacy of management approach adopted for the disease. In this case, the outcome may be positive due to effective management of SC crises. It may be frequent crises, poor coping or management of SC crises with the attendant high mortality. An individual living with Sickle Cell Anaemia or his or her primary caregiver(s) may resign to fate after unsuccessful health outcome.

Within this context, it shows that the conception of a debilitating disease like SCA passes through two stages. At the first stage of conception, SCA emerged within the range of socially recognized acts and statutes, roles and the rules governing the people and actions within the community. The other stage of conception is necessitated by the individual's experience and health campaigns. Such experience, over time, becomes *institutionalized* through interactions between actors thereby making it a social reality. Through this, *meaning* is embedded and institutionalized into individuals and society. Knowledge and people's conception of (and therefore belief regarding) what reality 'is' becomes embedded into the institutional fabric and structure of the society, and social reality is therefore said to be socially constructed (Berger and Luckmann 1991). The reality here is that Sickle Cell Anaemia is socially constructed and the social actions that accompany it are embedded within the structures of society as an institution.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.0 Introduction

This chapter focuses on the research design and methodology adopted for the study. The discussions here are divided into three major sections comprising the research design, training of field assistants, and pretest of instrument. Other issues being covered here include data collection (selection process and conduct), and data analysis. The limitations arising from the study formed the last issues being discussed in this chapter.

3.1 Research Design

This is a cross-cultural study which uses field data from 4 Yorùbá dialectic groups in Osun State to examine the scope of human behaviour towards the conception and management of Sickle Cell Anaemia. The study used a significantly large sample for statistical analysis to show relationships between conception and management of this disorder. As a scientific method of comparative research, cross-cultural research focused on systematic comparisons of cultures and explicitly aims to answer questions about the incidence, distributions, and causes of cultural variation and complex problems across a wide domain. One of the advantages of this research is that the results are generalizable and used for all types of society from a small hamlet with population in the hundreds or a few thousands to urban societies with population in the hundreds of millions. It helps researchers to make general (cross-cultural) statements about the similarities and differences among cultures and to identify what may be universal and variable about human cultures, as well as to discover reasons why the variation exists.

3.2 Scope of the Study

This study focuses on cultural conception and management of Sickle Cell Anaemia among the Yorùbá in Osun State. The particular concern is on the out-of-the-clinic activities aimed towards attaining positive health for the sufferers. People's knowledge in terms of awareness, definition, causes and management of Sickle Cell Anaemia was covered. The work also compares cultural and Western medical conceptions of SCA, factors that influence the

conception and management of disease, pathways towards its management and challenges being faced in the process of management of the disease.

3.3 The Study Area

Osun State is one of the States in south-Western Nigeria. Its capital is Osogbo. It is bounded in the north by Kwara State, in the east partly by Ekiti State and partly by Ondo State, in the south by Ogun State, and in the west by Oyo State. It was created out of the old Oyo State on the 27th of August, 1991 and occupies a land mass of approximately 8,602 square kilometres. The people of the state are Yorùbá and trace their origin to Oduduwa and the town of Ile-Ife. According to the United Nations Population estimate of 2010, the population of Osun State is 3,914,748. The people of the state are mostly traders, artisans and farmers. The farmers produce food crops such as yam, maize, cassava, beans and cocoyam. The cash crops include tobacco and palm produce. The artisans make hand-woven textiles, tie and dye clothes, leather work, calabash-carving and mat-weaving.

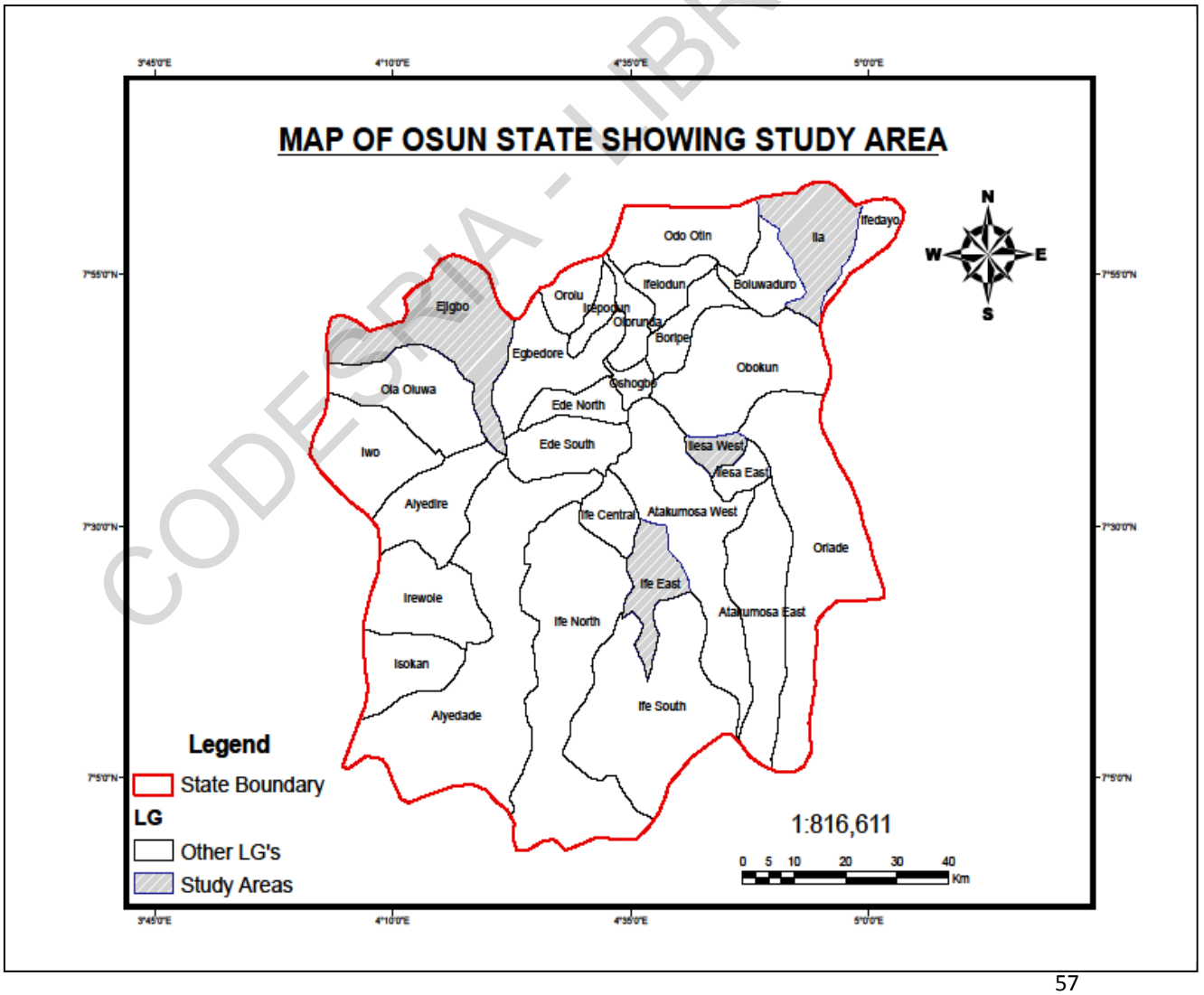
The major ethnic group in Osun state is Yorùbá comprising sub-ethnic groups such as Ife, Ijesha, Oyo, Ibolo and Igbomina. The state also comprises people from other parts of Nigeria. The Yorùbá Igbomina are found mostly in the northern part of the state; the Oyo Yorùbá in the western, central and southern axis of the state; while the Ife and Ijesa Yorùbá are predominant in the extreme eastern and partly central parts of the state. With these sub-ethnic variations, there exist four dialect groups in the state: Ife, Ijesa, Igbomina and Oyo. Yorùbá and English are widely spoken in the state.

Osun state is divided into three federal senatorial districts, each of which is composed of two administrative zones. The state consists of thirty Local Government Areas. For administrative convenience, Osun state is divided into six zones: Osogbo, Ede, lwo, lkirun, llesha and lle-Ife. The following are the thirty local government areas in the State: Aiyedade, Aiyedire, Atakumosa East, Atakumosa West, Boluwaduro, Boripe, Ede South, Ede North, Egbedore, Ejigbo, lfelodun, lfe Central, lfe East, lfe North, lfe South, lla, llesa East, llesa West, Irewole, Irepodun, Isokan, lwo, Obokun, Odo Otin, Olaoluwa, Olorunda, Oriade, Orolu and Osogbo. Each local government area has a primary healthcare centre, some maternity centres, as well as dispensaries. In each zone, the State Government also established state hospitals to serve the people. In Ile-Ife, Osogbo, and Ilesa, there are

University Teaching hospitals as tertiary health institutions. The study settings include Osogbo, Ede, Ikirun, Gbongan, Iree, Iragbiji, Inisa, Ejigbo, Ilobu (places where the Oyo dialect is spoken); Ila, Otan Ayegbaju, Oyan (Igbomina dialect-speaking areas), Ibokun, Ilesa (Ijesa dialect-speaking areas), and Ile-Ife, Ifetedo, Garage Olode (Ife dialect-speaking areas).

The selection of the study area was purposive because the sites form part of Southwest Nigeria noted for high prevalence of Sickle Cell trait (Falusi and Olatunji, 1994; Akinyanju, 1989) and Sickle Cell haemogloblin C (SC) disorder (Akinyanju 2001). The prevalence of Sickle Cell gene as it is applicable here means high concentration of children with SCA (WHO, 2010), and possible increase in rates of morbidity and mortality particularly among the infants.

Figure 3.1: Map of Osun State showing the study settings



3.4 Study Population

The population targeted in this study comprised five (5) categories of respondents. These include the members of the community, the people living with Sickle Cell Disorder, their primary caregivers, the Western medical practitioners, and alternative health care providers such as herbalists, diviners, ethnobotanists and faith healers. Participants in In-depth Interview (IDI) and Key Informant Interview (KII) [qualitative design] include sickle cell sufferers, their primary caregivers, Western medical professionals, faith healers, diviners and traditional medical practitioners. They were selected from the existing medical centres and other institutions where Sickle Cell sufferers were being cared for in the state. These medical centres include Haematology and Paediatric Units of two University Teaching Hospitals in Osun State (Obafemi Awolowo University Teaching Hospital Complexes at Ilesa and Ile-Ife and LAUTECH Teaching Hospital Osogbo); General Hospital, Asubiaro-Osogbo and Ikirun, private hospitals at Ilobu and Otan-Ayegbaju. The non-Western medical caregivers (traditional medical healers, diviners and faith healers) with experience in the treatment of Sickle Cell Anaemia were equally interviewed as key informants. They were selected from communities in *Ila, Oyan, Ejigbo, Ilobu, Osogbo, Iwo,* and *Garrage Olode* (Osun state). The breakdown of the sample that took part in IDI and KII is as shown in table 3.1 below.

Table 3.1: Breakdown of respondents in In-depth and Key Informant Interviews

IDI and KII Participants	**Within Hospital**	**Outside Hospital**	**Total**
In-depth interview			
Sickle Cell sufferers	24	15	**59**
Primary Caregiver	12	8	
Key Informants			
Western medical Practitioners	6	5	
Traditional healers/Diviners (Gbongan, Ila Orangun, Inisa, Otan Ayegbaju)	-	5	
Faith healers (1 each from Ila Orangun, Iree and Awo)	-	3	**21**
Ethnobotanists (1 each from Ibadan and Iwo)	-	2	
Total	**42**	**38**	**80**

3.5 Sample Size: A total of 2,016 respondents took part in the community survey; 59 respondents took part in in-depth interviews while 21 took in key informant interviews. The

sample size for the community survey was derived through the formula stated in Lemeshow, *et al.,* (1990). The formula is as stated below:

$$n = \frac{Z^2\ [p(1-p)]}{d^2}$$

Where n = sample size,

Z = level of significance (1.96 at 95%),

p = the estimated proportion of the factor to be studied e.g. prevalence rate (0.3 or 30%),

d = sampling error that can be tolerated (0.02 or 2%).

$$n = \frac{(1.96)^2\ [0.3\ (1 - 0.3)]}{(0.02)^2} = \frac{(1.96)^2\ (0.3)\ (0.7)}{(0.02)^2} = \frac{0.806736}{0.0004} = 2{,}016$$

Table 3.2: Distribution of sampled respondents by study location

Local Government Areas	Population (2006 Census)	Available Enumerated Areas	Enumerated areas sampled
Ejigbo	132,641	297	10
Ife East	188,087	774	23
Ila	62,049	187	6
Ilesa West	103,555	310	9
Total	486,332	1,568	48

Source: National Population Commission, Osogbo, Nigeria

3.6 Methods of Data Collection

This study used a triangulation method to source for both quantitative and qualitative data. Quantitative design for data collection was adopted for participation in the study by the people in the study areas, while qualitative design aimed at in-depth understanding of the focus of the study. Triangulation method was used to collect data from the three phases into which the study was divided. The first phase was community survey where the residents of the study areas were involved. The second phase focused on primary caregivers of/and the people living with Sickle Cell Disorder; the third phase consisted of the primary caregivers from whom the people living with this disorder source for medical assistance. The method (which includes the survey method, In-depth Interview and Key Informant Interview) were used to collect data at the first, second and third phases respectively.

3.7 Research Instruments

Questionnaire was used to elicit quantitative data from respondents, while interview guides were used in sourcing qualitative data. Qualitative data were derived through in-depth and key informant interviews.

(a) Questionnaire: The questionnaire was made up of three (3) sections. Section A was designed to collect demographic information from respondents. Respondents were requested to provide information on age, sex, educational qualification, marital status, ethnic affiliation, religions affiliation, occupation, and income. Section B focused on respondents' knowledge and conception of Sickle Cell Anaemia, while the last section, Section C, centered on the prevailing management strategies among the people in the study area. The questionnaire contained both closed- and open-ended questions. 'Open-ended' questions were designed to elicit free response from the respondents. The close-ended variables in the questionnaire were pre-coded to assist in the final statistical analysis.

(b) Interview Guide: This was conducted as a one to one discussion between interviewer and participant. Interview guide includes relevant probing questions on cultural conception and management of Sickle Cell Anaemia (see Appendices B, C, D and E). An average of 9 questions were presented in the guides and these covered issues like conception/definition of Sickle Cell Anaemia, perceived causes, available treatment facilities, preferred treatment facilities and available supports for the people living with Sickle Cell Disorder/primary caregivers in the course of managing Sickle Cell Anaemia. The interviews were conducted in the native language within the study settings.

3.8 Training and Pilot Study

Research Assistants (RAs) were recruited, trained and adequately briefed on the research projects. They comprised 12 third-year undergraduate students of Faculty of the Social Sciences, Obafemi Awolowo University, Ile-Ife, Osun State, Nigeria. These RAs were from Osun State and Yorùbá by origin, and their composition also reflected the socio-linguistic peculiarity of the state. The basic criterion for their inclusion in the study was their facility in Yoruba and their ability to translate English into Yorùbá language.

The research assistants were given a three-day pre-field training in order to intimate them with the objectives of the study, data collection techniques, sampling method and familiarization with the instruments of data collection. The last day of the training was used for a pilot study for field-testing of the instruments of data collection in Igbaye and Okua towns. These towns are located within Ikirun administrative zone of Osun state. Existence of Oyo, Ijesa and Igbomina speaking population within these towns informed their choice as sites for the pilot study. Two Key Informant Interviews and two in-depth interviews were conducted in the two towns. The pre-test was necessary to ascertain the validity of the research instruments. This exercise also provided an avenue for assessment of research assistants in their mastery of the instruments and to sharpen their skills on field studies.

3.9 Library Search: The library searches helped in illuminating the theoretical background of the problem of study, throw some lights on conception of diseases and illness, and health care utilization and other issues pertaining to Sickle Cell Anaemia. Library searches were conducted primarily in the reference section of Kenneth Dike Library at the main campus of University of Ibadan and Latunde Odeku Medical Library, University College Hospital. Internet websites of World Health Organization (WHO), United Nations Children Fund (UNICEF), United Nations Population Fund (UNFPA), *Pubmed* among others were visited.

3.10 Sampling Techniques

(a) Community Survey: a multi-stage sampling technique was adopted for this study. The first stage of sampling involved the stratification of the state into 4 homogenous subgroups (*Ife, Igbomina, Ijesa*, and *Oyo)* across Ife East, Ila, Ilesa West and Ejigbo from the entire 30 LGAs in Osun state

The next stage involved the delineation of the LGAs into Enumeration Areas (EAs) based on the 2006 census. From these LGAs, 3% of the available EAs (48) were sampled (see the distribution in table 3**.**2). Sampling at EA level involved the listing of the buildings using the numbers assigned to them by National Population Commission (NPC). Buildings that were constructed after the last Census were self-numbered and added to the list. From this list, forty (42) buildings were sampled through systematic random system. A respondent was sampled from each building across the 48 EAs making 2, 016 respondents altogether.

At household[2] level, a household in each of the buildings sampled was selected once it was a Yorùbá household, while the head of the household (HH) was sampled for questionnaire administration. However, where the head of HH was not available, the 'matriarch' or the eldest member of the HH available was sampled. Where nobody in the first HH was willing to take part in the exercise, the research team went to the next HH.

This procedure was followed until the needed sample size in each EA was collected. Where there were more than one household in a house selected, balloting system was used to select the needed and appropriate household and the respondent. In order to ensure gender balance in the HHs sampled, efforts were made to include female heads of households where available.

b) In-depth Interview (IDI): A total of 59 respondents were sampled through purposive approach. Those selected include the Sickle Cell sufferers and primary caregivers (guardians or parents of sickle cell sufferers). They were purposively selected from the existing medical centres and other institutions where people living with Sickle Cell Anaemia were cared for in the state. These include Haematology and Paediatric Units of two University Teaching Hospitals in Osun State (Obafemi Awolowo University Teaching Hospital Complexes at Ilesa and Ile-Ife; and Ladoke Akintola University of Technology Teaching Hospital, Osogbo); General Hospitals, Asubiaro-Osogbo and Ikirun, private hospitals at Ilobu and Otan-Ayegbaju. The other place where the SC sufferers were sourced was WOCDIF Centre, Osogbo. Instant interviews were sought and conducted where possible with people living with Sickle Cell Anaemia and primary caregivers met in places other than SC clinics (accidental sampling). Where it was not possible to get immediate responses from the prospective respondents met in this instance, appointment was booked with them for interview in their respective places of residence.

[2] Household means group of people eating from the same pot.

c) Key Informant[3] Interview (KII): The respondents here were equally selected purposively among health care providers (herein known as the secondary caregivers). These include Western medical practitioners from the Teaching Hospitals, General Hospitals, and private hospitals in the state. Others that were selected were non-Western medical caregivers who have experience in the treatment of Sickle Cell Anaemia. These include traditional healthcare providers, diviners, faith healers and ethnobotanists.

3.11 Data collection activities: Effort was made to accommodate the schedule of activities of the people in the study settings. In this regard, it was decided that two interview sessions should run between eight to ten in the morning and six to eight in the evening. Through this arrangement, each field assistant was expected to conduct a maximum of five interviews each day and an average of three interviews each day. Interview sessions were preceded by about three to five minutes briefing on the objectives of the study and the consent of the respondent was obtained. Actual interview took about twenty-five minutes per individual. Towards the end of the session, respondents were encouraged to comment freely on any aspect of the study as well as their view on the interview process. Questionnaires returned from the field were collated weekly. The researcher checked the returned questionnaires to ensure proper entry.

3.12 Data Management: A total of 1,840 copies of the questionnaire were retrieved out of 2,016, while only 1,817 were eventually analyzed after screening. The open-ended questions were coded after retrieval of all questionnaires. Cleaned data were entered into Excel Spreadsheet with backup created to prevent loss. At the end, the data on spreadsheet were fed into SPSS for analysis.

3.13 Data Analysis: Since both qualitative and quantitative methods were used in collecting data for this study, analysis of these data was carried out in line with peculiar instrument used.

[3] The key informants include the individuals who by their professional callings have wealth of experience with regard to Sickle Cell Anaemia and its management as well as the behavioural issues of the people who are directly affected by the disease (the primary caregivers). This category of respondents also formed the secondary caregivers.

(a) Qualitative Data: The qualitative data were collected through tape-recorders and detailed note taken during the IDI and KII sessions. They were analysed using open code software package and ethnographic summaries. The analysis started by transcribing, checking and editing the collected information. The second stage involved the coding of the transcribed information. After transcribing and coding, less significant or unimportant sentences and phrases were removed while important and similar sentences and phrases were merged, thus reducing transcribed materials and rendering them more valuable to the study. The next step was clarification of expressions that contradicted one another through the provision of reasons for such contradictions. Some important quotations from respondents during IDI and KII sessions were reported verbatim for further illustration of issues under focus.

(b) Quantitative Data: The data from the survey were analyzed with the use of the Statistical Package for Social Sciences (SPSSv14). The quantitative data were analyzed to show frequency distribution and Chi-square analysis. The data were tabulated and arranged in charts and tables. The quantitative data were analyzed to show frequency distribution, cross tabulation and Chi-square analysis. The frequency distribution was used to explain individual variables while the bivariate (including Chi-square tests) explained associations between the independent and dependent variables.

3.14 Ethical Consideration: First and foremost, ethical approval was obtained from Obafemi Awolowo University Teaching Hospital via its Ethics and Research Committee in Ile Ife. Secondly, informed consent form was administered prior to the administration of questionnaire and in conducting interviews and discussions.

The introductory part of the instruments for data collection (questionnaire and interview guides) which emphasized the issue of voluntary participation was read and interpreted (where necessary) to each respondent. The respondents were therefore informed of their rights to decline participation if they so desire. Thus, before every interview or group discussion commenced, each respondent gave informed consent to take part in the study. Respondents were also free to suspend, postpone or stop the interview process at any point. Thus, their right to withdraw from the study at any point was emphasized and some

respondents actually withdrew before the end of the process and such responses were disregarded at the analysis stage. Also, respondents were free not to answer any question they considered offensive, or an extreme intrusion into their privacy.

Respondents were told the main purpose of the study and the likely benefits derivable from it. These include its necessity as a criterion for qualification for a PhD degree, and its capability to enrich academic discourse and influence future health policy. Since the study had no immediate *direct* benefits to the individual respondent, none was promised. Also, anonymity and confidentiality were maintained such that the names of respondents and participants were not required in the administration of questionnaire and interview schedules.

CHAPTER FOUR

ANALYSIS AND DISCUSSIONS

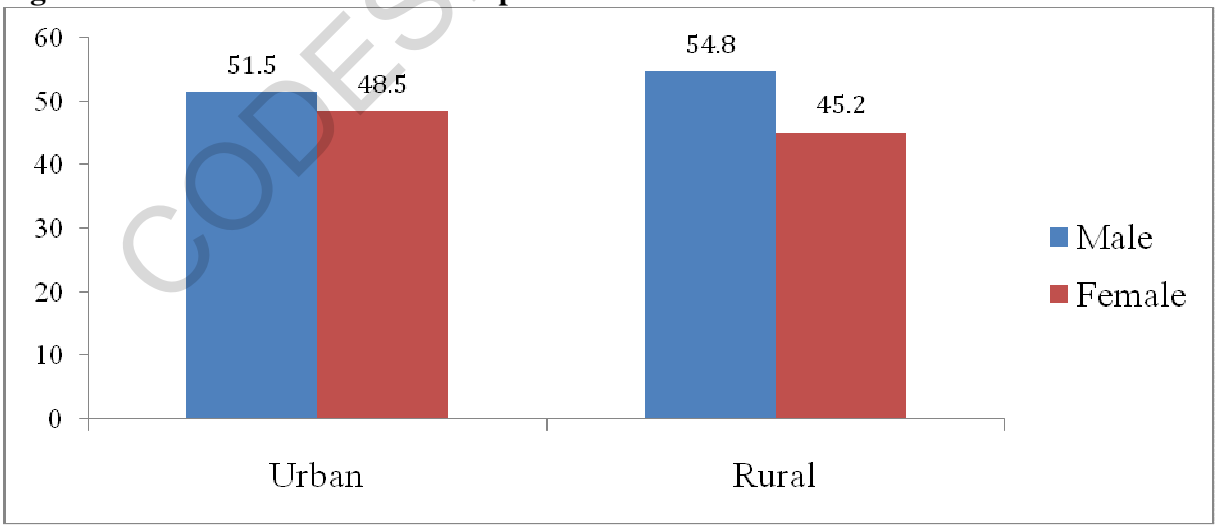
4.0 Introduction

The data presentation and discussions in this chapter are structured around the objectives of the study. The chapter is divided into three major parts. The first part discusses demographic characteristics of respondents; while the second part focuses on issues pertaining to conception and management of Sickle Cell Anaemia. Specifically, these are (a) knowledge of Sickle Cell Anaemia: awareness, definition and perceived causes (b) treatment options for the management of Sickle Cell Anaemia (c) preventive measures for Sickle Cell Anaemia (d) factors influencing the conception, therapeutic regimen and management of Sickle Cell Anaemia; (e) health budgeting, (f) decision making process and (g) factors militating against positive health outcome, while the third part involves the discussion of the findings.

4.1 Demographic Characteristics of Respondents

Out of 1,817 respondents that constituted the study population, 57.9% were from urban areas while the remaining 42.1% were from rural areas.

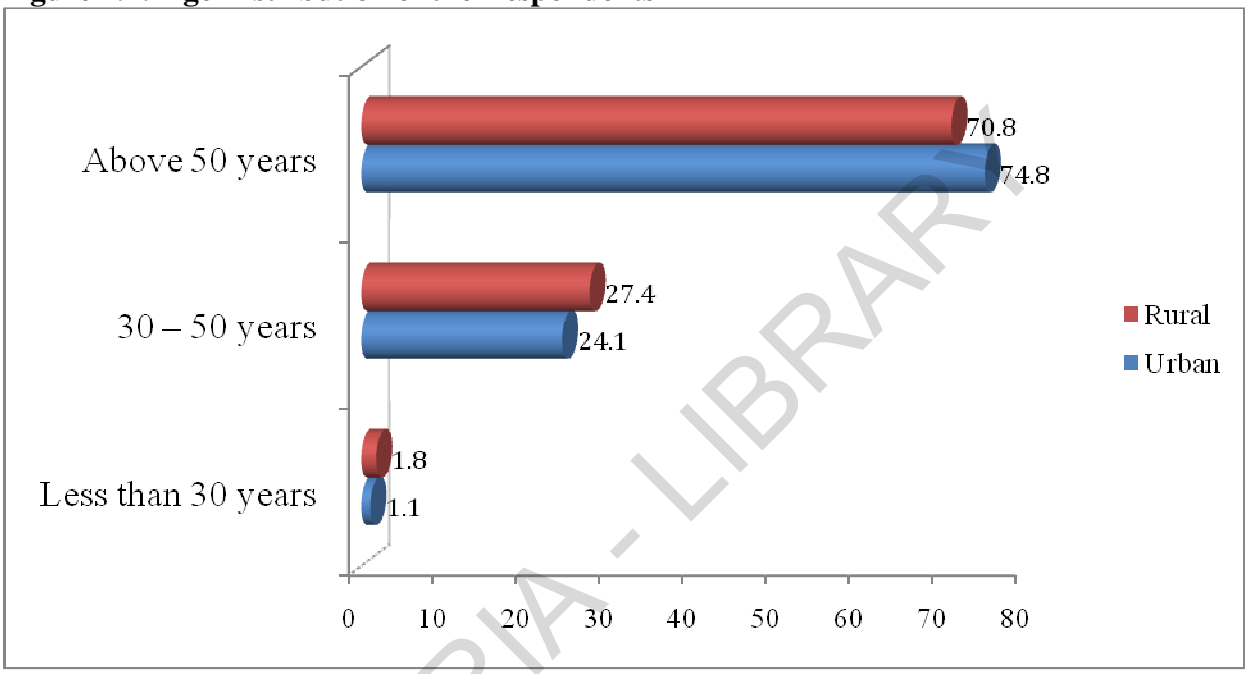
Figure 4.1: Gender Status of the Respondents



Source: Field Survey 2009

The above figure shows that 51.5% and 54.8% of the male respondents were from urban and rural areas respectively while the remaining population constituted the female respondents. The predominance of males over females is a product of sampling method adopted which was necessitated by the existing patriarchal family system in the study area.

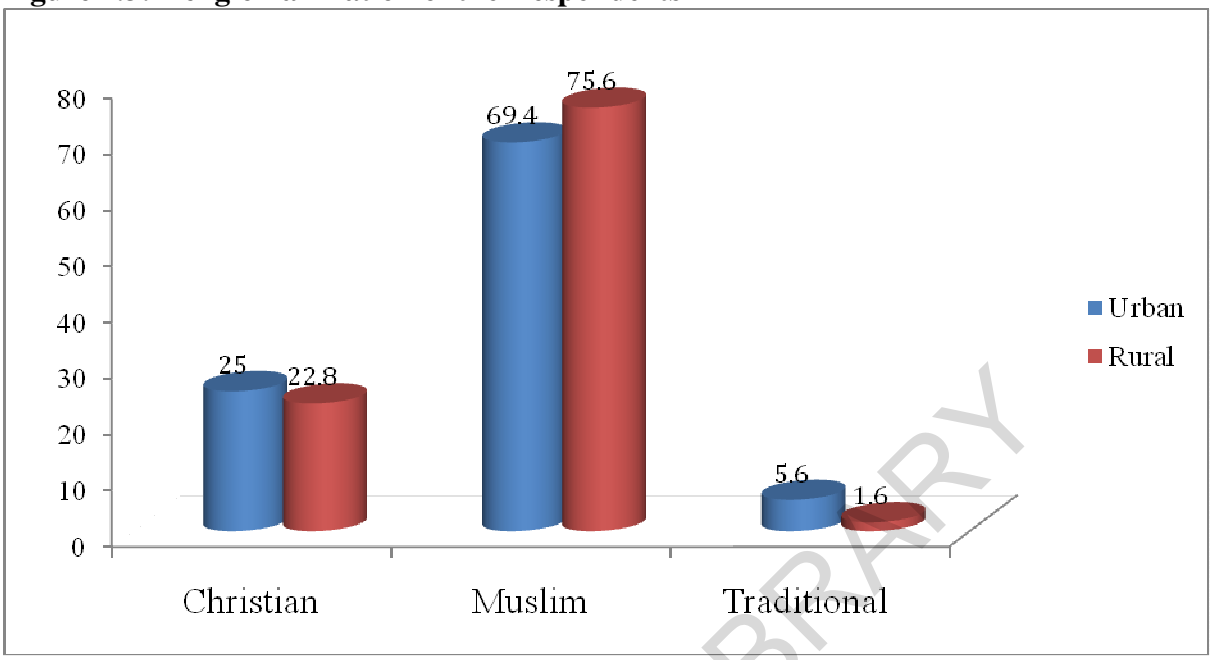
Figure 4.2: Age Distribution of the Respondents



Source: Field Survey 2009

Most of the respondents from the urban (74.8%) and rural (70.8%) areas were over 50 years of age. This was followed by those who were between 30 and 50 years of age, which is the reproductive age group as well as the economically productive group in the population of every society.

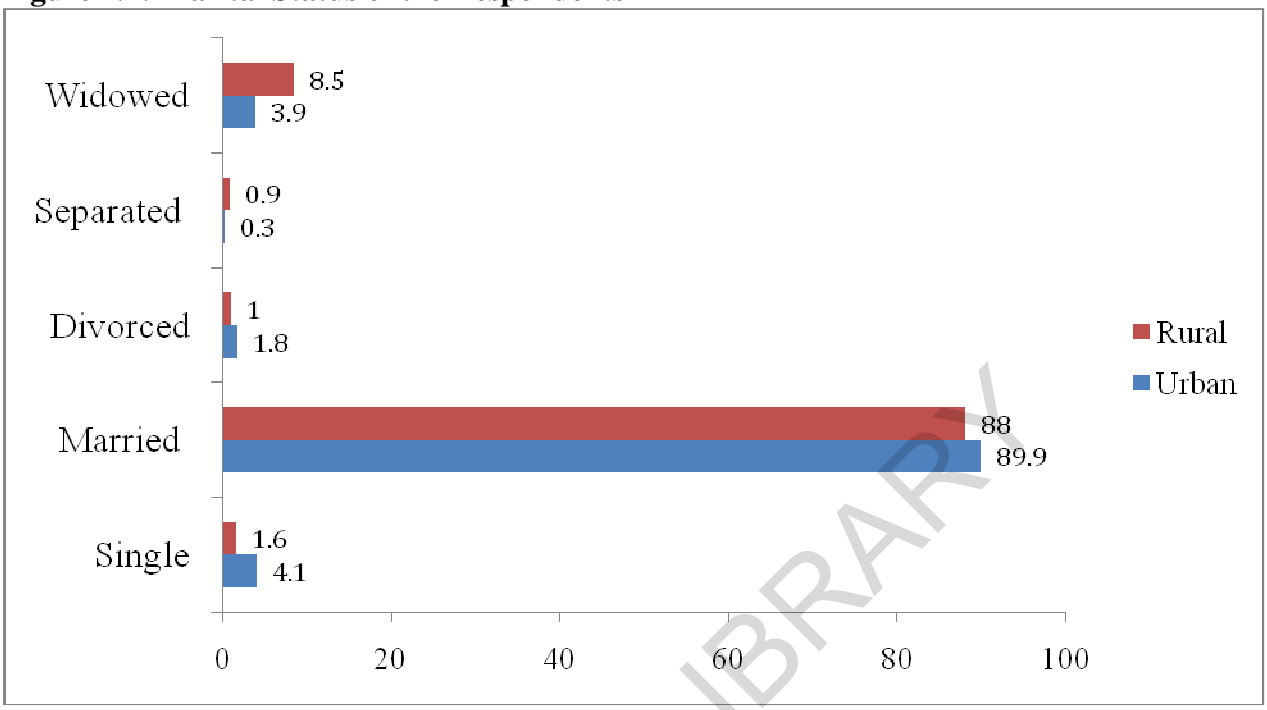
Figure 4.3: Religion affiliation of the Respondents



Source: Field Survey 2009

The religious affiliations of the respondents are presented in the above figure. The findings showed that the Muslims constituted 75.6% and 69.4% of the respondents from rural and urban areas respectively. The remaining percentage consisted of the Christians and the traditional religion adherents.

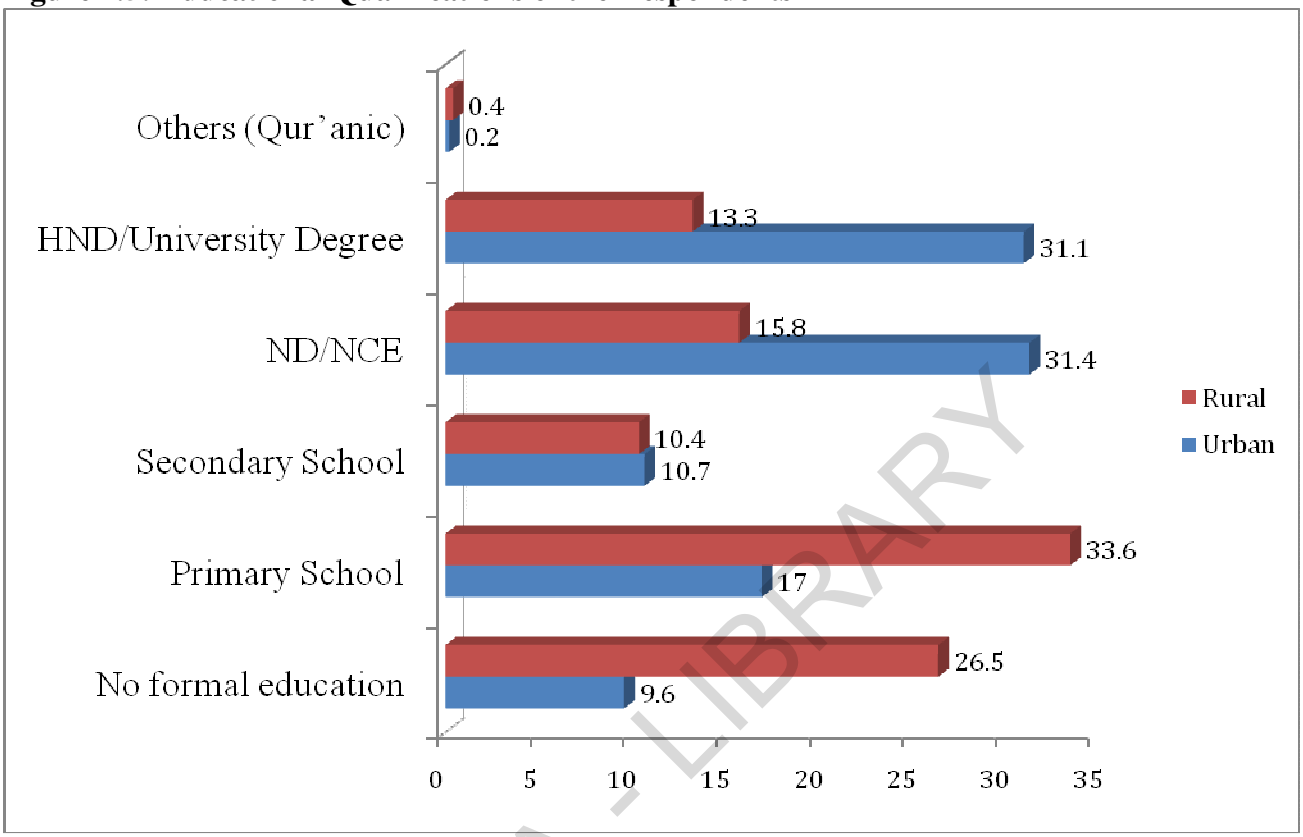
Figure 4.4: Marital Status of the Respondents



Source: Field Survey 2009

Substantial proportion of the respondents in urban (89.9%) and rural (88%) areas were married; the remaining percentages composed of widows, separated and divorcees.

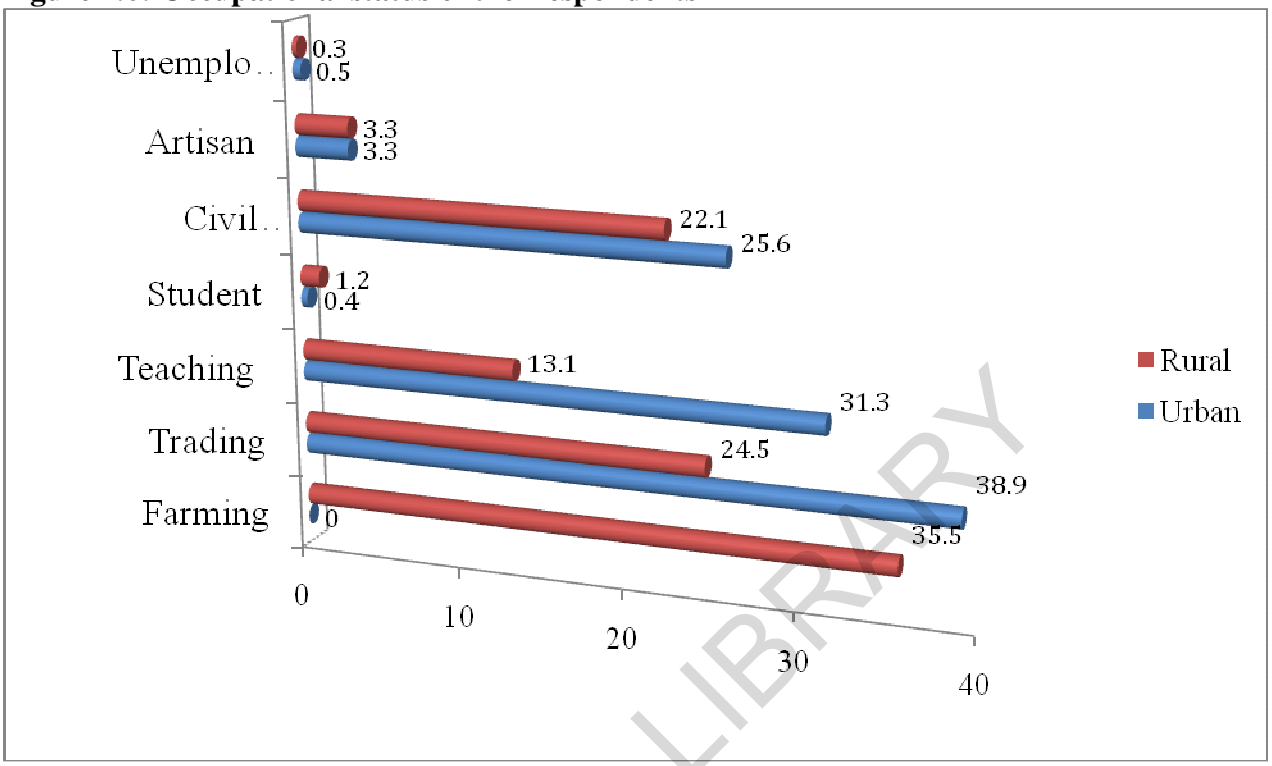
Figure 4.5: Educational Qualifications of the Respondents



Source: Field Survey 2009

Data in figure 4.5 show that educational attainment of the respondents from rural areas is lower than those from the urban areas. For example, 26.5% of the respondents from rural areas had no formal education, 33.6% had primary education, 15.8% had National Diploma/Nigeria Certificate of Education (ND/NCE) and 13.3% had Higher National Diploma (HND)/University degree. Similarly, majority of the respondents in urban centres had ND/NCE (31.4%) and HND/University Degree (31.1%). These figures corroborate the findings of Nigeria Demographic and Health Survey (NDHS, 2003) that educational attainment is higher in urban areas than in rural areas. The results also support the positions of Adetoro (2006) and Oyerinde (2002) regarding educational advancement in Osun State. The two scholars link the attainment of basic education in the study area to the fact that successive administrations in the state have continued to pursue the policy of Free Primary Education scheme that was introduced in the defunct Western Region.

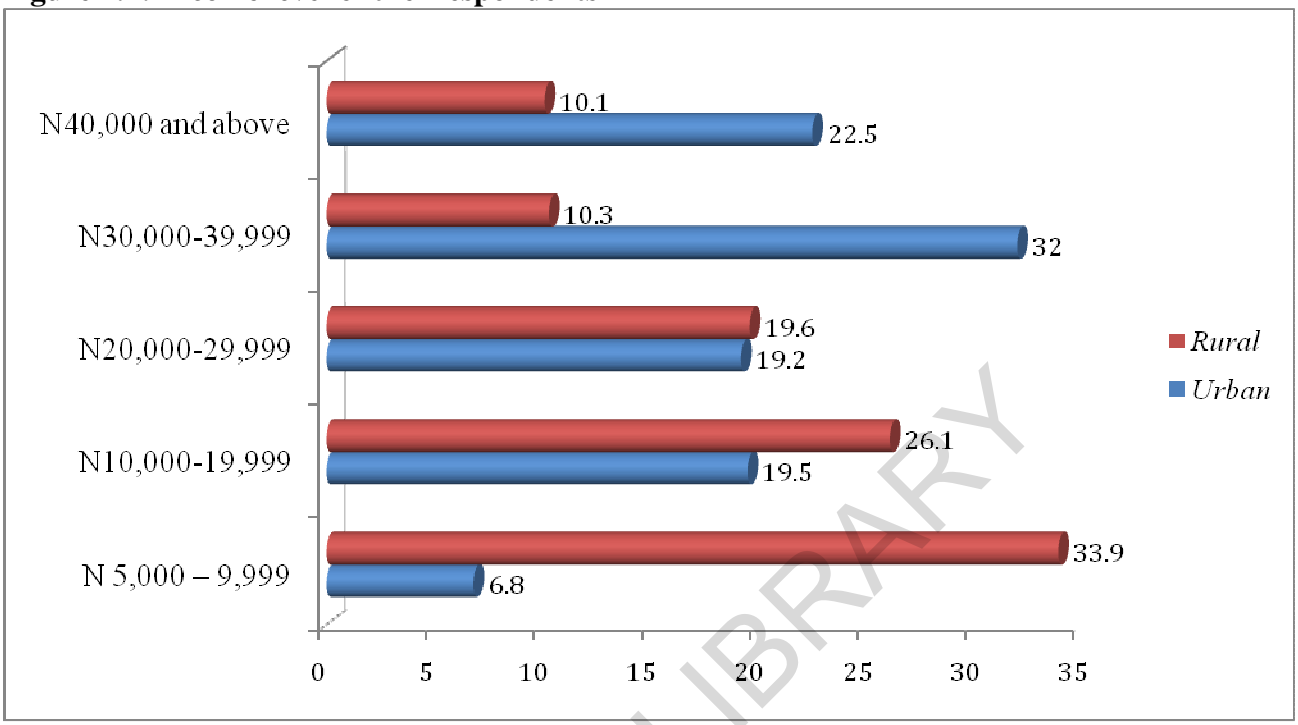
Figure 4.6: Occupational status of the Respondents



Source: Field Survey 2009

The above figure shows that 35.5% of the respondents from rural areas were farmers, 25.4% of them were into trading, 22.1% were civil servants while 13.1% were teachers by profession. Trading is the dominant occupation (38.9%) in the urban centre, followed closely by teaching (31.3%) and civil service (25.6%). This is an indication of the dominance of trading and farming as major means of livelihood among the population in Osun State.

Figure 4.7: Income level of the Respondents



Source: Field Survey 2009

The data in figure 4.7 reveal that the income level of most households studied was between ₦30, 000 and ₦39, 999. The bulk of households earning these amounts came from the urban area. In the rural area, the income level is generally low and it is here that a significant proportion of the household earns between ₦5, 000 and ₦9, 999 per month (14.3%). The disparity in the level of income from urban and rural areas may be attributed to the level of commercial activities which was higher in the urban centre than in rural areas. The lower level of monthly income from rural setting may also be a manifestation of subsistence level of agricultural activities in rural areas.

4.2 Issues on Conception and Management of Sickle Cell Anaemia

The concern here includes knowledge of Sickle Cell Anaemia (awareness, definition and perceived causes), treatment and preventive measures for Sickle Cell Anaemia, health budgeting, decision making for treatment, factors influencing conception and management of the disease as well as factors militating against positive health outcome.

Objective One: Awareness and Knowledge of Sickle Cell Anaemia

4.3 Awareness and Knowledge of Sickle Cell Anaemia

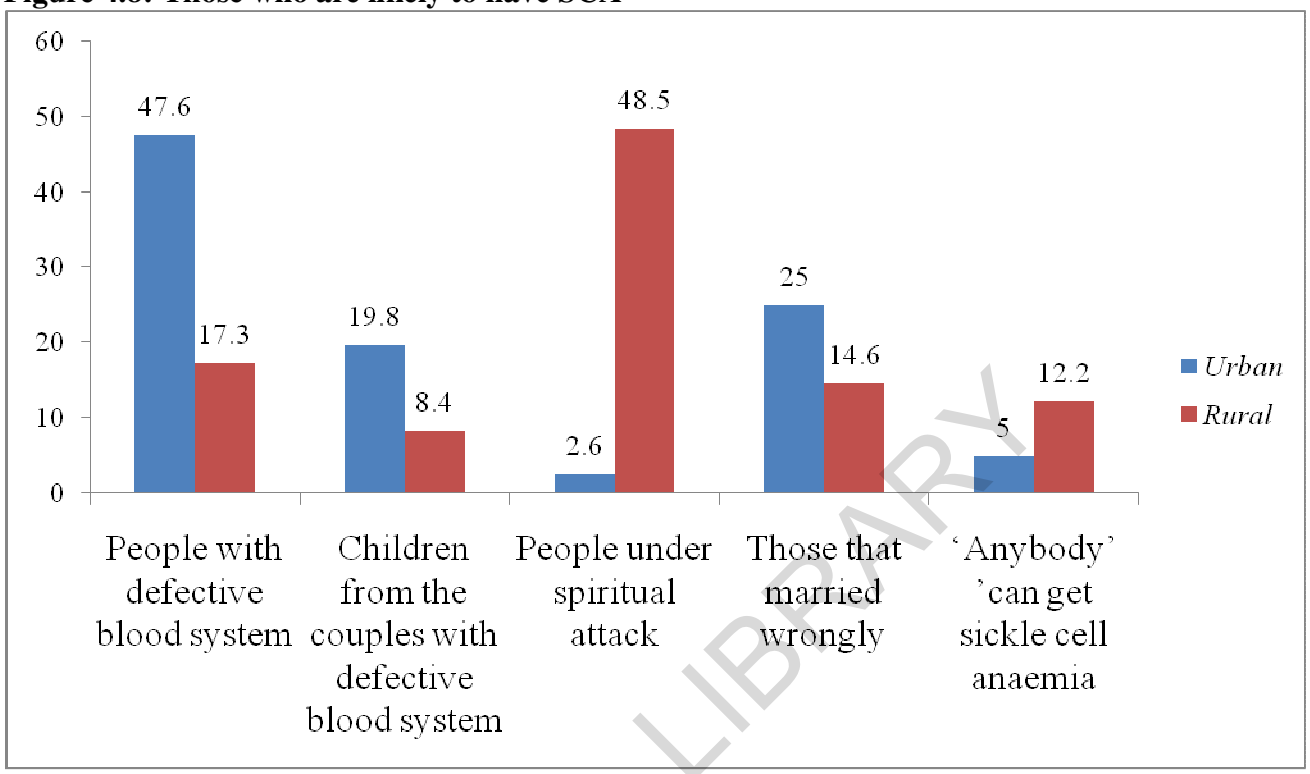
Data from this study show that 99.7% of respondents acknowledged the existence of Sickle Cell Anaemia (SCA). Such awareness was based on experience and information received through interactions with members of the community. One of the participants in the interview sessions clarified further by admitting as follows:

> It is very difficult to answer this question. However it would be wrong at the same time to conclude that people are not knowledgeable about SCA. The fact that cannot be ignored is that people always define this medical condition in line with their environmental peculiarity (Male KII, Medical Doctor, LAUTECH Teaching Hospital, Osogbo).

As a demonstration of their knowledge of Sickle Cell Anaemia, the respondents mentioned some of the signs and symptoms that usually accompany this disorder. These, according to them, include persistent crisis (34%), joint pain (16%), protrusion of the stomach (12%), discolouration (yellowish grey) of the eye (9%), pale skin (6%) and stunted growth (23%).

Respondents demonstrated adequate awareness and knowledge of Sickle Cell Anaemia by acknowledging its existence in the study areas and were able to mention important signs and symptoms that always accompany this disorder. Adequacy of individuals' knowledge of Sickle Cell Anaemia was based on the conformity of their representations of this disease (signs and symptoms) to its Western medical perspective. This further confirmed that the disorder is not alien to them.

Figure 4.8: Those who are likely to have SCA



Source: Field Survey 2009

Most (47.6%) of the respondents from urban centre in the study area were of the view that people with defective blood system are likely to have SCA. It was also asserted that children from couples with defective blood system[4] (19.8%) and those that married wrongly[5] (25%) can have SCA. From the rural area, people under spiritual attack were perceived as likely to have Sickle Cell Anaemia disorder (48.5%). Others (12.2%) asserted that 'anybody' can contract Sickle Cell Anaemia. The position that people under spiritual attack are likely to have Sickle Cell Anaemia had least response in the urban centre. The findings from urban centre showed a high level of agreement with Western medical perspective on what constituted Sickle Cell Anaemia and the people that can contract it. Qualitative data from in-depth interviews also revealed those who are likely not to have Sickle Cell Anaemia. A respondent submitted thus:

[4] The concept means blood system that is infected with the disease.

[5] This implies relationship between opposite sexes that resulted in marriage/co-habitation due to unintended pregnancy. Here the traditional control measure/due process in ascertaining the compatibility of the 'intending' couple was not allowed to take place hence the occurrence of avoidable circumstance like incidence of Sickle Cell Anaemia.

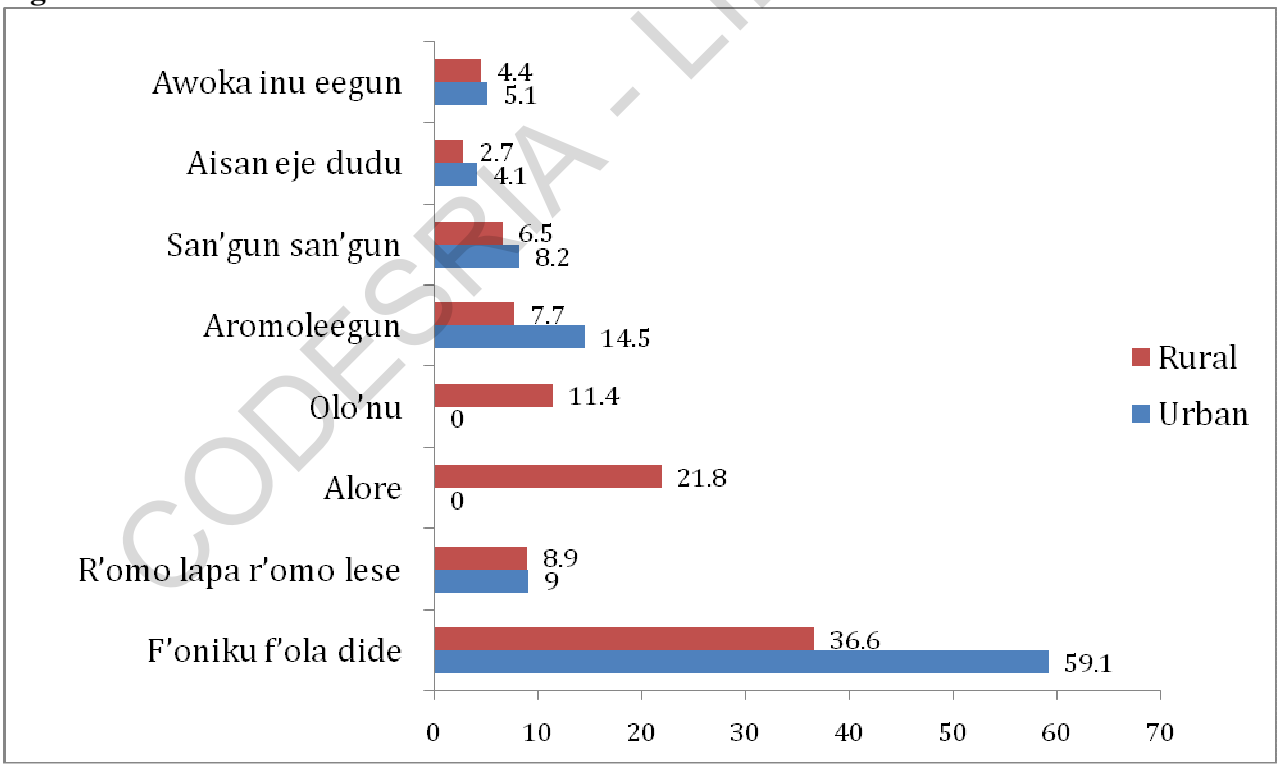
> The disorder is somehow difficult to understand, because it strikes unexpectedly; however, people who are careful when selecting their partners and those who have undergone genotype screening before marriage are likely not to have it (Male IDI, Male Caregiver at Ede).

Demonstrating their knowledge of this disorder further, most of the respondents (51.6%) were of the view that Sickle Cell Anaemia always remain with people living with it for as long as they live. Another proportion (25.1%) believes that the disorder stays with the people living with it until or unless a cure is found for it. This is an indication of belief in the prospect for the cure of the disorder.

4.4 Definition of Sickle Cell Anaemia

The focus here includes how Sickle Cell Anaemia is defined; especially the names given to it in local dialects.

Figure 4.9: Cultural definitions of Sickle Cell Anaemia



Source: Field Survey 2009

According to the findings, Sickle Cell Anaemia is defined in several ways by the respondents in both urban and rural parts of the study area. Most of the respondents from urban (59.1%)

and rural (36.6%) areas defined it as *f'oniku f'ola dide*[6]. Other definitions based on the findings include: *r'omo lapa r'omo lese*[7], *aromoleegun*[8], *san'gun san'gun*[9], *aisan eje dudu*[10], *awoka inu eegun*[11]. Numerical strength of these definitions is higher among the respondents in urban centre compared to those in the rural settings. Definitions like *Alore*[12] and *Olo'nu*[13] are peculiar to rural areas only (see Figure 4.9). This corroborated the Chi-square results of the first hypothesis raised in this study, which says geographical location of where individuals reside significantly influenced the interpretation of Sickle Cell Anaemia (χ^2 = 91.45, 18df, P<0.05). The findings from the interview sessions also affirmed some of the local concepts listed above. According to a Key Informant:

> The ailment is known as *San'gun San'gun*; some people also defined it as *Olonu* based on instances where SC patients experience protruding belly. However, it can be treated but on gradual basis (Male KII, Herbalist, Ila Orangun).

Another medical provider asserted that:

> Many people, including traditional healers, do not know this ailment as Sickle Cell Anaemia but used symptoms to name the disease. For instance, it is called '*ar'omoleegun'* because the patients normally feel pain at the joints and other parts of the body. The discomfort usually makes the patients feel as if

[6] This refers to recurring nature of crises in SCA which affects the social roles of the people living with the disease.

[7] This concept refers to the pain in the joint that is usually experienced by the people living with Sickle Cell Anaemia. Arms and legs are often the most affected parts during the episode of Sickle Cell crises; this thus becomes the concept with which the disorder is referred to among the Yorùbá in Nigeria.

[8] This means the health phenomenon that causes pain-of-the-bones. Interestingly, the same concept is used in describing rheumatism since major symptom of rheumatism equally includes pains in the bone.

[9] This also revolved around the issue of pain-of-the-bones; however, this concept lay special emphasis on the intensity of pain being experienced by people living with Sickle Cell Anaemia. By this concept, the pain is persistent and more alarming in nature.

[10] This is one of the few instances where the Yorùbá make reference to SCA as having something to do with the blood system. The belief here is that the blood has been transformed from its traditional red to black due to certain abnormalities in it. The belief here is that the blackness of the blood will not allow the body system to function normally hence the recurrence of crises in SCA patient.

[11] This means the movement of unknown element (probably virus) round the body with the primary objective of attacking the bones. This equally has synonym with issue of Western medical construction of SCA as bone marrow related health problem.

[12] The concept of SCA denotes unpredictable nature of the disorder. It means a phenomenon that can render a competent health practitioner inept.

[13] Part of the symptoms that usually manifest in the people living with Sickle Cell Anaemia of SCA is protrusion of the stomach. People refer to this scenario as *Olo'nu* which literarily means grinding stone placed in the stomach. This thus becomes one of the concepts with which SCA is described and identified.

> the pain is coming directly from the bone. Another fact is that people always understand the situation better when this disorder is identified and addressed this way (Male KII, Ethnobotanist, University of Ibadan).

Corroborating the above, a medical practitioner said:

> We've discovered that expression of the health problems always have peculiarity with other known diseases hence the necessity of not relying on their accounts of health problem until medical diagnosis. On diagnosis, we often discovered that such complaints usually differ from the actual problems complained of. The same goes for SCA. Our ability to have clear picture of incidence of SCA is through genotype screening; if not, the incidence of SCA narrated by patients as *'ar'omoleegun'* may be misconstrue for rheumatism. A management therapy applied along this line will surely not produce desired results (Female KII, Medical Doctor, General Hospital, Osogbo).

From the foregoing, it is evident that cultural definitions of Sickle Cell Anaemia do not align with its Western medical context. The implication of this is that consultation outside Western medical setting like medication from Patent medicine sellers may lead to wrong medical prescription.

Of all the culturally-informed definitions of SCA, *f'oniku f'ola dide* had wider acceptance among the participants in key informant and in-depth interviews. Other definitions of SCA derived from qualitative data were similar to what were obtained from the quantitative data. Also, the conceptual views expressed about Sickle Cell Anaemia were similar in spite of variations of dialects among the people in Osun State. A look at the way Sickle Cell Anaemia is conceptually defined in local idioms will show three distinct understandings of the disease. Firstly, it shows that the cultural conception of Sickle Cell Anaemia takes place within outward results *of the disorder* (*f'oniku f'ola dide, olonu* and *alore*) framework. Conception process also takes into consideration *the symptoms* (*r'omo l'apa r'omo l'ese*, *aromoleegun, san'gun san'gun*) exhibited by the disorder and lastly the identification of *causative agents of the disorder* (*aisan eje dudu, awoka inu eegun*). Nevertheless, cultural definitions and interpretation of Sickle Cell Anaemia did not align with its Western medical model.

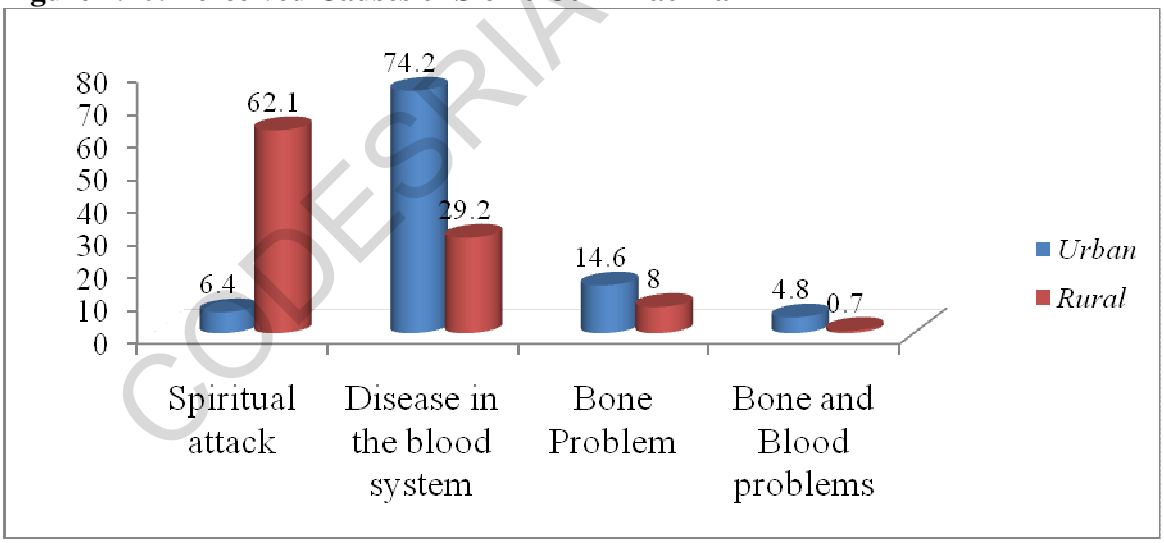
It can also be inferred from the data collected in this study that illnesses resulting from SCA influence the multiplicity of definitions given to the disorder. Within the context of submission by Wahlex (1999), Kleinman (1975) and Mechanic (1972), people defined

Sickle Cell Anaemia in various ways as shown earlier based on socially constructed meaning derived from experience of this disorder. This substantiates the position of Obeyesekere (1976) that 'cultural diseases' are created through cultural definition of the situation. It also supported the positions of Layiwola (2005), Fagbenle (2002), Litman (1974) and Fabrega (1972) that illness is shaped by cultural factors governing perception, labeling, explanation, and valuation of the discomforting experience, processes embedded in a complex family, social and cultural nexus. These scholars see illness experience as an intimate part of social systems where meaning and rules for behaviour are strongly influenced by culture. The findings are also in line with similar works by Jegede, (2010), Owumi (1996) and Oke (1995), which show that conception (definition, interpretation and perceived causes) of a chronic health problem like Sickle Cell Anaemia is a product of cultural interpretation.

4.5 Causes of Sickle Cell Anaemia

Discussion under this section highlights what the respondents' perceived as causes of Sickle Cell Anaemia in the study area.

Figure 4.10: Perceived Causes of Sickle Cell Anaemia



Source: Field Survey 2009

The data in figure 5.10 indicate that a substantial proportion of the respondents from urban and rural areas perceived SCA as being caused by a disease in the blood system. Most of the respondents from the rural area (62.1%) see spiritual attack as accounting for the cause

of Sickle Cell Anaemia. The least mentioned of all perceived causes of SCA was the combination of bone and blood problems (0.7%). In urban area, majority of the respondents attributed Sickle Cell Anaemia to the disease in the blood (74.2%). Qualitative data in this study equally affirmed this mixture of biological and non-biological explanations expressed above. Findings further showed that the actual cause of Sickle Cell Anaemia always becomes clearer after a series of consultations with medical experts. This situation thus highlights the fact that very often the causes of Sickle Cell Anaemia were interpreted at initial stage within cultural, spiritual and superstitious milieu. According to a female respondent:

> It is not always easy to see this condition as a biological problem. My interactions with other mothers of the people living with Sickle Cell Anaemia also confirmed this. It is either this problem is seen as a spiritual attack or as heavenly inflicted problems. But in the course of wider consultations for better health outcome, the SC sufferers/primary caregivers will come to terms on the credibility of Western medical explanation of SCA (Female IDI, Primary Caregiver at Osogbo)

In support of the above, another participant noted that:

> I did not know that my second child (a boy) is sickle cell anaemic until he was one and half years old. His case was being treated as ordinary fever at initial stage, later as rheumatism until about a few months ago when he was diagnosed as being Sickle Cell sufferer (Female IDI, Primary Caregiver at Ile-Ife).

Traditional healers and diviners emphasized the veracity of supernatural causes of disease and illness in general. The spiritual cause, according to them, could be in the form of attack and casting of spell, which could be determined and cured only through divination by consulting the gods and oracle. It was noted that the only way by which spirituality could come into play in the case of SCA was through casting of spell to cause *emotional trauma* in the people living with SCA and/or primary caregivers. The expectation of such spell is to bring about frustration and impatience as well as eventual non-compliance with treatment regimen, and in the long run poor health outcome. On the other hand, experience and interactions with medical practitioners, educated and enlightened individuals influenced the position of faith healers on cause(s) of Sickle Cell Anaemia. This is why they identify with the Western medical model of SCA as a genetic-dysfunction. In spite of the belief in the biological etymology of Sickle Cell Anaemia, both Christian and Islamic faith healers

(religious healers) were of the view that trauma from health problem could be spiritually induced to cause devastating effects on adopted management therapy. Chi-square results showed that conception significantly influenced the management of Sickle Cell Anaemia (χ^2 = 98.3, 8df, P<0.05). This reveals further that cultural conception of SCA is very relevant and an important determinant in the management therapy being adopted for the disorder. By this finding, the second hypothesis is, therefore, accepted. The emergence of non-scientific factors as parts of the perceived causes of Sickle Cell Anaemia in this study is a justification of previous studies (Maruzi, 2005, Akinsola, 1993 and Bourdillon, 1991) on multi-factorial aetiology of ill health. It showed the inadequacy of germ theory as an analytical category for understanding human behaviour on health matters. Box 1 illustrates the effects of cultural conception of an adopted management therapy.

Box 1: Christian Faith Healer (Male/Ila Orangun)

Pastor J.A. is a leading figure among the Pentecostal Clergymen in one of the Local Government Areas in the northern part of Osun State. His ministry has a Mission House where the medical needs of the church members and other interested members of the community are attended to. He has been in the Vineyard of the Lord in the last nineteen years. He believes in the potency of prayer as capable of solving any problem, whether physical or spiritual.

He said that SCA is called different names within the community. Some of these names include Alore, Awoka inu eegun, r'omo lapa romo lese and f'oniku f'ola dide. The interesting aspect of revelation by this man of God is that interaction with Western medical doctors and divine revelation showed that SCA is not curable but could be managed. He noted that most of the patients and primary caregivers are always troubled emotionally. This informed the usual desperate search for positive health outcome and multiple consultations for medical therapies. The role of prayer and fasting here is to ensure the stability of emotion of the patients and the primary caregivers for proper healing process to take place.

With faith on the part of the sick and the primary caregivers, the prayer has never failed to stabilize their emotion. After this, they are always directed to the nearest Western medical clinics where necessary referral will be effected to Obafemi Awolowo University Teaching Hospital, Ilesa or Ile-Ife, LAUTECH Teaching Hospital, Osogbo or University College Hospital, Ibadan. Where people are making use of hospital care, efforts are always directed towards spiritual monitoring and assistance. The people do come once in a while for spiritual counseling as well.

Pastor J.A. revealed that whenever these people come for healing, they usually share their problems with him. According to him, they found it convenient to discuss these problems with faith healers than doing the same with Western medical doctors. Most often the problems bothered on medical and personal issues. He disclosed that the personal problems that are not attended to adequately do aggravate the magnitude of medical problem.

The discussion in Box 1 justified the views of Fajemilehin (2009) and Williams *et al,* (1994) that man always reacts differently when confronted with the symptoms of disease in line with his basic goal of increasing the span of a healthy life with emphasis on health not just longevity. It also confirms that concepts of health and disease evolve with societies (Golini and Galvani, 2001). With this development, it is obvious that the possibility of emergence of new concept for disease, health and illness is constant especially with changes in socio-economic status of individuals within the society (Garuba, 1997 and Camozzil, 1992).

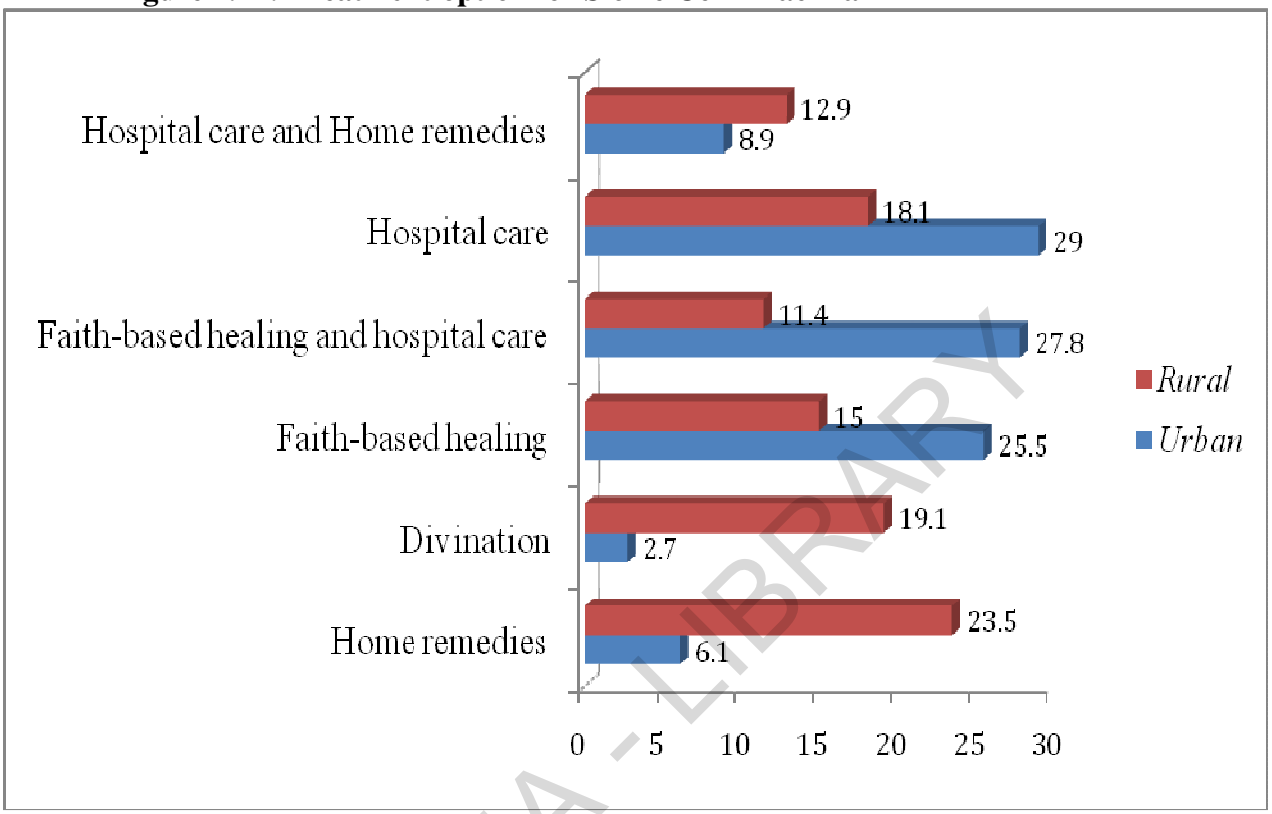
It further shows that the meaning of illness is shared and negotiated in everyday interactions and deeply embedded in the social world. Such meaning, in the words of Berger and Luckmann (1991), eventually becomes the consensual recognition of the coherence or realness of a constructed reality. This further substantiates the position of Atwood (1996) that the definition or meaning an individual gives to an illness is profoundly influenced by the person's social world (culture and social networks). This also affirmed the position of existing literature on the matter (Maruzi 2005, Fagbenle 2002, Atwood 1996, Bourdillon 1991, Atwood and Weinstein *nd*). The manifestation of the foregoing is that concepts of diseases, medical treatment and care, health and health promotion do not exist in a socio-cultural, institutional and political vacuum. Rather, they reflect what Fajemilehin (2009) called the values, belief, knowledge and practices shared by lay people, professionals and other influential sub-group.

4.6 Management of Sickle Cell Anaemia

Variables for the management are available treatment options and preventive measures of this disorder. Discussion on management of Sickle Cell Anaemia therefore cuts across these two variables.

Objective Two: The Pathways to Treatment of Sickle Cell Anaemia

Figure 4.11: Treatment option for Sickle Cell Anaemia



Source: Field Survey 2009

4.7 Treatment of Sickle Cell Anaemia

Treatments for Sickle Cell Anaemia (SCA), according to the figure above, were sought within and outside the perimeter of formal health care system. These include hospital care[14], faith-based healing[15], divination[16], home remedies[17], combination of faith-based healing and hospital care, and combination of home remedies and hospital care. In the rural areas, home remedies (23.5%), divination (19.1%) and hospital care (18.1%), among others, were the popular treatment options for SCA. Data from qualitative study also revealed similar results. In relation to this a Key Informant submitted thus:

[14] This includes Western medical clinics and hospitals

[15] This involves spiritual inquiry or diagnosis, guidance and healings through Christian and Islamic faiths

[16] The services of diviners are essentially relied upon for solution to medical problems

[17] Issues like traditional medicine, self medication using herbs and over-the-counter drugs are classified as home remedies here.

> There are varieties of ways by which people manage SCA; these include modern health system and traditional healing system. Some people do consult spiritualists as well. Over 90% of people living with Sickle Cell Anaemia always patronize virtually all local medical options available for the management of SCA before finally adopting orthodox medicine (Male KII, Medical Doctor, OAUTHC, Ile-Ife)

While a multiplicity of treatment measures was established, justifications were given for this. According to a key informant:

> ….all the primary caregivers and the people living with Sickle Cell Anaemia usually utilize the available treatment options found within their environments at one point in time before seeking for further treatment elsewhere (Female KII, Nursing Officer at Osogbo).

Other reasons include lack of adequate information about the disorder, financial predicament as well as influence of family members and neighbours. Information on SCA at the home front, according to the participants in interview sessions, often comes in skeletal form. In the words of a participant:

> …..it is not always easy for people to know that their children or wards have SC disease except in cases where a medically-informed individual is available within the family. The disease may set out in form of common cold, catarrh or malaria. At that point, community members will keep on assuring one that they have seen similar cases that have been treated successfully by one person or the other. That is why you see an average primary caregiver and people living with Sickle Cell Anaemia moving from one neighbourhood to another searching for better remedy until a laboratory diagnosis will show that the case is nothing but SCA (Female IDI, Primary Caregiver from Sekona).

In terms of preference of treatment options, data further showed that faith-based healing (25.5%), a combination of faith-based healing and hospital care (27.8%) and exclusive hospital care (29%) were preferred in the urban area. Key Informants could not ascertain the preferred treatment option by the people due to extensive search and multiple consultations of medical services. In the words of an Informant:

> It is circumstance that usually forced people to settle finally with Western medical facility. The problem is that people always expect miraculous healing hence the difficulty in settling with one particular treatment option. With this attitude one cannot be categorical on the preferred health facilities for the management of SCA among the populace (Female KII, Nursing Officer at Ikirun).

In support of the above, another Informant said:

> People are always impatient when seeking for solution to their health problems. They are very much interested in getting instant cure because of the painful conditions patients are passing through. On the basis of this, it is difficult to determine the health option these people preferred (Male KII, Herbalist from Gbongan).

Table 4.1: Classification of Preferred Treatment Options

Preferred Treatment Options	***Urban***		***Rural***	
	N	***%***	***N***	***%***
Home remedies	39	3.7	99	12.9
Divination	18	1.7	52	6.7
Faith-based healing	37	3.5	84	11.0
Faith-based healing and hospital care	102	9.7	43	5.6
Hospital care	335	31.9	130	17.0
Hospital care and home remedies	306	29.1	192	25.1
Hospital care, home remedies and faith-based healing	214	20.4	166	21.7
Total	1051	100.0	766	100.0

Source*: Field Survey 2009*

As shown in the above table, exclusive hospital care is preferred by most of the respondents (31.9%) in urban area. Other treatment options preferred include the combination of hospital care and home remedies (29.1%) as well as the combination of hospital care, home remedies and faith-based healing (20.4%). In the rural area, preference manifested in the form of treatment options like the combination of hospital care and home remedies (25.1%), the combination of hospital care, home remedies and faith-based healing (21.7%) and exclusive hospital care (17%).

Table 4.2: Justification for the Treatment Options preferred

Justification	***Urban***		***Rural***	
	N	***%***	***N***	***%***
Interpretation of the disease	402	38.2	299	39.0
Accessibility	131	12.5	126	16.5
Affordability of management option	103	9.8	95	12.4
Efficacy of previous utilization	214	20.4	111	14.5
Proximity of the treatment option	105	10.0	70	9.1
Spiritual reasons	96	9.1	65	8.5
Total	1051	100.0	530	100.0

Source: Field Survey 2009

Interpretation given to Sickle Cell Anaemia (SCA) ranked highest among the reasons given for the preferred treatment options in urban (38.2%) and rural (39%) areas. Efficacy of previous utilization of treatment options (20.4%), accessibility of treatment options (12.5%) and proximity of such facilities (10%) are the reasons given for the treatment options preferred in the urban areas. In the rural areas, the reasons include accessibility (16.5%), efficacy of previous utilization (14.5%) and affordability of treatment option (12.4%). There exist a small proportion of respondents who declare preference for traditional medicine due to the strength of faith in it and its perceived potency. A typical submission in this regard goes thus:

> ….because of our Christian background, almost every member of my family did not favour traditional healing. They see it as heretic in nature. But I've read and witnessed lots of cases that proved this position wrong. My belief in the efficacy of traditional medicine is what informed my decision to take my ward (the last born of my late parents) that has Sickle Cell Disorder for herbal healing. Since he started to receive treatment from traditional medical provider, he rarely had SC crises. The herbal doctor does his work meticulously; apart from herbal therapy, there were instructions for complementary therapy like massaging, hydrotherapy (uses of various water forms and temperature). However, attacks against traditional therapy from the church and my family continue. My family members expressed fear over the need for laboratory test to ascertain level of perceived toxicity of the traditional medicine being administered into my ward. I eventually succumbed to the pressure in order to maintain existing cordiality in the family. The new arrangement is that the boy should continue with Western medical services like regular test and counseling and usage of traditional medical services at the same time (Male IDI, Primary Caregiver from Ejigbo).

Most of the traditional healthcare providers who are key informants further asserted the efficacy of traditional medicine. Efforts at sustaining this feat as well as ensuring that the herbs produced had no negative effect were equally stressed. In the words of one of them:

> ..….all the leaves around us including those the educated elites called 'flowers' are herbs that can effectively cure one disease or the other. What is needed is for one to identify these natural medicine and their uses. Most often one does not need incantation or special protocol before they can be used. Contemporary herbal therapist is trained to take care of toxic matters in the herbs prepared. Where the problem lies is the issue of regimen compliance. Like the case of *ar'omoleegun* (Sickle Cell Anaemia), it can be cured with appropriate herbs. However, the process towards positive outcome in treatment is gradual, but what is common is that people don't persevere with treatment procedure or they stay away from further consultation and

> medication immediately a certain degree of improvement is noticed in their wards (Male KII, Herbalist Inisa).

Findings also showed that the management process of a debilitating health condition like Sickle Cell Anaemia through faith-based healing slightly differs from one place to the other. Religious inclination, cultural background and the source of training received by these healers determine such differences. This is glaring in the practices and processes of faith-based healing in Christianity and Islam. The next case being presented is a confirmation of this position.

Box 2: Faith-based healing: Muslim Cleric (Male/Iwo town)

Healing is not limited to offering prayer alone among the Muslim community. It usually involves the combination of herbs; in some instances, Qur'anic verses are written on a wooden slate and washed with water for drinking by the health seekers. Some Mallams (the Muslim scholars that also practice faith healing) utilize prayers and herbs alone. There are others who combine prayers, herbs and Qur'anic-inscription-liquid together to effect healing. Mallam B. belongs to the group of faith healers who combine herbs for healing and disease management.

A series of ailments (such as headache, fertility problems, spiritual problems and so on) are managed by Mallam B. He identified Sickle Cell Anaemia and was able to give accurate account of signs and symptoms associated with the disorder. Just like those that have spoken before him on the issue, he listed various cultural concepts of SCA as r'omo lapa r'omo lese, aromoleegun, san'gun san'gun, aisan eje dudu, awoka inu eegun and f'oniku f'ola dide. He equally saw f'oniku f'ola dide as the concept that is very common among the people that have identified the disease as SCA.

Mallam B. revealed further that people that conceptualize SCA as f'oniku f'ola dide rarely go for other forms of therapy for the disorder beside Western medical management. Economic constraint, according to him, was the only factor that usually makes people do otherwise. In this case, it is either the primary caregivers have exhausted their resources in the previous services utilized or do not have enough financial strength at all. The previous sources here may include self-medication, herbal remedy, hospital care and faith-based healing. He opined that prayer plays unique roles in medication. It provides spiritual assurance and spiritual guidance. Prayer brings about spiritual assurance by removing emotional trauma from the mind of the sick or caregivers. It is through this that the sick or caregivers can have faith in the medication being given. Mallam B. noted that since drugs that worked for one person may not work for others due to body system, prayer always assists in guiding the sick or/and caregivers (primary and secondary) on appropriate medication for the sick. He therefore stressed that the combination of hospital care, herbal remedy and faith-based healing could effect the cure of SCA. While he could not specifically say the cure would be total, he believes the health outcome would be reasonably sound provided the health seekers will be willing and able to endure the gradual processes involved.

Mallam B. did not believe in spiritual attacks as the cause of SCA. However, he was of the view that spiritual attack can be unleashed to create traumatic situation for the sick/primary caregivers. A traumatized individual in this case may not have faith in medical explanation for the ailment; rather than endure to the end for the gradual process of medical therapy being used, he will continue to imagine negative things and subsequent multiple medical consultations. A typical case like this is where faith-based healing (prayer) is needed to stabilize the mind of the sick or the primary caregivers. The positive outcome of this always endears many people towards faith-based healing and their readiness to share their intimate personal problems whether domestic or medical with the healers. This, according to the Cleric, has been assisting them in the course of tackling some of the issues being referred to them. It equally played greater role in the degree of success being recorded in medical outcome of these patients.

Similarly, the Diviners recognized the importance of emotional stability of their clients as requisite for positive health outcome, hence its incorporation into every aspect of therapeutic measures adopted for the management of Sickle Cell Anaemia (see Box 3).

Box 3: Healing through Divination - Practice and Process **(Male/Ejigbo)**

Baba Awo A.I. is a diviner who uses Ifa divination system in making inquiry into unknown problems especially when such problems defy all available solutions. A medical misery like Sickle Cell Anaemia (SCA) is not left out of such efforts. He combines divination with healings which qualifies him as Sawosesegun. Baba Awo does not believe that a disease exists that cannot be cured. The Yorùbá concept of disease that matched the story-line presented to him was r'omo lapa r'omo lese. Baba Awo stated that mortality through Sickle Cell Disorder differs from Ogbanje or Abiku syndrome. He noted further that the Yorùbá healing system does not recognize the idea of genotype-matching. What obtains in Yorùbáland is spirit-matching which could be rightly guided upon consultation with an oracle. Couples whose spirits are not compatible are likely to have problems; such problems may manifest in poor marital relationship between the couple and the type of children coming out of that marriage. Health problems like Sickle Cell Anaemia may occur in any or all of the children from such marriage, hence the usual ascription of such problem to spiritual cause. In the course of his work as a diviner, consultation of Ifa oracle is principal channel towards seeking health solution for his clients. According to him, treatment process for client sourcing for medical help passes through at least three stages. However, not all healers would necessarily pass through these stages, but the stages of diagnosis and treatment were considered paramount.

The first stage entails a warm welcome of the mother or primary caregiver to the compound and greetings according to Yorùbá culture. At this session, the mother is required to explain the ailment plaguing the child, when the ailment started and the steps taken by the mother so far to address it. The second stage involves efforts towards finding out the exact cause(s) of the situation in hand. This is done through divination which is carried out through the use of cowries and cowry tray. The essence of divination was to identify appropriate treatment or solution to the problem. The warm reception of the mother by the diviner was to allay her fear and help her achieve a level of emotional stability. This will prepare the primary caregiver for a smooth treatment process. The implication of this is that diagnosis of the problem goes beyond the immediate health issue. To a large extent, it also embraces the psychosocial factors in the primary caregivers. To the diviner, a traumatized primary caregiver may not comply with treatment regimen unless the person is convinced through words and deeds to assure him/her that he/she is in the right place. In the final stage, the treatment procedure commences with the divination or diagnostic process which will lead to prescription of appropriate treatment. Very often the treatment involves the use of herbs/charms or appeasement. Charms as option may involve oral medication or making of incision on whole or any part of the body. Appeasement may also be prescribed by the oracle if it is detected that the spirit of the client does not favour the use of charms. An individual who uses charms despite the incompatibility with his spirit may not get desired results. Appeasement entails ritual; pacify ancestral masquerade, deities, head/creator or the 'mother'. It may require placing ritual objects at the intersection of three roads or in a dense forest or as may be prescribed by the oracle. Proper follow-up, according to Baba Awo, will bring about solution to any problem including SCA.

Ethno-botanist centre is another source of healthcare service with appreciable patronage; it is being considered in this study for the understanding of conception and management of SCA. A case below gives further information about this.

Box 4: Ethno-botanist Perspective **(Male/University of Ibadan)**

The case here derives from an insight provided by a senior scholar in one of the Universities in southwest Nigeria. He has over two decades experience in active practice in herbs and plants for disease and illness management. As an academic, he has brought up and mentored many young scholars as well as those that preferred independent private practices in ethno-medicine.

On account of his educational background, he was able to discuss the issue of Sickle Cell Anaemia (SCA) from Western medical and cultural perspectives. According to him, the Yorùbá in Southwest Nigeria refer to SCA as Aisan Aromoleegun. He rejected the idea of SCA as a consequence of spiritual attack and that such conceptualization was always a product of concerned family/neighbours. The assurance from people that certain remedy (which usually was always outside Western medical line) was appropriate usually caused delay in seeking timely medication. Sick or primary caregivers had to try out all the suggested options first, so as to maximize resources and time thereby leading to delay due to trial and error approach. This explains why people living with Sickle Cell and/or their primary caregivers almost always utilize all forms of medications that are obtainable in their environment.

The prospect here is that SCA can be successfully managed to a level hardly imagined by Western medical doctors through the use of appropriate herbs. In his words, 'when the herbs are applied, the faulty part of the bone marrow that is turning the blood into 'crescent' or 'sickle' shape will be corrected.' He however noted that the shape of the blood may not be perfectly round, but irregular shape and hardness of the blood which always impede the movement of the blood through the bone marrow will be corrected. Such correction thus forms the antidote which the SC patients need to live normal life. He further noted that laboratory tests were mandatory in certain cases such as the management of SCA for clients so as to understand the medical situation and the kind of drugs to prescribe.

The foregoing highlights family dynamics in health care decision making. It equally shows that the decision to use and combine therapies most often is always a result of external influence. In relation to the illustration in Box 5, such influence, as usual, has effect on individual's definition and perceived causes of Sickle Cell Anaemia.

Box 5: Primary Caregiver (Mother of Four)

Mrs. L.B. is a devout Christian based in Ilesa town, Osun State; she was brought up in the vineyard of God under strict Christian doctrines. Her upbringing has made her to believe that with faith, prayer and fasting, all things are possible for God to do. Her marriage to her late husband in early 1970s was contracted under the control and guidance of the Holy Spirit. She has never had doubt or any course to regret her marriage to the person God chose for her.

The marriage is blessed with four children; two of them are twin. The first three children (twin inclusive) have SC disorder. The twin eventually died, while the last born was also lost to death, probably due to partial neglect in the course of coping with the three that had SC disease.

Going through memory lane, Mrs. L.B. recalled that she once dallied with the idea of seeing the situation as spiritual attacks. The husband was always around to enliven her spirit when she was stressed. Like every other person in traditional setting her idea of illness inflicting her children was seen as malaria at the beginning. When it abated, she met somebody who termed the illness 'Alore'. She knew almost nothing about SCA and what it stands for because her husband was a farmer, while she was into petty trading in a rural community located in Atakumosa East Local Government Area of Osun State.

Through her efforts and consultations in a bid to ensuring positive health for her children, the disease was termed 'San'gun san'gun', 'aisan eje dudu'. Bone problem was said to be the generally held belief within the community as the cause of the disease. The reality of the disease afflicting her family was made known when an Agric Extension Officer visiting their community advised the entire family to go for genotype screening. It was during the screening that the couple knew that their sick children have SCD, and that they and the last child have AS genes. The couple was later directed to the OAU Teaching Hospital at Ilesa for follow-up towards effective management of the disease.

Barely seven month later, the last of the three children with SCA died in quick succession. However, the knowledge gained from health educators assisted in the management of the health of the surviving child that is a SC patient. The knowledge gained really influenced the eventual physical and personality development of the surviving child who is now a legal practitioner and happily married with two children of her own.

Mrs. L.B. acknowledged the roles of the family members, neighbours and significant others in coming to her assistance during the early period of her ordeal in SC management. To her, identification of the disorder and various concepts associated with it are always through these people who most often have always suggested perceived 'best management options'. Such management option(s) is/are either based on personal experience or the information received from the third party who have used it or knew somebody who did.

The pattern of treatment options for this medical disorder shows that choices and alternatives are considered within the framework of existing knowledge, experience and how the case is defined. This is in line with the position of Onu (1999) that past experience of similar illness dictates the definition, diagnosis and treatment. Adoption of local herbs and nutritional

supplements like pigeon pea, pigeon leaves, etc to complement the management of Sickle Cell Anaemia particularly in the areas with inadequate hospital cares corroborated the assertion of Obasola (2005) and Bourdillon (1991) that relative availability of a particular treatment option makes its choice irresistible. The implication of this is that people more readily adopt a view of illness which is compatible with forms of treatment available to them.

Box 6: Local Management therapy - Pigeon Pea (Male, Garrage Olode town)

Mr. S.K. is a farmer, a widower and in his late 60s; he has been taking care of his grand-daughter who was left in his care after the death of his son and wife in a motor accident. As a result of this, he fully took over the role of caring for his grand-daughter who suffers from Sickle Cell Anaemia. The first challenge encountered in the course of managing this disorder was non-availability of a clinic that specializes in the treatment of SC cases.

The available clinics were of a general nature, catering to patients with other ailments. During severe crises, he was referred to the Teaching Hospital in Ilesa. To complement occasional treatment from hospital care, he relied on local therapy called 'ewe' and 'ewa otili' (pigeon pea and its leaves) which were used as herbal remedy and nutritional supplement. The plants that produce these seeds were available in the area. The seeds have the appearance of beans, except that they are bigger and flat compared to beans. This plant is good for controlling the crises arising from SCA. It is boiled and the water drunk while the seeds are eaten as part of the therapy.

The seed, when cooked, is not as sweet as common beans but the taste is still okay for consumption. What most people, using the plant, do was to adopt it as part of family menu especially during raining season when most people living with Sickle Cell Anaemia are susceptible to recurrent crises. Inclusion of this as family menu serves as encouragement for its consumption by the individuals living with Sickle Cell Anaemia in spite of its somewhat unappetizing taste. This has been very effective in SC management. The belief is that the combination of herbaceous liquid (agbo) of pigeon pea leaves (otili) and cooked pigeon peas (ewa otili) will help in taking care of any other ailments apart from SCA within the body system. Through this, the incidence of crises has been drastically reduced to the barest minimum. As a result of this, consultation for hospital care was regarded as routine exercise for health talk and check-up

The findings here affirmed the positions of previous scholars (Mustapha, 2007, Mailafia, 2005, Atwood and Ruiz, 1993; Rolland, 1993; McDaniel, *et al,* 1992) who noted that every family has strategies centered at meeting the ill person's medical and other caregiving needs. While the case in Box 6 demonstrated a novel idea injected into emotional supports system in the use of herbal therapy for treatment of Sickle Cell Anaemia, the next case shed light on the motive behind this.

Box 7: Local Management therapy - Pigeon Pea and Garlic (Male/Awo town)

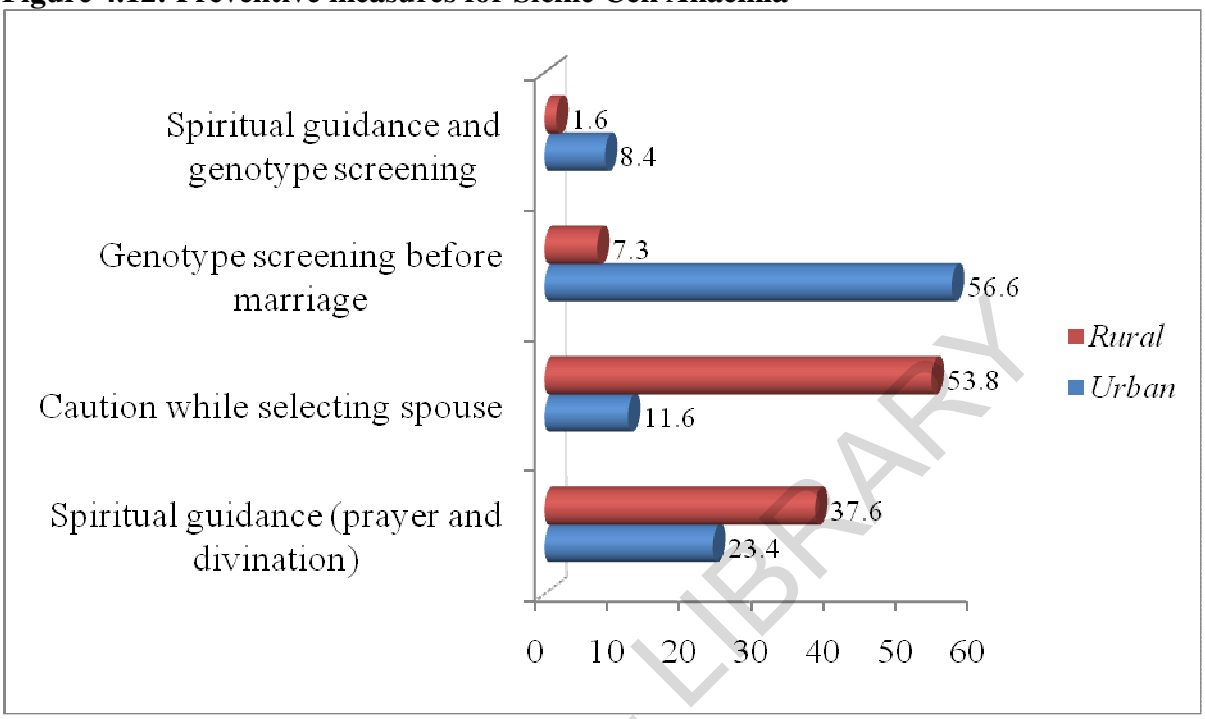
Another case presented here provides insight into why people are seldom involved in hospitalization over Sickle Cell Anaemia. A clergyman in one of the towns in Egbedore Local Government area of Osun State revealed that visitation to hospital still continues, but not as frequently as in the past. The rationale for this was alternative medical remedies that are available within this area. He stated that people living with Sickle Cell Anaemia who have attained the age of 8 to 10 years were encouraged to make use of 'Orin ata' (Fagara Anthoxyloides). This is a local plant that induces pepper-like sensation and tastes peppery when used as a chewing-stick. In the course of using it as chewing stick, a person living with Sickle Cell Anaemia is encouraged to swallow the saliva that is secreted in the mouth and mixed with this plant.

In this community, people also make use of 'ewe' and 'ewa otili' (plants and bean of pigeon peas). The plants are boiled as herbaceous liquid for drinking, while the beans are cooked for eating. To accelerate the rate of cooking the seeds, garlic (alubosa aayu) is added. The garlic itself formed parts of identified traditional medicine for SCA. The inclusion of garlic in the cooking of pigeon pea or any other family food was an attempt at avoiding its unpleasant smell and taste. Consumption of the above is always on communal basis, so that individuals living with Sickle Cell Anaemia do not seem odd. Through this, stigmatization will not occur. One can see as many individuals not living with Sickle Cell Anaemia embracing the drinking of 'Agbo otili' in order to motivate those living with this disorder to also drink it.

The data here confirmed the observations of Bourdillon (1991) that people seeking medical attention have the choice of soliciting care from two strongly competing systems of health care delivery: the traditional and the scientific.

Objective Three: The Preventive Measures for Sickle Cell Anaemia

Figure 4.12: Preventive measures for Sickle Cell Anaemia



Source: Field Survey 2009

Four main preventive measures were highlighted by the respondents according to the figure above. Spiritual guidance in the form of prayer and divination received higher response in both urban (23.4%) and rural (37.6%) settings of this study. Those that relied on prayer/divination in rural area were more than those in urban area. Caution in partners' selection received more prominence on the list in the rural area (53.8%). Majority of the respondents (56.6%) from urban area see genotype screening before marriage as the best measure towards the prevention of Sickle Cell Anaemia. This shows that knowledge of SCA in cities and urban centres inclined more towards Western medical perspectives. A combination of prayers and genotype screening was equally mentioned in urban areas (8.4%) as preventive measures. Majority of the respondents who opted for spiritual guidance and caution while selecting spouse as preventive measures against SCA were from the rural area.

Table 4.3: Classification of Preferred Preventive Measure

Response	*Urban*		*Rural*	
	N	*%*	*N*	*%*
Spiritual guidance (prayer)	117	11.1	428	55.9
Caution while selecting spouse	196	18.7	251	32.8
Genotype screening before marriage	593	56.4	61	8.0
Spiritual guidance and genotype screening	145	13.8	26	3.3
Total	1051	100.0	766	100.0

Source: Field Survey 2009

Genotype screening before marriage (56.4%), caution while selecting spouse (18.7%) and combination of spiritual guidance and genotype screening (13.8%) were the preferred preventive measures for Sickle Cell Anaemia in the urban centre. Preventive measures like spiritual guidance (55.9%) and caution while selecting spouse (32.8%) were indicated by respondents in the rural setting of the study area.

Qualitative data revealed lack of basic knowledge of this disorder on the part of primary caregivers. However, caution when selecting spouses as a preventive measure was suggested. According to one of them:

> Our knowledge of Sickle Cell Anaemia was through hospital diagnosis, prior to this, we did not have in-depth understanding of this disorder especially from Western medical perspective. If we had known about this before, maybe we would have been able to prevent our marriage and eventually giving birth to a child with the disorder would have been avoided (Female IDI, Primary Caregiver from Garrage Olode)

Information seeking for better management options and regimen compliance was another measure raised. In the words of another participant living with Sickle Cell Anaemia:

> To prevent myself from crisis, I've acquired information about the activities that could trigger it; this includes extreme heat and cold temperatures. To avoid escalation of unanticipated crises, I make sure my drugs are always within reach so as to minimize the crises (Male IDI, SC Patient from Modakeke).

Another participant submitted that:

> I have learnt from experience and information gotten in most hospitals visited that stress, anxiety and frustration are some of the stressor of Sickle Cell Anaemia. Also I have been intimated on how to increase the ability of people living with Sickle Cell Anaemia to manage and cope with crises and how best to reduce the frequency of pains, prevention and self-coping strategies (Female IDI, Primary Caregiver, Osogbo).

A primary caregiver revealed the preventive measure she adopted for her daughter thus:

> From the health talks received from Teaching Hospital in Ile-Ife, I have come to know much on how best to prevent my daughter from mosquito bites. She is very much in control of herself and easily interacts with other people, but we never fail to remind her of activities that can trigger SC crisis. Medication compliance is another step that helps in preventing crisis and accompanied pains in SCA (Female IDI, Primary Caregiver, Ile-Ife).

Other measures taken to prevent the occurrence of crises were revealed thus:

> We have been advised that the Sickle Cell patient should be kept warm at all times especially during the cold periods of the year. This does not entail the use of drab clothing or sweater at all times, but the patient could dress to his or her fashion taste. So also is the necessity of taking a lot of fluid especially water which is recommended to be at least 3 litres in a day to prevent dehydration (Female IDI, Primary Caregiver, Otan Ayegbaju).

Some have discovered and adopted antioxidant herbs to minimize the incidence of anaemia, pain and to improve their health. The highlight of this is expressed in the next Box.

Box 8: Local Management therapy- Pigeon Pea, Garlic and Orin Ata (Male/Ilobu town)

Mr. F.T. is a retired headmaster from one of the primary schools in Osun State; he identified Sickle Cell Anaemia as 'aisan aromoleegun' and noted further that some people within the community see it as 'aisan alore'. According to him, people are lately making reference to it as 'foniku fola dide'. He could not be categorical about the prevalence of this disorder within the community. He pointed out that some people ascribed cases of Abiku to extreme effects of SCA; certain circumstances associated with the Abiku phenomenon, according to him, did not make this theory tenable.

'Ewa otili' (pigeon pea) and 'agbo otili' (herb from pigeon pea leaves) have been longstanding potent local remedies for this disorder. The peculiarity of these remedies is that their application is seasonal. People make use of the leaves and seeds of pigeon pea during raining season, a season that is noted for high incidence of SC-induced crises.

'Orin ata' is another remedy; this is all-weather in terms of its utilization. However, its usage is common among the people living with Sickle Cell Anaemia within particular age grade (from adolescence upward). Some people utilize garlic (alubosa aayu). Here, garlic is usually used as food seasoning and herbs supplement while in some cases matured people living with Sickle Cell Anaemia may eat it raw depending on individual preference. The adoption or use of these local remedies is never easy. The issue is that people living with Sickle Cell Anaemia have bitter experiences of stress and chronic pains. Very often they would have experimented with a cocktail of drugs before becoming reluctant to use drugs any further. Family members, particularly those with whom these people have developed strong relationship and have confidence in are always the lender of last resort here. Through this category of people, the people living with Sickle Cell Anaemia are usually prevailed upon to make a trial of other remedies.

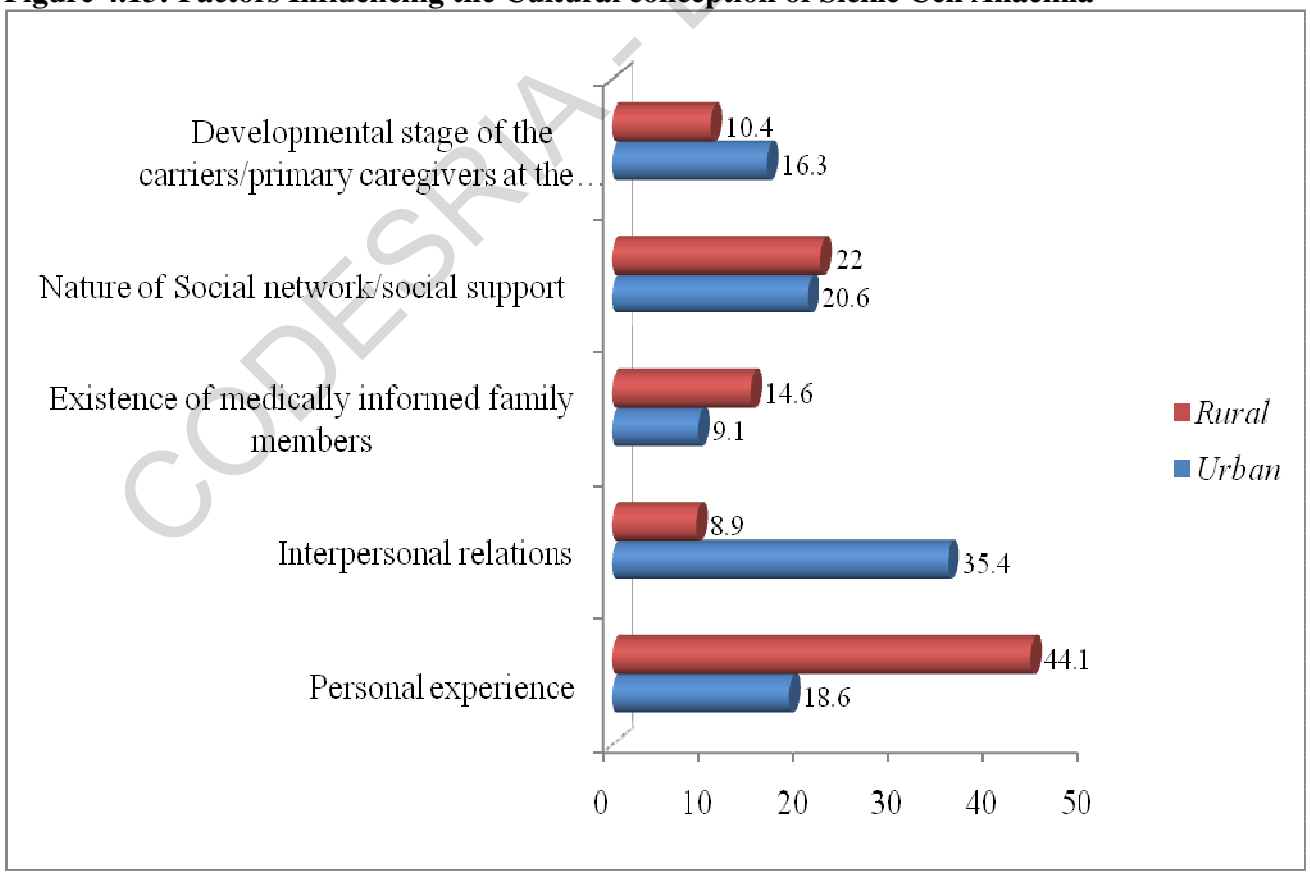
Existing literature corroborated some of the preventive measures adopted in the study areas as well as their necessity in positive health outcome. Some of these measures, according to Kotila (2010), include:

> ….taking plenty of water early in the morning, a balanced diet, eating a lot of fruits and green leafy vegetables is good for functional health among sickle cell patients. Adequate sleep will also help them to stay healthy and fresh and ready to face the challenges each new day bring…patients should stay in the houses with window screens; use of bed nets, though unpopular is advisable not only for children but for adults too (Kotila, 2010).

Objective Four: Factors that Influence Conception and Management of Sickle Cell Anaemia

The first part of this section itemizes and discusses factors that influence cultural conception of Sickle Cell Anaemia while the second part focuses on factors that influence the management of the disorder.

Figure 4.13: Factors Influencing the Cultural conception of Sickle Cell Anaemia



Source: Field Survey 2009

Factors influencing the cultural conception of Sickle Cell Anaemia, according to figure 4.13 above, include the personal experience of the people about the disorder; relationship between people (interpersonal relations); existence of medically-informed family members; the type of social network/social supports, and the developmental stage of the players (the people living with Sickle Cell Anaemia/primary caregivers/significant others) at the onset of the disorder. Of these factors, interpersonal relationship (35.4%), social network/social support (20.6%) and personal experience (18.6%) received the highest response from respondents in urban centre. In rural areas, personal experience (44.1%), social network/social support (22%) and existence of medically-informed individuals in the family (14.6%) were the factors indicated as affecting the conception of this disorder. Key informants also buttressed the above with issues like personal experience of caregivers and the people living with Sickle Cell Anaemia as well as effects of social network/support as factors influencing the conception of Sickle Cell Anaemia. A discussant in support of this noted that:

> People do conceive the disorder as *San'gun San'gun* due to the persistent pains associated with it. To the people living with Sickle Cell Anaemia, the pains affect mostly the bones in the body. This medical problem is also seen as *Olonu* based on the protruding nature of the belly of some SC sufferers (Female KII, Herbalist, Otan Ayegbaju).

Almost all the factors mentioned above reflected the influence of culture on the conception of Sickle Cell Anaemia in the study area. The implication of this is that the social environment remains an essential factor to be taken into consideration when studying health situation from a cultural perspective. This study thus demonstrated that man consciously or unconsciously depend on his environment for his survival, especially in the course of defining his/her health situations and the choice of therapy to be adopted. To illustrate this argument further, a case in the next box is hereby presented.

Box 9: Mother of Sickle Cell SC Patient (Female/Ile-Ife city)

Mrs. A. is a trader in one of the major markets in Ile-Ife city, Osun State; she got married about seven years ago to Mr. A. who hailed from one of the towns in Ife suburbs, but settled in Ife city. When they were about to get married in 2002, the woman suggested to her fiancé that they should go for genotype screening. This was partly based on the fact that she already knew the status of her genotype, which was AS. The information she had on the danger of an AS woman getting married to AS man equally informed her suggestion. According to the woman, her husband was certified AA genotype after screening. Based on this assurance, they went ahead with their wedding which was solemnized in the Christian way.

The first issue of the marriage was a boy that was born in the year 2004. This child was full of life and never experienced any unusual ill-health since birth. In the year 2006, the second child, also a boy was born. Just like the first child, this second issue of the family 'looked' healthy at birth until the third month after his first birthday when he developed a health problem when his father was away on business trip. What was thought to be a feverish condition at the beginning became a nightmare to the couple. Mrs. A at the beginning thought that the problem could be easily addressed with paracetamol and the application of cold compresses. However, when the condition worsened she ran to one of the elderly women in the neighbourhood for advice. She was advised to procure some drugs in the neighbourhood Patent Medicine Store. The drugs procured produced no tangible results hence the decision of her husband to cut his trip short when he was informed of development at home. With public health institution to which the child was taken failing to produce expected result, the couple decided to visit a nearby private clinic for treatment. Three days after signs of responding to treatment, the child was discharged from the clinic. A few weeks later, the child developed a high temperature again; this time around the child reacted with cry at every touch of every joint in his body.

With this new development, a neighbour who was a member of the couple's church identified the problem as 'aromoleegun'. The woman suggested herbal remedy, saying that it was an efficacious therapy for the ailment. Another woman who had a kiosk next to Mrs. A in the local market where she traded conceived the illness as 'Awoka inu eegun'. Herbal remedy and constant prayers were seen as the antidote. As a result of this, Mrs. A., being a member of the 'Prayer Warriors' in her church informed the leader of the group and some members for spiritual assistance. The couple had been battling with this ailment, with various advices coming from friends, relatives and other sympathisers. Soon, the child's had become yellowish eyes, he had begun to experience delayed growth and his stomach had become distended.

During a monthly 'Health Talk' that was organized by the couple's church in 2008, the couple was amazed when the visiting health educators mentioned all the symptoms that were observed in their child as those typical of SCA. After personal consultation with the organizers of the program, Mr. and Mrs. A were advised to go for genetic screening of their child. The results revealed that their child had Sickle Cell Disorder. They couldn't believe this, until confirmation from two laboratory tests carried out at Ladoke Akintola University of Technology (LAUTECH) Teaching Hospital, Osogbo and Obafemi Awolowo University (OAU) Teaching Hospitals, Ile-Ife, all in Osun State laid the matter to rest.

The couple could not think of SCA at the onset of the medical predicament of their child because of the genetic test they carried out before their marriage. This equally informed their refusal to accept the result of eventual screening and diagnoses carried out on their child which showed SCD. With this discovery, the couple particularly the mother has been taking the child for routine weekly medical check-up at OAU Teaching Hospitals Complex for positive health outcome.

The consequences of poor knowledge of health situation on the part of parents, according to Telfair (1994) and Wallander *et al.,* (1989), are poor psychological functioning and negative health outcomes. However, experiences have taught many parents to handle basic responsibilities needed for positive results on one hand, and facilitated the necessary adjustment and capability in handling complexities of the illness occasioned by this disorder on the other. This, therefore, corroborate the findings of Hill (1995), Hurtig (1994) and Evans *et al.*, (1988) regarding the influence of experiences on the ability to source for social support, resources, and functional interpersonal relationship for positive health outcome. The relevance of developmental stage of the primary caregivers and/or an individual living with SCA as a factor in the conception of this disorder is illustrated further by a participant who asserted that:

> An individual living with Sickle Cell Anaemia will surely have control over his situation when he is within age cohort of between 15 years and above depending on how assertive such a person is. At this stage he is likely to do away with initially held belief about his health condition especially with advancement in his educational pursuit and economic status. He will be able to make meaning out of this situation by defining and managing it in a way he understand for positive results. In somebody that is underage, this is not likely (Female KII, Medical Doctor at Ilesa).

The above confirms Atwood's and Weinsten's (nd) observation that family members usually take charge of all matters pertaining to underage patients including the definition and redefinition of their health situation. The process involves the incorporation of ideas that a family member is suffering from Sickle Cell Anaemia and the need for combined effort that is played out by different family members in different ways. The report in Box 10 further demonstrates the role of developmental stage of a patient in the conception of Sickle Cell Anaemia. As expected, this actually plays vital roles in how the disorder is managed.

Box 10: Individual Living with Sickle Cell Anaemia (Male/Osogbo city)

Mr. M.G. was born in the late 1970s at Osogbo. He graduated from Obafemi Awolowo University, Ile-Ife with Second class Upper division in Accounting. He has SC disorder and attended weekly clinical check-up at the Teaching Hospital Complex of the University throughout the period of his studentship. He is currently working in one of the Local Government Councils in Osun State. He grew up to learn from his parents the various efforts that were made to ensure his medical well being. He recollected that the efforts made included visiting various sources of healings. According to him, his parents took him to renowned herbal homes in different communities in Ilobu, Oyan (in Osun State), and Oyo town (in Oyo State) among others. Spiritual healing was also sought both from Muslim and Christian clerics. According to what he was told by his parents and what he could remember, all these measures only brought temporary relief.

He was informed by his parents that the episode of SCA manifested barely three months after the ceremony heralding his christening. Coincidentally, his father had quarrel with an old woman within the neighbourhood on the day of his naming ceremony over distribution of food. The woman in question was an introvert that doesn't mix freely with people; she was labeled 'evil doer' within the neighbourhood. For this reason, the woman was accused of having the 'evil eye' and blamed for the new child's condition when he (the child) began to show signs and symptoms of SCD. The belief then was that the cause of the illness of the newly born baby was a spiritual attack from the old woman. At that point in time, lots of appeasements in form of rituals were done. When other symptoms started to set in, the case was accepted as a full-blown disease condition and was called all sorts of names. All kinds of treatment and management therapies were roundly prescribed and administered.

Mr. M.G.'s parents were later introduced to laboratory test at Ibadan by a visiting Inspector of Education in 1988. The visiting Inspector of Education met the boy writhing in pain during one of the painful crises occasioned by SCA. Upon diagnosis of the disease as SCA, he was subsequently referred to University College Hospital, Ibadan for necessary medical assistance. From the health talk he listened to, he later developed full interest in knowing more about the disease. He has browsed and downloaded lots of information from the internet about SCA.

One clear lesson Mr. M.G. learnt from the internet was possibility of healthy and roboust physique as well as positive living due to timely identification of SCA and appropriate attendant medical attention. He has been following tips gotten from the downloaded materials on SCA from the internet. To him, this has helped in reduction of incidence of SC crises and improved working relations with colleagues and neighbours.

The effects of educational status and age in the conception and management of Sickle Cell Anaemia are very crucial. Caldwell (1979), though speaking from gender perspective, also asserted that Western education acquaints mothers with scientific causes of disease. This, in turn, makes them less fatalistic about illness, enhances their ability to identify illness early, manipulate the available healthcare sources, as well as relate effectively with agents of health

institution and return if measures were ineffective. The case in Box 11 points at a series of agony the people living with Sickle Cell Anaemia and their families pass through.

Box 11: Medical Life of an Octogenarian SC Patient

Alhaja Ashiata Adeke Olukoyi-Laguda has defied the permutations of medical science and lived with Sickle Cell Anaemia for 83 years. Her late husband, Mobolaji Alakija, a medical doctor, met her during one of her crisis moments and fell in love with her. They eventually got married. While Alhaja did not know that she had Sickle Cell Anaemia, her husband knew but decided to hide the information from her, preferring instead to handle her like an egg because of her delicate health. Ironically, Alhaja has outlived her husband and is the one left to mourn his exit.

It was during one of her medical trips to the Lagos University Teaching Hospital (LUTH) that she realized she had Sickle Cell Anaemia, a genetic derangement in the haemoglobin make up of some people. In her words, 'he (referring to her husband) used to give me a particular type of drugs, but I did not know why until I discovered that it was because of my genotype'. She described her experience with Sickle Cell Anaemia as terrible, comparing the pains she suffered to that of a woman in labour.

The octogenarian who was born in 1925 said although she used to fall sick frequently as a child, information about genotype was not common then. If there was any sign of rain, her parents would be worried, because rain must not fall on her. There was a day, according to her, when her clothes got burnt while she stayed beside fire to get warm because the weather was cold. In the morning she could be hale and hearty, but by evening she would have fallen sick. Her parents thought she was an 'abiku'. This belief of her parents was reinforced by the fact that her mother could not conceive a baby until 12 years after her marriage, and her first baby died shortly after it was born. It was after the death of the first baby that she was born. After her, two other children were born, but they were not falling sick the way she did. Because of her condition her parents went everywhere to seek a cure. They offered all sorts of sacrifices. They even travelled to the South-East (Nigeria) to secure a native powder which she mixed with pap and drank with the bone of a particular kind of bird. But from the knowledge she had now she knew her parents were both carrying the AS genotype.

The debilitating illness that became her lot adversely affected her education, making it impossible for her to start primary school until she was 13 years old. Her health crisis continued even after she arrived England on October 1, 1960 to study secretarial studies. She further had genotype tests which revealed that her genotype remained SS. Interestingly, none of her children has Sickle Cell Anaemia. She noted that for more than 30 years she has not experienced any serious crisis, she did not feel pains anymore. She now walks in the rain. Sometimes, she thought that her genotype has changed. She went to LUTH in 2005 for medical check-up and the doctor did not believe it when she told him she was a sickle cell patient. He ran a test on her and to his amazement, her genotype was SS.

Alhaja has stopped taking folic acid, a drug that the people living with Sickle Cell Anaemia must take every day. She described her freedom from the pains and dreadful experiences she had to pass through for more than 40 years as a mystery. She added that she has learnt to keep herself warm, eat good food and rest when necessary (Extracted from an article on Sickle Cell Anaemia by Ayodele Ale in Saturday PUNCH, 2009).

The case described in Box 12 below illustrates the efficacy of herbal remedy.

Box 12: Efficacy of Herbal Remedy

Mrs. Hilda Ogbe is not a medical doctor; she came from the United Kingdom to Nigeria with her Nigerian lawyer-husband in 1956. She loves her adopted country and vowed from the beginning to render all the help she could to the country and the community in which she now lives.

In 1978 she was by chance given an herb which allows Sickle Cell suffers to lead normal lives. At that time, her husband's niece, an 18 year-old girl, was always sick. She was in and out of hospital and her mother could no longer afford the hospital fees. Also she could not bear to see her child in such terrible pain. Mrs. Ogbe took her husband's niece to a botanist who took them to a field where he uprooted some small plants and gave them to her. She was advised to break off a piece of the plant and give the girl a piece to chew with assurance that if she swallows it twice a week, she will have no more serious crisis after that. After this was done, the girl was relieved of recurring excruciating bone pains. She lived happily ever after; she is over forty years old now and has two healthy children.

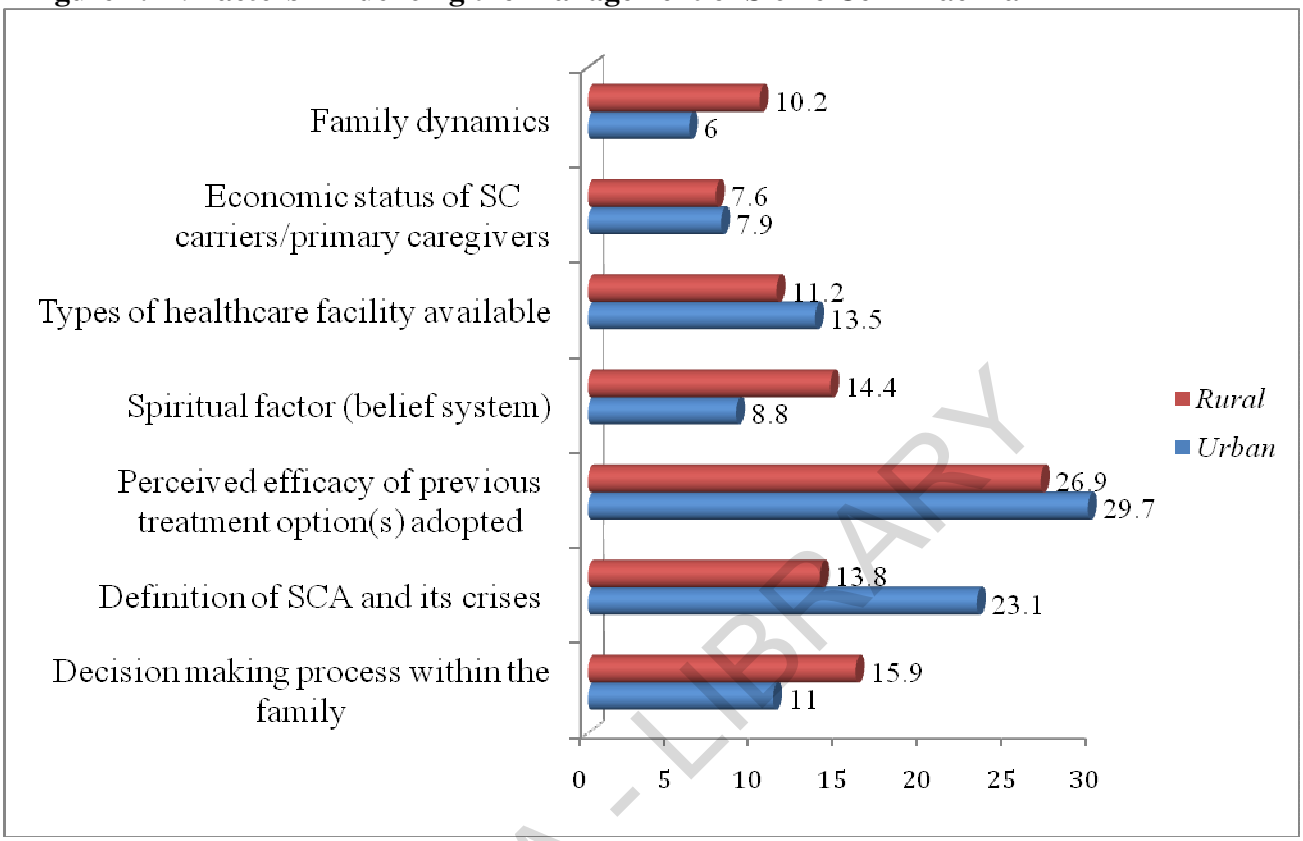
When Mrs. Ogbe saw the recovery of this niece, she was amazed at the efficacy of the simple, modest-looking herb. She thought she should plant this herb in her garden maybe she could help somebody with it someday. For the past 24 years, she has been growing this sickle-cell herb in large quantities. She processes it herself, and it is now available in capsule form. A team of researchers from the University of Benin took the herbs for analysis and were excited with their positive findings.

In the meantime, from a very small beginning when she helped a baby to recover, the news has spread and many people come with their sickle-cell problems. They come to her house in Benin City between 6 pm and 7 pm. After writing down the medical history of each patient, she provided them with enough capsules to last one month. After that time, the patients will come again so that she can check how effective the treatment has been. Sometimes the dosage needs to be adjusted because of differences in physiological make-up, but all of them show improvement with the use of the herbal capsules.

Ogbe (2004) listed some of the cases she had handled; one of them is expressed below:

> *The first one was a baby of four month-old. Mrs. Ogbe wondered how a four month-old baby could chew a piece of herb, she knew it was impossible and therefore decided to dry the herb, grind it and put it in the baby's food (pap or akamu), putting the herb in one corner of the plate and scooping it up with the pap when feeding. A quarter of a teaspoonful (½ a capsule) of herb remedied the pain of this baby in a short time. When the parents took the baby back to Jos, he was not crying any more. The swelling on his hands and fees had gone and he behaved like a normal healthy baby* [Extracted from a book titled 'Sickle Cell: How to Cope' written by Mrs. Hilda Ogbe].

Figure 4.14: **Factors Influencing the Management of Sickle Cell Anaemia**



Source: Field Survey 2009

From figure 4.14 above, seven factors were generated as influencing the management of Sickle Cell Anaemia; these include, available decision-making process within the family; perceived efficacy of previous treatment option(s) adopted; spiritual/belief system; availability of healthcare facility; economic status of the people living with Sickle Cell Anaemia and/or primary caregivers as well as family dynamics. Among the respondents in the urban centre, types of healthcare facility obtainable (7.8%), definition given to the disorder, its crisis or the illness from SCA (13.4%) and perceived efficacy of previous treatment option(s) adopted (17.1%) received high responses. Data from the rural areas revealed that perceived efficacy of previous healthcare option(s) adopted (11.3%), available decision-making process within the family (6.7%), and spiritual/belief system (6.1%). Though the rate of response on belief system as a factor in SC management is low, it however supported the position of Bourdillon (1991) that a person's belief influences the

type of treatment he or she prefers. Data from the interviews with key informants further corroborated some of the factors identified above. In the words of a respondent:

> The illness came suddenly when my daughter was six months old, and the fear that she was about to die forced me to desperately seek for medical assistance at the nearby chemist shop. After the initial treatment, I was introduced to a Nurse within the neighbourhood who rendered home services after her regular hospital works (Female IDI, Primary caregiver from Oyan).

From the data presented, it was apparent that people utilize multiple sources for their healthcare; in some instances, people utilize one healthcare option, try others and eventually return to the one they first utilized. This is at variance with the discovery of earlier scholars (Obasola, 2005; Jegede, 2002) on pathways to healthcare utilization. To most of these scholars, utilization almost always starts with home remedies before eventually graduating to hospital care. In certain cases, some of the medical problems are always taken care of successfully with home remedies. However, the cases highlighted by these scholars significantly differed with Sickle Cell Anaemia. While Sickle Cell Anaemia is widely acknowledged in Western medical setting as not having a known cure at present, the cases highlighted by scholars mentioned above are largely considered in medical circle as curable.

Table 4.4: Socio-Demographic Characteristics and Cultural conceptions of Sickle Cell Anaemia

Socio-demographic Characteristics		*Cultural concepts of Sickle Cell Anaemia*								*Test of Significance*
		F'oniku foladide	*R'omo lapa r'omo lese*	*Alore*	*Olo'nu*	*Aromo-leegun*	*San'gun San'gun*	*Aisam eje dudu*	*Awoka Inu Eegun*	
Sex	Male	440 (24.2)	84 (4.6)	93 (5.1)	58 (3.2)	122 (6.7)	85 (4.7)	25 (1.4)	54 (3.0)	χ^2= 23.9
	Female	463 (25.5)	80 (4.4)	71 (3.9)	31 (1.7)	89 (4.9)	51 (2.8)	38 (2.1)	33 (1.8)	df =1 P=0.003
Age	30-50 yrs	235 (13.0)	56 (3.1)	59 (3.2)	27 (1.5)	44 (2.4)	22 (1.2)	20 (1.1)	15 (0.8)	χ^2 = 89.2
	> 50 yrs	669 (36.7)	105 (5.8)	104 (5.7)	60 (3.3)	167 (9.2)	116 (6.4)	45 (2.5)	73 (4.0)	df =1 P=0.001
Education	Informal Educ.	187 (10.3)	20 (1.1)	7 (0.4)	11 (0.6)	33 (1.8)	5 (0.3)	11 (0.6)	4 (0.2)	
	Primary Sch.	211 (11.6)	22 (1.2)	24 (1.3)	15 (0.8)	55 (3.0)	55 (3.0)	13 (0.7)	24 (1.3)	
	Secondary Sch.	74 (4.1)	20 (1.1)	15 (0.8)	15 (10.8)	22 (1.2)	13 (0.7)	11 (0.6)	11 (0.6)	
	ND/NCE	223 (12.3)	55 (3.0)	40 (2.2)	20 (1.1)	58 (3.2)	36 (2.0)	15 (0.8)	24 (1.3)	χ^2 = 232.9
	HND/Degree	208 (11.4)	49 (2.7)	80 (4.4)	27 (1.5)	45 (2.5)	27 (1.5)	14 (0.8)	25 (1.4)	df =1 P=0.000
Marital Sta	Single	16 (0.9)	5 (0.3)	20 (1.1)	7 (0.4)	2 (0.1)	2(0.1)	7 (0.4)	-	
	Married	810 (44.6)	149 (8.2)	134 (7.4)	78 (4.3)	191 (10.5)	124 (6.8)	49 (2.7)	84 (4.6)	
	Divorced	25 (1.4)	6 (0.3)	-	2 (0.1)	2 (0.1)	4 (0.2)	2 (0.1)	2 (0.1)	χ^2= 80.3
	Widowed	51(2.8)	5 (0.3)	9 (0.5)	2 (0.1)	16 (0.9)	7 (0.4)	5 (0.3)	2 (0.1)	df =1 P=0.000
Religion	Christianity	214 (11.8)	36 (2.0)	49 (2.7)	24 (1.3)	55 (3.0)	24 (1.3)	20 (1.1)	20 (1.1)	
	Islam	640 (35.2)	125 (6.9)	113 (6.2)	64 (3.5)	153 (8.4)	111 (6.1)	42 (2.3)	65 (3.6)	χ^2 = 6.5
	Traditional	44 (2.4)	2 (0.1)	4 (0.2)	-	5 (0.3)	4 (0.2)	2 (0.1)	2 (0.1)	df =1 P=0.258
Occupation	Farming	153 (8.4)	15 (0.8)	16 (0.9)	11 (0.6)	35 (1.9)	24 (1.3)	7 (0.4)	13 (0.7)	
	Trading	329 (18.1)	44 (2.4)	27 (1.5)	22 (1.2)	65 (3.6)	55 (3.0)	24 (1.3)	24 (1.3)	
	Student	4 (0.2)	2 (0.1)	2 (0.1)	2 (0.1)	2 (0.1)	2 (0.1)	-	-	
	Salaried Work	394 (21.7)	94 (5.2)	111 (6.1)	49 (2.7)	93 (5.1)	53 (2.9)	31 (1.7)	49 (2.7)	χ^2 = 95.813
	Artisan	24 (1.3)	9 (0.5)	7 (0.4)	5 (0.3)	15 (0.8)	4 (0.2)	2 (0.1)	2 (0.1)	df =1 P=0.001
Income	N5,000-10,000	172 (9.5)	25 (1.4)	22 (1.2)	16 (0.9)	51 (2.8)	27 (1.5)	9 (0.5)	15 (0.8)	
	11,000-20,000	225 (12.4)	33 (1.8)	18 (1.0)	18 (1.0)	51 (2.8)	40 (2.2)	16 (0.9)	16 (0.9)	
	21,000-30,000	167 (9.2)	51 (2.8)	44 (2.4)	16 (0.9)	35 (1.9)	20 (1.1)	7 (0.4)	16 (0.9)	
	31,000-40,000	182 (10.0)	35 (1.9)	40 (2.2)	27 (1.5)	53 (2.9)	29 (1.6)	20 (1.1)	25 (1.4)	χ^2 = 82.5
	Above 41,000	154 (8.5)	20 (1.1)	38 (2.1)	11 (0.6)	20 (1.1)	22 (1.2)	13 (0.7)	16 (0.9)	df =1 P=0.003
Significant at p <0.05		df Degree of Freedom								

The table above presents the distribution of respondents' socio-demographic characteristics and cultural concepts of Sickle Cell Anaemia. Majority of the respondents in the above table conceived Sickle Cell Anaemia (SCA) as *f'oniku f'ola dide.* Most of them (25.5%) were females and closely following in terms of numerical strength were the males (24.2%). The nearest significant numbers among the males conceived Sickle Cell Anaemia as *aromoleegun* (6.7%), *alore* (5.1%) and *san'gun san'gun* (4.7%). *Aromoleegun* (4.9%) and *r'omo lapa r'omo lese* (4.4%) received significant responses from the female gender.

It was further shown that 12.7% of people within the age category of 30 and 50 years and those above 50 years old (36.7%) conceive SCA as *f'oniku f'ola dide*. The concept of *f'oniku f'ola dide* received higher responses from all the respondents across educational qualification except those with secondary school certificate (see table 4.4). To most of the married respondents (44.6%), SCA means *f'oniku f'ola dide*. Other concepts ascribed to the disorder include *aromoleegun* (10.5%), *r'omo lapa r'omo lese* (8.2%) and *alore* (7.4%).

Muslim respondents are in the majority (35.2%) among the people that conceptualized SCA as *f'oniku f'ola dide* while 11.8% of the Christian respondents shared the same view as their Muslim counterparts. The bulk of the responses come from those who define Sickle Cell Anaemia as *f'oniku f'ola dide*. Out of this, 21.7% are salaried workers; the rest are traders (18%) and farmers (8.4%). The distribution of responses on all concepts of SCA mentioned in this study cut across the available income levels of the respondents. The income categories of the people that define SCA as *'f'oniku f'ola dide'* include N10,000-19,999 (12.4%), N30,000-39,999 (10%), N5,000-9,999 (9.5%) and N20,000-29,999 (9.2%). Chi-square results showed that sex (χ^2 = 23.9, P<0.05), age (χ^2 = 89.2, P<0.05), educational status (χ^2 = 232.9, P<0.05), marital status (χ^2 = 80.3, P<0.05), occupational status (χ^2 = 95.813, P<0.05) and income level (χ^2 = 82.5, P<0.05) significantly related with cultural conception of Sickle Cell Anaemia. On the other hand religion has no significant relationship with conception of this disorder (χ^2 = 6.5, P>0.05).

Table 4.5: Socio-Demographic Characteristics and Management Option(s)

Socio-demographic Characteristics		*Preferred Management option(s) for Sickle Cell Anaemia*							*Test of Significance*
		Home Remedies	*Divination*	*Faith-based healing*	*Faith-based healing and hospital care*	*Hospital care*	*Hospital care and Home remedies*	*Hospital care, Home remedies and faith based healing*	
Sex	Male	33 (1.8)	29 (1.6)	55 (3.0)	85 (4.7)	215 (11.8)	293 (16.1)	253 (13.9)	χ^2=23.994
	Female	58 (3.2)	42 (2.3)	62 (3.4)	59 (3.3)	168 (9.3)	212 (11.7)	253 (13.9)	df =1 P=0.001
Age	<30 yrs	-	-	2 (0.1)	2 (0.1)	5 (0.3)	2 (0.1)	2 (0.1)	
	30-50 yrs	18 (1.0)	20 (1.1)	20 (1.1)	32 (1.8)	107 (5.9)	143 (7.9)	123 (6.8)	χ^2 =88.9
	> 50 yrs	76 (4.2)	50 (2.8)	96 (5.3)	111 (6.1)	271 (14.9)	356 (19.6)	380 (20.9)	df = 1 P=0.001
Education	Informal Educ.	7 (0.4)	29 (1.6)	11 (0.6)	24 (1.3)	71 (3.9)	56 (3.1)	76 (4.2)	
	Primary Sch.	14 (0.8)	18 (1.0)	27 (1.5)	29 (1.6)	82 (4.5)	114 (6.3)	129 (7.1)	
	Secondary Sc	11 (0.6)	2 (0.1)	5 (0.3)	18 (1.0)	35 (1.9)	69 (3.8)	45 (2.5)	
	ND/NCE	29 (1.6)	11(0.6)	36 (2.0)	35 (1.9)	98 (5.4)	144 (7.9)	120 (6.6)	χ^2= 231.8
	HND/Degree	29 (1.6)	11 (0.6)	36 (2.0)	40 (2.2)	98 (5.4)	122 (6.7)	135 (7.4)	df =1 P=0.000
Marital	Single	2 (0.1)	2 (0.1)	9 (0.5)	5 (0.3)	23 (1.3)	18 (1.0)	9 (0.5)	
	Married	82 (4.5)	65 (3.6)	87 (4.8)	138 (7.6)	338 (18.6)	462 (25.4)	445 (24.5)	χ^2 = 80.294
	Widowed	7 (0.4)	2 (0.1)	20 (1.1)	2 (0.1)	24 (1.3)	26 (1.4)	51 (2.8)	df =1 P=0.000
Religion	Christianity	23 (1.3)	16 (0.9)	27 (1.5)	45 (2.5)	94 (5.2)	105 (5.8)	131 (7.2)	
	Islam	65 (3.6)	49 (2.7)	82 (4.5)	94 (5.2)	278 (15.3)	387 (21.3)	354 (19.5)	χ^2 = 11.694
	Traditional	2 (0.1)	2 (0.1)	5 (0.3)	5 (0.3)	13 (0.7)	15 (0.8)	20 (1.1)	df =1 P=0.631
Occupation	Farming	13 (0.7)	22 (1.2)	15 (0.8)	24 (1.3)	55 (3.0)	58 (3.2)	85 (4.7)	
	Trading	26 (1.4)	24 (1.3)	29 (1.6)	42 (2.3)	127 (7.0)	191 (10.5)	158 (8.7)	
	Salaried Work	53 (2.9)	22 (1.2)	73 (4.0)	71 (3.9)	185 (10.2)	240 (13.2)	238 (31.1)	χ^2 = 105.384
	Artisan	-	-	2 (0.1)	9 (0.5)	17 (0.9)	18 (1.0)	24 (1.3)	df =1 P=0.000
Income	N5,000-9,999	13 (0.7)	22 (1.2)	16 (0.9)	29 (1.6)	71 (3.9)	76 (4.2)	109 (6.0)	
	10,000-19,999	11 (0.6)	20 (1.1)	18 (1.0)	27 (1.5)	89 (4.9)	124 (6.8)	125 (6.9)	
	20,000-29,999	29 (1.6)	13 (0.7)	36 (2.0)	16 (0.9)	67 (3.7)	109 (6.0)	84 (4.6)	
	30,000-39,999	27 (1.5)	7 (0.4)	20 (1.1)	47 (2.6)	102 (5.6)	91 (5.0)	116 (6.4)	χ^2 = 82.457
	Above 40,000	9 (0.5)	7 (0.4)	25 (1.4)	25 (1.4)	49 (2.7)	107 (5.9)	74 (4.0)	df =1 P=0.000

Significant at p <0.05 df Degree of Freedom

Similarly, the above table compares socio-demographic characteristics of the respondents with the type of healthcare facilities preferred for the management of Sickle Cell Anaemia (SCA). A combination of hospital care and home remedies received the highest responses (16.1%) as the management option for SCA among the males. Other management options among the males include the combination of hospital care, home remedies and faith-based healing (13.9%) as well as only hospital care (11.8%). The female respondents listed a combination of hospital care, home remedies and faith-based healing (13.9%); hospital care and home remedies (11.7%) as well as exclusive use of hospital care (9.3%) as the management therapies for SCA.

A substantial proportion of the respondents who were above 50 years of age preferred combinations of hospital care, home remedies and faith-based healing (20.9%); hospital care and home remedies (19.6%) as well as only hospital care (14.9%) as management options for SCA. The management options for the respondents in age category 30 and 50 years included

the combinations of hospital care and home remedies (7.9%); hospital care, home remedies and faith-based healing (6.8%) as well as only hospital care (5.9%). The highest responses in terms of preferred management options recorded among the holders of National Diploma/Nigeria Certificate of Education were hospital care and home remedies (7.9%) as well as hospital care, home remedies and faith-based healing (6.6%). Others included hospital care, home remedies and faith-based healing among the holders of Higher National Diploma/Degree (7.3%) and primary school certificate holders (7.1%).

The married respondents preferred hospital care and home remedies (25.4%), hospital care, home remedies and faith-based healing (24.5%) and exclusive use of hospital care (18.6%) for the management options of SCA. A significant relationship was equally established between marital status and preferred management options.

The Muslims have higher preference for the combination of hospital care and home remedies (21.3%) as well as hospital care, home remedies and faith-based healing (19.5%). The highest preference among the Christians and Traditional Religion adherents included 7.2% and 1.1% respectively for combination of hospital care, home remedies and faith-based healing. A combined management options of hospital care, home remedies, and faith-based healing were the preference of the salaried workers (31.1%) and farmers (4.7%). On the other hand, hospital care and home remedies (10.3%) were the choices of the traders. The respondents on income categories of N10,000 – 19,999 (4.9%) and N30,000 – 39,999 (5.6%) also preferred hospital care. Chi-square results showed that sex (χ^2=23.994, P<0.05), age (χ^2 =88.9, P<0.05), educational status (χ^2= 231.8, P<0.05), marital status (χ^2 = 80.294, P<0.05), occupational status (χ^2 = 105.384, P<0.05) and income level (χ^2 = 82.457, P<0.05) significantly related with management of Sickle Cell Anaemia. On the other hand religion has no significant relationship with the management of this disorder (χ^2 = 11.694, P>0.05). From the foregoing, the third hypothesis which states that socio-demographic characteristics such as sex, age, education, marital status, occupation and income have significant influence on the conception and management of Sickle Cell Anaemia is therefore affirmed. The implication of the foregoing is that age determines experience, and the type and status of friendship one has. For example, an underage cannot make independent decision about the definition and causes of SCA; this is different from the case of adults who make consultations, and cross-reference ideas and experiences with network of friends and

acquaintances on prevailing health problems. In a similar vein, it was shown that the female gender has higher drive than the male in the search for the cause of this disorder. This often comes in the form of extensive interpersonal relationship which, according to Smiths (2006), is always wider and composed of experienced individuals. This suggests why women appear to be quicker in making up their minds when confronted with certain medical problems. A married woman cannot take healthcare decision without the approval of her husband or that of his immediate family where applicable (Mustapha, 2007). Occupation determines income, while income reflects socio-economic status and associates (Mailafia, 2005), both of which invariably influence the thinking, experiences, perception of an issue and finally financial solvency to source for appropriate medical service for the management of SCA. This, thus, pointed at the significant relationship that occupation and income have with conception and management of Sickle Cell Anaemia. Less consideration for religious factor in the utilization of healthcare facilities among the people explains why a Muslim may not mind going for healing in the church or vice versa due to the perceived positive outcome. This is also an affirmation that religion has no significant relationship with the conception and management of this disorder.

4.8 Decision making for Treatment Option(s)

The findings showed that treatment decision-making was a joint affair when the husband and wife were together. At that point, everybody makes suggestions on treatment measures best suited for Sickle Cell Anaemia based on available information, but final ratification lies with the husband. Meanwhile, such suggestions and final approval were always based on interpretation of present health condition.

The data further showed that in the absence of the husband, women are more open to the idea of consulting members of the extended family. In case of emergency, such assistance is sought from any available adults (friends and/or neighbours). Counseling on probable and appropriate medical services are also common during emergency. On the issue of decision-making for treatment option(s), a participant volunteered thus:

> I couldn't take decision in the absence of my husband, but his absence on business trip means I have to turn to his elder sister who lived nearby. It was through her advice that we consulted first a herbalist and later when he came

> we had to visit the hospital because he is the boss and I am not working (Female IDI, Primary Caregiver from Oba Oke/Olorunda LGA).

In the same context a participant submitted:

> I was advised by a traditional pharmacist *(elewe omo)* that Western medical option will end up aggravating the degree of SCA hence my reliance on traditional medicine. Even if I had wanted to go for Western medical service I may not be able to foot the bill because my husband did not allow me to work, he believes in providing for my needs and that of the children (Female KII, Primary Caregiver at Osogbo).

Inquiry was made to know whether there were standing rules governing decision-making within the family system. A participant clarified thus:

> ….there is no rigid law or custom that says one must contact the immediate family during emergencies occasioned by Sickle Cell Anaemia and related health problems. Though as a sign of respect for the kin group, they need to be informed when the child is formally admitted in whatever health care facilities chosen later. This will prevent group reprisal in the event of death following decision made without first consulting them (Male IDI, Primary Caregiver from Ilobu).

Further inquiry reveals that the above was not peculiar to Sickle Cell disorder alone; the participant buttressed this further:

> This is not limited to Sickle Cell Anaemia alone; in other types of ill-health, particularly cases of minor illness, the partner that is at home makes treatment decision and payment for services. The exceptional cases include where the appropriate health care facility is outside the community or located in considerably far distance. The assistance of the family may be sought at this level. Also, a couple may need to consult the member(s) of kin group if the couples are living either in the same house or neighbourhood with the group. It should not be expected of a couple living in Maiduguri to contact members of their kin that are based in Osogbo for treatment decision-making. Since health emergency cases always bring about confusion and apprehension, it is always better to make do with matured friends and/or neighbours that are around in the course of decision making (Male IDI, Primary Caregiver from Ilobu).

The fact that healthcare decisions in the study area were made with approval of the husband or his family in his absence corroborated the findings of Agbonlahor (1995). By this, it is obvious that women were expected to abide by the traditional norms and expectation of the existing patriarchal system in which decision-making on a crucial matter like healthcare lies

with the husband. While this was identified as a mark of respect for the husband, it was also a means of protecting the interest of the woman in case of negative health consequence. However, this finding contradicts that of Murphy and Baba (1981) which showed that wives in Northern part of Nigeria are expected to seek and obtain the permission of their 'husbands' only before using hospital services for their children/and or themselves.

4.9 Health budgeting for Treatment Option(s)

Data on household health expenditure show that a large proportion of the respondents did not have budgetary allocation for health. They were of the view that budgetary allocation for health management was morally unacceptable and indirect ways of praying for illness, hence their resolves not to engage in this practice. Similar findings in the study area revealed that people relied on faith (Lawal, 2002) and associated preventive measures as the surest ways out rather than budgeting for emergency (Ogundijo, 2008). For the few that keep health budget, further analysis revealed that they kept less than N20, 000 per month. Inadequate source of finance accounts for the failure of some respondents to keep health budget. This translates to delay in healthcare at the point of needs thereby defeating the perceived knowledge of appropriate steps for positive health outcome. It also shows that knowledge of what to do to maintain the desired health status becomes useless when one lacks the resources to act (McDouglas, 2007). A participant made further clarification on health budgeting situation in the study area thus:

> It would be unwise for any of the primary caregivers and adults living with Sickle Cell Anaemia not to prepare for emergencies in view of unpredictable nature of the disorder. What is obtainable here is that there is no precise budgeting for this disorder basically due to adverse effects of this health problem on the businesses. Diversion of money meant for reinvestment into the business is very rampant. So rather than call what we have on ground for such emergencies as 'budget', it is better classified 'reserve' (Male IDI, Primary Caregiver at Ifetedo).

The source of money for health expenditure, according to the data from the participants in the in-depth interviews, include (a) personal savings (b) proceeds from business (c) financial assistance from family as well as friends, and (d) support from church/mosque. At times, it was revealed that they do resort to borrowing from

friends and/or neighbours when they are at the critical period. Findings show that males were involved in borrowing than females. In other instance, women borrow money to take care of health treatment of anaemic children at the instance of their husbands. This equally supports the position of David (1993) in a study conducted in rural Liberia that men were more likely to use borrowed money to pay for medical expenses.

It is also shown that husband and wife have separate budgetary allocation. In the case of payment for services incurred for the management of Sickle Cell Anaemia, especially in time of emergencies, whoever is available among the couples during the crisis is responsible for the cost of treatment. However, the husbands are always responsible for the payment at the end of the day. Where only the wives are available and are the ones paying for the medical services, such monies are usually refunded to the wives. The basis for this is illustrated further by a female primary caregiver thus:

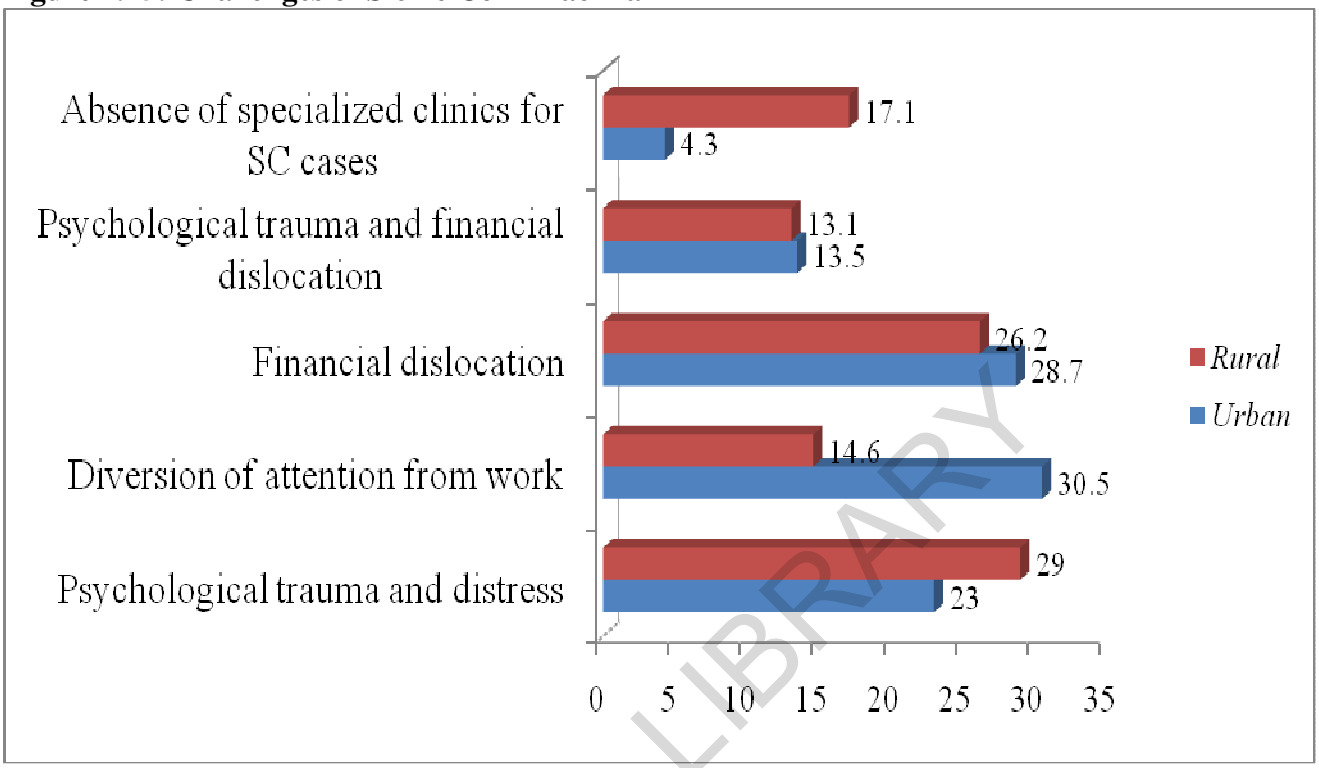
> The husband by custom is the head of the house, so he is expected to be responsible for the upkeep of the family including health matters. Any amount incurred on family health in his absence must be refunded for the progress of the husband himself. Apart from the fact that he is financially better off and have significant say in treatment decisions, the belief among the Yorùbá is that a man who allows his wife to take over financial responsibility in the house is indirectly praying to God to transfer his blessing to the wife (Female IDI, Primary Caregiver, Ibokun).

The positions of previous scholars (David, 1991; Abu, 1983; and Guyer, 1980) were further confirmed with revelation that husband and wife maintain separate budgets due to their desire to control their own income and the practice of polygyny. In this study, the practice of polygyny was not included among factors enumerated as influencing divided budgeting among the couples. However, Orubuloye *et al.* (1991) expressed fear that such divided budgets and treatment decision-making responsibilities in this context may delay treatment and consequently contribute to high mortality rates.

4.10 Factors Militating Against Positive Health Outcome

According to the respondents, the factors hindering better health results of SCA treatments are expressed in the next figure.

Figure 4.15: Challenges of Sickle Cell Anaemia



Source: Field Survey 2009

Psychological trauma/distress, financial dislocation (26.2%) and absence of Sickle Cell clinics (17.1%) were reported by majority of the respondents (29%) in the rural area as the challenges against positive health outcome. On the other hand, the respondents from urban centre listed issues like financial problem due to diversion of attention from their means of livelihood (30.5%), and psychological trauma/distress and financial dislocation (13.5%). Data from qualitative study revealed financial embarrassment, constant diversion of family income towards their medical well being and psychological trauma as the militating factors revealed. In the light of this, a participant said:

> It is obvious that people are always stretched financially in the course of managing SC crisis. Whenever this occurs I'm always tired and confused. Sometimes I pray that death should come so as to put an end to the whole situation (Female IDI, SC Patient at Ile Ife).

Withdrawal of social support on the part of some family members due to inability to withstand the stress and trauma occasioned by this disorder was also noted. According to a participant:

> I've heard unpleasant comments about my plights from members of the family as well as my neighbours. I know it was a result of the stress they are facing while assisting me during the crisis occasioned by this disorder. In my own understanding, living with SCA is hellish; the people taking care of SC sufferers are always shared substantially out of the problem. For these people, they are at crossroad on the need to satisfy the societal norm of being their brothers' keeper and their limitation to continue with such norm as a mere mortal so I cannot blame them (Male IDI, SC Sufferer at Iree).

From the perspective of the Key Informants, delay in taking appropriate action due to the inability to either define or identify this health problem as SCA at the onset, failure to stick to a particular medical option, problem of distance and inadequate health facilities with specialization on SC services were the main challenges against SC management. In the words of a participant:

> The aftermath of this is the application of inappropriate remedy which may provoke horrible crises that may shorten the life of an individual living with Sickle Cell Anaemia (Male KII, Medical Doctor at Osogbo).

A secondary caregiver also pointed at delay in decision to procure medical help for the management of SCA as a challenge. In her words:

> The delay in seeking clinical remedy as first option is rampant and poses a lot of challenges to positive health outcome. Also people hardly adhere to prescribed medication. At the end of the day the case will become complicated (Female KII, Medical Doctor from Iragbiji).

On the part of a faith healer, the problem of accessing specialist clinics where SC cases can be properly handled is a serious challenge. In his words:

> People with SC cases are usually referred to LAUTECH Teaching Hospital in Osogbo or Obafemi Awolowo University Teaching Hospital Complex either at Ilesa or Ile-Ife. This has been adding to the plights of SC sufferers and primary caregivers. Available clinics around have not been able to handle SC cases effectively hence the usual referral to Teaching Hospitals when cases become more complicated (Male KII, Christian Clergyman/Faith-based healer at Iree).

Dearth of specialized Western medical clinics was a common challenge against positive management of Sickle Cell Anaemia. This shortage of facilities was also perceived as the cause of escalating adoption of home remedy as source of management of health problems

like SCA. Insight into this is illustrated further by the Key Informants. According to an Informant:

> I formerly worked for Osun State Health Management Board before moving to the Teaching Hospital. In the course of my work I was aware of available healthcare facilities in the State. I'm still current with event in medical circle in Osun state because I still consult for my friends who are into Private medical practices within the state. In Osun State every political ward has one Western medical health facility such as Maternity Centre, Health Centre, Health Post, Comprehensive Health Centre, or General Hospital. Also Federal Government owned PHC Model Clinics are spread across Senatorial Zones in the State. The three Teaching Hospitals at Ile-Ife, Ilesa and Osogbo are still there. The only shortcoming is that SCA cases are treated like any other ailment in virtually all the health facilities across the state except in Teaching Hospitals where formal clinics for SC cases are handled. However, the case is not like this in Oyo state where five functional formal SC clinics are operated. While one can say Western medical facilities exist for general ailments, the same could not be said of SCA in the State. A client that is treated by non-specialist may not receive satisfactory services hence the loss of faith in Western medicine and adoption of alternative sources like home remedy (Male KII, Medical Doctor at Ile-Ife).

Also supporting the above stand, a participant said:

> Before my husband got transferred here due to the creation of Osun State in 1992, I was privileged to know about five SC clinics located at Oni and Son Children Hospital, Ring Road, State Hospital Ring Road, Oluyoro Catholic Hospital, University College Hospital, all located in Ibadan, and General Hospital at Igboora town. But in Osun State, you are expected to visit just any Clinics available within your locality, whether the person there is a specialist in that area is another thing entirely. This has not been helping matters as people keep on complaining about the type of services being rendered to the SC patients. What they do at these health facilities is to send the SC patients on referral to either Ilesa or Ile-Ife; with LAUTECH Teaching Hospital now in existence, people are being referred there. The implication of moving from osogbo to Ilesa or Ile-Ife in the course of treatment SCA is unimaginable. Many have been discouraged due to the stress occasioned by this; hence their reliance on what to them is credible alternative (Female KII, Primary Caregiver at Iragbiji).

The practice of relying on symptoms and other illness manifestations to define health conditions by the people was very common in the study area. Ethically, this practice is utterly unreliable because certain diseases may exhibit symptoms similar to another ailment. The implication of this is the application of inappropriate treatment and subsequently poor

health outcome. To avert a situation like this, a severe medical problem like SCA requires in-depth diagnosis through laboratory screening for effective management and positive health outcome. In view of the revelation above, the challenges faced by people living with Sickle Cell Anaemia/primary caregivers could be further grouped into three. The first one was '*psychological'* in nature; the second was *medical* in nature (search for the right medication) while the third was *finance*. However, the entire challenges are interwoven and each category could be viewed as a product of the other. For instance, psychological challenge results from frustration occasioned by poor health outcome. Parts of this are problems of management-routine and medication compliance as well as the fear of possible death. Similarly, incessant crises, inaccessibility of timely medical services that can enhance positive health outcome, unending search for better management option and stress occasioned by incessant crises were the medical-based challenges. The third challenge was on where to turn for help in order to ensure family sustenance due to dwindling financial resources.

4.11 Discussion of the findings

Conception and management of Sickle Cell Anaemia in Osun State were found to be heavily influenced by interpersonal relationship. Data from all sources in this study pointed to this. Incidence of Sickle Cell Anaemia is usually interpreted within cultural perspective based on environmental dictate. The findings showed that perception of good and bad health along with health threats and problems are culturally constructed and in effect home remedies usually come first in the course of treatment based on knowledge, accessibility and affordability (Kofoed *et al,* 2004; Uzochukwu and Onwujekwe, 2004; Kottak, 2004, Heilman, 2001). This accounts for the variance in recognition and definition of diseases and illnesses as well as healthcare system and treatment strategies developed for them. Also, Western medical service was found to be popular among the people, but almost always the last resort after the failure of other sources in bringing about positive results. Traditional medicine and faith-based healing were most favoured by those who utilized more than two or more healthcare sources. Faith-based healing usually becomes the next alternative mostly during the period of financial insolvency. This is an affirmation of the findings of

Ugochukwu (2000), Adegoke (2001) and Banji (2002) to the effect that faith-based healing is a phenomenon when talking of health care management in Nigeria.

It was revealed that most of the respondents gathered information and acquired experience about this disorder through interpersonal relationship. The same medium is ever present during decision making-process for the management of this disorder. The effects of such interpersonal relationship at times are so strong that it always overrides educational attainment of the sufferers or/and their caregivers. This is exemplified in situations where educated elites adopt and utilize popular medicine[18] due to environmental influence. However, this does not mean that educational status is irrelevant. The relevance of education in this situation was illustrated as having significant effects in effective management of health situation including Sickle Cell Anaemia.

The female gender sourced for health information more than their male counterpart; married females also relied more on their husbands for definition (conception) and management of health situation. Where the husbands are absent, family members and/or neighbours are relied upon. The need for this is to encourage cross-fertilization of ideas on actions to be taken and to prevent possible accusation in the event of negative health outcome occasioned by decision thus taken. Additional data on SC management showed that people resort to home remedies due to financial insolvency; the usage of which often stops when economic situation improves or continues.

Responses on healthcare financing show that most of the respondents did not have budgetary allocation for the management of Sickle Cell Anaemia due to lack of sustainable sources of income. While this is buttressing earlier studies (Ogundijo, 2008 and Lawal, 2002), it also showed that husbands and wives maintained separate budgets. Also, healthcare decisions in the study area are always made with the approval of the husband or his family. Challenges being faced by the people living with Sickle Cell Anaemia and/or their primary caregivers include medical issues such as incessant crises (fear of losing the sufferers to death), inaccessibility of timely medical services that can enhance positive health outcome, unending search for better management option and stress (occasioned by incessant crises), financial difficulty (fear of where to turn to for help in order to ensure family sustenance due

[18] Popular medicine implies home remedies (like traditional medicine, self medication) and/or faith based healing.

to dwindling financial resources) and psychological problem (frustration occasioned by poor health outcome, problem of regimen-routine and medication compliance). The need for healthcare service for positive living equally led to a series of choices which in the words of Abdulsalam (1992) appeared to be somewhat independent of any overall belief system. That is why it is common to come across a Muslim consulting Christian-based faith healing or vice versa. For purposes of clarity and convenience, the salient issues noted are outlined as follow:

- Multiple cultural concepts are available for Sickle Cell Anaemia among the Yorùbá in Osun State. This was influenced by social network around the people living with Sickle Cell Anaemia and their primary caregivers, existence of medically informed family members, interpersonal relations and personal experience of the stakeholders. These concepts revolve around the painful nature of its crisis situation and reflect the various perspectives from which the disorder is viewed.
- The disorder was perceived as a biological issue among the respondents in the urban centre while those in the rural area defined it within spiritual perspective.
- Very often, the influence from within and outside family system determined the step taken in the management of SCA. As a result of this, many cases of SCA remain unreported for hospital care on time.
- Treatment pathways for SCA in Osun state were not different from what were obtainable for other types of medical problems in most developing societies.
- These pathways are classified into two broad categories, the Western medical source and non-Western medical source. The Western medical source included medical services obtainable in either public or private hospital/clinics. Non-Western medical source consisted of healing services obtained through divination, use of herbs and faith-based healing.
- Pathways for the management of SCA in Western medical setting involve diagnosis in order to document medical history of the sufferer, referral for genotype test so as to understand the types of sickle haemoglobin present, prescription of drugs and other treatment regimen upon receiving the results of laboratory test by the medical practitioners, mandatory follow-up for routine test and further prescription, precautionary

measures and, finally, compliance with prescription and other directives for healthy living for the people living with Sickle Cell Anaemia.

- Findings show that the utilization of hospital care is more frequent than other treatment options for the treatment of SCA. However, the pattern of usage of these treatment options is irregular.
- Where hospital care was adopted, not every Sickle Cell case reported is given follow-up to the end, which means people do opt out of the hospital care. Put differently, people do abandoned hospitals for other perceived alternative care(s).
- It showed that the definition of SCA along Western medical model did not translate to automatic usage or reliance on hospital care for its management.
- Age, sex, marital status, educational status, occupation and income have significant relationship with the cultural conception and management of Sickle Cell Anaemia.
- Management of Sickle Cell Anaemia involves treatment of this disorder and prevention of crises through various measures. Some respondents also acknowledged that procreation of children with Sickle Cell disorder can be prevented through genotype screening before marriage and spiritual guidance.
- Preventive measures for those already living with Sickle Cell Anaemia were targeted at sickle cell-induced crises. Such preventive measures were incorporated into the treatment being applied for this disorder at the point of usage.
- Conversely, management of Sickle Cell Anaemia in the study area has irregular pattern. People made use of any healthcare service they fancied in terms of perceived efficacy or convinced of its efficacy for the management of this disorder. At times, more than one source of healing was combined. The usage can start from within non-Western medical source or within Western medical source.
- It is a fact that multiple pathways in the management of this disorder were common. The incidence of multiple pathways was linked to:
    a) Problem of timely identification of Sickle Cell Disorder at onset where everybody ascribed various names and explanations to it.
    b) Misapplication of concept and perceived causes of the disorder and the usage of services that couldn't bring about positive result.

c) Perceived slow progress due to long treatment routine involved in medication through hospital care.
d) Desperation on the part of people living with Sickle Cell Anaemia/primary caregivers to overcome the seemingly unending crises in this disorder and the accompanied excruciating pains.

Meanwhile, it should be noted that appropriate treatment regimen does not mean hospital care. It could be herbal remedies or hospital care; what, however, makes such remedy appropriate is the identification and prompt usage of a healthcare centre with expertise in the use of either herbal remedies or hospital care for the treatment of Sickle Cell Anaemia to bring about positive health outcome. Information on where to come about such experts, especially in herbal remedies, is not always available. People only keep on hoping, which often makes it a wishful thinking. Delay often occurs in the course of this; so also is eventual returns to hospital cares that must have been ignored or abandoned in the first instance. Usage of hospital cares at this point in time is usually at critical period, which most of the time leads to treatment failure and high mortality. Finally, the findings have corroborated the theoretical positions (social action theory, social construction of reality and health belief model) of this study with the fact that people defined and managed Sickle Cell Anaemia based on the peculiarity of their cultural environment.

4.12 Findings and Conceptual framework

The finding is in support of the theoretical base of this study. The study further reveals that the conception of Sickle Cell Anaemia substantially takes place within cultural milieu. This understanding lies in the fact that awareness of a pain or symptoms of this disorder lays the basis for acting on it. Such action is necessarily preceded by an interpretation of the nature and causes of Sickle Cell Anaemia. As a result, it is possible for the individual to move from awareness of an illness to the choice of care system. When considered from Western medical perspective, this disorder is defined within germ theory as a result of which diagnostic attempt is carried out in the hospital. On the other hand, attempts to diagnose the nature and cause of Sickle Cell Anaemia from cultural model are mostly carried on outside the healthcare system and largely by lay managers. The managers' interpretations and

acknowledgement of SC cases as deserving attention usually lead to the choice of a particular health facility among alternatives within the environment. Such facilities include prayer, traditional medicine, and rituals to appease gods and ancestral spirits.

The role of family members is very crucial in the process of defining and managing Sickle Cell Anaemia. The findings indicated that family played crucial roles in the conception and choice of management of Sickle Cell Anaemia. The analysis of figures 4.10, 4.11, 4.13 and 4.14; tables 4.1, 4.2 and 4.3 also demonstrated the fact that a community's and individuals' definition of Sickle Cell Anaemia are a product of the available value system within the environments in which they operate. It shows that actions are constructed by the actors out of what they interpreted. In furtherance of this, how people perceive what they take into account is to a large extent a function of their world, level of education and the amount and quality of information at their disposal. In pursuance of various factors that influence the conception and management of Sickle Cell Anaemia, it was revealed that cultural definition and perceived causes of SCA influenced the management measures adopted for the disorder. This is evident in the interpretations given to the disorder. So also is the issue of perceived causes of the disorder, which a significant proportion of the respondents ascribed to spiritual attack, and bone and blood problems. This is an affirmation that the conception of Sickle Cell among the Yorùbá goes beyond mere germ theory but an amalgam of both the physical and cultural realms.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

Introduction

This chapter summarizes the significant findings of the study and implications for healthcare management in society especially as it concerns the issue of Sickle Cell Anaemia. The chapter is divided into three parts. These include (a) summary (b) conclusion and (c) recommendations.

5.1 Summary

The study was a cross-cultural research and the major objective of which was to investigate the cultural conception and management of Sickle Cell Anaemia among the Yorùbá in Osun State. The specific objectives were to examine awareness and knowledge of Sickle Cell Anaemia; explore the pathways to treatment of Sickle Cell Anaemia; examine preventive measures for Sickle Cell Anaemia; and document the factors influencing cultural conception and management of Sickle Cell Anaemia. Osun state was purposely selected because of its unique features as central location to other Yorùbá states and its uniformly distributed population of people living with Sickle Cell Disorder and its trait. The study was carried out in four randomly selected Local Government Areas (Atakumosa East, Ila, Ejigbo, Ife East, and Ilesha West) with male and female residents of Yorùbá extraction as its target population. Both qualitative and quantitative data were collected in the household-focused study. Data were collected through triangulation methods (IDI, KII and Questionnaire). The quantitative data were discussed alongside qualitative results that explicate findings. The fact that the weaknesses of each individual method will be remedied by the strengths of the other methods informed the choice of these methods. The study population involved 2,016 heads of household, 59 primary caregivers/people living with Sickle Cell Anaemia (KII), and 21 healthcare providers (KII). Geographical location of where the individuals reside has significant relationship with interpretation of Sickle Cell Anaemia. Cultural definition and perceived causes of Sickle Cell Anaemia have significant relationship with efforts towards prevention and treatment of the disorder, while socio-demographic characteristics (such as age, sex, educational attainment, marital status and income) have significant relationship with conception and management of Sickle Cell Anaemia.

People made choices of treatment facilities out of numerous options within their reach. At times, healing methods were combined according to the environmental dictates. Such combination included home remedies and hospital care. Hospital care, the combination of faith-based and hospital care are the treatment measures considered as appropriate for SCA in the urban area. On the other hand, faith-based care, divination and home remedies receive more consideration in the rural area. Prayer/divination, genotype screening and caution in partner selection were the preventive measures against Sickle Cell Anaemia. This outcome is not surprising going by the fact that majority of the urban population defined SCA as biological problem, while those in rural area largely saw it as supernatural issue. Adoption of a home remedy like faith-based healing is an indication that it was not in every situation that the adopters of non-Western medical options resorted to traditional rites (rituals) in the management of health problems

Findings in this study negate the initial expectation that cultural conception of SCA and its management will go along with linguistic peculiarities of Osun State. Data show that, SCA has similar interpretation across four dialectical groups in the state. Inference into this is that similarity in the conception and management of this disorder in the study area must have been a result of constant interactions among the populace which has led to cultural diffusion. On the basis of this, it is hereby concluded that linguistic variation in the study area did not have significant relationship with the conception and management of Sickle Cell Anaemia. However, geographical location of an individual was shown as having significant influence on interpretation in terms of perceived causes of SCA.

The conceptual framework for the study was derived from Marx Weber's Social Action Theory which focuses on the course of action as determined by the condition of the end, which the actor seeks, and the means the individual will use in attaining them. The conceptual framework hypothesized the influence of cultural conception on management of Sickle Cell Anaemia.

5.2 Conclusion

Sickle Cell Anaemia is prevalent in Osun State as demonstrated in the study. The Yorùbá recognize Sickle Cell Anaemia, its symptoms and causes. Qualitative data also indicated that people were conversant with the signs and symptoms of this medical disorder. The

findings from this study thus disagreed with the usual assumption that people are ignorant of the disease, as the Yorùbá in Osun State, Nigeria, have developed different concepts for this disorder as well as healthcare systems and treatment strategies at the home front. Most of the local concepts of this disorder largely centre on the symptoms of the disorder and differed markedly from Western medical model.

While demonstrating Yorùbá conception of Sickle Cell Anaemia, the behavioural and other factors influencing conception and management, it can be safely concluded that cultural interpretation of Sickle Cell Anaemia remained similar across sub-cultures in spite of variation in dialects. Aside this, it is also obvious that, the management of Sickle Cell Anaemia has remained inadequate. Other apparent facts include the absence of national control programmes; the absence of facilities to manage the patients and near-absence of systematic screening which ultimately leads to late diagnosis with attendant severe complication. It is strongly held that the belief of the people about Sickle Cell Anaemia is still an inhibition to the much desired success for its eradication. Consequently, scholars of Yorùbá customs and ways of life should also re-examine the belief of the people and bring to the fore, those key issues that can assist in stemming the prevalence of Sickle Cell Anaemia.

The outcome of this study underscores the need for emphasis on public enlightenment for behavioural change to accommodate Western medical model of the disorder for effective management and its control. Therefore, the focus of research and interventions on Sickle Cell Anaemia in Nigeria and Africa as a whole needs to be redirected to accommodate the people's cultural perception as a way of fast-tracking the elimination of the disease. Intervention programmes on SCA should be based on a holistic approach that would involve people and institutions at the grassroots, including market men and women associations and faith-based associations/organizations. This would ensure that each set of people and their unique way of life are taken into consideration. Finally, the study has shown that healing process goes beyond the administration of drugs to the sick; emotional condition of patients determines to a large extent the treatment outcome as indicated by the World Health Organization through the Alma-Ata Declaration of 1978.

5.3 Recommendations

In the light of the need to improve the prospects of people living with sickle-cell anaemia in developing countries, the following recommendations are offered:

(a) Enabling environment and Logistic supports

First and foremost is the need for provision of requisite resources as part of intervention programme. The resources include Sickle Cell centre, training of Nurses with specialization in Sickle Cell Anaemia and other paramedics. For better accessibility, these should be distributed across the nine (9) Federal Constituencies into which the State is divided.

(b) Awareness creation and Information empowerment

There is need for public enlightenment, education and efficient dissemination of information on SCA. There is need for specific cultural concept for Sickle Cell Anaemia in local languages so as to enhance a common identity during public enlightenment programme on this disorder. This should include community-based programmes and associations/organizations-targeted interventions to ensure that information about Sickle Cell Anaemia, how it can be prevented and reduced get across to the people. There should be religious-based awareness creation programme to help in enhancing the emotional stability of the people living with Sickle Cell Anaemia and their primary caregivers and for regimen compliance and positive living. There is need for re-education of the secondary caregivers (Western medical practitioners) on approach to foster effective relationship between caregivers and people living with Sickle Cell Anaemia for positive health results.

(c) Research and Collaborative efforts

Research and surveillance are important for planning and evaluating appropriate interventions. There is need for further partnerships at national, regional and global levels and high-level advocacy to ensure that, governments of affected countries and international aid agencies are fully aware of the extent of the problem and pay attention to sickle-cell anaemia. There should be adequate and sustained funding for health research. Through this, the sector will be abreast of new developments as well as able to fashion out more reliable responses to the growing threat to healthy living.

(d) Traditional Medicine Promotion and Development

Since other sources of medical process (like diviner, herbalists, and faith healers) are contracted for medication, efforts should be made to educate these providers on the need for improved service delivery in Sickle Cell management. Research on traditional medicine for Sickle Cell management should be funded alongside bio-medical research. Also, the publicity of herbal products, diet and plants that are effective in managing SCA should be encouraged and made accessible.

Government should give official recognition to and develop co-operation with traditional healers. Health authorities should aim at establishing structures that will permit progressive integration of the two systems (modern and traditional medicine) and the eventual development of a truly African medicine that will address this medical disorder.

(e) Economic empowerment and Health funding

Medical care alone cannot bring health to hungry and unempowered people. Health for such people requires a whole new way of life and fresh opportunities to provide themselves with a better and decent standard of living. People should be intimated with the fact that, allocation of resources for unforeseen health problems is not lack of faith in God's protection but an issue that should be taken seriously.

5.4 Policy Implications

The following policy issues have cropped up and should be addressed. First, the study suggests that, women should be empowered educationally and economically. Women education should include empowerment to take healthcare decision especially in the absence of their husbands. Also, economic empowerment through vocational education and soft loans to start small businesses should become a policy issue. Health workshop should be organized to equip womenfolk with Western medical knowledge about prevailing diseases in their environment and home management techniques about them. This will go a long way in enhancing effective health intervention for a drastic reduction of morbidity and mortality rates in society.

Second, the study has shown that, many people don't always see their vulnerability to Sickle Cell Anaemia. So also is the case of misinterpretation of this disorder for other

medical conditions with similar symptoms. On the basis of this, this study is suggesting that, the practice of mandatory genotype screening should be encouraged so that people will be aware of their genotype before deciding to get married and to whom.

Third, nationwide public enlightenment backed by policy enactment should be put in place to intimate people with what SCA is all about and the need to make appropriate choice of spouse for a happy marriage life. The best approach to achieve this includes incorporation of this into primary and secondary schools curriculum and as a course under General Studies programme in tertiary institutions. The policy should encourage the involvement of traditional and religious institutions as purveyors of change in this project.

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APPENDICES

APPENDIX A: Questionnaire

DEPARTMENT OF SOCIOLOGY
FACULTY OF THE SOCIAL SCIENCE
UNIVERSITY OF IBADAN

Dear Respondent,
This questionnaire seeks information for the purpose of PhD degree in Sociology focusing on Cultural conception and Management of Sickle Cell Anaemia in this community. Please kindly respond to each of the questionnaire items. There is no wrong or right answer. Your confidentiality will be highly ascertained.

Thanks for your usual cooperation.

A: Socio-Demographic Data

Instruction: Please pick the option that best applies to you by ticking the code provided.

S/N.	QUESTIONS/OPTIONS	CODE
1.	Sex:	
	(a) Male	( ) 1
	(b) Female	( ) 2
2.	What is your age?	
	(a) Less than 30 years	( ) 1
	(b) 30 – 50 years	( ) 2
	(c) Above 50 years	( ) 3
3.	What is your level of education?	
	(a) No Formal education	( ) 1
	(b) Primary School	( ) 2
	(c) Secondary School	( ) 3
	(d) OND/NCE	( ) 4
	(e) HND/University Degree	( ) 5
	(f) Others	( ) 6
	(specify)……..…….	
4.	Marital Status?	
	(a) Single	( ) 1
	(b) Married	( ) 2
	(c) Divorced	( ) 3
	(d) Separated	( ) 4
	(e) Widowed	( ) 5
	(f) Others	( ) 6
	(specify)……..…….	
5.	What is your religious affiliation?	
	(a) Christianity	( ) 1

	(b) Islam (c) Traditional religion (d) Others (specify)…….……..	( ) 2 ( ) 3 ( ) 4
6.	What is your occupation? (a) Housewife (b) Farming (c) Trading (d) Teaching (e) Student (f) Civil Service (g) Artisan (h) Unemployed (i) Others (specify)……	 ( ) 1 ( ) 2 ( ) 3 ( ) 4 ( ) 5 ( ) 6 ( ) 7 ( ) 8 ( ) 9

B: Knowledge and Conception of the Disease

Various types of illness have been noted as affecting people; in Western medical circle some are known, and some are classified as unknown. A typical case here is a disease that has the following characteristics:

The symptoms of the illness usually start after the age of four to six months. The patients usually perceive pain in the arms, legs, back and stomach. Sometimes, this pain is quite severe. This can happen to the patients at home, school or working place – in fact anywhere.

The illness can result to swelling of the hands and feet, with stiff painful joints and extreme tiredness. Swollen hands and feet are often the first signs of this illness in babies. It can slow growth in infants and children and delay puberty in teenagers; causes yellowing of the skin and eyes. In people with dark skin, this is visible mostly as yellowing of the eyes.

In children with this illness, pain happens more often on an average of one third of all days; lasts longer generally all day, even if not continuously all day; it is associated with great tiredness about half the time; causes them to spend significant time in bed. On average, the time spent wholly or partly in bed adds up to about a week of every school term.

S/N	QUESTIONS/OPTIONS	CODE
8.	Are there cases of this nature in this community? (a) Yes (b) No	 ( ) 1 ( ) 2
9.	What is the name given to the illness in this community?..... …….....	
10.	What causes this illness?.....	
11.	Do you know any individual in this community who has this type of illness? (a) Yes (b) No	 ( ) 1 ( ) 2

12.	Who is most likely to get this illness?..... ……..……	
13,	Can this illness kill? (a) Yes (b) No	 ( ) 1 ( ) 2
14.	Are there people that cannot get this illness? (a) Yes (b) No	 ( ) 1 ( ) 2
15.	If Yes, specify……..... …….....	
16.	How long do you think the illness can stay in the body of the patients?..... ..... …….....	
17.	What are the signs and symptoms that are commonly found on the people living with this disorder?.....	
18.	What are the effects of this disease on the patients' life and general well being?..... .....…….....	
19.	Do you see this illness as being of any consequence to the people who are close to the patients? (a) Yes (b) No	 ( ) 1 ( ) 2
20.	If Yes, specify various ways by which it impacts on those who are close to the patients …….……..……..... ……..……	
21.	Are there ways by which this disease could be prevented? (a) Yes (b) No	 ( ) 1 ( ) 2
22.	If Yes, state them……..... ……..……	
23..	State the factors that could assist people in the understanding of this disorder at its onset..... ……..	

C: Issues on Management Strategies

S/N	QUESTIONS/OPTIONS	CODE
24.	Do you think the illness could be cured or managed? (a) Cured (b) Managed	 ( ) 1 ( ) 2
25.	Have you seen anybody who has cured it before? (a) Yes (b) No	 ( ) 1 ( ) 2
26.	If Yes, What measure did that person utilize to cure it? (a) Home remedy (Use of herb/Self-Medication) (b) Diviners (c) Faith healing (Muslim and Christian)	 ( ) 1 ( ) 2 ( ) 3

	(d) Clinics/Hospitals (e) Others (specify)…..……..……...	( ) 4 ( ) 5
27.	(If management option is picked) How could it be managed?..... ……	
28.	Do you know of any clinic in this community where the patients of this illness are treated? (a) Yes (b) No	 ( ) 1 ( ) 2
29.	If Yes, Are you aware of people's patronage of such clinics? (a) Yes (b) No	 ( ) 1 ( ) 2
30.	Do you know somebody who uses it? (a) Yes (b) No	 ( ) 1 ( ) 2
31.	Which of the following treatment options is preferred most by the patients in managing crises emanating from this disease? (a) Home remedy (Use of herb/Self-Medication) (b) Diviners (c) Faith healing (Muslim and Christian) (d) Clinics/Hospitals (e) Others (specify)…..……..……...	 ( ) 1 ( ) 2 ( ) 3 ( ) 4 ( ) 5
32.	What informs people's preference for the answer above (Q29)? (a) Interpretation of the illness (b) Accessibility (c) Affordability (d) Proximity (e) Spiritual reasons (f) Others (specify)….....	 ( ) 1 ( ) 2 ( ) 3 ( ) 4 ( ) 5 ( ) 6
33.	What are the likely preventive measures for Sickle Cell Anaemia?..... ……	
34.	Which of these measures do you prefer most?.....	
35.	Who takes responsibility for the management option adopted? (a) Self (b) Parents (c) Family members (d) Others (specify)……..	 ( ) 1 ( ) 2 ( ) 3 ( ) 4
36.	What are the factors that will influence the choice of management strategy for Sickle Cell Anaemia?.....	
37.	What are the common challenges against the management of Sickle Cell Anaemia in this community?.....	
38.	Any other comments on conception and management of Sickle Cell Anaemia?..... ……....	

APPENDIX B: INTERVIEW GUIDE (Primary Caregivers)

*Give a brief introduction of oneself and the objectives of the exercise. Let participant introduce him/herself then permission will be sought from them to use a tape-recorder to record their voice.

- How do you define Sickle Cell Anaemia? (*Probe for cultural conception of the illness, Probe for possibility of variety of concepts for this illness, Probe for possible signs and symptoms of the illness*)

- What are the major causes of this disorder (SCA)? (*Probe for personal view on the causes of the illness, Probe for the community view on the causes of the illness, Probe further for as many causes as the patient could remember, probe for the participant's view of the illness and its causes at initial stage and what the view is at present*)

- How do people define this disorder in terms of the cause(s) and related treatment option(s) (*Probe for whether it is seen as biological issue that demands the use their modern medicine as treatment option, probe for the way members of the community relate with the people living with Sickle Cell Anaemia, probe for possibility of stigmatization of patients by the community members*).

- What are the medical facilities available for the management of this illness (SCA) in the community? (*Probe for the usage of the facilities mentioned, probe for the previous medical facilities utilized by the patient, probe the factors that influence the patients decision to utilize such facilities, probe for the people who take the responsibility for the facilities utilized*)

- Which of these treatment facilities do you preferred most (*Probe for reasons for choice of preference, probe to know the likely treatment facility(ies) to be recommended to others in similar situation if the need arose*)

- How long have you been managing the illness? (*Probe for the problems people usually encounter in the course of managing this illness; probe for how often the patient usually has the illness crisis, Probe for the person(s) that usually assist the patient in time of crisis, Probe for who is expected to render assistance to the patients during crisis, Probe to know if any of the patient's relatives/children/wards is suffering from the illness (SCA), Probe for how often the patient's relatives/children/wards usually suffer from SC crises, Probe for signs or symptoms perceived during the crises*)

- What type of support is available in the community for the Sickle Cell patients? [*Probe for the roles of: (a) Community (b) the personnel of available medical facilities of (c) Government (d) Household (relatives, friends, etc) in ensuring effective management of the illness, probe for the needs (aside from clinical) that make life more meaningful for the patients of the illness, Probe for financial situation in the management of Sickle Cell Anaemia; Probe for sources of finance for the management of Sickle Cell Anaemia]*

- Please, could you shed light on decision making process for the management of Sickle Cell Anaemia (*Probe for the dynamics of such decision making? Probe for the person who take decision, when and how; Probe for the condition(s) that influence the role every stakeholder plays during decision making on the type of management approach to be adopted to help the people living with Sickle Cell Anaemia*).

- What recommendations do you have to achieve the following?
  - How patients could achieve better health outcome?
  - How the community could be of assistance to the patients of this illness (SCA) to achieve better health outcome?
  - The expectations from secondary caregivers to assist the patients achieve positive outcome.
  - The expectations on how government could be of help towards ensuring better health outcome for the patients and to control the spread of the disease.
  - How to reduce the incidence of Sickle Cell Anaemia in the community.

Thank the participants for their time.

APPENDIX C: INTERVIEW GUIDE (Sickle Cell Patients)

*Give a brief introduction of oneself and the objectives of the exercise. Let participant introduce him/herself then permission will be sought from them to use a tape-recorder to record their voice.

- How do you define Sickle Cell Anaemia? (*Probe for cultural conception of the illness, Probe for possibility of variety of concepts for this illness, Probe for possible signs and symptoms of the illness*)

- What are the major causes of this disorder (SCA)? (*Probe for personal view on the causes of the illness, Probe for the community view on the causes of the illness, Probe further for as many causes as the patient could remember, probe for the respondent view of the illness and its causes at initial stage and what the view is at present*)

- How do people define this disorder in terms of the cause(s) and related treatment option(s) (*Probe for whether it is seen as biological issue that demands the use their modern medicine as treatment option, probe for the way members of the community relate with the people living with Sickle Cell Anaemia, probe for possibility of stigmatization of patients by the community members*).

- Chronic pain has been stressed as major manifestation of the Sickle Cell Anaemia; due to your experience, which parts of the body are always involved? (*Probe for when children with sickle disorder usually experience pain; probe for their ability to tell if pain is coming; probe for any other manifestation(s) on Sickle cell disorder*)

- What are the medical facilities available for the management of this illness (SCA) in the community? (*Probe for the usage of the facilities mentioned, probe for the previous medical facilities utilized by the patient, probe the factors that influence the patients decision to utilize such facilities, probe for the people who take the responsibility of the facilities utilized*)

- Which of these treatment facilities do you preferred most (*Probe for reasons for choice of preference, probe to know the likely treatment facility(ies) to be recommended to others in similar situation if the need arose*)

- How long have you been managing the illness? (*Probe for the problems people usually encounter in the course of managing this illness; probe for how often the patient usually has the illness crisis, Probe for the person(s) that usually assist the patient in time of crisis, Probe for who is expected to render assistance to the patients during crisis, Probe to know if any of the patient's relatives/children/wards is suffering from the illness (SCA), Probe for how often the patient's relatives/children/wards usually suffer from SC crises, Probe for signs or symptoms perceived during the crises*)

- What type of support is available in the community for the Sickle Cell patients? [*Probe for the roles of: (a) Community (b) the personnel of available medical facilities of (c)*

Government (d) Household (relatives, friends, etc) in ensuring effective management of the illness, probe for the needs (aside from clinical) that make life more meaningful for the patients of the illness, Probe for financial situation in the management of Sickle Cell Anaemia; Probe for sources of finance for the management of Sickle Cell Anaemia]

- Please, could you shed light on decision making process for the management of Sickle Cell Anaemia (*Probe for the dynamics of such decision making? Probe for the person who take decision, when and how; Probe for the condition(s) that influence the role every stakeholder plays during decision making on the type of management approach to be adopted to help the people living with Sickle Cell Anaemia*).

- What recommendations do you have to achieve the following?
  - How patients could achieve better health outcome?
  - How the community could be of assistance to the patients of this illness (SCA) to achieve better health outcome?
  - The expectations from secondary caregivers to assist the patients achieve positive outcome.
  - The expectations on how government could be of help towards ensuring better health outcome for the patients and to control the spread of the disease.
  - How to reduce the incidence of Sickle Cell Anaemia in the community.

Thank the participants for their time.

APPENDIX D: INTERVIEW GUIDE (Health Workers)

*Give a brief introduction of oneself and the objectives of the exercise. Let participant introduce him/herself then permission will be sought from them to use a tape-recorder to record their voice.

- How is Sickle Cell Anaemia defined by the people in this community? (*Probe for cultural conception of the illness, Probe for possibility of variety of concepts for this illness*)

- From your observation and experience, how knowledgeable are the people in this community on the issue of the causes of Sickle Cell Anaemia? (*Probe for the usual causes often talked about in the community*)

- What are the major causes of Sickle Cell Anaemia in this community? (*Probe for personal view on the causes of the illness, Probe for the community view on the causes of the illness*)

- Chronic pain has been stressed as major manifestation of the Sickle Cell Anaemia; due to your experience, which parts of the body are always involved? (*Probe for when children with sickle disorder usually experience pain; probe for their ability to tell if pain is coming; probe for any other manifestation(s) on Sickle cell disorder*)

- What are the medical facilities available for the management of Sickle Cell Anaemia in the community? (*Probe for the usage of the facilities mentioned; probe for the facility(ies) preferred most by the patients; probe for reasons for the choice of preference*),

- What type of support is available in the community for the Sickle Cell patients? Probe for the roles of: (a) Community (b) the personnel of available medical facilities (c) Government (d) Household (relatives, friends, etc) in ensuring effective management of Sickle Cell Anaemia.

- Do you notice any gender difference in the management of Sickle Cell Anaemia? (Probe for the causes of the difference, health implication of gender differences in the management of Sickle Cell Anaemia)

- Do you know of any unit/department or any organization that is charged with the responsibility of providing supports to the people living with Sickle Cell Anaemia?

- What recommendations do you have to achieve the following?
  - How patients could achieve better health outcome?
  - How the community could be of assistance to the patients of this illness (SCA) to achieve better health outcome?
  - The expectations from secondary caregivers to assist the patients achieve positive outcome.

- The expectations on how government could be of help towards ensuring better health outcome for the patients and to control the spread of the disease.
- How to reduce the incidence of Sickle Cell Anaemia in the community.

Thank the participants for their time.

APPENDIX E: INTERVIEW GUIDE (Traditional Healers, Diviners, Christian and Muslim Clerics)

*Give a brief introduction of oneself and the objectives of the exercise. Let participant introduce him/herself then permission will be sought from them to use a tape-recorder to record their voice. Before this narrate the story line as obtained in SECTION B of the questionnaire in order to provide basis for the probing of interviewee's knowledge of Sickle Cell Anaemia.

- How is the just narrated health problem defined by the people in this community? (*Probe for existence of such disease in the community, Probe for possibility of variety of concepts for this illness*)

- From your observation and experience, how knowledgeable are the people in this community on the issue of the causes of this disease? (*Probe for the usual causes often talked about in the community*)

- What do you see as the major causes of this disease (Sickle Cell Anaemia) in the community? (*Probe for personal view on the causes of the illness, Probe for the community view on the causes of the illness*)

- Chronic pain has been stressed as major manifestation of the disease; due to your experience, which parts of the body are always involved? (*Probe for when children with sickle disorder usually experience pain; probe for their ability to tell if pain is coming; probe for any other manifestation(s) on Sickle cell disorder*)

- Have you ever received and handled cases like this in the course of treating healthcare issues? (*If yes, probe for the treatment procedure, health outcome and other information that will help the study)*

- Are there efforts being made outside the purview of your field in order to enhance treatment outcome? (*Probe for such efforts, the process and the rationale behind it)*

- What recommendations do you have to achieve the following?
  - How patients could achieve better health outcome?
  - How the community could be of assistance to the patients of this illness (SCA) to achieve better health outcome?
  - The expectations from secondary caregivers to assist the patients achieve positive outcome.
  - The expectations on how government could be of help towards ensuring better health outcome for the patients and to control the spread of the disease.
  - How to reduce the incidence of Sickle Cell Anaemia in the community.

Thank the participants for their time.

APPENDIX F: ETHICAL APPROVAL

OBAFEMI AWOLOWO UNIVERSITY TEACHING HOSPITALS' COMPLEX, ILE-IFE, NIGERIA

ETHICS AND RESEARCH COMMITTEE

CLEARANCE CERTIFICATE

IRB/IEC NUMBER: 00005422

PROTOCOL NUMBER: ERC/2009/01/08

PROJECT TITLE: CULTURE CONCEPTION AND MANAGEMENT OF SICKLE CELL ANAEMIA AMONG THE YORUBAS, SOUTHWEST, NIGERIA: A STUDY OF OSUN STATE.

INVESTIGATOR(S) MR. M.O. LAWAL

DEPARTMENT/INSTITUTION Department of Sociology, University of Ibadan, Ibadan.

DATE CONSIDERED 15-01-2009

DECISION OF THE COMMITTEE Approved

CHAIRMAN: Professor E.O. Ogunbodede SIGNATURE & DATE: 15/1/2009

Supervisor: DR. A.S. JEGEDE

DECLARATION BY INVESTIGATOR(S)

PROTOCOL NUMBER (Please quote in all enquiries): ERC/2009/01/08

To be completed in four and three copies returned to the Secretary, Ethics and Research Committee, Clinical Services and Training Section, Obafemi Awolowo University Teaching Hospitals Complex, Ile-Ife, Nigeria.

I/We fully understand the conditions under which I am/we are authorized to conduct the above-mentioned research and I/we guarantee that I/we will ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved, I/we undertake to resubmit the protocol to the Ethics and Research Committee.

Signature ..... Date 03/2009.....

APPENDIX G: SUBJECT INFORMATION SHEET

CULTURAL CONCEPTION AND MANAGEMENT OF SICKLE CELL ANAEMIA AMONG THE YORÙBÁ IN OSUN STATE, NIGERIA

Principal Investigator: Lawal M. Olufemi **Telephone:**
E-mail:
Institution: University of Ibadan **Department:** Sociology

Title of Study: Cultural conception and management of Sickle Cell Anaemia among the Yorùbá in Osun State, Nigeria

Co-Investigator: None
Sponsor (if any): None

- **Some general things to know about this study:** It is about Cultural conception and management of Sickle Cell Anaemia
- **What is the purpose of this study:** Understand the relationship between cultural and management of this disorder
- **Procedure:** It will involve interviewing of the patients (Sickle Cell Patients and their Primary Caregivers) and the secondary care Providers
- **Benefits:** To advance knowledge and enhance management of Sickle Cell Anaemia
- **Costs of Participation:** NONE
- **Risk:** None envisaged
- **Compensation:** None
- **Confidentiality:** Guaranteed
- **Respondents' Rights:** Protected through confidentiality
- **Conflict of Interest:** None envisaged
- **For the Records:** Not applicable

APPENDIX H: SUBJECT AGREEMENT (INVESTIGATOR'S ASSURANCE)

CULTURAL CONCEPTION AND MANAGEMENT OF SICKLE CELL ANAEMIA AMONG THE YORÙBÁ IN OSUN STATE, NIGERIA

This interview schedule seeks information for the purpose of PhD degree in Medical Sociology at University of Ibadan, Nigeria. It focuses on *Cultural Conception and Management of Sickle Cell Anaemia among the Yorùbá in Osun State, Nigeria.* There is no wrong or right answer. Participation is voluntary; you are not required to declare your identity (in terms of names) and refusal to participate will involve no penalty or loss of benefits.

Your confidentiality will be given utmost priority.

Thanks for the anticipated Cooperation.

Musediq Olufemi, LAWAL
Department of Sociology,
University of Ibadan,
NIGERIA

APPENDIX I: SUBJECT AGREEMENT SHEET (KII and IDI)

CULTURAL CONCEPTION AND MANAGEMENT OF SICKLE CELL ANAEMIA AMONG THE YORÙBÁ IN OSUN STATE, NIGERIA

I have read the information provided above, or it has been read to me.

I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to participate in this study and understand that I have the right to withdraw from the study at any time.

Yes ☐ **No** ☐

....
Signature/Thumb Print of Research Respondent Date

....
Signature/Thumb Print of Research Respondent Date

....
Signature/Thumb Print of Research Respondent Date

.....
Printed name of Person Obtaining Consent

APPENDIX J: CONSENT FORM FOR RESPONDENT (QUESTIONNAIRE)

Hello, my name is……..……and I am asking people from your community to answer a few questions, which we hope will benefit your community and possibly other communities in the future.

I am undertaking this work for academic purpose and in partial fulfillment for the award of PhD Degree in Sociology at University of Ibadan, Nigeria. The purpose of the study is to understand how people conceive Sickle Cell Anaemia and how this influences the management process of the disorder. The survey also aims to better assess people's views of chronic medical condition like Sickle Cell Anaemia among the Yorùbá in Osun State, Nigeria.

We have randomly chosen you and your household as one of our sample of 2,016 in the selected Local Governments of Osun State and are requesting one adult in the household to respond to a few questions. We are doing this among various groups of people, such as people living in towns and in rural areas.

Please understand that you are not being forced to take part in this study and the choice whether to participate or not is yours alone. However, we would really appreciate it if you do share your thoughts with us. If you choose not take part in answering these questions, you will not be affected in any way whatsoever. If you agree to participate, you may stop me at any time and tell me that you don't want to go on with the interview. If you do this there will also be no penalties and you will NOT be prejudiced in ANY way.

The information will remain confidential and there will be no "come-backs" from the answers you give. Researchers may conduct random back-checks to check whether I have interviewed you and recorded your responses accurately.

The interview will last between 40 and 60 minutes. I will be asking you a few questions and ask that you are as open and honest as possible in answering these questions. Some questions may be of a personal and/or sensitive nature. I will be asking some questions that you may not have thought about before, and which also involve thinking about the past or the future. We know that you cannot be absolutely certain about the answers to these questions but we ask that you try to think about these questions. When it comes to answering questions there are no right and wrong answers.

Contact persons:
Project leader: Musediq Olufemi Lawal; Tel. 0803-445-58856 or 0807-765-0454
Fieldwork manager: Kolawole Adisa; Tel. (011) 807-1194 or 073 401-1673

CONSENT
I hereby agree to participate in this research on land reform. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can

stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally.

I have received the telephone number of a person to contact should I need to speak about any issues that may arise in this interview.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

…….. ……
Signature of Participant Full Names

……
Date

APPENDIX K: STANDARD OPERATION PROCEDURE

FIELD INSTRUCTIONS

Dear Colleague;

You are being involved in this study on the basis of your track record and thus constitute one of the major resources at this stage of the above named study. Your assistance will no doubt go a long way in ensuring that the study achieved the objectives for which it was designed. You are kindly requested to help facilitate the administration of the questionnaires being entrusted to into your care. Please go through the instruction below. You would have done us a good favour by complying with them.

Objective of the Study

- The major objective of this study is to understand the conception and management of Sickle Cell Anaemia among the Yorùbá in Osun State, Nigeria.
- The respondents for the questionnaire will be the members of the communities in each of the selected areas in Ife, Ijesa, Oyo and Igbomina dialect speaking areas of Osun State.
    - Its sample frame covers all levels of the population
    - It covers both male and female students
    - Kindly ensure that this is answered by the right and competent person
    - The questionnaire could be self-administered or researcher-administered depending on the circumstance or the level of literacy of the sampled respondents.

Process and Procedure to be followed

- Always introduce yourself and your colleagues and explain the purpose of your study. It will be necessary to establish at outset that you will not pay the villagers or handout gifts for participation.
- A thorough explanation of the purpose of this research, and the role of information collected from the respondents (which is to help in prevent current and future difficulties in the management of Sickle Cell Anaemia) should be given.
- Include information on how many communities will be visited and how they were selected.

General Instructions on Data collection (Interviews and Questionnaire)

- In conducting group interviews, it is important to allow the people to discuss matter among themselves before recording an answer. Such discussion should be encouraged, not discouraged.
- Avoid accepting answers from a single spokesman for all the community members. Stress that there is no 'right' answer; that your interest is in their views, experience, problems and concerns on issues pertaining to cultural conception and management of Sickle Cell Anaemia. Attention should be paid to differences in their answers.
- Questions should be 'neutral' that is, avoid 'leading questions'. Leading questions have a particular answer embedded in the question itself. An example of a leading question is:

- Is Sickle Cell Anaemia a medical problem? (a) Yes ( ) or (b) No ( )

- This leading question is suggesting to the respondents that the Sickle Cell Anaemia is a medical problem. The question should be better phrased:
  - What do you know about Sickle Cell Anaemia.....
- Interview schedules of any sort should be pretested with a small number of communities (or individuals if appropriate). Modify any questions the respondents have difficulty in understanding.
- Eliminate questions which result in ambiguous answers. Pre-tests should not include part of your final sample.
- Allow time in research planning for pre-testing and revising the questionnaire.
- Always record date of interview and interviewers names on each form, as well as an indication of the location of the interview.
- Interview schedule should also be dated in case you make later revisions, and have more than one version of the interview schedule.
- In closing the interview, always thank the participants sincerely for their time and information. As if there is any information that they would like to add on the topics that have been discussed. It may be helpful to ask if they have any questions.
- Review the material at the end of each day with other team members. Note any problems or ambiguities in responses. These may be cleared up by the follow-up visits, or at least corrected in future interviews.
- Also on a daily basis the team should get together to review how things are going in terms of interactions with population in the study area, team work, logistical problems, and so on.
- The team should also spend times each day on a preliminary discussion of the information gathered to see if adjustments to the work plan are needed.

Observation

Observation is a key method for leaning. During the process of data gathering, it is important to look carefully at the places, people, resources and conditions described by the participants.

- Direct observations help to support and cross-check the findings from other methods, and can reveal new details and raise new questions.
- For every observation made, remember to write down two things:
  (1) What was observed, and
  (2) Personal interpretation of what it means.
- It is important to cross check your interpretation with the findings from other methods and with other participants.